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**“They just do my dressings”: Children’s
Perspectives on Community Children’s
Nursing.**

Volume one of two

by

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I confirm that this thesis is my own work. It has not been submitted for examination
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Abstract

The increase in the number of children living with complex, long term nursing needs has led to an expansion of services. The growth in community children's nursing has been influenced by local politics and the needs of individual children, rather than by research investigating children's perspectives (Whiting 2005). At the same time, policy and professional agendas have included a willingness to listen to children as service users (Department of Health 2001a, Coad and Shaw 2008). The aim of this study was to address the lack of an evidence base for community children's nursing by exploring children's experiences of receiving nursing care in community settings.

A mosaic of qualitative methodologies, within the philosophical framework of Clark's (2004) Mosaic approach, was used to investigate the experience of children, aged 5-12. The study engaged a core group of seven children in participatory activities spread over one year. A larger, non-core group of fourteen children was also observed receiving nursing care. The children's perspectives were placed in context using data from observation of six nurses' working days, and individual and group interviews with community children's nurses.

Four themes emerged. Firstly, the dominant theme for children was how they portrayed themselves as children, like other children. Secondly, findings show, for the first time, that children have negative as well as positive regard for nurses. Children's regard for nurses seemed to be influenced by children's understanding of their illness and their involvement in receiving care. Thirdly, children and nurses focused on highly visible clinical interventions, not on the work of nurses which

helped children to access social or educational opportunities. Finally, some of the children wanted to receive care from a nurse of the same sex as themselves.

These findings have significant implications for quality measurement, the management of relationships between children and nurses, and the organisation of children's nursing.

Introduction

For some time now there has been a growing number of children who require increasingly complex nursing care to be delivered to them in community settings. There has also been a recognition that people receiving health care could and should be involved in shaping the services they receive. In the next few pages these statements are justified in the rationale for this study, the research aims of the study are set out and the structure of the thesis is detailed.

Rationale for the study

This study was conceived at a time when there were reports of an increase in the number of children receiving nursing interventions in community settings (Glendinning et al 2001, Cramp et al 2003). This increase was attributed to improving medical care, which resulted in children who previously would not have survived trauma, illness or prematurity, not only surviving, but often surviving to live with complex health needs. This coincided with technological advances which made receiving some forms of medical intervention at home possible e.g. adaptation of ventilator technology to permit ventilation in community settings (Earle et al 2006, Wang and Barnard 2008). This increase in children requiring nursing interventions at home resulted in close to a ten fold increase in community nursing teams from 1988 to 2004 (Whiting 2005).

The provision of nursing care to children living with illness in community settings has not received the same attention as the provision of nursing services to adults in the community (Acornley 2005). This is because while local health authorities are not obliged by statute to provide community children's nursing services, they are

required to provide adults with district nursing services (Whiting 2005). This has led to the ad hoc development of community children's nursing and a confusing picture of services based on local political agendas that met local needs, rather than on empirical research, or nationally agreed levels of service provision (Whiting 2005).

The dramatic expansion in community children's nursing services during the 1990s stimulated a number of evaluations of the services provided (Jennings 1994, Lewis 1999, Sartain et al 2001, Cramp et al 2003). However, these evaluations focused on professional agendas, economic evaluations and parental satisfaction. None of these studies focused exclusively on children's views. Often the studies lacked rigour, with few adequately addressing the research relationships between adults and children.

The limited research about how children experienced receiving nursing care in community settings, as opposed to receiving care in hospital settings, meant that little was known about what children expected, or the factors which shaped the experience for children. Children's voices about their community children's nursing services were therefore poorly understood and often went unheard.

This study was designed to address these gaps in the current literature and to inform community children's nursing policy and practice. The study was undertaken to negotiate for children's voices to be heard. The use of Clark's (2004) Mosaic approach includes an ethnographic element which allows the children's expressed views to be placed in context, revealing new insights into how children participate in receiving nursing care, and the relationships between children and nurses. This is the first study in the UK to observe children receiving, and nurses delivering, care in community settings.

Researching children's voices

It seemed to be a good time during the establishment of this study to take stock of the state of community children's nursing, especially given the refocusing of services to community settings (Department of Health 2001b), the increasing number of children requiring nursing services at home, and the increase in service provision (Whiting 2005). There are a number of reasons for taking account of children's voices in this study of community children's nursing.

One reason for listening to children when developing services is, as Kirby (2004) suggests, that it is a child's right, under the United Nation Convention on the Rights of the Child, article 12 (United Nations 1989), to be involved in all decisions that affect their lives. The incorporation of the Convention into UK law in 2000 (British Parliament 1998), and other consumer pressures, has led to a growing realisation that involving children who use services can be beneficial (Department of Health 1996, 2001a, 2002a, National Children's Bureau 2004). Public and Patient involvement can be helpful in not only shaping children's clinical care, but also in the strategic development of services for children (Bury et al 2004, Lightfoot and Sloper 2002). Giving children a voice in their own health care relies on the assumption that what children have to say about nursing is worth listening to and that children can make a coherent and valuable contribution to knowledge about children's nursing (Coad and Shaw 2008).

Research aims

The aim of this research was to give voice to children's experience of being nursed at home, by exploring with children their experience of receiving care at home, their

expectations of nurses, and what they wanted from nursing services. The study also sought to understand the factors which may affect how children experience receiving nursing care at home, to inform future developments in the service.

The structure of the thesis

This thesis begins by setting out, in chapter 1, the context in which the study was undertaken. The chapter explores the history and current state of community children's nursing services. The literature review, in chapter 2, reveals the relationships between research conducted in hospital and community settings.

The chapter also examines how adult voices influence children's voiced opinions of receiving nursing care, as part of the relationship between adults and children, as members of different generations.

How this study addressed these relationships between the generations of children and adults is explored in chapters 3 and 4, which set out how Clark's (2004) Mosaic approach informed the methodology and methods of the study. A mosaic of phenomenology, ethnography and visual methodologies and methods are described, as is how these methodologies can be held together in the mosaic to make a coherent ethical approach to researching with children.

Chapter 5 explores how this study enacted the ethical and reflexive research practice demanded when researching with children living with illness. The findings of two bracketing interviews (see section 4.5.1. and 5.3.1) are used to formalise the principal researcher's reflexivity towards researching with children. The chapter also details ethical approval, funding, access and consent issues.

The findings of the study are set out in three chapters. Chapters 6 and 7 examine the findings which were derived from conversations with children and from the images they made. Chapter 6 looks at how children present themselves as being like other children, while chapter 7 focuses on the relationship between the children and the nurses. The last findings chapter, chapter 8, attempts to place the views of children in the context of community children's nursing. Observation of nurses and conversations with nurses are used, not to negate the voices of children, rather they are included in much the same way that orchestral music incorporates a number of musical instruments. Adult voices are added, sometimes to reinforce children's views, sometimes to provide a counterpoint, and on occasion, to bring out discordant notes.

The findings from chapters 6, 7 and 8 are drawn together in chapter 9, where the themes that emerged from the study are discussed in further detail. Once the limitations of the study have been acknowledged, a children's agenda is proposed, which addresses each of the themes in terms of children's nursing practice, education, research and policy directions.

Chapter 10, the final chapter, sets out the conclusions of the study and proposes recommendations for the development of community children's nursing based on active listening to the children who receive nursing care in community settings.

Chapter 1. Historical and political development of community children's nursing

1.1. Introduction

This chapter sets out the context for this study of children's experience of receiving nursing care in community settings. In order to understand children's experience of receiving care it is necessary to understand the political and historical context of community children's nursing. It is important to consider the influence of the current context of community children's nursing on children's experience of receiving care. These influences are also important factors which shape how children receive care.

Thus this chapter begins with the historical background of community children's nursing in Britain, which informs the exploration of community children's nursing as a part of the profession of children's nursing. Historical perspectives also inform the analysis of current models of service provision. The increase in the number of children requiring nursing care in community settings is discussed, along with the resultant increase in community children's nursing services.

A discussion of children's experience of nursing care needs to be set in the context of the historical development of community children's nursing. Because there is a history of separating children's health care from adult health care, which continues to influence the provision of community children's nursing. This history shapes the provision of children's nursing and therefore influences children's experience of receiving care. It is also argued that services delivered to children are shaped by the political structures of nursing, including gender issues.

1.2. Historical development of community children's nursing

Community children's nursing, like hospital nursing, has a separate development from community services for adults. Although the first community children's nursing teams at Great Ormond Street date from the same time as the beginnings of district nursing and health visiting, in the 1880s (Whiting 2000), children's nursing in the community did not spread to form a national network at the inception of the NHS. Indeed the provisions of the act meant the Great Ormond Street service, as a private nursing service, could not continue and was stopped (Whiting 2000). Despite community children's nursing being included in the education framework for post registration nurses (United Kingdom Central Council for Nursing 1995), it has not benefited from inclusion in the provision of services under the National Health Service Act 1946 (Whiting 2005). This required all local health providers to provide district nursing and health visiting services for their populations. So, while district nursing and health visiting services are provided by all local authorities, community children's nursing services have developed in some areas, but not in others, according to local priorities and personal interests (Whiting 2005).

After the closure of the Great Ormond Street service new services eventually opened in Rotherham and Birmingham in the 1950s and slowly services spread until the 1990s when their number grew dramatically. Estimates, from the Royal College of Nursing's database of community children's nursing teams (Royal College of Nursing 2007) now puts coverage of the UK at 90% (Cramp et al. 2003). Whilst children living in 90% of areas in the UK now have access to community children's nursing services, what is delivered will vary according to local developments (Whiting 2005, Acronley 2005). Nor is there any requirement for local health

authorities to continue to provide community children's nursing services, as it is only a government recommendation that they do so, not a legal duty (Department of Health, 1997a; Department of Health, 2004a).

The fragmentary and divisive historical development of community children's nursing in Britain has resulted in it developing on an ad hoc, local basis, rather than as a national service. What emerges is a disparate development of models of service provision (Eaton 2000). Despite this fragmentary development, community children's nursing is unified by its inclusion in the profession of children's nursing. The next section explores the construction of children's nursing as a profession and as a profession dominated by women (Purnell 2007).

1.3. Is children's nursing a profession?

The professional status of children's nursing is an important concept to explore, because the responsibility for caring for children living with illness is contested with parents and health care professionals both claiming various levels of responsibility (Coyne 2007). A useful structure to explore the claims of children's nursing, including community children's nursing, to being a profession may be provided by Abbott and Meerabeau (1998) who argue that caring professions are subject to the sociological concepts of profession, which demand that an aspiring profession demonstrates; a body of knowledge, attempts at social closure, and the social contract of vocation. For nursing these concepts of profession themselves occur in the gendered context of medicine (Witz 1992, Davies 1995).

Lee (2003) has used Fawcett's framework to argue that children's nursing lacks the level of nursing knowledge required to make it a separate body of knowledge. Lee

(2003) assigns the models of children's nursing to mid range theory and points out that these are derived from adult nursing models, based on adult views of person, health, environment and nursing.

The poor theoretical basis for children's nursing is evident in the way that the concept of family-centred care has been applied. Much of the rhetoric in children's nursing concerning "family-centred" care is founded on an article written by Ann Casey in 1988. Casey's work was never developed into a model, but articulated a tripartite relationship between child, parent and nurse. This reflected a shift in children's nursing during the 1970s to include parents in their child's care (Coleman 2002). However, Coleman (2002) suggests that the concept of family-centred care is socially constructed, albeit that the concept is not one shared by all families, and is perhaps more professionally constructed. Coleman (2002) also suggests that it is a concept that has not translated well into all areas of practice, citing poor education of nurses and power issues between nurses and parents as possible barriers to its implementation.

Despite the weak evidence of a separate body of knowledge, children's nursing has sought social closure. The concept of social closure, which enables one social group to control specified work, is based on the ideas of Weber (Freidson 1970).

Professions exclude others by means of education, accreditation and by use of the law. One has to pass a Nursing and Midwifery Council (NMC) approved course to become a nurse, and only those on the NMC register can legally practice as a registered nurse (British Parliament 2002). As Witz (1992) discusses at length, the history of social closure in nursing has been riven with gender politics, with women

struggling, and, Witz suggests, ultimately failing to achieve social closure for nursing separate from the male dominated medicine.

These claims of nursing to professional status remain contested areas (Liaschenko and Peter 2004). During the past century nursing has struggled to portray itself as a profession, independent of medical power, with its own worth (Witz 1992, Davies 1995). In addition post modernist voices have challenged nursing's standing as a profession (Liaschenko and Peter 2004, Lister 1997). These writers argue that re-casting nursing as work would allow nurses to take on many roles and responsibilities rather than attempting to present a restricted "expert" professionalism. It would also allow recognition of nurses' intellectual as well as manual labour (Liaschenko and Peter 2004). However, as the authors admit, the conception of nursing as work has yet to be put into practice.

These arguments about professional care assume, of course, that nurses want to claim that children's nursing is a profession. The concept of profession is itself influenced by masculinity. As Davis (1995) points out, what appear on the surface to be gender-neutral bureaucratic and professional systems, on closer inspection, reveal systems that value male views of work. This male view rewards work that is impersonal, logical, autonomous and situated in the public space, while ignoring and devaluing female work as "supportive" and subordinate. Davies argues that the male perspective of the autonomous worker, dedicated to the profession and the organisation (the NHS) is rewarded with status and career advancement. She further argues that the male gendering of profession places nursing in a triple bind by denying nursing professional status, as it is not autonomous, and by rejecting

nursing's feminine aspirations to nurturing and holism, while the highly bureaucratic/military nature of nursing organisation supports the male hegemony (Davis 1995).

Lastly, professions profess to a vocational ethic. Ballou (2000) has argued that nursing has a social contract, which is inherently moral. Yet the work of caring for children living with illness is a contested field. Both parents (especially mothers) and nurses lay claim to it (Kirk 2001, Coleman 2002). Thus the value to society of professional children's nursing is open to question, as in part this work is undertaken by parents (this debate is explored further in section 9.3. *Responsibilities for children parents, professional nurses and the state*: page 253).

The claims to professional standing of children's nurses are limited. The evidence for a separate body of knowledge about children's nursing is weak, the gender politics of health care has led to ineffective social closure and confusion over the work of caring for children living with illness weakens nurses' claim to a vocational social ethic.

These weak claims to profession may have contributed to the development of various models of service as community children's nurses seem to have struggled to articulate what community children's nursing is to other health care professionals (Acornley 2005).

1.4. Provision of nursing services for children living with illness

Despite these difficulties of whether community children's nursing can claim professional status, nurses are delivering care to children in community settings. This section sets out the models of service provision in use and attempts to estimate the

number of children who receive care as well as examining the type of interventions that nurses deliver. The number of children who receive care, the interventions offered and the way the work is organised make up part of the political landscape of community children's nursing and may influence children's experience of receiving care.

1.4.1. Models of service provision

The ad hoc development of community children's nursing may explain why nurses have not developed specific models of community children's nursing, but borrowed concepts from hospital nursing and focused on similar agendas (Kirk 2001). Eaton (2000) showed that there were various models of what constituted a community children's nursing service, including adult district nursing services;

- Hospital outreach generalist. Nurses based in hospital deliver care in community settings for children with a number of medical labels.
- Hospital outreach specialist. Nurses based in hospital deliver care in community settings for children with a specific medical label e.g. Cystic Fibrosis.
- Community based teams. Nurses based in Primary Care Trusts both generalist and specialist (see above).
- Hospital at home. Services delivered mostly by nurses which would otherwise be delivered in the hospital setting.
- District nursing service. Adult nursing service delivering nursing interventions to children.
- Ambulatory or assessment unit. Services delivered to children on an outpatients basis either hospital or community settings usually in a dedicated facility (i.e. not the child's home).

(adapted from Eaton 2000)

The variation in service also extends to the hours that services are available to children (Forys 2001). Even the skills and qualifications within teams vary. While

and Dyson (2000), in their study, showed that nurses in hospital based teams who provided outreach services in the community had different skills and qualification from those in community based teams. The various configurations of services and the levels of qualifications and skills make assessing the impact of community children's nursing complex. The confusion over provision of services and the lack of a "corporate" identity for community children's nursing may well cause children and parents to be uncertain about what to expect from nursing services.

1.4.2. Estimating the number of children receiving nursing care and the activity of nurses

Estimates of the number of children receiving nursing in community settings and the interventions they receive are fraught with problems of definition. Children living with illness and receiving nursing care have been given various labels such as medically fragile (Leonard et al 1993), technology dependent (Wang and Barnard 2004), and having complex health care needs (Miller 2002). These children may also be considered disabled (British Parliament 2005 Disability Discrimination Act).

When these terms are added to those of chronic illness, life threatened and life limited, what emerges is a confused picture where children are often given multiple labels. This confusion of terms means that counting the numbers of these children is very difficult (Glendinning et al 2001).

Determining how many of these children receive nursing care in community settings is no less difficult. A calculation of the number of children living with illness or disability is insufficient as some may receive nursing care, but others will have their needs met by a combination of parental, or informal care; hospital based care; non-

governmental or charity sector care and social care. While there are no reliable figures to indicate how many children are receiving nursing care available from government sources or non-governmental sources, an estimate of the number of children being seen by community children's nurses can be calculated using figures provided by Cramp et al (2003) as follows.

Cramp et al's (2003) study suggests that each community children's nursing team, on average, manages almost 600 children per year at home. Multiplying Cramp et al's estimates by the recent estimates of number of teams in the UK, which stands at 247 (RCN 2007) i.e. 600×247 , gives a figure of 148,200 children per year being cared for in community settings.

There are a number of difficulties with this estimate. As discussed above, the configuration of teams is variable and not all teams offer the same levels of provision. Some teams within the 247 may have smaller caseloads as they may provide specialist services, such as services just to children with oncology conditions (Cramp et al 2003). Other services may offer hospital at home provision and see children with medical or surgical conditions. These teams provide services to a much larger number of children (Cramp et al 2003). This estimate of 148,200 is only based on mean caseload numbers. Cramp et al's study was conducted in 2001, since when the numbers of children surviving with nursing needs that can be met in the community may have increased. Advances in technology and clinical practice have also led to an increase in the number of children cared for in community settings, for example the provision of Total Parental Nutrition at home (Glendinning et al 2001). In some areas services once delivered in hospital have been redesigned and are now

offered in community settings (Jennings 1994). These hospital at home type services tend to have high caseloads with children being seen for short periods of time, rather than the services to children with long term conditions which have lower case loads, but less turnover. Thus this estimate may be inaccurate.

However, this estimate is in part supported by government calculations that put the number of disabled children in England who have complex needs, which may require community children's nursing, at 100,000 (Department for Education and Skills and HM Treasury 2007). This report only suggests that these disabled children may require nursing services. Some may, others will not.

Until April 2004 statistics were collected via the Körner form KC59 which detailed the number of initial contacts by community children's nurses. The final report of these statistics shows the growth in community children's nursing from 23,300 initial contacts for 1994/5 to 42,600 in 2003/4. However, of 302 known providers of specialist nursing care, 27 did not complete their return in 2003/4 and some of these may have been providers of community children's nursing. The terminology used on the KC59 was Community Paediatric Nurse, not a term used in the profession of nursing because of the confusion with Community Psychiatric Nurse (CPN) (United Kingdom Central Council 1995). This confusion of terms may have led to some inaccuracies in the data. Finally, the statistics may not capture children receiving nursing from adult district nursing services, or from nurses "out-reaching" from hospital.

The statistics provided by government on palliative care services are equally unhelpful in regard to community nursing services (Cochrane et al 2007). Although it estimates that 18,000 children 0-19 yrs (excluding neonates) require palliative care services, it does not detail the community nursing provision for these children. It does give the percentages of children who die at home, which ranged by region from 14.5% - 25%. However, again the involvement of community children's nursing services is not indicated. Although statistics on care packages provided at home to adults are published, those for children are not (Department of Health 2004b).

Thus there are no reliable, published data on the number of children receiving nursing care at home. However, the figure for England may lie somewhere in the region of between 50,000 and 100,000 children receiving nursing care at home per year. This may rise to something closer to 150,000 children for the whole of the UK.

It may be possible to get a sense of the sort of children who are included in these overall estimates of children who may be receiving nursing care in community settings from the work of Glendinning and her colleagues (2001). Through examination of applications to the Family Fund, they calculate that there may be as many as 6000 children in the UK who rely on technology, many with substantial nursing needs. This figure includes an estimated 1000 children living with a tracheostomy, some 800 children at home on supplementary oxygen and about 100 children who are ventilated at home (Glendinning et al 2001). However, these figures are reliant on parents making applications to the Family Fund (a government sponsored charity), and as such, they may underestimate the number of children, as

applying for funds may carry a stigma and involves filling out government forms (Glendining et al 2001).

The range of activities undertaken by nurses with children at home is very varied. Cramp et al (2003) report that most teams monitored vital signs, administered medications, altered pharmacological regimes and were involved in feeding and wound care. While and Dyson (2000) also reported that teams were active in making nursing assessments, providing psychosocial care, postoperative care, palliative and end of life care as well as teaching parents and family members. Although these studies give an insight into the range of activities undertaken by community children's nurses, they were conducted in 1997 (While and Dyson 2000) and 2001 (Cramp et al 2003). The period between these studies has coincided with a shift in the National Health Service from a hospital focus to a primary health care focus, based in community settings (Department of Health 2000, 2001b, 2002 a/b). This shift in policy and service provision is evident from the rise in community children's nursing teams. Whiting (2005) identified 24 teams in 1988, by 2004 this had risen to over 200 teams. The latest version of the RCN's directory of community children's nursing teams puts the figure at 247 (RCN 2007). The expansion of community children's nursing during the 1990s and 2000s may have led to nurses taking on new activities.

The confused picture of community children's nursing, where categorising and counting the children who receive care is difficult, the organisation of nurses' work follows different models, and what they deliver is difficult to define, may leave children receiving these services confused as to what they should expect from nurses.

1.5. Summary of context of the study

This chapter has explored the background to this study, looking at the context of community children's nursing. A historical perspective of community children's nursing was used to argue that division in adult and child health care has led to fragmentary, and localised, services for children being nursed at home. However, simultaneously medical and nursing advances have led to an increasing number of children requiring nursing care at home, which in turn has led to a relatively rapid increase in community children's nursing. In part, the expansion in community services has been fuelled by a shift in government policy from hospital based services to primary care and community settings.

This has come at a time when hearing the voices of children speaking about their own health care has started to be recognised as beneficial to service development. As there is confusion about models of service provision, and about the identity of nurses delivering care to children at home, listening to children's voices may provide useful insights to bring clarity to the role of the community children's nurse.

The next chapter will review what we already know from the literature about how children experience nursing care, both in hospital and in community settings, in order to inform specific research questions about children's experience of receiving nursing care in community settings.

Chapter 2 Literature review

2.1. Introduction

Bearing in mind the context of the development of community children's nursing, from the previous chapter, this chapter explores what is already known from the nursing literature about how children experience receiving nursing care. The chapter starts with the method used to search the literature. Then the issues identified by the analysis of the literature are detailed. Two overarching issues were identified. One, that children present themselves as like other children, and two, children's relationships with nurses and nursing. The strength of the evidence base relating to children's experience of receiving nursing care is examined and finally, the issues from the literature are related to the emerging research questions.

For the purposes of this literature review, aspects of a phenomenological approach are used as part of a mosaic of methodologies and methods (see chapter 3). A descriptive phenomenological approach, in line with the ideas of Husserl, advocates the researcher entering the field free from preconceptions (Welton, 1999).

Performing an extensive literature review, it could be argued, may prejudice the research in that the researcher attends only to the data that supports what is already known about the phenomenon, rather than allowing research questions to arise from the data (Miles and Huberman 1994a). However, not searching the literature and entering the field with no focus runs the risk of generating lots of data which may be irrelevant to exploring the phenomenon. Miles and Huberman (1994a) have characterised this dilemma as "tight versus loose", where "tight" is a more structured, pre-conceptualised, approach most suited to phenomena about which some aspects are already known. "Loose" refers to a study like this one where the

phenomenon has not been explored in depth and a more inductive and emergent approach can be useful.

Clark's (2004) Mosaic approach would suggest the need for a "loose" literature review and setting of research questions, as a principle which underpins Clark's mosaic is the co-creation of knowledge by children and adults (see section 3.2). A researcher armed with a "tight" set of questions based on an extensive literature review may miss cues from children about issues which they would want to address, but which might not appear in professional literature.

In this study the approach has mixed aspects of "tight" and "loose". While research questions arise from this review of the literature to give a "tighter" structure. The research questions were deliberately kept open and general to allow the exploration of the phenomena using "how" and "what" based questions, in a "looser" approach. Brown and the World Café Community (2002) suggest that these "how" and "what" questions are useful in allowing conversations to develop.

The chapter begins with perhaps more of a "tight", structured approach and looks at how the literature for the review was selected.

2.2. Literature review methods

This literature review follows a method adapted from Parahoo's framework for a systematic review process (Parahoo 2006). As this literature review is intended to support the study of children's views of being nursed at home, a specific research question to guide the literature review was not set. However, the steps that Parahoo suggests for a review of literature have been followed:

- Define terms.
- Design a search strategy including setting inclusion/exclusion criteria.
- Search evidence.
- Select items to review.
- Synthesise the evidence.
- Appraise evidence.
- Conclude and make recommendations in terms of the current study.

(adapted from Parahoo 2006 p 137)

Although a number of approaches have been suggested for reviewing literature (Creswell 2003, Hart 2001), these all seem to follow similar processes. Parahoo's suggested framework is as systematic and logical as those recommended by other authors.

2.2.1. Defining terms

Terms which need to be defined are: children, nursing and community setting. In the context of this study "children" is used as short hand term for children and young people. It assumes a 0-19 age range in line with the National Service Framework for Children (Department of Health, 2004a), while appreciating that childhood is socially constructed. This means persons born before 1988 might be assigned the label adult, while those born after 1988 may be labelled as a child, given that at the time of writing those born after 1988 would be aged 0-19 years.

Children's nursing is meant to reflect nursing care, which meets the needs of children, using the Royal College of Nursing definition of Nursing (2003):

"Nursing is the use of clinical judgement in the provision of care to enable people to improve, maintain, or recover health, to cope with health problems, and to achieve the best possible quality of life, whatever their disease or disability, until death."

(Royal College of Nursing, 2003)

Children's nursing is used in preference to paediatric nursing, as paediatrics is the study of children's illness and arguably objectifies children by taking a view of children as defined by medical labels (Shaw 1996).

Community settings refer to children receiving nursing care in a space outside the institution of a hospital. This is normally the child's own home, but may include their school or a GP practice, or community health centre.

2.2.2. Search strategy

An electronic search was conducted using the following databases;

British Nursing Index 1985-2007

Journal Ovid full Text 2007

EMBASE 1988-week 46 2007

International Bibliography of Social Science 1951-week 2 2007

Medline 1950-Week 1 November 2007

Psychoinfo 1967- week 2 November 2007

A keyword search was undertaken by combining the words *children* and *nursing* with the following keywords; *perception, views, conceptions, social construction, therapeutic relationship* and *image*. This was repeated as a search of words in the title of papers with the addition of the terms *nurse* and *child*. Both these searches were limited to papers on children aged 0-18 years old.

However, only one study was identified from this electronic search strategy - While and Dyson (2000), therefore the strategy was supplemented by hand searching of the following nursing journals;

Journal of Paediatric Nursing
 Journal of Child Health Care
 Journal of Clinical Nursing
 Journal of Advanced Nursing

To ensure the quality of the reported studies, only peer reviewed journals were used. Copies of the journals from the past 10 years were hand searched, or the content list for each issue was reviewed online.

The author's experience as a children's nurse and of teaching children's nursing had made him familiar with a number of sources. Other sources were recommended by colleagues, students and practitioners in the field of children's nursing and research, for which grateful thanks are due. This informal searching brought so called grey literature and policy documents into the review. Although grey literature and policy documents may not be peer reviewed they can offer useful insights (Oermann et al 2008). Including these sources may also reduce publishing bias. Peer reviewed, published work may be biased because studies are only published if they fit with the editor's and peer reviewers conceptions of what is worthy of publication. This may exclude studies which have negative findings (Stern and Simes 1997). Studies were either included or excluded from the review using the following criteria:

Inclusion criteria	Rationale
Studies that reported the views of children (0-19) on or about nursing, or some aspect of nurses, or nursing care either in hospital and, or community settings.	Relevance to area of study
Written in English and reporting studies conducted in developed western, minority countries	Findings are more likely to be transferable/of relevance to a British cultural context of nursing children.
Studies not limited by age or methodology	Studies into children's views are rare therefore including all sources increased the number of studies available.

Exclusion Criteria	Rationale
Studies that only report views of adults of nursing, or some aspect of nurses, or nursing care.	This study is focused on children's views, and does not accept adult's views are a proxy for those of children.
Studies not written in English and which report on studies conducted in developing, non western, majority countries.	The cultural context of childhood may make these studies less transferable/of relevance to British nursing practice.

The lack of studies taking a children's perspective of receiving nursing care at home, has led to the inclusion criteria for this review being set wide, to capture as many aspects of the phenomenon as possible. It is acknowledged that some of the methods used to identify sources, such as personal contacts from teaching children's nursing, may mean that some sources may not be accessible to any one wishing to repeat this literature review. However, these methods have added to the breadth of the review and highlighted aspects which conventional search strategies, such as electronic searching and hand searching, did not reveal.

2.2.3. Synthesis, appraisal and conclusions

The studies which relate directly to children's views of receiving nursing care were organised into issues and are presented in the section on children's experience of nursing care below. The strength of the evidence base is considered in the section, "Evidence base and methodological issues" (section 2.4.).

2.3. Findings of literature review

This section explores the studies that have asked children about how they experience receiving nursing care. At first this may seem a relatively simple task- asking children for their views. However, as is pointed out in the discussion of methodological issues, few of these studies set out clearly how the researchers ensured that adults did not influence, or answer for children. Despite this, the

analysis of these studies reveals two aspects of the social phenomenon of children's nursing.

Firstly, there are aspects which relate to the issue of children, being like other children, where children focus on family and friends rather than on receiving nursing care.

Secondly, there are recurring issues that relate to children's relationships with nurses and nursing. An issue emerges from the literature about how children construct their relationships with nurses within a cultural context of childhood and health care provision. In these studies children suggest that they look for a certain persona in nurses, where nurses are fun, but also connect with them as people and are competent as nurses. The studies also show that children sometimes feel that in hospital nurses take away their sense of control.

Community and hospital based studies did not show a great deal of variation, in terms of what they reveal about children's experiences, so these studies have been reviewed together.

2.3.1. Children, like other children

Perhaps the most prevalent issue identified in the literature is that of children attempting to portray themselves as just like other children. Rather than focusing on the nursing care that they receive children appeared to prefer instead to talk about family, friends and playing. It could be argued, that these are concerns they have in common with any other child, rather than focusing on the health needs which may be specific to them.

In the community setting, studies of community children's nursing have shown how children focus on their family, friends and play. Carter's (2005) study of ten children (aged 2.5-13 years) from five families reported one of its main themes as how children measured nurses' care against the standard of their own parents' abilities to deliver care. Children also expressed a desire for parents to deliver all of their care. This could be interpreted as children attempting to portray themselves as being like children not living with illness, as they may believe that "other" children have their care needs met by their parents. Sartain et al's (2000, 2001) study of 11 children aged 5-12, also found that children preferred home care and focused on family, friends and play when asked about nursing care. This finding was confirmed in a larger scale study of 123 families by Lewis (1999). Horne's (1999) phenomenological study of two young people with Duchens Muscular Dystrophy highlighted how the young people appreciated the need for nurses, but preferred receiving care from family and friends:

"They acknowledge that nurses are there for their safety and health but both expressed that they would like people they are close to such as family or friends to be the people with them and not a nurse"

Horne, 1999 page 39

Earle et al's (2006) study of five children (aged 4.5-17 years) who required ventilator support at home, in Canada, describes the children having a stoical acceptance of medical and technical nursing interventions but with a focus on family, friends and school.

Studies of children receiving hospital nursing care also reported children's focus on their family, friends and play (Coyne 2006, Carney et al 2003). Carney et al's study in two Scottish district general hospitals with 213 children aged 4-17 years, showed

how children focused on home life. In this study, 11.7% of children referred to returning home and 52.1% referred to how they had tried to manipulate the hospital environment to resemble their own home. The children referred to a desire to go home, to have parents present and to missing their home life. Coyne's (2006) study in two English hospitals, which used in-depth interviews to research the views of 11 children (aged 7-14 years), showed issues of children's separation from home and uncovered how hospitalisation disrupted the children's social life including school activities, sport and holidays.

Carnevale (2007) has suggested that the focus of children on family, friends and play could be seen as an attempt at performing "normality" and perhaps indicates what Goffman (1968) termed "passing". Goffman (1968) described how those who are stigmatised by society for a number of reasons, including illness, attempt to disguise or deny their status as members of a stigmatised group. They attempt to pass as being "normal" i.e. not belonging to a stigmatised group. "Passing" as normal may involve many strategies to avoid the social censure of being stigmatised. Carnevale (2007) has applied Goffman's theories to the experience of families with a child requiring home ventilation, and describes how children are highly motivated to engage in passing strategies. For example a parent in Carnevale's study described how their daughter hid her need for ventilation over night:

"She doesn't want to be different from others. She wants to be like the others. The fact that she has a machine overnight doesn't bother her because no one sees it."

(Carnevale 2007 page 15)

The preference for home care (Sartain et al 2000, 2001, Carter 2005) could also be seen as a “passing “ strategy, as home care is arguably less visible and less disruptive to children’s social interactions, such as schooling.

2.3.2. Children’s relationships with nurses and with nursing: negotiating living with illness

An issue present in some studies was that of how children understood and negotiated the delivery of nursing care. It could be argued this is children exercising their social agency to negotiate the social interactions of health care. Mayall (2002) describes such interactions as examples of what she terms the socially structural child. Mayall (2002) suggests that as well as children and childhood being constructed by society, the actions of children themselves influence the construction of children and childhood. Here the suggestion would be that while nursing is socially constructed (Fealy 2004), children are also active in constructing nursing for themselves.

This construction of nursing by children is seen in the main in hospital studies, and perhaps the best example is the classic ethnographic study by Bluebond Langner (1978). Her study of children (aged 1.5-14 years) in a North American leukaemia ward, showed that children understood the social structure of the hospital and of professional groups. For instance, children knew that they were not allowed to enter the doctor’s room, but could go into the nurse’s room. Children also subverted these rules, by hiding in a cupboard in the doctor’s room, or waiting just outside to listen in on the doctors to pick up vital information about children on the ward, which was then circulated. The children had a clear sense that they and their families were separate from the healthcare providers.

Fletias' (1997) study of hospitalised children in North America also showed that children understood the cultural aspects of the hospital. Children appreciated that low morale and the relationship between the hospital management and the nursing staff could affect a nurse's delivery of care. Children also commented that some nurses were able to deliver a standard of care unaffected by these factors. Nurses, in contrast to medical staff, were seen as crucial to the child's experience, as a parent substitute and as a constant source of care. Holyoake's study (1999) in a mental health unit, showed how children perceived the relationship between nurses and medical colleagues. Young people (aged 13-17) recognised that doctors made the important decisions, while, as one participant put it:

“The nurses do most of the actual work, but they have to check with the doctors don't they?”

Holyoake 1999 page 35

The young people were also aware of how nurses reported their behaviour as patients to doctors, and that this influenced care delivery.

As well as the professional and bureaucratic organisation of care, children were aware of their parents' interactions and needs. Bluebond Langner (1978) describes how children colluded with their parents by pretending to be unaware of their prognosis in order to protect their parents. Carter's (2005) community based study also found that children's preference for home care was expressed in terms of it being more convenient for their parents. Children understood that receiving care at home also allowed parents to take a break from care.

Another aspect of how children and young people may reflect the social construction of nursing was revealed in Ramm et al's (2004a) qualitative study, used to prepare for the national Young Patients Survey of 2004. This included a focus group which was biased towards young men as 10 of the 14 participants (aged 12-19) were male. The view of nursing portrayed is obviously one that comes from gender stereotypes:

*“Most of the male participants agreed that nurses should be **young and attractive**.*

“My Dad thinks the nurses should be a bit more good looking...I think the same. I think you need a fit nurse looking after you.””

Ramm et al 2004a page18

It seems evident that children and young people's ideas about nursing do not exist in a vacuum, but are influenced by their experience of hospitals as professional and bureaucratic institutions, and by cultural and social constructions of nursing.

Little attention has been paid to how conceptions of nursing may vary for children of different ages. It seems likely that as the abilities of children, their physical size, and social recognition changes during the period assigned as childhood (Bee and Boyd 2004, James et al 1998), that their conceptions of nursing may also change during the period.

Brewster's (1982) study does consider age, although it looked at children's conception of health care workers generally, rather than nurses specifically.

Brewster's (1982) study was also informed by child psychology, rather than sociology and used a mixed positivist and staged approach, based on the work of Piaget using qualitative interviewing. Although its' theorising perhaps claims too

much for the data, it does suggest how children's concepts of nurses may change over the period of childhood. Brewster divided her results into three stages:

- 5-6 year olds, tended to see medical treatment as punishment for things they perceive they have done wrong.
- 7-10 year olds, saw health care workers as being there to help them, but not always in an empathetic way. Children felt that nurses only knew that the child was in pain if they saw the child crying.
- 10+ in the last stage children inferred helpful intention and empathy in health care workers.

This is of course now a rather dated study. However, it has not been replaced by studies taking a more sociological approach to how children of differing ages view health care professionals. Fealy (2004) has shown how nursing is culturally constructed and temporal. Fealy tracks the course of the "good" nurse in Ireland from the 1820s, pointing out how the establishment of the Irish state brought with it the concept of the good Catholic nurse in the 1920s. Children's cultural construction of nursing and how this may change with time has yet to be fully explored.

2.3.3. Children's relationships with nurses and with nursing: "Fun", connecting and competence

The literature shows a high degree of agreement about how children view the characteristics of children's nurses. This quote from Carter's study perhaps captures the essence of the numerous studies:

"Sophie said "They'd not be much use if they were good [competent] but no fun".

Carter 2005 page 56.

Being "fun" and "nice" was a recurrent issue in much of the literature (Fleitas 1997, Carter 2005, Carney et al 2003, Coyne 2006, Ramm et al 2004a). The "fun" or "nice" nurse seemed to involve more than superficial behaviour and refer to the nurse as a person:

“There was a really nice nurse. She helped me a lot....Just her personality and that stuff.”

Participant quote: Ramm et al 2004a page 106.

Both Fleitas (1997) and Ramm et al (2004a) have reported a deeper relationship between hospitalised children and nurses, something akin to friendship:

“They enter the hospital with vulnerability and found in the nursing staff a protective intimacy that buffers their fear and helps them “learn the ropes.”

(Fleitas 1997) pp197.

“I like to be able to talk to the nurses – like friendly and happy everything – they are like mates and not nurses because they are there every day and you don’t see anyone else.”

Participant quote: Ramm et al 2004a page 19.

Carter’s (2005) study of a community based service found that as well as the personality traits of being “fun” and “nice”, children looked for nurses to entertain them and the ability to connect with them, their families and their pets. The children also wanted nurses to do things the way they liked them to be done. In a list of things that nurses should not do, the children in Carter’s study included acting like an adult, saying “don’t do that” all the time, and being like the hospital nurses.

In Randall et al’s (2008) report of a consultation event where hospitalised children were asked about the educational preparation of children’s nurses, children set out a professional persona of nurses as calm, caring, courageous and connecting. The courage children looked for was for nurses to stand up for children’s rights. As well as this professional persona, children identified personal attributes of nurses that

could be enhanced by attitudinal learning. These personal attributes included: being fun, being patient, respectful and clever. For children, part of being clever was for nurses to know about children's illness. They also expected care to be timely, with prompt delivery of pain relief and attention to toilet needs:

“Teach them to not rush and to take all necessary precautions. They should speak to you nicely and explain what they are going to do and why. They need to take their time and listen to you. Important to be sociable and have non-medical chat”

Notes from Girl 2 interview: How can we make nurses good at their job- nursing you?”

Randall et al 2008.

Rather than relating to particular actions “fun” seems to be a personal attribute along with being “nice”. However, there is some evidence that children look beyond the personal attributes of nurses and demand nurses who are also able to connect with them and their families, as well as nurses who are competent in caring for children who are ill. However, the issue of the “fun” nurse can be contrasted with another issue present in the literature, that of resistance to hurtful nursing.

2.3.4. Children's relationships with nurses and with nursing: resisting hurtful nursing care

A number of sources seemed to indicate that children may attempt to resist receiving nursing care. Children in these studies seem to be indicating that they perceived nursing as not just physically painful, but also psychologically hurtful. Rather than being aimed at particular nurses, there was a sense that the children in these studies were resisting nursing per-se, as an activity.

This resistance was often expressed as a desire to have nursing care carried out by parents, rather than by nurses (Carter 2005, Horne 1999, Earle et al 2006, Carney et

al 2003, Coyne 2006). It may therefore relate to children's focus on family, friends and play described above. For instance in Carter's study the resistance to nursing care is expressed as a desire to change the name of the service children received to exclude the title nurse. As Carter explains:

"They proposed "The Diana Caring Team", "The Diana Caring and Playing People" and "Diana Ladies". They thought including the word "nurse" sounded quite "scary" and explained that the "Diana ladies don't have needles like real nurses, but look after you and have scissors and glue and games"

Carter 2005 page 57.

Although the service in Carter's study was a health and social care respite service and included social as well as nursing activities, it is clear that the children associated the title "nurse" with scary things such as needles. Horne (1999) found a similar resistance to the professional intervention of nurses in his study. The two participants described their lack of freedom, not in terms of their dependence on machines to breathe, but with regard to having to be with nurses, as one of them stated, "48 hours a day" (Horne 1999).

Both Carney et al (2003) and Coyne (2006) found children to be reluctant to talk about nursing. When the children did discuss nursing they focused on procedures, investigations and treatments. These were viewed as hurtful and even potentially fatal (Coyne 2006). Coyne (2006) suggests that the language used by children indicates that the child sees invasive medical procedures as invasions of their privacy as well as of their body. These investigations and treatments, in which nurses are instrumental, were more than just painful, because they had an emotional aspect which made them also hurtful (Coyne 2006). Ramm et al (2004a) also found that this emotional response could be sexualised for children aged 12-17:

“Their explanation helped because her biggest fear was in *having to take off her clothes*.

“It was just, ‘Oh no! I’m going to be lying there with no clothes on, and there’s going to be those two doctors there and you know.’”

Participant quote: Ramm et al 2004a page 101.

Battrick and Glasper (2004) also reported privacy issues. Almost half of their sample (5 out of 13) of 11-16 year olds reported dissatisfaction with levels of privacy while receiving care.

In contrast to this resistance to talking about nursing, Kortessluoma & Nikkonen (2004) found children (aged 4-11 years) in Finland keen to talk about their experience of hurt induced by basic nursing and diagnostic procedures. They also found that children’s experience of pain and hurt was subjective and influenced by factors such as the sight of instruments prior to the intervention, and bleeding during procedures. Although these children were keen to share their experience, they still characterised receiving nursing care as both physically and psychologically hurtful.

The resistance to, as children see it, hurtful nursing care reported in many of these studies may also relate to the last issue to be discussed here, that of control. The resistance to nursing care and the emotional response to nursing may be understood as the child’s reaction to losing control over their body and their social world.

2.3.5. Children's relationships with nurses and with nursing: control

Coyne's (2006) and Carney et al's (2003) studies of hospital nursing suggest that children feel a loss of control, or as Coyne puts it of self-determination. The hospital staff, their priorities and the bureaucracy of the hospital control many daily rituals. Children talked about how they were told when to go to sleep and when to wake up. They also had to seek permission to access food, drink and to use the bathroom (Coyne 2006).

The issue of control is also found in the literature on children's experience of illness (Carter, 2002 et al, Kyngas et al 1998). Kyngas et al (1998) set out in some detail how young people (aged 13-17) in Finland with diabetes categorised the actions of nurses as falling into three types: motivating, in accordance with physicians instructions, or routine. Nurses who provided motivating care started with the young person's own opinions, and worked with them to find practical ways in which to incorporate self care into the young person's life. Each consultation was unique. Nurses who followed physicians' instruction were perceived by the children as reinforcing medical advice and not listening to the young person, putting the physicians' requirement for compliance above the needs of the child. As a child from the study put it:

“This is of no help to me, because the nurses do exactly what the physicians say. They dare not change anything. They have no flexibility in what they do. Their actions helps the physician not me.”

Kyngas et al 1998 page 764.

Nurses delivering routine care were seen as meeting the needs of the hospital and of hospital routine rather than those of the young person. In Kyngas et al's (1998) study

9 out of 12 (75%) children who described motivating care had good diabetic control, but good diabetic control was only achieved in 15 out of 36 children (42%) who related nurses delivering care which was in accordance with physicians' instructions or routine care. Kyngas et al's study was conducted in Finland. However, Carter et al (2002) report similar findings when talking to young people about chronic pain management in Britain. While most were positive about their interactions with health professionals, even though their pain was unresolved, they also described a "here to do a job ... we won't ask about you" attitude. The children expressed a preference for nurses and doctors who acknowledged the human experience of chronic pain, asked about their experience and whether they were coping.

Issues of control also feature in Bury et al's (2004) qualitative study of a children's constipation clinic in London. The study used Simmel's triad of communication applied to the child, medical professional and parent, where partnerships between the child and doctor are forged to transact social interaction of the medical consultation to meet group needs. The study showed that sometimes this child/ doctor partnership could be in opposition to the parents' view. The ethos of the medical team was to encourage children to "own" their problem and to take responsibility for their treatment, rather than enforcing solutions or allowing parents to do so. Using this approach, the team reported improved bowel control for the child.

Giving the patient control of chronic conditions has also featured in adult care where expert patient programmes have demonstrated better management of care and higher levels of satisfaction with life (Lorig 2002, Bodenheimer et al 2002). Qualitative research is beginning to show positive results for programs which aim to improve children's own self management skills, such as the Stay Positive program (Salinas 2007).

Issues of control in the literature seem to be related to the professional and bureaucratic ways in which nursing may be enacted. Children preferred a more individual, creative approach which allows them more autonomy. There is evidence that giving children more autonomy may improve some health outcomes.

Before discussing the implications of the literature reviewed here the strengths and weaknesses of the studies are considered in order to assess the validity of the evidence base on children's views of nursing.

2.4. Evidence base and methodological issues

This section examines the strengths and limitations of these studies. Firstly, claims of representation of children's views are examined. Studies which focus on children's perspectives face a challenge given the hegemony of the adult world. How do they negotiate the power relationships between different generations to ensure that they collect children's views, rather than those of adults? The section finishes by exploring how these studies may point to useful methods in researching with children.

2.4.1. Intergenerational issues

Intergenerational issues relate to the relationships between the generations of children (people born post 1988) and the generation of adults (people born prior to 1988), which may include parents and nurses. Mayall (2002) has argued that aspects of generation can significantly shape children's experience of childhood. It has also been suggested that adults' views cannot be used as a proxy for those of children in research (Scott 2000). Furthermore the power difference between adults and children may lead adults to manipulate or suppress children's views (Robinson & Kellet

2004). A fundamental question for research which seeks children's views is, how does the research account for the potential and actual influence of adult generations on the views expressed by children? In order to claim that such studies give a voice to children, the influence of adults who inhabit the same social spaces as children needs to be understood.

Of the studies reviewed here, only Coyne's (2006) study mentions that children were interviewed away from adult carers. The lack of information on how data was collected from children and the potential influence of adults in all the other studies raises questions about how representative these studies are of children's views. If children were interviewed with their parents, as stated in some studies (Lewis 1999, Sartain et al 2001), it is possible that the views of children were affected by the presence of adults. Only Carter (2005) informs the reader of the stance taken towards children and sets out a sociologically based stance that attempted to include children, to some extent, as co-researchers. While other studies state that children are sociological actors (Sartain et al 2000), the efforts of the research team to ensuring children's views were collected with minimal interference from adults, are not made clear.

What is clear is a bias in these studies towards reporting adult views. In studies that looked at both adult and children's views, such as Lewis (1999) and Sartain et al (2001), the papers report findings focusing on adult views. Although Lewis (1999) claims to involve children, she only reports on the views of 52 healthy siblings and their views only warrant a single paragraph, while adult views are more extensively

reported. In Sartain et al's (2001) paper, the parental findings take up at least 2 pages in the report. The children's findings are given just over half a page.

The power difference between child participants and adult researchers is also clear in the Young Patients Survey 2004 (Ramm et al 2004b). This was a national survey based on preliminary work using qualitative methods (Ramm et al 2004a). However, the issues raised by children in the preliminary stages, such as privacy, disruption of home life and the personal qualities of nurses, were not present in the final, more quantitative survey. Instead the survey focused on bureaucratic and governmental concerns, such as waiting times, and standards of hospital food. Although the survey sample looks comprehensive and perhaps representative, with 62,277 responses, giving a 50 % response rate, the breakdown of who actually completed the survey gives a different picture. The majority of responses (83%) were completed by parents, or by parents with their child with just 16% of responses completed by young people alone. Despite this, the main report rarely distinguishes between parental views and those of children. Similar problems are perhaps present in Battrick and Glasper's (2004) survey of hospital services. With a poor overall response rate of just 50 families out of 130 responding, the authors admit that determining whether children completed the questionnaire without adult influence is impossible.

The methodological difficulties of ensuring that children answer surveys without adult influence may explain why the national young patients' survey has not been repeated since 2004, while surveys of adult patients' experiences are conducted each year (Boyd 2007, Garratt and Boyd 2008).

The claims of this literature, to represent children's views on their experience of receiving nursing care, are then open to question because so few studies reported the stance of the researchers towards children. Only two studies (Carter 2005, Coyne 2006) gave any details as to how the relationships between the generations were managed by the researcher. In addition the rigour of many of these studies may also affect the ability to base decisions on their findings.

2.4.2. Rigour of the studies

The rigour with which these studies were conducted is highly variable. For instance Horne's (1999) is a phenomenological study involving just two participants. Horne was also delivering nursing care to both participants whilst undertaking a participant observation yet he did not report on the ethical dilemmas of practitioner research.

Some of the studies are not balanced in terms of gender (Holyoake 1999, Ramm et al 2004a) and some favour older children (Kyngas et al 1998, Ramm et al 2004a).

There is also a strong leaning towards hospital studies, with studies that report on both settings reporting more about hospital than community experiences (Sartain et al 2001). However, the main problem in assessing these studies is the poor description of the research methods used. For example, Fleitas's (1997) study seems to be based on comments made by children on the Internet, but how these were collected, analysed or verified is not clear. None of the studies report any independent review of data analysis, which could enhance rigour.

Despite the limitations of the studies they do raise some methodological issues, which, if considered in more depth, may suggest ways to research with children in this area.

2.4.3. Children's cultures of communication

Some of these studies, on how children experience nursing, support Christensen's (2004) assertion that children respond to research which is about their daily lives. In Bluebond Langner's (1978) study, children gave detailed accounts of living with leukaemia. However, they could only comment on the stages of accepting the prognosis and trajectory of the illness as they experienced at each stage. The children in each of the reviewed studies had experience of hospitalisation or of receiving care at home. However, Carter's (2005) study points to the difficulty described in chapter 1 about how community children's nursing services vary in their service models. The service delivered in Carter's (2005) study had elements of social care as well as nursing care. It could be argued that children's experience of receiving nursing may be different depending on the service model.

As well as the importance of research asking children about their experience, some writers have suggested that the use of visual methodologies can be helpful when researching with children (Pridmore & Bendelow 1995, Riley & Manias 2004). Carney et al's (2003) study would seem to support this view. This study used four methods to ask the same questions. These were structured and unstructured verbal methods, using interviewing and structured and unstructured visual methods, where photographs were used and children made their own images. The visual methods elicited different data, resulting in a more emotive content than the data generated by verbal methods. This also supports the point made by Darbyshire et al (2005), that qualitative methods used with children, rather than providing multiple views of the same data, may provide more data.

This review has highlighted some important methodological issues which any study in this area would need to address. Firstly, studies need to address how adult influence can be minimised in order that children's views can be obtained. Secondly, the study should utilise children's abilities and ways of knowing rather than applying adult research methods. Lastly, the study design needs to be clearly set out with a description of how rigour was ensured. How this study addressed these methodological issues is discussed in greater detail in the next chapter (sections 3.4, 3.5).

2.5. Recommendations from literature review

This section outlines how the research questions of this study relate to the issues of this literature review and the way in which this study took account of the methodological issues raised by this review.

2.5.1. Issues and questions

The literature reviewed in section 2.3.1. suggests that for children, the experience of receiving nursing care is related to their attempts to portray themselves as like other children. While how children experience receiving nursing care in hospital settings has received some attention, children's experience of receiving nursing care in community settings has been somewhat neglected. Although Carter's (2005) study goes some way to describing children's experience of community services, her study was of a Diana palliative care team whose service included social care. Given the lack of research on children's experience of receiving nursing in community settings, and the focus of children on family, friends and school seen in hospital studies, it seemed reasonable to investigate further how children experience receiving nursing care in community settings.

The literature reviewed in this chapter has described some aspects of the phenomenon of children receiving nursing care, albeit mostly in hospital settings. However, these studies have not explored the factors which may influence how children receive nursing care. As there is little prior work to indicate what may influence children's experience the researcher drew on the work of Mayall (2002) on childhood to suggest gender, ethnicity, and social position as relevant issues. These were combined with factors that in the researcher's professional experience often influence debates in the field of children's nursing, such as continuity of care and the nursing procedures being delivered.

The literature review has explored in more depth what children want and expect from their children's nurses. However, again there are few community based studies, and those that have looked at community settings have often not accounted for intergenerational relationships, or have researched services which provide social as well as nursing care.

Given these conclusions from the literature review in this chapter the following research questions emerge:

- How do children experience receiving community children's nursing services?
- What factors shape how children experience receiving community children's nursing services?
- What is it that children expect and want community children's nurses to do for them?
- What are the implications of children's views for the delivery of community children's nursing services and the wider nursing of children?

2.6. Summary of literature review chapter

This chapter has set out the literature which has influenced the development of this study. The literature review identified the two main issues of how children presented

themselves as like other children and children's relationships with nurses and nursing. Where researchers have asked children about their experience of receiving nursing care, the findings of these studies reveal that children have a strong sense of maintaining their sense of normality. Focusing on family, friends and play was an issue across many of the studies. Children in these studies did not portray nursing as central to their experience of living with illness. However, children were aware of the professional, bureaucratic aspects of nursing within the hospital institution, and the cultural stereotypes of nurses. Another issue identified in many of these studies was that nurses should be fun and needed to be able to connect with children on more than a professional level. Although many of the studies reported how children looked for personal qualities in their nurse, of being nice and fun, there is some evidence that children also look for competence in meeting their health needs and delivering timely nursing interventions.

The issue of resisting nursing care, and the descriptions of the hurt that children felt nursing interventions caused, emerged from some studies, both in community and hospital settings. The desire of children to have care delivered by their parents, thus resisting nursing care, may be related to their perceptions of normality. They may perceive that other children, whether they are ill or not, are cared for by their parents. Therefore to present themselves as like other children they want to receive nursing care from their parents, rather than nurses. However, the perception of nursing care as hurtful may also relate to a sense of loss of control. The issue of control, or lack of control, was evident in a few studies from hospital settings.

The findings of this review need to be treated with some caution, as the evaluation of the methodological issues showed that few studies took account of the influence adults may have had on children's accounts. The limited number of studies and difficulties with the rigour of the studies makes the evidence base weak. However, the studies in this area do point to the inclusion of visual methodologies, as a useful way of capturing aspects of children's experience that text based methods may miss.

The next chapters on the methodology and methods set out how this study attempted to address the research questions and deal with some of the methodological issues highlighted by this review of the literature.

Chapter 3 Methodology: Research with Children

3.1. Introduction

In the last chapter, in section 2.4, three methodological challenges for this study were set out. One, that the study design should ensure, as far as possible, that the voices of children are heard. Two, that the methodology and methods used in the study utilise children's abilities. Three, that the study is rigorous. To address the first two points, Clark's (2004) Mosaic approach was used as an overarching research strategy. This chapter sets out the theoretical basis of Clark's approach and then relates this to the qualitative methodologies which were drawn upon for this study. The study drew on aspects of phenomenology, ethnography and visual methodologies and incorporated them into a mosaic approach. Once the overarching methodologies have been explored, the chapter explores how the third point, that of the rigour of the study, was addressed.

3.2. The Mosaic approach

The Mosaic approach as described by Clark (2004) is a multi method, participatory framework for researching with children. Clark identifies three aspects which she claims give her Mosaic approach a sound theoretical base (Clark 2005). Firstly, the approach is informed by the sociology of childhood as it suggests that children are seen as competent to comment on their own social worlds (Mayall 2002, Prout 2001). Secondly, she points to the use of participatory methods used to empower disadvantaged adults and children in community development work (Kemmis & McTaggart 2005, International Institute for Education and Development 2001). Thirdly, Clark aligns her approach with educational theorists from Reggio Emilia,

Northern Italy, who suggest that children are active partners with adults, seeking learning together (Edwards et al 1998).

In the Mosaic approach Clark combines these theoretical strands to outline her approach. She values the perspective children can give on their social world, and uses a range of participatory methods to allow children with different interests and abilities to contribute to research. Adults and children are involved in making sense of the data and planning how to use the information (Clark and Moss 2001). The effect of this approach is to offer children a “voice”, by valuing what they have to say and designing ways of them saying it within their existing abilities. The different methods give different perspectives on the children’s social world, all of which add to the picture or “mosaic” of the children’s view. Controversially, Clark includes observation and interviews with adults in her approach. Adult perspectives of children and their social relationships are gathered through ethnographic observation of children in their social setting and by interviewing adults about children’s use of social settings. Clark (2004) argues that these adult perspectives allow the researcher to place the children’s participatory data in the social and political context of an adult orientated world. There is a risk in using participatory methods alone of a sort of child’s cultural ghetto view emerging. Combining methods and including adult participant observation may ensure that a mosaic approach connects children’s experience with the adult orientated society in which it occurs.

The danger of adding adult perspectives is that, as was the case in a number of studies reviewed in the last chapter, adult voices drown out those of the children. The ethos of valuing children and of partnership in exploring findings, may, if combined

with good reflexive practice, guard against such an adult bias. However, how generational issues between children and adults are to be addressed in practice is not made explicit by Clark's approach.

The lack of more detailed guidance on the management of intergenerational issues is one of a number of possible challenges to the Mosaic approach. Clark herself points to critiques of participatory methods. These critiques argue that participatory methods have not resulted in the emancipation which was part of their original purpose (Kemmis and Mc Taggart 2005). Clark (2004) does not comment on whether the Mosaic approach has been any more successful in getting adults to act on the views of children. The use of multiple methods, which Clark suggests can lead to triangulation, has been challenged by Darbyshire et al (2005), who suggest that multi methods used with children may not give triangulation of data, but just more data to analyse. A difficulty of qualitative research can be data overload: the generation of so much data that the analysis process becomes unmanageable (Miles and Huberman 1994b). The use of multiple methods in the Mosaic approach may lead to just such data overload. These challenges to the Mosaic approach have not been fully explored in research practice, as the approach has not been widely used by other researchers.

The Mosaic approach may have some weakness, but it does appear to offer an overarching strategy which creates a space to consider children as active partners in research, to consider children's abilities when designing research, and ways of taking account of intergenerational relationships between children and adults. The use of the Mosaic approach in this study, combined with reflexive practice (see section 5.3)

may address the intergenerational issues raised in chapter 2, and provide a framework that facilitates children's voices.

What the approach does not provide is a detailed methodology or methods. Thus applying the Mosaic approach to this study requires an exploration of the specific methodologies adapted to feature in the mosaic.

3.3. Mosaic of methodologies

Mosaics, such as roman mosaics, are pictures made up from small fragments of a material (Longman Group 1991). Unlike a collage, mosaics are generally made from the same material, albeit the pieces are of different colours. Thus in a mosaic approach to research with children, although different methodologies are used, they are from the same paradigm of qualitative research, unlike mixed methodologies, which use methodologies from both quantitative and qualitative paradigms (Creswell 2003). This section explores the rationale for the inclusion of each of the different "colours" of qualitative methodologies, phenomenology, ethnography and visual methodologies, and explores their use in this study. As indicated above, Clark (2004) has described the use of methods often associated with phenomenology, ethnography and visual methodologies, such as interviews, observation and engaging children in image making. Thus while Clark (2004) does not directly link these methodologies to her Mosaic approach, it could be argued that she does advocate their use.

3.3.1. Phenomenological methodologies

Parahoo (2006) has described Phenomenology thus:

“Phenomenology aims to explore the different ways in which people experience and understand their world and their relationship with others and their environment”

Parahoo (2006) page 68

It has been argued that phenomenology underpins most qualitative nursing research, although this is not often acknowledged (Thomas 2005). This is in spite of Heidegger, one of the founding fathers of phenomenology, being closely associated with Nazi fascism (Holmes 1996). This study draws on Husserl’s descriptive phenomenology which predates Heidegger’s interpretive phenomenology (Welton 1999) and draws on the work of writers such as Van Manen (1990) and Merleau-Ponty (1962) whose work does not promote fascist ideology.

Understanding the basic concepts of phenomenology can present a challenge.

Phenomenology is a research philosophy, rather than a particular method (Kleiman 2004). The flexibility which this philosophical approach affords is both a strength and a weakness, it is a strength in that it allows phenomenology to cross various fields unhampered by research traditions; but a weakness in that it presents, at times, a confusing complexity without clear answers (Paley 1998). The potential problems as well as the potential advantages of a phenomenological methodology for research with children are outlined below.

Phenomenology and researching with children: potential problems

Phenomenology has at least two potential problems in relation to research with children. These centre on whether adults can trust children’s perceptions of their social world as relayed through their talk. The first challenge is ontological.

Phenomenology relies on experiencing the world through the human lens of perception. As James et al (1998) have highlighted the naturally developing child view, proposed largely by child psychologists, assumes that children are incomplete adults rather than complete children, largely due to cognitive and linguistic incompetence. The naturally developing child view relies heavily on theories of development. Such developmental theories are based on an assumption that an adult cognitive state exists with the implication being that children's cognition is less sophisticated, or effective compared to that of adults, as children's cognitive states are a step on the way to adult cognitive abilities.

The potential problem is then whether adults believe that children can competently perceive the world, or rather perceive the world as adults do? In contrast to the naturally developing child view, Corsaro (2005) has pointed out how adult society appropriates childhood and how children appropriate elements of adult society. Adult and child cultures are not wholly separate, rather they overlap to a large extent, influencing each other, thus, Corsaro (2005) claims that children interpret and reproduce the cultures (adult and child) of which they are a part.

A potential problem of using adult concepts with children in research is that in looking for adult concepts, one tends to find only adult concepts. This is because of adult bias toward concepts with which adults are familiar, and because as children get older they learn that society values adult concepts. Raman and Winer (2002) found just such an age gradient in their work on how one catches a cold, with older children reporting more adult-like explanations. However, this does not diminish the fact that children had their own explanations of how one caught a cold.

The second potential problem is adult interpretations of children's cultures of communication (Christensen 2004). Van Manen (1990) has stated that phenomenology relies on language, as meaning is constructed and relayed by language. James et al (1998) have suggested that adults' mistrust of children's talk is evident from the fact that childhood studies either focused on older children or on very young children. Older children are judged, by adults, as able to speak for themselves, based on an assumption that they have adult cognition and linguistic skills. The views of pre-verbal, younger children are often collected by using parents as a proxy (James et al 1998, Scott 2000). Thus the talk of the majority of children is rarely used in current research practice.

That children are able to comment on their social world was demonstrated by the Economic Social Research Council (ESRC) programme 5-16 (Prout 2001). This programme of research showed, through various projects, that children aged 5-16 could comment competently, and often eloquently, on their social worlds. These studies and others which engaged children using participatory methods, where children control how they respond to data collection in research, have shown that children often prefer to use non-text based forms of expression (International Institute for Environment and Development 2001). For example, Sharples et al (2003) showed that children can use photography to comment on their social worlds. However, much of the research reported in chapter 2 demonstrates that children can also use text based methods, or talk to express their views on receiving nursing care. These potential problems with phenomenology perhaps reveal more about the relationships between the generations of adults and children than they do about the

particular shortcomings of phenomenology as a methodology for research with children. Placing phenomenological methods and methodology within Clark's (2004) Mosaic approach may reduce these potential problems, as long as intergenerational issues are addressed using reflexive research practice (see section 3.5.1 and 5.3.2.).

Phenomenology and research with children: potential advantages

The first of the potential advantages of phenomenology is that it may formalise reflexivity for adult researchers. A number of authors have commented on the requirement for adult researchers to approach researching with children with a high degree of reflexivity, in order to negotiate intergenerational issues (Mandell 1991, Hill 1997, Davis et al 2000, Corsaro and Molinari 2000, Connolly 2008). Bracketing is the tradition within descriptive phenomenology, for examining preconceived ideas of a phenomenon through the process of reflexion before entering into a study. This process may provide a way of formalising the reflexivity in the research process. The exploration of the natural or everyday ideas about children, childhood and the study phenomena, could be a useful way of making explicit the adult researcher's stance. This could help researchers to avoid some of the methodological problems set out in the last chapter, where the degree to which the research represents the child's voice was in question (see section 2.4.1.).

Bracketing as a concept is controversial. Le Vasseur (2003) has set out the arguments thus: followers of Heidegger argue that one cannot remove oneself from the world in which we exist and research, while those who look to Husserl and descriptive phenomenology argue for a temporary suspension of the self, to focus on how the phenomenon appears to the un-reflexive observer. It is this temporary suspension of

the self to which followers of Heidegger object, as it seems to suggest reverting to the objectification of natural science based on a Cartesian view of dualism – self and the world, which phenomenology was created to critique. Le Vasseur (2003) has proposed a solution to these arguments, by defining bracketing as only reflection focused on the everyday assumptions that an un-reflexive observer may have of the phenomenon. This allows the researcher to be “constantly curious” and to move from received ideas about the phenomenon to a reflexive stance. This would be part of the hermeneutic cycle where prior knowledge is questioned in order to move towards sense and meaning, which, once reached, becomes prior knowledge and the cycle begins afresh. The use of bracketing in this study is discussed in more depth in section 4.5.1. and 5.3.1.

Phenomenology may have another significant advantage, as it only refers to children’s lived experience. Christensen (2004) has argued that children will only respond to research which falls within their realm of experience. Children will often fall silent and lose interest if asked questions on matters of which they have no experience (Christensen 2004). Phenomenology therefore is engaging for children because it is about their lived experience.

Since phenomenology focuses on the context of children’s lives without drawing generalisations, it avoids the trap of making generalisations about all children based on a sample which is often predominately white, middle class and male (Berman, 2003). The context base of phenomenology means it can allow children of both genders and different abilities to describe the lived experience of their faiths, cultures

and social groups. This affords a much more realistic picture of the diversity of children and their childhoods.

Finally, because phenomenology is flexible and is not limited to certain methods, it can accommodate methods based on children's abilities. This makes phenomenology fit well with Clark's (2004) Mosaic approach, as it allows children of different abilities to participate in research.

Some clear advantages can be seen in phenomenology as a part of a mosaic approach to research with children. Bracketing allows for adult researchers' attitudes towards children to be made explicit, formalising the reflexivity of the research.

Phenomenology, because it focuses on children's lived experience, is engaging for children and can capture the diversity of children's experience. The lack of rigid methods allows for participatory methods and non-text methods as suggested by Clark's (2004) Mosaic approach.

The Mosaic approach described by Clark (2004) also includes observation of children. Observation as a method is associated with ethnography (Parahoo 2006). Thus it may be useful to also evaluate ethnography as a part of a methodological mosaic for research with children.

3.3.2. Ethnography and researching with children

Ethnography developed from early studies by anthropologists and seeks to gain an insiders view of cultures through prolonged engagement with people in their natural settings (Bazanger and Dodier 2004). Ethnography has been suggested as the

methodology of choice in children's research (Prout & James 1997). Before the growth of a sociology of childhood, ethnography perhaps seemed a natural choice for adults to investigate the "foreign lands" of childhood, where childhood was seen as a separate culture (James et al 1998). However, if one accepts the assertion of Corsaro (2005), Mayall (2002), and James et al (1998), that children are social actors taking an active part in society, interpreting and reproducing society across the generational divides, then the argument for ethnography as the study of separate cultures fades somewhat.

This is of course to take a colonial view of ethnography as the study of exotic cultures, that is to say other cultures, by the minority or western culture. Ethnography has responded to colonial critiques by including postmodern ideas of difference between and within cultures (Chambers 2003). One such response is Bazanger and Dodier's (2004) description of combinative ethnography, which recognises difference in cultural groups. Combinative ethnography takes separate cases and acknowledges their contextual nature and their difference, rather than attempting to describe the totality of a cultural group's "otherness", separate from the ethnographer. This approach is particularly useful in studies with children in that childhood can not be seen as heterogeneous for children within a culture (Qvortrup 2000). As Mayall (2002) has pointed out, the experience of childhood is dependent on a child's individual social circumstance and generational relationships, as well as temporal cultural aspects. It may be useful then to explore how ethnography can contribute to a mosaic of methodologies when researching with children.

Ethnography and researching with children: potential problems

A potential problem with the ethnographic approach to researching with children is the power imbalance that observation may reinforce (Chambers 2003). Psychological research on children's development often uses observation to categorise children (Bee and Boyd 2004), rather than eliciting their views. Adults continually observe children in school and at home (Mayall 2002), thus the observation of children carries overtones of assessment and control (Robinson and Kellett 2004).

Ethnographic methods may reinforce the view of children as incompetent in terms of adult abilities, by suggesting that adults are required to observe children and place an adult interpretation upon what they observe (Mandel 1991).

The adult researcher as participant observer also presents potential problems that could undermine the claims of ethnography to represent children's social world. The difficulty of an adult participating in and observing the child's world are not dissimilar to those of any observer from a more powerful group observing those of a less powerful group (Foley & Valenzuela 2005). There seems to be little evidence that adults observing children have more or less effect than that of any observer upon what they observe.

The observer effect has been theorized in the dilemma of Schrodinger's cat (Lewis 2000). The dilemma of Schrodinger's cat is a thought experiment where a fictional cat is placed in a sealed opaque box with a radio active atom and a Geiger counter, which is rigged to release a poison that will kill the cat should the atom emit radiation. The waveform of the atom gives a 50 % chance of the cat being killed, or not. Until an observer looks in the box, the cat, in theory, is both dead and alive at

the same time. Therefore the act of observing either saves, or kills the cat (Lewis 2000). This dilemma implies that once a phenomenon is observed it changes and, therefore the observed phenomenon can never truly be the same as the unobserved. Moreover, research with children is perhaps more akin to being with Schrodinger's cat in the box, which Lewis (2000) points out changes the observer as well as the observed phenomenon.

Ethnography and research with children: potential advantages

Despite the difficulties, ethnographic methods have been used by researchers such as Clark (2004) and O'Kane (2000) to allow children to participate in their own way, showing the observer aspects of their world that were important to them. Clark (2004) suggests that such methods can be used to give a voice to very young children often excluded by text based/ verbal methods. Further, Christensen (1993) has argued that the act of showing adults aspects of their experience of pain or hurt is important to children. Clark (2004) and Christensen (2004) have also both pointed out that ethnographic observation of children is vital in order to understand the relationships between children and the adult society in which they are living their childhoods. Ethnographic methods, such as observation, are key to Clark's Mosaic approach. Clark (2004) suggests that observation of children's social interactions allows adult researchers to understand the context of views expressed by children, which is vital to the meaning of children's data.

It could be argued that minimizing the potential problems and maximizing the potential advantages of ethnography is dependent on the adult researcher being reflexive about their role as an observer. Corsaro and Molinari (2000) argue for just

such a heightened level of reflexive ethnographic research practice. It may also be useful to consider critical ethnography as a way to increase reflexivity when using ethnography to research with children. Manias and Street (2001) have suggested that critical ethnography may be useful in empowering nurses and those they look after, to reconstruct relationships and challenge medical hegemony, which suppresses alternative views. Although, Manias and Street (2001) were not writing about children, they refer to the potential for critical ethnography, combined with post-structural discourses to disrupt and challenge historical systems of oppression. It has been argued that children suffer just such oppression because of the historical dominance of adult society (James et al 1998, Robinson and Kellet 2004).

The addition of post-structural discourse of combinative ethnography (Bazinger and Dodier 2004) to critical ethnography may allow the views of children from different social contexts to be expressed, rather than seeking an absolute cultural truth (Manias and Street 2001).

Although ethnography historically has arguably been a colonial study of the exotic, ethnographic approaches which have responded to the critiques of the post modern era, including combinative and critical ethnography, may offer the potential for researchers to empower children by reconstructing their relationships with them. The use of visual methodologies within a mosaic approach may also offer the opportunity to empower children in the research process.

3.3.3. Visual methodologies

Prosser (1998) has argued that qualitative research has been biased towards text based methods and this has influenced qualitative methodology. This bias towards text can make contributing to research difficult for children who may not be able to use language in the same way adults do (see discussion above on phenomenology and its potential problems 3.3.1). Prosser argues further, that the visual relates to ways of knowing which are different from text or language based ways of knowing. These visual epistemologies, Prosser (1998) argues, can add to social research.

Visual methodologies and research with children: potential problems

Although images are made by children in research the interpretations of these images are often adult interpretations and may not reflect the intention of the child who created them (Backett-Milburn and McKie 1999). Nor does presenting children's images within research dissemination solve the problem. Presenting the child's image out of context could allow many different interpretations which may or may not match the child's intended message. Although textual data are also open to interpretation, visual data would seem to allow more flexible cultural interpretations. Backett-Milburn and McKie (1999) have commented that the use of images in the write and draw technique has received little scrutiny while being seized upon as a technique that children can participate in, with little consideration of the consequences for children, or for the philosophical and epistemological bases of the technique. Backett-Milburn and McKie (1999) argue further that the images children produce may be dependent on their abilities to draw; a skill which is variable by age and between individuals, and dependent on the images the children have been exposed to in their social and cultural context.

For some children the act of creating an image may become more important than the message about the research subject. Thus rather than being a communication about the child's experience of a social phenomenon, the image is a piece of art, an object in and of itself. Harper (2003) suggests that making images gives power to the creator, as well as to the subject. For children living with illness, who may be socially disadvantaged (Lewis and Kellet 2004), the images they make may be a reflection of the power they feel in making them, rather than the images communicating how children feel about nursing. There were occasions within this study when children (especially boys) took photographs perhaps to capture the image of an adult, in attempts to play a trick on the adult, to exert power over the adult. When the children were asked about these images they could not relate them to the study topic. However, this sense of control and power may also be an advantage of using visual methodologies with children.

Visual methodologies and research with children: potential advantages

Visual communication may be seen as emancipatory for children. Since Harper (2003) has pointed out that it takes social power to take photographs, and taking photographs or making images of a subject gives the subject matter social standing. Taking photographs and making images of home care may give such social power to children disenfranchised by illness. It may also raise awareness of community children's nursing, which is an activity that has traditionally occurred behind the closed doors of private homes, unseen.

Children may instinctively use visual epistemology (Prosser 1998), or as Christensen (2004) has termed it, the "act of looking", this was illustrated in Christensen's (1993)

work on minor injuries in Danish children. Christensen's (1993) study suggested that rather than seeking remedies from adults, children wanted them instead to "see" the hurt they were feeling.

The draw and write method developed by Pridmore and Bendelow (1995) also attests to children's ability to communicate through image making. Backett-Milburn and McKie (1999) suggest that image making is perceived by adults to be an enjoyable activity for children, although they also caution that image making can access emotional responses which children may find disturbing. Sharples et al's (2003) study of children in three age bands showed how children used photography to record their social world. The use of photo elicitation in health research has also uncovered aspects of young peoples' lives which other aspects of research have not revealed (Riley and Manias 2004, Carney et al 2003). For example, as noted in the last chapter, visual methods may allow children to express emotion about receiving nursing care (Carney et al 2003).

Making images and using images in research with children has been perceived as an easy and fun way to access the views and perceptions of children on social phenomena (Backett-Milburn and McKie 1999, Carney et al 2003). However, issues of children's social position, ethical considerations as well as methodological issues of validity and data analysis remain relevant. Using visual methodologies may also bring other complexities such as the extent to which children are making an image, or exerting the power image making gives them over adults rather, than communicating their ideas on receiving nursing care. However, visual methodologies

also offer the prospect of eliciting a more emotional response from children which may give insights not revealed by other methodologies.

3.3.4. Putting the mosaic together

As described above the methodologies used in this study can be thought of as different “colours” of qualitative methodologies. In order for these “colours” to be combined to make a picture which reflects the phenomenon that is being studied the methodologies need to work together and not oppose each other.

The fact that in analysing the data from these various methodologies no sub set of themes emerged associated with a particular methodology, rather the themes identified were seen in the text, visual and observation data, suggests that the methodologies were coherent. However, there are potential philosophical tensions which could have affected the study.

Taking each methodology in turn, phenomenology, as argued above is perhaps more of a research philosophy which can accommodate the ethnography and visual methodologies if these are seen as ways of exploring the lived experience of children receiving nursing care. However, ethnography is premised on the concept of the researcher as an “outsider”, to a culture, looking in (Bazanger and Dodier 2004). This would seem to be in direct conflict with the exploration of the lived experience of participants which is central to phenomenology (Van Manen 1990). The difficulties of adults researching children’s lived experiences are examined further in section 3.5.1.

However, as set out at the beginning of this chapter, Clark (2005) suggest that ethnographic principles are used only to place children's lived experience into a context of the adult orientated world, in which they live. Without such a context there is a risk adults may misinterpret children's lived experiences. There may also be a tension between the epistemology of text upon which phenomenology relies (Van Manen 1990) and the ways of knowing suggested in visual methodologies (Prosser 1998). This tension relies on an assumption that only textual understandings can represent children's lived experience, yet a number of studies point to how children can represent important aspects of their experience of social phenomena through visual methods (Carney et al 2003, Sharples et al 2003, Wang and Pies 2004). Such visual representations are perhaps influenced by children's cultural backgrounds (Backett-Milburn and McKie 1999) and are therefore useful ethnographic data.

Thus, while there are tension between these methodologies combining them under the mosaic approach offers children a flexible approach, which allows them to contribute to research according to their skills. It does not provide a pure phenomenological approach, but allows children's experience to be placed in the context of their social networks.

This study used Clark's (2004) Mosaic approach to design research based on a mosaic of different "colours" of qualitative research methodologies. Each methodology adds a different perspective or piece to the overall picture of the methodology of the study. The principles of Clark's approach; that research recognises children as active social actors, who should be empowered through

participatory methods to co-create knowledge with adults, were used to draw the methodologies together under one framework. Although phenomenology, ethnography and visual methods all have potential problems when used in research with children, these could be minimised by researchers taking account of generational relationships through reflexive research practice (see section 3.5.1.). Having considered the methodologies selected for this study, it may be useful to reflect on those not chosen.

3.4. Alternative methodologies

Considering other methodologies not selected for this study allows the researcher to reflect further on the rationale for selecting the methodologies which were used (Creswell 2003). This study has taken a qualitative, naturalistic approach rather than a quantitative reductionist approach. In the main this is because this study explores the meaning of community children's nursing to children, rather than attempting to quantify aspects of children's nursing. The focus is not on the services offered to children, but on the meaning to the children of being nursed at home. The understanding sought is the children's lived experience of being nursed at home. Creswell (2003) suggests that this sort of understanding, where meanings of individuals' construction of the phenomenon are sought, fits with the qualitative approach. Creswell (2003) argues that qualitative approaches are best suited to situations, such as the study reported here, where little research exists and therefore variables which influence the phenomenon are unknown. Creswell (2003) also suggests that qualitative approaches can help to build theory where existing understanding does not provide enough information for theory building.

If this study were to have taken a quantitative approach as opposed to the qualitative approach, it would have required the definition of the variables to be studied.

The literature review in the previous chapter showed there has been a bias in studies of children's experience of nursing towards hospital studies, and towards the voices of adults rather than children. Variables from the literature review that seem to influence children's experience of nursing in hospital settings could have been used to see if these were concerns for children at home. However, this would be a more comparative study comparing hospital and community settings, rather than one which explores community settings as important in their own right, not simply in comparison to hospital settings. There is also a danger in this comparative approach of not uncovering factors which may be unique to children's experience of community settings. Given that community settings, such as children's homes, are perhaps more private spaces and hospitals more public spaces (Halford & Leonard 2003), it could be reasonable for the experience of receiving nursing care to be very different in these spaces, due to differences in the degree of privacy and in the bureaucratic context of the settings. The lack then of well defined variables which influence children's experience of receiving nursing care, especially in community settings, would suggest a more explorative and qualitative design is required.

It would appear from the consideration of methodologies taking account of the relationships between generations, or intergenerational issues' such that the study promotes the voice of children may be just as important to consider as methodology and rigour. With this in mind the next section returns to the methodological issues outlined at the beginning of this chapter.

3.5. Methodological issues from the literature review

The setting out of the Mosaic approach and the methodologies used in this study (see above, sections 3.2 and 3.3) has perhaps highlighted that to enact these methodologies and the Mosaic approach, researchers need to consider how, as adults from a different generation, they interact with children. The issues of the relations between generations involved in the study are explored in more detail below. Firstly, by considering Christensen and Prout's (2002) classifications for how adults involve children in research and their concept of ethical symmetry. Secondly, by re-examining Mandell's (1991) "least adult role" in light of how other researchers have approach researching with children.

3.5.1. Intergenerational issues: relationships between generations

Children and adults by definition come from different generations (Mayall 2002). Nominally these might be defined as adults born in the period before 1988 and children born in the period after 1988. The date, 1988 is used to ensure the study is in line with the National Service Framework for children which defines a child as being 0-19 years old (Department of Health 2004a). As Punch (2002) has detailed, researching with adults is different from researching with children. Much of this difference is in the cultural and social approach that adults take to children and childhood (Punch 2002). Research with children requires negotiation between generations. Arguably before such negotiations can begin, adult researchers need to be aware of their own conceptions of children and childhood (Mayall 2008), as well as being aware of how they present themselves in the field to children (Connolly 2008).

In considering the intergenerational issues in this study it may be helpful to look at the underpinning ethical and philosophical ideas that informed how the methodologies were applied in practice.

Christensen and Prout (2002) have outlined four approaches that adults may take to research involving children:

- Research *on* children: an approach that regards children as incompetent, and unable to contribute meaningful research data. Typically it uses parents' or carers' accounts as a proxy for children.
- Research *for* children: this approach acknowledges that children are social actors and is child centred. It operates within a framework of the developing child (James et al 1998) which uses age related conceptions of cognition to limit children's involvement.
- Research *with* children: here children are seen as participants in research as full social actors in their own right.
- The child *as researcher*: this category is described as an emerging approach where children act as researchers investigating their own social worlds with minimal adult involvement

(Christensen & Prout 2002).

To evaluate these approaches to research involving children it may be helpful to consider Christensen and Prout's (2002) discussion of ethical symmetry. Christensen and Prout (2002) argue that researching with children requires a particular ethical stance. Ethical Symmetry, Christensen and Prout (2002) suggest, should take account of the differences between children and adults as social actors. In their paper they draw on Bauman's ideas on researching the "other" in the post modern world, where

a distinction is drawn between taking responsibility for children within research and taking responsibility away from children. Deciding where responsibility lies is useful in rejecting the first two approaches set out above of research *on* and *for* children, in which the responsibility for research is taken away from children, in the belief that they are incapable of contributing to research, often on the presumption of cognitive incompetence. The fourth approach that of child *as researcher*, devolves responsibility to children. Devolving responsibility to children would suggest that children are the same as adults in power, capability and research culture. However, Punch (2002) has suggested that research with children is not the same as with adults, chiefly because of the way adults view children and the marginalized position of children in societies rather than the cognitive or physical differences between the two groups. Christensen and Prout (2002) have argued that for adults to expect children to take full responsibility for research, when they are marginalized, may be inappropriate. In this study children are, in effect, thrice marginalized by being children aged 5-12, by living with illness and often disability (Lewis & Kellett 2004) and by receiving care in isolation in community settings. Children in hospital settings may derive some support from receiving care in a group, while children in home/community settings may not have access to peers who are in a similar situation. To ignore the social relationships of these children, that result in them being marginalised, may create conflict for children and their families with the health care providers upon whom the children and their families rely. Therefore it may be unrealistic to expect children so marginalised to take full responsibility for designing and completing research projects.

For this study the position of researching *with* children seems the most appropriate as the children are marginalised by age, illness and the setting of care. Christensen and Prout (2002) suggest that researching with children requires a reflexive dialogue between researcher and children, which justifies children's level of involvement, and takes account of children's social, cultural and political position, while rejecting assumptions about children's age related abilities.

This study has been influenced by the decision to address the relationships between generations with a policy, where possible, of separation; separating child participants from adult carers. Mayall (2008) has pointed out by that children's data collected in the presence of adults can be influenced by adults, resulting in the data being biased towards adult views. The literature review in the previous chapter would appear to support this, as when data were collected from both children and adults, there was a heavy bias to reporting adult views. The review also showed that adult professional agendas may be presented rather than the agenda of children (Lewis 1999, Sartain et al 2001, Ramm et al 2004b).

It can be argued that collecting data with parents and children together may increase the trust children feel in the researcher, and that children may derive some confidence and support from their parents (Mayall 2008). Some researchers advocate interviewing children with peers, or siblings, in small groups to increase children's sense of power and reduce that of the adult interviewer by the sheer factor of numbers (Mayall 2008, Horner 2000, Kortesluoma et al 2003). However, the discussion below on the "least adult role" approach would suggest that mere weight of numbers in favour of children may not address the power differences between child participants and researchers.

While accepting the complexity of the child-researcher relationship, it was felt that where possible children should be brought together to give their views away from adult carers. The nature of children receiving nursing care at home is that it is delivered in isolation to an individual, rather than to a group of children in a ward/hospital setting. Using group work in this study was perhaps driven more by moral and social imperatives of bringing children, isolated by their illness and nursing care, together to share their experiences.

Even when using group work, a number of writers have described how researching with children requires a high level of reflexivity to consider the implications of being an adult researching children's social worlds (Corsaro and Molinari 2000, Davis et al 2000, Hill 1997, Connolly 2008). Perhaps the earliest attempt to define this reflexive approach was the "least adult role" set out by Mandell (1991). Mandell (1991) uses the principles set out by the ethnographer Mead to underpin her "least adult role" approach. Although Mandell's "least adult role" has been critiqued by Christensen (2004) it is argued here that, Mandell's approach touches on a number of the same aspects of the relationship between children and adults as those used by Christensen and other writers (Christensen 2004, Davis et al 2000, Corsaro and Molinari 2000).

Least Adult Role

Mandell's "least adult role" uses three principles drawn from the work of George Herbert Mead. Firstly, Mandell (1991) suggests that just as Mead describes the difficulties of ethnographers in adult to adult research, the adult researching with children has to attempt to minimize social difference between themselves as an adult and the children in the study. Part of this minimizing the adults' role seems to be

related to answering children when they ask “who are you”. Both Mandell (1991) and Christensen (2004) suggest that children use this question to ascertain what sort of adult the researcher is. Both describe how children presented the adult researcher with situations to test them. This involved rule breaking and rule stretching: to see if the researcher would impose adult rules, or report the behaviour to other adults. More subtle behaviour included looking to the adult researcher to set rules of games or to initiate activities. Both Mandell and Christensen were working in schools so the children had to be convinced that the researcher was not a teacher. This extract from Mandell’s field notes demonstrates her attempt not to be cast as the teacher:

“Cystall is dressed up in black shoes and is carrying a purse. She wanders into the lunchroom, drops her purse and puts on a plastic apron for painting. She starts to paint all over Kyle’s painting and on the actual paint board. Kyle turns to me and says, “She’s painting my picture”. I shrugged and replied “tell Pam (the teacher) if you want to stop her, I can’t stop her, I’m not a teacher.” Kyle repeated his request, I repeated my reply. Finally he went and got Pam”.

Mandell 1991 page 51

The second principle Mandell (1991) uses to underpin her approach is that of valuing children and regarding their social worlds as being as important as those of adults. It could be argued that this aspect of the least adult role is similar to Christensen and Prout’s (2002) ethical symmetry, in that Mandell calls for the researcher to treat children as “social members” and to suspend adult judgments on children’s abilities (she uses the phrase “children’s immaturities”). This valuing of children and of the ways in which children express their feelings or ideas about their social worlds is also a part of Clark’s (2004) Mosaic approach described above. Christensen’s (2004) concept of “cultures of communication”, in which she considers the ways in which children act and speak to communicate, as well as their interactions with adults and the behavior of adults towards children, perhaps builds upon these ideas and adds

more detail to how researchers can enact the principle of treating children as social actors (Christensen 2004). Christensen describes “cultures of communication” thus:

“This approach is an important step away from the idea of researchers developing and using particular methods for particular groups of people. Rather, my work emphasised the importance of seeing fieldwork as a practical engagement with local cultural practices of communication. Thus, by observing children’s language use, their conceptual meanings and their actions, I pieced together a picture of the social interactions and the connections between people.”

Christensen (2004) pg171

Observing the ways in which children communicate with other children and with adults in the context of adult dominated society can, Christensen suggests, help to answer research questions about children’s social world (Christensen 2004).

Finally Mandell (1991) uses Mead’s idea that people coming from different perspectives, such as children and adults (researchers), can find shared meaning through participating in social activities. Mandell gives the example of the social activity of playing in the sand pit. Although “sand” has different meanings for Mandell (or adults) and for the children, both can enjoy playing with sand and through this joint action communicate. This principle of joint action underpins many of the participatory action research methods used in research with children and in the Mosaic approach (Clark 2004, O Kane 2000).

Perhaps as important as the enactment of these principles is the effect of rapport between those involved in the research. Mandell (1991) describes how she built trust with children and adults, so that neither saw her as a threat, in order to be permitted to enter the field and collect data. Cree and her colleagues (2002) have described similar issues of trust and suggested building trust through the involvement of other trusted people, such as a social worker and parents, and the use of social events such

as shared meals. In this study a social trust building event was used before groups with children. This involved the research team and the children going bowling and sharing a meal (see section 4.5.2.).

Christensen has criticized Mandell's "least adult role" as being perhaps simplistic in suggesting that adults can shed their social role and enter the social milieu of the children they are studying (Christensen 2004). The aspects of being an adult researching with children that Mandell identifies appear in a number of other writers' work. Mandell's suggested principles for adult researchers seems at least a useful place to start in reflecting on the way in which adults may go about researching with children. In the next section the communication cultures of children and the effect this may have on data collection are considered.

3.5.2. Children's cultures of communication

In part, aspects of how children choose to communicate with researchers and the ways in which they give data are strongly influenced by the intergenerational issues, discussed in the last section. The use of three methodological approaches also allows for children to contribute to the study in different ways, allowing, to a certain extent, a degree of choice. The selection of just one methodological approach with a restricted choice of methods would force children to contribute according to a certain communication style, which may not be a communication style the child feels able to undertake. For instance the use of draw and write techniques has been criticised as it favours children who enjoy writing or drawing, and may exclude the views of children unable, or uninterested in these ways of communicating (Backett-Milburn and McKie 1999). Giving children a number of ways of contributing data may allow

them to choose the method that best fits with their abilities, and thus encourage children to contribute who would otherwise stay silent.

However, allowing choice of qualitative methods runs the risk that the data collected by different methods, linked to different methodologies may not give data about a single phenomenon, but data about different aspects of a phenomenon (Darbyshire et al 2005). However, as Darbyshire et al (2005) point out, although multiple methods may not allow for triangulation, they do provide for different perspectives to be uncovered. Bryson et al (2008) also argue that research with children requires a degree of flexibility in applying methods and methodologies.

Using observation of children's cultures of communication to suggest suitable methodologies and allowing a choice of ways of giving data may still not result in research which is truly research *with* children. In this study, children were asked what methods should be used (first children's group), however, the methodologies selected all come from adult research. These methodologies are being adapted here to suit children, but have not been generated by children, either for or with children, thus while efforts to acknowledge children's ways of knowing and ways of communicating were used, this study remains an adult research *with* children project.

Taking account of children's cultures of communication again requires adult researchers to be reflexive about their stance as researchers and the methodologies they use. However, if this study is to be used to change nursing practice or inform service development and health policy, it needs to demonstrate not only that it is a

reasonable representation of children's experience, but also that the study has been rigorous.

3.5.3 Rigour of study

Although debates about the rigour of qualitative research in comparison with quantitative research continue (Guba and Lincoln 2005), there is perhaps now a greater acceptance of the value of qualitative work. Evidence of this acceptance can be found in the inclusion of qualitative approaches in research textbooks (Polit & Beck 2004, Parahoo 2006), and the development of tools to evaluate qualitative research (Public Health Resource Unit, England 2005).

The literature review (chapter 2) revealed that research into children's experience of nursing has used qualitative approaches. However, the rigour with which these studies have been conducted was not always evident and this makes for a weak evidence base. Although this study has continued the qualitative trend and not selected quantitative methodologies, the research design attempts to address the issue of rigour.

These issues of rigour are now considered using Guba and Lincoln's (1989) concepts of "trustworthiness" and by drawing on Polit and Beck's (2004) review of these concepts. Guba and Lincoln (1989) have suggested that qualitative research can be evaluated using the concepts of credibility, dependability, confirmability and transferability to give an overall estimation of "trustworthiness". These concepts also underpin tools to evaluate qualitative research (Public Health Resource Unit, England 2005).

Credibility

Credibility is considered to be an overriding aspect of qualitative rigour (Polit and Beck 2004). It involves two aspects, the first aspect relates to validity, or the confidence that the data, and the researcher's interpretations of the data, portray an accurate picture of the phenomenon. The second aspect relates to attempts to demonstrate this confidence to consumers of the research. This study has a number of features which are in line with those that Polit and Beck (2004) suggest enhance credibility. Firstly, they suggest prolonged engagement. Data in this study were collected from children for over a year. Secondly, children participated in different activities which allowed for some triangulation of the data. Although Guba and Lincoln (1989) limit the use of triangulation to matters of fact, Polit and Beck (2004) suggest that it can provide different views of a phenomenon and identify three types of data triangulation: triangulation in time, space and person. This study allowed for triangulation over time by collecting data when the nurses visited the children at different times of day, and by collecting data at different times over a year long period. Triangulation by space was achieved by collecting data in children's homes, in a neutral site (local theatre) and in the work place of community children's nurses in two different areas. Finally, data were triangulated by persons, as data were collected from children away from their main carers, from children and their main carers, and separately from nurses. Data were also collected from individual children, carers and nurses as well as from groups of children, and nurses. The study also included aspects of investigator triangulation, with the supervisory team checking transcripts and images alongside the researcher's interpretations. An independent, experienced researcher from the field of children's nursing also evaluated the

material and interpretations. The use of phenomenological, ethnographic and visual methods provided triangulation of methods.

Another way of increasing credibility suggested by Guba and Lincoln (1989) is member checking. This is a process of taking emerging interpretations of the data back to participants. This was done in this study by taking three statements of emerging interpretations to the final children's group. As Guba and Lincoln (1989) point out, member checking is not without difficulties, such as the possibility that participants will agree to a common myth, or cover up aspects of a phenomenon, so that agreement may not indicate credibility (Emerson 1981). However, in this study member checking was used as much for rigour as it was as a statement of respect for children's knowledge about their experience of nursing i.e. acknowledging children as the "experts" in their own nursing.

The view of child participants as "experts" is perhaps in contrast to the perception of the researcher as "expert". Polit and Beck (2004) argue that researcher credibility, in terms of the researcher as a data collecting instrument, is an important factor in demonstrating credibility to consumers of the research. Researcher credibility is addressed in this study in the account of bracketing, which allows for a discussion of the researcher's personal connections with the study topic and participants (see section 5.3.1.). Researcher credibility is also enhanced by the use of independent review of the researcher's analysis of the data

Lastly, Guba and Lincoln (1989) suggest that credibility can be enhanced by a systematic search of data for negative cases, which allow for interpretations to be

challenged until the conclusions can include all cases. The analysis of data from this study allowed for the consideration of negative cases when developing the thematic approach (see analysis of embarrassment section 7.7. page 210).

Dependability and Confirmability

Polit and Beck (2004) have pointed to the similarities of the concept of dependability to those of stability and equivalence in quantitative research, and also that the stability of data may in part be demonstrated through time triangulation. Aspects of how this study addresses dependability have already been outlined above, namely through time triangulation and by data being evaluated by the supervisory team and an independent expert in the field. The review by colleagues of the raw data may also contribute to the confirmability of the studies findings. Confirmability refers to the potential for those other than the researcher to draw the same conclusions from the data (Polit and Beck 2004).

In this study the “trustworthiness” of using phenomenology, ethnography and visual methodologies is supported by the use of these methodologies by other researchers who have asked children about their experience of nursing (Carter 2005, Horne 1999, Bluebond-Langner 1978, Carney et al 2003). That the data from these studies can be organized into common issues (see chapter 2) suggests that these methodologies may afford a degree of transferability and dependability.

Transferability

The concept of transferability relies, as Guba and Lincoln (1989) point out, on the presentation by the researcher of enough contextual detail to allow the consumers of

the research to find similarities with their own contexts, so that they can apply the findings to their own contexts. Although, some aspects such as sampling and the location of the study may affect this, in the main, transferability is achieved through the use of thick description (Rosenbaum and Silber 2001) in the presentation of data. Geertz (1975) describes thick description as where the reader is presented with detailed information, often alluding to the social context and historical aspects, which allows the reader to interpret the data presented within a cultural context. This approach is used to set out the context of the study in section 6.2.

The credibility of this study was enhanced by the triangulation of methods in terms of time, space and persons. Independent analysis of the data contributed to the dependability and confirmability of the study. Transferability is addressed by the use of “thick” description of the context of the participants set out in section 6.2. Thus the design and implementation of this study has attempted to address the issues of rigour using Guba and Lincoln’s (1989) concepts of “trustworthiness”.

3.6. Summary of methodological issues

This chapter has explored the use of Clark’s (2004) Mosaic approach to address the methodological issues which were highlighted in the last chapter. The principles of the Mosaic approach, which respects children’s abilities, encourages their emancipation through participatory methods and acknowledges that children and adults create knowledge together, gives a framework for research with children to address these intergenerational issues. The ability of the Mosaic approach to address the relationships between generations is enhanced by also considering Christensen and Prout’s (2002) concept of ethical symmetry, which adds a consideration of the

child's social network when considering children's abilities. The Mosaic approach also provides a space to consider children's cultures of communication that encourages adult researchers to question the use of adult methodologies.

The Mosaic approach consists of combining different methodologies to give a mosaic of the children's experience of the phenomenon. In this study three methodologies: phenomenology, ethnography and visual methodologies were reviewed. Although each has drawbacks when used with children, it was argued that in the main, these potential problems could be addressed by improving adult reflexivity in research with children and especially by considering intergenerational issues. It was further argued that multiple methodologies contributed to the rigour of the design of this study, especially by contributing to the credibility of the study through triangulation of data by time, space and persons.

The methods used, which relate to these methodological approaches, are set out in the next chapter.

Chapter 4: Research design and methods

4.1. Introduction

Following on from the previous chapter, on methodologies, this chapter sets out the research design and methods employed. After discussing the access issues, consent and sampling, the chapter explores each of the methods used in this study.

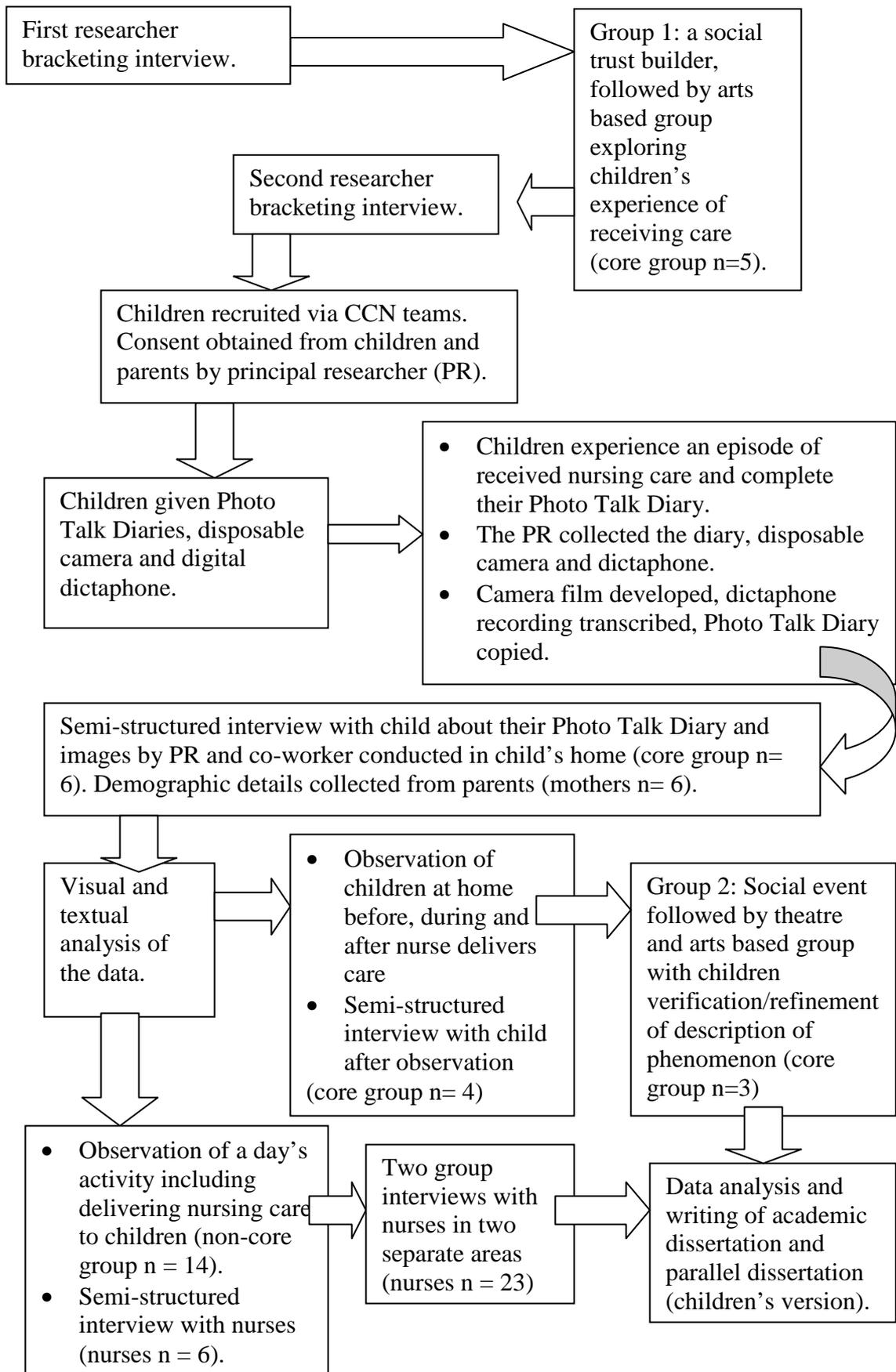
The chapter concludes by exploring how the data collected by these various methods were analysed using a framework based on that of Colaizzi's (1978). The chapter begins however, by setting out the research design.

4.2. Research design

As discussed in the previous chapter (chapter 3) this study drew on Clark's (2004) Mosaic approach as an overarching research strategy. Within this overarching strategy phenomenology, ethnography and visual methodologies shaped the methods employed. These methodologies and methods were combined in the following stages (also see figure 4.1):

- Researcher bracketing interviews
- Group 1 with 5 core group children using arts based activities
- 6 Photo Talk Diary with interviews with core group children
- Observations of 4 core group children receiving care and interviews
- Group 2 with 3 core group children using art and theatre based activities
- Observations and interviews with 6 nurses during their working day including observations of 14 non-core group children receiving care
- Two group interviews with 23 nurses

Figure 4.1. Research design flow chart



The methods used relate to each of the methodologies which make up the mosaic of methodologies described in the last chapter. Phenomenological methods include bracketing interviews, semi-structured interviews and participatory methods used in group sessions and in one-to-one work with children (Photo Talk Diary).

Ethnographic methods included observation of children receiving nursing care and of nurses delivering care, followed by semi-structured interviews. The prolonged engagement with children in the core group for over a year also adds to the ethnographic aspects of the study (data collection with children and nurses spanned a two year period from August 2005 until October 2007). Visual methodologies were realised by using the images made by children in their Photo Talk Diaries and groups.

4.3. Access and consent issues

Before setting out the detail of the sample and the methods of the study, it seems appropriate to consider in particular how children were recruited to the study and a sample established. Ethical approval and other ethical issues are dealt with in Section 5.2. Issues of access and consent were particularly important in this study because of the role of adults as “gatekeepers” as defined by Coad and Shaw (2008) and by Cree et al (2002). Children’s participation in the study was determined in the main by adult “gatekeepers”. However, the role of adult “gatekeepers” needs to be seen in the context of a relationship of trust that is established between the researcher, children and their social networks, as well as between the researcher and other adults concerned with regulating research and delivering care to children.

4.3.1. Access issues

In this study, issues of access have revealed what Cree et al (2002) have termed “gate keeping”, where adults seek to protect children by preventing them from taking part in research. This project had three sets of adult “gatekeepers”:

- Research governance bodies, consisting of the ethical committee and research and development departments of participating clinical areas.
- The community children’s nurses, who controlled access to the case load of children receiving nursing care at home.
- The parents of the children, or other adult carers (e.g. grandparents).

Each of these groups will have its own motivations to allow children to participate, or to block the participation of children. They are also adult groups, and as such are part of the adult hegemony in a society which until recently has not empowered children in health care, or research (Lightfoot & Sloper 2002; Woodhead & Faulkner 2000). While researchers may view children as social agents, adult “gate keepers” may view children as innocents, or immanent or even as evil (James et al 1998). These are views which could lead them to exclude some children, to deter others and to encourage participation amongst children they see as more able to contribute to the research (Curtis et al. 2004). This can be seen in the reported bias towards including older children in research and excluding those under 7/8 years old (Robinson & Kellett 2004; Hill 1997). This tendency becomes more evident when researching children living with illness and or disability, particularly where communication difficulties may be present (Robinson & Kellett 2004).

Research governance bodies

Bodies responsible for research governance and ethical approval may act as “gate keepers”, seeking to protect innocent children from ambitious researchers (Carter 2009). Berman (2003) has suggested that this view of children as innocents in need of protection acts to silence children. Alderson (2004) supported this view when she stated that research with children can resemble the role playing found in Berne’s classic study of the roles people play, where children are cast as “victims” and adults as “rescuers” or “persecutors”. Members of ethics committees may cast themselves as “rescuers”, and may exclude some children from participating in research who they see as “victims”, because they perceive them as too vulnerable, or over researched, while casting researchers as “persecutors” from whom the ethics committee attempts to protect children. This type of bureaucratic “gatekeeping” does not seem to be well coordinated with reports of some children contributing to several consultations and research projects at one time: hence the calls for a national register for children contributing to research and public consultations (Coad & Twycross 2006). Ethical approval for this study is discussed in section 5.2.2.

Community children’s nurses

Nurses, as professionals controlling access, will have their own agenda. The nurses’ relationship with children and families may lead them to over protect their clients (Muir & Sidey 2000). They may make assumptions about parents’ or children’s abilities to cope with participating in research as well as coping with chronic illness. There is, perhaps, a tendency to promote the research with participants with whom the professional has a good relationship, rather than those with whom the therapeutic relationship is less well established, because the professional may believe that these

clients will report the professional's work less favourably. Although Badger and Werrett (2005) comment on the difficulties they had in recruiting via health professionals (health visitors), their review of sampling and recruitment in nursing studies did not show a significant difference in response rates when researchers recruited, in comparison with other professionals recruiting for the researcher. However, many studies did not report who conducted the recruitment and practitioners from the research area were only identified as the recruiters in 8.5% of studies. It should also be noted that Badger and Werrett (2005) found that in studies like this, which are qualitative, community based and use a letter as a means of introduction, reported uptake was poorer. The role of nurses in recruiting participants is explored further in section 4.4.1.

Parents

Parents, too, may have certain agendas in permitting their children to participate in research (Tait et al 2004). Parents may wish to collaborate with professionals to exclude children with negative views of home nursing, fearful that home nursing may be withdrawn if the child expresses these negative views. Equally, parents may feel that allowing their child to participate will ensure favourable treatment from the nursing service in the future. The fact that both these scenarios are excluded in the consent and research information (Appendices 11, 12 and 13.) may not deter some parents from holding these views. Parents may be motivated by a desire to portray their family, their child and, by extension, themselves, as being worthy of research interest and as socially conscientious in participating in research. Parents who fear their child may portray the family and them in a negative way may seek to block their child's participation. One mother contacted the researcher expressing interest in

the study, but concerned that her child would hold negative views. Despite reassurance from the researcher, this mother did not take up the offer for her child to participate.

The motivation for children to participate in research has yet to be fully investigated. It would also be useful to know how children negotiate with these various “gatekeepers” to facilitate their own involvement in research. However, these questions are beyond the scope of the present study.

These “gatekeeping” behaviours of adults who are connected to the child have a direct effect on the child’s ability to consent to being part of the study, in that adult “gatekeepers” may have prevented, permitted or persuaded children to consent to participate.

4.3.2. Consent issues

Alderson (1995) has compared informed consent in research to consent in health care. Drawing on the Children Act 1989 and the Gillick case, Alderson concludes that children’s consent in research terms is a grey area and that researchers may be best advised to adhere to health care consent guidance. As in health care informed consent can be seen as a process of discussion with children and their social networks (family, friends, teachers etc) rather than a one-off point of consent (Brook, 2000; Alderson, 2004).

In considering consent, careful thought has to be given to legal, ethical and social acceptance issues (Masson, 2004). As Masson (2004) sets out, while consent may not be legally required of children, it is ethically desirable. Further, consent which

may be legal and ethical may still fall short of reassuring parents and families about the child's involvement. If the manner of gaining consent is not acceptable to "gatekeepers" then recruitment to the project may be affected (Cree et al 2002). Asking for children's consent can highlight differences in the approach to children that different parties in the research may take (Christensen & Prout, 2002). As Davis et al (2000) discovered, this could result in parents refusing consent if they feel their child cannot contribute. This refusal may be based on conceptions of children as innocents or incapable of making a serious contribution to the research (Davis et al. 2000; Alderson 1995). While "gatekeepers" such as parents or teachers can have a positive effect in protecting children from poor research, they can also control and censure children's responses (Davis et al. 2000, Masson 2004). Views of children as cognitively immature have also raised questions about their ability to give informed consent, especially for vulnerable children living with illness. However, Broome et al. (2001) have shown that children living with illness can distinguish between treatment and research regimes when these are clearly separated.

Some researchers using participatory methods question the practice of offering children the right to withdraw from the research, as participatory methods are supposed to be fun and engaging (Ring, 2000). Despite this, it is generally felt that it is more difficult for children to refuse to participate, or to refuse to answer certain questions; or in the case of participatory research, to refuse to join in activities (Robinson & Kellett, 2004; Hill, 1997). In this study children were encouraged to take control of the data collection process and reassured that refusal to participate, or to answer any questions was acceptable. Parents were also informed of this policy in the consent information (Appendices 11, 12 and 13).

This study followed Miller's example (2000) with separate consent information and forms being used for children and their parents (Appendices 7-13). Like Miller, verbal information was given to parents and children before each stage, with an opportunity for them to ask questions. It was made clear that data would be collected with children away from parents and carers, and that the children's confidentiality would be respected, with anonymity in published work. Parents or carers who wished to know what their child had said or contributed, were asked to discuss this with the child. Written consent was also obtained from all the nurses who participated in the study (Appendix 15)

4.3.3. Confidentiality

Confidentiality cannot be totally guaranteed in research with children, as issues of abuse may need to be shared with others in order to safeguard children (Department of Education and Skills et al 2003; NMC 2008). In addition, in this study, the principal researcher, as a registered nurse, also had a duty to report malpractice (NMC 2008), which may require information sharing in the public interest. However, information, both verbal and written, was given to children to emphasise that their contribution, where possible would remain confidential, both from their parents and from the community children's nurses. While confidentiality when doing research with children may not be absolute, attempts were made to ensure that the research and the researcher were not seen as part of the community children's nursing services. Obviously children may have been reluctant to comment on services, which because of their medical condition they may be reliant upon, if they felt that this could affect their treatment.

In order to protect the identity of the children in written work, the children in the study were asked to pick a pseudonym. It was suggested that this might be a name that their family would use for a new baby of the same sex as themselves, but not a real person in their family. This was not strictly adhered to, but the choice of the children was respected, unless it would obviously breach confidentiality. If the child's chosen name risked identifying the child, the name to be used was negotiated with the child, pointing out the risk of them being recognised by the use of their chosen name. The children were told that these "research names" would be used in any publications. It has been suggested that children may want others to know that they contributed to research and enjoy seeing their words and images in print (Carter 2005).

Children and their parents also consented to the use of some images in published material. Consent has been given by children, their parents for all the images reproduced in this thesis. Any other recognisable person who appeared in photographs also gave their consent for the image to be published. It was made clear to children that the use of their images could allow others to see that they had contributed to the study. Given that children and their carers had consented to the use of their images, and had been informed about how the use of these images may affect their confidentiality, it was felt that it was un-necessary to pixilate the faces of children in this thesis. Not pixilating faces was seen as enacting ethical symmetry (Christensen and Prout 2002), because adult's faces are not usually pixilated in research findings, if they have given consent for their image to be used. Therefore, not pixilating children's face's demonstrates a ethical symmetry with the treatment of adults in research. However, ethical symmetry also requires that one consider the

social context of the child. Neither children, nor their carers asked for faces to be pixilated, it was also made clear that confidentiality was not guaranteed because of the use of images. It was perhaps assumed that if carers felt the images were inappropriate, or might cause embarrassment to the child, that they would veto the use of the image (a number of images were not used because consent was withheld either by children or by their carers).

The ethical issues, highlighted above, perhaps emphasise once again the need for adult researchers to be aware of their role as adults when doing research with children. This requirement for reflexivity is discussed in more detail in Chapter 5.

4.4. Sampling

This section outlines the approach taken to recruiting a purposeful sample of children, their carers and nurses. It details the inclusion and exclusion criteria and the recruitment methods for the study, and then describes the sample of children, their carers and the nurses who deliver care to children in community settings.

4.4.1. Inclusion and exclusion criteria

As outlined in the last chapter on methodology, it was felt that children would be best able to contribute to the study if they had direct and recent experience of receiving nursing care at home. Thus a purposeful sample of children was sought who received community children's nursing services, and were aged between 5 and 12 years of age. The following inclusion /exclusion criteria were used:

- Inclusion criteria: Children 5-12 years old, living in the study area, who received more than one home visit per month from community children's nurses, and had done so for six months or more.
- Exclusion criteria: Some children were excluded if the community children's nursing team (CCNT) deemed that inclusion would be harmful to the child or their family. As far as is possible children were not excluded on the basis of communication difficulties or their first language not being English.

The imposition of an age range is an interesting social phenomenon. Aries (1979) has discussed the use of number to define age as being a relatively modern obsession.

However, as discussed in the previous chapter, one of the principles which underpins Clark's (2004) Mosaic approach is that research methods should use children's abilities. The age range 5-12 years was chosen because it was felt that it was likely that children of this age range would have the abilities that could be accommodated within a single study, as it was felt that different research methods might be required to investigate the social worlds of younger or older children. Younger children may require more action based research methods (O'Kane 2000), while children over 12 were felt to be more influenced by the onset of adolescence and would perhaps respond to more text based methods. Including younger or older children in a study designed for children aged 5-12 may run the risk of the methods appearing to children as either "babyish" or too adult orientated and failing to engage the children. During the observation of the nurses' working day some children were observed who fell outside the age range 5-12. These observations have been included because they were focused on the work of nurses, although they also yielded some insights from observing and talking to the children.

The initial approach to children and families regarding their involvement in the study was delegated to community children's nurses. The nurses were asked to invite the child's main carer to contact the principal investigator for more details of the study.

This delegation of the initial approach was deemed ethically necessary as the nurses delivering care may be aware of factors which would make it unethical to invite children to be part of the study, such as excessive stress from treatment or progression of illness. The nurses were asked not to include children and families if they felt that participating in the study might be harmful to the child or their family. This judgment of “harm” was left to the professionals concerned and as such may have introduced an element of bias. This risk of bias was discussed with the community children’s nursing teams. The teams were asked to include as many children as they could, even if they felt they would not be able to communicate, or if they thought they might hold negative views. All the children whose parents responded to the invitation were included in the study.

The sample of children observed receiving nursing care as a part of the observation of nurses’ practice was dependent on the nurses’ planned work for the day of observation. It is possible that nurses, knowing they were to be observed, selected children and families who they felt would allow for them as nurses to be portrayed in a positive way.

4.4.2. The children

This section provides details of the children recruited to the study. Children participated in this study in a number of ways. However, the children perhaps fall into two groups: a core group who participated in group work/interviews and or Photo Talk Diaries, and a non-core group who were observed receiving care from nurses, but who did not participate in other aspects of the study.

Core group children

The seven children in the core group, who participated in group work/interviews and or Photo Talk Diaries, took part in research activities at intervals for over a year.

Four of the children were also observed receiving care at home. The children's participation in the study varied according to their health status (see table 4.1. below). Some children participated in all aspects of data collection, others just in the group work.

Four of the children from the core group were observed receiving nursing care at home (see table 4.1.). The four were selected because early analysis of the data suggested these children would provide insight to aid the theorising of children's relationships with nurses. Further details of the core group children which may place their views in context can be found in section 6.2

Table 4.1. Matrix of core group children's involvement with the study

Case	Group 1 Text	Group 1 Images	PTD	PTD Int Text	PTD Photos/ Images	Mothers Int	Dict Text	Obs visit Int	Obs visit Field notes	Group 2 Text	Group 2 Images	Group 2 Video
Honey	•	•	•	•	•	•	dnu	R	R	•	•	•
Nanny	•	•	•	•	•	•	nud	•	•	•	•	•
Mohammed	•	•	•	•	•	•	•	•	•	S	S	S
Gizzmo	•	•	•	•	•	•	•	•	•	S	S	S
Kelly	nc	nc	•	•	•	•	dnu	•	•	R	R	R
Joanne	nc	nc	•	•	•	•	dnu	ns	ns	R	R	R
Rabbit	•	•	R	R	R	R	R	ns	ns	•	•	•

• = involved in data collection

PTD= Photo Talk Diary, Dict= Dictaphone, Obs =Observation, Int = interview,

R = refused, dnu= did not use, nud = no usable data

S= sick, nc= not consented at time of group, ns = not selected

Non- core group

Fourteen non-core group children were observed receiving nursing care (for details see table 4.2). These observations were made during the working day of the

community children's nurses who were delivering care to the children. The observation period with these children was limited to the time the nurse spent in the home. So unlike the core group children, where the duration of the observation was influenced by the researcher, parents and children, for non-core group children the community children's nurses had much more influence over access, and the duration of the observation.

No demographic details were sought from the children being observed. Thus the details of the children set out in table 4.2 below are based on information gained either from direct observation, or from the community children's nurses delivering care.

Table 4.2 Age, gender and nursing involvement for children and young people observed receiving nursing care in community settings (non-core group)

Age	Gender (F/M)	Reason for receiving nursing care	Nursing interventions observed
8	F	Oncology condition	Flushing of long line
17	F	Oncology condition	Thumb prick test
11/12	F	Complex health needs sequela to prematurity	Respite including enteral feeding, parental advice
3	F	Liver disease	Taking off Total Parental Nutrition
2	M	Tracheostomy	Respite including suction-health advice to parents
16	M	Oncology condition	Flushing of long line
12	F	Cerebral Palsy (profound)disability	Joint visit with social worker, weight, enteral feeding advice
10	F	Arthritis	Injection
16	M	Abscess	Dressing
4	M	Metabolic disorder	Injection
2yrs 6/12	F	Oncology condition	Flushing of long line
14	M	Abscess	Dressing
6	M	Constipation	Advice
3	F	Abscess	Dressing

4.4.3. Main carers and nursing teams

Clark's (2004) Mosaic approach suggests the inclusion of data from adults as a way of placing children's data in a social context. In this study these data were sought from the main carer of the children (all mothers) and from nurses who delivered care to children.

Main carers (mothers)

The data collected from mothers (main carers) was on the whole demographic data while some concerned the nursing and medical services the children received. Most of these data came from the structured interview (Appendix 4) conducted with the children's main carer after the child's interview about their Photo Talk Diary.

However, other insights were given by mothers in conversations during observations as well as through the data recorded by the children (see section 7.5. page 190).

Table 4.3. Matrix of main carers' (mothers') involvement in the study

Case	PTD Photo Talk Diary Interviews	Dictaphone text	Observation visit interview	Observation visit Field notes
Honey m ^o	•	dnu	R	R
Nanny m ^o	•	nud	•	•
Mohammed m ^o	•	•	•	•
Gizzmo m ^o	•	•	•	•
Kelly m ^o	•	dnu	•	•
Joanne m ^o	•	dnu	ns	ns

NB Rabbit only participated in group work no data was collected from her mother

• = involved in data collection

R = refused, dnu= did not use, nud = no usable data, ns = not selected.

Nurses

The nurses' contribution to the data came from two community children's nursing teams which were selected as a convenience sample, as they were both involved in

the recruitment of children to the study, although all the children who participated came from one area. The two teams delivered care in neighbouring areas. One is an inner city area with a large minority ethnic community and a regional children's hospital, while the second is a rural area with large market towns. The second area has a number of children's services situated within adult hospitals. Community children's nursing is well established within both areas.

A third team involved in recruiting was excluded as no children were recruited from the team. This third team consisted of two nurses based in a hospital which provides outreach services in community settings in the form of a hospital at home service, rather than the community based services that the core group children in the study received. Table 4.4 sets out the involvement of nurses in this study.

Table 4.4. Matrix of nurses' involvement in the study

Cases	Observation visit Field notes Children	Dictaphone Text	Observation of nurses Field notes	Observation Interview Text	Group Interview Text
Area 1	•	•	•	•	•
Area 2			•	•	•
CCN1		•			•
CCN2		•			np
CCN3	•	•			np
CCN 6			•	•	•
CCN7			•	•	np
CCN 8			•	•	•
CCN10			•	•	•
CCN11			•	•	•
CCN 12			•	•	•

• = involved in data collection
np = not present.

Community children's nurses were recruited for the observation element by the team leaders from each of the areas, who had liaised with the principal researcher over the

children's participation. They identified team members who were willing to be observed. This recruitment method meant the researcher had little control over the sample. Selection by the team leader and an aspect of volunteering to be observed may have biased the sample towards nurses more confident in their delivery of care. Nurses less confident, or uncertain of their practice are perhaps less likely to have volunteered to be observed.

The recruitment to the nurse group interviews was perhaps more inclusive. The interviews were held at the beginning of one of the nurses' regular team meetings. Attendance at team meetings seemed to be expected of nurses, but they could avoid the meeting by arranging clinical care at the same time as the meeting. Thus the sample of nurses attending the group interview/team meeting may have been self selecting, although there may also have been an element of the nurses being a "captive" audience because of the peer expectation that they attend the team meeting. Demographic details for all of the nurse participants are given in table 4.5. These data were supplied by nurses and not independently verified.

While attempts were made in this study to set wide inclusion criteria and to minimise exclusion of children based on children's abilities, the necessary ethical considerations of the study of such a vulnerable group meant that the sampling strategy was largely determined by professional children's nurses and the children's main carers. It is probable that these adult influences on the sample will have led to the sample being biased towards a more positive view of community children's nursing.

Table 4.5 Demographic characteristics of nurses involved in study

	Years practicing as children's nursing in FTE	Nursing qualification	Agenda for change banding	Case load ¹
Observation				
CCN 6	3	Bachelor of Nursing (Hons)	5	36
CCN 7	16	RGN/BSc nursing (child)/ BSc (Hons) Community Health Nursing (CCN)	7	12
CCN 8	5	Diploma	5	45
CCN 10	7	RGN/RSCN	6	31
CCN 11	10	RGN/RSCN BSC(Hons) Health Visiting.	6	46
CCN12	9	RSCN/Diploma	6	47
Mean years of practice = 8.3*			Mean case load =36.2	
Areal Group interview				
	2	Diploma	5	-
	3	Diploma/BSc(Hons)	5	-
	6	Diploma/ Nurse prescribing	5	5
	7	BSc(Hons)	5	32
	9	Diploma	6	45
	11	Diploma/ BSc(Hons) Community health nursing (CCN)	6	35
	12	Bachelor of Nursing/Nurse prescribing	6	35
	12	Diploma/ENB 998	6	35
	12	Diploma/ Health visiting	6	50
	12	RGN/RSCN	7	25
	16	RGN/RSCN	7	35
	24	RSCN ENB 405 & 730	7	36
Mean years of practice =10.5			Mean case load =33.3	

Methods

	Years practicing as children's nursing in FTE	Nursing qualification	Agenda for change banding	Case load
Area 2 Group interview				
	3	BSc (Hons)	5	8-10
	5	Diploma	5	-
	5	BSc (Hons)	6	-
	8	Diploma/ BSc (Hons) community health Nursing (CCN)	6	40
	9	Diploma /RGN	6	3
	11	RGN/RSCN/ ENB 998/ Asthma Diploma	6	8
	22	RGN/RSCN	6	35
	-	Diploma	7	-
Mean years of practice = 9			Mean case load =19.2 ²	

Sample included 3 support workers in area 2 (these participant chose not to supply demographic details). All nurse participant described themselves as White British and were female.

1 Case load was estimated by the nurses and not verified

2 Missing data not included.

4.5. Mosaic of methods

In the previous chapter on methodology, a case was made for Clark's (2004) Mosaic approach. Clark advocates the use of participatory methods which allow children to participate in research according to their abilities as children. The methods set out in this section were primarily selected to allow children with different abilities to participate in the study. Allowing children some choice over which methods they used, perhaps is an enactment of Clark's principle of children and adults co-creating knowledge. Rather than dictating to children a method, the children were allowed some choice, although from a restricted palette of methods.

4.5.1. Researcher bracketing interviews

In this study two bracketing interviews were conducted, one before the initial group and one before the Photo Talk Diaries data collection. The concept of bracketing is controversial, and the practicalities of how one attains bracketing are not well defined (Beck 1994). The use of a bracketing interview was suggested by Colaizzi (1978). He describes how an experienced colleague can be used to challenge and uncover the researcher's preconceived ideas about the phenomena of the study. In this study an insightful colleague was sought, who had experience of interviewing and a sociological background. Dr Robert Williams of the University of Birmingham kindly agreed to assist in the bracketing interviews. Dr Williams had no association with the project other than being a supportive colleague.

Each interview lasted 60-90 minutes and was recorded and transcribed. The interviews took place in the work office of the principal researcher during the working day. The first bracketing interview focused on the principal researcher's approach to researching with children and the general methodology of the study. The

second interview focused on the principal researcher's expected results from the study.

It is difficult to say whether the use of a critical outside party in bracketing interviews is any more efficient than self-guided reflection. Either type of reflection is liable to fail from lack of critical thought. A bracketing interview may be subject to interviewer bias, as in any interview process (Parahoo 2006). Yet the bracketing interview is much more of a negotiated conversation, especially as the interviewee may well know more about the subject of the interview than the interviewer. This view of the interview as a collaborative effort is not new (Fontana & Frey 2005). However, there is a risk that, in negotiating the conversation, the "helpful" colleague may focus on their own areas of interest, rather than on helping the researcher to reflect. In the bracketing process a helpful colleague should help the researcher to move from the every day understanding of the phenomenon towards a more philosophical stance. If both parties take a reflective stance, then the bracketing interview may hold certain advantages. An insightful and reflective colleague may uncover areas of prejudice that the principal researcher may be unaware of, and which self-guided reflection may not reveal. As pointed out in the previous chapter (section 3.5.1.) research with children may require a greater degree of reflexivity in order to address intergenerational issues. Whether the use of bracketing in this study helped the principal researcher to address such issues is explored in section 5.3 and in particular, section 5.3.1. Suffice to say here that more research may be required to decide which of the old adages is more applicable " too many cooks spoil the broth" , or "two heads are better than one".

4.5.2. Group activities and interviews

In this study the term group activities has been applied to two meetings of the children and the research team (principal researcher and co-workers). These groups served the following purposes:

Group 1: This group acted as a consultation group on how to approach collecting data and as an initial data collection group.

Group 2: This group involved member checking of the researcher's interpretation of the data. The children also created a video presentation showing their 6 part story of "when the nurses visited", which was used as data and in dissemination of the findings of the study.

The activities for these groups are outlined in Appendix 1. The term group has been used here for these interactions. Although some of the literature on focus groups has been used to justify the use of these groups, they are perhaps not truly focus groups as used in adult research, because the focus group or group interview conducted with adults is a negotiated conversation in which individual views are often modified by group interactions (Gaskell 2000). In the arts based groups, used in this study, children were often asked to undertake the same activity at the same time, but to create an image or piece of art based on their own experience (e.g. drawing a picture of when the nurse visits). They tended to produce a picture or a six part story which could have been influenced by others, but essentially was a reflection of their own experience, not a group product. Some other activities did provide for more of a group response, where the child's own experience contributed to more of a group view (for instance the good nurse/ not so good nurse outline in group 2). However, children rarely negotiated for their contribution to the group piece of art to include the views of others, as one might see in an adult focus group (Gaskell 2000).

Logistics of children's groups

Setting aside these concerns about how these groups represented individual or group views for a moment, this section details the logistics of setting up and running the groups. It draws on the literature about focus groups. Krueger (1994) has set out how focus groups can be used with adults and the importance of creating an environment and atmosphere conducive to the purpose of the group. It has been suggested that focus groups work best where a natural group already exists (Krueger 1994, Kitzinger 1995). The children in this study were not part of a natural group. Often they were isolated by their illness and disability. In order to bring the children together, and to form a group, it was decided to follow Cree et al's (2002) suggestion of providing a social trust building event prior to the groups. This took the form of a game of ten-pin bowling. The activity was the suggestion of Matthew, the principal researcher's 11 year old son. Ten-pin bowling provided an activity that all could join in, regardless of ability, and one it was hoped all would enjoy. A snack meal with a soft drink was also offered. Although the event worked well in bringing the children together, it could be seen as an inducement to take part in the study (Cree et al 2002). Some of the children enjoyed the bowling so much that they asked repeatedly in the research group and in data collection sessions when they were going bowling again! It could be argued that these children only wanted to take part in the study because it gave them the opportunity to go bowling. This point is given further consideration in the discussion of ethics and reflexivity in the next chapter (section 5.2.3).

Mayall (2008) has suggested that the location of group interviews is important to children. Taking this into account, the venues for the groups were selected to avoid associations with health care. A large regional theatre and entertainment centre were

used. Both venues host many events for children and young people, and they both catered for children living with disability. The refreshments at all events were designed for children and included vegetarian options. Where possible the menu choice avoided saturated fats and sugary drinks, but included chocolate.

The principal researcher facilitated the first group with assistance from two co-workers and a colleague with a background in psychology, who observed the session and noted the interactions of the group. The co-workers were second year child branch student nurses. In the second group, two arts therapists were used to help guide the activities together with the principal researcher and the same student nurse/co-workers as in the first group. All those involved met before and after the events for briefing and to provide feedback on the sessions.

Initially it had been planned to hold separate gendered groups, one for boys and one for girls. Various writers in the field have noted that groups for children are more effective if run as single sex groups (Coad and Lewis 2004, Horner 2000). However, in this study not enough children from each gender were recruited to make single gender groups viable. Mixing the genders certainly made the groups more challenging to manage, but did not seem to reduce their effectiveness in terms of generating data and ideas. For instance, girls in the groups wanted more time to do their drawing activities, while boys were keen to leave their drawings and move to the next activity. However, both girls and boys were able to talk about their drawings and contribute to the group activity.

Krueger (1994) suggests that in preparation for the focus group, the researcher sets out a questioning route. This is a list of cue questions to be put to the group, designed to stimulate the discussion and provide data relevant to the research question. For the groups in this study, a series of activities were planned. For the first group, experienced colleagues reviewed the activities and their suggestions were incorporated into the group schedules. These colleagues included the supervisory team, two researchers with experience of running groups, including running groups with children, and another experienced researcher from the field of children's nursing. The schedule for the groups is given in Appendix 1. A potential weakness of this scheduling is that although it appears structured, the activities need to be flexible to keep the group focused on the topics of discussion. Some activities worked well, others were not so useful. For instance, the use of soap bubbles was too exciting and the children focused on the bubbles instead of the discussion. The review of the group activities by what could be described as an expert panel (supervisors and colleagues from the University of Birmingham), is arguably similar to the development of other tools in research, where instruments are based on previous studies and reviewed by an expert panel (Parahoo 2006).

The selection of methods used in the groups was not however, random, but based on the use of similar methods in other studies. Word selection and map making have been used in other studies with children (Darbyshire et al 2005, International Institute for Environment and Development 2001). The "helping tree" was derived from the concept of the "telling tree" used with children in self protection work (Warwickshire County Council 2006), although the use of "idea" bubbles and of a jigsaw theme to draw the session together, were original to this study.

A possible criticism of the way these groups were set up is that the purpose was not clear. The groups had dual roles, both as data collection groups and as involving the children as co-researchers. However, as Miles & Huberman (1994b) have discussed, within the interpretist approach everything can be considered data. Therefore, even groups held with the intent of involving children in the research process will generate data. Large scale national research with children for the NHS has taken a similar approach, using groups to scope the sort of questions and the wording of questions to be used in survey studies, but also reporting the data from the scoping study (Ramm et al. 2004a&b).

Focus groups in general have been noted as being susceptible to a polarisation of views, often to extremes (Gaskell 2000). To avoid such extreme views biasing the research it is often suggested that focus groups are used together with other methods (Gaskell 2000; Kennedy et al 2001). The extent to which polarisation may occur in arts based groups with children is perhaps debateable. As argued above arts based activities with children in groups often result in individualised data, rather than mediated group data or “group think”. Despite this, in this study the data from the groups has been combined with individual accounts, which should balance any possible polarised views of nursing expressed within the groups.

Confidentiality in children's groups

A further criticism of the focus group method is the difficulty of ensuring confidentiality. Although Horner (2000) has suggested that focus groups are a useful way of exploring sensitive subjects with children, she does not discuss how the confidentiality of children, or others the children may talk about, can be protected.

Coad and Evans (2008) suggest that confidentiality can be addressed by establishing ground rules with children, although they caution that the imposition of an adult agenda of confidentiality can disrupt power relationships between adult researchers and child participants.

Within the groups for this study, confidentiality was explained to the children using a large lockable trunk and “thinking hats” or boxes. It was explained to the children that all the activities and equipment used in the group would be taken out of the trunk and at the end of the session, all thoughts and feelings could be placed in the “thinking hats” or boxes and then put back in the trunk, with all the equipment and materials. Thus it was emphasised to the children that what was spoken about in the group would stay “locked” in the trunk. At the end of the session all materials used were returned to the trunk and a child from the group was invited to lock it. The children were asked to trust the safe keeping of the trunk and its key to the principal researcher.

The “thinking” hats used in the group were of various designs of dressing up hats and baseball style hats. This caused some distress when there were not enough pirate hats to go round. So hats of the same design may be more useful in future. Boxes were provided for those who did not like wearing hats. Some of the children who had had treatment for oncology conditions which caused hair loss were particularly sensitive about wearing hats and preferred the boxes.

Some children found the presentation of confidentiality confusing. Some of the children wanted to take the boxes home, some wanted to take home the pictures they

had made. These issues were negotiated with the children. They were allowed to take the boxes, once they had acted out tipping their thoughts into the trunk. The pictures were copied and the originals sent to the children who requested them.

The issues of ownership that surfaced in the first group were useful in preparing for the next stage of the research. As a result, all the children were given the original copy of their Photo Talk Diary to keep and copies were made for the study. Also some activities that worked well in the group were replicated in the diaries e.g. the “helping tree”.

Nurses’ group interviews

As noted above, group interviews may be more effective if they are organised to use existing groups (Krueger 1994, Kitzinger 1995). In this study the group interviews with nurses used this principle and were held during a monthly team meeting to which all team members were invited. An interview schedule was used to guide the conversation (Appendix 6). The group interviews were held in the team’s normal team meeting venue and an hour was allotted to the group interview. Lunch was provided as a gesture of gratitude to the nurses for giving up their time.

The power relationships between the principal researcher and the participants in the nurses group may not feature the same intergenerational aspects as with the children’s groups. However, relationships still need to be considered. For one of the groups, the principal researcher had in the past been a colleague working as a community children’s nurse. The status of the principal researcher as an ex-colleague may produce aspects of practitioner researcher (Shaw 2005). However, this was not a practitioner research project as critiqued by Shaw (2005), who argues that such practice led research is fraught with difficulties, as the principal researcher was not a

current member of the clinical team. However, some of the ethical problems outlined by Durham (2002) did still apply. The principal researcher's status as an ex colleague could have affected the choice for participants to disclose certain information; the participant's right to withhold data can be compromised if the researcher has prior knowledge gained through working with them in the past. There is also a danger that participants will feel obliged to participate because of their relationship with the researcher (Durham 2002). It could be presumed that both groups of nurses would be aware of the researcher's role as an academic in a local higher educational institution, this may have led to the nurses assuming that the researcher is an expert in children's nursing. However, at the time of the study, neither area had provided, or was planning to provide, student placements for the researcher's institution.

In this study these potential dilemmas of practitioner researcher were addressed by emphasising the rights of participants to withdraw at any time during the data collection, or not to participate at all. The purpose of the group interviews was explained before each group and confidentiality assured.

4.5.3. Photo Talk Diaries

One of the main data collection tools used in this study was the Photo Talk Diary. This is original to the study and combines a photo voice technique (Wang and Pies 2004), activity books as used by the National Evaluation of the Children's Fund (2005) and the element of a diary, as used in other studies with children (Scott 2000).

The children were given an activity book (Appendix 2) together with a digital dictaphone (Olympus VN-120) and a disposable camera. They were asked to make a diary of what happened before, during and after the nurse's visit to them at home.

The diaries were left with the children for 2 weeks, or a period to cover at least two visits by the nurse, whichever was the longer. The children were invited to make the diary in any way they wished. They could write in the activity book, use the dictaphone, or the camera, or do all three. Parents were asked to assist the children if asked, but to allow the children to do the diary in their own way.

After the agreed period, the diaries were collected. The dictaphone recordings were transcribed, camera films processed and the diaries were copied. The children then took part in a semi-structured interview using the diary they had made, including dictaphone transcription and photographs as prompts. The interview was conducted by the principal researcher, in the presence of a co-worker, in the child's own home. Parents and carers were invited to step out of the room so that the research team and child were alone. However, in practice, ensuring children's confidentiality was difficult (see discussion at section 5.3.3 *Guest and host behaviours of researchers, adults and children*). At the conclusion of the child's interview, parents were interviewed using a structured proforma (Appendix 4). This parental interview collected demographic data on the child and family and the parent's perceptions of the community nursing service received by the child. Both the interviews with the child and parent were recorded and transcribed.

Contained within the Photo Talk Diary was an activity sheet (see Appendix 2 *My Health page*) based on the Dartmouth Primary Care Cooperative Information Project charts (COOP charts). The COOP charts have been used with a number of populations, including children and young people (Nelson et al 1990, Wasson et al 1995, Bess et al 1998). The COOP charts were developed to allow people to self-

assess their health status (Nelson et al 1990), they use line drawings and simple statements to invite people to score their health from 1 to 5 in relation to a number of health and social areas. In this study, children were asked to consider physical fitness, their feelings, their school performance and relationships with friends. A score of 1 in each of these areas would equal good health (possible total of 4) and a score of 5 would indicate poor health (possible total of 20). Bronfort and Bouter (1999) have shown that the COOP chart system can be favourably compared with other measures of health status such as the SF-36 (MOS short form). Although in adults there seems to be some question over the use of line drawings on the charts (Larson et al 1992), for adolescents, the COOP charts seem to be an acceptable method of self assessment of health status (Wasson et al 1995). The COOP charts were used in this study to allow children to report on their own perceptions of their health, which added to the context of the data they provided about nurses and receiving nursing care (see section 6.2).

Although the Photo Talk Diary benefited from the inclusion of the more flexible semi-structured interview, it was structured to the extent that it was set out as an activity book for children to fill in. This could have shaped the views expressed by children, guiding them to comment on certain aspects, rather than allowing them free expression. If such free expression had been permitted, it may have revealed other topics not covered in the diary. However, as discussed in the methodology chapter, such a purely phenomenological approach would risk children not answering the instrumental research questions on receiving nursing services at all. While the activity book element of the diary was structured, the children were given freedom to use the camera and dictaphone as they wished. Researchers using photographs with

children have commented on how the visual data revealed aspects not present in language based methods (Riley and Manias 2004).

An advantage of the Photo Talk Diary method is that it does not require children to think back over events, or to use memory (Scott 2000). Events can be recorded with the dictaphone, or the camera, or by writing and drawing as they happen or immediately afterwards. Christensen (2004) has commented on how research for children has to be relevant to their lived lives, since children often do not answer research questions which are abstract, such as events in the past which may not have made a significant impression on the child.

A limitation of the Photo Talk Diary is the fact that it was completed by the child away from the researcher. This meant that although parents were asked to allow children to complete the diary in any fashion they wanted, parents were able to influence what the children did (see discussion 5.3.2. and picture 5.1.). Parents were able to use the diaries to present a particular social picture of the family. However, interviewing the children about their diaries made it possible to ask the children about how the diary was made and to question them about the production of images.

Semi-structured interviews

Semi-structured interviews were used in this study as part of the Photo Talk Diary method and in combination with observation of children receiving nursing care.

Semi-structured interviews were used in both cases after the child had participated in the Photo Talk Diary and observation. This allowed the researcher to ask directly about issues which became evident in the preceding activity.

The use of semi-structured interviews is not without limitations (Parahoo 2006). It can be difficult to ensure that similar data are collected from all participants. There may also be problems of social presentation bias, where participants tell the researcher what they think the researcher wants to hear, or what they think will portray their family in a positive light (Parahoo 2006). The use of a topic guide has been suggested as a way of focusing the interview to ensure similar data are collected from each participant (Parahoo 2006, Gaskell 2000). For this study, a list of topic areas, some with associated questions, was developed from the first children's group and refined following analysis of early interviews (Appendix 3). The need to focus the interview in order to answer the research questions was balanced with the need to allow children to tell their own stories. It could be argued that for children living with illness, part of telling their story was the presentation of themselves and their family as just like other families (Carnevale 2007). Thus social presentation may be an important part of the data.

Kortelsumoa et al (2003) have commented on the lack of guidance for researchers on how to interview children, especially in the context of health. However, much of their advice to researchers could perhaps apply to any interview situation, such as the use of open questions, or using reflection to clarify meaning. Kortelsumoa et al's (2003) reliance on developmental psychology means that at times they show a tendency not to trust children wholly as reporters of their social worlds:

“At the beginning of qualitative interviews, when evoking children's experiences, it is good practice to accept their answers without any criticism whatsoever. If the answer is unsatisfactory, the interviewer can resume the question later on or in another way.”

Kortelsumoa et al (2003) pp 440.

What Kortelsumoa and her colleagues provide is an overview of practical considerations which point to researchers being aware of the context of interviews, and of being reflexive about children's responses to questions. They recognise, as do Waterman et al (2001), that children may feel that they should answer adult questions, even if no answer is possible. Waterman et al (2001) suggest that children may respond even to nonsensical questions because of the expectation that adults are asking children questions to which the adult already knows the answer and to which the child is expected to give "the answer" as in a teacher/pupil exchange. Kortelsumoa et al (2003) also mention the need for interviewers to spend time with children before conducting an interview (as do others, Carter 2005, see section 5.3.3. *Establishing a rapport*).

While the semi-structured interview and Photo Talk Diary method may have some limitations, some of these were mitigated by the use of topic areas to focus the interview. Interviewing children away from their parents allowed some verification of the child's part in the production of the Photo Talk Diary and images. What the method did not show was how children actually communicated with the nurses. This required observation of the children, family members and nurses interacting.

4.5.4. Observation

Observation of children receiving nursing care

Observation was used in this study to understand the cultures of communication (Christensen 2004) that surround receiving community children's nursing. An unstructured approach to observation was used as not enough is known about how children and nurses interact in community settings to form useful units of

observation for a more deductive/structured method (Parahoo 2006, Emerson 1981). The unstructured approach was also useful in bringing an open mind to the phenomenon of children receiving care at home. Such an approach has proved useful in other nursing studies (Mainas et al 2002).

A purposeful sample of children who represented different attitudes towards nurses was selected from the core group. The children's behaviour and communication interactions were observed up to one hour before the nurse arrived, during the nurse's visit and up to one hour after the nurse departed the home. The nurses delivering care consented to the observation. Field notes were taken and an account written as soon as possible after the observation session. A naturalistic approach to observation was taken and the observer interacted with the subject of the observation (Parahoo 2006). While attempting not to disrupt normal aspects of communication, the researcher entered some play activities and joined some conversations. After each observation session, children were interviewed about the nurses' visit. This conversation was recorded and transcribed. The interview questions arose from the events of the observation and early analysis of the child's Photo Talk Diary. As such, each was individual to the observation and the child. The duration of the observation was also dependent on children's circumstances. In Mohammed's case the observation before the nurse arrived was shortened, as he received care before school and was only woken by his mother shortly before the nurse's visit. The observation after the nurse's visit was also curtailed for Mohammed and Kelly, because Mohammed went to school, and it was Kelly's tea time (see section 5.3.3 on collecting data in children's homes).

Although the observation period was relatively short, it was considered appropriate as the time focused on the receipt of nursing care. The children had at this stage met the principal researcher on a number of occasions, often at home, so it was felt the children would feel reasonably comfortable in his presence.

Observation of nurses delivering care in community settings

Early in the analysis of the data collected from children, it became evident that aspects of nurses' work were not appearing. In order to document whether these aspects were simply unseen but present, or were not appearing because they were not present, it was necessary to add observation of nurses to the study. Only by the researcher undertaking observation of nurses delivering care could it be ascertained whether the aspects, that were under reported by the children, were actually present or not (see section 7.3).

An unstructured approach was taken to observations of six community children's nurses. The argument advanced for the unstructured observation of children can perhaps also be made for the unstructured observation of nurses, in that although there are participant observations of nurses delivering care to children in hospital and other institutions (Shin and White-Traut 2005, Hunt et al 2007, Carnevale et al 2008), no studies of observations of community children's nurses could be found. The lack of previous studies makes the construction of observation schedules difficult. Thus as with the children, unstructured participant observation of nurses was undertaken. For nurses, the observation period was a working day. The nurses were observed in their offices and cars as well as on visits to children's homes and schools. The nurses were then interviewed after the observation. The observations occurred between 8 am and 5 pm Monday to Friday in the late summer, early autumn

of 2007. Field notes were recorded as soon as possible after observation, and often during the observation period. Each nurse was also interviewed directly after the observation period using a semi-structured interview schedule (Appendix 5). During the interview, the nurses were encouraged to reflect on the activities that they had undertaken in the observation period. This collection of data from individual nurses occurred before the group interviews with each of the teams. Many of the nurses who had been observed also took part in the group interviews.

The next section of the chapter focuses on how data from these methods were analysed using an approach based on the work of Colaizzi (1978) and Miles and Huberman (1994b).

4.6. Analysis of data

This section describes the inductive approach taken to data analysis in this study. It outlines the analysis framework used which was based on Colaizzi's (1978) work, and includes how aspects of Colaizzi's concept of exhaustive description was adapted for use with children.

This was a qualitative study and data analysis followed an inductive approach as suggested by Miles & Huberman (1994b). The model suggested by Miles and Huberman integrates the four stages of: data collection, data reduction, data display and drawing conclusions and verification.

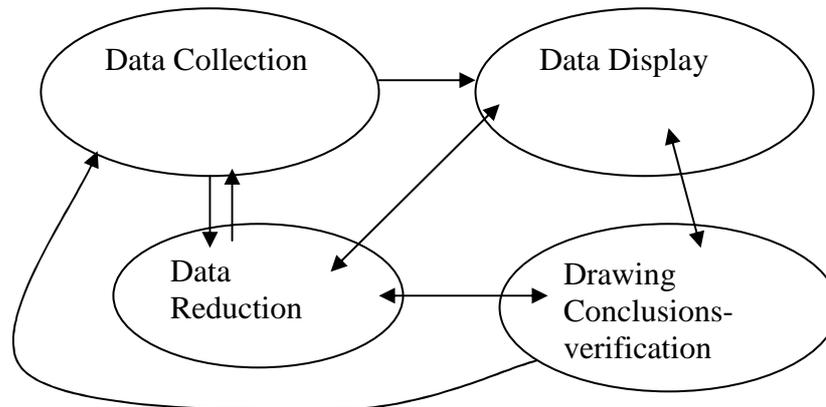


Figure 4.2. Interactive model of data analysis adapted from Miles & Huberman (1994b)

Miles and Huberman’s model allows for data collection to be influenced by the data analysis process. Indeed data analysis is not separate from data collection, as the researcher selects the data to collect which is a form of data reduction. In this project some data display also occurred in the data collection phase, as children made images and created video footage to depict home nursing. Early interpretations of data also informed later stages of data collection, thus data analysis was integrated into the research process, rather than being seen as a separate activity at the end of data collection.

In Miles and Hubermann’s model, the processes of data reduction and conclusion drawing /verification, were managed using a data analysis framework based on Colaizzi’s (1978) work. The steps taken in this study drew on the summary given by Beck (1994) of Colaizzi’s approach and were as follows:

- Review of all participants' descriptions using text and visual data.
- Returning to the data to consider significant statements/ images and context in which the data were given.
- Formulation of meanings with descriptions of each i.e. coding of data.
- Organisation of the codes into themes in a "tree" formation.
- Consideration of significant statements/ images that do not fit into codes and themes and reorganise codes/themes accordingly.
- Formulation of statements which captured participants' descriptions of the phenomenon
- Putting these statements to participants and noting their comments (participant verification/ member checking)

The first stage in the data analysis process for this study was to organise the data.

The data in this project can be categorised into four groups:

- Field work and diary notes of the principal researcher, including field notes of observations of children receiving care at home and of nurses delivering care.
- Audio taped speech which was transcribed into text. This came from groups, dictaphone tapes or individual interviews with children, their parents and nurses.
- Text written by children in their Photo Talk Diaries or during activities in groups.
- Images made by children, such as drawings etc made during groups and in the child's Photo Talk Diary, photographs taken by children, or parents and video footage made at the final group session.

Text was generated from transcriptions of interviews and dictaphone recordings.

These texts were added to written text in the form of field notes and text generated

by the children in groups and their Photo Talk Diaries. All of the text generated in the project was analysed together, as similar codes and themes appeared in all the different sources of textual data.

Visual materials were analysed by creating text descriptions of the images intended audience, method of production and content (Harper 2003). This approach, while unifying the data, also led to visual data being analysed as textual descriptions. The visual analysis was integrated into the analysis of text to give a unified analysis of data. Prosser (1998) has criticised such approaches as being evidence of a bias towards language and text in research. However, in pragmatic terms expression of the study's findings in text rather than a visual format may be less open to interpretation by the consumers of the study's findings. While multiple interpretations of the study's findings may stimulate debate they may not communicate adequately the researcher's conclusions. In this study a mixed approach is taken describing images in text to aid analysis, but presenting some images in the findings. The images presented are limited because consent was sought from all those who appear in the images. Other images were produced which may have given other interpretations, but these could not be used because consent was refused.

The process of organising the data from texts generated in fieldwork (Photo Talk Diary, image descriptions, interviews, observation notes, transcripts of group session) was managed using the NVivo (version 7) computer programme (Kelle 1997). The use of computer programmes in qualitative research has been criticised as being biased towards grounded theory approaches rather than allowing a diversity of qualitative approaches (Coffey et al 1996). However, the amount of data generated

by this study made the use of computer software invaluable for organising the data for analysis.

By reading and re-reading the text generated, as well as returning to the images significant statements and tentative meanings began to appear. These were organised by categorising them into codes. Each code was given an overarching description and inclusion and exclusion criteria were set. New statements and meanings were then assessed according to these code descriptions and criteria. If they met the criteria and were judged to be consistent with the description they were included within that code, using Nvivo to catalogue the statement, or image as part of that code. If the statement or image was judged not to fit the code, a new code was created. The study supervision team and an independent expert from the field of children's nursing reviewed a sample of the raw data with examples of how the coding framework was applied. The suggestions and comments from the reviewers were incorporated into the coding framework.

For this study, simplified versions of Colaizzi's exhaustive descriptions were used. Colaizzi describes these exhaustive descriptions as lengthy textual representations of the phenomenon. In this study, short statements were used, written in simple language in an attempt to engage with children in describing the essence of the phenomenon (see Appendix 1, group 2: *Member checking statements*). In line with the concept of ethical symmetry (Christensen and Prout 2002), these statements were put to both children and the nurses who participated (see Appendices 5 and 6), although in terms of member checking the researcher's interpretation of the nurses data was not checked, only the interpretations of the children's data.

The process of participant verification in the data analysis seemed to fit with Clark's (2004) Mosaic approach in that as Beck (1994) points out, Colaizzi's inclusion of participant verification is based on a philosophical stance that researcher and participants co-create knowledge as partners. This stance is the same as Clark's (2004) conceptualisation of children as co-creators of knowledge in research (see section 3.2). The verifying of the adult researcher's interpretation of the data by children seems important when researching the experiences of children, because as discussed in the methodology chapter, the intergenerational issues mean that it is difficult, if not impossible, for adults to fully interpret children's social worlds.

Analysis of data in this study was approached as an inductive and iterative process integrated into the research process. The use of Colaizzi's approach to analysis, especially his suggestion of member checking, was in line with the study's principles of ethical symmetry and that children and adults should co-create knowledge.

4.7. Summary of methods

The mosaic of methods for this study has been detailed in this chapter. The overall picture is given in figure 4.1 to show how the various methods of: semi-structured interviews, arts based activities, visual methods and observation, fit together. The sampling in this study was heavily influenced by the "gatekeeper" behaviour of research governance bodies, nurses and parents. However, ethical and clinical considerations made other approaches to sampling untenable.

Bracketing was used as a way of formalising the reflexivity required for researching with children. Group activities were used with children to shape the research and to

collect initial views about the phenomenon. These group data were supplemented by individual data collected from children in their own homes. The children completed Photo Talk Diaries about receiving nursing care in which they could write or make images in an activity booklet, or take pictures with a disposable camera, or make dictaphone recordings using a digital recorder. The children were then interviewed about their diary. Four children were selected from the core group to be observed receiving nursing care at home and were again interviewed after the observation. Early analysis showed that children did not attend to some aspects of the nurses' work. As a result, observation and interviews with nurses as individuals and as a group were added to the design. Finally, an arts based group was held with children in which early interpretations of the data were explored with the core group of children. The children also created images and a video which were later used to disseminate the study's findings.

The data in the study were analysed with support from the Nvivo computer package using an iterative process of open coding and thematic analysis in line with Miles and Hubermann's (1994b) approach and using a framework based on Colaizzi's (1978) ideas. Textual and visual data were analysed together as equally important in contributing to the description of the phenomenon

As pointed out in the methodology chapter (Chapter 3), researching with children requires a high degree of reflexivity. As this study was concerned with the lived experience of children living with illness, often prolonged illness and occasionally life limiting illness, ethical considerations as well as reflexivity were key to

implementing these methods and methodologies. The next chapter considers how these issues of ethics and reflexivity were addressed.

Chapter 5 Ethics and reflexivity

5.1. Introduction

It was argued in the methodology chapter (section 3.5.1.) that research with children requires that researchers have high levels of reflexivity. It has also been noted by various authors that research with children involves a heightened concern with ethical questions (Shaw 1996, Alderson 2004, Christensen and Prout 2002). This chapter examines the ethical issues that arose in this study, which include concerns surrounding research with children living with illness. It is argued that research with children living with illness raises particular concerns about the benefits that children can expect from research, and whether participating in research increases the burden of illness on them. How this study met the requirements of the ethical process for research in the National Health Service (NHS) is detailed, together with a discussion of the effects that funding from the Health Foundation may have had on the study. This is followed by a discussion of gender and its effect on the ethical approval process, during data collection, and in the analysis of data.

Related to the ethical issues is the concept of reflexivity which is defined and critiqued in this chapter. Reflexivity is also examined in relation to how bracketing was used in this study. The relationship between the researcher, the study and the participants is discussed, which highlighted intergenerational issues in the research. These intergenerational issues and the tensions for children between being a child and being a research participant are explored. Finally, how the setting of the child's own home may have affected data collection is considered. Issues such as: establishing a rapport, aspects of time, consent and safety, are considered which are

related to how the researcher, child and other adults interacted as both guests and hosts in the child's home.

The ethical issues of consent and confidentiality for children participating in this study were addressed in the previous chapter, specifically in section 4.3. These ethical issues were also considered for adults in the last chapter (section 4.3, 4.5.2. *Nurses' group interviews*).

5.2. Ethical issues

This section deals with the ethical issues which this study raised. As well as issues which may be found in many studies, such as ethical approval and funding issues, there were aspects such as researching with children living with illness and gender which were more pronounced in this project.

5.2.1. Research with children living with illness

The production of ethical guidelines for those doing research with children indicates that children are seen as a vulnerable group in society and in need of protection from researchers (Alderson 1995, Medical Research Council 2004, Carter 2009). If all children, as a social group who may be assumed to be generally healthy are seen as vulnerable, those living with illness are arguably even more vulnerable (Broome et al 2001). The Medical Research Council (2004) guidance suggests that research with children should only be undertaken if the relevant knowledge cannot be achieved by doing research with adults and that the purpose of the research is to obtain knowledge about children's health, or health care. This study meets both these criteria. The study is about the health care that children receive, delivered by nurses and is about children's experiences and therefore must involve children. Scott (2000)

has argued that adults cannot answer for children's experience. In health care, Knutsson et al (2006) showed that parents, nurses and children had different perceptions of pain. This supports the notion that children and adults may not share the same perceptions of health care and justifies the involvement of children in this research.

Berman's (2003) argument may also apply. Berman argues that adults' perceptions of children as vulnerable and in need of protection serve to silence children. If adults perceive of children living with illness as exceptionally vulnerable and less competent than well children, they may act more vigorously to "protect" these children, excluding them from research studies. These children's voices are then often silenced (Coad and Shaw 2008). However, there seems to be no evidence that children living with illness find participating in research burdensome, or that it negatively affects the management of their illness (Broome et al.2001).

For children living with illness, being involved in research may provide some benefits. Participation in research which values their voice may allow them to communicate with their parents, other adults and with health care professionals in ways perhaps not open to children under normal circumstances. Just participating in research that focuses on their experience may alter the dynamic between child, parents and health professional, which is often adult centred (Shin and White-Traut 2005), allowing children to perhaps be more assertive in their health care. Having their voice heard in their health care may also improve children's self esteem (Abbott et al 2008)

Children receiving nursing care at home may be isolated by their illness, which prevents them attending school. They may be further isolated because their nursing care is not being delivered in a public space, such as in a hospital setting, but at home. Children experiencing nursing in hospital do so as a group, albeit a transient group. In the hospital children are gathered together, often on the basis of health condition, and are placed in close proximity. This does not apply to children in community settings where nursing care is delivered in isolation. The use in this study of social trust building events and group activities allowed children to meet others with similar health needs. These opportunities to share experiences may lessen children's sense of isolation. This in itself is justification for children's involvement in the study.

However, research with children, or adults may touch on difficult and painful experiences, as indeed this study did, raising issues for children about the hurtful nature of nursing and about being different from their peers. Although telling a stranger about these experiences may be traumatic, it may also be cathartic and therapeutic. Whether such therapeutic gains or other altruistic motivations are factors in the motivation of children to take part in research studies, is unclear. Although Ashcroft et al. (2003) claim that when children have experience of research studies they can give clear and often altruistic reasons for participating. Thus arguments for children's participation, as those for adults, may include altruistic motivations, such as the benefit to future children derived from improvements in care that arise from the study, but which may not benefit the participants themselves.

5.2.2. Ethical approval

This study involved children who receive community children's nursing services from the National Health Service (NHS). Ethical approval was therefore sought from the Central Office of Research Ethical Committees (COREC), a predecessor of the National Research Ethics Service (NRES), through the Solihull Local Research Ethics Committee (LREC). Access was negotiated with all relevant NHS organisations via their respective Research and Development Departments. Community children's nurses delivering care, and their direct line managers were involved in the early development of the study. This involved negotiations with three separate NHS organisations, two Primary Care Trusts and one hospital NHS Trust. Three substantive amendments were applied for and approved by the LREC during the study.

5.2.3. Funding issues

In the second year of doctoral studies the principal researcher was awarded a *Leading Practice Through Research Award* from the Health Foundation. The award fully funded all aspects of the study. This allowed the principal researcher to devote 2 days a week to the study. The award also paid for social trust building events, group activities, co-workers' costs, translation costs and arts consultants.

The source of funding for research may influence the focus of a research project. However, the Health Foundation is an independent non-governmental charity set up in 1998 with an endowment from the sale of PPP Medical Healthcare. The Foundation funds projects across the health care sector with no particular focus on children or children's health care (The Health Foundation 2009). As the Health Foundation is not involved in supplying community children's nursing services, or

any other competing services to children it could be argued that the funders' interest in influencing the findings of this study were minimal. However, the focus on health service improvement, which is a concern of the Health Foundation, ensured that the study remained focused on the potential implications for community children's nursing services, rather than an emerging children's agenda not related to healthcare e.g. such as children being like their peers.

As adults are often given incentives to participate in social research it seemed fair, and in line with ethical symmetry, to offer this to children also. However, as Cree et al (2002) discovered, offering incentives can be difficult, as the incentive rather than interest in the research topic can become the main motivation for participation (Cree et al 2002; Curtis et al. 2004). In this study children received incentives in terms of fun activities, opportunities to network with other children, and sharing food at the groups. In addition, for core group children, after the child's contribution had ceased, a £10 book voucher was offered by way of thanks for their time and comments; but neither children, nor families were informed of this before or during the study. This policy of not informing participants of this benefit was used as it was felt that some children and or parents may participate for the financial reward, if this was known at the outset.

5.2.4. Gender and research with children

The ethical approval process highlighted interesting dilemmas in conducting research with children. It was strongly suggested, both at the ethical review meeting and in subsequent correspondence, that the principal researcher, as a male researcher, would need a chaperone in order to interview children away from their parents or main

carers. The focus of discussion at the ethical review was very much on child protection, rather than methodological issues.

This may reflect the view of male nurses as described by Evans (2002), where men who deliver nursing care are deemed unorthodox, suspicious and even sexual predators, while caring by women is seen as “natural”. Although the evidence is anecdotal, female colleagues who research with children report that in similar submissions to various ethical committees the focus has been on methodological issues rather than child protection. Issues of men as suspect researchers were also described by Scourfield and Coffey (2006), when Jonathan Scourfield sought access to men who abuse children. He found himself being accused by social work colleagues of paedophilia by association. Rather than rejecting such accusations as prejudice, it may be helpful in understanding such reactions to compare and contrast how perpetrators of sexual abuse operate, with the behaviour of researchers as suggested by established research protocols.

Finklehor’s model of child sex abuse (Finklehor 1986), would suggest that gaining private access to children away from the public gaze is essential to any potential child abuser, as abusing children in public would quickly result in the perpetrator being vilified. Child abuse is a common taboo and in most cultures is deemed illegal. Abusing children would normally result in the perpetrator being removed from children through incarceration and or distrust and increased surveillance. Abusers of children who want to maintain their access to the child seek to keep their abusive behaviour secret from the rest of society in order to be able to continue with the abuse. In this study the request to see children away from their main carers could be

misinterpreted as seeking an abusive opportunity for privacy to abuse, rather than seeking to hear children's voices and to reduce the influence of adults. According to Finklehor's model, abusers work by ensuring a degree of secrecy, to ensure that the child does not tell others in the society, which again could result in the perpetrator being "discovered". Often the building of such secret relationships is referred to as "grooming". For research with children, the language of consent has a great deal of potential for being misinterpreted as "grooming". In establishing consent, the researcher and child are entering into a "secret arrangement" where what the child and researcher do in the study is kept "secret", or confidential from others, much as a paedophile would use secrecy to prevent detection (Finklehor 1986).

Mindful of these potential problems, guidance was sought from the Royal College of Nursing on care of children in community settings (Royal College of Nursing 2001). This guidance recommends that care is either delivered in the presence of parents, or by two members of staff. Given that the concerns of the ethics committee may be shared by parents, as the mistrust of men in caring roles seems widespread (O'Lynn 2007, Evans 2002) and that the professional community suggests chaperoning in this situation, the principal researcher decided to accept the ethics committee suggestion and use a co-worker when interviewing children at home away from their main carer. However, it is acknowledged that the presence of a co-worker may have altered the dynamic between the principal researcher and the children. Of course it is possible that the principal researcher and co-workers may collude in abusing children. There have been a number of high profile cases where adult men and women have worked together to abuse children (Gibson 1995). The use of a co-worker then should not prompt the abandonment of measures to safeguard children from abuse. In this study,

all those working directly with children had enhanced Criminal Records Bureau clearance and information was provided to children and parents about how to make a complaint to the nurse responsible for safeguarding children in a local NHS trust. Participant information also included details of sponsors of the research to whom more general complaints could be addressed (Appendices 7, 8, 11 and 12).

A favourable ethical opinion was received from Solihull Local Research Ethics Committee, once co-workers and measures to emphasise safeguarding children were written into the study protocol and participant information sheets. However, as Masson (2004) has pointed out, gaining access in research with children is more complex than simply gaining ethical acceptance. Rather, researching with children requires reflexivity around the researcher as a social actor, the environment and the social setting of the research.

5.3. Reflexivity

Connolly (2008) has argued that research with children does not represent any one “true” picture of children’s social worlds, but rather that data need to be conceptualised as social interactions that represent one of many representations of the child’s social world. He further argues that understanding the context of the research is vital to understanding the representation put forward through the data. Part of any context of research is the researcher themselves. In Connolly’s case, he argued that his gender, race and class, as well as the school environments in which the research was conducted, all influenced the data collected and any interpretation placed on that data.

Although definitions of reflexivity vary (Carolan 2003), the need for the researcher's role and influence in qualitative studies to be given critical scrutiny is widely accepted (Carolan 2003, Hand 2003, Parahoo 2006). Reflexivity is taken here to be the critical scrutiny of the researcher's role throughout the research process, through research design to data collection, analysis and data display/ knowledge transfer.

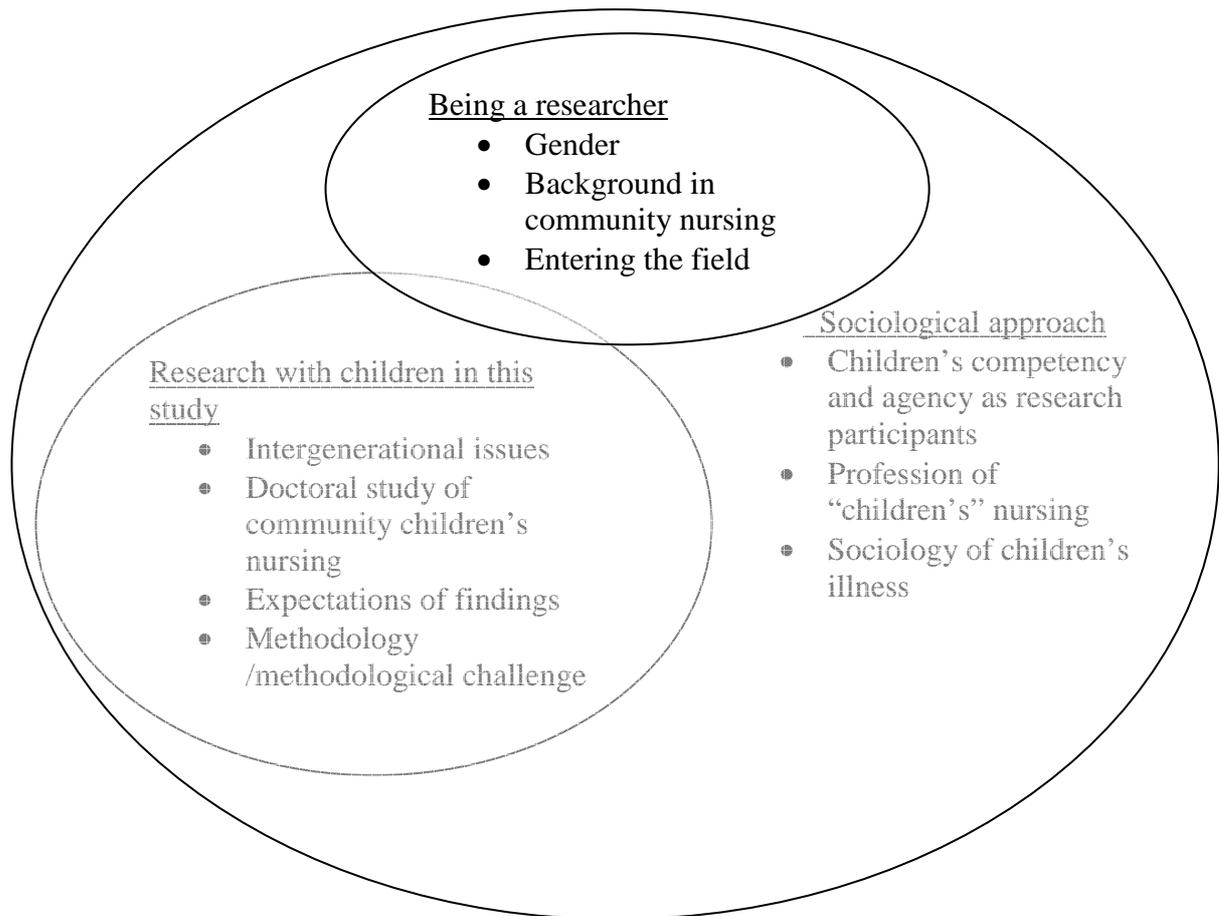
Aspects of reflexivity were included in the research design for this study through the use of the phenomenological device of bracketing.

5.3.1. Researcher bracketing interviews

The controversies which surround bracketing as a method and the various views of the philosophy which underpin it were discussed in the methodology chapter (section 3.3.1. *Phenomenology and research with children: potential advantages*). The process itself was outlined in the previous chapter on methods (section 4.5.1). This section summarises the data generated in the bracketing interviews and the insights this process generated.

The data from the two bracketing interviews have been brought together here to give an overall account of the bracketing process. Three main issues emerged from the analysis of the bracketing interviews: being a researcher, research with children in this particular study, and a sociological approach to childhood, nursing and illness (see figure 5.1).

Figure 5.1 Overview of issues identified in bracketing interviews



Being a researcher

The issue of “being a researcher”, emerged as the predominant issue. The personal and professional history of the principal researcher was identified as influencing the approach taken to research with children living with illness. The gender of the principal researcher emerged as a particular issue and provoked a discussion around “hegemonic masculinity” and how the principal researcher’s background did not follow this traditional model, with experiences as an amateur actor and in nursing leading to the development of more emotional and relational skills. This discussion mirrors that of Evans (2002) who refers to a number of masculinities, rather than one accepted “hegemonic” masculinity. Evans (2002) also points out that for men pursuing careers as nurses it is difficult to claim hegemonic masculinity. Dr Williams

and the principal researcher both recognised, in the bracketing interviews, that the principal researcher's gender would influence the perception that children and parents had of him. The principal researcher also proposed that different styles of communication would be required for children of different genders, where boys may respond more to active physical approaches, such as playing games, and girls to more intellectually focused activities, such as drawing and writing. It was also recognised that gender impacted on how the principal researcher intended to prepare co-workers for field work and the impact that co-workers may have on the interview process with children, as all the co-workers were female.

The researcher's education and class background as well as his gender were seen as aspects which would make him an "outsider" when talking to children, and perhaps more so when talking to mothers. His lack of personal experience of illness, or of having a child who lives with illness, could add to the sense of being an "outsider" to a community of children and adults living with illness in childhood. The bracketing interview also highlighted aspects which could make the principal researcher seem more of an "insider" to children, parents and nurses. These included: being a father of two children in the same age range as the children in this study, his experiences as a community children's nurse, health visitor and as a children's nurse, or as the bracketing interviewer (Dr Williams) put it:

Bracketing interviewer *On a personal level you are saying that your identity is not traditionally masculine. It's not hegemonic masculine, but it's more contradictory and fragmented, but at the same time you're also telling me that you come from a background where there is some cash about... So you've got the personal and the structural, and I think that you've got to be*

aware of that, yourself, but that's not to deny what you told me about your process skills, as a children's nurse being the major resource in the research project.

2nd Bracketing interview.

The “process skills” referred to in this quote related to skills in making relationships with children quickly in various settings, as well as communicating with parents. The skills acquired by the principal researcher through an 18 year career as a children's nurse and his experiences in community nursing, also informed his approach to research with children. In the second bracketing interview the principal researcher recognised that these “process skills”, gained as a children's nurse, could also have negative effects.

Principal researcher That's a danger of those skills as a children's nurse. That you know, one of the things you have to do is when you get the 2 and 3 year olds is to persuade them that they really want to take this medicine. Well they really don't and they are quite adamant that they don't.

2nd Bracketing interview

The bracketing interviews highlighted issues of gender and the principal researcher's background as a children's nurse which needed to be taken into consideration when entering the field.

Research with children in this study

Issues that related to how this study would be conducted as research with children, as a distinct group, were almost as prevalent in the bracketing interviews as those about being a researcher. These issues could be categorised as follows: intergenerational issues, doctoral study of community children's nursing, expectations of findings and how the study challenged aspects of qualitative research methodology.

Many of the intergenerational aspects related to the concepts of ethical symmetry and research with children have already been discussed in the methodology chapter (section 3.5.1). Through the bracketing process, the principal researcher was able to explore the challenges of implementing ethical symmetry. While the principal researcher espoused ethical symmetry, putting this into practice was more difficult. On re-reading the data obtained from children, it became clear that on occasions the researcher could be guilty of using his adult status, especially when trying to get the children to focus on nursing (see below section 5.3.3. page 151-152). Other issues about communicating with children revealed by the bracketing interview were perhaps more successfully realised in the field. These included challenging adult to adult conventions of communication, to make sure the researcher talked to children before their parents, and that the researcher joined children in the joint action of play. The bracketing interviews were also useful in exploring the tensions between the researcher's phenomenological approach and the instrumental aspects of research into a clinical specialty, as part of doctoral studies. These challenges over the philosophical approach of phenomenology and the possibility that for children, community children's nursing may not be a phenomenon which has meaning in their lives, led the principal researcher to adopt the approach that the study was influenced by phenomenology, rather than this approach being the sole methodology (see Methodology chapter section 3.3):

Principal researcher *Yeah I think (Pause), I think you're right. I need to be alive to the possibility that this research could take a completely different tack, that children may well say I don't really think much about the nurse at all, It's not a really big part of my life.*

1st Bracketing Interview.

The bracketing interviews revealed what the principal researcher thought might be the likely outcomes of the study. In short these were that children would be keen to talk about their community children's nurses and make comparisons between hospital and community services, although it was also acknowledged that children in other studies often did not identify nurses as helpful. The principal researcher thought that important factors would be: continuity of care, whether procedures were painful (or not), the duration of the relationship with nurses, the gender of the child, their cultural background and social position. He also felt that children would compare and contrast receiving nursing from parents with care delivered by nurses and that the relationship between children and nurses in the community setting would reflect a closeness of friendship built up over a period of time. Other issues the researcher was keen to explore were how and what children told their peers about receiving nursing care at home, how transitional objects such as teddy bears were helpful to children receiving nursing care and how children understood nursing, especially what they looked for in nurses, and whether competence as well as personality mattered.

As can be seen from the findings chapters, most of these preconceived ideas about the findings of the study proved to be wrong.

The last aspect in relation to this study and researching with children came from comments made by the bracketing interviewer indicating a view that the study design was challenging, especially the use of visual methodologies and the intention to interview children at home. These discussions allowed the principal researcher to think about some aspects which had not previously been considered, such as whether parents could leave the house during the Photo Talk Diary interviews, leaving their

child alone with the researcher and co-worker. Although these problems were not always realised in this study thinking about the relationship between the researcher, the child and other adults helped to prepare the researcher for field work.

Sociological approach

The issue of how the study was underpinned by the sociology of childhood and other sociological writing (Mayall 2002, La Tour 1993) appeared in a number of aspects of the bracketing interviews. Discussions centred on how the principal researcher saw children as social actors, fully integrated into their society, and childhood as a quasi phenomenon (La Tour 1993).

Aspects of the sociology of childhood were seen to underpin the approach to the study, such as the principal researcher's approach to children's competency as research participants, although it was acknowledged that not all adults in the study shared this view of children as competent research participants.

The sociology of the profession of nursing also emerged as one of the issues for this study in the bracketing interviews. It was suggested that professional agendas may contribute to the tensions in the study between research about living with illness and researching community children's nursing, as discussed above and illustrated in this data quote:

Principal researcher *One of the things the CCNs are quite interested in is, do children appreciate what's being done for them? Which is a very interesting kind of professional question, but [do] they appreciate that if they didn't come and replace their nasogastric tube they would actually have to go to an A&E department and wait for three hours?*

1st Bracketing Interview.

The use of bracketing interviews in this study could be argued to have been successful, in that they did provide an opportunity for the researcher to reflect on his role in the research and his relationship with the participants. The fact that virtually all the assumptions that were expressed about the likely outcome of the research were not borne out by the actual findings, suggests that an open and flexible approach was enacted. The formalising of reflexivity through the device of bracketing has then allowed for the approach of the principal researcher to research with children to be critically reviewed.

5.3.2. Intergenerational issues

Despite exploring intergenerational issues in the bracketing interviews, they continued to surface in the fieldwork of this study. The interactions between adults, adults and children, and children with other children (peers, and siblings), were a constant feature in the fieldwork. These interactions between adults, children and other children, on occasions presented the researcher with difficulty in enacting the approach of children as active research participants, where arguably the intention to treat children as research participants clashed with the child being a child in a social network. Perhaps an example may illustrate this more clearly. Although this example is from a social event, meant as a trust building exercise, and not for the collection of data, similar issues arose in data collection and throughout the study.

The boy in the taxi

The “boy in a taxi” incident is described here and used as an example to explore the relationships between generations (intergenerational issues) which arose in this study. A participant, a boy of six, agreed to attend the bowling event held on a Friday evening, after school, before the focus group the next day. His mother took up the

offer of the research team to pick her son up in a taxi and take him to the event. This resulted in a co-worker, a student nurse, who the boy had not met before, picking him up in a taxi and taking him off to an unfamiliar activity, on a Friday night when he may have been tired. In hindsight, the co-worker should have been introduced to the boy prior to the event, or parents asked to accompany their children to the event. Later in the study it emerged that the boy has had difficulty integrating into school and is quite dependent on his mother. With hindsight it was perhaps predictable that he should decide en-route to the event, in the taxi, that he wanted to go home and not to the bowling. The co-worker, as a student children's nurse was used to persuading small children to take medication and put up with all sorts of invasive procedures. In this role as a nurse she did what it could be argued many student children's nurses would do and consistently persuaded the boy that he really did want to go bowling (see data extract above 5.3.1.). On arrival at the event the boy still stated that he did not want to do bowling. Through negotiation with him, it was agreed that he could watch and would have a go on the video games he had seen on his way into the venue. However, once the bowling began the boy joined in. He stated several times at the event how much he had enjoyed the bowling and asked repeatedly and without prompting, to go again at almost every subsequent contact with the principal researcher.

This incident demonstrates how in this study intergenerational issues were played out. Adult to adult behaviours included the negotiation of childcare between the parents and the research team, with the offer to pick up the child allowing his mother some time free from her commitment to care for her son. Adult to child behaviours can be seen where the co-worker was acting in loco parentis, in persuading the boy to

try something he may have never tried, and the boy is acting as a child in resisting being persuaded or “bribed” with the video game and joining in play and having fun. Child to child behaviours were present when the boy observed the other children having fun bowling and was allowed to join a team and bowl.

There is perhaps a tension between these social interactions and the child’s role as a research participant. While adults often insist that children try new activities, if they did not it could be argued that children would not be exposed to new situations and therefore have restricted social experience. However, in research terms, the boy was refusing consent in the taxi and should have been taken home to his mother. While not condoning the actions of the co-worker, they are understandable in terms of the relationship between adult and child (nurse in loco parentis and child). The danger is of course that children’s refusal to take part in research could be interpreted as “childish” behaviour and ignored. Children could then be forced to take part in research. This could occur unconsciously. Children are used to being told what to do by adults, thus if an adult says “do this activity”, the child may feel that, as at school, the activity has to be done whether they wish to do it or not. The influence of schooling was felt in this study. Even though it was not conducted in educational settings, some children were keen to supply the right answer, despite the principal researcher insisting no right answer existed and that it was just their experience he was interested in. Although in this study children were given many opportunities not to take part in activities, and to refuse to answer particular questions, because the activities were led by adults, children may have felt obliged to participate.

The effects of intergenerational relationships may also affect data analysis. In this study the use of disposable cameras, and to a lesser extent digital Dictaphones, emphasised intergenerational issues. The boys in the study used the cameras and dictaphones to assert their power over adults in their lives, capturing adults on film, sometimes against their wishes and tricking adults by recording their voices on the dictaphones. However, more often parents used these devices to assert their view of the research and to present a socially acceptable view of the family. When discussing the photographs taken for the project with the children, it became clear that some had been taken by adults (the angle and framing of the picture as well as its contents may also indicate adult production).

Some photographs were taken by adults in order to show the child and family in a positive light. Pictures were taken of children with their friends (the child as a popular child) there were staged photographs of the child receiving treatment (the child as a good patient) and of the child dressed for a religious ceremony (the child as a believer). Picture 5.1 below is a good example of how a child was presented as representing the family. It could be argued that here we see the child as a “good scholar”, doing his Photo Talk Diary, as though it were “homework”. It could further be argued that the message to the researcher is that this family values education and that this is an intelligent child. The flowers and neat stack of books and tables portray an orderly household that is well cared for.



Picture 5.1. Photograph representing the child as a good scholar

The boy in the taxi incident and this discussion of intergenerational issues shows how the approach to the child participant in research may differ from other relationships between adults and children. This is perhaps part of what Christensen and Prout (2002) mean by considering children's social relationships within the concept of ethical symmetry, in that doing research with children requires a negotiation of the relationships with children, between the social interactions of adults and the child, and between researcher and participant.

5.3.3. Collecting data in children's homes

In this study the negotiation of, both social and research relationships, took place in the context of the community setting of the child's home. Coad et al (2008) identify the following aspects of interviewing children in the home setting:

- Establishing a rapport

- Aspects of time (e.g. length of time spent in the home and potential disruption to “family time/life”),
- Guest and host behaviours of researchers, adults and children,
- Consent and confidentiality within the politics of the home
- Issues of safety both for children and researchers.

Establishing a rapport

In this study a rapport was established with children by meeting the children in their home to discuss consent and to deliver the Photo Talk Diaries (disposable cameras and dictaphones). During the visits, appropriate opportunities were taken to engage the children, and or their siblings, in play activities. For instance on one such visit the researcher and the children of the household played with a slinky spring making it tumble down the house stairs. As Mandell (1991) suggests, engaging in such activities allows children and adults to begin to communicate. In effect, play may say to children that the researcher is willing to listen. Thus establishing a rapport through play activities establishes that the researcher is the sort of adult who will listen to children and this allows communication between child and adult (see section 3.5.1. *The least adult role*). Mayall (2008) has suggested that interviewing children at home involves the researcher as a guest in the house negotiating with children and their parents. This would seem to be quite different from the researcher as an adult in the school setting, or in a hospital, where children’s behaviour is often directed and surveyed by adults (Connolly 2008, Coyne 2006).

For some of the core group children, rapport building also included attending social trust building events (bowling and meal). However, not all the children were able to

attend these events, but this did not seem to impact on the quality of the data they gave. Some children who did not attend the social events felt able to reveal intimate and embarrassing details about receiving nursing care, albeit on the third occasion that the researcher visited the child's home. The data given by children in the non-core group who were observed at home, but where there was less opportunity to establish a rapport, seemed less rich in comparison with that from the core group children (see chapters 6 and 7).

The use of co-workers, as required by the ethics committee, may have affected the building of rapport between the principal researcher and the children. Apart from an interpreter used with one child, the co-workers attended the social trust building events and the Photo Talk Diary interviews, but not the consent visits or observation visits, as parents were present. This may have allowed the principal researcher to build more of a rapport with the children than the co-workers, which was then disrupted by the co-workers presence at the Photo Talk Diary interview. It is perhaps difficult to evaluate the role of rapport in researching with children based on this study. The effect of the social trust building events (bowling and a meal) seems especially difficult to evaluate in terms of how such events affected rapport, trust and data quality. However, there was a noticeable difference in the data given by children not in the core group, (i.e. those who participated as part of the observation of community children's nurses practice) where there was less opportunity to establish a rapport.

Aspects of time

An aspect of establishing rapport is arguably time spent with a child and family (Carter 2005). However, it should also be noted that children living with illness may have a number of professionals visiting their home and this can cause distress to families, who feel that playing host to professionals interrupts their time as a family and invades their privacy (Kirk 2001). Coad et al (2008) suggest that the researcher needs to be clear about the length of time they intend to be in the home and to have a sense of “knowing when to leave”. In this study the length of visits was made clear to parents and children through the information leaflets (Appendices 7, 8, 9, 11 and 12.) and restated when contacting the child and parents to negotiate visits, and during the visit. The following extract taken from field notes of an observation visit shows that the researcher was sensitive to the family’s time schedules:

Keep interview to 20 mins as Mother obviously getting tea and getting out the plates.

Kelly field notes from observation.

While clear statements of the time research activities may take in the home are helpful, they need to be combined with an awareness of when children and or parents may want the researcher as an invited guest to leave.

Guest and host behaviours of researchers, adults and children

Mayall (2008) notes that conversations with children and parents in the home setting are guided by negotiations with the researcher as a guest, and by the child and or parents as hosts. Although Kirk (2001) suggests that parents may defer to professionals, even in their own home, this may be because parents see the professional as the “expert”, but whether this applies to research practice is unclear.

Host behaviours were seen in this study with parents often offering the researcher drinks and sometimes food. Children were also keen to show the researcher around their house, including showing the researcher their bedrooms.

Mayall (2008) describes three aspects of the guest/host relationship:

- The researcher as a guest has to accept conditions offered to them.
- The researcher must take account of what the child and, or parents deem appropriate.
- The child and parents have to negotiate, between themselves, how the visit will be structured and who will be involved- which leads to the social presentation of the family that the child and parents present to the researcher.

Adapted from Mayall (2008).

These guest/host behaviours were seen in this study. The children's parents determined the location within the house where the research activities took place. Some interviews were difficult as family members kept interrupting, or noise from other parts of the house or the street made hearing children difficult. An example of the last two aspects described by Mayall (2008) was encountered in this study when a girl (aged 8) wanted to show the principal researcher her bedroom. This was firmly ruled out by her mother. Thus the child and mother negotiated which parts of the home the researcher was allowed to access. The researcher supported the mother's decision by changing the subject and distracting the child with another activity. In doing so it could be argued he demonstrated that as a researcher he respected what the mother deemed appropriate, while attempting to remain engaged with the child through the joint action of play activities.

Consent and confidentiality

Issues of consent and confidentiality may be affected by the setting of the research within the child's home. Aspects present in school settings such as: wishing to

participate because one's peers or classmates are participating, participating to avoid lessons, or a feeling of compulsion because a teacher has told one to participate, may not be present in the home situation. Confidentiality may be difficult for the researcher to negotiate as a guest in the child's home, as outlined above, guest status does not allow the researcher to control the activities of the child or other occupants of the home. On a number of occasions during this study, research activities in the home were interrupted by other household members (both children and adults), as a guest the researcher had little control over these interruptions. As a researcher, his response was to stop the research activity and renegotiate consent and confidentiality, both with the household members who had interrupted and with child participants.

Both these issues of consent and confidentiality were seen in this study. Consent, especially with regard to talking about nurses and nursing, had to be constantly negotiated with the children, often using play and art activities as this conversation with Mohammed demonstrates:

Researcher	What does the nurse do different from your mum do you think?
<i>Mohammed</i>	<i>Umm [pause].</i>
<i>Mohammed's mother</i>	<i>[from other room]Mohammed, [names researcher] asking you something.</i>
<i>Mohammed</i>	<i>I forgot what he said.</i>
<i>Researcher</i>	<i>Too busy colouring aren't you.</i>
<i>Mohammed</i>	<i>What did you say?</i>
<i>Researcher</i>	<i>O.K, O.K Tell you what let's just stop colouring for a minute.</i>
<i>Mohammed</i>	<i>Ohh!</i>

<i>Researcher</i>	<i>I know you are not going to like me for this. Let's pop this down for a minute.</i>
<i>Mohammed</i>	<i>Ohh!</i>
<i>Researcher</i>	<i>I just want to ask you a few questions.</i>
<i>Mohammed</i>	<i>Ohh that's not fair.</i>
<i>Researcher</i>	<i>...and have you concentrate and perhaps play a game before I go.</i>
<i>Mohammed</i>	<i>I can still concentrate.</i>
<i>Researcher</i>	<i>Mmmm! All right [Mohammed continues colouring]</i>
<i>Mohammed</i>	<i>I concentrate if I am colouring.</i>

Mohammed interview after observation

It would seem that the children were aware that what they did at home was determined by themselves and their parents, and that adult guests have little influence. The passage above shows the difficulty of ensuring confidentiality for children when interviewing them in the home. It is obvious that Mohammed's mother is listening into the conversation from another room. She was doing various household tasks and came into the room where the interview was being conducted on two occasions. Although parents were asked to allow the children to talk to the researcher (and co-worker) on their own, this behaviour of being in the background, listening in, or of interrupting the interview was not uncommon. When interrupted during data collection the researcher stopped the interview and renegotiated privacy with parents and other family members. However, the child was obviously aware that he could be overheard, or that his family members may interrupt the interview again and this may have affected the quality of the data given.

Safety

The potential and actual dangers of working in community settings and especially in the private homes of children for nurses and other health professionals have been documented (Kendra and George 2001). It would seem likely that many of these risks would apply to researchers going into children's homes, as they too are guests with little control over the home setting. Potential risk may include attack by animals, risk of violence etc. As discussed in section 5.2.4., the private nature of the home space and the legitimate desire to hear children's voices independent of adult influence could present an opportunity for abuse of children by researchers.

Despite these concerns, as suggested in the section on phenomenology (Methodology chapter section 3.3.1.), it may be useful to collect children's data in the place where they have experienced the phenomena (Clarke and Moss 2001). This may help them to relate the research questions to their own lived experience of receiving nursing care at home. The ethnographic aspect of the mosaic approach, which included observation of children receiving nursing care at home, self evidently required data collection in children's own homes, as this is where the phenomenon of children receiving care occurred. Thus despite the complexities outlined above, collection of data in children's homes was essential to this study.

5.4. Summary of ethics and reflexivity

This chapter has covered both ethical and reflexivity aspects of the study and examined the researcher's role in collecting and analysing data, as well as exploring other intergenerational issues and the context of collecting data in children's homes.

The effect of the gender of the researcher was explored. It was acknowledged that many regard men as “suspicious” care givers. These views influence not just ethical committees, but the “gatekeepers” who are vital to the recruitment and participation of children in research. The use of female co-workers, social events and visits to build a relationship with children and their carers was seen as a vital part of the consent process, where building trust in the researcher was regarded as a prerequisite to securing consent for participation from “gatekeepers” and children.

Through the bracketing process reflexivity was formalised. This process challenged perceptions of masculinity in health care research. The process highlighted a tension between a pure phenomenological approach, and research designed for doctoral study of community children’s nursing. The bracketing process also uncovered many intergenerational issues and aspects of a sociological approach to childhood, illness and nursing children, which surfaced and resurfaced in this study.

Intergenerational issues were also present in the fieldwork and analysis of data. These revealed tensions between children in their social networks and children as research participants, which had to be managed in this study. These intergenerational issues and tensions also surfaced in aspects of conducting research activities in children’s own homes.

The findings presented here need to be placed in the context of a study with children living with illness in community settings conducted by a male principal researcher whose professional background is in children’s and community nursing.

It is to the findings of this study that the thesis now turns. The next three chapters explore the findings and discuss their implications. First, chapter 6 explores how children experience receiving nursing care. Chapter 7 then examines the relationship between children and nurses and between children and nursing, chapter 8 explores the generational and professional context of the study. This allows, as Clark (2004) suggests, for the findings from the children's data to be placed in the context of their interactions with adults in their social worlds.

Chapter 6 **Children, like other children**

6.1. Introduction

This was a study of how children experienced receiving nursing care at home. What became clear from the literature review and the early interactions with children was that despite children being asked about their experiences of receiving care children often focused, not on nursing, but on their family, friends and school.

This chapter reports the findings from the children which relate to their focus on family, friends and school, which it is suggested is an attempt by the children to portray themselves as being children, like other children.

It is important to consider children's data in the context of the social world in which they live (Clark 2004, Christensen and Prout 2002). However, as discussed in section 2.4.1, studies of children's views have in the past perhaps been biased towards reporting adult perceptions. To avoid adult voices appearing more dominant than those of the children, this study reports first and foremost the findings derived from data given by children (chapters 6 and 7). Chapter 8, in reporting the data collected from nurses and carers seeks only to set these findings in a context of a generational landscape, not to justify or moderate the children's voices.

6.2 Thick description: the context of the children's lives

In order to give some context to the data of the children a short description of the context of the lives of each of the core group children is set out below. These descriptions attempt to provide what Geertz (1975) describes as thick description.

That is descriptions of the context of data which allows the reader to gain a sense of

the data and the context in which it was collected. These descriptions are in no particular order, the first is Honey (the names used here are not the real names of the children, but names chosen by them to be used in the study). The information in these descriptions came from various elements of the study including the demographic details collected from mothers (see Appendix 4) as well as COOP scoring from the Photo Talk Diary (Appendix 2). Further detail of the children can also be found in section 4.4.2 where the sample of the study was described.

Honey

Honey is a girl who was 7 years old at the time of the data collection. Honey lives with her mother and her younger brother in a small terraced house, her father lives separately in another town. Honey has contact with her father and her extended family. Her grandmother lives locally. Honey describes her family as coming from England and Africa. In her COOP scoring (see section 4.5.3.) she scores herself as fit (COOP score of 1), and as having good friends (1). She also felt she was doing as well as she could at school (2). However, she recognised that sometimes she felt anxious or sad (3). This gave her an overall COOP score of 7 (out of 20, where 20 represents the worst health status and 4 the best). Honey was receiving treatment for Acute Lymphoblastic Leukaemia. Her diagnosis and subsequent treatment had not been easy for her, or her family. She had recently refused to have a finger prick blood test at home, and had had difficulty taking medication for which her mother consulted a psychologist.

Although Honey had some difficulties engaging with the study, which was perhaps surprising as she is a girl who enjoys art, she engaged well in the social trust building

activities (bowling event). When she was involved in activities, Honey appeared to be a very bright girl with good social skills, and she talked about a wide circle of friends.

Nanny

Nanny, like Honey, is a girl. At the time of the study she was one year older (8). Nanny lives with her foster parents and her dog in a large well presented house in an affluent area. Nanny reported that some of her family were from Ireland. In the COOP scoring Nanny gave herself 3 for fitness (able to walk at a fast pace), and for school work she evaluated her performance as between 2 and 3 (doing as well as she can and could do a little better). She rated her friendships as 2 (as spending quite a bit of time with friends) and her feelings as 3 (sometimes sad). This gave a score of between 10-11. This may seem quite a high score, but could have been increased by Nanny's anxiety. At the time of the study Nanny's foster mother reported some difficulties with the process of adoption in which the family were engaged. Nanny was receiving treatment for precocious puberty which included insertion of growth hormone implants at home. Nanny presented as an anxious child, who was keen to participate in the study, however, at times she was worried that she was not giving the "right" answer, despite reassurance that any answer given was fine. School work, teachers and friends seemed to be important to her.

Mohammed

At the beginning of the study Mohammed was 6 years old. He is a British Asian boy from a Muslim family. He was born with a relatively rare genetic skin condition called Epidermolysis Bullosa (junctional). This condition has a number of variants

which are characterised by blistering of the skin. Some children may develop gastric complications and or aggressive squamous cell carcinomas (Varki et al 2006).

Mohammed's community children's nurse reported that the clinical team had recently revised his diagnosis and now felt he had a good prognosis, but this view did not seem to have been adopted by Mohammed or his mother. His Epidermolysis Bullosa was very visible in that his face and hands were affected and his dressings could be seen even when he was dressed. At the time of the study Mohammed had dressings to his trunk and all four limbs. Every morning, he had a bath, creams applied and all his dressings changed. In the evening he also had some dressings changed and he received overnight enteral feeding via a gastrostomy. The nurses were assisting his mother for three mornings a week, but the majority of his care needs were met by his mother.

Mohammed's COOP scoring was a little confusing. Although someone scored his fitness as very poor (5) in his Photo Talk Diary, in his interview Mohammed suggested he could run fast and scored himself as 1. Overall he scored; fitness 1, feeling 1, school 2 and friends 1, giving him a very low score of 5. This would suggest that despite his health problems he saw himself as a healthy boy.

During the study Mohammed presented himself as an intelligent, energetic and engaging boy. Controlling situations about him seemed important to Mohammed. He enjoyed using his dictaphone to "capture" people on tape, and using his camera to "take" people's photographs. Mohammed often avoided answering questions using drawing, or playing games to distract the researcher. At times Mohammed would give contradictory answers to questions. For example regarding continuity of care, in

one response he claimed to like having different nurses and the same nurse.

Mohammed's answers perhaps reflects the complexity he faces in living with his condition.

The next child, Gizmo, also has a complex medical and social history.

Gizmo

Gizmo is also a boy who was 6 years old at the time of the study. He is a White British boy. On his COOP scoring he indicated he felt fit (1), happy (1) and that he had friends to listen to him (1). Only "school" was scored negatively with a 5. His overall score was 8. This was in stark contrast to the data Gizmo gave in his Photo Talk Diary and to the picture gained from his mother. When collecting the demographic data, Gizmo's mother revealed that he was at the time seeing a specialist neurologist for epilepsy, an oncologist for leukaemia, a dermatologist for eczema, a respiratory specialist for asthma, and a cardiologist for Noonan Syndrome. Noonan Syndrome can be associated with learning difficulties (Strobel et al 2007). Gizmo was also seeing a psychologist. Although there was a suggestion that Gizmo had some learning difficulties, he seemed to grasp what was required in the study activities, including new concepts such as the help tree. At the time of the study Gizmo was receiving regular visits from the nurse to infuse heparin solution into a long line in order to maintain its patency (Hockenbury 2003) and to replace a nasogastric tube. His mother was delivering an enteral feeding regime overnight.

Along with his health problems Gizmo had some difficult social circumstances to contend with. He lives with his mother and two older brothers, one of whom was reported as having a learning difficulty. No one in the house was in employment. Gizmo's father, who he has regular contact with but who does not live with the

family, has a history of alcohol abuse. During the study the family moved into local authority housing. The picture which emerged from talking to Gizmo's mother was one of her as a lone parent coping on her own.

Although Gizmo avoided some questions about nurses and receiving nursing care, he was less skilful than Mohammed in his avoidance, sometimes using "don't know" as a default answer, sometimes using fantasy to express himself (see page 201). Despite concerns over Gizmo's learning abilities, he presented in this study as a happy and cooperative boy who did all that was asked of him.

Kelly

Kelly was older than Gizmo, being 9 at the time of the study. She is a girl from a White British family, whose mother stated the family had no religion. On her COOP scoring Kelly recorded that her levels of activity fluctuated from a 4 (light walking) to a 2 or 1 (run fast). Her activity levels fluctuated with cold weather and had improved in the last year since starting new treatment. She felt she was performing as well as she could at school (2) and was happy (1), with lots of friends (1). Thus Kelly's overall COOP score fluctuated with cold weather from 5-8. This is perhaps not surprising as she has arthritis. About a year before her participation in the study, Kelly had an "operation" in hospital (steroid injections) and since then had received weekly injections (of Methotrexate) from the community children's nurses. Kelly lives with her mother and younger brother in a high rise local authority flat. The block of flats has a local reputation for illicit drug use, although there was no suggestion that Kelly or her family were involved in the illicit drug culture. Kelly's father does not live with the family, but has regular contact.

In the study, Kelly engaged well with the activities she participated in. She presented as an intelligent girl with a wide circle of friends and good social skills.

Joanne

Joanne was quite a bit older than the other children at nearly 12 $\frac{3}{4}$. She comes from a large Muslim family and is British Asian. Joanne's family live in a mid-terrace house. Seventeen people live in the house including Joanne's parents, her 10 siblings, two husbands of her siblings and their children. The family income was reliant on social benefit payments, as her father has a long term health condition. The family appeared to be part of a larger local community.

Although Joanne indicated low COOP scores for fitness, school performance and friends (1,2,& 2 respectively), which might indicate good health, she scored her feelings as 4, indicating that she felt sad most of the time. Her overall COOP score was 9. Joanne received a weekly injection from the community children's nurse for Psoriasis. Joanne reported that her psoriasis had caused some sight loss. Her mother reported that Joanne had just one nurse who delivered care, a male nurse. She had received care at home for over 2 years. Joanne was quietly spoken, but responded to all the questions asked of her.

Rabbit

Rabbit participated in the group work, but did not participate in the Photo Talk Diary as by the time of the data collection she had stopped receiving nursing care at home. She was receiving treatment for Acute Lymphoblastic Leukaemia. Rabbit engaged enthusiastically in the group work and gave some wonderful insights. She was a

bright, sociable girl who worked well in groups. Sadly, Rabbit passed away shortly after the completion of the study. Hopefully her contribution to this study will help other children in the future.

Non-core group observations

As well as this core group of seven children, 14 children also participated in the study when they were observed receiving nursing care. For this group (i.e. not those in the core group) it was not possible to address the relationships between the adults generation and children in the same way as it was for the core group children. The non-core group children had not met the researcher before the observation, nor had their parents/carers. This meant there was no opportunity to build social trust before the observation. Although the researcher attempted to engage children and ask them about their agency in receiving nursing care this was often thwarted by adults (nurses and parents/carers). In reporting this data as far as possible the context is given in which they were collected, and comment made on the possible influenced of adults. Further details of the non-core group children are given in section 4.4.2 and table 4.2.

Table 6.1. Core children’s demographic details

	Age	Gender	Ethnicity	Religion	Family structure (lives with)	Household income (£)	House tenure	Maternal education (age left education)	Paternal education (age left education)
Honey	7	Female	Mixed	Muslim	Mother & younger brother	18,200- 31,200	Mortgage	Degree (21)	GCSE (16)
Nanny	8	Female	White	Christian	Foster parents	31,200-52,000	Mortgage	Diploma (18)	Degree (22)
Mohammed	6	Male	Asian/ Asian British	Muslim	Both biological Parents & 2 older Brothers	18,200- 31,200	Own	NVQ2 (18)	Certificate (16)
Gizzmo	6	Male	White	Christian	Mother & 2 older brothers	5,200-18,200	Non rent Local Authority	None (16)	None (16)
Kelly	9	Female	White	None	Mother & younger brother	5,200-18,200	Non rent Local Authority	BETEC (18)	None (16)
Joanne	12	Female	Asian/ Asian British	Muslim	Both biological Parents & extended family 10 siblings	5,200-18,200	Mortgage	GCSE (18)	A level (18)

NB Rabbit did not participate in the Photo Talk Diary, no demographic or nursing intervention details were recorded

Table 6.2. Details of nursing involvement with core group children

	N ^o named nurses	N ^o nurses visiting	Time receiving care (years)	N ^o of visits per week	N ^o of visits per month	Care tasks	Pain
Honey	2	4	1.5	1	2	Multiple	Sometimes Painful
Nanny	1	5	0.75	0	1	Injection	Painful procedure
Mohammed	0	4	5	3	12	Dressings	Sometimes Painful
Gizzmo	2	3	0.5	0	2	Multiple	Sometimes Painful
Kelly	1	6	1	1	4	Injections	Painful procedure
Joanne	1	2	2	1	4	Injection	Painful procedure

6.3. Relationships: family, friends and school the context of receiving care in community settings

In this study the prevailing experience of children receiving community children's nursing seems to have been focused on how they could present themselves as being children, like other children. This included talking about their family, friends and schools, rather than talking about nursing. There was a reluctance amongst some children to discuss nursing and a general sense that children resisted the hurtful aspects of nursing. Both of these aspects perhaps have the effect of reducing the visibility of community children's nursing. The focus of children on therapeutic interventions which are more technical rather than other aspects of nursing, adds to a sense of community children's nursing being experienced by children as a minor part of their living with illness.

6.3.1. Children, like other children

The possibility that for children nursing is not a central part of their experience of living with illness was raised in the bracketing interview (see section 5.3.1). In the study, children normally first mentioned aspects which perhaps portray themselves to be like other children, not living with illness. The children talked about their mothers, their fathers and their friends. To a lesser extent they talked about their siblings and the extended family (grandparents, aunts, uncles etc). Some children also talked about their school and teachers and this was often linked to their school friends. For some children, transitional objects or animals seemed to be important in their ways of coping with illness.

6.3.2. Mothers

For the core group of children, mothers were almost exclusively the parents who helped them the most to live with illness. Mothers were often involved in administering therapeutic interventions and as such were directly comparable with the nurses:

<i>Researcher</i>	<i>Who's the best at doing your dressing?</i>
<i>Mohammed</i>	<i>My, mum, my, my mum</i>
	<i>Mohammed: Photo Talk Diary interview.</i>

All of the children placed their mothers on the first branches of the help tree (see Appendix 4) indicating that their mothers are the person most helpful to them.

Mothers also feature first on the help page of the Photo Talk Diary.

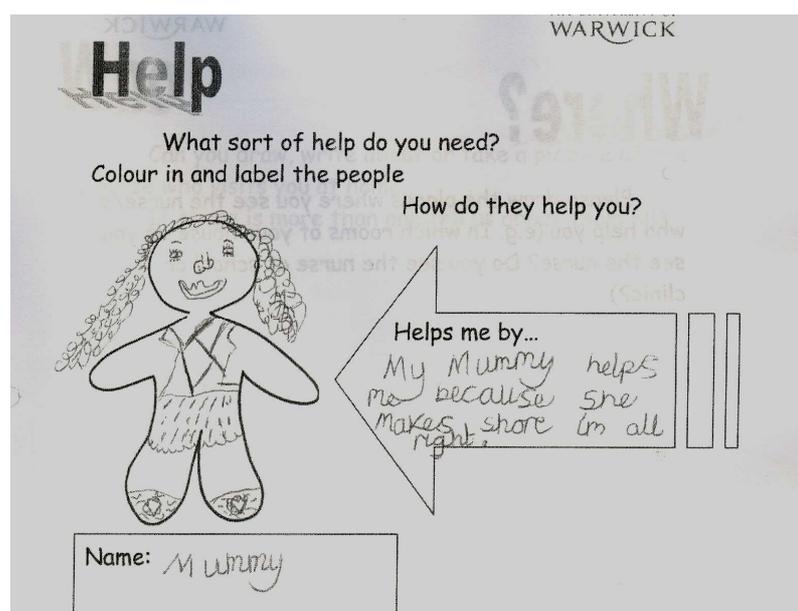


Image from Honey's Photo Talk Diary.

In the main, the children showed an unconditional acceptance of their mother's role in caring for them. The children expected their mother to fulfil the caring role and perform complex nursing tasks, such as enteral feeding or dressings, as though this were a natural part of being a mother:

<i>Researcher</i>	<i>Would that be better than the nurses come to see you at home, if mummy could do it all?</i>
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show mothers alongside other family members or friends. In part this may be explained by the fact that mothers took some of the photographs with the child's disposable camera, and were therefore behind the lens.

However, it may also reflect how children view the role of mothers as more than just administering therapeutic interventions. Mothers were also seen as being generally supportive and to perhaps fulfil Benner's concept of the nursing domain of the helping role (Benner 2001):

<i>Researcher</i>	<i>How does your mummy help you? What sort of things does your mummy do that help you?</i>
<i>Honey</i>	<i>Cuddles me.</i>
	Honey: Photo Talk Diary interview.
<i>Nanny</i>	<i>Because my mummy has to be up with me, and I feel it is like needles, and when I look at it, it looks even sharper, and it is going into my tummy.</i>
<i>Researcher</i>	<i>So is it important to have your mummy with you when the nurse is there?</i>
<i>Nanny</i>	<i>I like grab on to her. Without mummy I would be just watching her and then go shout and then kicking... I have slept in hospital they put me on something and cause like they were wheeling me round in this bed and we went in a lift, and then all the noise woke me up and then mummy just squeezed my hand.</i>
	1 st children's group.

In the non-core group mothers were observed organising care. Mothers often directed the work of the nurses, setting out their equipment and agreeing when the nurse could visit. Mothers were also instrumental in ensuring children cooperated with nurses (see section 7.6).

The interactions of parents and nurses in relation to the delivery of nursing care are discussed further in section 8.2.1 and in chapter 9. In common with the literature

reviewed in chapter 2, there is a bias towards mothers in this study. However, the children did also talk about their fathers.

6.3.3. Fathers

In contrast to mothers, the children saw fathers as “fun” people. Dads took the children out, brought them presents and did fun things. Rarely were they directly involved in administering technical therapeutic interventions. Fathers were also seen as helpful and they featured on six help trees at the 1st branch level (most helpful), and twice on the 2nd branch. The following data quotes perhaps show how fathers were seen by the children as helpful, although less involved in delivering nursing care:

Researcher *Who’s this that helps you?*
Gizmo *Daddy.*
Researcher *Daddy, how does your Daddy help you?*
Gizmo *Takes me to the shop.*
Gizmo: Photo Talk Diary interview.

Researcher *So if your mum and dad could give you the injections would you like to have your mum and dad do it? or would you like to have the nurses do it?.... What do you think?... Mum and dad or nurses if they could, if your mum and dad could do the injections.*
Joanne *Dad could do it cause he’s put some injections in himself.*
Researcher *Does he? ... So what do you think? ... Still prefer to have the nurses do it or would you like to have your dad do it ?*
Joanne *The nurses because my dad wouldn’t be home on Fridays.*
Joanne: Photo Talk Diary interview.

Researcher *Does your dad do anything to help with your skin?*
Mohammed *Umm yeah.*
Researcher *What does he do to help you with your skin?*
Mohammed *My dad?*
Researcher *Yep.*

Mohammed

He, he don't do that much My mum has to wake him up tell him to do my back, but he don't he always say ahh and he come down stairs and does it. No look at this brise brise ah na [singing].

Mohammed: Photo Talk Diary interview.

The visual data also showed a gendered division of caring roles of parents. Only two of the children made images of their fathers, and only one of these related to a care role (helping the child dress). Only one child took photographs of her dad, both of which show him pulling funny faces. It is perhaps relevant that only 3 of the 7 core group children lived with a male parent, although all had contact with their fathers. Some aspects of fathers' "fun" role were also observed during the observation of non-core group children receiving care, when children demanded physical, boisterous play of their fathers.

For the children in this study, fathers offered a different form of caring from that offered by mothers. Caring, which the children perceived as more about fun activities than about administration of technical therapeutic interventions. In part, the children's data seems to support a view of masculinity as public and autonomous (Halford and Leonard 2003). The children talked of being taken out into public places and reported activities which arguably fathers provided alone, rather than in collaboration with others. The "fun" aspect of the fathers' role which appeared to be present at home too, is not commented upon by researchers who have sought the views of fathers of children who live with illness and disability (Pelchat et al 2007). However, researchers have not sought the views of children themselves. Instead the literature, reviewed by Pelchat et al 2007, focuses on how fathers avoid taking responsibility for caring for children, an aspect also seen in the children's data in this study, and on the differences between mothers' and fathers' coping. The data collected from nurses in

this study suggest that some fathers take a much more active role in caring for their child living with illness (see section 8.2.1).

6.3.4. Siblings and extended family

Other members of the immediate and extended family were seen by children to be helpful. They featured on the 2nd, 3rd and top branches of the help tree, but rarely seemed to be involved in administering technical therapeutic interventions. One child had a brother who helped their mother roll bandages for example. Other siblings were helpful in less direct ways, by giving emotional support (cuddles) and playing (distraction). In one case siblings helped by taking on the child's domestic duties:

Researcher: How do your sisters help you do you think?
Joanne: Erm, I meant to do some of the housework, can't do it like err you have to make flour for the chapattis. I can't do it cause I get marks on my hands so my sister has to do it for me.

Joanne: Photo Talk Diary interview.

The impression given by the children of the role of their siblings seems to be one of general support. The level of siblings' involvement does not seem to meet Becker's (2007) definition of a young carer which stipulates that the care given is substantial, regular and that the young person assumes responsibilities outside the role expected by their family or culture. What children in this study seem to be reporting is siblings acting as siblings, rather than taking on a substantial or regular caring role.

Other members of the extended family were also seen as helpful by the children, but again whether their help involved more than might be commonly expected within families was not clear. The visual data supports the textual. Photographs were taken of siblings and extended family members. These photographs show people in the family home, usually seated. There are no pictures of siblings or extended family

members helping the children by helping to administer technical therapeutic interventions. The pictures appear to be taken more to show the siblings or extended family members to the researcher, rather than how they were connected with the child receiving care. This showing the researcher their family may be an aspect of the children attempting to portray themselves as children in a family, like other children.

The observation of non-core group children receiving care showed that extended family members may be more involved in delivering care than might be suggested by the core group of children. For example nurses were observed teaching grandparents about Total Parental Nutrition and one grandfather facilitated the nurse's visit as the parents were abroad. There were also examples of nurses including siblings in care delivery, as demonstrated in the field notes below. This was a visit to a child (G) with a central line whose sibling was also present during the visit:

CCN 6 took tray and syringes into lounge, G on sofa. CCN 6 asks the children to get her a table (involving children in care). Child moves small table from a nest of tables to beside sofa. Little discussion as flushes given... Sibling excited once flush finished as wanted her stickers. She collects them. CCN 6 back in kitchen, writing up notes, gives stickers to sibling, none for G.

Field notes observation CCN6

It would appear that siblings and other extended family members offer general support to children living with illness and were sometimes, but not always directly involved in helping to deliver care. This finding is in line with Findler's (2008) study which investigated health professionals' attitudes towards grandparents' involvement in the care of children living with illness. Findler (2008) found that nurses and doctors were unsure of how grandparents were involved in supporting their grandchildren, other than by providing general support and some financial assistance. As Findler

comments, extended family members seem to be an untapped social resource for children living with illness.

6.3.5. School and friends

All of the core group of children in the study were attending school and school life was important to them. Teachers featured in some help trees at the level of 2nd and 3rd branches and some children included them on their help page. Teachers were reported to provide general support to the children living with illness and to help them to cope with school and their peers.

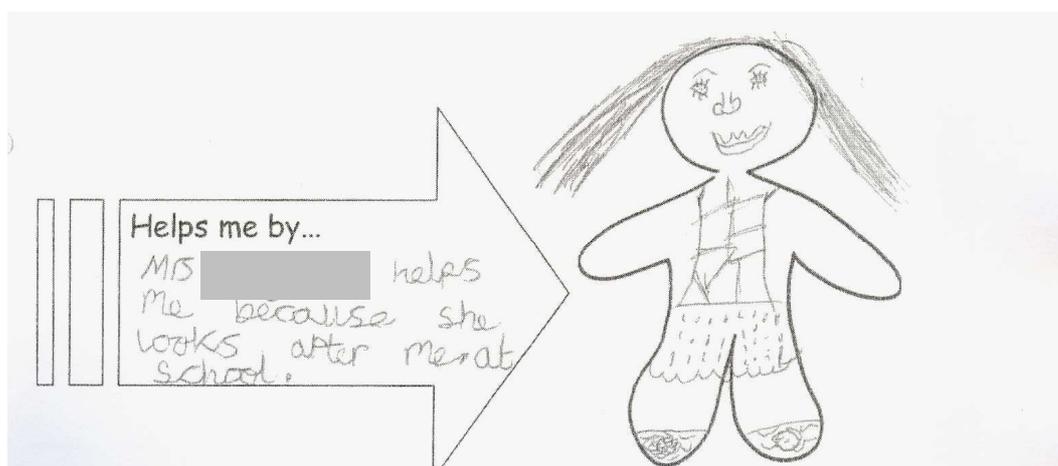


Image from Honey's Photo Talk Diary

- Kelly:* Erm, my class, when I was in year 3, I had a teacher called [names teacher] that was, she was nice and erm.. She told the class that I had Arthritis and to be careful and that, and...
- Researcher:* Right...(Pause)... ok.
- Kelly:* They've always helped me, the class has.
- Researcher:* Ok, that's good isn't it...(Pause)... that's nice.
- Kelly:* They helped me up and down on the floor and stuff.
- Researcher:* Ok...(Pause)... so you still have to sit down with everybody else on the floor for circle time do you?
- Kelly:* Sometimes, and sometimes I sit on a chair.

Kelly: Photo Talk Diary interview.

Friends, both from school and from the neighbourhood, featured in some conversations, but it was unclear how they helped the children live with illness.

Children on the whole told their friends about the nurse visiting, but did not go into detail:

- Researcher* *So do your friends know that you have a nurse come to see you at home?*
- Nanny* *They both know, but one of them doesn't believe me.*
- Researcher* *Oh all right, ok, we talked about this didn't we before.... Why do you think that she doesn't believe you?*
- Nanny* *I'm not sure.*
- Researcher* *Does she think that you have to go to a hospital to see a nurse or do you think that's how it works?*
- Nanny* *Yeah.*
- Researcher* *...Do you talk to them about why you have a nurse come and see you at home?*
- Nanny* *No.*
- Researcher* *No, ok, you just say "I've got to go home now because the nurse is coming".*
- Nanny* *Yeah.*

Nanny: Photo Talk Diary interview.

A number of the children seemed to only tell their friends that the nurse was coming if it was unavoidable e.g. they had to leave school, or a social activity early in order to meet the nurse and needed to provide a reason for leaving.

The reluctance to include friends in discussions about illness can also be seen in the visual data. Only two children took a picture of their friends and one parent took photos of their child with a friend in the back garden (4 images in total out of 133).

The non-core group children were observed receiving nursing during the school day, so the fact that only one young person was seen with a friend present is perhaps not surprising. Nurses did often ask children about school, however, they did not discuss

with the children how to deal with their peers and living with illness. Russell (2005) provides some evidence that community children's nurses do help children to negotiate how they live with illness in educational settings. Although, as Russell's paper also demonstrates, much of the literature in this area focuses on policy and the public health agenda rather than on the need of children to be like other children despite their medical conditions.

Although children were observed receiving care from nurses in school settings, with their peers, none of the core group children received care in this way. It would be interesting in future studies to explore children's strategies and experiences when receiving nursing care in educational and social settings with their peers (see section 9.7.3).

6.3.6. Transitional objects

Three of the core group children were very fond of certain transitional objects, these included soft toys and family pets. Transitional objects, or treasured objects, have been described as objects used by children as pacifiers or soothers to bridge the transition between maternal attachment and their sense of independence from their primary social care giver (Steir and Lehman 2000). However, not all the children had these sorts of relationships with pets or objects. While transitional objects seemed important to three of the children, it was not clear, beyond general support, what their specific role was in helping them to live with illness or to receive nursing care at home. Lookabaugh and Fu (1992) describe a similar role for transitional objects in their study of pre-school children's daily hassles. However, Lookabaugh and Fu's (1992) study relies on mothers' reports of children's daily hassles as recalled by mothers for the prior two weeks. A more ethnographic approach could have recorded

the use of transitional objects by children rather than the diary method which may just record children's distress when it became the focus of parents' attention. Lookbaugh and Fu's (1992) study found no significant differences between coping in children who used a transitional object and those who did not. Thus while the use of transitional objects may be a useful coping method for some children, children may develop other ways of coping with receiving care (Lookbaugh and Fu 1992):

Researcher *How does Gizmo¹ help you?*
Gizmo *I don't know, he's got hands, but I don't know.*
Researcher *Ok, do you give him a nice cuddle?*
Gizmo *Yeah*
Researcher *Does that help you?*
Gizmo *Yeah.*

Gizmo: Photo Talk Diary interview.

Mine
Go on do it again
I have Gizmo¹
I take him to bed
Every day, every night, every bedtime
I take him everywhere even in the car

1 Gizmo had a favourite toy which he called Gizmo

Gizmo: dictaphone recording.



Image from Nanny's Photo Talk Diary

6.4. Early analysis and member checking

During the final group interview with the core group children the following two statements were unanimously endorsed by the children. These statements were constructed from early analysis of the data to form statements that attempted to encapsulate the findings. These statements were put to the children in order to check the interpretation of the data, a process known as member checking (Colaizzi 1978, see section 4.6.):

- I don't like to think about being ill I prefer to think about playing with my friends and being with my family.
- I would rather have my mum or dad do all the things I need to keep me well, than have nurses visit me at home.

The endorsement of these statements seems to support the view that children were portraying themselves as children, like other children. Rather than focusing on aspects of their illness or associated nursing care they focus on their families, friends, school and pets perhaps making the assumption that these are topics that children not living with illness would also focus on (see discussion section 9.3).

6.5. Summary of children, like other children.

The first thing children talked about and the focus of much of their talk and image making was not nursing, even though they were specifically asked about this, and they knew this was a study about nursing. They chose not to focus on the experience of receiving nursing. Instead they talked about their family, friends, school and pets.

The children spoke of how their parents helped them. Mothers were involved in nursing care, but were also seen by the children as a virtually unconditional source of

help and support, whereas fathers played a lesser role in nursing care, but were a source of help through play and distraction.

The role of other family members, transitional objects, pets, friends and schools seemed to be more in supporting the child in living with illness rather than contributing to the child receiving nursing care.

Statements from early analysis of the data that the children endorsed supported the view that the children portray themselves as being children, like other children. With the children's focus on being like other children in mind, the next chapter reports on the researcher's attempts to move beyond children's initial response, to explore the relationships between children and nurses and between children and nursing.

Chapter 7

Children's relationship with nurses and with nursing

7.1. Introduction

This chapter explores the regard children had for nurses. Both a positive and negative regard were found and a continuum of regard for nurses is proposed with children's position on the proposed continuum being associated with their understanding of illness and children's involvement in their care. The effect of children's regard for nurses on their evaluation of nurses as good or not so good is also discussed. Finally the gender of nurses delivering care and the effect of this on children's experience of receiving care is considered. The chapter begins by exploring how children in this study, like those in some previous studies, resist nursing care.

7.2. Children resisting nursing

The literature reviewed in chapter 2 showed that children often resisted talking about the nursing care they were offered (section 2.3.4, Carter 2005, Horne 1999, Earle et al 2006, Carney et al 2003, Coyne 2006). Although work by Kortessluoma & Nikkonen (2004) found children more willing to talk about nursing, their descriptions of nursing still showed it to be associated with physical and psychological pain. As explained in section 2.3.4. the term "resisting hurtful nursing" is used here to reflect children's view that nursing interventions are often perceived as both physically and psychologically painful.

In this study, some of the children appeared to find talking about nursing difficult and used a range of tactics to avoid discussing their nurses or nursing care, although each child expressed their resistance to nursing in different ways. It is also perhaps worth

noting that the children who showed most resistance to nursing had a negative overall regard for nurses, as discussed below. The data quotes given here show the strength of feeling children had about resisting nursing:

	[after repeated attempts to talk about “carers”]
<i>Researcher</i>	<i>About the carers, when the carers come what happens?</i>
<i>Mohammed</i>	<i>Umm [pause].</i>
<i>Researcher</i>	<i>Can you tell me what happens when the carers come?</i>
<i>Mohammed</i>	<i>Na na na na na naahh [singing]...</i>
<i>Researcher</i>	<i>Do you not want to talk about that?[pause] Shall we talk about something else?</i>
<i>Mohammed</i>	<i>Yeah.</i>

Mohammed: interview after observation.

One child from the non-core group was more direct in resisting the nurse:

*Visit described in notes by previous CCN as traumatic.
Welcomed at door by mother ... Child looks very frightened standing with her back to the wall in the hall way at the bottom of the stairs, looking petrified.
As we move through to lounge she runs away upstairs ... Crying from upstairs eventually mother brings [the child] down...*

Field notes observation CCN 12.

The nurses in both areas gave similar accounts of children running away or hiding when faced with a visit from the nurse (see section 8.2.2.).

During the second group interview with the core group children, the following statement, derived from early analysis of the data, was not endorsed by the children.

- A good nurse is fun, but also knows how to do things right to make me better, they respect me as a person and work with my family and friends.

Unlike the other statements put to the children, which perhaps support the children’s conception of themselves as children, like other children (see section 6.4), this statement relates directly to nursing care. In contrast to the children’s reaction to the statements which were endorsed in section 6.4 this statement about nursing met with a

7.3. Visibility of community children's nursing

Children's reluctance to talk about nurses and nursing in this study may contribute to a sense that nurses' work is less visible than other aspects of health care. The concept of the visibility of nursing has been advanced by a number of authors (Davies 1995, Bjorklund 2004, Meerabeau 2005), but perhaps is most coherently expressed by Liaschenko (Liaschenko 1997, 1998, Liaschenko and Peter 2004). The concept comes from empirical work on nurses' moral and ethical practices (Liaschenko 1997, Rodney and Varcoe 2001). In essence, the concept of visibility poses a thought experiment which invites one to consider what different groups may be able "to see" from their social position within the various "landscapes" in which they are situated. To take the example of children living with illness, such children can be thought of as being situated in a landscape of health care, which is part of adult society. As the last chapter showed, in the landscape of health care, family friends and school were highly visible to children but nurses were not. It could be argued that the review of the literature in chapter 2, which largely reflects the view of adults, shows that to adults children's friends and schools are less visible, while professional and bureaucratic agendas are more visible.

The visibility of the work of community children's nurses is discussed here from the point of view of children receiving community children's nursing, while in the next chapter the visibility of community children's nursing is revisited in a professional context in section 8.3. The concept is discussed further in section 9.5. The findings suggest children have a limited view of children's nursing. The data from the core group children and from the observation of nurses were dominated by reports of the administration of technical tasks and therapeutic interventions. The impression was that nurses came, did the task they had come to do and left:

<i>Researcher</i>	When a nurse comes to see you at home, what happens?
<i>Mohammed</i>	They don't come Monday, Tuesday, Wednesday
<i>Researcher</i>	What sort of thing happens when they come, what they do?
<i>Mohammed</i>	Nothing
<i>Researcher</i>	Nothing?
<i>Mohammed</i>	They just do my dressings

1st children's group

In the last group with the children, a theatre therapist helped the children script a 6 part story, which was then acted out using finger puppets the children had made. In this data extract Nanny is practicing her story of when the nurse visits:

<i>Nanny</i>	<i>Hello my name is Nanny and I am watching TV, but I have to turn the TV off now [knock]. Hiya nurse...</i>
<i>Co-worker 5</i>	<i>Do you want to explain what the nurse does?</i>
<i>Nanny</i>	<i>She's drinking a cuppa tea and filling forms in and then, and then you go up stairs and she says which bed do you want to lie in? [pause –Nanny stabs her finger into the puppet representing her, indicating her injection]. We come back down stairs and, we both, and I sit there watching her while [names CCN4] has another cuppa tea, fills more forms in and then, and then what happens. She says good bye to me, good bye ... Finished.</i>

2nd children's group.

This task orientation of nurses was a constant feature across the data appearing in the children's Photo Talk Diary interviews, in the researcher's observation field notes, and in children's group work and images:

<i>Researcher</i>	<i>What happens when the nurses come?</i>
<i>Joanne</i>	<i>First they come and they get all the stuff out, and then they get the stuff ready, and then I go in the other room cause I feel sick, and then they get the injection, and when they are ready they call me, and I have the injection, and then I go to the room, and then they put their things away, and then they wash their hands, and then they write in their book, and then they go.</i>

Joanne: Photo Talk Diary interview.

CCN re enters [having washed hands] and prepares injection, little interaction with Kelly or [names brother]. Asks if Leg OK? Asks if ok to give injection? Kelly says yes, and takes off Mr Bump. CCN injects and gives Kelly some tissue. Kelly holds this on her leg while CCN clears away.

Field notes observation Kelly.



Image from Honey's Photo Talk Diary.

My Album

This is space for your pictures and photos about you and about your nurse.



Image from Kelly's Photo Talk Diary.

During these conversations [between adults] CCN10 is preparing line flush, mostly with back to child does not talk to him until needs access to lines, then asks about line, about health generally and about his holidays. Once finished with line little interaction as clearing field and putting sharps in bin. Once flush done child dismissed by father, [child] leaves room.

Field notes observation CCN 10.

Although this focus on the technical tasks of nursing has been reported by Coyne (2006) in hospital settings, literature on community settings suggests nurses have a more personal relationship with children (Samwell 2005), which might suggest that children would be more likely to recognise the helping, or teaching/ coaching roles of nursing as described by Benner (2001).

Some of the core group children recognised that the administration of therapeutic interventions should not be purely task orientated. Children with a positive regard

spoke of how the nurse would talk to them and play with them. Sometimes observation supported this view (Nanny), but not always. Here, Kelly is talking about why some children might not like their nurse (although she herself has a positive regard for nurses):

- Kelly* *Because some nurses might just Umm, might just go in and they are not as good, they might just go in wash their hands. Don't ask if they are allowed to use the bathroom, or anything. Which would make them a bit angry and then they just give the needle without asking if they were alright, or not giving them time to do the Mr Bump.*
- Researcher* *Mmm, that's true, but in your diary you were talking about how when your nurses came and they had real fun with you, they tickled you, but , when [names CCN] came today she didn't do that. She didn't tickle you, didn't play any games with you or [names brother]. She pretty much came gave you your injection, wrote the notes... ..and went...*
- Kelly* *..and went yeah.*
- Researcher* *Because sometimes like the nurses that tickle me like they've been to every single house and I'm like the last one, so.*

Kelly: Interview after observation.

Although a few children in the core group recognised that nurses offered their mothers psychosocial support, the role of nurses as teacher seemed to be less visible to them. None of the children recognised that nurses had taught their mothers to deliver aspects of the care they received when the nurse was not present, such as administering medication, enteral feeds and doing dressings:

- Researcher* *Because your mum does quite a lot for you, like your medicines, your tablet and things.*
- Kelly* *Yeah.*
- Researcher* *Who taught your mum to do that?*
- Kelly* *Umm, nobody its just as you get older, you like find out, like more things. When you get into, about year 6, or past, you like, the teachers, like tell you more things about like medicines and how to treat them.*

Researcher So your mum learnt it at school, how to look after you with your arthritis?
Kelly Yeah or maybe in college.
 Kelly: interview after observation.

Researcher So your mum does your dressings...
Mohammed Yes.
Researcher Who, who taught your mum to do that?
Mohammed Err, the doctor.
Researcher The doctor, ok.
Mohammed Her name is Dr [names dermatology consultant]...
Researcher ...who does the food in your tummy?
Mohammed err, well my mum, she puts it on actually.
Researcher Ok.
Mohammed ...and it just works automatically.
Researcher Ok, and, who taught your mum how to do that?
Mohammed I just told you [names dermatology consultant]
 Mohammed: Photo Talk Diary Interview.

The observation of community children’s nurses reported in section 8.3 shows that although the children did not see the nurse’s teaching, it did occur. The visibility of certain aspects of community children’s nursing to children is explored further in section 8.3. and section 9.5.

Despite the children resisting talking about nursing and their limited view of community children’s nursing, it was possible to explore with them the factors that shaped their experience of receiving nursing care.

7.4. What factors shape how children experience receiving community children’s nursing services?

Although social position and ethnicity were initially thought by the researcher to influence how children experienced receiving nursing care in community settings the data did not support these factors as being significant. In this respect, when asked, the children in the core group all felt that nurses would treat them the same as other

children from different communities, or religious/cultural backgrounds. None felt they were treated differently because of their ethnicity or social position:

Researcher ...Do you think that the way you might see the nurses that come to see you at home would that be different from perhaps you know, if I had a daughter the same age as you, do you think that, that would be different or do you think that would be the same?
Joanne Same.

Joanne: Photo Talk Diary interview.

Kelly was the only child to feel that the nurses would be influenced by where she lived:

Researcher Do you think it matters to the nurses where you live?
Kelly Erm...
Researcher What, do they mind about where you live?
Kelly All of us do in the lifts...It's always filthy in the lifts but... (Pause)... nothing else.
Researcher Ok... (Pause)... Do you think they might look at you differently? Because you live in a flat or...
Kelly No.

Kelly: Photo Talk Diary interview.

This cultural, ethnic and social neutrality stands in stark contrast to the importance accorded to ethnicity and social position in social and health literature and policy (Backett-Milburn et al 2003, Department of Health and Department for Children Schools and Families 2009). It is possible that the researcher's ethnicity and social standing, together with the focus of the study being on nursing, combined to limit the children from discussing these factors in depth. Further research would be helpful to understand how children's ethnicity and social position influences how they live with illness and their relationships with health care workers.

Other factors, such as the nursing interventions delivered and continuity of care (having care delivered by the same, or a small number of nurses) also did not emerge

as important factors. However, what did seem to be important was how children regarded the nurse, and their response to the gender of the nurse.

The factor which shaped how the children experience being nursed at home the most was the regard children had for nurses. The findings suggest a continuum from negative to positive views, with the child's position on this continuum being influenced by their illness belief and how they were involved in receiving care. The next section explores this regard for nurses in more detail.

7.5. Children's regard for nurses

Before exploring children's regard for nurses, it should be noted that there was considerable resistance from adults in the study to children expressing negative views of nurses. The data reported here may therefore have been biased towards more positive views. Even for the children who were permitted to participate, their parents may have applied pressure to try to ensure that the child portrayed nurses in a positive way:

<i>Mother:</i>	<i>Are you nice to the nurses?</i>
<i>Gizmo:</i>	<i>No!</i>
<i>Mother:</i>	<i>Why not? Are they nice to you?</i>
<i>Gizmo:</i>	<i>No.</i>
<i>Mother:</i>	<i>They are! Why aren't they nice</i>
<i>Gizmo:</i>	<i>Cause they don't come.</i>
<i>Mother:</i>	<i>Yes they do. You play them up when they come</i>
<i>Gizmo:</i>	<i>I play ready...</i>

Gizmo: dictaphone recording.

As these mothers and children may be reliant on nurses to prevent children having to return to the hospital, it may not be surprising that they were keen to present themselves as supporters of the services nurses deliver. Despite this intergenerational pressure to report positive regard for nurses, some children did however express a negative regard for nurses. It should be noted that none of the children associated their

negative regard with particular nurses or a particular nurse's behaviour. Rather children's regard for nurses seemed to be related to their understanding of their illness.

7.5.1. Children with a positive regard for nurses

Children with more positive regard for nurses seemed to have a good understanding of their illnesses. Nanny and Kelly provided perhaps the best examples of this association between positive regard and understanding of illness:

<i>Researcher</i>	<i>Why does a nurse come and see you?</i>
<i>Nanny</i>	<i>To have my needle.</i>
<i>Researcher</i>	<i>You have a needle? Ok why do you have a needle?</i>
<i>Nanny</i>	<i>Cause I have growing spurts.</i>
<i>Researcher</i>	<i>You have growing spurts. So what does the needle do?</i>
<i>Nanny</i>	<i>Makes me not grow as quickly.</i>
<i>Researcher</i>	<i>Right ok, so is there something, is it a medicine that you have?</i>
<i>Nanny</i>	<i>Yeah.</i>
<i>Researcher</i>	<i>Right ok.</i>
<i>Nanny</i>	<i>It's like medicine in the needle.</i>

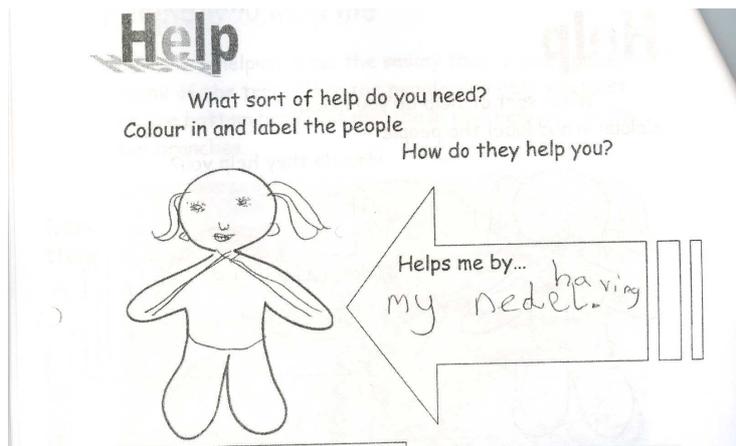
Nanny: Photo Talk Diary interview.

<i>Researcher</i>	<i>Did mummy say that was going to be your last needle?</i>
<i>Nanny</i>	<i>Well she doesn't want me to have any more, so</i>
<i>Researcher</i>	<i>Might be? Might need a few more</i>
<i>Nanny</i>	<i>Cause I have precocious puberty...</i>

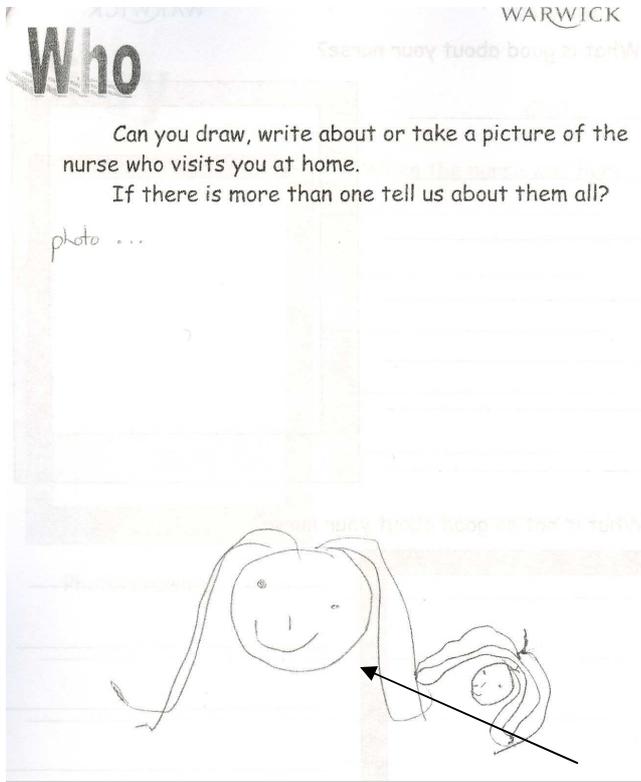
2nd Children's group.

Although Kelly did not show much insight into her condition in her Photo Talk Diary, in her interview after the observation of her receiving care, she was able to give a complex description of her pain, describing how the pain she felt was like a wind passing through her joints:

<i>Kelly</i>	<i>Yeah, I think it's. I hate having the wind yeah, but like.</i>
<i>Researcher</i>	<i>Or the pain of the wind.</i>



CCN4



Identified as CCN 4 by Nanny during Photo Talk Diary interview.

Images from Nanny's Photo Talk Diary.

Nanny

If [names CCN4] was away she wouldn't want another nurse doing it. Because if they are new and I am shouting and kicking them she wouldn't like them to be hurt and me upset and everything.

Researcher

So you have the same nurse all the time?

Nanny

Yes.

Researcher

So you didn't like it when you had a different nurse from [names CCN4].

Nanny

No I didn't like it, no. [names CCN4] my normal one...

Nanny: Photo Talk Diary interview.

The observation of a home visit by CCN4 to Nanny to administer her injection showed that there was indeed a close relationship between Nanny and the nurse. This was perhaps facilitated by the community children's nurse sharing aspects of her own life with the family and showing an interest in Nanny's family and her home life:

*Very genuine warm reception for CCN[4] hugs and CCN kisses Nanny head in hallway. Went into lounge and sat on sofa invited Nanny for a cuddle on lap and talked about Christmas, whether bedroom finished. Sharing self-discussing weight loss. This was quite a feature of conversation and especially in relationship with Mother with whom CCN shared dieting and exercise tips. CCN also talked to Nanny about worrying and encouraged contact with CCN on the phone and in person if worried. Mother brought in notes, injection/implant sharps box. While CCN talked with Nanny...
[injection given]*

*... CCN[4] asks to see Nanny's new bedroom. All go to bedroom shown small spare room where injections used to take place.
Lovely new bedroom like a make over programme, done by dad.
Back down stairs Nanny invited to help herself to stickers, which she does and adds them to front of notes which stay in house.
CCN[4] writes notes. Shares self, talking about party she is going to offers to bring photos next time. Mother and CCN swap diet tips...
... More hugs and kisses. CCN asks after fathers work.
Set new date CCN offers morning visit as family on Easter hols. Mother offers breakfast, CCN accepts.*

Field notes observation Nanny.

Nanny's relationship with CCN 4 may also have been influenced by CCN 4's approach to play. Nanny's mother described how the community children's nurses had brought Nanny a nurse's play kit with her own syringes on their first visit (interview with Nanny's mother after Photo Talk Diary). The gift of stickers and certificates was also mentioned by Nanny several times. These small gifts seemed important to Nanny and to be part of her relationship with CCN 4.

Nanny's relationship with CCN 4 seemed to make it difficult for her to find any fault with nurses in general. Her experience may also have been influenced by the first implant that she had in hospital administered, according to Nanny, by a doctor. This did not go well. Nanny's recollection was that the doctor was rushed and his approach was less than helpful:

<i>Co-worker 4</i>	<i>Yeah but what about the not so good nurse?</i>
<i>Nanny</i>	<i>I've never had a not so good nurse.</i>
<i>Co-worker 4</i>	<i>... You must know what makes a good nurse, so what do you think would make a not so good nurse? Can you think of anything that you wouldn't like?</i>
<i>Nanny</i>	<i>Well I had a doctor put a needle in me when he said I promise I won't do it, and he did it.</i>

2nd children's group.

It could be argued that Nanny held an idealised perception of her relationship with her nurse. However, she was aware of the nurse's feelings, reporting that her nurse was smiley even if she felt unwell (2nd group):

<i>Researcher</i>	<i>[names CCN4] comes and does your needle?</i>
<i>Nanny</i>	<i>Needle yeah. There was nothing I didn't want to write about her.</i>
<i>Researcher</i>	<i>Right ok</i>
<i>Nanny</i>	<i>I did the good, but I didn't do anything bad cause there was nothing bad about her.</i>

Nanny: Photo Talk Diary interview.

Kelly also had a positive regard for nurses. She took a number of photographs of "her" nurses, and drew a picture of herself receiving nursing care in her Photo Talk Diary. Kelly could name all six of "her" nurses who she placed on the 1st branch of the help tree, along with her mother. Kelly could appreciate that the injection the nurses administered allowed her to play with her friends and to enjoy riding her bicycle. As this data quote shows, Kelly was aware of how effective the nurses were because without them her wellbeing would have suffered:

Kelly Well I am poorly, but I wouldn't like think of myself, like the poorest child, or because...

Researcher What if we did this thing from sort of ten is the well, the best you could be, and zero is like very, very ill.

Kelly I wouldn't think I was like really ill. I wouldn't think I was that.

Researcher What would you say what sort of number would you put on it?

Kelly I would like , just , just over 5

Researcher Ok put a cross or something.

Kelly About 7.

Researcher A 7, oh OK. So what makes you well do you think?

Kelly Umm, like my needles make me well.

...

Researcher If you didn't have the nurses where do you think you would be on that nought to ten?

Kelly I would be about on number, on number 3.

Kelly: interview after observation.

For Kelly, nurses were fun. They tickled her and her brother and played games with them. However, Kelly recognised that during the observed visit by the nurses this did not occur. In rationalising this, she showed that she understood some of the pressures on community children's nurses:

Kelly Because sometimes like the nurses that tickle me, like they've been to every single house and I'm like the last one, so.

Researcher Do you think they want to get home to their children, or their tea?

Kelly Maybe, or sometimes like they've been to like two houses and then they came to me, and then like and then like, they had to go to other houses as well, or sometimes they like to go home.

Kelly: interview after observation.

Despite this level of sophistication, Kelly also seemed unable to be critical of the nursing care she received:

Researcher Your nurses are erm, really good. Do you think OK... What would make them better, do you think?

Researcher *Are you poorly, or are you healthy? You were in hospital not last week, but the week before, wasn't it? Why did you go to hospital?*

Honey *Cause I wasn't feeling very well.*

Researcher *Cause you wasn't feeling very well, cause you said on the dictaphone you were saying about your tummy hurting erm. What do you think made your tummy hurt?*

Honey *Don't know.*

Honey: Photo Talk Diary interview.

It is possible that Honey's resistance to nursing masked her limited understanding of her illness. She may have been aware of her illness state, but did not want to talk about it either as a part of her attempt to be like other children (see section 6.3.1.) or her fear of hurtful nursing (see above section 7.2.)

Honey's relationship with nurses did not appear to be positive. On her "help" trees she placed nurses in the top branches (less helpful) in the 1st children's group, although in her Photo Talk Diary she placed them on the 1st branch (helpful). However, it seems likely that her placement of nurses on the first (helpful) branch in her Photo Talk Dairy was influenced by adults, as it was evident from the first group that Honey did not have a good rapport with her nurses. Honey did not draw any pictures of her nurses in her Photo Talk Diary and took no photographs of them either. Further she was unhappy that her mother had taken a picture of the nurse:

Researcher *Honey, what about you, do you talk to the nurse when she comes to see you?*

Honey *No.*

1st children's group.

Researcher *Why didn't you like doing it[Photo Talk Diary]? Because you love drawing don't you? Yeah. Was it because it was about nurses? Yeah. Do you not like your nurses? No, you're shaking your head.*

Honey: Photo Talk Diary interview.

Only in the second group did she begin to relate how she would like to be more involved in receiving nursing care, which seemed to hint at the possibility of a better relationship (see section 7.8.1.).

For Honey the hurt nurses caused, especially during the thumb prick, seem to be a major factor in her resistance to nursing. During her Photo Talk Diary interview she was withdrawn and the researcher had to comment on her body language to record a response (where the researcher states “yes”, or “no” these were in response to Honey nodding or shaking her head). She may also have used the “don’t know” response as a default answer rather than refusing to answer. Waterman et al (2001) have suggested that because adults expect children to answer their questions, children may use default answers rather than simply refusing to answer the question. This data extract shows Honey’s resistance to talking about nursing:

<i>Researcher</i>	<i>...So these nurses that come to see you, how do you think they could make it better? If it didn't hurt would that help? Yeah. What about if the nurses talked to you would that help? No, that wouldn't help, ok. What about if they played with you? No, OK... So really it's just the fact that it hurts that you don't like...</i>
<i>Researcher</i>	<i>OK, so a nurse who's a lady, a nurse that doesn't talk to you. Would that be a good nurse? Just comes in, does the thumb prick makes sure it doesn't hurt you and goes, would that be good? Yeah.</i>

Honey: Photo Talk Diary interview.

Honey’s negative regard for nurses seemed not to be based upon a particular nurse’s personal characteristics, nor did she seem able to define why she did not like nurses, or how nurses could build a better relationship with her:

<i>Researcher</i>	<i>Why is you don't like the nurses, can you tell me why that is?</i>
<i>Honey</i>	<i>Don't know.</i>

Honey: Photo Talk Diary interview.

Honey's resistance to nursing did not seem particularly limited to receiving care at home. She seemed as indifferent to hospital nurses as she was to the community nurses:

<i>Researcher</i>	<i>You don't want to go to hospital, but you know the thumb pricks, you need to have them done to make you better? Where would you like to have the thumb pricks done?</i>
<i>Honey</i>	<i>Don't know.</i>
<i>Researcher</i>	<i>Have you got any friends at hospital? No, ok, are there any of the nurses that you like at hospital?</i>
<i>Honey</i>	<i>Don't know.</i>

Honey: Photo Talk Diary interview.

Honey's resistance to nursing seems to be part of a generally negative regard for nurses. Her resistance to talking about nurses or nursing made it difficult to explore her understanding of her illness, and unlike Nanny or Kelly, she did not show insight into her health in any of the group work or individual interviews.

The issue of Gizmo's understanding of his illness was more complex, as at the time of the study he was seeing five different medical teams. It is perhaps not surprising then that Gizmo seemed to have a very poor understanding of the various medical labels being applied to him (see section 6.2). Although there was a suggestion that Gizmo may have some learning difficulties, he seemed to grasp what was required in the study activities. It is possible that Gizmo also used "don't know" as a default position when faced with questions he was unsure about (Waterman et al 2001). He claimed at one point not to recognise his brother's girlfriend, though he clearly knew who she was, as he demonstrated later in the same data collection session (Photo Talk Diary interview). However, Gizmo's understanding of his illness seemed to be poor across all the activities in which he took part, and persistent questioning did not reveal any improved understanding:

Researcher Because you go to the hospital a lot don't you?
Gizmo Yep.
Researcher ...and you go see a doctor?
Gizmo Yep.
Researcher ...and you have nurses come?
Gizmo Yep, it's stupid.
Researcher You don't need them really. Because you are perfectly well? No [Gizmo shakes head] You do need them, yeah [he nods]. Because you are poorly yeah [he nods].

Researcher Why do you think you are poorly?
Gizmo Because I am.
Researcher Because you are, what is it that makes you poorly do you think?
Gizmo Mmm , one answer.
Researcher One answer, yep.
Gizmo I don't know.

Gizmo: interview after observation.

Throughout the data it is clear that his relationship with nurses was a difficult one. He did not place them on his help tree despite prompting from the research team and made no images of nurses:

Researcher What about you, Gizmo, when the nurse comes to see you at home, do you talk to her?
Gizmo No.
Researcher No? What sort of things happen?
Gizmo I just sit there.

Nanny What about the nurses Gizmo, do they help you?
 The nurse and doctor.
Gizmo They don't help me.

1st children's group.

Researcher So when the nurses come, what do they do?
Gizmo I don't know.
Co-worker 1 You forgotten?
Researcher Ok, you know really don't you? Do you not want to tell me? No, cause you remember when they come?
Gizmo [laughs]
Researcher Don't you?
Gizmo Yes.
Researcher Yeah you do remember when they come, is it that you don't like it though. What is it that you don't like?
Gizmo I don't know.

Researcher Ok, what would make it better, what would you like them to do?
Gizmo Nothing.

Gizmo: Photo Talk Diary interview.

Gizmo comes up to CCN and hits her on the head. CCN does not admonish Gizmo, nor does Mother. Gizmo moves away then returns and hits again. Gizmo's behaviour has become much more demonstrative since CCN entered, throwing sweets and toys to the floor, language more aggressive. Gives me a hug then mimes shooting me in head with "finger" gun, goes to CCN and mimes shooting her.

Field notes observation Gizmo.

Gizmo's negative regard for nurses may have made him blind to the nurse's actual behaviour, just as Kelly and Nanny's positive regard made them unwilling to acknowledge the actual behaviour of nurses. This lengthy data quote also shows how Gizmo's negative regard may be associated with the hurt caused by nursing interventions:

Researcher How are the ones [the nurses] who come and see you at home different then do you think?
Gizmo Don't like them I hate them
Researcher I know, I know, you said that. Why is that?
Gizmo Pulling my tube.
Researcher What about when they come and give wiggly's a drink what's that like?
Gizmo The same.
Researcher Yeah [pause].
Gizmo Put that one on as well.
Researcher How do you think they could make it better for you, the nurses ?
Gizmo By playing.
Researcher By playing a bit more, [names CCN] did didn't she, when she came in you were playing doggie, you were hiding in there, yeah. She came and tickled you didn't she?
Gizmo She made me laugh.
Researcher Do you remember that?
Gizmo She never found me though.
Researcher She did! She was playing a game with you though wasn't she?
Gizmo Yeah, but the idea is to play more games than one game.
Researcher Yeah spend a bit longer with you, would that help mmm...
Gizmo But not the tube.

Researcher *No the tubes do , don't like the tube, but does the tube make you better?*

Gizmo *Yeah.*

Researcher *Yeah and it has to be changed doesn't it?*

Gizmo *I hate it though.*

Gizmo: interview after observation.

It may be that some of the community children's nurses also found Gizmo difficult to deal with. On the observation visit, the community children's nurse warned the researcher that Gizmo used swear words and described him as "cheeky", "trouble", and a "rascal". Although this was done in a jokey fashion, it may be that Gizmo has picked up on these cues and acts accordingly.

Gizmo's view was to some extent slightly more ambiguous towards hospital nurses. Although he stated he liked the hospital, he also intimated that he felt being in hospital was akin to being in jail. Gizmo used a picture in the Photo Talk Diary of a lion to talk about being in hospital as like being in jail:

Gizmo *Look made jail [for the lion].*

Researcher *Made jail for him. Is that what it's like being in hospital?*

Gizmo *Yeah, he's in jail cause he's been naughty.*

Researcher *Oh right...Are you naughty Gizmo?*

Gizmo *No.*

Researcher *What was it like in hospital, cause when I came to see you, you were in hospital weren't you? What was that like?*

Gizmo *In jail.*

Researcher *Like being in jail.*

Gizmo: Photo Talk Diary interview.

It seems that Gizmo has a difficult relationship with nurses. Although his attitude towards receiving nursing care in hospital seems less negative, he was not able to explain why, and was ambiguous about his preference for the hospital setting.

Rather like the children with a positive regard for nurses, the children with poor understanding of their illness and a negative regard also showed a lack of involvement in receiving nursing care, although only Gizmo was observed receiving care. Gizmo appeared to have little control over the care he received, rather he resisted the nurses interventions:

CCN ready suggested Gizmo taken on to Mother's lap Mother cradles Gizmo restraining his arms as she removes his old tube. CCN suggests different nostril for NG tube. Gizmo upset wants the same side. CCN insists, some explanation, do not want to get sore. Mother restrains Gizmo while tube is inserted, Gizmo very upset crying. States he hates nurse. When over cuddles into Mother.

Field notes observation Gizmo

In this study, understanding of illness and regard for nurses did not seem to be related to difficulties in diagnosis. Both Kelly, with a positive regard for nurses, and Honey with a negative regard had had difficult diagnosis of their illnesses. Their mothers reported health care professionals who did not recognising their child's condition and delays in arriving at a diagnosis. Nor did parents' positive regard for nurses affect the views of children who had a negative regard for nurses.

7.5.3. A continuum of children's regard for nurses

While the cases of Honey and Gizmo mark an extreme of negative regard and those of Kelly and Nanny an extreme of positive regard for nurses, the cases of Mohammed and Joanne perhaps fall between these positions. Although Joanne and Mohammed had good insight into their illness, they seemed ambivalent about nurses.

In part these findings from the core group of children were supported by the observation of the non-core group children receiving care. These observation data

suggested that older children, with long term conditions, were often more involved in their care. In the brief time allowed by the observation, these children (young people) gave rich accounts of their understanding about their illness:

Quite extensive negotiations between CCN 6 and [young person] about which needle to use for thumb prick 2 types, had decided on a previous visit which one to use, but neither could remember which one they had decided upon... [researcher] asked about blood test [young person] stated for Leukaemia diagnosed 2004, had teeth trouble that did not clear up and taken to Dr diagnosed on blood test. Very knowledgeable and confident in knowledge of illness talked about information sources.

Field notes observation CCN 6 .

Getting a sense of children's illness beliefs and their regard for nurses was not always possible because of the short interaction between nurses and children during the observation sessions, and because of intergenerational issues. These intergenerational issues particularly affected children who may have had negative regard for nurses:

[Child] appeared not to like nurses. Adults were shocked at this and tried to deny the fact, or said she was in a mood. Tried to get to illness knowledge, but difficult with adults present especially grandfather. CCN 7 and mum report [child] calls TPN [Total Parental Nutrition]dinner and pudding and aware TPN makes her "big and strong".

Field notes observation of CCN 7.

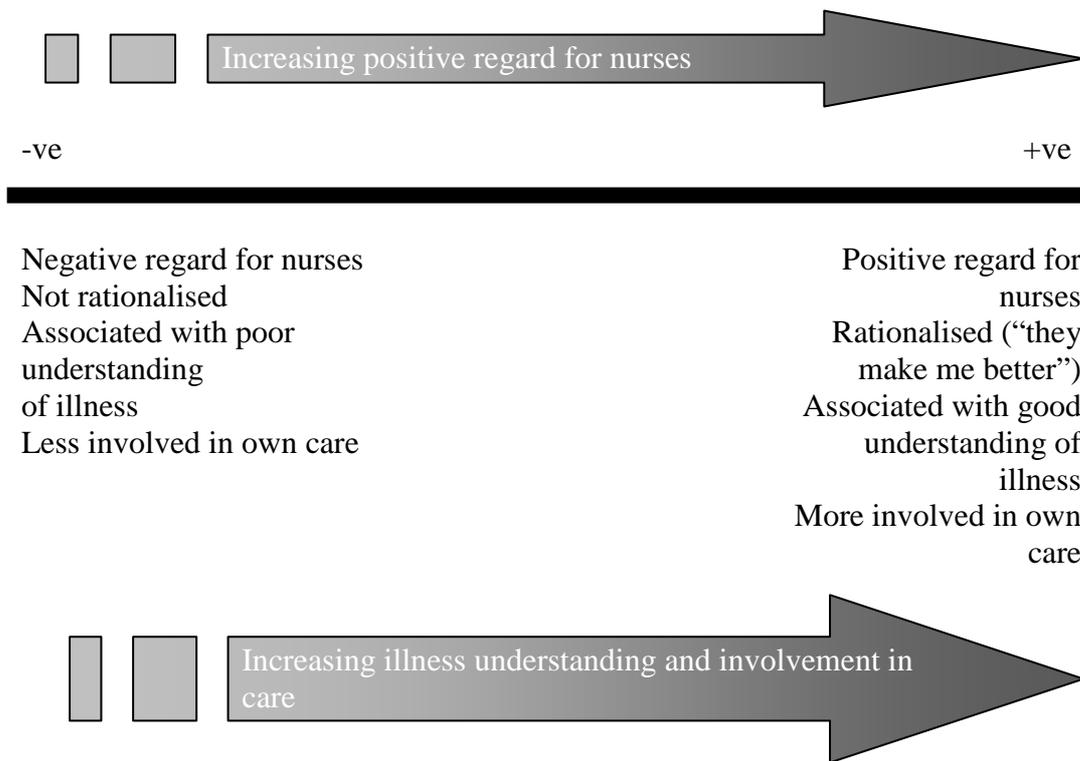
CCN often refers to child as being grumpy and hospitalised, has known her since very little on ward in hospital.

Field notes observation CCN 9.

(NB these data extracts relate to the same child.)

The findings from this study seem to suggest that a continuum may exist upon which children can be located according to the extent of their negative or positive regard for nurses, this is illustrated in figure 7.1

Figure 7.1: Continuum of children's regard for nurses



The position of children on this continuum of regard for nurses seems to be influenced by children's understanding of their illness and their involvement in receiving care, rather than the actual behaviour of nurses or the interventions children receive. The continuum of children's regard for nurses is discussed further in chapter 9, section 9.4.

Children's involvement in receiving care and their location on this continuum warrants some further exploration, as it could be argued that this involvement needs to be understood in the context of the relationships between the adult generation and children.

7.6. Children's involvement in receiving nursing care at home

The observation of children receiving nursing care showed that children's involvement was often limited. Adults, primarily mothers, intervened to ensure that children cooperated with nurses in whatever task the nurse had called to perform:

Mother opens negotiations checking when ready, mentions sing song . CCN 10 distract by discussing aunty's holiday gifts. Mother insists time for injection, child resists, protests. Child delays: talking about future holiday plans, bribed with cuddle from dad, threatened with removal of dad's cuddle. Child takes Mr Bump [ice pack] off, throwing it away and hides beneath cover (gives permission to do injection i.e. takes control) injection done. Offered stickers child wants her auntie to help her choose, Aunt called from upstairs. CCN produces certificate from notes family comment on how child has only a few more stickers to get before she can claim a prize. When asked not clear what the prize is but child excited.

Field notes observation CCN 10.

This example was typical of many of the observations in that the child appeared to take control of receiving nursing care in ways permitted by the adults present. For this child and for others, this was by physically resisting the intervention with non-verbal communication and controlling the moment at which the injection was given. The act of throwing away the freezer pack (Mr Bump), it could be argued is the child's signal to the nurse that they are braced and ready for the injection. Children in the core group described how, in community settings, there was an impression that the intervention is not delivered/ received until the child is ready, sometimes in contrast to hospital settings where children felt staff did not always wait until they were ready:

*Kelly
Researcher
Kelly*

*Cause they wait till I'm ready, and...
OK.*

*If I don't want to have the needle in that second,
or something they won't give it me.*

Kelly: Photo Talk Diary interview

Rabbit

*The nurse is putting my tube in. So I put my
thumb up to say she can go and when she's
finished I put my hand up.*

2nd Children's group

Reed et al (2003) have argued that a sense of control is central to children's dignity in receiving nursing care. However, contrary to Reed et al's (2003) contention that children have very little control over what happens to them when receiving nursing care, this study seems to suggest that children attempt to exert control over receiving nursing care in ways that are open to them.

One of the factors which seemed to affect how children experienced received nursing care, but which they had little control over was the gender of the nurse delivering care.

7.7. Children's experience of community children's nursing- Gender influences

In the core group of children, where arguably the intergenerational issues were more comprehensively addressed, there were a number of incidents in which the children expressed embarrassment at receiving care from nurses of the opposite sex. As community children's nursing is predominately delivered by women (Nursing and Midwifery Council 2007), this was less of an issue for girls in the study. However, Kelly and Joanne did receive care from a male community children's nurse:

Researcher *One of the other things was you have a man come, you have [names male CCN] come sometimes... How is it different when a man comes? Do you think?*

Kelly *Because, like I've got loads of girl nurses and it's just a bit strange having a boy come to your house and giving it ya.*

Researcher *Yeah? Can you tell me why it's strange?*
Kelly *Because like you saw I wear shorts up to, cause I ain't got any longer shorts and it's a bit like scary cause like I got my shorts on and...*

Researcher *Would you like longer shorts, do you feel a bit exposed a bit...*

Kelly *Like most of my legs are showing, then and the rest of them.*

Researcher So when [names male CCN] comes would you like to have longer shorts so he doesn't have to see so much of your leg?

Kelly Well I've always worn them shorts, but, they are a bit short.

Researcher You don't feel as comfy as if it were a lady?

Kelly No I wouldn't mind if they were a lady because umm, or girl, because like, because they are the same as me, and they have got the same things as me like [pause] like they got the same things as me.

Kelly: Interview after observation.

Although Joanne stated she did not have any strong feelings about having care delivered by a man, she was clear that she would prefer a female nurse.

The boys in the core group, who occasionally received care from a male nurse, but on the whole received care from female nurses, had a different experience:

Researcher Whether you had a man nurse come and see you, what would that be like do you think?

Gizmo mmm better.

Researcher Better, right why would it be better?

Gizmo Cause I don't like ladies.

Researcher You don't like ladies [laugh with Gizmo]. Do you think a man nurse, why would a man nurse be better? What would they do? [pause] What would a man nurse do if he came?

Gizmo Look after me.

Researcher Would they play, have a game, yeah? What else?

Gizmo Do stuff.

Researcher OK what's it like for you, being a boy and having a nurse come, do you think?

Gizmo Stupid!

Gizmo: interview after observation.

Mohammed's experience of receiving care from females may have been influenced by the dressings required for his skin condition, which involved exposure of his genital area. His mother remarked, on a few occasions during the study, that she felt he had begun to be more self-conscious about this exposure. It should also be noted

that Mohammed's positive relationship with his father may have influenced his preference for male nurses, such that he may equate male carers as being more likely to be fun and to do things with him, like his father. Mohammed's relationship with his mother was more complex and he may have associated female nurses with his mother and the performance of dressings, to which his father did not contribute. He appeared to have a low opinion of women more generally:

<i>Researcher</i>	<i>I was wondering what it is like for you as a boy...</i>
<i>Mohammed</i>	<i>Yeah.</i>
<i>Researcher</i>	<i>When all the ladies come to do your dressings?</i>
	<i>[pause] Why do you think a man might be better?</i>
<i>Mohammed</i>	<i>Man's are good man's are better than girls.</i>
<i>Researcher</i>	<i>Do you think you would have more fun?</i>
<i>Mohammed</i>	<i>Yeah we have more fun with a man.</i>

Mohammed: interview after observation.

When considering the data from the observation of non-core group children it should perhaps be remembered that the observation period did not allow the researcher to build the same degree of trust with these children as with the core group. It should also be noted that while the researcher is male, the nurses involved were all female. With these caveats in mind, it seems that children's embarrassment about receiving nursing care from a member of the opposite sex was variable:

CYPC 14 with abscess very quiet lad, commented painful. Tried to ask about history and assess illness knowledge, but conversation taken over by mother. When mother out of room, taking a phone call, got that he preferred home and did not mind about nurses gender, which given wound very close to groin area quite a surprise.

Field notes observation CCN 12.

An issue common to both the observation data from of the core group and the non-core group children was the presence of the male researcher. During these observations the researcher became aware that on some occasions his presence was causing the children distress and he negotiated to move to a separate room in the house while care was delivered:

Mother negotiates for child for all others to leave the room apart from dad and mother and CCN and researcher. Child C tries to roll tight jean up from bottoms. Becomes evident, and mother states will have to take off trousers. Child C looks at researcher: appears uncomfortable. Mother states "she doesn't like to show her bits off". CCN10 and researcher offer to step out. Researcher waits in kitchen. Mother has fetch blanket. Called back when trousers down and blanket positioned to cover groin and upper thigh. Child C laying on Dad's lap.

Field notes observation CCN10.

Researcher You felt a bit uncomfortable with me being here like when you had your injection. Was that because you had to take your trousers down?

Nanny Yes.

Researcher Why did that make you feel uncomfortable?

Nanny Cause you are a man.

Researcher OK, great cause we talked, before, about some nurses are men, umm .What that might be like if you had a male nurse come ?[pause]. How that would make you feel?

Nanny Well because they're a nurse and your mummy and daddy obviously it's not so embarrassing.

Researcher OK.

Nanny But if any one is looking at you like this you feel...

Researcher People looking at you when. If you had your injection with your trousers on if it was say in your arm.

Nanny Yeah.

Researcher What would that feel like?

Nanny Umm, I'd be ok to do that in front of anybody, yeah like a blood test. I'd be fine to do that.

Nanny: interview after observation.

Receiving care from a nurse of the opposite sex did seem to embarrass some children.

Although as Nanny intimated, it may be that some children are conscious of the social convention that allows nurses to perform intimate procedures, but this may not ameliorate their embarrassment.

The findings of this study suggest that some children receiving nursing care at home may feel embarrassment. While some hospital based studies reported similar findings (Coyne 2006, Reed et al 2003, Lundquist & Nilstun 2007) this is the first study to

show that this is an issue in community settings. Some of the children appear to link these feelings of embarrassment to the gender of the nurse delivering nursing care.

This is discussed further in section 9.6.

Children's regard for nurses and, for some children at least, the gender of care providers seem to be influential factors affecting children's experience of receiving nursing care. The effect of children's regard for nurses, which, as shown above, may make them either uncritical in their praise, or over critical in their condemnation, should perhaps be borne in mind when considering what children state are their expectations of nurses.

7.8. What is it that children expect and want community children's nursing services to do for them?

This section sets out some of the children's expectations of good nurses and not so good nurses. These expectations seem to be dependent on children's regard for nurses. For many of the children in this study receiving stickers or certificates seemed a part of their expectation of the nurse's visit. This section also explores how children negotiated their involvement in receiving care, which, it is argued, involved expectations of both guest and host behaviours. Finally, the desire of children to receive nursing care from a nurse of the same sex is examined.

7.8.1. Children's expectations of a good nurse /not so good nurse

Children in the core group were asked what they considered to be the characteristics of a good nurse, and a not so good nurse. Children with a positive regard for nurses identified good nurses by personal characteristics and their abilities to perform as children's nurses (see Nanny and Kelly section 7.5.1.) These characteristics have been

identified in other literature (Coyne 2006, Randall et al 2008, Battrick and Glasper 2004). However, it has not been previously reported that children may have a negative as well as a positive regard for nurses, nor that children's regard for nurses may effect how they perceive of nurses as good or not so good. The following words were written by the children in the second group around body outlines for a good nurse and a not so good nurse:

Good nurse

Honey

She gives us stickers for bravery
Sometimes lets me help
She rebound [sic responds] to what I say
She'll speak slowly

[written around head in the hair some prompting from Co-worker 5]

Nanny

Smily, hugs, kisses me
Stickers, bravery
citsct. When not
~~Smily~~ well still
Sm:ly. Very special

[Written to right side of head as viewed in a block]

Not so good nurse

[from left of head clockwise around body out line]

Big ears haha [Rabbit]
Doctor lied to me [Nanny]
Stop that now [in speech bubble]
You do all the work new
She didn't stop and go slowly when I said go slowly [Honey]
She said I couldn't help [Honey]

[In body shape

Left shoulder]

Fat bum

[right chest over heart area]

Big math [sic mouth]

Words written on body outlines 2nd Children's group.

Children's expectations of nurses' performance as good, or not so good, should perhaps be considered in light of the data in section 7.5.1. and 7.5.2. where children with a positive regard reported positive behaviour, which was not always borne out by observation, while children with a negative regard did not acknowledge positive behaviours. This finding means that the characteristics of good and not so good nurses may be less important to children than their regard for nurses.

7.8.2.Children's expectations of receiving stickers- Children, like other children

All the children in this study loved stickers. There seemed to be a ritual, or social contract, that the nurse delivered the nursing intervention and in exchange for enduring the intervention, and some times in part for cooperating with the nurses, children received stickers (or a certificate/ small reward). The use of stickers (etc) did seem to be limited to younger children and often was not offered to older children:

Child B asks for sticker and takes alco gel from nurses diary, takes pen- TV going children's TV ...

...CCN writing up notes little interaction with child who has gone back to CCN's diary and alco gel.... Gets a sheet of stickers out for child only one as wants them all, child takes a few and sticks them on herself, she only protests when stickers are put away. Mother bribes successfully with chocolate, sibling sent to get chocolate from kitchen.

Field notes observation CCN 12.

Nurses support this social contracting use of stickers (see section 8.2.3). The strength of children's feelings about stickers, the fact that their use re-surfaced at a number of data collection points (both children's groups, Photo Talk Diary, and observation), suggests that the receiving of stickers is a well established and cherished expectation children have of community children's nurses. The use of stickers is discussed further in section 9.3.

7.8.3. Children's expectations of involvement in receiving care

Although the children in the core group focused on the administration of therapeutic interventions, they also recognised that purely technical, inhumane approaches were not acceptable (see section 7.3.). The data in this study seem to suggest that children want to be involved in their care:

- | | |
|-------------------|---|
| <i>Researcher</i> | <i>Are some nurses really good?</i> |
| <i>Kelly</i> | <i>It depends on how they do it like. I like [names CCN] because she asks me if I am ready and every thing, well most of them do , well all of them do, but like I actually think it's better when I actually see the needle.</i> |
| <i>Researcher</i> | <i>OK.</i> |
| <i>Kelly</i> | <i>Cause like, cause you can see how big the needle is, cause if some nurses like [names CCN] don't show me the needle they hold it behind the tissue, and I am like has it got bigger, has it got bigger.</i> |
| <i>Researcher</i> | <i>OK</i> |
| <i>Kelly</i> | <i>But when they show like me, cause sometimes if you don't know you just exaggerate it and think it's about that big or something, but if you see it you realise it ain't as big as what you think.</i> |
- Kelly: interview after observation.*

It may be that children express the desire to be involved in receiving care in different ways. Kelly wanted to see the needle before her injection, Nanny controlled the moment of the implant by a ritual counting of 1,2,3, Mohammed used humour to connect with the nurse performing the dressings to his body, Honey wanted to be more involved (see section 7.8.1.), Joanne stayed in another room until the nurse was ready to minimise her contact with the nurse, while Gizmo attempted to negotiate ,unsuccessfully, the site of his enteral feeding tube:

Mohammed had little say. Felt like the dressings were done to him, or to his skin. Mohammed did have a say over comfort issues and pointed out once, or twice if dressings not done as he liked, but his focus was on me and playful talk.

For the core group of children and those observed receiving care (non-core group) the degree of involvement the children seemed to have was dependent on generational issues, in that adults seemed to control the involvement of the children. However, all of the children observed appeared to attempt to exert their agency to be involved in receiving nursing care.

Other studies have pointed out that children have often been passive in receiving nursing care (Shin and White-Traut 2005, Coyne 2006). This study found that some children were passive in receiving nursing care, but some children appeared to negotiate a more active role. The degree of the child's involvement seemed to be dependent, in part, on the child's understanding about their illness. The child's relationships with other generations and the expectations of the child's parents of host and guest behaviours also seemed significant in determining the degree of involvement.

The degree to which children were allowed by adults to be involved in receiving care was perhaps a part of the intergenerational landscape which surrounds the child. From many comments made during this study this would seem to be related to the child's age, in that adults seemed more willing to accept that older children were able to be involved in their care.

The general social expectations of children and the degree adults in society are willing to allow them to be involved in their health care is perhaps one factor in children's involvement in receiving nursing care in community settings. Another is the social expectations which surround being a host to a visitor in one's home and of being a

guest, since when receiving nursing care at home, children are part of the family which plays host to the nurse who is in effect a guest.

Guest and host behaviours

The findings in this study suggest that similar behaviours to those described by Mayall (2008) in research terms (see section 5.3.3.) applied here to receiving nursing care. Parents and children (see Nanny section 7.3.) reported host behaviours, and these were also observed. These included, escorting the nurse from the front door to the public areas of the house (living room/kitchen), offering drink and food to the nurse, bringing equipment left in the house to the nurse and escorting the nurse to the front door when she or he left. Nurses joined in with these behaviours, for example asking parents before washing their hands, and accepting drinks and food.

As Mayall (2008) points out, accepting such host/guest behaviours means the researcher, or in this case the nurse, has to accept that she/he is not fully in control of the environment or the interaction. Thus, even assuming that nurses wished to facilitate children's involvement in their care, other adults in the household can restrict children's involvement. In this study, mothers and other adults were often seen to direct the nurse's visit, setting out their equipment, marshalling the child and persuading, or cajoling the child to cooperate (see section 7.6 above). For nurses to empower children, they will need to persuade other adults that allowing children to be more involved in receiving care is beneficial, both to the child and to the adults. A consistent empowerment stance was not observed in this study. Issues of children's consent and assent in this study are discussed in more detail in section 8.4. in the next chapter, where these issues of children's involvement in their care re-surfaces.

7.8.4. Children's expectations of gender - being nursed by a nurse of the same sex

The children in this study expressed a preference for receiving care from a nurse of the same sex as themselves. This preference amongst children has been given very little attention in previous studies (Taylor and Green 2008). All of the core group children who were interviewed at home expressed a preference for a nurse of the same sex to deliver care:

<i>Researcher</i>	<i>So you have a lady nurse come to see you?</i>
<i>Nanny</i>	<i>Yeah</i>
<i>Researcher</i>	<i>Is that important to you or would you like a man nurse come to see you?</i>
<i>Nanny</i>	<i>I'd rather have a lady</i>
<i>Researcher</i>	<i>You'd rather have a lady, ok why do you think that is, why do you?</i>
<i>Nanny</i>	<i>I'm just not very comfortable with a man.</i>

Nanny: Photo Talk Diary interview.

This preference may be influenced by many of the factors discussed in section 7.7. Although this preference for a nurse of the same sex as themselves was not always evident in the non-core group sample, this may be because the observation did not allow for trust to be built between children and the researcher to facilitate the discussion of this more delicate issue (see section 7.7.)

7.9. Summary of children's relationship with nurses and with nursing

This chapter builds on the last chapter where children talked about how they experienced receiving nursing care in relation to their family, friends and school. The findings reported in this chapter relate to children's relationships with nurses and nursing. Accessing the voices of these children was challenging, as they were often reluctant to talk about nurses and nursing care. The researcher had to look beyond children's initial responses to uncover how their regard for nurses influenced how they received nursing care. Children's regard for nurses seemed to be dependent on their understanding of illness and the degree of involvement in receiving care, with a

more positive regard being associated with better understanding of illness and more involvement in receiving care. Observation data showed that children's regard for nurses made them less aware of the behaviour of nurses, such that children with negative regard for nurses failed to acknowledge the positive behaviours of nurses' e.g. play. While those with positive regard for nurses failed to recognise the less negative behaviours e.g. task orientation.

The expectations and desires of children receiving nursing care suggested that they want nurses to support them in being children, like other children, and want to be involved in receiving nursing care from a nurse of the same sex as themselves.

As Clark (2004) has pointed, out placing children's data in a generational context can be very helpful. The next chapter seeks to place the findings reported in this chapter and chapter 6 into such a generational landscape, not to diminish the child's voice, but to enhance understanding of it.

**“They just do my dressings”: Children’s
Perspectives on Community Children’s
Nursing.**

Volume two of two

by

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Chapter 8 Generational landscape and profession

8.1. Introduction

This chapter seeks to place the findings derived from data given by children into a generational and professional context. The purpose of the chapter is not to negate, or call into question any aspect of the children's voices. Rather, the voices in this study can be thought of as like instruments in an orchestra, where each instrument adds to the music made. The adult voices, far from cancelling out the children's voices add to them, and in certain areas amplify the voice of children. For instance, this chapter examines how adults supported children's attempts to be children, like other children, amplifying the children's voice. In other areas, such as the visibility of community children's nursing, and children's involvement in receiving nursing care, adult voices produce different notes that add to the richness of children's voices to give a fuller chord, which produces a more rounded sound, giving different insights into the phenomenon of receiving nursing at home. Finally, some of the notes from the adult voice, perhaps on gender issues, provide a discordant contrast to children's perceptions.

Generational context is used here to mean a context in which there is a relationship between different generations, between children (people born after 1988) and adults (people born before 1988), where the relationship between generations is influenced by social and cultural expectations and power differentials (Mayall 2002, Robinson and Kellett 2004). In discussions with the author Professor Christensen has referred to these relationships between generations as a generational landscape, the vistas of

which stretch far beyond the child's home to their extended family, friends, schools and communities (personal communication 11th March 2008).

Professional context refers to taking account of the relationships between nurses who claim to be members of a profession, which seeks to deliver nursing care for children (where nursing is defined as by the Royal College of Nursing, 2003) and those excluded from such professional claims, but who may also lay claim to the work of caring for children, including delivering nursing care to children.

This chapter firstly sets out how adults supported children's portrayal of themselves as like children not living with illness. Then the resistance to receiving nursing care discussed in the last chapter is re-examined as part of adults' support for children's attempts to portray themselves as children. Nurses revealed how they used stickers as part of this support provided to children. This leads to the findings from adults about the visibility of community children's nursing, although nurses focus on technical therapeutic interventions just as the children did (see section 7.3), they also reveal other roles of nurses such as teaching/coaching and helping (Benner 2001). The re-examination of how children are involved in receiving nursing care also revealed different "notes" in the adult voices, which add to the picture of how children negotiate their involvement in care. Finally, the issues of gender in the profession of children's nursing is explored again, with the adult data providing discordant notes in opposition to children's stated preference for a nurse of the same sex.

It is argued here that both the generational and professional contexts, which surround children receiving nursing care, influence how children receive care and what they expect and want from community children's nurses.

8.2. Supporting children, to be children, like other children

The findings from the data given by mothers and nurses support those of the children in describing how they portray themselves as children, like other children.

8.2.1. Children, like other children -family, friends and school

Mothers in the study supported their children's attempts to be like other children.

Some did this by taking photographs with their child's camera to present the researcher with a representation of their child and their family as being like other families (see section 5.3.2). Nanny's mother took pictures of Nanny in her garden playing with friends. Kelly's mother took pictures of the area in which they lived, Kelly's school and her friends. The mothers of Gizmo, Honey and Joanne were less active in constructing their children's Photo Talk Diaries, but they supported their children in other ways e.g. by facilitating their attendance at school.

The nurses in the study all recognised and agreed with the statements endorsed by the children.

- I don't like to think about being ill I prefer to think about playing with my friends and being with my family.
- I would rather have my mum or dad do all the things I need to keep me well, than have nurses visit me at home.

The nurses also recognised that being like other children was important to children and to their experience of receiving nursing care at home:

CCN12

I am involved with a child that, umm he, because of the way his family are in relation to diagnosis. I think he picked up on the not wanting to draw attention to himself. He's an oncology child, has had his treatment and lost his hair, so he wears a hat all the time. He doesn't like to think about it, or talk about it much. He just wants to be doing his normal routine and is like that child said

about playing with his friends, or his family. He just wants to try, I think in a way its keeping occupied, so you haven't got to think about it and if that's their coping mechanism.

CCN 12: Interview after observation.

CCN

If they know, "oh I've got to go home my nurse is coming to do this" they are different from their friends, so they feel like they probably stick out, or this is probably again where they do not want to comply with what the nurses, what's required for, with them because they are different, in their eyes.

CCN Group interview area 2.

With regard to parents' gendered division of caring roles in children's experience of receiving nursing care, the nurse's data provided a complex picture. While some of the nurses reflected a more traditional view of men, going out to work in the public sphere and leaving the care of children at home to women, for others the gendered view of parents' roles seemed to be contingent on relationships within families:

CCN

I mean time, and time again, you will ring up families and you will get dads on the phone and they'll say "Oh I don't know what's going on you'll have to talk to mum". And it's not you are disregarding dad's place in a family situation, his importance and his relationship with his child, its just that he has made that, I don't get involved with that , for all the right reasons, like he is not at home during the day so doesn't fall to him to do it. It might be a girl and she doesn't want to talk to her dad about it, umm, but I would say more often than not our relationships are with mums rather than dads.

CCN

They are but...

CCN

...it depends.

CCN Group interview area 1.

During some of the observations of nurses delivering care there were occasions when the nurse seemed to display solidarity with mothers in their attempts to engage their male partners in child care. This was done in a half joking way, suggesting that the

women leave the man to care for the child while they go away on holiday, or that the father should take a more active role in child care.

The nurses from area 2 felt that fathers were becoming more involved in their children's care. They claimed that there was a type of "new wave father", who not only took on technical aspects of delivering nursing care, but also allowed their partner to step back from their caring role:

CCN *There seems to be a new wave father on the block, really and it is a father that wants to be involved with their child. It's a father that's available to look after the child and is very active in looking after the child. I do know a few more recently over the past two years maybe, 2-3 years, than when I first started doing CCN work.*

Researcher *So when we say active in the care of their child?*

CCN *They are the one who puts the nasogastric tube down, if it comes out, they are the one who'll do the feeds, they are the ones that will do a lot of the technical procedures and when the fathers say they will do it, it gives the mothers the opportunity to opt out...*

CCN *...Also sometimes I've done the evening respite and the father comes in from work and he's had, he will actually take over from what mum's done in the day. So mum can take a step back and have time with the other siblings. So he has time with the child, then go back to his, so he will share his time with both siblings and when he's come in from work and then he gets involved. I mean it's quite nice that dad used to come in and do what he had to do and then you know, get his child ready for bed and help with the care.*

CCN Group interview area 2.

Nurses also supported children's view that other family members, not just parents were important in children's experience of receiving nursing care. Some of the nurses in the study felt that they delivered care to the "family" rather than just to the child. Often nurses used the term "family" in a loose sense. Sometimes family was used

instead of “parents”, sometimes it seemed to mean child and parents, while at other times it meant child, parents and extended family members:

- Researcher* ... Who do we include in that family network?
CCN Any main care givers and siblings [pause]
CCN ...and pets and Multi ethnic [laughter]
CCN Sometimes it's grandparents isn't it some time grandparents give...
CCN ...The extended family.
CCN Yeah, the extended family sometimes they have a lot of input with helping out. So it's not always just mum and dad you get to know auntie, uncle and Geoff next door don't you.
- CCN Group interview area 2.
- CCN 8* ... One family I go and see, I go and see a little girl who we weigh, once a week. I always make sure I include the brother in that, we weigh the brother, we weigh her, we weigh the dolly and we weigh his toys. So it's just incorporating the whole family centred caring. So I just don't go in and weigh her and come out again, so I kind of make it into a bit of a, so he feels included and he doesn't feel resentment towards us coming into his house. Because it's quite difficult for him.
- CCN 8 Interview after observation.

The nurses were aware of how school provided children with an opportunity to be like other children. They were active in supporting children in school, but conscious of the potential for the child to be stigmatised by their presence:

- Researcher* ...How do you build those relationships with teachers, I suppose?
CCN If for some reason what ever going on with them affects sort of their school life, or if you know children have got nasogastric tubes in school we go in and do teaching and things to teachers and carers and so. Some of the children with constipation we might liaise with the teachers and things so.
CCN Some children that are statemented we will actually go into the review you know the annual reviews.
Researcher Within school?
CCN Yeah.
- CCN Group interview area 1.
- Researcher* So who would request? [teaching of school staff] sorry.

CCN

If school felt that they needed it for the children then they would request it, but you don't want to. Well my philosophy is you don't single a child out and make them any more different than they feel anyway so.

CCN Group interview area 2.

The use of carers (not registered nurses) had allowed a number of children to access school:

Researcher

Would those children go to school if they didn't have a carer? Or....

CCN 10

Some children wouldn't no. Um, children with tracheostomies wouldn't go to school if they didn't have carers, they wouldn't be able to go. Er, children who are enterally fed who need feeding at school would possibly still be able to go to school, but obviously their day would be interrupted by having to go home, or parents having to come in.

Researcher

Yeah.

CCN 10:

To do the feeds so it just makes it so they can stay at school be part of the school community if you like, and um, parents then get that respite.

CCN10 Interview after observation.

Nurses were less clear on the role of transitional objects in children's experience of receiving nursing. What does seem clear is that adults, including nurses, are supportive of children's attempts to portray themselves as being like children who do not live with illness. There seems to be a common view of childhood supported by both children and adults of the child receiving care primarily from their family, normally mothers, and attending school, where they form friendships. Illness and therefore nurses and nursing do not feature in this view of childhood.

8.2.2. Resisting hurtful nursing

Mothers in the study attempted to ensure their child portrayed receiving nursing care in a positive way (see section 7.5.). However, nurses, in both areas, acknowledged a common experience of children resisting nursing care:

CCN *I think some children can see us in that role. I mean I have had children hiding under kitchen tables when I turn up at the door [laugh], and nothing, nothing would change that. Soon as you done what you needed to and you go, that is fine get on with it, you know, they hear the door bell and they start, but they know that's the role you have to do. It's five minutes you know in their week and that's the way they cope with it.*

CCN *Don't worry [names CCN] I had one lad who hid in the bathroom.*

CCN *Yeah, locked the door [laugh].*

CCN *Yeah so it's not just you.*

CCN Group interview area 2.

The data from nurses further illuminates the “hurtful” aspect of nursing care mentioned in the children’s data. Nurses talked about building a trusting relationship which is perhaps at odds with the administration of often hurtful interventions. The pain inflicted by interventions administered by nurses is amplified by a sense of the nurse breaking the trust relationship, which arguably made the nursing interventions “hurtful”, as they involve pain and a sense of betrayal for children:

CCN *That's what I meant by empowerment, because that where that comes in, by obviously building up their trust in you and the knowledge of what's happening, their development, their age and level of understanding, you are empowering them in their treatment really. So for some of them, you know, for some of them are more accepting because they understand why, but then again that depends on their development, their age and their conditions...*

Researcher *Right.*

CCN *...and sometimes their level of trust can depend on their previous experience as well, cause you know we go out to see some children who have obviously not had a good experience in hospital, and that's already colouring their view of you before you have done anything...*

CCN *...trust comes in more doesn't it you know in that they don't see you as a threat then, they actually see you as their ally and somebody who is helping them, rather than a threat to them.*

CCN Group interview area 1.

These data extracts highlight the debate had by the nurses as to whether giving children stickers etc, was bribing children to cooperate, rewarding children's bravery, or a sign that they (the nurses and the child) had survived the procedure and that it was now behind them. For nurses, stickers may be an instrument of control, as well as a way of acknowledging the child as being like other children and a sign of the work they have done as nurses.

It may be that as well as a visual reminder the sticker also serves as compensation for nurses inflicting pain. In the nurses' data it seemed nurses felt that maintaining trust between the child and nurse was vital in ensuring cooperation to deliver interventions. They used stickers to show children, that they deemed unable to rationalise the nurse's actions that although they had inflicted hurt their intention as a nurse was to help them. In the observation of Gizmo, stickers were used to re-establish the relationship as positive between nurse and child. The nurse continued giving Gizmo stickers until she elicited a smile from him (this may constitute a sign of a positive relationship from the nurse's perspective, if not necessarily the child's). Thus the nurse compensated the child for the hurt they feel they have inflicted, in order to rebuild trust in the relationship and to ensure the child's cooperation when administering the intervention in the future. This explanation may account for why older children were not offered stickers, because nurses deemed them able to rationalise the hurt inflicted as a part of the intervention. However, it may not explain why children were still given stickers even though the intervention was non-painful (such as flushing long lines) and did not cause upset. The use of stickers is explored further in section 9.3.

For nurses, the visual aspects of stickers may serve as a motivation to continue giving them. As much of the nurses' work seems to go unrecognised by children (see section 7.3.) and occurs in the private space of the home, the sticker may serve as a way of making the nurses work both visible and to some extent public. For instance, a child may show their sticker to other family members. For nurses in community settings, as opposed to hospital settings where the nurses' work is more visible to parents, children and other professionals, the nurse may feel their work is unrecognised (Acornley 2005). Nurses in both areas in the study commented on plans to inform other professionals of their services, despite both services being well established for many years. The sticker may be an attempt to place a visible mark, which others can see, to bear witness to the nurses' intervention.

8.3. Visibility of community children's nursing

The nurses' in this study agreed with the children that the focus of their work was the administration of technical therapeutic interventions. This made technical tasks much more visible than other aspects of community children's nursing. However, the nurses' data places this focus on the technical tasks of administering therapeutic interventions in a professional context in which nursing supports medical practice:

- | | |
|-------------------|---|
| <i>Researcher</i> | <i>OK so how would you characterise your relationships with children? [pause]. What would be the basis upon which they are built I suppose?</i> |
| <i>CCN</i> | <i>Well we only go in to a child if there is a nursing , clinical nursing need, so that would be the basis of our interaction with a child, that it had a clinical nursing need, that would be the first reason why we entered the house.</i> |
| <i>Researcher</i> | <i>Can you give me some examples of what you mean by clinical nursing needs.</i> |
| <i>CCN</i> | <i>Dressings, enteral feeding, what else do we do? Injections, central lines.</i> |

CCN Group interview area 1.

Researcher Do you do other things at work that we have not seen today, and if so can you list them? Save a bit of time.

CCN 12 Have to think what we do, we do methotrexate injections ... We do a lot of nasogastric and gastrostomy care. Whether it is passing a tube, changing a button or just the skin care around sites. Obviously teaching in school and teaching families in the home environment. We do a lot of the line flushes, chemo therapy. We do lenograstin injections as well, sometimes we do zoladex injections.

CCN 12 Interview after observation.

Some nurses agreed with the children (see section 7.3.) that the administration of therapeutic interventions needed to be done in such a way as to not be dehumanising and purely task orientated:

CCN12 The last thing you want to do is go in being all sort of abrupt and just roll your sleeves up and get on with it. You want to at least try and relax and calm them and maintain that calming environment for them...You have to build some sort of relationship with them in order to be able to get their confidence to be able to let you do anything to them. At the end of the day haven't you? cause if you haven't got that sort of relationship, you can't just go in and grab their hand and give an IV for exampleI don't want them to feel as though we are just seen as this person who comes in, does the treatment and goes out again.

CCN 12 Interview after observation.

CCN I think it depends I mainly do respite nursing and playing with the child is a very big part of my job. Because I can be there for four hours and of course you've got to interact with the child and play with them, but obviously some other nurses are only in for a procedure and they are gone again. So it is whether or not you need to actually introduce play into that situation.

Researcher So those of you who go and do procedure is that...

CCN I play through my procedures.

CCN Yeah [some voices].

CCN I think you have to don't you?

CCN

You do it with out even thinking about it .It's part and parcel of what we do, and who we are, and when we sit down and actually think about it we say "oh yes we do, do that " you know, but you do it as part and parcel of the job you have gone in to do, or the procedure you have gone in to do.

CCN Group interview area 2.

Despite the more personal approach evident in the data quotes above, the nurses also placed this focus on interventions within a professional context and spoke about their interactions with children as being "just a job". Often this related to a more task orientated approach to therapeutic interventions and was linked in some cases to maintaining professional boundaries between nurses and parents:

CCN

At the end of the day we are a professional team going into a house. We have got that barrier we have to stick to and if we over step it then we are not doing our job properly. It's all to do with accountability and autonomy.

CCN Group interview area 1.

CCN12

...At the end of the day we are a professional that's doing treatment. When we can be seen as a friend at the same time things can change with in that relationship and you might have to sort of , once you get to involved, that you can't sort of step back and sort of judge the situation appropriately. Really it is difficult everyone's interpretation of what professional boundaries is different so, because there are families I get involved with that other colleagues might not feel as much as I do. It's just you can't help being like "oh I like them".

CCN 12 Interview after observation.

Within community children's nursing there is a discourse on professional boundaries (Samwell 2005). This relates to how nurses in community settings may form friendships that lead to conflicts with their professional role, although, often these friendship relationships seemed actually to be with parents, rather than with children.

For some nurses this professional approach was linked to supporting children in their attempts to be like other children not living with illness. The focus on getting an intervention done with the minimum disturbance to the child's life was justified by claims to be supporting the child to be like the others, e.g. accessing social events and preventing hospital visits. If nurses are to facilitate children "To be like the others" it may be that they need to keep their interventions to a minimum and be as unobtrusive as possible. Such a stealth approach, which would often give limited time for interactions, may encourage a more technical task orientated approach. As the nurse below argues, some children do not want the friendship of nurses, but instead want a technical approach which allows them to return as soon as possible to their own activities and friends:

CCN

Sometimes they don't want that relationship. They just actually want what needs doing at home as quickly as possible and just go out. While you are there you are stopping them going shopping, stopping them meeting their friends, stopping them doing what ever. Actually, what you are there to do is to prevent them having a hospital admission, travelling 2 hours to [names city regional centre] or where ever that would be. Actually you are just there to do a job to get it done, so they can go back to a normal life, thank you every much.

CCN Group interview area 2.

There is a dilemma here for community children's nurses. By being invisible community children's nursing can assist children to be like other children, which seems important to children, but invisibility means the care they deliver is likely to be under valued (see section 9.5).

The observation of children receiving nursing care showed that some of the care that children received was not technical, but perhaps more akin to Kyngas et al's (1998) description of motivating care. The nurses took an individualistic approach, often

through the joint action of play, to connect with children on a personal level and to adapt the care delivered to the child's particular needs.

What this study showed, which has not been explored in the literature before, was that nurses used technical, rational approaches that characterised their work as "just a job", alongside approaches which could be categorised as what Kyngas et al (1998) described as motivating care. For the nurses these did not seem to be conflicting concepts.

While the nurses support children's focus on technical therapeutic interventions, their accounts also illuminated other aspects of the nurse's role. Nurses were able to confirm that, although the children did not recognise the teaching role (Benner 2001), the nurses did teach the children's parents aspects of care that enabled parents to provide care for the children at home:

<i>Researcher</i>	<i>Thinking about the visits we did today, those in some circumstances, the dressings may be done by the mother themselves.</i>
<i>CCN 12</i>	<i>Yep, yep.</i>
<i>Researcher</i>	<i>Who teaches the mum to do that?</i>
<i>CCN 12</i>	<i>We would do that, for example if we felt well it might be that sometime the families from day one, after they have seen what you want to do they do want to become independent and are quite happy to take on that responsibility. So it might be we go in and observe them a couple of times just to make sure they are doing it appropriately.</i>

CCN 12: Interview after observation.

When the nurses were asked about the lack of recognition of the teaching aspects of their work from the children all agreed that nurses would have taught parents the skills for parents to deliver nursing care at home. Some suggested these skills may have been taught to parents in hospital, and some that children may not have been

- Facilitating access to social interaction- taking children to play areas, shopping (in one case to a local café).

While the children in the core group may not have had direct experience of all of these activities, they had experienced some of them. For instance Mohammed had received respite care and attended a self help group, yet these aspects did not appear in the children's data (section 7.3.).

Other aspects which were observed, and which have a direct effect on children's lives and on how they receive nursing care, but which did not feature in the data were: completion of diary sheets that facilitate service evaluation, team meetings and documentation which facilitate communication about children's care, organisation of the team that ensures safe provision of the service to children (off duty, skill mix, out of hours telephone cover etc), organising transition to adult services and contributions to policy documents in collaboration with other health care workers that set standards of care (enteral feeding policy, thumb prick policy). While these activities may not be directly experienced by children, they do ensure children receive safe and effective services. However, the nurses did not mention these aspects as part of the nursing care delivered to children.

Nurses agreed with the children about the focus of nursing on administering therapeutic interventions, but added that a professional approach which minimises the disruption to children's lives and supports children in portraying themselves as children, like other children. Observation of nurses' working days revealed many other functions of nursing performed by the community children's nurses. The visible and less visible aspects of nurses' work with children are explored further in chapter 9 (see section 9.5.) where the implication of visibility and the lack of visibility are

considered for children's nursing. Nurses' vision of children's involvement in receiving care is the subject of the next section.

8.4. Negotiating children's involvement in receiving care

The children's data in this study suggested that the factor which most strongly influenced how children experienced receiving nursing care was the regard children had for nurses (see section 7.5.3.). In turn it was suggested that this regard for nurses was determined in part by children's involvement in their own care, as well as their understanding of their illness.

Although the adult data shed little light on children's understanding of illness, it does illuminate how children negotiated their involvement in receiving care.

Children in this study identified the issue of controlling the timing of interventions as one way in which they were involved in receiving care. Some nurses supported the view that the timing of the delivery of care was one way control could be exerted:

CCN

I mean it's all about reassurance isn't?... You talk to them, not necessarily their mum, if it's appropriate. Give them some control is a very definite tool that we all use isn't it? I know kids that you meet who say "you will give the injection slowly won't you?" and I bet we would all trip out "I'll give the injection how ever you need it to be given, you tell me how you like it done". The care plan identify how often it's them in control. It's all about reassurance isn't it really and it links in with the honesty, because you don't promise them something that you can't deliver.

CCN Group interview area 1.

However, nurses from both areas also stated that if a child delayed the intervention for too long, the nurse would take control, whether the child was ready or not:

CCN

There comes a point where you have to draw it to a close, you know. You know those children are going to dance about, and dance about. So you know as soon as they see you, start crying, so rather than discuss the pleasantries and how nice the weather is. Then I go in and do it and then have the talk afterwards. Because they are all right then, because the tube is down, because as soon as they see you, they know what you are going to do and all the reassurance and play and everything in the world isn't going to change the fact that they don't want to have the tube down, and you can't make it. You know the actual passing of it you can't make pleasant, because it is not pleasant.

CCN Group interview area 1.

For the nurses it seemed that some children, perhaps older children, were given a lot of autonomy over their own care. Some of these children seem to have negotiated their care once they had established their autonomy through resisting the adults involved (parents, nurses and on occasions medical staff):

CCN

We have one particular enteral feeding. Haven't we? Who decided when he was going to start enteral feeding, how he was going to be feed, that he would pass his own tube. Umm, what time it was going to start and that was all by working with him unless we had incorporated that he wouldn't have been, he wouldn't have any enteral feeding which he desperately needed, but by negotiation he agreed to it, but he directed how he wanted it done and to a successful conclusion as well really.

CCN

..., that's where the empowerment comes back in again isn't it? Because he didn't want it and we had a child as well who didn't want to be enterally fed, didn't need to be because he could eat and drink, but enteral feeding would have enhanced his quality of life and by talking him through it you know he was 14 and Gillick competent, we could talk him through all the stages about, you know his options as well and you know and he actually came, it wasn't a case of saying we were going to do it and that's that. He eventually consented to it and he passes his own tube so he is, because he has been empowered he is actually

happy with that process and can see the benefits of it of being enterally fed and again he calls the shots really. Because he takes his tube out every morning, because he doesn't want to go to school with it in and passes it at night time when he needs it.

Researcher

So that's like special who empowered him to do that? Who was that?

CCN

Well that was the children's hospital and we did it as a team, and his parents obviously, because his family wanted the feeding in the beginning, but the clinicians at the hospital, but he didn't because he didn't want to be tube fed.

CCN Group interview area 1.

Although nurses from both areas describe individual cases where children exerted control and directed their nursing care, they also described how children were denied the right to consent to treatments. This seemed to be routine in the nurses' practice, rather than giving children the right to refuse an intervention, the child would be given a limited choice of how the interventions were delivered. If the child was still not cooperative, the nurses would refer the child back to the hospital, as the nurses pointed out the threat of a trip to the hospital often prompted parents to intervene:

Researcher

...So what do you do if they actually refuse?

CCN

I go that's fine I'll refer you back to the consultant [laughter], or you go back the next day, it's about choice and in an ideal world about time ...

CCN

...It depends how experienced you are in doing it. If they have got to have the injection you need to let them, make them, make sure they know why they are having it. What happens if they don't have it? It has to be delivered to them in information they understand, you can have a play specialist in to for the child to join in and see how to give an injection and at the end of the day if you say you really need this injection. It's your choice which leg you have it in. You can have it in your right leg, or your left leg and then you've got the consent haven't you if they say I'll have it in this one this time.

CCN

And then you go for it.

CCN

It is very rare that they don't, that they say no if you do it properly.

- CCN *I think children are going to try and say no aren't they? Because they always test you and see if they can get away with it.*
- CCN *It's like [names CCN] says if you give them a choice not of opting out, but a choice about the way they have it and they basically said OK then you have got consent.*
CCN Group interview area 2.
- CCN *Or we might say I can give the injection now, or you can go up to the hospital and have it done.*
- Researcher *Yeah, yeah.*
- CCN *You can sit on your mum's lap or your dads lap.*
- CCN *At which point parents chip [in]. "If we are going to the hospital you are not going to football training tonight", or we won't be doing this, or we won't be having tea*
CCN Group interview area 1.

The adult data presented here perhaps places the children's data about how they were involved with care in a limiting context. This limited scope of children's participation is also evident in some of the literature on dignity in children's nursing which takes a view of children as innocent passive victims of hospitalisation who require nurses to act to protect them, rather than as active participants in receiving care (Popovich 2003).

The attitudes to children's consent which seemed to be present in the nurses' data would suggest that a stance on the rights of the child is not currently embedded in practice. Although there is an extensive rhetoric on children's rights and especially about consent (Alderson 1993, Brook 2000), the data in this study suggests that children are, in practice, often denied consent, being only allowed to assent.

The practice of threatening children with a return to hospital, or actually referring them back to hospital services, with the attendant disapproval of parents, could be seen as a punitive measure which may be counter-productive. Children who know

that if they do not cooperate they will be forced to attend the hospital, which will upset their parents and make their own attempts at being like other children more difficult, may assume a more passive role.

Children's agency in receiving nursing care in community settings seems to be determined by adults. These intergenerational relationships sit within a general generational landscape of perceptions of children as either competent to participate, or not. When children receive nursing care in home settings the social expectations of host/guest behaviours influence children's involvement. Although some children, often older children, can negotiate more of an autonomous role the rhetoric about children's consent seems to be routinely ignored.

The findings from the nurses' data suggests that nurses do not share children's views on the importance of the gender of the care giver in children's experience of receiving nursing care.

8.5. Gender issues and children's nursing

The findings presented in section 7.7. and 7.8.4. showed the importance to some children of the gender of the care giver in receiving nursing care. The preference of some children for a nurse of their own sex to deliver care perhaps needs to be considered in the context of nursing as a gendered profession (Davies 1995) and one which is predominately female (89.24% versus male 10.73% (Nursing and Midwifery Council 2007)). During the field work for the study the only male nurse in either area left. Thus when the nurses were asked about gender issues they commented on the fact that there was not a male in the team, and suggested that

meeting children's preferences would be impossible. None of the nurses knew of any plans to recruit men into their teams, or of measures to encourage men to apply to join the team:

- Researcher* *When you had a bloke in the team, did that make a difference to the team ...or?*
- CCN 10* *No, not at all. He worked for [names area]. He had his own caseload. No I think it all seemed, we still worked very well. Um, there were restrictions in Asian girls and they didn't want him to do their dressings. As I say it doesn't raise a problem at the time.*
- Researcher* *Are there any plans to recruit more men now?*
- CCN 10* *There are jobs, so if they want to apply, they're more than welcome to.*
- Researcher* *OK, so you haven't specifically gone out to target men as it were?*
- CCN 10* *No.*

CCN 10: Interview after observation.

The nurses did however, appreciate that gender issues could cause embarrassment for some children, although it was not clear how these were addressed:

- Researcher* *If children could specify the gender of the nurses that visited them, what issues would that raise?*
- CCN 8* *I guess for teenaged children it would raise more issues than younger children. I guess teenaged girls would want a female nurse go and I guess teenaged boys would prefer a male. I guess they would be embarrassed if it was the opposite gender, but I think with younger children I don't think it makes that much difference. In the community and even in the hospital, it wasn't an issue.*

CCN 8: Interview after observation.

The data in this study reflects an attitude amongst nurses that sexuality develops in children in early adolescence. Popovich (2000) found a similar assumption amongst children's nurses, that sexuality developed in older children. The findings reported in the previous chapter suggest that this assumption may be inaccurate. To avoid the potential for embarrassment, nurses may need to consider children's preferences

irrespective of age. This may be in line with a sociological approach to children's nursing practice which would suggest that childhood is temporal (James et al 1998). The perception of an increasing sexualisation of childhood (Renold 2006) and awareness of sexual abuse in Britain (NSPCC 2007) requires nurses to respond by considering the potential embarrassment for children of intimate care. In other words, children's nursing which recognises the sociology of childhood recognises that childhood changes over time, thus while the nurses' own childhoods may have been less sexualised they need to recognise that childhood has become more sexualised in recent times. Gender issues are discussed in more detail in section 9.6.

8.6. Summary of generational landscape and profession

The addition of adult voices to children's voices as part of a mosaic approach in this study has had the effect, at times, of enhancing the child's voice and adding depth to the view presented by children. Occasionally the child and adult voices are discordant.

Adults agreed with the children about the importance for children of presenting themselves as being like other children. The adult findings suggest that an approach which limited the role of the nurse could be seen as supporting children in their attempts at being like children not living with illness. The findings from nurses were able to enhance the understanding derived from the children's data about the role of nurses, confirming that although children did not recognise the role of teacher, nurses did perform this role. The data also highlighted other roles that nurses performed that impacted directly on children's lives and often on their portrayal of themselves as children, like other children, but which the children seemed unaware of, such as how nurses facilitated children's holidays, or attendance at school.

The nurses' findings also placed the involvement children seek in receiving care in a professional and generational context such that children's involvement is often limited by adults but with a bias that allows more autonomy for older children and to those who are more assertive.

The nurses' views about the need for an equal gender mix in nursing make it unlikely that there will be a groundswell of political will sufficient to ensure that enough men will be recruited to meet the desire of some boys to be nursed by male nurses.

The next chapter uses these findings from children, which have now been situated in a generational and professional community children's nursing context, to explore further the themes set out in this chapter and in chapters 6 and 7 in order to propose a children's agenda for nursing.

Chapter 9: A children's agenda for nursing: practice, education, research and policy

9.1. Introduction

There have been few studies that have asked children what they think about receiving nursing care at home, and of these studies most do not set out how the researchers tried to minimise the influence of adults in order to listen to children's opinions. This study, perhaps because it addressed the relationships between children and adults, has uncovered aspects not seen before in the literature on children's views of nursing.

This study has highlighted how children portray themselves as like other children. It is argued here that this focus of children on their social networks should be reflected in how children's nursing services are evaluated. The resistance of children to receiving nursing care, and in particular how some children have a negative regard for nurses in general, has not surfaced in other studies. The proposal that a continuum may exist ranging from positive to negative regard may have important implications for the practice of nursing, raising as it does the possibility that children's understanding of illness and their involvement in care may be instrumental in how they receive nursing care, rather than the actions of the nurse.

The understanding of the visibility of community children's nursing explored in this study also has important implications for nursing, exposing as it does the poor visibility, and therefore lack of importance, given to many aspects of nurses' work.

The debates presented here about the visibility of children's nursing explore the moral and social contracts which underpin the practice of nursing. Finally, as Taylor and

Green (2008) have pointed, out few nursing studies have considered gender issues. This study is the first to report how some children may feel their dignity is affected by receiving care from a nurse of the opposite sex, in community settings.

This chapter explores the limitations of the study. Then re-examines the themes uncovered by this study in more detail, and relates them to how children's nursing might profit from listening to children's voices. The stance taken is to explore how the voices of children through this study might be understood and contribute to an agenda for children's nursing. The principle of the mosaic approach, that children and adults co-create knowledge, is used here, in that the voices of the children from this study are interpreted and an agenda formulated by the researcher, who is an adult. This agenda is based on the following themes taken from chapters 6-8:

- *Children, like other children* -children's attempts to portray themselves as being like children not living with illness, which is evident in how children focused on their families, friends and schools as well as the role of transitional objects and stickers, rather than on nursing. The lack of focus on nursing may be a part of children's resistance to nursing.
- *Children's relationships with nurses and nursing* –proposes children can be situated on a continuum of negative to positive regard for nurses. Their position on this continuum may be based on their understanding of illness and or their negotiated involvement in receiving care.
- *Visibility of community children's nursing*-relates to aspects of the work of nurses in delivering care which were highly visible to children i.e. technical therapeutic interventions, and other less visible aspects, such as teaching, helping and coaching roles.

- *Gender and children's nursing*- How gender issues influenced how children receive nursing care in community settings.

These themes also feature in a parallel dissertation, or children's version of the findings, available on line from the Association of British Paediatric Nurses website (abpn.org.uk (under publications)). This parallel dissertation, designed with the help of a graphic designer, presents the findings of the study in an accessible form for children and their carers. It has been distributed to the children and nurses who took part in this study and is freely available to other children, their carers and nurses delivering or receiving care at home.

Each of the themes above is discussed in turn, focusing on how the themes can be understood and how this understanding might be informed by literature from children's nursing and other disciplines. These themes are considered then in relation to how children's nursing practice and education might be shaped by a children's agenda, based on the findings of this study. Consideration is also given to what further research might be needed and what policies are required to implement the recommendations of the study in practice, education and research.

9.2. Limitations of the study

Before considering the findings of this study it may be useful to consider the limitations of the study. As stated in the introduction to this thesis, the child's views of being nursed at home have not been extensively researched. The lack of previous research has meant that this study has been exploratory, uncovering the phenomenon of children receiving nursing care in community settings, rather than seeking to confirm previously proposed theories, or empirical data (Polit and Beck 2004).

9.2.1. Exploratory research

The exploratory nature of this study means the findings describe the perceptions of children receiving nursing care. The study did not test theory or predict the likely outcomes of interventions, but attempted to describe more fully the phenomenon (Polit and Beck 2004), with the hope that a better understanding of the phenomenon may lead to theorising and suggestions for confirmatory research, as outlined below.

The exploratory nature and the innovative methodology of this study meant that the methods and tools used were to some extent unique to this study. The lack of established tools for the collection of children's perceptions about nurses may make the findings of this study less transferable. Although in chapters 6,7 and 8 the findings have been placed in context by the use of thick description the lack of standardised measures may make comparisons with other studies difficult.

9.2.2. Recruitment issues

A number of recruitment difficulties were experienced which meant the number of children who undertook the Photo Talk Diary and attended the groups was small (7), although this was offset by the inclusion of data from observation of community children's nurses and interview data from nurses. The recruitment to the study highlighted a number of concerns. The effects of "gatekeepers" on the study, as discussed above, may have biased the sample towards children who may be more positive about nursing. It seems likely these children were more articulate, coming from more organised, socially cooperative families than perhaps the general population of children living with illness.

Although some efforts were made to address adult concerns about recruitment of children and children's cognitive abilities to participate, future studies could benefit from a more coordinated engagement with adults, to explore their conceptions of children and childhood.

9.2.3. Intergenerational issues

Despite the efforts of the principal researcher to collect data from children away from their main carer, some of the data were influenced by adults. Adult carers imposed their views at several points during the study: by using the children's camera to take photographs, by influencing children during home observations and interviews and during the recordings their children made on dictaphones. The claims of the study to represent children's voices need to be moderated by the potential influence that adults may have had over children's participation and the data they provided.

This research did not arise from children's concerns, but from the researcher's experiences of professional children's nursing. As such its concerns can be seen as those of adults rather than those of children. Whether research initiated and designed by children would focus on children's nursing is unknown. The extent to which it would be practical or ethical for children living with illness to act as child researchers is perhaps open for debate (see section 3.5.1). It may be unreasonable to expect children to design, implement and evaluate research programmes while coping with, in some cases terminal illness, and in all cases illness which increases their social isolation and affects their educational opportunities.

Thus, while accepting that some level of adult involvement in the research process is perhaps unavoidable for research with children living with illness, the methods in this study could have reduced the influence of adults. Ironically, involving adult carers (parents) in the study further may have enabled children to have expressed their views more freely. Holding group interviews with parents and children at the same time and interviewing children and parents at the same time, but in separate areas at home could have prevented adults from interrupting when the children were giving their views (Coad et al 2008).

The discussion of the findings below should be considered with these limitations in mind. That this was an exploratory study which set out to discover more about how children receive nursing care at home rather than to confirm previous findings. The study may give a more positive view of nursing due to the behaviour of “gatekeepers”. Finally, some of the children’s data may have been influenced by adults, especially the text and images in the Photo Talk Diary, which were not completed in the presence of the researcher.

9.2.4. Rigour

Aspects which can be considered as indicators of rigour in qualitative research were set out in section 3.5.3. In this study the concept of “trustworthiness” is employed. Long and Johnson (2000) suggest that the concepts of credibility, dependability, confirmability and transferability that are used to arrive at a judgement of “trustworthiness” are virtually synonymous with the concepts of reliability and validity used in quantitative positivist research.

Credibility, dependability, confirmability

In this study these aspects were addressed by triangulation of the data in terms of person, time, and space. The phenomenon of children receiving nursing care was considered by children, their mothers and nurses at different times and in different places. The researcher interpretations of the raw data were also scrutinised by the supervisory team and an independent expert (see section 3.5.3). The possible assumptions of the researcher which may have influence the analysis of data were explored in the researcher bracketing interviews (see section 5.3.1).

However, the use of member checking was restricted to the interpretations of children's data. Inclusion of similar member checking of data collected from adults would have improved the rigour of these aspects of the study. Although, some negative cases were accounted for in the analysis (see section 7.7 page 210) the small core group sample and the intergenerational issues in the collection of data with the non-core group means that other negative cases may not have been uncovered.

Transferability

Although the thick description of the core group shows a diversity of experiences and family/cultural backgrounds the findings of this study may have limited transferability, as the description of the non-core group children is thin. The restricted time the researcher had with non-core group children meant that few details were collected about their experience of nursing, or their family and cultural background.

The prolonged engagement with children in the study, and the fact that aspects of the themes identified above in section 9.1 appear in all the data sources, from all the

methods used, perhaps suggests that despite these concerns over rigour this study does present a representation of how children experience receiving nursing care in community settings.

9.3. Children, like other children

As outlined in section 6.3, a dominant feature of the findings of this study was children's attempts to be children like other children, not living with illness. The whole of chapter 6 could be seen as a report on children's attempts to be children, like other children. These attempts to portray themselves as children surface again and again through the findings of this study.

Carnevale (2007) has suggested that the attempt by children to present themselves as like other children, not afflicted by illness, could be seen as children attempting to enact a passing strategy as defined by Goffman (1968). However, Goffman's (1968) concept of passing relies on illness being seen as a stigma. It is based on his observations of mental illness, which carries substantial social stigma (Pinfold et al 2003). The question is then whether for children being ill carries a social stigma? Although there is some empirical work on well children's perceptions of health and illness (Pridmore and Bendelow 1995, Brannen et al 1994), arguably the experience of living with illness is different from that of being healthy. Admi (1995) investigated young people's experience of growing up with Cystic Fibrosis (CF). Her study of 10 children, using a retrospective life story method, revealed that decisions to disclose information about illness were more complex than previous theories about illness and disability might suggest.:

“The life stories of people with CF, in this study, fall between these two approaches: They reflected more self display than Goffman (1963), but less

than what Frank (1981,1984,1988) found. The basic approach of individuals with CF was that of ordinary people who have nothing to be either ashamed of or proud of. This view was best described in the words of one of the informants who said he had “nothing to hide and nothing to advertise”.

Admi 1995 page 498

Participants in Admi’s study (1995) talked about how their approach to disclosing information changed over the course of their childhood. Before early adolescence, children related their illness to others by saying they had to take medication etc. because they were told to by adults. Around early adolescence (Admi suggest 10-13 years old), the participants reported an increasing awareness of their illness and significant turning points in their disclosure strategies (e.g. telling their first boy/girl friend). Despite the quote above, what emerges from Admi’s study is a complex and contextualised negotiation of illness information between those living with illness and others. Although on occasions the participants reported full disclosure, this was perhaps in situations in which they felt that the stigma of the illness had been reduced. They talked about selecting their audience and disclosing to people they felt would understand, empathise and arguably not stigmatise them because of their illness. If, as Admi (1995) and others (Thomas 2007) have suggested, the concept of stigma or negative expectations of social identity as a result of illness is overstated, and that people experience illness as part of their life narrative, as part of leading an “ordinary” life (Admi 1995), then one would expect unconditional full disclosure. There would be no need to select a sympathetic audience, nor make disclosure decisions based on the social context.

What may be overstated in the analysis of stigma is, as Admi (1995) points out, the extent to which children are denying their illness. Rather than a denial of illness, Admi’s study, and arguable some aspects of this study, would suggest that children

are attempting to portray themselves as being like children not living with illness, as part of their negotiated social experience. The children in this study recognised that they were ill, even those who had poor understanding of their illness (see Gizmo section 7.5.2 page 201), but they wanted to be like other children. Rather than being about denying illness or as a “passing” strategy children in this study may have told us about their family, friends and schools because these are important to them as children. The way that children used stickers and certificates is perhaps indicative here. Stickers, it could be argued, were used by the children as part of a culture of communication of childhood. Stickers are used in schools, they are used as part of commercial campaigns, by parents and others to reward “good” behaviour or achievement. It is possible that for children, stickers and certificates are not a symbol of the nurse’s visit, but an indicator that their illness and the way they cope with their illness is part of their childhood, making them “ordinary” because they receive stickers like other children do for being “good” (see section 7.8.2 and 8.2.3.).

It can be argued that for children, the negotiation around disclosing illness information is part of their negotiated access to social interactions, and further, that these social interactions (play, attending school, making friends etc.) influence children’s social, cognitive and physical development (Bee and Boyd 2004). If children are successful in portraying themselves as just like other children they will be accepted by other children and adults and be given access to social interactions e.g. play or school. There is some evidence to suggest that children living with illness, where their illness is more visible, for instance children who are frequently hospitalised or who have complex health problems, may have difficulties maintaining their friendship networks and are sometimes excluded from schools (Noyes 2000,

Sandeberg et al 2008). It should be noted that adults in this study also expected children to be children and claimed to support children, especially in educational settings, to be like other children (section 8.2.1.). It may be useful to consider the wider political and cultural frameworks which influence how children present themselves in a social context.

Responsibilities for children, parents, professional nurses and the state

For children in Britain, childcare is a private undertaking done, in the main, by women (Mayall 2002). The provision of a state funded service to children in their own homes, such as community children's nursing marks out children living with illness as being unlike other children. When the state gets involved in children's lives in the family home this is normally to censure or monitor parenting (Department of Education and Skills 2003). Therefore community children's nurses could be seen as state workers, part of whose function is to monitor parents and to take action to protect children from abusive parents. Many of the nurses in this study mentioned their role in safeguarding children and the training and supervision they receive to perform this function of assessing and monitoring parenting. This monitoring and potential for censuring parental behaviour conflicts with much of the rhetoric of children's nursing, which advocates a partnership approach centred on "family needs" (Coleman 2002).

There is a fundamental question that seems to suggest itself. Who is responsible for the care of children living with illness? For children living with illness to be like other children in British society, the answer may be parents. However, there are a number of factors which might prevent parents from delivering all of their child's nursing

care, as some children in this study recognised some adults may not want to provide nursing care (see section 6.3.2.). Not all parents may be able to learn all the skills their child requires. Further, some interventions are delivered on an *ad hoc* basis and it may be impractical for parents/carers to learn all these interventions, when they may not be regularly required by their child, or are required on such an irregular basis that reasonable skill levels cannot be maintained.

Some parents may not wish to deliver some aspects of nursing care. However, this should perhaps be seen in a wider social context, as it could be argued that there are a number of aspects of parenthood that people may dislike and even avoid. Some parents would perhaps rather not deal with infants' nappies, but this unpleasant task is accepted as a part of parenting. Nursing procedures may be painful for a child, but parents may inflict pain on their children in many ways in what they perceive as the child's best interests. For example, most toddlers resist being restrained, but if they did not hold a parent's hand they may well run into the road and be seriously injured. There may be an argument that although parents may find nursing procedures distasteful, or want the nurse to inflict pain instead of themselves (a point made by the nurses in this study), there is a social expectation that parents will provide lay nursing care for their children. This seems to be supported by health policy. Standard 2 of the Children's National Service Framework clearly lays out the support for parents in children's health care.

“Standard 2:

Parents and carers are enabled to receive the information, services and support which will help them to care for their children and equip them with the skills they need to ensure that their children have optimum life chances and are healthy and safe.”

(Department of Health 2004a)

Children are not mentioned in the National Service Framework without the postscript of “and families” or “and their parents”. There is no standard to support children’s self-efficacy in health care. This is perhaps indicative of the social standing of children and their lack of involvement in healthcare development (Sloper and Lightfoot 2003, Coad & Shaw 2008).

In contrast to the parental advocacy of the National Service Framework which arguably promotes the rights of parents as consumers (Department of Health 1996, 2004a), other health policies have sought to increase the power of nurses. *The Modern and Dependable*, and the *Making a Difference* strategy documents (Department of Health, 1997b&c) led to nurses acquiring new powers to prescribe and to influence health policy.

The delivery of nursing care to children by professional nurses may have some advantages. On a logistical level, while parents need to provide care for their own children, nurses provide care for many children. The sheer numbers that nurses deliver care to allow nurses to develop skills which may be required by children infrequently. Prolonged exposure to clinical practice also allows nurses to build up their skills over time. This means nurses can provide a level of technical knowledge which it may be unreasonable to expect parents, even with teaching, to obtain. There are also the issues of child development and the natural history of the illness. Parents providing nursing to their child will be exposed to the phases of their child’s development and to the natural history of the illness as a sequence over time. Nurses, on the other hand, are exposed to a number of children at different points in children’s life spans and at different points in the naturally history of the illness. Thus nurses can make comparisons across cases, which would be difficult for parents to make.

There is however, an ethical problem with the delivery of care by professional nurses, the demands of the nursing profession to exclude others from the work (Witz 1992), would seem to be fundamentally against what children in this study were telling us about receiving nursing care at home. Children were not seeking an autonomous professional, but a nurse who would work collaboratively with them, their family and to some extent their community (school etc.), in order that the child may present themselves as being like other children. In considering how nurses might respond to this collaborative approach, suggested by children in this study, it may be useful to draw on Walker's (1998) ideas of expressive-collaborative morality.

Walker argues that expressive-collaborative morality should replace theoretical-judicial morality. Walker's concept of morality recognises interpersonal relationships and structural social influences that are created between people, where responsibility is assigned according to relationships in a social context, rather than by theoretical frameworks applied irrespective of social contexts or structures (Walker 1998).

Walker also recognised that those with less power in society are often restricted in their ability to decide who is responsible for actions. Children living with illness would seem to be a particularly disempowered group (Reed et al 2003, Coyne 2008, Robinson and Kellett 2004), if one accepts Walker's argument it would follow that children would be restricted in negotiating who is responsible for delivering care.

It could be argued that Walker's conception of morality would lead to a rejection of the right of hegemonic medical theory to be applied to all health care (Bjorklund 2004). Adopting Walker's morality would instead suggest that nurses advocate for services underpinned by principles based on the lives of those concerned. It could be

argued, that some of the nurses in this study demonstrated just such an approach when they facilitated children's access to social interactions, such as school attendance and holidays, which might be experienced by children not living with illness (see section 8.2.1 and pages 235-236). The language nurses used was very much of collaboration and of empowerment, with references to the relationship between themselves and parents, and to a lesser extent, children. However, nurses also saw their work as predominately delivering technical therapeutic interventions (see section 8.3.) within a professional framework. It should also be noted, that the children in this study also focused on nurses delivering therapeutic interventions. Although, as pointed out by the nurse on page 231, delivering technical therapeutic care in support of medicine in a timely and task orientated fashion may support children's attempts to be like other children, both children and nurses in this study recognised the need for more than a purely technical approach.

This study, then, arguably highlights the dilemma for children living with illness between the desire to be like other children, but also needing to receive health care constructed in professional and bureaucratic systems, which may not prioritise children's social needs. It may not be possible for children living with illness to be entirely like other children and avoid nursing altogether. However, there were examples in this study of how nurses and parents worked together to facilitate the child's social opportunities, such as when the nurse and Mohammed's mother worked together to get his dressings done so that he could take a taxi to school. This ensured he arrived at school at the same time as other pupils. Arguably this shows just the sort of negotiation of responsibilities that Walker (1998) advocates.

Resisting nursing

In chapter 7 the concept of children resisting hurtful nursing was linked to children's attempts to be like children not living with illness (section 7.2), although it was acknowledged that children's resistance may be linked to children's fear of hurtful nursing interventions. The reluctance of some children to talk about nursing found in this and other studies (see section 2.3.4 and 7.2.) might suggest that children's resistance is more complex than avoidance of a subject associated with hurt. As Christensen (1993) has pointed out, children often want to share their painful experiences with adults. A more simple picture, of children avoiding talking or even thinking about nursing and nurses because of the hurtful procedures nurses perform, would seem to be challenged in this study, as some children with a positive regard for nurses were willing to talk about nurses and nursing, even though they too received hurtful procedures from nurses. Albeit as Nanny remarked, even children who had a positive relationship with nurses would prefer to be playing with friends (page 182).

Some strategies used by the children may amount to what Admi (1995) called "silent telling", where children may not talk about their illness or nurses because they chose to assume that the researcher already knows. In Admi's study, young people recalled not mentioning their illness because they knew the other person knew about their illness from a third party. The illness therefore remained an unspoken, but accepted fact between them. The children in this study may have assumed that as the research approach was made through the community children's nurses and the researcher had spoken to their parents, that he was well aware of their involvement with nurses.

Children's use of "passing" strategies and their resistance to nursing interventions may present community children's nursing with a dilemma. While nurses may wish to support children in portraying themselves as children, like other children, resisting nursing interventions may put children's health at risk. A child may successfully resist the administration of therapeutic interventions and thus enhance their chance of being accepted by other children (e.g. the child may stay on playing in the park after school with their friends, rather than making their excuses and going home to receive their injection, or dressing etc). However, not receiving the nursing intervention may carry health implications, which in turn may have social and educational implications. For example, if Kelly did not to receive her injections her arthritic pain would probably increase, which would most likely affect her mobility, possibly preventing her attending school, which would affect both her friendship networks at school and her academic progression.

In resolving this dilemma, nurses need to understand children's attempts at "passing" and have ways of making judgements as to when "passing" strategies may be harmful. Thus there needs to be much better understanding of children's attempts to be like children not living with illness. The work of Bluebond Langner (1996), on parents' and siblings' experience of Cystic Fibrosis, suggests that rejection of interventions is associated with periods in the natural history of coping with the illness. It would be useful for nurses to know if children's attempts to be like other children and or their resistance to nursing are associated with the course of their chronic illness. Children in the study who had different medical labels applied to them had very similar views on being like other children. However, further studies are required to determine

whether children's attempts to be like others change as their experience of illness changes over time.

Children's focus on their families, friends and schools in this study may be an attempt by children to present themselves as being like other children, rather than a denial of illness, as suggested by Goffman's ideas on passing. Portraying themselves as like other children may be part of children's negotiations to access social interactions such as play, education and peer friendships. Access to these social interactions is important to children in developing social skills and promotes their educational achievement.

9.4. Children's relationships with nurses and with nursing

This is the first study to expose children's negative regard as well as positive regard for nurses, perhaps because other studies have not paid as much attention to the generational relationships between children and adults, which may obscure children's views.

It could be argued that children's negative regard for nurses is not a surprise. Instinctively it seems reasonable to dislike people who inflict pain, or as it has been termed here, hurt. Many of the interventions delivered by nurses in this study, and routinely by nurses, are hurtful to children (Carter et al 2002, Kortessluoma and Nikkonen 2004). What is surprising is that children who also received hurtful procedures (injections) still had positive relationships with nurses. However, this possible contradiction may be explained by the connection made in Figure 7.1 between understanding of illness and regard for the nurse. If children understand that

the nurses actions are intended to relieve suffering then it may follow that they would be better able to endure the interventions nurses deliver. Children with a positive regard arguably understood that the nurses' actions enabled them to play with their friends, or ride their bicycle i.e. to be like the other children they see around them, while those with a negative regard may not make this connection between the hurt inflicted by nurses and the purpose of nursing.

It could be argued that children have different regard for nurses because they may be at different stages in their illness trajectory. As the children in this study had different medical labels and this was not a cohort study, the findings may just show that children were at different stages of progression through an illness process. This view may be somewhat supported by Bluebond Langner's 1996 study which suggested that for parents, and to some extent siblings of children with Cystic Fibrosis, there was a natural history to the condition. This leads parents to seek information about the condition in an initial phase. However, when parents experience a period of remission followed by complications that suggested deterioration in their child's condition, the parents often rejected attempts to provide information and resisted receiving medical care. They defaulted on appointments and requested home administration of intravenous antibiotics, in an attempt, as Bluebond Langner saw it, to avoid being reminded of the illness. Thus in this study the cases of Honey and Gizmo may represent children at a particular stage of their acceptance, or coping with illness rather than being positioned on a continuum of regard for nurses according to understanding of illness and involvement in care.

It was suggested in section 7.5.3 and Figure 7.1 that children with a positive regard for nurses were more involved in receiving nursing care. It would seem likely that

children with a positive regard for nurses may be able to use their relationship with nurses to open negotiations, such that a positive approach is perhaps more successful for children in negotiating with adults to allow them to be involved in receiving care. However, as was also pointed out in section 7.6, children's involvement with their care was predominantly influenced by the adults around them and their perceptions of the child's competence, which in turn was contingent on the child's age.

The relationship between children and nurses may be constructed then as being on a continuum from negative to positive and may be influenced by the child's understanding of their illness. However, it is also possible that it is related to a process of coping with illness which changes over time. This is the first study to describe children's negative regard for nurses. More studies are required to explore the relationship between children and nurses and the effects on health and wellbeing that this relationship has, if any. The implications set out in section 9.7 are then tentative and would need to be supported by further studies (see section 9.7.3.).

9.5. Visibility of community children's nursing

The concept of visibility was outlined in section 7.3. In this section the concept is explored in more depth. Liaschenko (1997) has related visibility in nursing to the concept of place taken from geography, such that nursing and nurses are placed in relation to individuals within a social and cultural landscape of health care. She argues that the relationship between patient and nurse, where the patient has problems which the nurse may act to help solve, is situated in a landscape dominated by scientific medicine and issues of gender, but also featuring other societal sanctions and prohibitions. Furthermore, Liaschenko (1997) suggests this geographical concept of

visibility includes “spatial vulnerabilities”. These are potential and actual harms which occur to parties because of their location in the social landscape. Viewed from certain standpoints in the landscape, aspects of nurses’ work, or of patients’ experience appear visible while others are obscured. Arguably it is here that Liaschenko’s concept becomes more metaphorical than empirical, but she argues that the gendered and scientific medical landscape obscures aspects of nursing work because it does not fit with medical beliefs, or is deemed “women’s work”, a point supported by the work of Davis (1995) and Witz (1992). Liaschenko (1997) argues that nurses are better at recognising interpersonal aspects of the landscape about them than they are the structural social nature of the landscape in which they deliver nursing care. This causes them to focus on relationships with patients when delivering health care and to miss, or ignore macro social factors.

Liaschenko and others (Liaschenko 1997, Liaschenko and Peter 2004, Bjorklund 2004) claim that this reduced political visibility of aspects of nursing work results in “spatial vulnerabilities”, such that aspects of the work are vulnerable because of their position in the social landscape. These vulnerabilities are inherently damaging to those living with illness, to nurses, and ultimately to nursing and society as a whole. Liaschenko (1997) argues that these less visible aspects of nurses’ work are undervalued by the health care system and society, and because the work is not sufficiently valued it may not be adequately financed or resourced and therefore can be lost. Further, she argues that not recognising this hidden work devalues those living with illness and dehumanises them (Liaschenko 1998). The focus on medical science and its ways of understanding health reduces people to disease symptoms and does not recognise patient experience, or the limitations of medical science (Liaschenko 1998).

Although the concept of visibility within landscapes was developed from empirical research into nurses' moral actions (Liaschenko 1997, Rodney and Varcoe 2001), the effects of some aspects of nursing work being less visible has not been empirically examined. In this study, the work of facilitating children's social interactions, where nurses helped children to attend school regularly and to have family holidays, was less visible to children and nurses, but the work was still delivered by nurses and received by children (section 8.3.). Consequently the lack of visibility of nursing's boundary or interdisciplinary work was not problematised by children, or by nurses. It could therefore be argued that the costs of this work and threats are acceptable to both children and nurses. However, that is not to say that were these areas of work to become more visible to children, or nurses that they would not then want to address the costs and threats to this work. For instance, if family holidays became more visible through disabled children's rights campaigns children, their carers or nurses may press for more training for nurses on how to arrange such holidays.

Rather than being less visible, the facilitation work undertaken by nurses in this study, may be unwanted, and not visible because it is not being looked for. Children may perceive the role of nurses as supporting medical practice (Holyoake 1999), and look to their parents and family to provide access to social interactions such as provided by family holidays or attending school. The extension of the medical gaze (Armstrong 2001) may not be welcomed by children, especially if, as argued above, children want to be like other children, they may fear that if nurses are extending their influence beyond delivering medical interventions this may make being accepted as like other children more difficult. Adults too seem confused as to how nurses and mothers

divide the work of caring for children living with illness (Kirk 2001, Coyne 2007). Some of the work listed in section 8.3. pages 235-6, could be seen as the responsibility of parents, while others are dealings between professional groups on behalf of children. The poor visibility of nurses' work to facilitate children's social interactions may be a result of this role confusion, rather than of the domination of the health care landscape by medical sciences.

The findings of this study suggest that there are aspects of the nurses' work which although less visible, are enacted. The costs, benefits, desirability and vulnerability of this less visible work need to be established. At present the concept of a visible landscape dominated by a masculine medical science is a theoretical construct, which although conceptually helpful in understanding the politics of children's health care, may not give an accurate picture.

9.6. Gender and children's nursing

As discussed above, gender and the visibility of children's nursing are closely linked, in that the gendered nature of the landscape of healthcare means that children's nursing as arguably female work, is often less visible to most of society than medicine which has been characterized as more masculine (Witz 1992, Davis 1995, Liaschenko 1998). As children's nursing is delivered by a predominately female workforce (Purnell 2007, NMC 2007) the political issues surrounding gender are important. However, in the previous chapters it seemed that gender was more than just a political issue for health care workers, but also affected how some children received nursing care in community settings.

Gender issues may have been highlighted in this research because the principal researcher is male. Although the distress observed in children receiving nursing care in the presence of the principal researcher may not have been associated with his gender, but with role confusion. Anxiety about the role of the researcher as an observer may have added to children's distress at having painful interventions. However, some of the children in this study had received care from a male nurse in community settings and some related receiving care from a male nurse to embarrassment caused by receiving care from a nurse of the opposite sex (see Kelly section 7.7.). However, not all children displayed signs of distress when receiving care from a nurse of the opposite sex. These children may have been more skilled at hiding their distress, or it is also possible, as Nanny (page 211) seemed to imply, that children may have a complex understanding of the social boundaries of nursing. Some children may not feel embarrassed by the interventions of the nurse because they are aware of the social contract, that nurses can invade people's bodies and administer hurtful interventions as long as such interventions are for the patients' benefit (Freidson 1970).

Variation in children's embarrassment may be explained then by how the child perceives of themselves and of nurses' roles. Meerabeau (1999) suggests that patients' embarrassment is influenced by their own self perception, perceptions of social norms and of the role of the nurse. Although Meerabeau (1999) was writing about adults, it could be argued that for children receiving care at home, the social norms and the roles of nurses are more easily confused, as delivery of care is not taking place in the hospital setting which children may associate with nurses and health care (Pridmore and Bendelow 1995). Magnusson and Lutzen (1999), in their study of mental health,

found confusion over the role of the nurse in delivering care in the “home” setting, with nurses expressing concern that delivering care in the person’s home could be an intrusion on the person’s privacy.

Although other studies have explored the issues of dignity and embarrassment in hospital settings and related these to gender (Reed et al 2003, Popovich 2003), there has been a lack of research focus on gender issues in children’s nursing (Taylor and Green 2008). This is the first study to explore children’s preference for a nurse of the same sex in community settings. Much more work is required to understand how gender issues affect children receiving nursing care in community settings. A part of this work might be how children’s embarrassment at receiving nursing care from a member of the opposite sex should be understood within children’s constructs of nursing care.

9.7 A children’s agenda

This section sets out how the themes discussed above may influence the practice of children’s nursing, the education of nurses and the research and policy agendas that inform and shape children’s nursing.

9.7.1. Implications for practice of children’s nursing

In this study, children voiced a desire to be children first and foremost. However, for children living with illness this desire to be children , like other children conflicts with their need to receive nursing care constructed in professional and bureaucratic systems. For nurses to help children living with illness to be , as far as possible, like

other children may require a critical review of the position of children's nursing within these professional and bureaucratic systems.

Although the term *practice of nursing* has currency in professional circles, Liaschenko and Peter (2004) have argued that conceptualising nursing as health care work would allow health care workers and those receiving care to critically evaluate the work of nurses as intellectual, emotional and physical labour. Considering nursing as work would free it from the constraints of its historical place as being viewed as subordinate to medicine, and allow the consideration of the division of health care in a social context. An approach to resolving this conflict may be to recognise the morality of children's nursing as expressive and collaborative. This would lead nurses to recognise the social position of children, and to critically renegotiate children's involvement in receiving care.

This study showed some of the complexities in the relationship between children receiving care and nurses. It was however, an explorative study. Although it has revealed that children may be placed on a continuum of negative to positive regard for nurses, it has perhaps only begun to explore the relationships between children and nurses. Further work as outlined below will be required before decisions on how to improve practice can be formulated with confidence.

However, perhaps a first, but difficult step will be for nurses to accept that children may have negative as well as positive attitudes towards them as nurses. Some nurses in this study acknowledged that children may have had negative experiences of the health care system, which could mean that nurses had to negotiate children's

cooperation against some background hostility. However, nurses also found it difficult to accept that children held negative regard for nurses. When children displayed negative regard, nurses often dismissed their behaviour as being variously “grumpy”, “cheeky”, or “hospitalised”. It may help nurses to reflect that the regard children have for them was not associated with particular nurse’s behaviour. It would seem that rather than children’s regard for a nurse as a person being based on the nursing care delivered, it has more to do with the child’s understanding of their illness, or their coping with their illness and their involvement in care. If as suggested above, children’s regard for nurses is dependent on their illness trajectory, nurses may not be able to influence children’s regard for them at all. Instead it will be important for nurses to find ways in which to work with children who hold them in negative regard.

If nurses were to acknowledge that children may have a negative regard for them and that they may resist nursing, this could allow children, their carers and nurses to have different negotiations of children’s involvement in receiving nursing care. It would seem that children like Honey would welcome such opportunities to re-negotiate their involvement in care.

If as Liaschenko (1997) suggests, less visible work is vulnerable then a major challenge for children’s nurses in practice is to make their work visible. Not least, this study would suggest that nurses need to make their facilitation work visible to children.

The visibility of facilitation work could be enhanced by involving children in the work. As nurses in this study pointed out, teaching of parents and of others often

occurred when the child was not present. Even when children were present, they were often not invited to be part of the learning. Involving children in teaching, helping, /coaching work (Benner 2001) and liaison work with other professionals would not only make this work more visible to children and their carers, but may also allow children and nurses to negotiate children's involvement and what children want from the services offered to them. For instance, when making a referral to a service in another area, which would allow the child to go on holiday, the child could be invited to state their preferences and help design a plan of care.

Given the lack of understanding about the impact of gender on children receiving nursing care (Taylor and Green 2008), at this stage recognition of the issue may be all that is possible. This would not be a gender neutral approach, but one that recognised that children, carers and nurses are all situated in a gendered social and cultural landscape. Such an approach would recognise that the nurse's gender may make a difference to children depending on the child's gender, such that the gender of the nurse may be an important factor in interacting with the child, the child's family and social networks. The difference that men or women may bring to nursing boys and girls and the difference between fathers and mothers would not be ignored, but explored openly with children and their carers. This may be increasingly important if, as suggested by the nurses in area 2, men are becoming more involved with delivering care to their children.

Popovich (2003) has suggested the safest course in considering issues of dignity, sexuality and embarrassment may be for nurses to consider how they would feel in a similar situation. Such an approach could draw on the concept of ethical symmetry

mentioned in section 3.5.1. (Christensen and Prout 2002). This would require nurses to set aside preconceived ideas about children's development of sexuality and consider children's experience of receiving nursing care as a gendered social interaction.

The changes in the practice, or work of children's nursing advocated in this section require a workforce to be educated to be ready to accept children as social actors and to take a critical gendered look at how children's nursing is practiced.

9.7.2. Implications for the education of children's nurses

Educational qualifications are used in children's nursing to exclude people from the work of nursing children. This is a legal barrier, as without an educational qualification recognised by the Nursing and Midwifery Council, a person cannot be registered as a children's nurse and therefore cannot adopt the title or work claiming to be a children's nurse (British Parliament 2002, The Nursing and Midwifery order 2001, section 44). Although the Nursing and Midwifery Council regulates courses leading to registration, it does not prescribe a curriculum for children's nursing, but instead offers guidance on what should be included (NMC 2002). This guidance is not informed by extensive consultations with children, but comes from "expert" views. Although NMC guidance and most textbooks on children's nursing include aspects of play and the psychological effects of hospitalisation (Glasper and Richardson 2006, Hockenberry 2003), the majority of the suggested curriculum is focused on quasi-medical knowledge (understanding therapeutic interventions), or knowledge that supports medical practice (understanding how to monitor and report the effects of therapeutic interventions).

Meerabeau (2005) has argued that the visibility of medical science in academia obscures nursing as a subject, and that the voice of nursing academics is lost in higher education institutions which value medical sciences voices over nursing, although as Meerabeau notes, recent developments have sought to address the chronic under funding and poor career structure in nursing research and teaching (Department of Health 2008a, UK Clinical Research Collaboration 2007).

If nurses entering children's nursing are to support children's attempts to be like other children, they will need to learn how to do this. Such learning could be encouraged by re-focusing curricula to include what Benner (2001) terms the helping and teaching/coaching roles of nursing and what Liaschenko (1998) has termed knowledge of how to get things done, knowledge of patient experience and the limits of medical science. Such a shift in the curricula may lead nursing academics to a greater recognition of nursing as a boundary discipline (Liaschenko 1998). Nursing's position in the landscape of healthcare allows it to span the boundaries between medicine, social care and education. Liaschenko (1998) argues that nursing often operates to bridge the gaps for patients between these various disciplines. Curricula which attend to these boundary functions of nursing would logically be multi-disciplinary. It would encourage students to explore the interactions of children's nursing and other disciplines in order to learn, as Liaschenko (1998) put it, "how to get things done" across various disciplines and agencies to support children's access to social opportunities as well as their healthcare needs. Such curricula might see children's nursing students working alongside education and social work students on a module that would assess their abilities to provide services in their respective disciplines to children living with illness. This multi-disciplinary learning would also

need to engage children and parents in helping students to understand the impact of their actions on the lives of children and their social networks.

Within the hospital setting nursing appears more visible than in community settings as demonstrated in the literature review for this study. This lack of visibility is also evident in the teaching of children's nursing, with little reference to community settings in guidance on curricula (NMC 2002). Although the Nursing and Midwifery Council stipulate that 50% of learning must occur in community settings, how this is achieved in practice seems to be in doubt (Keyon and Peckover 2008), often due to a lack of clinical placements for students in community settings (Keyon and Peckover 2008). Continued development for community children's nurses is often under threat with anecdotal evidence that approved specialist practice courses struggle to be financially viable for universities. Although no studies have been conducted, the researcher's experience of teaching children's nursing and involvement with national bodies promoting the teaching of children's nursing, suggests that few lecturers of children's nursing have a community background, and of those who do, it is often in health visiting rather than community children's nursing.

Re-focusing the curricula to give more prominence to Benner's (2001) helping and teaching roles, may also help nurses to critically explore their relationships with children. As well as academic study, this perhaps should include attitudinal learning and reflection on practice situations that encourage nurses to critique their relationships with children. It may be helpful for students to do thought experiments which place themselves in a landscape of healthcare, gender and generational relationships. In their analysis of this landscape, children's nurses should consider

how the geography of their relationships with children relate to other features of the landscape such as the relationships between children and other generations, children and people of the same and different genders, children and their social networks, as well as children and various health care workers including nurses.

The suggestion that children's nursing is part of a generational landscape indicates that curricula need to equip students with a sociological understanding of generation. If children's nurses are to take account of the sociology of childhood in delivering nursing care they will require an understanding of sociological principles, the sociology of childhood, and intergenerational relationships, as well as the sociology of illness and disability. Bringing sociological perspectives into the curricula for children's nurses could allow space for nurses to critique professionalised approaches and to consider children's perspectives.

If we accept the findings of this study, that at least some boys prefer to receive nursing care from men, and recognise that children's nursing is a female dominated profession (Purnell 2007), it seems logical that education programmes which permit people to work as children's nurses would need to recruit and retain many more men. However, as La Rocco (2007) has pointed out, recruiting men to nursing and facilitating them staying in nursing requires wide ranging strategic approaches which address the image of nursing as a female profession, as well as economic factors and career structures.

To dramatically alter the ratio of men to women in children's nursing to reflect the proportions of each gender of children receiving nursing care will require long term political will.

Thus the findings of this study may suggest a re-balancing of children's nursing curricula, to include learning how to support children in their attempts to be like other children. Moreover, it would suggest that children's nurses need opportunities to learn with other disciplines in order to improve their understanding of how they can support children to be like other children.

9.7.3 Implications for research and children's nursing

This study was exploratory in nature (Polit and Beck 2004), as such it raises a number of further research questions. In relation to how children portray themselves as children, like other children one such question is: Are there positive as well as negative aspects to children portraying themselves as children, like other children? Following on from this, if it can be shown that children portraying themselves as like other children have negative as well as positive health effects, then research would be required to determine how nurses might intervene to promote positive enactment of children's portrayal of themselves as children, like other children.

For children who require nursing care to support them in educational settings it would seem that studies into how this can be achieved while allowing children to present themselves as being like their peers will be important. Although educational settings were not the focus of this study, some children were observed receiving nursing care in schools. The nursing care in such settings may be highly visible to the child's

peers, making attempts to be accepted as being like other children very difficult for the child living with illness. As more children receive complex health care in community settings, environments other than the child's home need to be considered in order that children may avoid becoming housebound, unable to access social interactions. Thus studies of how children negotiate their social presentation of illness and relationship to health care in various settings will be required to facilitate children living with illness in communities.

The relationship between nurses and children within the generational landscape also requires further investigation. Firstly, to determine what effect, if any, the quality of the relationship has on health outcomes. Do children with positive regard for nurses have better health outcomes? Secondly, as a part of this further research it would be useful to determine whether children's regard for nurses can be altered by improving children's understanding of illness, or whether regard for nurses is part of an illness trajectory that cannot be altered. Perhaps a related question is whether there is a relationship between children's regard for nurses and the children's perception of the efficacy of nursing interventions? Children with a negative regard may perceive nursing interventions as ineffective, and those with a positive regard them as effective, perhaps in spite of objective evidence to the contrary. Future research is needed then to unravel whether this is a chicken or egg question i.e. does negative regard for nurses develop because of the perceived ineffectiveness, for children, of nursing interventions, or does a negative regard for nurses per se colour children's perceptions of nursing such that all interventions by nurses are viewed negatively? It would also be useful to investigate whether children can move from positive to negative regard, where children may become less certain of their illness belief. In

such a scenario, Kelly or Nanny's illnesses may change unpredictably, and this would make them less certain in their understanding of their illness. The question would be whether such an adjustment to children's understanding about their illness would result in a shift to a more negative regard for nurses.

There are perhaps some subtleties about children's understanding of illness and their regard for nurses which need to be investigated further. For example, what happens where an illness defies medical labels and the child and adults may struggle to understand what is happening to the child's body? In all the cases in this study, children were given medical labels of physical illness. Does the continuum of regard for nurses apply for children living with mental health problems?

With regard to the visibility of children's nursing perhaps one of the questions for future research is whether visibility is important in terms of health outcomes? What is required from research is a study of the costs of and threats to less visible aspects of children's nursing. When nursing teams are struggling through lack of resources, do they indeed sacrifice the less visible aspects of their work for the more the visible? Some nurses may pay the costs of less visible work (e.g. giving up their own time to complete work not valued by their employer). If they do so what are the implications for children and for the nurses themselves? Such a study should include the management and commissioning of children's nursing services to determine whether less visible work is under valued, under funded and when resources are reduced, sacrificed for a focus on the more visible work of nurses which supports the practice of medicine.

Studying less visible aspects of nursing is likely to be difficult work, and attracting funding for such work and recruiting participants a challenge, as the focus on medical science amongst research funding bodies is so strong (Meerabeau 2005). However, recent policy direction to create a more person focused health service (Department of Health 2008b) may create opportunities to study the less visible, boundary work of nurses.

Although the findings of this study suggest some children prefer a nurse of the same sex, it did not examine the effect of the gender of nurses delivering care on health outcomes, or the effects of gender on children's involvement in receiving care. It could be argued that if children's nursing is to invest in recruiting and retaining men as nurses, evidence is required that men have a positive contribution to make.

Masculinity has in recent times begun to be an area of investigation in health care (Pelchat et al 2007). In the main, these studies have considered the role of fathers, rather than the effects of the gender of nurses (Taylor and Green 2008). Research into the masculinities of male children's nurses and the effects these have on their relationships with children, health outcomes and participation of children in health care could provide the evidence to support the rationale for programmes to recruit and retain men.

Answering these research questions should help to inform new policy directions in the practice of children's nursing and the education of children's nurses, to strengthen commitments to equal treatment for children living with illness, so they can access similar social and educational opportunities as afforded to their peers (Department of

Education and Skills 2003, Department for Education and Skills and HM treasury 2007).

9.7.4. Implications for policy and children's nursing

As pointed out in section 9.3, there is perhaps conflicting policy on the roles of parents and nurses in the care of children living with illness. Some policy seems to support parent's involvement, while others extend and strengthens the role of nurses in children's lives. For policy to enable nurses to support children in their attempts to be children there needs to be clarity about the role of nurses, and the expectations of parents. This is arguably a wider social debate about the role of the state in children's lives and of what society expects from parents, families and social networks of children living with illness. Children's nursing itself seems to be faltering in this debate with the rhetoric of family-centred care not being realised in practice (Coleman 2002). It could be argued that until children's nursing determines its philosophical base (Lee 2003), which would set out the purpose of children's nursing, such a debate cannot move forward.

Children in this study were clear about their desire to be like other children not living with illness. Thus it could be argued that an important way of evaluating children's nursing, from the perspective of children is to use metrics designed to measure the degree to which nursing interventions support children to be like other children.

Measures might include days the child attends school and the continuity of school attendance, as school attendance promotes friendship networks as well as educational attainment (Sandeberg et al 2008). Another measure may be how well children's friendship networks are facilitated by nursing interventions. This could include

facilitating children's friendships during exacerbations of illness as well as facilitating children's social interactions by enabling them to attend out of school activities e.g. Scouts or sports clubs. Enabling children to access other social interaction, such as occur during family holidays, should also be considered as potential measures.

Considering the outcomes for children of nursing interventions in terms of being like others would suggest that measuring nursing interventions should occur in the context of social and educational as well as health services. The unique contribution of nursing may be in bridging these children's services to ensure children access social as well as educational opportunities as far as possible, just as their peers would. There are then elements of interdisciplinary policy and social justice to be considered in measuring the efficacy of nursing care for children, as well as health outcomes.

These metrics for children's nursing as suggested by this study and others on children's desire to be like their peers (Carnevale 2007), do not seem to be in common use at present. Rather, most evaluations seem to rely mostly on patient satisfaction, and often parental satisfaction (Lewis 1999, Sartain et al 2001, Cramp et al 2003). However, the children's findings in this study suggest that these approaches may not be helpful, as children with a positive regard for nurses are likely to rate nurses highly irrespective of their actual behaviour. Similarly parents are likely to influence children to ensure they rate nurses' performance positively. Children with negative regard for nurse, if they were given a free choice, would rate nurses negatively, again irrespective of their actual behaviour. The likely results of such survey methods are that the nurses' service will be rated positively. This is borne out by the literature on

community children's nursing, all of which is positive about parents and children's perceptions of the services (e.g. Sartain et al 2001, Lewis 1999).

a more ethical issue that this study has highlighted, that children may avoid talking about nursing as this may remind them of their illness and of the painful interventions nurses deliver. However, parents anxious to please the providers of a service they value, may coerce, or force children to participate. Thus it could be argued that a survey of children's views could be harmful to children's mental health causing psychological distress and therefore unethical. It would seem then that purchasers of community children's nursing services should not rely on children's satisfaction levels alone in determining the quality of nursing services.

If there is a consensus that children should be involved in the development of their own nursing services, and this may be a contested area (Coad and Houston 2006), then instead of using satisfaction levels, purchasers and those responsible for the quality of children's nursing services may need to develop other measures. These quality assessment methods could include observation of nurses delivering nursing care. In this study, the inclusion of observation proved very useful in detecting behaviours which other methods did not reveal. For instance, through observation it was possible to see that although Gizmo felt nurses did not talk to him, or play with him, they in fact did. Currently observation of practice is not widely accepted and is perhaps under used in research with children in health care settings (Carvenale et al 2008). Although there is a danger of observation of work performance being portrayed as a punitive, time and motion exercise, it could be used instead as part of peer evaluation and support in clinical supervision. The schedule for such observations

would need to be developed and agreed with community children's nurses. Such an observation schedule would focus attention on how nurses deliver individualised care and could include the extent to which nurses facilitate the child's involvement in receiving care through negotiation with carers.

Children in this study appeared to want to be involved in their nursing care. British governmental policy seems to promote children's involvement in their health care (Department of Health 2002c), albeit that the children's National Service Framework (NSF) does not include standards for children's involvement (Department of Health 2004a). If the research questions posed in section 9.7.3. were to demonstrate that children's regard for nurses can be changed by improving their understanding of illness and increasing their involvement in care, and that these interventions improve health outcomes; then it could be argued that there is a need for patient education programmes which empower children in the management of their illness or long term condition. Such programs are starting to be established based on the success of adult self management programmes (Bodenheimer et al 2002, Salinas 2007). If such programmes prove to be beneficial, then consideration should be given to including self management standards within the NSF for children.

The visibility of aspects of children's nursing, where the focus is arguably on medical science, together with the lower status of children in adult societies (Mayall 2002, Robinson and Kellett 2004) may suggest a lack of policy from governments on children's nursing. In recent years however, in Britain, a strong policy framework for children's health care has been put in place (Department of Health 2002c, Department of Health 2004a, and Department for Education and Skills and HM treasury 2007),

together with policy guidance on children's nursing (RCN Community Children's Nursing Forum 2000, NMC 2002, RCN Children's Leadership and Management Forum 2004). These policies, despite a rhetoric of involving children (Department of Health 2001a/b, Coad and Houston 2006) are heavily influenced by adult agendas of professional and parenting issues (Coad and Shaw 2008).

The poor visibility to the children in this study of some aspects of nurses work may suggest that while policy makers and commissioners of community children's nursing services should be considering the metrics of children's nursing, as set out above, they also need to consider aspects which may be less visible, but which may be key to children accessing health, social and educational opportunities this may mean a more complex approach to evaluating community children's nursing services, which seeks out the less visible aspects of nurse's work.

Policy makers also need to consider the harm that may result from some aspects of nurses' work being less visible, and the potential rewards to children of making the boundary/interdisciplinary work of nurses more visible. One such benefit could be improvements to safeguarding children, as closer interdisciplinary working may enhance professionals' abilities to safeguard children (Long et al 2006).

If children's nursing is to respond to the preference of some of the boys and girls in this study, to have care delivered by a nurse of the same sex as themselves, then policies will need to be developed which encourage men to become children's nurses and which support them to remain as clinical children's nurses. The work of La Rocco (2007) may suggest that these policies need to address career progression as well as

cultural and economic factors to be successful, to make the work of nursing as attractive to men as it seems to be to women. In part, this requires a balancing of the division of labour around child and health care in society generally. Financial policies are also required which would put nursing on a level footing with other careers open to men. These are arguably wider social policies which need to be sustained over the long term.

In the short term, children's nurses also need policies, at local and national levels, to recognise that some children may feel embarrassment at receiving nursing care from a member of the opposite sex. Such policies need to set out appropriate responses to promote the dignity of children and ameliorate their discomfort. Current guidance on chaperoning (Royal College of Nursing 2001) does not address the concerns raised by some of the children in this study. The findings of this study suggest that the dignity of children needs to be considered in community as well as hospital settings.

In summary, this study suggests that involving children in evaluating nursing services may be more complex than just asking them to rate their satisfaction with the service. Peer observation of nurses within a structure of clinical supervision may be useful to facilitate quality reviews. However, ultimately new metrics for children's nursing services need to be developed that measure how nurses facilitate the child's educational and social, as well as health outcomes. These evaluations of nursing need to be placed in a context of a wider social debate on the care of children living with illness, which would clarify the relative responsibilities of children, parents, families, communities, the state and health professionals.

9.8. Summary of A children's agenda for nursing: practice, education, research and policy

This chapter has re-examined the findings of this study and explored the implications for children's nursing. It has proposed how children's nursing might look were it to be shaped by listening to children. This of course assumes that nurses are going to champion children's views over and above their own. This may be a naive hope. However, current trends in health policy are making listening to and hearing children's voices more possible. The findings of this study might suggest that taking a children's agenda forward into the work of nurses, and their education, will require more research into how children build and maintain relationships with nurses.

A children's agenda for the way forward in children's nursing has the following key features:

- A re-focusing of children's nursing to a more balanced approach supporting children living with illness to be like other children and supporting children's interactions with medical practice so that children can access the same social and educational opportunities as their peers, as well as benefit from medical science.
- Improving the understanding of how children living with illness present themselves as being like other children in order to identify strategies which enhance well being and strategies which may damage health. Improving the evidence base on how children live with illness and the effects of illness trajectories and illness belief on children's relationships with nurses, in order to facilitate children's involvement in receiving nursing care.

- An exploration of the effects on children's health of aspects of community children's nursing work being less visible.
- Improving the evidence base on the effects of the gender of nurses on how children receive nursing care, health outcomes and their involvement in receiving nursing care.

Of course this remains an adult agenda constructed for children derived from research with children, but it would need to be taken forward in partnership with children.

Whether such an agenda is enacted will be determined not just by children, children's nurses, nor children's nursing, but by the many adults who hold the power to change children's health care.

Chapter 10: Conclusions and recommendations

10.1. Introduction

In concluding this thesis this chapter begins by setting out the context of this study giving a rationale for the research questions and aim. Then the mosaic of methodologies and methods used in the study are reviewed. This includes a review of the approach taken to data analysis. The findings which the data analysis revealed are detailed, including the new aspects this study offers to the understanding of children's experience of receiving nursing care. Finally, the recommendations for children's nursing are set out related to practice, education, research and policy.

10.2 Context and research questions

Two factors were influential in establishing this study. Firstly, health policy began to promote the voice of those who use health services (Department of Health 2001a, 2002c), and at the same time there was a greater recognition of children as social actors, supported by sociological approaches to children and childhood (Mayall 2002). Secondly, community children's nursing services had expanded over the past decade (Whiting 2005), partly in response to increasing numbers of children who, through health care advances, were surviving with complex health care needs. This expansion in nursing services was, however, ad hoc and seems to have been driven by local needs and politics (Whiting 2005).

A review of the literature focusing on children's views of nursing revealed a limited literature, biased towards hospital based studies giving preference to reporting adult views, rather than those of children. Very few researchers accounted for how they, as adults, researched children's views, and ensured that the opinions of children were not

unduly influenced by adults in the research process. As most of these studies lacked rigour and did not identify factors which influence how children receive nursing care in community settings open and wide ranging research questions were set:

- How do children experience receiving community children's nursing services?
- What factors shape how children experience receiving community children's nursing services?
- What is it that children expect and want community children's nurses to do for them?
- What are the implications of children's views for the delivery of community children's nursing services and the wider nursing of children?

The aim of answering these questions was to propose a children's agenda for community children's nursing, which would at least begin to underpin the work of community children's nursing with evidence, rather than relying on local needs and politics. To achieve these aims Clark's Mosaic approach (2004/2005) was adopted.

10.3 Methodologies and methods: A Mosaic approach

Clark's Mosaic approach (2004) seemed to fit well with the aims of this study as it is underpinned by a sociological approach, advocates the use of participatory methods and suggests that children and adults co-create understandings. However, the Mosaic approach does not ensure children's voices are heard, unfiltered by adults' behaviours, nor does it negate the need for reflexivity, especially in relation to the researcher's adult status. The approach did however, seem to have advantages, in this study, for researching *with* children.

This study, drew on phenomenology, ethnography and visual methodologies in a mosaic of methodologies. Each of these methodologies seemed to add to the study.

The use of phenomenology led to a “loose” approach (Miles and Huberman 1994a) which allowed for a free exploration of the phenomenon. Bracketing, as suggested by Husserl’s approach to phenomenology, helped to formalise the reflexivity in the study. Ethnography brought the principle of prolonged engagement in the field which perhaps facilitated the rich data provided by the children. The method of observation, which comes from an ethnographic approach, was extremely useful in this study in exploring the views given by children and how they related to the behaviour of nurses when delivering care. Visual methodologies allowed children to participate in non textual ways, for some children using visual media may have been more appealing than talking or writing. In this study the visual data supported the textual, and did not reveal aspects undiscovered by the textual methods.

Combining these methodologies the following methods were used in these stages:

- Researcher bracketing interviews
- Group 1 with 5 core group children using arts based activities
- 6 Photo Talk Diary with interviews with core group children
- Observations of 4 core group children receiving care with interviews
- Group 2 with 3 core group children using art and theatre based activities
- Observations and interviews with 6 nurses during their working day including observations of 14 non-core group children receiving care
- Two group interviews with 23 nurses

The data collected using these methods were analysed using a framework based on that developed by Colaizzi (1978). This included creating descriptions of the phenomenon which were put to participants for verification. From the inductive and iterative analysis of the data collected the themes discussed below began to appear.

10.4. Themes from the findings

This was an exploratory study (Polit and Beck 2004), as there has been little research focusing on children receiving nursing care in community settings. As an exploratory study, many of the findings will need to be explored and confirmed by further inquiry.

While accepting this caveat, this study has revealed aspects not seen in previous studies. This is the first study to:

- Report on how children nursed in community settings attempt to portray themselves as children, like other children
- Note the resistance that children offer to receiving nursing care in community settings
- Propose that children's regard for nurses may be placed on a continuum reflecting both negative and positive regard
- Explore the visibility of community children's nursing from the view points of both children and nurses
- Document children's embarrassment at receiving nursing care in community settings from a nurse of the opposite sex

The findings of this study offer then some unique insights into how children receive nursing care and the factors which shape children's experience, as well as their expectations and desires. The main findings were:

Children, like other children

The overwhelming message from children in this study is that children living with illness wanted to be like children not living with illness. Although Carnevale (2007) has written about Goffman's passing in relation to children living with illness, and

other hospital based studies describe behaviours which might be seen as children attempting to be like other children (Coyne 2006, Battrick and Glasper 2004, Carney et al 2003), this is the first study to describe children's attempts to portray themselves as like children not living with illness when receiving nursing care in community settings. The findings in this study support Admi's (1995) critique of Goffman (1968), in that children's attempts to be like other children are perhaps not a denial of their illness, but rather an attempt to lead a life, through negotiating access to social interaction equal to that of their peers. How much nurses support children in this endeavour, or frustrate their efforts to be like their peers perhaps influences children's relationship with nurses and nursing. This important aspect of living with illness needs to be investigated further. Of special concern should be how nurses may determine when children's attempts to be children, like other children, put the child's health at risk.

Children's relationships with nurses and with nursing

Perhaps because this study paid attention to the relationship between children and adults as separate generations, it is the first to describe children's negative regard for nurses. This study suggests that children's regard for nurses is not contingent on the nurse's behaviour, but is related to how children understand their illness and the degree to which adults allow children to be involved in receiving nursing care. Further study is required to determine if children's regard for nurses affects health outcomes, whether children's regard for nurses is fixed or malleable, and whether it is related to the child's illness trajectory.

Visibility of community children's nursing

Tasks performed by nurses which support the practice of medicine were more visible in this study than those which support children in their attempts to be like children not living with illness. In the study, both children and nurses focused on the technical therapeutic interventions that children being nursed at home received. However, nurses were observed to deliver care which could be expected to help children to access social interactions equal to those of their peers. These aspects of the work of nurses seemed to be less visible to children. Whether the poor visibility of this work has implications for children, nurses and society in general, needs further study and debate.

Gender and children's nursing

Although there have been reports of children's embarrassment at receiving nursing care from a member of the opposite sex in hospital settings (Ramm et al 2004a) and there is a small literature on dignity in hospital settings (Reed et al 2003), this is the first study to raise the issue of gender and children's perceptions of embarrassment when receiving nursing care in community settings. The gender of nurses seems to be an issue for some children, beyond the gender politics of nursing. If the desire of some boys to receive nursing from male nurses is to be realised, the effects of gender on the health outcomes for children living with illness will need to be explored in more depth. If it can be shown that there are benefits to children from receiving nursing care from nurses of the same sex, then long term and sustained efforts will be required to encourage more men to enter and stay in children's nursing.

10.5. Recommendations

Children's desire, expressed forcibly in this study, to be children first and foremost has implications for children's nursing. At a fundamental philosophical level, children's nursing needs to respond to children's need to be like their peers. There needs to be an open debate with children, their carers and society about the purpose of children's nursing. Currently there seems to be confusion over the role of parents and of children's nurses. If "good" children's nursing is to facilitate children's access to social interactions such that they are equal to their peers, then children's nursing must be rebalanced to make medical science less visible and to increase the visibility of nurses' work which supports children to be like their peers. Educational programmes would need to prepare nurses for this more social interdisciplinary activity. Research would be required to determine the limitations of nurse's roles in supporting children in this way, as well as determining the association between being like other children and health outcomes. Consideration should be given to how nurses' support of children to access the same opportunities as their peers is measured and how such measurements are used to evaluate nursing services.

The relationships between children and nurses need to be studied in more depth, in the first instance to determine whether children's regard for nurses affects their health outcomes. It may be useful at the same time to determine whether children's regard for nurses can be changed, or is related to illness trajectory. A longer term programme of research is required to determine whether nurses and parents working together with children can empower children to be more involved in their care and the effects of such involvement on health outcomes. Further research is also needed to determine whether less visible work undertaken by nurses which facilitates children being like

their peers is vulnerable, as Liaschenko (1997) suggests, to being under valued, underfunded and ultimately not delivered.

Finally, the desire of some children to receive nursing care from a member of the same sex needs to be considered. This would require evidence that the gender of the nurse delivering care affects children's health outcomes, or level of involvement in receiving care. If it could be shown that boys' health benefited from receiving nursing care from men, then consideration should be given to increasing the number of male nurses to provide boys with the opportunity to receive nursing care from nurses of their own sex.

The messages from this study are perhaps at times difficult to hear. Nurses may not like to think about children having a negative regard for them, or consider children as gendered members of society, but these difficult messages give an opportunity for nurses to hear the voices of children, and to allow children to shape the future of children's nursing.

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Appendix 1: Question route and activities groups 1 and 2

Group 1

Time	Activity	Equipment
10:00-10:05	<p>Introductions:</p> <p>Reminder of first names.</p> <p>“Would you all like to write on the cards a new name just for the study. Choose a name that might be used in your family, but not the name of your brother or sister”</p>	<p>Paper with children’s names on and space for study name.</p> <p>Envelopes.</p>
10:05-10:10	<p>Outline the session</p> <p>Investigators</p> <p>“Before we start perhaps I should ask you all what you think we are going to do this morning?”</p> <p>Ask each child</p> <p>“You’re right in a way we are like detectives trying to piece together a jigsaw about the help and care you get at home with your health needs.</p> <p>Here we have our four pieces of the jigsaw and we need to fill each with our clues to put them together, so that we can understand better how children like you think and feel about the help you get at home.”</p> <p>Not school, no right or wrong, no one gets told off here.</p>	<p>Large coloured card cut into 4 jig saw pieces.</p>
10:10-10:15	<p>Confidentiality “the box with the golden key”</p> <p>All equipment for the session is in the box and must return there. In the box are also hats that each child and worker puts on/ or boxes.</p> <p>“These are to remind us that all we say and feel and think in this session stays here and when we finish we lock them away again in the box. You don’t have to tell anyone what was in your hat or box. When I write about what you have said I will use your, special name.”</p>	<p>Large painted box with large padlock and key.</p> <p>All session equipment/ Audio equipment.</p> <p>Hats assorted- thinking caps.</p> <p>Plain boxes and string/ribbon.</p>

Time	Activity	Equipment
10:15-10:25	<p>Putting together a jig saw:</p> <p>Piece One</p> <p>“OK just to get us started can you quickly pick out words that show the sort of thing that happens to children like you”</p> <p>“Can you think of other words?”</p> <p>What do kids have done to them?</p> <p>What can kids do for themselves?</p>	<p>Word bank/picture bank</p> <p>Divide paper children to place activities.</p> <p>Blank labels for children to write on pens.</p>
10:25-10:40	<p>Piece Two:</p> <p>“That’s been really useful thanks, now I want you to very quickly draw a map of the places you get help when you are poorly/sick.”</p> <p>“ It doesn’t have to be perfect just a rough map will do”</p> <p>What sort of things do children do at home when sick? Things one can’t do.</p> <p>What happens at school?</p> <p>What about out and about, street clubs etc?</p>	<p>Map making pens paper.</p>
10:40-11:00	<p>Talk Back</p> <p>So tell me about your map [child’s name]</p>	
11:00-11:20	<p>Break.</p>	<p>Refreshments.</p>
11:20-11:35	<p>Piece Three:</p> <p>“So before our break we were talking about where you get help when you are poorly or sick. Now I want you to draw on these helping trees the people who help you. The people who help you most would go on the trunk of the tree and those who are not so helpful go on the out side branches.”</p> <p>Who does what: relate to where?</p> <p>Who helps children at home who have health problems? / when they are sick (pick out nurses)</p> <p>Who should help but perhaps does not?</p> <p>What makes a good helper?</p>	<p>Helping tree out lines</p> <p>paper pens.</p>
11:35-11:50	<p>Talk Back</p> <p>So [child’s name] tell me about your helping tree</p>	

Time	Activity	Equipment
11:50-12:10	<p>Piece Four:</p> <p>“Ok so we have one last piece of our jigsaw which is to find out how you think we can find out about children at home who have health problems?</p> <p>I want you to blow idea bubbles, when you have an idea blow a bubble let it pop then say your idea” (one at a time)</p> <p>Steer towards diaries</p> <p>Recorded over time – don’t have to remember everything at once</p> <p>Ownership</p>	<p>Bubbles some bubble guns</p> <p>Famous examples of diaries</p> <p>Adrian Mole reading.</p>
12:10-13:00	Lunch.	
13:00-13:25 13:25-13:30	<p>Summing up:</p> <p>“Well thank you for all your hard work this morning it has been great.</p> <p>I want now to look at our jigsaw and for you to tell me what you think we have found out this morning?</p> <p>Well what I think we have found out is</p> <p>What do you think is that right?”</p> <p>Confidentiality</p> <p>Putting the session in the box and locking the box (ask one of the children to lock the box.)</p>	<p>Box and padlock.</p>
13:30-13:50	Games.	Games.
13:50-14:00	Thank you.	Certificates of participation, party bags to take home.

Group 2

Time	Activity	Equipment
10:00-10:05	Introduction-welcome Name game	
10:05-10:30	<p>What did we find?</p> <p>Pass the parcel</p> <p>With member checking statements* between layers.</p>	<p>Parcel with member checking statements * between the levels and sweets (prize)– something to share in the middle (chocolate?)</p> <p>Music system- music.</p>

Time	Activity	Equipment
10:30-11:30	6 part story method.	Art materials.
11:30-11:45	Break.	Refreshments.
11:45-12:45	Puppet making.	Digital camcorder/ Art materials.
12:45-13:15	Lunch.	Lunch.
13:15-14:00	Good nurse /not so good nurse- drawing around Co workers Good nurse /not so good nurse statements	Paper Masking tape Post it notes with statements **
14:00-14:30	Rehearsal time.	Art materials.
14:30-15:00	Film puppet plays (6 part story)	Camcorder Video Play house
15:00-15:30	Children and parents invited to watch puppet plays- days filming.	Camcorder Video projector, lap top.
15:30-16:00	Saying good bye End of group, Summary of day and project.	Refreshments (tea/coffee biscuits).
16:00	Thank you!	Certificates of participation, party bags to take home.

** Member checking statements*

A good nurse is fun, but also knows how to do things right to make me better, they respect me as a person and work with my family and friends.

I don't like to think about being ill I prefer to think about playing with my friends and being with my family.

I would rather have my mum or dad do all the things I need to keep me well, than have nurses visit me at home.

*** Statements on post it notes used in group session for Good nurse / not so good nurse sort.*

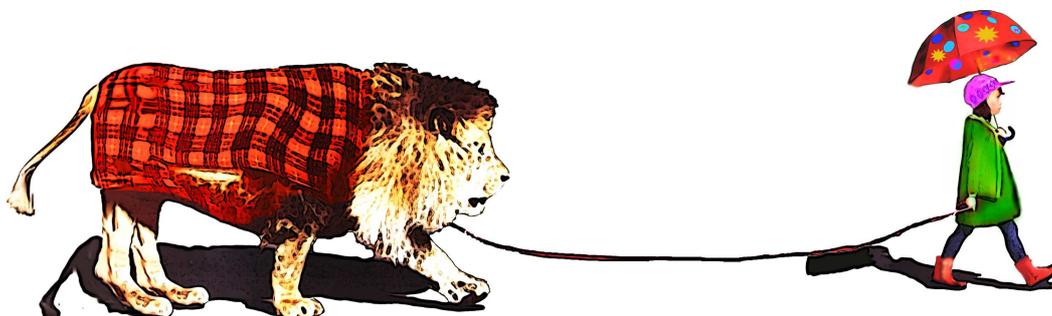
- I am well enough to play with my friends.
- My mum. or dad are there to help me too.
- The nurse works with my mum and/or dad to look after me.

- The nurses include my brother/s or sister/s.
- It does not stop me seeing my friends at school.
- I can have all my favourite things near me.
- The nurse is good fun and makes me laugh.
- I like the nurse as a person.
- The nurse knows what she/he is doing.
- Mum and dad like the nurse.
- They are a lady nurse for girls.
- They are a man nurse for boys.
- I am so poorly I can not play with my friends.
- Being ill means I don't get to see my friends at school.
- The nurse does not play enough with me.
- The nurse does not respect me and my family.
- The nurse does not talk to me.
- The nurse does not include my brother/s or sister/s.
- If I am a boy or girl.
- Where I live.
- Where my family come from.
- Which god my family worship.

Appendix 2: Photo Talk Diary

Children's views of being nursed at home: Photo Talk Diaries

My Diary



Any questions?
Call Duncan Randall
on 0121 414 8377
or email d.c.randall@bham.ac.uk

What to do with My Diary

Thank you for taking part in our study.

This diary is for you. You can do as much of the diary as you like.

Please record how you felt about the nurse visiting you at home just before they arrive and as soon as the nurse has left. Please record 2 or more visits.

We want to know a little bit about you so we can better understand how children like you think about nurses.

You can draw, and write in the diary or if you like you can use the tape machine and the camera Duncan will give you. You can add extra pages or put things in the clear wallets. It is up to you it is your diary!

When you have finished Duncan will come and collect your diary, tape machine and camera. Duncan will then copy the diary, have what you have said on the tape written down and have your photographs printed. He will bring back your copy of the diary when he comes to talk to you all about your diary and the nurses who visit you at home.

Special Note to Mums & Dads

Your mum and dad or any one you choose can help you with your diary. But please remember it is your diary. The ideas and thoughts in the diary should be yours.

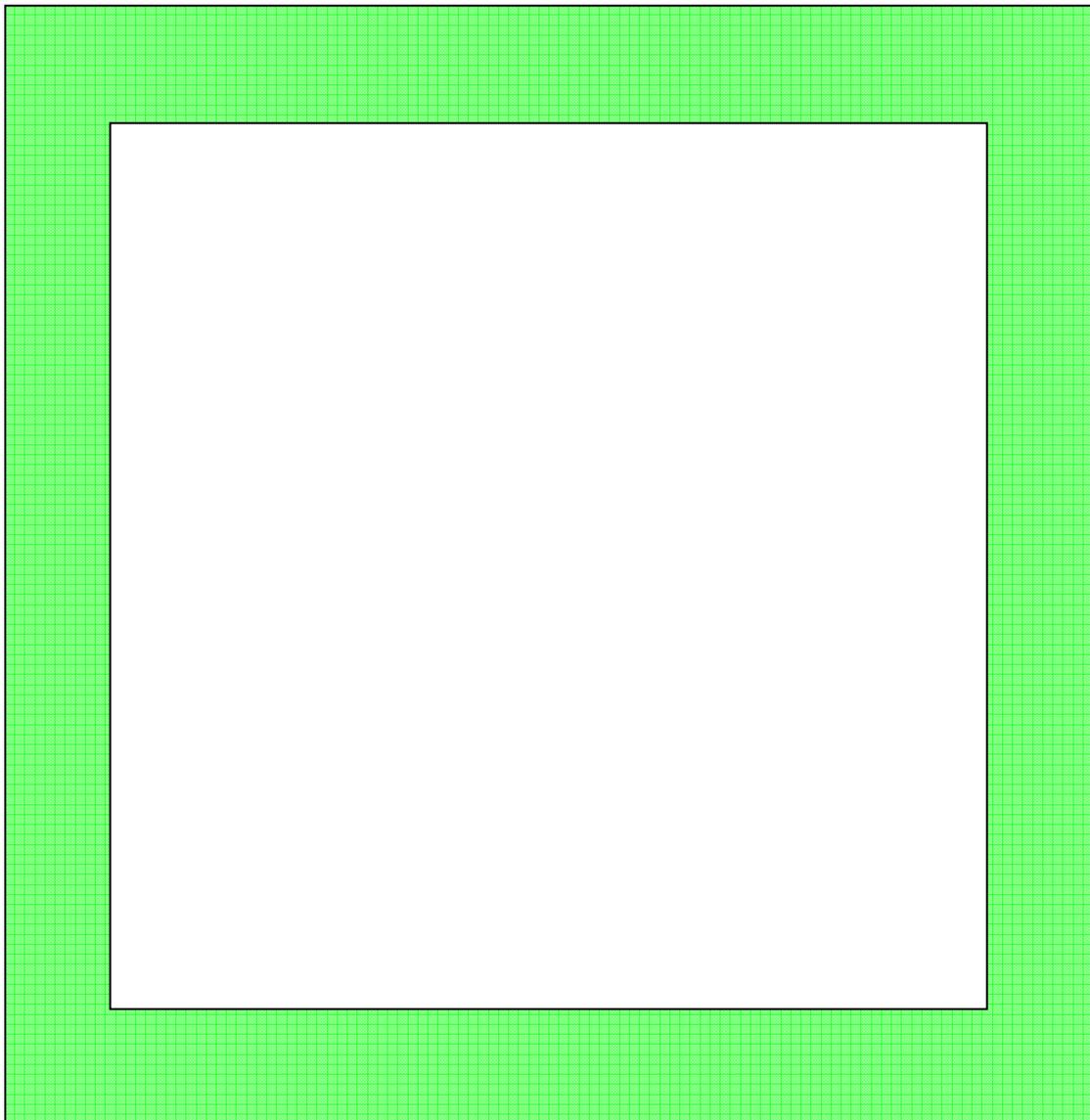
My name is

My study name is

(This is the special name we will use when we write about what you have said.)

About Me

This is me (draw a picture or take a photo).



I am a Girl/ Boy.....

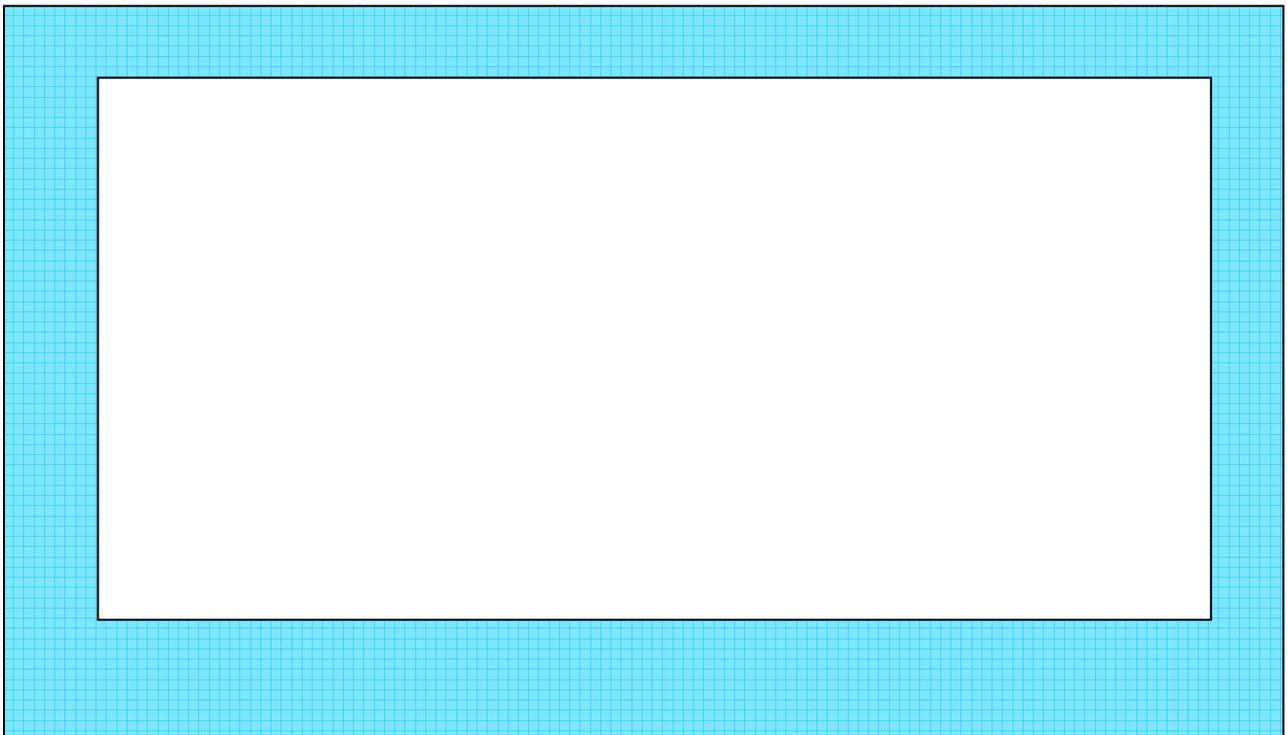
My age is

(Please draw a circle around your age)

5 6 7 8 9 10 11 12

I live with

...(draw a picture of who you live with in your house and write their names).



My family comes from.....

Our religion is

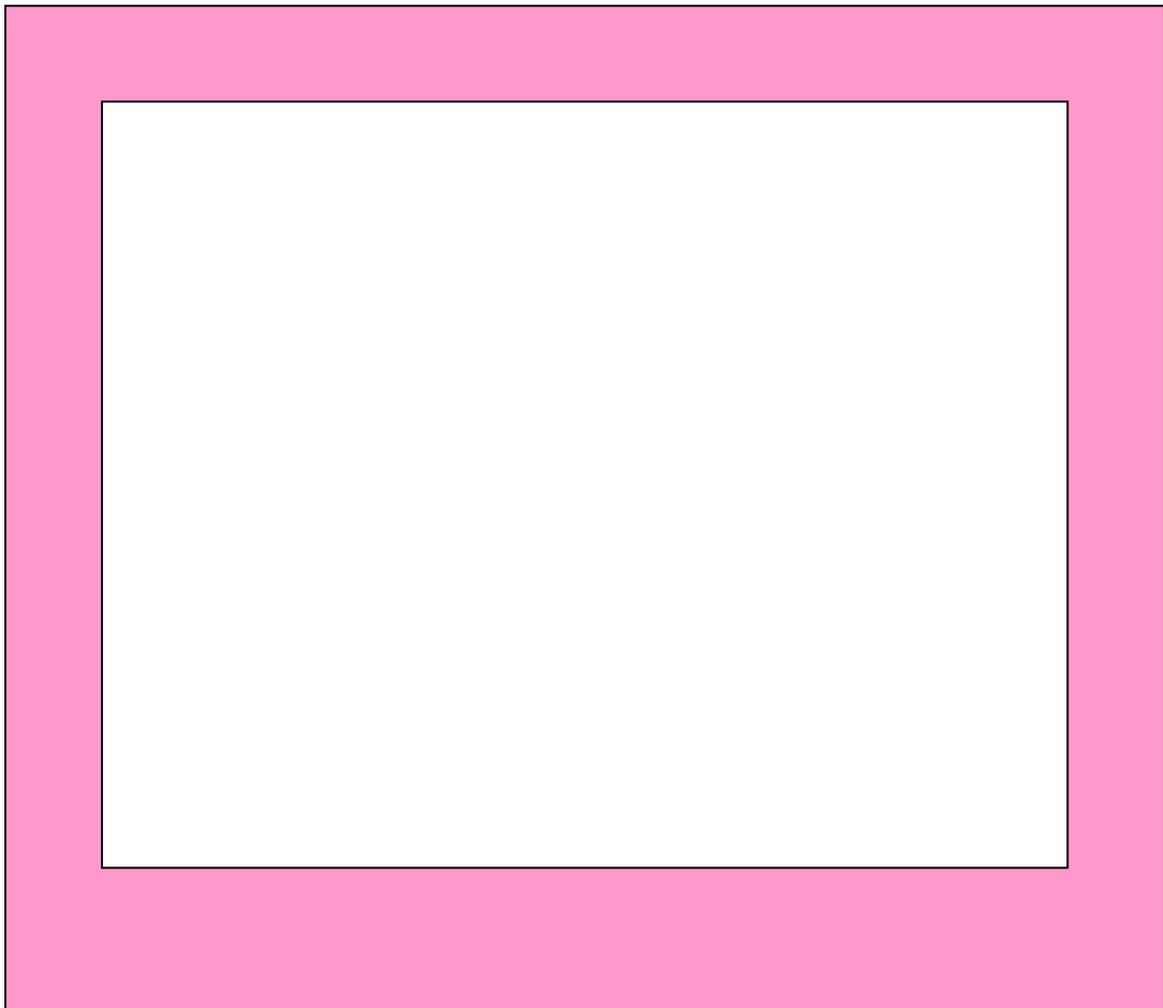
My favourite thing is

.....

My best friend/s is

I live in (neighbourhood).....

(If you would like you can draw a picture or take a photo of where you live.)



Best thing about where I live.....

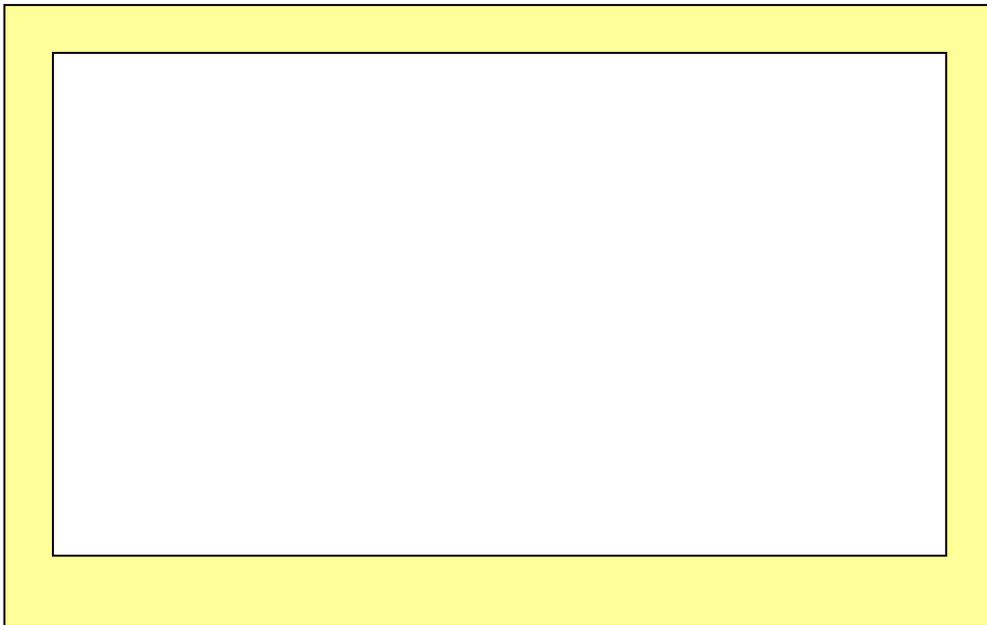
.....

Worst thing about where I live.....

.....

My school is.....

(If you would like you can draw a picture or take a photo of your school.)



My friends at school are.....

.....

Best thing about my
school.....

.....

.....

.....

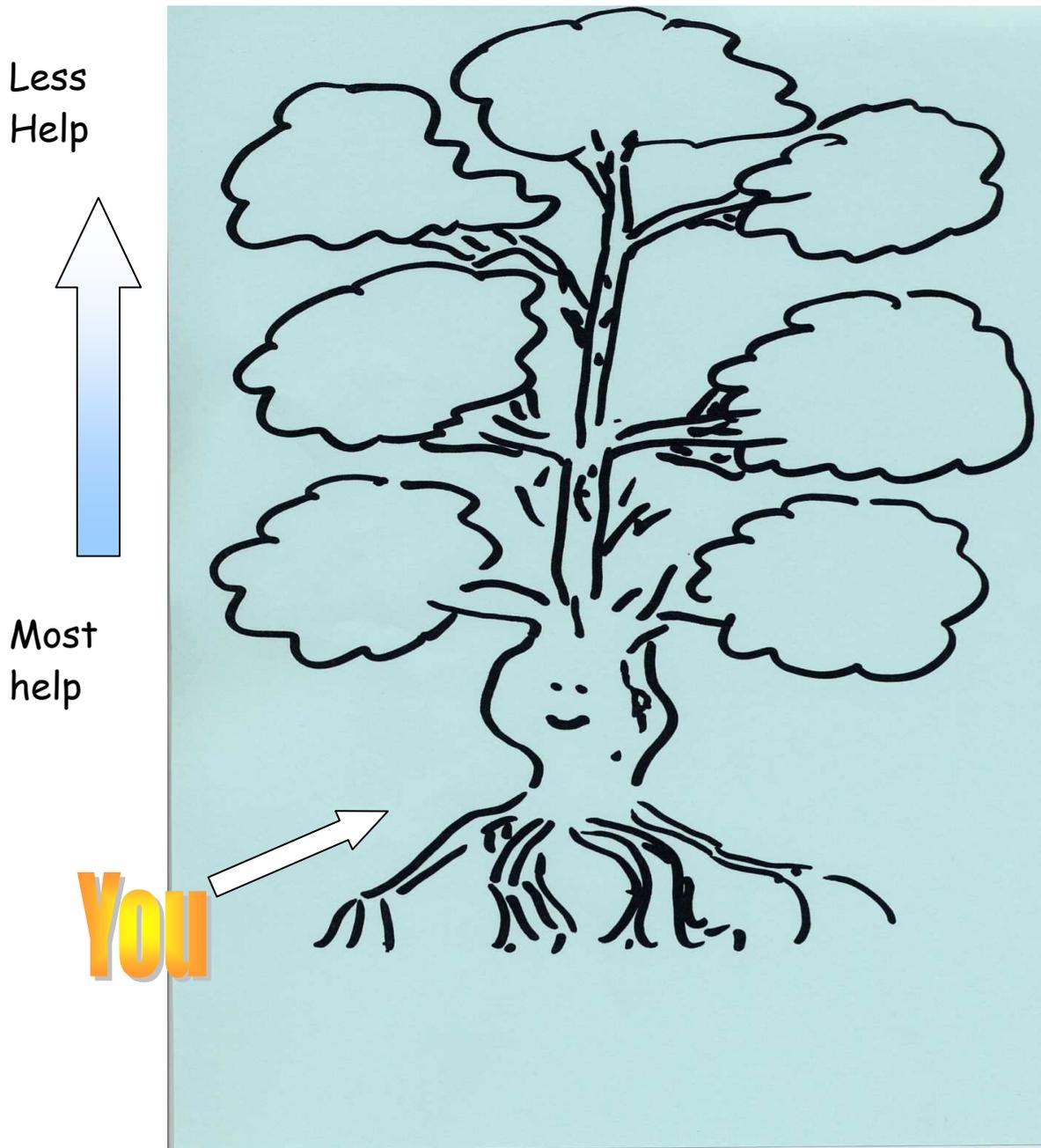
Worst thing about my
school.....

.....

.....

People who help me

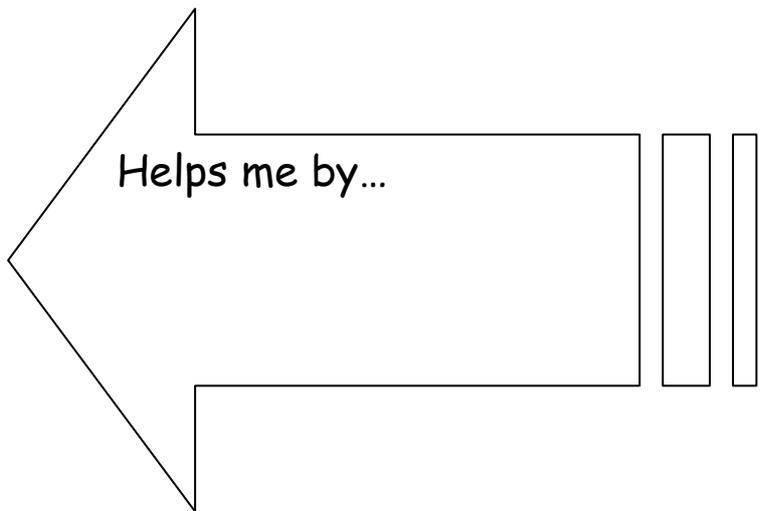
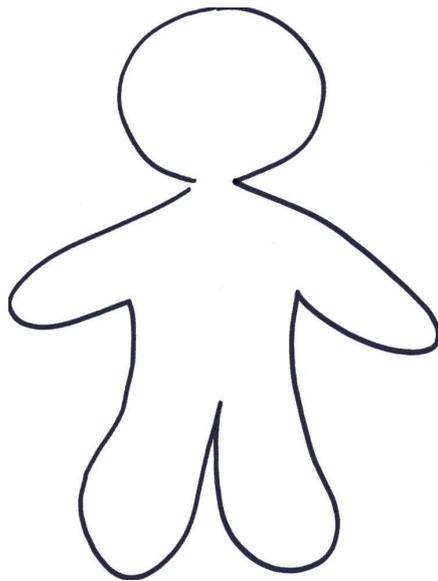
Below is a helping tree; the smiley face is you, the trunk of the tree. Place the people who help you most on the bottom branches and those who help less in the top branches.



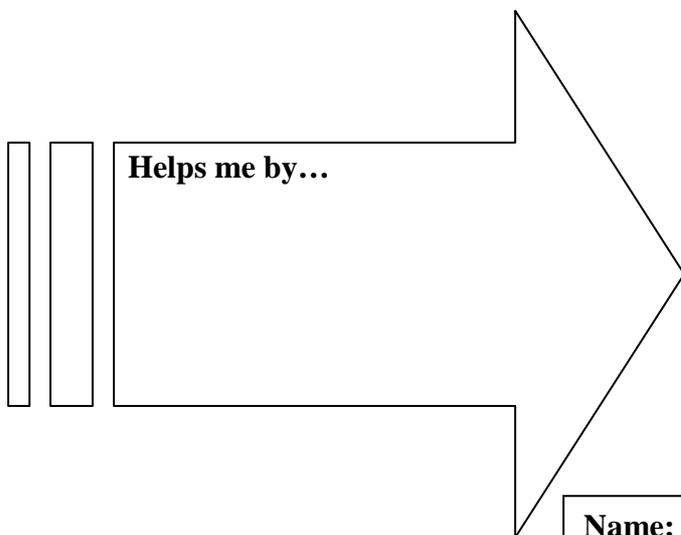
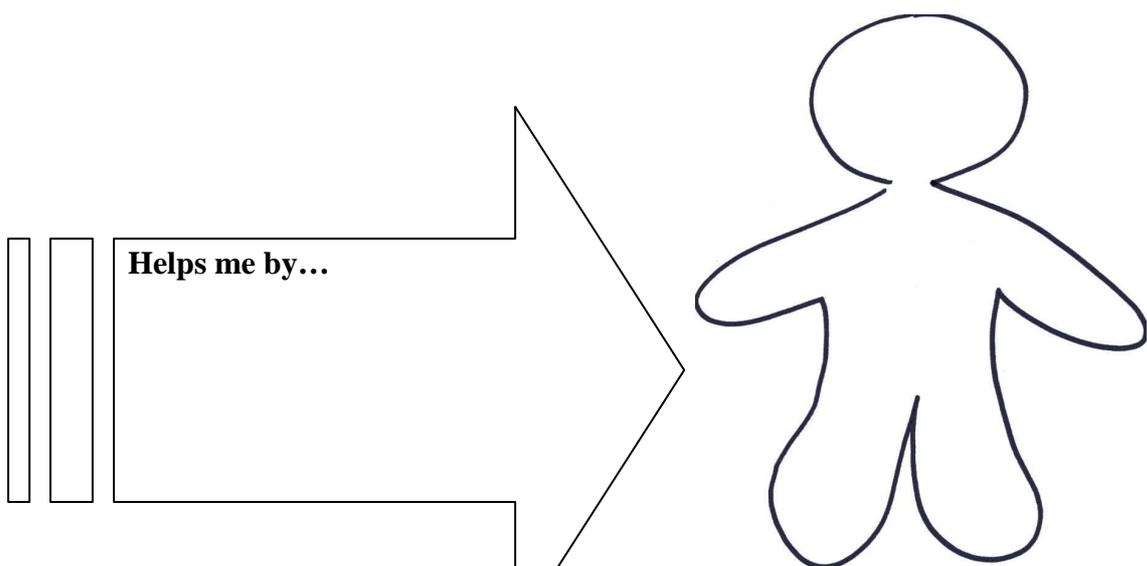
Help

What sort of help do you need?
Colour in and label the people

How do they help you?



Name:



Name:

Where?

Please draw the places where you see the nurse/s who help you (e.g. in which rooms of your house do you see the nurse? Do you see the nurse at school, or clinic?).

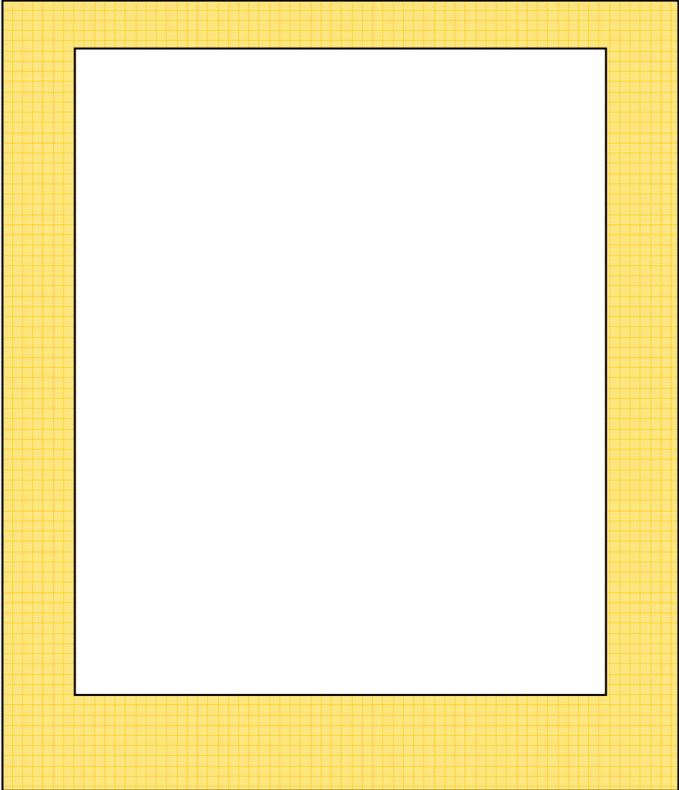


Who

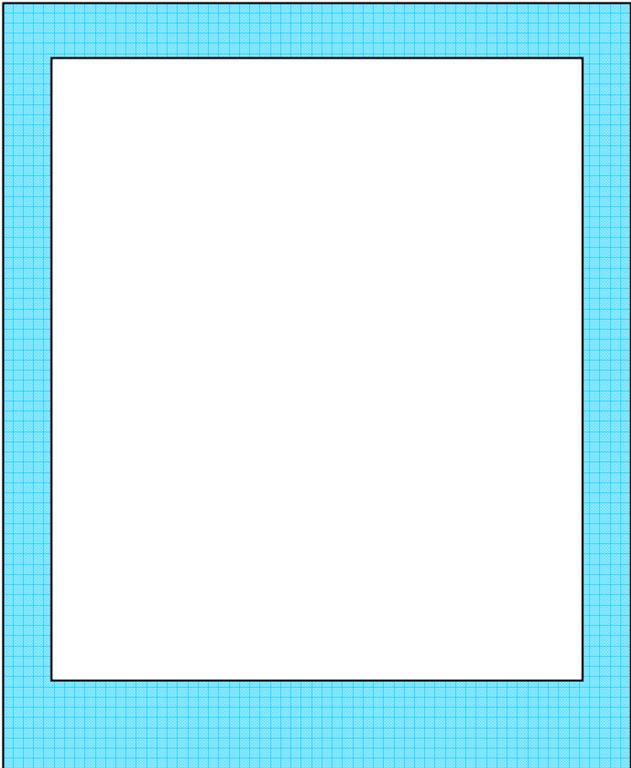
Can you draw, write about or take a picture of
the nurse who visits you at home?

If there is more than one tell us about them all.

What is good about your nurse?



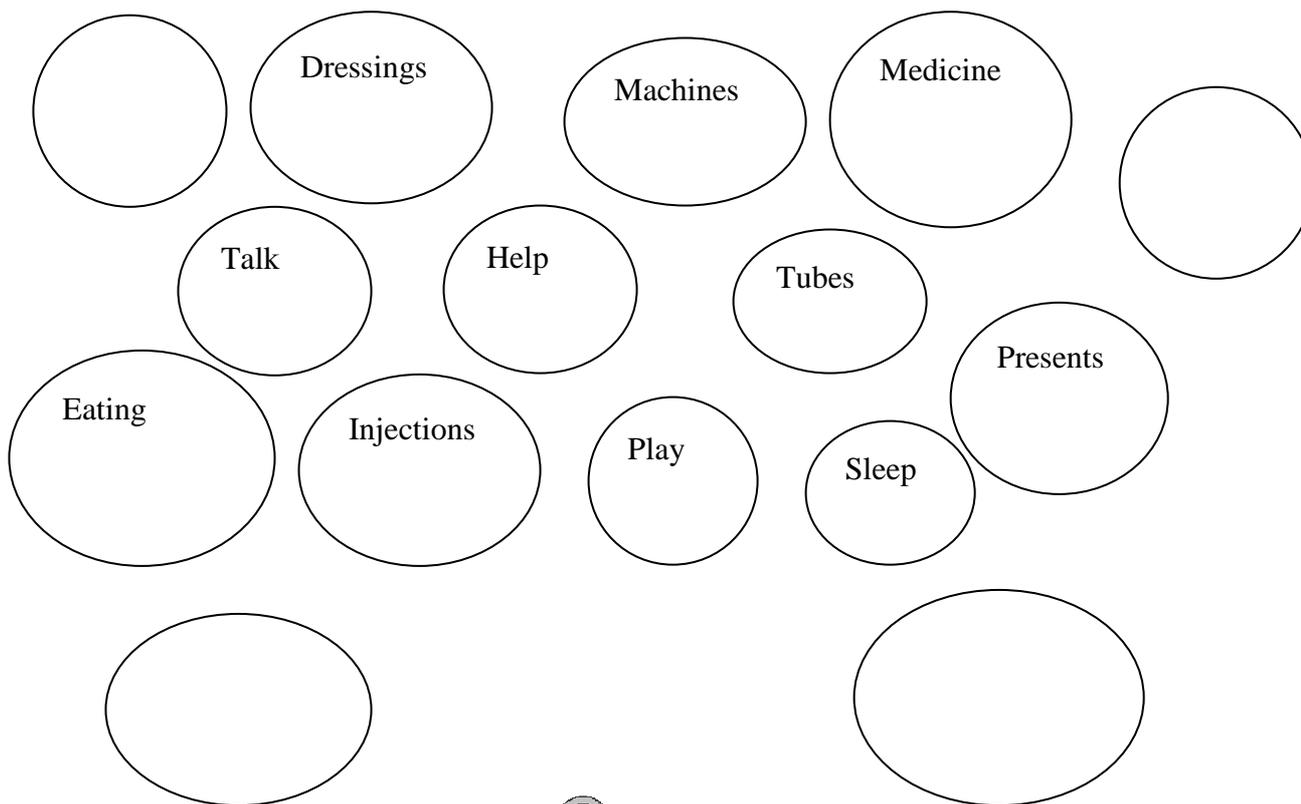
What is not so good about your nurse?



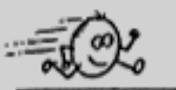
Why does a nurse visit you at home?

What do the nurses do for you at home?

Please colour in the word balloons that tell us best what the nurses do for you at home. Then draw a line to the box. Or you can write in the empty balloons and join them to the box.



Please draw a circle around one answer from each box.

FITNESS		FEELINGS			
During the past month, what was the hardest physical activity you could do for <u>at least 10 minutes</u> ?		During the past month, how often did you feel anxious, depressed, irritable, sad or downhearted and blue?			
Very heavy • Run, fast pace		1	None of the time		1
Heavy • Jog, slow pace		2	A little of the time		2
Moderate • Walk, fast pace		3	Some of the time		3
Light • Walk, regular pace		4	Most of the time		4
Very light • Walk, slow pace		5	All of the time		5
A					B
SCHOOL WORK		<i>Friends</i>			
During the last month you were in school, how did you do?		During the past month, if you needed someone to listen or to help you, was someone there for you?			
I did very well	 	1	Yes, as much as I wanted		1
I did as well as I could	 	2	Yes, quite a bit		2
I could have done <u>a little</u> better	 	3	Yes, some		3
I could have done <u>much</u> better	 	4	Yes, a little		4
I did poorly	 	5	No, not at all		5
C					D

When you write or record your diary these questions may be useful.

What else happened today?

Who else helped you today?

How did they help you?

What happened last night?

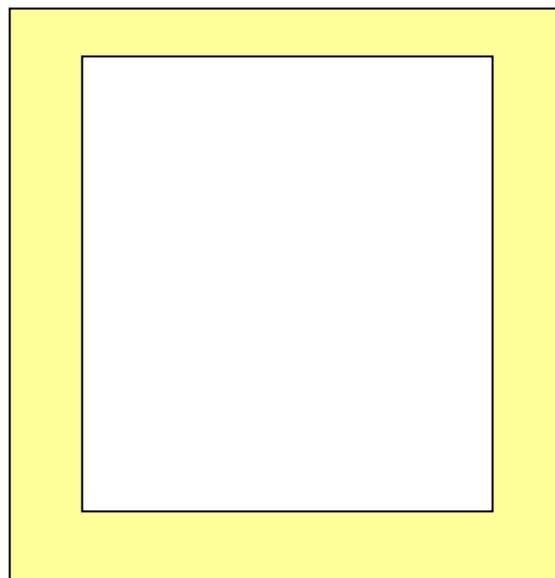
Did you sleep well over night?



Diary

Please write or use your tape machine to tell us what happened when the nurse came today.

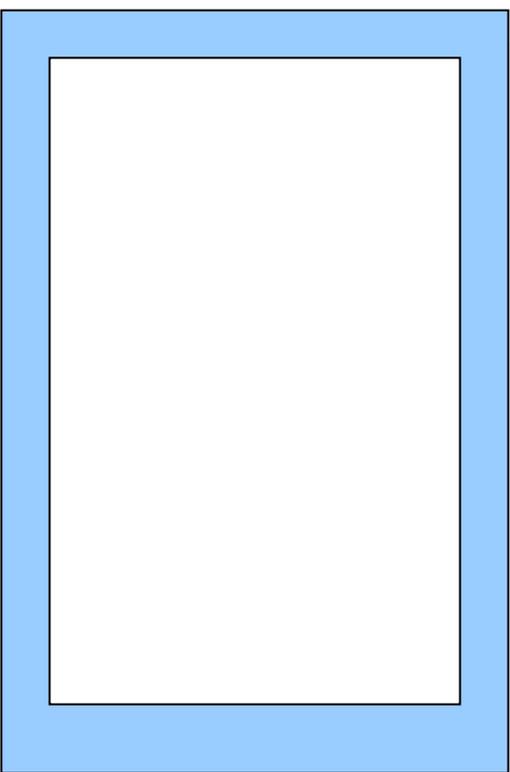
Before the nurse came ...



Photo/drawing

Diary

Cont...

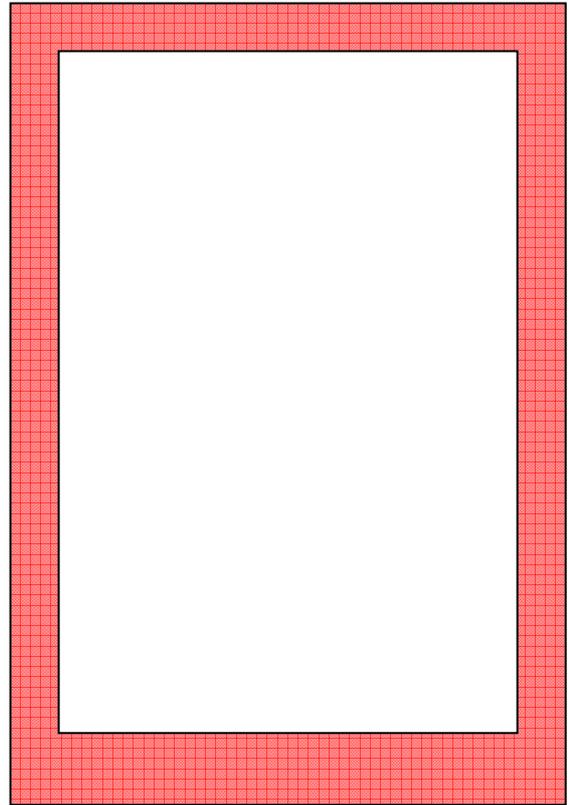


When the nurse was here...

Photo/drawing

Cont...

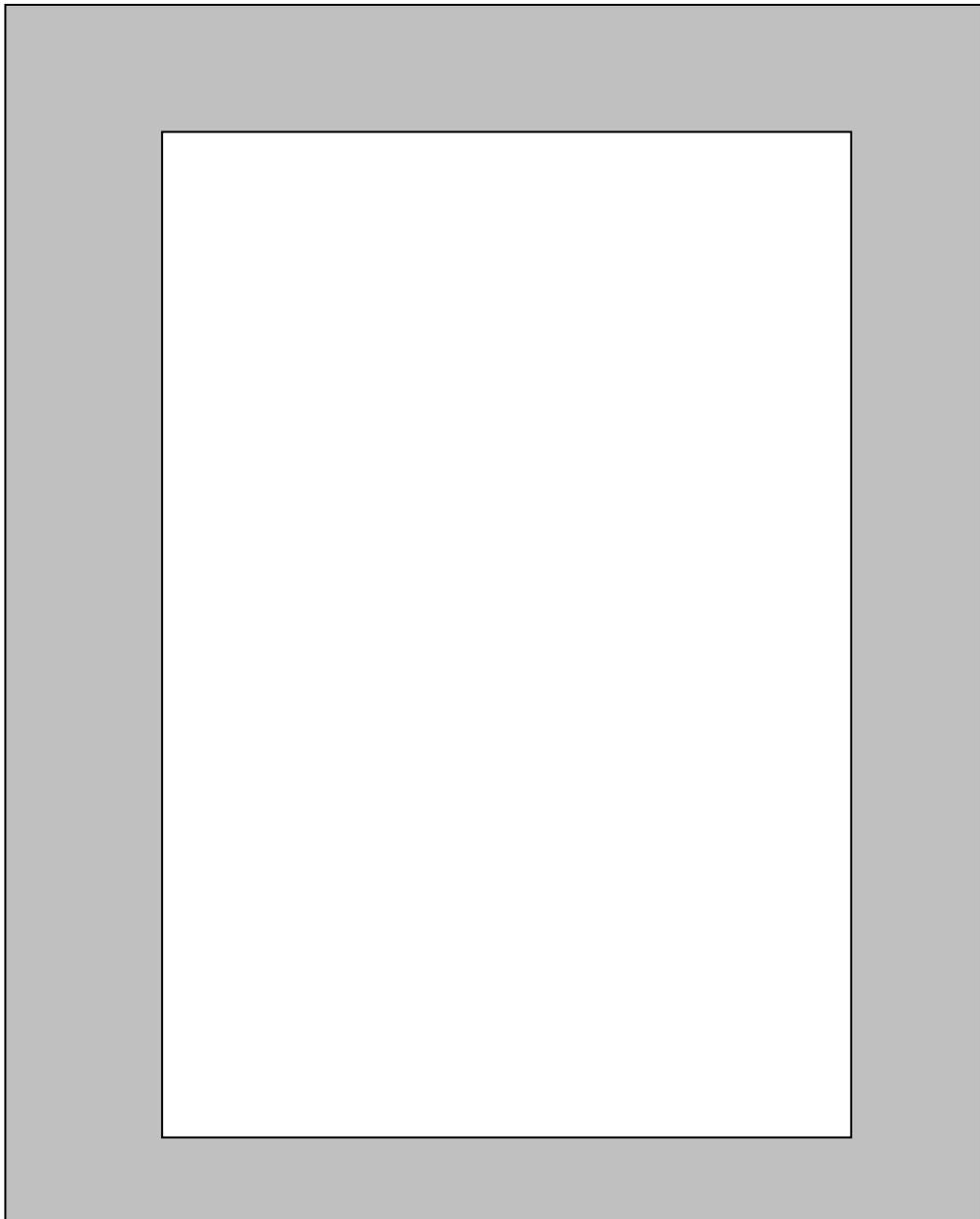
After the nurse left



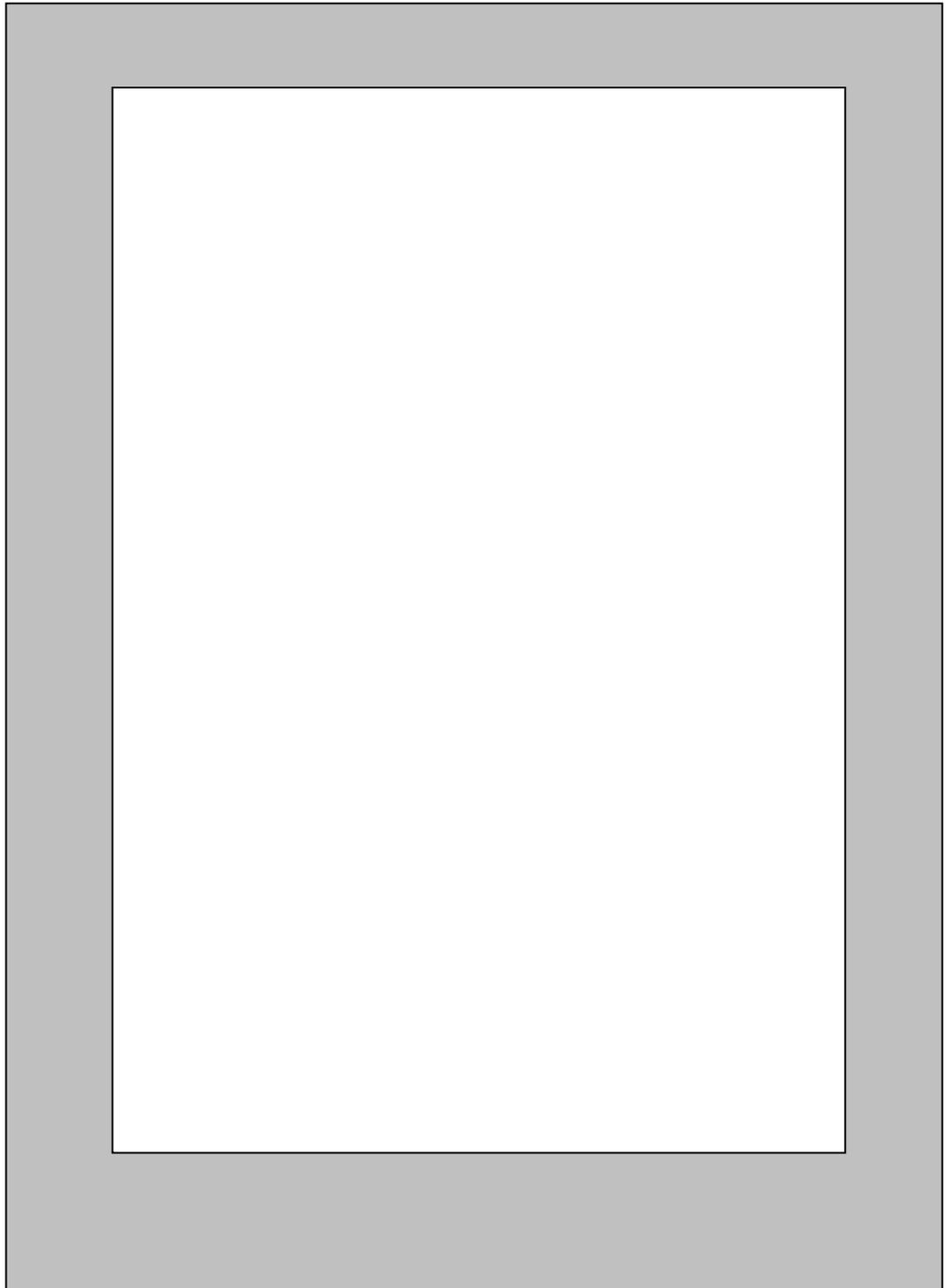
Photo/drawing

My Album

This is space for your pictures and photos about you and about your nurse.



This is space for your pictures and photos.

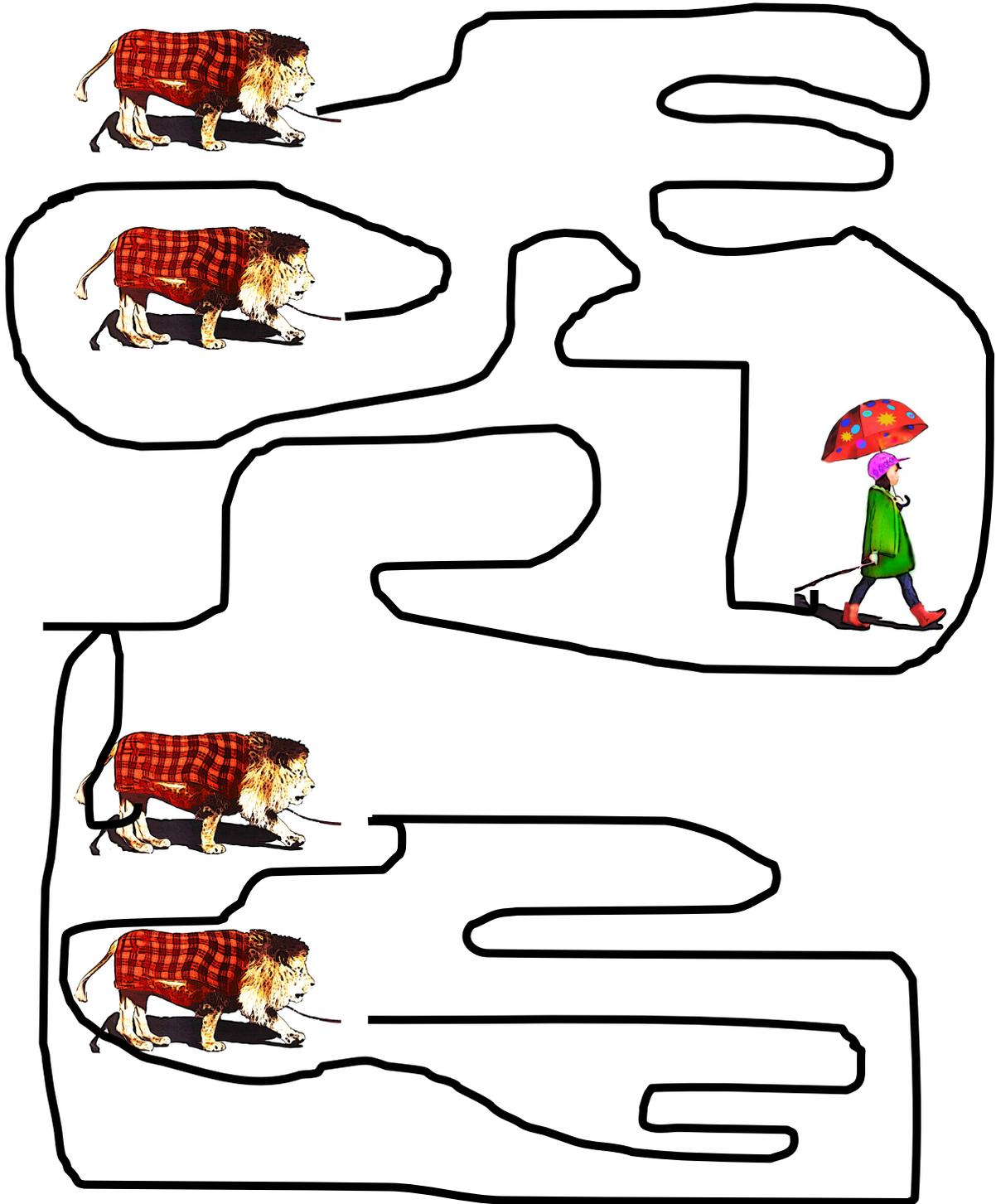


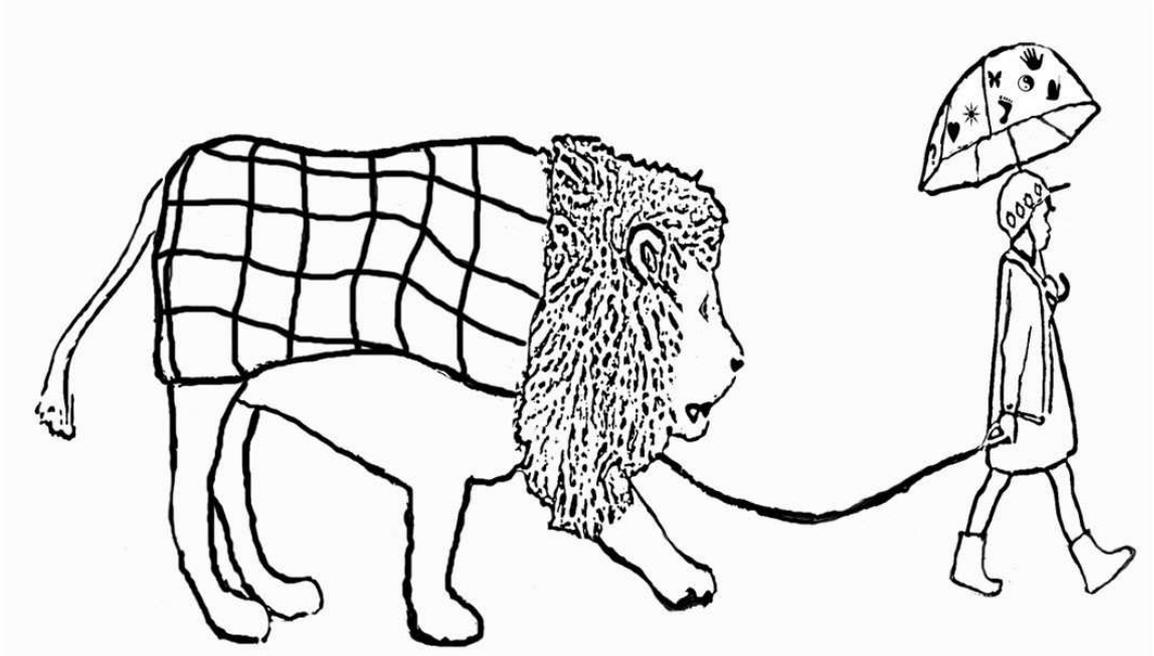
And Now!

Is there any thing else you would like to write about or make pictures about?

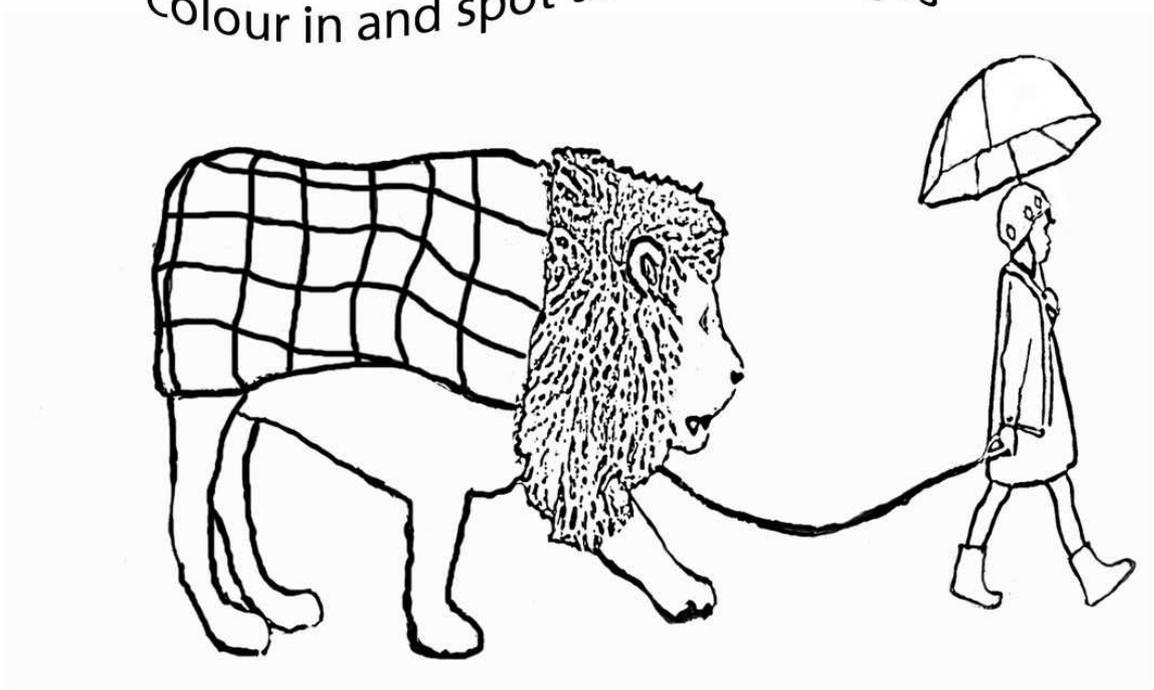
Just For Fun

Can you help the little girl find which is her lion?





colour in and spot the five changes

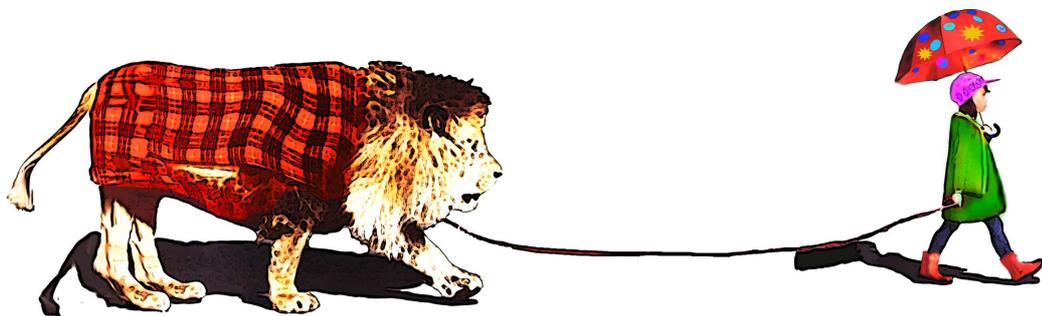


Can you find the words about this diary in the word search?

W	A	U	P	R	H
A	O	M	L	E	E
R	D	B	E	T	S
W	I	R	H	U	R
I	A	E	O	H	U
C	R	L	I	O	N
K	Y	L	Y	M	W
R	T	A	E	E	B

WARWICK LION UMBRELLA

NURSE HOME HELP DIARY



Certificate

This is to certify that

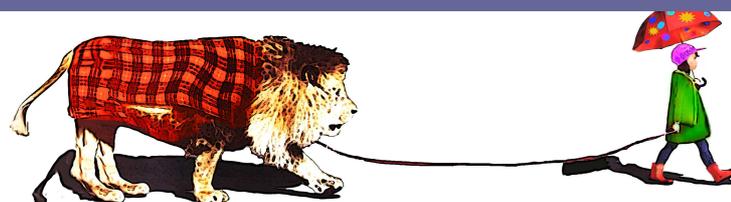
**HAS SUCCESSFULLY
COMPLETED THEIR DIARY OF
BEING NURSED AT HOME**

WITH GRATEFUL THANKS

Duncan Randall

DUNCAN RANDALL.

DATED _____



Appendix 3: Semi-structured Photo Talk Diary interview

Review diary content: text and pictures

Study name (confirm)

Picture of me – discuss if present

Age gender (confirm)

(Family religion see below)

Best friend/s – (from diary)

- Do your friends know about the nurse visiting you at home?
- What do you tell them?
- What do your friends think about the nurse visiting you at home?
- How do you feel if the nurse visits when you have friends over?

Neighbourhood/ house-

- Best thing/ worst thing (from diary)
- Do the people you play with locally know about the nurse visiting you at home?
- What do the children you play with in your street think about the nurse visiting you at home?
- Do you think having a nurse visit you at home makes it harder or easier for your family? Why?
- Here there is a picture /you talk about your house do you think it matters to the nurse who visits you what sort of house you live in?
- Here there is a picture /you talk about your street do you think it matters to the nurse who visits you where you live?
- Would the nurse look at you differently if you lived in another place (part of city/town)

School-

- Who are your friends at school?
- What do they think about a nurse visiting you at home?
- Does your teacher know you have a nurse visit you at home?
- How does your teacher help – with the health problem/ nurse visiting at home? (Check help tree in diary)
- Best thing worst thing about school (from diary).

Family comes from religion (confirm from diary).

- Do you think children from different backgrounds/religions would make the same sort of diary?
- Would a child who has a nurse come and see them at home, but comes from a different sort of family think the same as you?

Help tree

- How does (person named on tree) help (probe before , during and after visit use help people outlines)
- Do you have a special toy? How does that help you when the nurse comes?
- I noticed that there were/were not lots of picture writing about your brother/sister/s tell me about your brother/sister/s
 - Do your brother/sister/s help you if so how?
 - Do your brother/sister/s know you have a nurse visit you at home?
 - What do they think about the nurse?
 - How do you feel if the nurse visits when your bother/sister/s is at home?
- I noticed that there were/were not lots of picture writing about your grandparents/aunt/uncle (extended family) tell me about your (extended family)
 - Do your (extended family) help you if so how?
 - What, if any thing, do you tell your (extended family) about the nurse who visits you at home?
 - How do you feel if the nurse visits when you have (extended family) over?
- There are pictures here of your pets how do they help you when the nurse comes?

Where

- Where do you see the nurse?
- In which rooms in your house?
- Where do you like to see the nurse?

Who

- How many nurses come and see you at home (check pictures)?
- Would you like to have just one nurse?
- Do you like having lots of nurses?
- The nurses pictured here are all (male/female) do you like having nurses who are female/male?
- Do you think a nurse would treat you differently if you were a (boy/girl ie opposite of gender)?

My health – talk through.

What happens before the nurse comes?

- So why does a nurse visit you at home? tell me about that (see balloons in diary)
- Tell me about this picture is this before the nurse comes?
- What are you doing before the nurse comes?

During the visit

- What does the nurse do?
- What does your mum/dad do?
- Here is a bit where you talk about / a picture of your mum/dad/other doing X for you who taught them to do that?
- So the nurse does X and so does your Mum/dad who would you prefer? (probe in detail)
- Have you stayed overnight in hospital , did you have X done in hospital, which do you prefer
- Do you think having a nurse visit you at home makes it harder or easier for your family? Why?

After the visit

- What do you do when the nurse goes? (refer to diary).
- From looking at your diary it seem to me that you are saying that for you a nurse is....?
- What makes a good home visiting nurse for you?
- Is there any thing you think nurses should do for you when they visit you at home, but they don't do?
- What else do you think nurses could do for you, or your family when they see you at home but that at the moment they don't do?
- Is there anything you would like the nurses who visit you at home to stop doing?

Good nurse?

- So from your diary you say a good nurses is....(talk, fun, competence)
- What would make your nurses better?

Thank you!

Praise diary!

Appendix 4: Demographics and nursing care information. (version 4 11/4/06).

Title of Project: Children's views of being nursed at home

Demographic data and parents' perceptions of care delivery.

Introduction.

I want to get to know you and your family would it be all right if I asked you some questions about yourselves and your family?

We will not use your details or name when we publish the study, but use your answers to describe the sort of children and families in the study and the sort of nursing they receive at home.

May I use a tape recorder just to help me remember what you have said?
Y/N

Research Number.....Research pseudonym.....

Could we start by confirming some details [name of child] is a boy/girl and [name of child] is how old?

Child receiving care

Gender Male/Female

Age

Nursing Care

How many nurses visit you and [child name] at home?

How many nurses do you consider to be [child name] nurse/s?

How long have you known the nurse/s who visits [name of child] at home?

When did the nurse last visit [name of child] at home?

How often does the nurse visit [name of child] at home?

When the nurse comes what sort of things does she do for [name of child]

[Probe all appropriate to child may tick more than one box]

N.G feeding		Tracheostomy care		Dressings	
Injections		Care of long line		Chemotherapy	
Traction		Care of venous catheter			
Stoma care		Drug administration		Oxygen therapy	
Growth monitoring		Intravenous therapy		Enemas	
Urinary catheter insertion or care					
Chronic illness monitoring and management					
Psychosocial support					
Any other intervention					

When did the nurse last phone you?

--

How often does the nurse phone you?

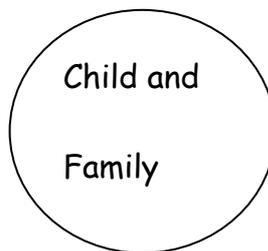
--

Do you see the nurse who visits [name of child] at home in other places?

[Probe all may tick more than one box.]

At hospital		At GP surgery	
Clinic at hospital		Local Health Centre	
School		Street	
Any where else [write in]			

Who else gives you /your child care at home? Please draw a care map.



Consider

Doctor (GP), Hospital Doctors, Social Worker, Home Help (social care), Home Teacher, Physiotherapist, Occupational Therapist, Carers (health care), Psychologist, CAMH Nurses, Health Visitor, District Nurses (Adult services) Nursery Nurse and School Nurse

Consider informal care (e.g. baby sitters).

Family details

Can I ask now about who lives at home with [name of child]?

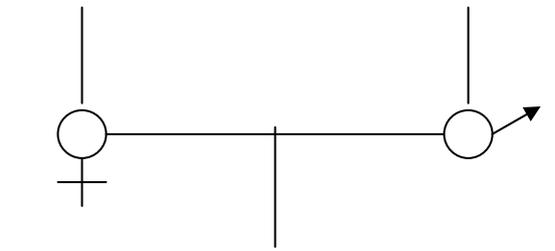
Who is your child's main carer?

[Indicate with a tick]

Both biological parents	<input type="checkbox"/>	Mother only (Biological)	<input type="checkbox"/>
Biological mother and non biological father	<input type="checkbox"/>	Father only (Biological)	<input type="checkbox"/>
Biological father and non biological mother	<input type="checkbox"/>	Grandparent/s	<input type="checkbox"/>
Extended family members Please state	<input type="checkbox"/>	Looked after Foster parents/adoptive parents/ residential care. (delete as appropriate)	<input type="checkbox"/>

Who else lives in your house?

[Draw a genogram of every one who lives in your household (include pets and special toys/TO).]



Housing tenure

We know that for some families that have a child nursed at home housing can be an issue can I now ask about your house.

Do you rent your house, own it outright or are you buying the house and paying a mortgage.

[probe all]

Own it outright/ Buying it with the help of a mortgage or loan/ Pay part rent and part mortgage (shared ownership)/ Rent it/ Live rent free (including rent free in relative's/friend's property; excluding squatting)/Squatting.

We know from other research that family income and parents education can influence children's health. So we can understand how these might affect children's views of being nursed at home I would like to ask about these now, would that be OK?

Income

First I would like to ask some questions about the family income

[SHOW CARD A]

This card shows incomes in weekly, monthly and annual amounts. Which of the groups on this card represents *(your/you and your husband/wife/partner's combined)* income from all sources, before any deductions for income tax, National Insurance, etc?

Just tell me the letter beside the row that applies to *(you/your joint incomes)*.

Parental education.

I'd like now to ask about your own education, what age were you when you left full time education?

Age at which parents/Guardians left full time education

Mother Father other Guardians.....

What is your highest educational qualification?

Mother	Father	other Guardians.....

Ethnicity/culture/religion.

We know that nursing and nurses are seen differently in different cultures so could I ask you now about your family's cultural and religious background?

Complete for child receiving care

Country of birth?			
England		Scotland	Northern Ireland
		Wales	Republic of Ireland
Elsewhere: <i>Please write in the present name of the country</i>			
Ethnic group? Chose one section A-E then tick one box to indicate cultural background			
A White	British		Irish
Any other	Please write in		
B Mixed			
White and Black Caribbean	White and Asian		White and Black African
Any other mixed background	Please write in		
C Asian or Asian British			
Indian		Pakistani	Bangladeshi
Any other Asian background	Please write in		
D Black or Black British	Caribbean		African
Any other black background	Please write in		
E Chinese or other ethnic group			Chinese
Any other	Please write in		

(Office of National Statistics 2001)

Please complete for carers/parents/guardians

Relationship to child receiving nursing care?			
Country of birth?			
England		Scotland	
		Wales	
		Northern Ireland	
		Republic of Ireland	
Elsewhere: <i>Please write in the present name of the country</i>			
Ethnic group? Chose one section A-E then tick one box to indicate cultural background			
A White		British	Irish
Any other		Please write in	
B Mixed			
White and Black Caribbean		White and Asian	White and Black African
Any other mixed background		Please write in	
C Asian or Asian British			
Indian		Pakistani	Bangladeshi
Any other Asian background		Please write in	
D Black or Black British		Caribbean	African
Any other black background		Please write in	
E Chinese or other ethnic group		Chinese	
Any other		Please write in	

(Office of National Statistics 2001)

What is the main religion of the household? Please tick **one** box only.

None		Christian: Including Catholic and Protestant denominations	
Hindu		Jewish	Muslim
Sikh		Buddhist	
Any other religion		Please write in	

Abilities illness status.

I want to get a sense now of the day-to-day difficulties you and [name of child] may face.

Does [name of child] have any difficulties with any of these?
[PROBE FOR ALL PROBLEMS]

	Y	N
1. Walking and or running		
2. Sleeping		
3. Communicating with others		
4. Movement generally moving limbs, back		
5. Eating and or drinking		
6. Passing urine (incontinence, enuresis, dysuria)		
7. Bowel movements (incontinence, encorporisis, constipation)		
8. Breathing at rest (oxygen supplementation, mechanical support)		
9. Difficulty in seeing		
10. Difficulty in hearing		
11. Behavioural problems		
12. Pain		
13. Acute episodes of a chronic illness (e.g. hypoglycaemia in diabetes)		
14. Allergic reactions		
15. Maintaining integrity of skin (eczema other skin conditions, pressure sores)		
16. Fits (grand mal, petite Mal, absent attacks)		
17. Mental health issues (depression, anxiety)		
18. Difficulty with perceptions/ Mental Health Issues - psychosis		
19. Learning difficulties		
20. Other difficulties affecting daily life Please specify		

[National Centre for Social Research 2003]

How old was [name of child] when [this problem/these problems] started?

[if more than one problem ,list problems as mentioned and when started]

Problem	Started

What medical diagnosis have you been given for [name of child] problems?

Medical diagnosis *please write in*

Thank you for answering all these questions. We will not publish any of your answers, but use your answers to describe the sort of children and families in the study and the sort of nursing they receive at home. Hopefully this will help Community children's nurses to improve their services to children like yours.

Children's views of being nursed at home

CARD A

WEEKLY or		MONTHLY or		ANNUAL	
Less than £10	A	Less than £40	A	Less than £520	A
£10 less than £100	B	£40 less than £430	B	£520 less than £5,200	B
£100 less than £350	C	£430 less than £1,500	C	£5,200 less than £18,200	C
£350 less than £600	D	£1,500 less than £2,600	D	£18,200 less than £31,200	D
£600 less than £1,000	E	£2,600 less than £4,300	E	£31,200 less than £52,000	E
£1,000 less than £1,900	F	£4,300 less than £8,300	F	£52,000 less than £100,000	F
£1,900 less than £2,900 or more	G	£8,300 less than £12,500 or more	G	£100,000 less than £150,000 or more	G

Adapted from *General Household Survey 2003*, Office of National
Statistic 2003.

Appendix 5: Semi-structured interview with individual community children's nurses.

Visits

- Can you tell me about the visits we have done today?/ can we just go over the visits we did today?
- Do you have aims or objectives for the visit before you go, if so do you think these were met?
[prompt if not why not]
- How do the visits you did today fit into the overall care for the children?
- Were these typical visits?
- Are the children and the things you are doing for them typical of your caseload?
[Prompt: typical conditions, age range, social position, family structures]
- Was this a typical day for you?
- Do you do other things at work that we have not seen today? If so can you list them for me?
- What do you think makes a good nurse?
- What do you think would make not so good a nurse?
- What influences or determines what happens during your visit to a child?
[Prompt Issues of control- child, mother, nurses role]
- Thinking about the visit we did today mums take on nursing care at home [give example i.e. ng feeding], who taught them to do that care?
[Prompt: children did not see this teaching why?]

Children's views of being nursed at home

I want to move now to what we found from talking to children in an earlier part of the study.

I just want to get your views on these statements that came out of the study;

1. I don't like to think about being ill I prefer to think about playing with my friends and being with my family.
2. I would rather have my mum or dad do all the things I need to keep me well, than have nurses visit me at home.
3. A good nurse is fun, but also knows how to do things right to make me better, they respect me as a person and work with my family and friends.

- If children could specify the gender of the nurse who visited them what issues would this raise?
- Do you think nurses need to build a therapeutic relationship with children?

[Prompt: with children or with parents (mothers)
if no why not?

- If yes, can you tell me a bit about how you build and maintain a therapeutic relationship with children?

[Prompts: professional friendships?

Does the way you work, help or hinder therapeutic relationships with children?

- How do you motivate children to co-operate/cope with their nursing care?

[Prompts:

Do you use stickers/ certificates or other rewards?

if so how?

For what purpose?]

- What role, if any, should children have in developing community children's nursing?

[note Gender of interviewee]

Demographics/ nursing career details

- Could we perhaps start/finish with a few things about you, and your nursing career just to help put your views in context is that OK?
- When did you qualify as a children's nurse?
- Was that a diploma or degree course?
- Do you hold any other nursing qualifications?
- Can you estimate for me the number of years in full time equivalents you have practiced as a children's nurse, not including any career breaks, both in hospital and community?
- Have you done the specialist nursing CCN course? If so when did you finish?
- How long have you practiced after qualifying as a CCN? Again if we could in full time equivalent years.
- So what is your highest academic qualification? Is that in nursing or another subject?
- What is your current role in the CCN service?
- Can I ask how many children you currently have on your caseload, and how many families is that?

We know that nursing and the way we think about children can sometimes be affected by our culture and family background could I ask you which of the following best describes your own background?

Country of birth?			
England		Scotland	
		Wales	
Northern Ireland			
Republic of Ireland			
Elsewhere: <i>Please write in the present name of the country</i>			
Ethnic group? Chose one section A-E then tick one box to indicate cultural background			
A White		British	Irish
Any other		Please write in	
B Mixed			
White and Black Caribbean		White and Asian	White and Black African
Any other mixed background		Please write in	
C Asian or Asian British			
Indian		Pakistani	Bangladeshi
Any other Asian background		Please write in	
D Black or Black British		Caribbean	African
Any other black background		Please write in	
E Chinese or other ethnic group			Chinese
Any other		Please write in	

(Office of National Statistics 2001)

Thank you

Appendix 6: Question route for community children’s nurse’s groups interviews.

Time	Activity/Question	Equipment
0-5	<p>Introduction:</p> <p>Thank you all for coming this afternoon as you may know this is a group session for a project looking at children’s views of community children’s nursing that I have been conducting over the past few years. The project is part of a PhD at the University of Warwick.</p> <ul style="list-style-type: none"> • Has any one done group interviews before? (e.g. market research) • There are no right answers. • Please speak one at a time. • You are allowed to disagree with others in the group- looking for group interaction. • Some questions may seem obvious but needed to fill detail of study. • Group will last about an hour. • This session will be taped and your words may be used in the study. <p>Before we start could I ask you all to complete consent forms and the short questionnaire, this should only take a few moments and will help me build a picture of the group. Has every one got or seen an information sheet? Are there any questions?</p>	<p>Lunch.</p> <p>Mini disk recorder + microphone, disk and spare disk.</p> <p>Topic guide.</p> <p>Paper /pen.</p> <p>Consent sheets CCN group questionnaires (demographic s).</p>
5-10	<p>Confidentiality</p> <p>As I hope you know any thing said in this group will be treated as confidential. All references to particular children, members of staff, areas of the city or establishments will be ammonized in the transcript. Can I suggest that we adopt Chatham House rules; that anything said in this room stays in this room the only exceptions being where information may be required to safeguard children.</p>	
10-15	<p>Just to get things going could we throw around the idea of childhood or children. What I’ll do is pick some one at random to give me just one word that for you sums up how you think about children as a community children’s nurse, that person then picks the next person and so on,</p>	<p>Flip chart paper pens Ask some one else to scribe.</p>
15-20	<p>Can you perhaps tell me a bit more about how you see children</p>	
20-35	<p>With whom do you build relationships when delivering care to children?</p> <ul style="list-style-type: none"> • Who is it most important to build a relationship with? • Do you build relationships with fathers? • Are your relationships with fathers the same as with mothers? (if not why not). • Do you build relationships with Extended family-siblings? • Do you build relationships with Teachers community contacts e.g. social group leaders? 	

20-35	<p>How do you build and maintain these relationships</p> <ul style="list-style-type: none"> • How would you characterise your relationships? (one of trust or not). • Do you think parents have expectations about how their child will behave during your visit? • How do you get children to cooperate? (Bribery , stickers, certificate or prizes). • What do you do if a child refuses treatment/care? • Does children’s understanding of their illness affect their relationship with you as nurses? If so how? • Do parents help you to build therapeutic relationships with children? • Do you involving children in care- how? To what extent? Hart’s ladder of participation. • Does this affect your relationship with children? • What other factors might affect your relationship with children? (Profession/ organisation). 	Harts Ladder of participation on flip chart
35-45	<p>I want now to get your reactions to some statements that come from the work I have done with the children .[read separately-allow for ideas/feelings].</p> <ul style="list-style-type: none"> • I don’t like to think about being ill I prefer to think about playing with my friends and being with my family. • I would rather have my mum or dad do all the things I need to keep me well, than have nurses visit me at home. <p>[Prompt- These statements show how children in the study often did not focus on nursing why do you think that was?]</p>	
45-50	<p>What do you think makes a good nurse? What do you think would make not so good a nurse?</p>	
50-55	<p>Return to statements</p> <p>4. A good nurse is fun, but also knows how to do things right to make me better, they respect me as a person and work with my family and friends</p>	
55-65	<p>What do you think drives the care delivered to children at home?When making appointment who decides when you visit?</p> <ul style="list-style-type: none"> • Who decides what you do on a visit? • Are there other things, which determine what happens during a visit? • Are there other things that determine how care is planned or delivered? Or how care is planned. • What are the limits of adapting care to family needs/wishes? <p>[nursing, medicine, parents, child? adapting care to fit family how why?]</p>	
65-70	<p>Any other thoughts, any thing you want to say?</p>	
	<p>Thank you for your time and your ideas. I will let [names team leader] know when and where the results are available. Thanks again.</p>	

Community Children Nurses Group

• Have you been interviewed on your own for this project?	Yes /No						
• Year in which you qualified as a children's nurse.							
• Level of children's nursing course.	<table border="1"> <tr> <td>Diploma</td> <td></td> </tr> <tr> <td>Degree</td> <td></td> </tr> <tr> <td>Higher Degree</td> <td></td> </tr> </table>	Diploma		Degree		Higher Degree	
Diploma							
Degree							
Higher Degree							
• Please estimate for the number of years in full time equivalents you have practiced as a qualified children's nurse, not including any career breaks, both in hospital and community?							
• Do you hold any other nursing qualifications?	Yes / No						
• Please state your nursing qualifications.							
• Do you hold a specialist nursing CCN qualification?	Yes/No						
• Please indicate your agenda for change banding.	5, 6, 7, 8						
• How many children are you responsible for on your caseload?							

Country of birth?			
England		Scotland	
		Wales	
		Northern Ireland	
		Republic of Ireland	
Elsewhere: <i>Please write in the present name of the country</i>			
Ethnic group? Chose one section A-E then tick one box to indicate cultural background			
A White		British	Irish
Any other		Please write in	
B Mixed			
White and Black Caribbean		White and Asian	White and Black African
Any other mixed background		Please write in	
C Asian or Asian British			
Indian		Pakistani	Bangladeshi
Any other Asian background		Please write in	
D Black or Black British		Caribbean	African
Any other black background		Please write in	
E Chinese or other ethnic group			Chinese
Any other		Please write in	

(Office of National Statistics 2001)

Children's views of being nursed at home: focus groups

What will happen to the results of the study?

You will get a copy of what we find out. We hope you will help us to make a small book about the study so that all children can understand what you think about the nurses and the nursing care you get at home.

Who is doing this study?

Duncan is doing the study: he is a student at the University of Warwick. The Solihull ethics committee has approved this study.

Want to know more?

Ask? E-mail or call

Duncan Randall

52 Pritchatts Road

Edgbaston

Birmingham

B15 2TT

0121 414 8377

d.c.randall@bham.ac.uk

Thank you for finding out about this study

8/8



Duncan Randall

You are being asked to take part in a research study. Before you decide to or not, you need to know why the study is being done and what we want you to do. We will tell you all about the study and you can keep this to look at later. If you want to ask me any questions call or E-mail me at

Duncan Randall d.c.randall@bham.ac.uk Tel 0121 414 8377

Please take time to make your mind up. Talk about the study with your friends and family.

Thank you.



1/8



Why me?

We are asking you to help us as you have a nurse who visits you at home.

Why do this study?

More and more children have nurses come to their home to look after them. Care of children in hospital has been looked at for many years but the care nurses give at home has not.

This will be the first study that asks children what they think about the nursing care at home. We want children like you to help us understand the help you need at home and to make the nurses looking after you understand what you need.

We also want help to know what sort of questions to ask and how to ask them.

2/8



Where can I get help?

If you do not like anything we do or say please tell us.

You or your mum /dad can E-mail

gillian.hundt@warwick.ac.uk

If something we have talked about has upset you and you want to talk to someone these may help you...

Child line <http://www.childline.org.uk/>

Tel 0800 1111

Contact a family <http://www.cafamily.org.uk/>

Helpline tel 0808 808 3555 or Text phone 0808 808

3556 Freephone (10am-4pm, Mon-Fri)

e-mail: info@cafamily.org.uk



7/8

What is good about being in the study?

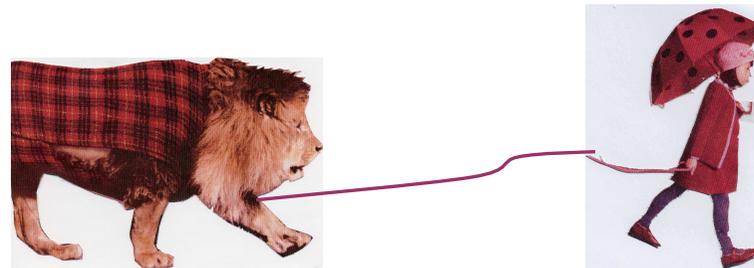
We hope it will be fun! You get to meet other children and play games together. By helping in this study you can help make nursing at home better for all children.

Who will know what I have said?

We will not tell your parents, family or nurses who look after you what you have said in the study.

But if you tell us something and we think you or other children might get hurt. We will have to tell other people, who can help you and other children to be safe. We will tell you if we feel we have to do this and try to find a way to sort it out together.

We hope you will enjoy telling us what you think and meeting with other children.



Do I have to do this?

No it is up to you!

We hope it will be fun!

You can do all of the study or just bits.

You can say no when you want to.

The help that your nurse gives you at home will not change.

You can only be in the study if you and your mum/dad agree. We will ask you to sign your name to say you agree to be in the study and give you a copy of this book to keep.



What things will we be doing in the study?

Have fun that is the most important thing.

You will be asked to come to three meetings each 2-3 hours long at each you will be given drinks and a meal.

- **1st** Meeting: this will be to get to know us and the other children in the study. We might go bowling and have a meal.
- **2nd** Meeting: is to help us ask the right questions in the best way. We will ask you how to make a diary of what happens when the nurse cares for you at home. You can make your own diary in another part of the study, if you want to.
- **3rd** Meeting: is to see what you and other children think about the nurses who visit you at home. We will also be making something to tell other children about what we have found out.

4/8

At the 2nd and 3rd meetings we will record what you say on tape and your words will then be typed so we can read what you have to say.

Will other people know I am doing this study?

You can tell any one you want, but we will not tell any one else. If we use your words when we write about what you think of nursing at home. We will not use your real name, but you can choose a special name. Some people who know you well may be able to guess it is you.

If we write about you we will use a number instead of your name only Duncan will keep a record of who you are and which is your number. This will be kept safe.

What happens when the study stops?

When the study stops we will only keep what you have said using your chosen special name. We will write about what you have said and tell other people about what you have said.



5/8

Children's views of being nursed at home: Photo Talk Diaries

What will happen to the results of the study?

You will get a copy of what we find out. We hope you will help us to make a small book about the study so that all children can understand what you think about the nurses, and the nursing care you get at home.

Who is doing this study?

Duncan is doing the study: he is a student at the University of Warwick. The Health Foundation has funded the study. The Solihull Research Ethics Committee has approved this study

Want to know more?

Ask? E-mail or call

Duncan Randall

52 Pritchatts Road

Edgbaston

Birmingham

B15 2TT

0121 414 8377

d.c.randall@bham.ac.uk



Duncan Randall

Thank you for finding out about this study

8/8

You are being asked to take part in a research study. Before you decide to or not, you need to know why the study is being done and what we want you to do. We will tell you all about the study and you can keep this to look later. If you want to ask me any questions call or E-mail at

Duncan Randall d.c.randall@bham.ac.uk Tel 0121 414 8377

Please take time to make your mind up. Talk about the study with your friends and family. You can ask us anything you like.

Thank you.



1/8



Why me?

We are asking you to help us as you have a nurse who visits you at home.

Why do this study?

More and more children have nurses come to their home to look after them. Care of children in hospital has been looked at for many years, but the care nurses give at home has not.

This will be the first study that asks children what they think about nursing care at home. We want children like you to help us understand the help you need at home, and to make the nurses looking after you understand what you need.

2/8

Where can I get help?

If you do not like anything we do or say please tell us.

You or your mum /dad can E-mail

gillian.hundt@warwick.ac.uk

If something we have talked about has upset you and you want to talk to someone these may help you...

Child line <http://www.childline.org.uk/>

Tel 0800 1111

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Helpline tel 0808 808 3555 or Text phone 0808 808

3556 Freephone (10am-4pm, Mon-Fri)

E-mail: info@cafamily.org.uk



7/8

What is good about being in the study?

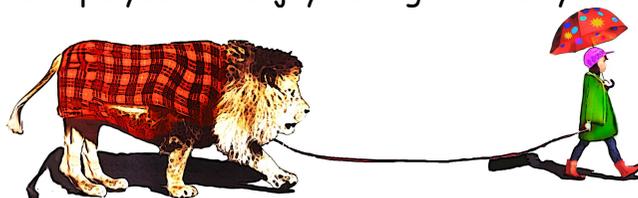
We hope it will be fun! You get to make your own diary. By helping in this study you can help make nursing at home better for all children.

Who will know what I have said?

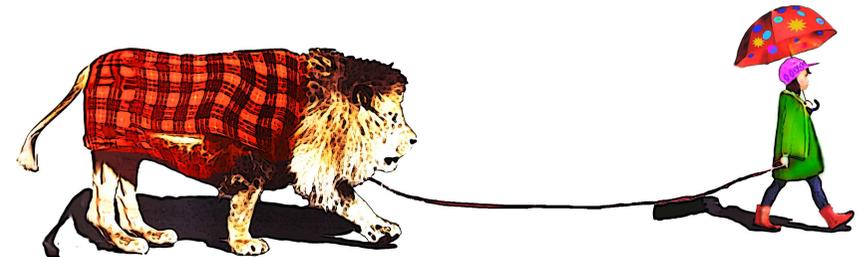
We will not tell your parents, family or nurses who look after you what you have said in the study.

But if you tell us something that makes us think that you, or another child may get hurt, we will have to tell people who can help you, like the special nurses who try to make sure children are safe. When we can we will tell you first who we are going to talk to, and what we are going to say.

We hope you will enjoy telling us what you think.



6/8



Do I have to do this?

No it is up to you!

We hope it will be fun!

You can do all of the study or just bits.

You can say no when you want to.

The help that your nurse gives you at home will not change.

You can only be in the study if you and your mum/dad agree. We will ask you to sign your name to say you agree to be in the study and give you a copy of this book to keep.

3/8



What things will we be doing in the study?

Having fun that is the most important thing.

You will be asked to make a diary for 2-4 weeks about the help you get from nurses at home and things that nurses may have taught your mum and/or dad to do for you at home.

How you make the diary is totally up to you.
You can draw, write, paint, make collage what ever you are into is OK.

We will give you a tape machine to talk into, if you want and a camera to take pictures. Duncan may also come and see you at home when the nurse comes. Once you have made your diary we will get the tape you have made typed up, and any photographs printed, we will then come and talk to you about your diary for about an hour. We will come back and talk again for about an hour to check we have got what you said right.

We can do this at your house or another place if you like.

4/8

Because we want to know what you think we will ask to talk to you on your own a way from adults.

Will other people know I am doing this study?

You can tell any one you want, but we will not tell any one else. If we use your words when we write about what you think of nursing at home, we will not use your real name, but you can choose a special name. Some people who know you well may be able to guess it is you.

If we write about you we will use a number instead of your name only Duncan will keep a record of who you are and which is your number. This will be kept safe.

What happens when the study stops?

When the study stops we will only keep what you have said using your chosen special name. We will write about what you have said and tell other people about what you have said.



5/8

Appendix 9: Children's information sheet observation (version 1 30/4/07)

Children's views of being nursed at home: nurses work

You are being asked to take part in a research study. Before you decide to or not, you need to know why the study is being done and what we want you to do. We will tell you all about the study and you can keep this to look at later. If you want to ask me any questions, call or E-mail me at

Duncan Randall d.c.randall@bham.ac.uk Tel 0121 414 8377

You can ask us any thing you like.

Thank you.

Why do this study

We have been talking to children who have a nurse visit them at home. The children have given us their view of what they think about the nurse who visits them at home. We would now like to see what nurses really do. That is why Duncan is going around with your nurse looking at what nurses do for children when they visit them at home.

Why us?

You have been selected because the nurse was due to visit you on a day that Duncan is with the nurse.

Do we have to take part?

No you can say, no.

You can also ask Duncan to leave at any point during the visit.

If you say yes or if you say no, to doing the study, it will not change what your nurses and doctors do for you.

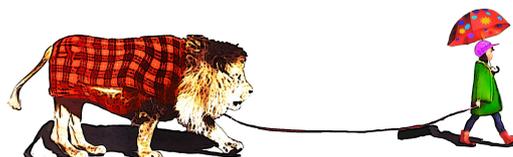
What will happen in the study?

We want to find out what happens on a "normal" day when the nurse visits. Duncan will be watching what the nurse does for you and your family. He will come with the nurse and leave when the nurse does.

You may ask any questions you like.

Duncan may write some things down during the nurse's visit.

When Duncan writes about this study he will not use your name or write anything which may help others find out you took part in the study.



What is good or bad about being in this study?

Some people don't like to have too many people come to their house, especially when the nurse is visiting. We hope you do not mind Duncan coming for this visit with the nurse. This study will help nurses understand more about looking after children at home so that they can make their visits to children even better. It will also help us to understand how nurses may help mums and dads look after their children at home when they need a nurse.

What will happen when the study has finished?

Duncan's notes, that he has made about when the nurse visited you, will be kept safely at the University of Birmingham for 5 years. We will not keep a note of your name or anything else that could help other people know that you did the study.

We will tell other nurses and people who help children about the study, without using your name.

We will give a copy of what we find in the study, made especially for children, to your nurse. You can get a copy from your nurse or by asking Duncan.

Who is doing this study?

Duncan is doing the study: he is a student at the University of Warwick. The Health Foundation has paid for the study. The Solihull Research Ethics Committee has approved this study

Want to know more?

Ask? E-mail or call

Duncan Randall

52 Pritchatts Road

Edgbaston

Birmingham

B15 2TT

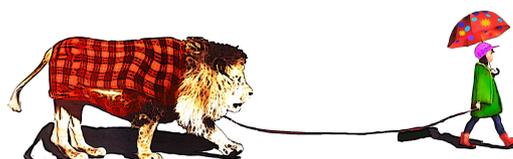
0121 414 8377

d.c.randall@bham.ac.uk



Duncan Randall

Thank you for finding out about this study.



Appendix 11: Parent information sheet for group sessions (version 3 28/12/05)

Parent information sheet

Children's views of being nursed at home: focus groups

Your child is being invited to take part in a research study. Before you decide, whether or not to allow your child to participate, it is important for you to understand why the research is being done, and what it will involve. Please take time to read the following information carefully and discuss it with your child and other family members, if you wish. Ask me if there is anything that is not clear or if you would like more information. I can be contacted at...

Duncan Randall

52 Pritchatts Road
Edgbaston

Birmingham, B15 2TT

Tel 0121 414 8377 E-mail d.c.randall@bham.ac.uk

Please take time to decide whether or not you wish your child to take part.

Thank you for reading this.

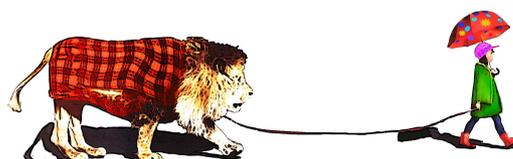
What is the purpose of the study?

Nursing care of children is changing, and more and more children are being nursed at home. While care of children in hospital has been studied for many years the care of children by nurses at home has not. This will be the first UK study, which asks children what they think about the nursing care they receive at home.

In the study we want to

- Explore how children experience community children's nursing.
- Understand what children want and expect from their nurses.
- Explore what factors shape their experience.

We hope that the children will show us how to shape children's nursing for the future. As part of the study a small group of children will help to make presentation material that can easily be understood by children, which will inform other children and health care professionals about the research findings.



Why has my child been chosen?

Children who receive home care at least once a month, and have done so for at least six months are being asked to take part.

Does my child have to take part?

No, this should be a decision for your child. The research is designed to be fun and we hope the children will enjoy contributing to the project. Children may choose to take part in the activities they want to and refuse other activities without giving a reason, and if they wish, continue to contribute to the study, or withdraw completely. Children's decision not to contribute to part or all of the study will in no way affect the standard of care they receive from the community children's nursing service.

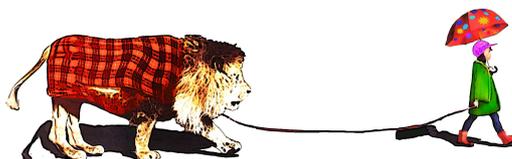
While respecting children's right to withhold or give consent we recognise that parents can support their child's choice to participate and we hope that you will encourage your child to have their voice heard in this study. If you and your child decide to take part you will both be given an information sheet to keep (this one is for you, there is a separate one for your child) and both will be asked to sign a consent form. If your child decides to take part you are still free to withdraw your child at any time and without giving a reason. This will not affect the standard of care you receive.

What will my child have to do if they take part?

Have fun! that is the most important thing for children contributing to research.

Your child will be invited to three meetings each lasting approximately 2-3 hours, at each the children will be given refreshments and a shared meal.

1. A social event(to be confirmed, but possibly bowling and a meal) to meet and get to know the research team and the other children in the group.



2. A focus group to help design the main way of collecting information and to help the research team ask the right questions.
3. A focus group to feed back the findings of the study and check these fit with the children's experiences. This meeting will also help to design presentation materials to inform others of the studies main findings.

These meetings will be recorded on audiotape and the discussion transcribed for use in the study. These recordings will be kept confidential and stored under lock and key at the University of Birmingham.

What do I have to do?

Parents and children may have different views of the nursing care they receive we hope you will be able to support your child and the study by offering encouragement and support to your child that helps them to express their own view. The researchers will not be able to discuss your children's individual contribution to this study. However we would encourage families to talk about the study with their child.

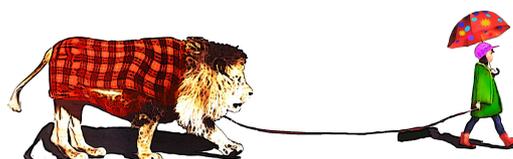
What are the possible benefits of taking part?

It is reasonable to expect that the empowering nature of this study, where your child's view's and opinion will be listened to and valued, may increase children's self esteem and assertiveness. Working with others to express their views through their own chosen media may help social and thinking skills. However the most important benefit, we hope, will be having fun!

Will my child be safe?

Duncan Randall the principal investigator has many years of experience in nursing children in hospital and in community settings. All the study researchers will have enhanced Criminal Records Bureau clearance to work with children.

There is a possibility that during the study your child may report a situation, which may be considered harmful to themselves or other children. If this does happen the researcher will follow child protection procedures set out by South Birmingham Primary Care Trust (available from: http://www.southbirminghampct.nhs.uk/about/foi/docs/child_protection.pdf)



including informing the designated nurse for safeguarding children. Confidentiality may be broken and other agencies involved. Where possible we will work with you and your child, keeping you both informed, to resolve such situations.

What happens when the research study stops?

All tapes of group discussions will be destroyed. All information on your child will also be destroyed. We will keep the transcripts of what your child has said, but use a pseudonym instead of their name. These will be kept for five years at the University of Birmingham. If we plan to change this we will seek your consent, and your child's consent.

Where can I get support, and make complaints?

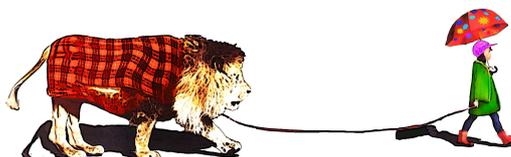
Your child's clinical care will be unaffected by this study. However, if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the usual National Health Service complaints mechanisms are available to you. If you wish to make a complaint to the University, this should be addressed to Professor Gillian Hundt, School of Health and Social Studies, University of Warwick, Coventry, CV4 7AL, E-mail gillian.hundt@warwick.ac.uk

The University of Warwick has professional liability for all staff and students, which covers negligent harm.

If taking part in this research has raised issues you wish to discuss with someone not connected with the study the following contacts may be helpful

Contact a family <http://www.cafamily.org.uk/>
Helpline 0808 808 3555 or Textphone 0808 808 3556 Freephone
(10am-4pm, Mon-Fri)
E-mail: info@cafamily.org.uk

Hansel Trust, 62 Johnson Road, Birmingham B23 6PY. Tel: 0121 373 2747



Will my taking part in this study be kept confidential?

All information, which is collected, about your child during the course of the research will be kept strictly confidential unless to do so may be harmful to your child or other children/ people. Any information stored about your child will have their name and address removed so that you cannot be recognised from it. Your child and family details will be assigned a research number, only Duncan Randall, the principal researcher, will have these details and these will be stored in a locked filing cabinet in a locked room at the University of Birmingham.

What will happen to the results of the research study?

The results of this study will be publicised through professional publications and conferences. The presentation materials designed by the children will be used in conference presentations. A copy of the research results in the format designed with help from the children and easily accessible for children will be given to you and your child.

Who is organising and funding the research?

This study is part of doctoral study at the University of Warwick and is funded by the Health Foundation.

Who has reviewed the study?

This study has been peer reviewed at the University of Warwick and ethically approved by Solihull Local Research Ethics Committee.

Contact for Further Information

Duncan Randall

University of Birmingham

Room 309, 52 Pritchatts Road, Edgbaston, Birmingham, B15 2TT

Tel 0121 414 8377 or email d.c.randall@bham.ac.uk

Thank you for considering your child's involvement in this study
[The second copy of this information sheet should be attached to your copy of the signed consent form]



Appendix 12: Parent information sheet for Photo Talk Diary (version 4 10/7/06)

Parent information sheet

Children's views of being nursed at home: Photo Talk Diaries.

Your child is being invited to take part in a research study. Before you decide whether or not to allow your child to participate, it is important for you to understand why the research is being done, and what it will involve. Please take time to read the following information carefully and discuss it with your child and other family members if you wish. Ask me if there is anything that is not clear or if you would like more information. I can be contacted at...

Duncan Randall

52 Pritchatts Road

Edgbaston

Birmingham, B15 2TT

Tel 0121 414 8377 E-mail d.c.randall@bham.ac.uk

Please take time to decide whether or not you wish your child to take part.

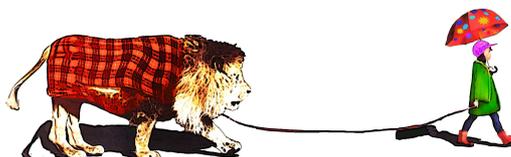
Thank you for reading this.

What is the purpose of the study?

Nursing care of children is changing, and more and more children are being nursed at home. While care of children in hospital has been studied for many years the care of children by nurses at home has not. This will be the first UK study, which asks children what they think about the nursing care they receive at home.

In the study we want to

- Explore how children experience community children's nursing.
- Understand what children want and expect from their nurses.
- Explore what factors shape their experience.



We hope that the children will show us how to shape children's nursing for the future. As part of the study a small group of children will help to make presentation material that can easily be understood by children, which will inform other children and health care professionals about the research findings.

Why has my child been chosen?

Children who receive home care at least once a month, and have done so for at least six months are being asked to take part.

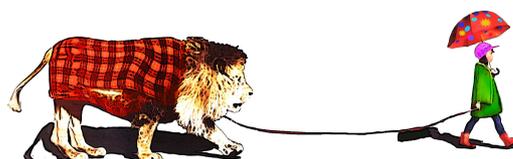
Does my child have to take part?

No, this should be a decision for your child. The research is designed to be fun and we hope the children will enjoy contributing to the project. Children may choose to take part in the activities they want to and refuse other activities without giving a reason, and if they wish, continue to contribute to the study, or withdraw completely. Children's decision not to contribute to part or all of the study will in no way affect the standard of care they receive from the community children's nursing service.

While respecting children's right to withhold or give consent we recognise that parents can support their child's choice to participate and we hope that you will encourage your child to have their voice heard in this study. If you and your child decide to take part you will both be given an information sheet to keep (this one is for you, there is a separate one for your child) and both will be asked to sign a consent form. If your child decides to take part you are still free to withdraw your child at any time and without giving a reason. This will not affect the standard of care you receive.

What will my child have to do if they take part?

Your child will be asked to create a diary over a 2-4 week period of their experiences of nursing care at home. How they make, and what the children put into their diaries, is up to them. Each child will be given a dictaphone and single use camera to help them record their diary. Topics they may wish to comment on are listed below



- What do nurses do when caring for children at home?
- Areas where parents and nurses may do similar tasks.
- What makes a good community children's nurse?
- Likes and dislikes about receiving care at home.
- Improvements, other things nurses should be doing.
- How receiving care at home affects their interaction with peers?
- Effects on family life of receiving care at home.
- School and home care.

You may wish to encourage and support your child in making their diary, but we would ask that you allow your child to make their own diary as much as is possible.

Duncan may ask to visit you and your child to see what happens before during and after the nurse visits your child at home.

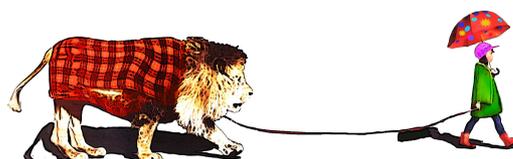
Once the diary is completed the research team will have the photographs processed and the dictaphone tape transcribed to give a text. We will then bring your child's diary to them at home and ask them to talk to the researcher about the content and the production of the diary. This should take no more than 1-2 hours. Your child's voice will be recorded on audiotape.

When we have read and understood what your child has said about their diary we will return for the last home visit to check with your child that we have understood what they have said. This should take no more than 1-2 hours. Again the conversation will be recorded on audiotape.

We would ask that your child be given privacy to discuss their views with the researchers. If it is difficult to arrange privacy in your home we may arrange to interview your child in a place of your child's choice.

What do I have to do?

Parents and children may have different views of the nursing care they receive, we hope you will be able to support your child and the study by offering encouragement and support to your child, that helps them to



express their own view. The researchers will not be able to discuss your children's individual contribution to this study. However we would encourage families to talk about the study with their child.

What are the possible benefits of taking part?

It is reasonable to expect that the empowering nature of this study, where your child's views and opinion will be listened to and valued, may increase children's self esteem and assertiveness. Working with others to express their views through their own chosen media may help social and thinking skills. However the most important benefit we hope will be having fun!

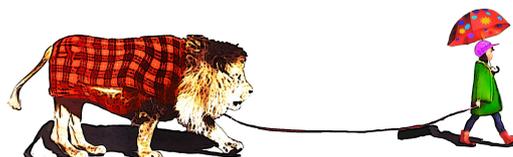
What are the possible risks of taking part?

Duncan Randall the principal investigator has many years of experience in nursing children in hospital and in community settings. All the study researchers will have enhanced Criminal Records Bureau clearance to work with children.

There is a possibility that during the study your child may report a situation, which may be considered harmful to themselves or other children. If this does happen the researcher will follow child protection procedures set out by South Birmingham Primary Care Trust (available from: http://www.southbirminghampct.nhs.uk/about/foi/docs/child_protection.pdf) including informing the designated nurse for safeguarding children. Confidentiality may be broken and other agencies involved. Where possible we will work with you and your child, keeping you both informed, to resolve such situations.

What happens when the research study stops?

All tapes of group discussions will be destroyed. All information on your child will also be destroyed. We will keep the transcripts of what your child has said, but use a pseudonym instead of their name. These will be kept for five years at the University of Birmingham. If we plan to change this we will seek your consent, and your child's consent.



Where can I get support and make complaints?

Your child's clinical care will be unaffected by this study. However, if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the usual National Health Service complaints mechanisms are available to you. If you wish to make a complaint to the University, this should be addressed to Professor Gillian Hundt, School of Health and Social Studies, University of Warwick, Coventry, CV4 7AL, E-mail gillian.hundt@warwick.ac.uk The University of Warwick has professional liability for all staff and students, which covers negligent harm.

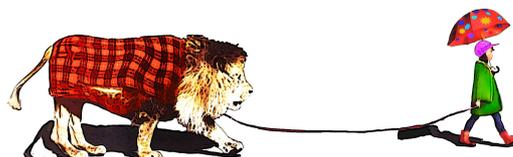
If taking part in this research has raised issues you wish to discuss with someone not connected with the study the following contacts may be helpful

Contact a family <http://www.cafamily.org.uk/>
Helpline 0808 808 3555 or Textphone 0808 808 3556 Freephone
(10am-4pm, Mon-Fri)
E-mail: info@cafamily.org.uk

Hansel Trust, 62 Johnson Road, Birmingham B23 6PY. Tel: 0121 373 2747

Will my taking part in this study be kept confidential?

All information, which is collected, about your child during the course of the research will be kept strictly confidential unless to do so may be harmful to your child or other children/people. Any information stored about your child will have their name and address removed so that you cannot be recognised from it. Your child and family details will be assigned a research number, only Duncan Randall, the principal researcher, will have these details and these will be stored in a locked filing cabinet in a locked room at the University of Birmingham.



What will happen to the results of the research study?

The results of this study will be publicised through professional publications and conferences. The presentation materials designed by the children will be used in conference presentations. A copy of the research results in the format designed with help from the children and easily accessible for children will be given to you and your child.

Who is organising and funding the research?

This study is part of doctoral study at the University of Warwick.

Who has reviewed the study?

This study has been peer reviewed at the University of Warwick and ethically approved by Solihull Local Research Ethics Committee.

Contact for Further Information

Duncan Randall

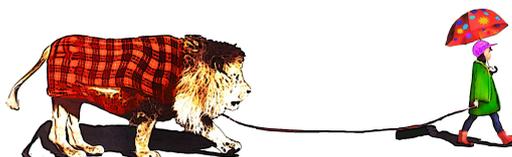
University of Birmingham

Room 309, 52 Pritchatts Road, Edgbaston, Birmingham, B15 2TT

Tel 0121 414 8377 or email d.c.randall@bham.ac.uk

Thank you for considering your child's involvement in this study

[The second copy of this information sheet should be attached to your copy of the signed consent form]



Appendix 13: Parents consent form (version 2 4/5/06)

Centre Number:

Study Number:

Patient Identification Number for this trial:

CONSENT FORM: Parent/legal guardian

Title of Project: Children's views of being nursed at home.

Name of Researcher: Duncan Randall.

Please initial boxes

- 1 I confirm that I have read and understand the information sheet dated (Version ...) for the above study and have had the opportunity to ask questions
- 2 I understand that my child's participation is voluntary and that he/she is free to withdraw at any time, without giving any reason, and without my child's medical care or legal rights being affected.
- 3 I understand that my child's voice may be recorded, and that their words and the images produced by them will be used in the study.
- 4 I agree that my child for whom I have parental responsibility may take part in the above study.
- 5 I agree to provide information about my child and our family, which may be required to conduct the study.

Name of Parent/legal guardian

Date

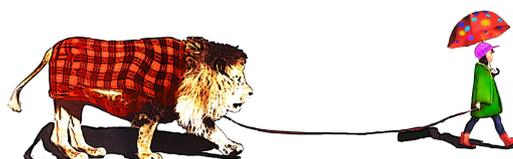
Signature

Researcher

Signature

Date

Copies 1 for parent; 1 for researcher.



Appendix 14: Nurses information sheet (version 1 18/4/07)

**Nurses' information sheet
Children's views of being nursed at home.**

You are being invited to take part in a research study. Before you decide whether or not to participate, it is important for you to understand why the research is being done, and what it will involve. Please take time to read the following information carefully and discuss it with other members of the team, if you wish. Ask me if there is anything that is not clear or if you would like more information. I can be contacted at...

Duncan Randall

52 Pritchatts Road
Edgbaston

Birmingham, B15 2TT

Tel 0121 414 8377 E-mail d.c.randall@bham.ac.uk

Please take time to decide whether or not you wish to take part.

Thank you for reading this.

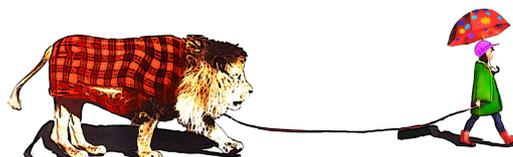
What is the purpose of the study?

Nursing care of children is changing, and more and more children are being nursed at home. While care of children in hospital has been studied for many years the care of children by nurses at home has not.

In the study we want to

- Explore how children experience community children's nursing.
- Understand what children want and expect from their nurses.
- Explore what factors shape their experience.

In the first part of the study we gathered information on what children think about being nursed at home. Now we want to compare what nurses actually do for children with how children view nurses and being nursed at home.



Why have I been chosen?

You have been chosen because you are part of a team that delivers care to children at home.

Do I have to take part?

No, the decision to take part is entirely yours. You may also refuse to answer any questions or decline participation in any activity. You may of course withdraw from the study all together at any time. If you decline to take part in all, or any part of the study, or if you decide to withdraw you will not be asked for your reasons, no other colleague or manager will be informed of your actions.

What will I have to do, if I take part?

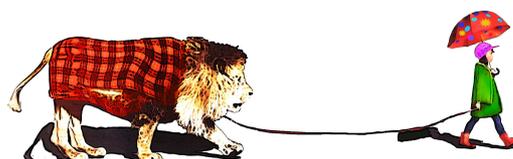
There are 2 parts to this study and you may be asked to participate in both.

1. To be observed for a day while you go about your normal work, including home visiting. At the end of the day you will be asked to take part in a short interview about the day. This interview will take 30-60 minutes. It will be recorded on audio tape.
2. To take part in a group discussion of no longer than 1 hour duration. This will involve discussion of the results of the study. The group will take place before or after a normal team meeting. Refreshments will be provided. The discussion will be recorded on audio tape.

The purpose of this study is not to make judgements on clinical competence, but to observe to role of the community children's nurse in action.

What are the possible benefits of taking part?

The findings of this study will be used to inform children, parents and professionals. By taking part you have an opportunity to influence the outcome of the study and ensure that a clear picture of the work of Community Children's Nurses is transmitted to a wide audience.



What are the possible risks of taking part?

As the principal researcher (Duncan Randall) is a registered Children's nurse, he has a duty to report any issues of concern in regards to safeguarding children.

No report will be submitted without informing you, unless to do so would place children at risk.

The principal researcher will follow child protection procedures set out by South Birmingham Primary Care Trust (available from: http://www.southbirminghampct.nhs.uk/about/foi/docs/child_protection.pdf) including informing the designated nurse for safeguarding children. Confidentiality may be broken and other agencies involved. Where possible we will work with you, children and families to resolve such situations.

What happens when the research study stops?

All tapes of group discussions will be destroyed. All information on you will also be destroyed. We will keep the transcripts of what has been said, but use a pseudonym instead of people's real names. These transcripts will be kept for five years at the University of Birmingham. If we plan to change this we will seek your consent.

Where can I get support and make complaints?

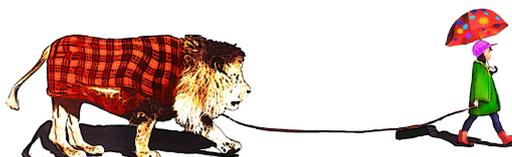
If taking part in this study has raised issue that you would like to discuss further you could contact the Community Children's Nursing forum

http://www2.rcn.org.uk/cyp/forums/rcn_professional_forums/community_childrens_nursing

Or contact Duncan Randall 0121 414 8377.

If you wish to complain about any aspect of the way you have been approached or treated during the course of this study please write to Professor Gillian Hundt, School of Health and Social Studies, University of Warwick, Coventry, CV4 7AL, E-mail gillian.hundt@warwick.ac.uk

The University of Warwick has professional liability for all staff and students, which covers negligent harm.



Will my taking part in this study be kept confidential?

All information, which is collected during the course of the study, will be kept strictly confidential unless to do so may be harmful to children or their families. Any information stored about you will have your name removed so that you cannot be recognised. All personal information will be stored in a locked filing cabinet in a locked room at the University of Birmingham.

What will happen to the results of the research study?

The results of this study will be publicised through professional publications and conferences. The presentation materials designed by the children will be used in conference presentations. A copy of the research results in the format designed with help from the children and easily accessible for children will be given to all participating Community Children's Nursing teams.

Who is organising and funding the research?

This study is part of doctoral study at the University of Warwick. Funding has come from the Health Foundation in the form of a Leading Practice Through Research Award.

Who has reviewed the study?

This study has been peer reviewed at the University of Warwick and ethically approved by Solihull Local Research Ethics Committee.

Contact for Further Information

Duncan Randall

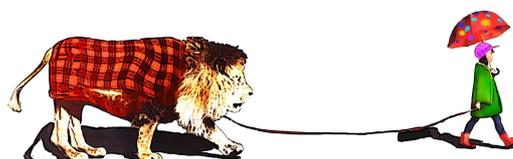
University of Birmingham

Room 309, 52 Pritchatts Road, Edgbaston, Birmingham, B15 2TT

Tel 0121 414 8377 or email d.c.randall@bham.ac.uk

Thank you for considering your involvement in this study.

[The second copy of this information sheet should be attached to your copy of the signed consent form]



Appendix 15: Nurse's consent form Version 1 18/4/07

Centre Number:

Study Number:

Patient Identification Number for this trial:

CONSENT FORM: Nurse

Title of Project: Children's views of being nursed at home.

Name of Researcher: Duncan Randall.

Please initial boxes

- 1 I confirm that I have read and understand the information sheet dated (Version ...) for the above study and have had the opportunity to ask questions.
- 2 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without penalty.
- 3 I understand that my voice may be recorded, and that my words may be used in the study.
- 4 I agree to be observed in clinical practice and in my role as part of a Community Children's Nursing Team.

Name

Date

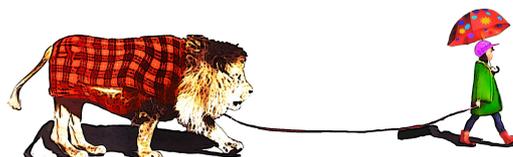
Signature

Researcher

Signature

Date

Copies 1 for participant; 1 for researcher.



Appendix 16 Photo consent form (version 1 21/7/05)

Title of Project: Children's views of being nursed at home

Name of Researcher: Duncan Randall

Consent to publish

We agree to the publication of the attached images produced for the study: Children's views of being nursed at home.

These images may only be published for teaching to do with the study. They may not be used for making money.

We understand that confidentiality is not guaranteed, as people may know who made the image, or people in the image, from looking at the image.

_____	_____	_____
Name of Parent/legal guardian	Date	Signature
_____	_____	_____
Name of child	Date	Signature
_____	_____	_____
Name of person in image	Signature	Date
_____	_____	_____
Name of person in image	Signature	Date
_____	_____	_____
Name of person in image	Signature	Date
_____	_____	_____
Researcher	Signature	Date

[copies for parent, child, persons in image, researcher.]

