Children's stories on managing their chronic illness at home.

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Children's Stories
on Managing their Chronic Illness at Home

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Abstract

Changes in the epidemiology of child health have resulted in the reduction of acute infectious disease and an increase in the numbers of children who live with a chronic condition. Children with a chronic condition are more likely to be hospitalised due to complications, or exacerbation of their condition. Repeated hospital admission for children has been shown to be detrimental to their psychological and physical health. However the provision of care at home by community children's nursing service has been reported as less stressful and facilitates normality for the child and family.

Within this thesis I have explored the experiences of thirty (n-30) children between the ages of seven and eleven years of age of managing their chronic illness at home. I adopted a narrative inquiry approach to the research which was based on the concept that children are social actors who can act with intention in their own lives. The thesis is grounded within the new sociology of childhood and adopted the framework of the Mosaic Approach to focus this study to involve child participants as co-constructors of meaning.

The study shows that children prefer to be looked after at home by the community children's nurse. They are able to recognise the knowledge and skills of the community children's nurse, and the study has identified that the community children's nurse empowers children with a chronic illness to enable them to develop the knowledge and skills they require to manage their chronic illness at home.

The study highlights the need for more research that includes children as participants and also as co- researchers to ensure that services provided to children are designed to meet needs that the children themselves have identified.

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed.. ..(candidate)

Date....13th December 2012....

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated.

Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed.. .(candidate)

Date....13th December 2012....

STATEMENT 2

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

Signed.. .(candidate)

Date....13th December 2012....

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I would not have been able to conduct this thesis without the commitment of the children who told me their stories, and the willingness of their parents to consent to their child participating in the research. I am very grateful to them.

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I wish to dedicate this thesis to my parents. My mother who has always encouraged me to fulfil my ambitions, she has been a constant support and help to me during my career. My final acknowledgement goes to my late father who I know would have been very proud of my achievement.

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Chapter 1: Introduction and background to the thesis

1: INTRODUCTION TO THE THESIS

For this qualitative study I have chosen to explore children's stories of managing their chronic illness at home. By telling their individual and unique stories these children have offered the adult world an insight into their world. Within this study I have challenged the traditional ideas of exploring children's lives through the views of their adult caretakers, and instead taken the stance that children are social actors who are competent to act as agents in their own lives (Christensen and James 2000, James and James 2004).

Historically childhood and children's lives have been explored through the views of adults therefore denying children the right to have their voice heard. However a paradigm shift in childhood research has recognised that children can be the subjects rather than the objects of research and can act with intention to represent their own interests (Christensen and James 2000, Prout 2003). Legislation such as the Children Act (DoH 1989, DfES 2004), and the United Nations Convention on the Rights of the Child 1989 promote the importance of ascertaining children's wishes and feelings, and emphasise that children should be routinely consulted about their everyday health care by professionals (Horstman and Bradding 2002, James and James 2004, WAG 2004a, Coad *et al* 2008, Carter and Coad 2009, WG 2012a, WG 2012b). The Welsh Government has set up the Funky Dragon web site (funkydragon.org) to encourage children and young people to become actively involved in decision making and to ensure that services respond to the needs and aspirations of children and young people in Wales. The commitment of the Welsh Government to participation with children and young people clearly shows that health and social care services must be seen to be increasingly listening to the views and wishes of children when decisions are made about their welfare and should actively involve them in participatory activity. This is because children have their own set of opinions which have the same moral legitimacy as those of adults. Issues perceived by adults as relevant to children might not be those articulated by the child, providing evidence of the need for a children's rights based agenda which involves consultation and provision of opportunities for children to be self advocates (Foley et al 2001, Jones and Welch 2010).

The increasing life expectancy of children with a chronic illness has created a need to listen to them about their experiences, expectations and preferences about the health care they receive. Children with a chronic illness are of greater risk of repeated hospitalisation due to complications, or acute deterioration associated with their condition. Frequent admission to hospital has been shown to impact negatively on the child's social and psychological health, they may experience sadness, anger, frustration and separation anxiety (Horstman and Bradding 2002, Angstrom-Brannstrom et al 2008).

The increasing provision of community children's nursing services in the UK and the perceived benefits of home care for children as opposed to hospitalisation wherever possible highlighted by the Platt Report (MOH 1959), and more recently by Carter (2005), and Carter and Coad (2009) has transferred the care for many children with a chronic illness from secondary to primary care. This reflects both the changing epidemiology of childhood illness and needs of sick children and their families. During the 21st century the ultimate aim is for only the most acutely or seriously ill children to be admitted to hospital, and as a consequence children's nurses are required to provide complex and highly skilled care and support to children and their families within a community setting (Carter 2000). This shift in service provision for sick children is promoted within social and nursing policy (Welsh Office 1997, RCN 2000, 2009a, 2009b, WAG 2004a, 2004b). However the Community Nursing Strategy for Wales (WAG 2009a) warns that there is still a lack of community children's nurses (CCN) in Wales which means that in some areas district nurses have to care for children as well as adults. The RCN (2009a) recommends that a minimum of 20 (Wte) community children's nurses are required to provide holistic care within a child population of 50,000, whereas Davies (2010) in her scoping exercise of community children's nursing provision in Wales found no more than 40-45 qualified CCN's (Wte) practicing across the whole of Wales.

The Community Nursing Strategy for Wales (WAG 2009a) recognised CCN's as professionals who provide skilled nursing care for children, young people and their families. The CCN role is seen to provide care predominantly at Level 3 of the Pyramid of Patient Need (p 16). Level 3 is defined as 'medium/high risk management including intermediate care services, network based services, outreach clinics and specialist nurses' (WAG 2009a p37). The aims of Level 3 care include, a reduction in hospital stays, with patients receiving the care they require within the community setting as soon as it is safe to do so. Current practice for CCN's set out by the strategy includes –

- Providing care in all settings in the community
- Enhancing the quality of life
- Providing health promotion for the whole family
- Empowering parents and increasing their confidence in caring for their child at home

Whilst I agree that these are all essential aspects of current CCN practice I have shown within this study that CCN's also empower children and young people with a chronic illness so that they can manage and make informed choices about their health care needs at home. I found that the vast majority of the research in the area of community children's nursing has traditionally focused on either the experiences and views of the parents (for example Wang and Bernard 2008, and Nuutila and Salantera 2006) or of the CCN service (for example Carter 2000, Tuffrney *et al* 2007, and Pontin and Lewis 2008a, 2008b). This reflects the tradition of viewing children as passive recipients of health care as opposed to seeing them as active consumers of health services who should be consulted and given choices about the services they receive (Coad and Shaw 2008).

The rationale for excluding children from participating in research as active participants originates in adults having an idealised view of childhood remembering it as a time of freedom from responsibilities, and a period of physical, and psychological development in preparation for the adult world. Children are viewed as the next generation and as the future of human kind, this perspective according to Quortrup (1994) views children as human becomings rather than human beings, meaning that children are only valued as an investment for the future. Children are seen as on a journey, the ultimate goal of which is adulthood where they will reach their full potential (James and Prout 1997, Daniel and Ivatts 1998, James and James 2004). This perspective represents adulthood as an ideal end state and therefore obscures the importance of engaging with children because they are viewed as future citizens rather than citizens with rights in the present (Fawcett et al 2004, Jones and Welch 2010).

As I have suggested policy drivers and sociological thinking have resulted in a cultural shift from this perspective to embrace the concept of children as social actors and active consumers of health care. This shift has been reflected in contemporary research studies regarding the provision of community children's nursing where children have been active participants in the process for example (Carter 2005, Carter and Coad 2009). However the volume of research studies that focus solely on the views of children with a chronic illness regarding receiving care at home and how they develop the skills to become competent to care for themselves remains limited. It is my belief that to gain a better understanding of children's experience of managing their illness, and the care they receive, it was vital to listen to the children and to break away from the reliance and need to have children's experience validated by adults. Therefore I feel this study reflects my view that children have an inherent value as individuals in their own right and not merely, or mainly as future adults.

I now move on to discuss my aim and objectives and provide an overview of the research approach and theoretical context of the study. I discuss the prevalence of chronic illness in childhood and provide an explanation of terms I have used within the study.

1.1 AIM AND OBJECTIVES

Aim

This study set out to explore children's stories regarding the management of their chronic illness at home.

Objectives

- To examine children's views on the skills they require to so they can manage their chronic illness at home.
- To determine images that children associate with home care.
- To identify children's perspectives of the care provided by the community children's nurse.

1.2 THE RESEARCHER

My interest in this area of study developed from both my clinical experience and my academic study. Since 1991 I have worked as a lecturer in nursing concentrating on children's nursing. During this time I gained valuable experience managing the community children's nursing pathway for the Specialist Practitioner Qualification. Prior to setting up this course I visited established CCN teams and spent time home visiting with clinical colleagues. The value of such a service to the children and their families was clearly evident and I have worked with many students and clinical colleagues to develop and expand the CCN service within South Wales.

My first degree in social science started my sociological journey and made me realise how influential social factors are on the lives of individuals and groups in society. Completing a Masters in Nursing allowed me to explore issues relevant to my practice discipline; my research examined the experiences of children's nurses of caring for sick children, findings of this study were published in 2000 (Bodycombe-James 2000). I chose to study for a Doctorate in Nursing Science as opposed to a traditional PhD as I felt it would allow me to develop a breadth and depth of knowledge and apply this to children's nursing practice as the philosophical core of a professional doctorate is its application to practice and the generation of knowledge from practice (Rolfe and Davies 2009). Part one of the Doctorate in Nursing Science required students to submit six extended essays. Two very significant assignments helped shape this thesis. Firstly an essay for the module Political and Economic Contexts of Nursing, for this assignment I wrote about children in social policy and it was here that I really engaged with the new sociology of childhood (James and Prout 1997) and the concepts of children as social actors (Daniel and Ivatts 1998). This was a major influence in the development of my thesis. Secondly for the Qualitative Methods of Nursing Research module I completed an assignment on the use of narrative stories to elicit the experiences of children about issues that are important to them. This gave me valuable insight into story telling as a method of data collection.

For this study I chose to use narrative inquiry methodology which is an accepted mode of inquiry within sociological and nursing research and an appropriate methodology to understand how people interpret meaning from life experience (Oliver 1998, Holloway and Freshwater 2007). This is because I wanted to use a methodology that would help explore the lives of children with a chronic illness and narrative inquiry would give me the opportunity to use stories to describe human experience and action (Polkinghorne 1995). Stories also show whose voices can be heard, who are silenced and whose stories are valued and whose are devalued (Gilbert 1994). In my view using stories would help me explore the lives of children with a chronic illness from their perspective. Stories we hear and also stories that we tell shape the meaning of our lives, our stories connect us with each other, with our own histories, connect our past, present and are an insight into our future. Listening to and telling of stories encourages reflexivity (Davies 1999) and through out this thesis I have reflected on my thoughts and feelings regarding the many complex issues uncovered during my research journey. For the study thirty (n=30) children who had been diagnosed with a chronic illness were invited to tell me their story of managing their chronic illness at home

Although I remained convinced that narrative inquiry was the most appropriate methodology for the thesis I became more and more interested in the theory of engaging children in the research. As my aim was to carry out this research with children as participants, I was aware of the importance of choosing a method that would be acceptable to the children, and answer the research question (Grieg and Taylor 1999, Christensen and James 2000, and Green and Hill 2005),

Following an extensive review of the literature on research with children and young people I found the work of Clark and Moss (2001) on the Mosaic Approach. This is a methodological framework for listening to children about important details of their daily lives based upon the new thinking within the sociology of childhood which view children as 'beings not becomings' (Qvortrup et al 1994), the concept of listening to children's voices, and also the notion of children's competency to participate in research (Clark 2004, Alderson 2007). A further advantage to this framework is its inclusion of a range of methods which allows children with different abilities and interests to take part in research projects. I felt strongly that this provided me with an appropriate framework as it encapsulated the vital essence of my theoretical stance for this thesis.

1.3 PREVALENCE OF CHRONIC ILLNESS IN CHILDHOOD

The World Health Report (WHO 2008) states that, on the whole, people are healthier, wealthier and live longer than 30 years ago. Urbanization, ageing and global lifestyle changes are combining to make chronic and non-communicable diseases increasingly important causes of morbidity and mortality. The Global Burden of Disease (WHO, 2004) uses the term *disability* to refer to *loss of health,* where health is conceptualized in terms of functioning capacity in a set of health domains such as mobility, cognition, hearing and vision. Moderate and severe disability is defined as the equivalent of having angina, arthritis, low vision or alcohol dependence. The average global prevalence of moderate and severe disability ranges from 5% in children aged 0-14 years, to 15% in adults between 15-59 years, and 46% in adults aged 60 and over. In the industrialized world, as many as 25% of 65-69 year olds, and 50% of 80-84 year olds are affected by two or more chronic health conditions simultaneously (WHO, 2004) therefore even the poorest countries will have to deal with expanding needs of people with chronic and noncomunicable diseases (WHO, 2008). Understanding the impact of chronic illness on the lives of individuals is vital to ensure the provision of effective health care.

Improvement in medical care means that survival rates for children with chronic conditions has improved significantly. However this improvement in survival is often associated with lifelong treatment and management that often limits children's activities, socialization, and school attendance (Snethen et al. 2001).

Due to the lack of available reliable data it has been a difficult task to elicit the prevalence of chronic illness in childhood. This is supported by Stein and Johnson Sliver (2009) who state that there are 'many important gaps in available information about children who have chronic conditions and disabilities' (p.68). They suggest that estimates vary from 4%-30% in the United States depending on the definition and methods used to collect information. Health Statistics in Wales (WG, 2011a) report that 20% of children have a long standing illness and 6% have a limiting long standing illness. The Welsh Health Survey (WG, 2010) also reported the same statistics for long-standing illness and limiting long standing illness in children. The most common long standing illnesses reported were, asthma (7%), a skin complaint (3%) and mental illness (3%). However this information is reliant on parents understanding of their children's health and not based on clinical assessment of the children's medical condition. The Together for Health Report (WG, 2011b) identified a rise in chronic conditions amongst the Welsh population as one of the major health challenges for the Welsh Government.

The Health and Circumstances of Children in Wales Report (NPHSW, 2004), states that there is a lack of robust routine data available to describe chronic childhood illness. Although this report is some years old there still appears to be dearth of statistics on the topic. The most common chronic condition in childhood is asthma, with estimates of the prevalence in children and young people in Wales as 39.7 per 1000 person years at risk (PYaR) with a higher prevalence among children aged between 5-15 years (NPHSW 2004); comparisons suggest this is one of the highest rates in the world. Cystic fibrosis is the most common genetic condition in Caucasian children the incidence is 1 in every

2,500 births. Childhood diabetes is also regarded as a significant chronic illness in childhood as it can lead to disability and premature death if it is not managed well. In Wales there is estimated to be 1.8 thousand children aged 0-16 with Type 1 diabetes. There is also an increase in the prevalence of Type 2 diabetes in children and young people. Childhood cancer is relatively rare affecting 1 in 10,000 children in Britain each year, the most common diagnosis is leukaemia with an age standardised rate of 40.3 per million (NPHSW, 2004).

1.4 EXPLANATIONS OF THE TERMS USED

Definition of child

According to the United Nations Convention on the Rights of the Child (1989) '*a child means every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier' (Article 1)*

Approaches to Chronic Illness

There are two distinct approaches to understanding chronic conditions in children, firstly a *disease specific* approach which involves studies with children who all have the same illness or condition. The advantage of this approach is that it has the potential to minimise the variance in variables related to the disease. However there are disadvantages as the findings would be limited to the disease studied (Grey and Sullivan-Bolyai 1999).

An alternative is to use a *noncategorical approach*; with this type of approach the researcher assumes the experience of chronic illness is more important than the specific illness (Stein and Jones Jessop 1989). The methodological challenge for this approach is to identify and control descriptive information and relevant dimensions that are similar across illnesses. The advantages are that there are more subjects available for potential studies and the researcher is not restricted to one condition. It also allows for examination of other variables across diagnosis for comparisons (Grey and Sullivan-Bolyai 1999). However Stein and Jones Jessop (1989) warn that illness burden associated with different conditions may affect management, treatment and the child's and family's perception of the illness.

For this study I have adopted a *noncategorical approach* to chronic illness as this more generic approach defines children with chronic conditions by examining the functional limitations resulting from the health condition. It also takes into account the similarities of specific consequences of various diseases and conditions such as dependency on medication, assistive devices, or medical care.

Definitions of Chronic Illness

An unequivocal definition of chronic health conditions in childhood has been lacking within the literature. However an overview of definitions by van der Lee et al. (2007) found 64 articles (written in English or Dutch) that stated a conceptual definition of chronic health conditions on children (aged 0-18 years). The three most frequently cited definitions according to van der Lee et al. (2007) are Pless and Douglas (1971), Perrin et al. (1993) and Stein et al. (1993). All of these definitions provide a definition of chronic conditions that is independent of diagnostic labels or aetiology.

The oldest definition by Pless and Douglas (1971) defines chronic illness as:

> '*a physical, usually nonfatal condition that has lasted longer than 3 months in a given year or necessitated a period of continuous hospitalization of more than 1 month'* (p 407).

The study was operationalized within the National Child Development study in England, Scotland and Wales and is the only definition located within the United Kingdom as the second and third most cited definitions were located in the United States of America.

Perrin et al (1993) stated that a definition should be comprehensive, generic, and flexible and that a two level approach to defining chronic illness is necessary.

The first level - the condition should be regarded as chronic if:

> *'it has lasted or is expected to last for more than 3 months'(p.792)*

The second level - the definition takes into account:

> *'the impact of the condition on the child, e.g., level of functional impairment or medical need greater than expected for a child of that age.'(p. 792)*

The third most cited definition by Stein et al (1993) states that ongoing health conditions are disorders that:

> 1 *Have a biological, psychological, or cognitive basis; and*
> 2 *Have lasted or are virtually certain to last for at least 1 year, and*
> 3 *Produce one of the following sequelae:*

a. *Limitations of function, activities, or social role in comparison with healthy age peers in the general areas of physical, cognitive, emotional, and social growth and development;*
b. *Dependency on 1 of the following to compensate for or minimise limitations of function, activities or social role:*
   (1) medications,
   (2) special diet,
   (3) medical technology,
   (4) assistive device,
   (5) personal assistance;
c. *Need for medical care or related services, psychological services, or educational services above the usual for the child's age or for special ongoing treatments, interventions, or accommodations at home or school (p.345)*

In this definition three domains or components are conceptualized these being – functional limitations, dependence on compensatory mechanisms and service use or need beyond routine care. Although this is the longest definition it relies on consequences-based criteria, not diagnoses of specific conditions or groups of conditions. In my estimation I believe this provides the most comprehensive definition and supports a *noncategorical approach* to chronic illness therefore is the definition that has been used for this study.

Definition of Home Care

Paediatric home care services can be described as '*an alternative to traditional provision, enabling suitable children to receive treatment at home which would otherwise be provided in hospital'* (Tateman and Woodroffe 1993, p.677).

Definition of a Community Children's Nurse

A community children's nurse was defined by the UKCC (1998) as:

> *'A registered children's nurse who has completed a programme of education in community nursing leading to registration with the United Kingdom Central council for Nursing Midwifery and health Visiting and whose main focus of work is predominantly those children requiring treatment and care for acute and chronic ill health in a home setting' (p.17)*

1.5 ORGANISATION OF THE THESIS

Within this opening chapter I have provided the rationale for choosing to explore children's experience of managing their chronic illness at home. I have outlined the research approach I have taken, and described the aims and objectives of the study.

Chapter two presents a critical review of the literature. The first section reviewes the literature surrounding the theories on children's concepts of their bodies and their understanding of illness which I felt was of fundamental importance for self management.

The second section analyses children's experience of living with a chronic illness. It highlights issues such as normalisation, adaptation, and locus of control, which are vitally important if children are going to develop the skills necessary to become self caring.

The third section focuses on what children view as essential for them to acquire self caring skills, these include, support, education, and being involved in decisions about where they are cared for.

The fourth section evaluates the care being provided to children with a chronic illness, and critically analyses the development of the community children's nursing service within the United Kingdom.

The literature review demonstrates that children with a chronic illness want to be actively involved in decisions about their health care but have not routinely been involved in this process. Through the literature I discovered that the majority of research regarding the care of children with a chronic illness at home has been conducted with either parents or professionals leaving a gap in research that focused on the views and perceptions of the children themselves.

Within chapter three I discuss the methodological approach I chose in order to explore children's experience of home care. I explain how I gained access to and recruited a sample of thirty (n-30) children to participate in the study. I have also discussed the ethical issues involved in research that chooses to use children as informants. I have described how I handled the data for the research study, and my rationale for using two forms of analysis for this narrative inquiry study. Within this chapter I have also highlighted how importantly I viewed reflexivity within the research process.

Within chapter four the findings from the study are presented in four themes and the data was analysed using paradigmatic analysis (Polkinghorne 1995). These include:

> ***Memories of diagnosis***- within this theme I have analysed aspects of the stories where the children talked about their first memories of their chronic illness, their feelings and symptoms during this time and also what they said they understood about their condition.
>
> ***There is no place like home***- within this theme I have analysed the stories about the children's experiences of being cared for in hospital and at home. Important issues were highlighted by the children such as boredom, fear of the unknown, and homesickness in relation to hospitalisation, and also how much the children valued home comforts such as good food, comfort and being with their family and pets.

That's my community children's nurse- this theme discusses the attributes that the children saw as desirable in their CCN, and how the children recognised the CCN as the professional who provided support, teaching and skilled nursing care within the home setting.

Taking control – lastly this theme provides an analysis of what the children felt they required to become self caring. The analysis shows the children felt they had been able to achieve independence because of the support and guidance offered to them by their family and CCN.

Chapter 5 presents two of the children's stories which were analysed using narrative analysis based on the criteria described by Polkinghorne (1995). For this section of the results two individual stories have been presented.

Blue's Story
Rhiannon's Story

In chapter six I have provided a discussion of the findings from this study, and highlighted the original contribution this research thesis has made to children's nursing practice. I have also included the limitations to the study and recommendations for future research that recognises children as social actors and also for community children's nursing practice. Within this chapter I have also highlighted the contribution this study has made to understanding of the needs and expectations of children with a chronic illness whose care is managed at home by the CCN service.

Chapter 2: Literature review

2.1 INTRODUCTION

In the previous chapter I have identified that historically the lives of children have been described mainly by adults and that they have been seen as passive recipients of health care. However there is also evidence to support the view that children are able to participate in decisions about their health care needs which is particularly important for children with a chronic condition. The aim of this chapter is to analyse the current literature regarding the management and care of children with a chronic illness.

Within first section I have analysed the literature surrounding children's concepts of their bodies, and their understanding of illness. The second section critically analyses the literature on the effects of chronic illness on the child and family, and their adaptation to chronic illness. The third section focuses on what services children report facilitate their ability to successfully manage their chronic illness at home. Lastly the review concludes with an analysis of the evolution of home care for children and the development of community children's nursing practice.

2.1.1 SEARCH STRATEGY

The role of this literature review is to place the research question in the context of previous work, identify gaps in knowledge and to justify the decisions made regarding the proposed study (Holloway and Wheeler 2002). The literature review and critique of the papers was informed by Parahoo (1997) who states that the literature review should provide a rationale for the study by comparing, analysing, and summarising the methodologies and previous findings of published literature which then leads the researcher to make their own conclusions.

As this study examines children's experiences of home care, initially I focussed my examination of the literature that had conducted research on the views of children regarding the management and care of their chronic illness. My aim was to present the views and understanding of children in relation to their specific chronic illness, to evaluate the literature on what children felt they required to manage their illness effectively, and to identify the services that are available to children with a health care needs in the community.

The following databases were accessed to identify relevant literature for this study. PubMed, CINAHL, British Nursing Index, Medline, ASSIA, Synergy and internet search engines such as Google Scholar. Using Swansea University library I conducted a hand search of the journals that were too old to be accessed via the on line data bases. I also traced articles by reading the reference lists of already sourced material and made use of the inter library loan facility at Swansea University library for books and articles that were otherwise unobtainable. Articles used for this literature review were published in English, however I have included publications from an international perspective where relevant. The majority of articles were published within the last 20 years, however certain papers have been included as they have been deemed to be classical seminal work. The search terms entered into the data bases included: 'chronic illness in childhood', 'children's understanding of illness', 'children's experience of chronic illness', 'effects of chronic illness on the child', 'children and diabetes', 'children and cancer', 'home care', 'community nursing' and 'community children's nursing'. However the published literature that specifically matched the research parameters was limited so where there was little or no evidence of research with child participants the literature was augmented with research evidence that was found on 'parent's experience of caring for a chronically sick child', 'professionals experiences of caring for a child with a chronic illness within the home setting' and 'family centred care'.

The papers that were selected for this literature review were evaluated and critiqued using the models presented by Greenhalgh (2001), and Dempsey and Dempsey (2000). The qualitative papers were critiqued by using the model presented by Greenhalgh (2001) set out specifically in chapter 11, entitled 'Papers that go beyond numbers' (p166-178). I chose to use this model as it focuses on qualitative research, and helped guide my reading and critical appraisal of papers. The papers that used a quantitative approach were critiqued using the guidelines presented by Dempsey and Dempsey (2001 p 335), using both of these guidelines within this literature review ensured that I was able to evaluate the merits of the research that had already been conducted and to determine how my study could add to the body of nursing research regarding children's experiences of home care.

2.2 CHILDREN'S CONCEPTUALIZATIONS OF THEIR BODIES AND ILLNESS

Within this section I have focused on the literature surrounding chronic illness in childhood paying particular attention to children's concepts of their bodies, their understanding of illness and the effects of chronic illness on themselves and their family. My analysis presented here examines literature that utilises a traditionalist theoretical perspective on child development and understanding of illness, and contrasts this with literature that adopts an alternative theoretical perspective to understanding children's constructed realities.

Vessey and Mebane (2000) suggest that children's perspectives about their bodies, illness, medical procedures, and death differ depending on their age and experience. The understanding of children's knowledge of their bodies and their understanding of illness has been guided by the Piagetian perspective (Bibace and Walsh 1980 and 1981; Crider 1981; McEwing 1996). This traditional theoretical perspective derives from psychological notions of cognitive maturity and the development of causal reasoning (Hansdottir and Malcarne 1998). Therefore children's development could be assumed to progress along a continuum from the concrete to the abstract, however Eiser (1989) suggested that development should no longer be seen to be primarily dependent on maturation, but instead it should be recognised that it is influenced by factors such as social and cultural variables. This alternative theoretical perspective supports the view that children's understanding about issues such as illness is not as dependent on cognitive level as on previous experience (Yoos 1994; Crisp et al., 1996). Therefore children's thoughts about illness should be seen as a combination of their understanding and experience of the illness, and not something limited by a structural stage of logical development (Rubovits and Siegel 1994).

2.2.1 *Children's concepts of their internal bodies.*

Children's conceptualization of their internal bodies is thought, according to maturation model assumptions, to follow a well established developmental sequence. Preschool children's views of their body are seen to be linked to fantasy, whereas school aged children can name several body organs and describe their function but do not understand their interrelationships. The adolescent however has a more sophisticated integrated view of anatomy and physiology (Crider 1981; McEwing 1996; Vessey and O'Sullivan 2000).

According to McEwing (1996) children need to have a basic understanding of their body's anatomy and the function of organs in order to make decisions about lifestyle and health issues. Her study aimed to gain an understanding of children's knowledge of the human body. The study involved 112 children aged between 4.5 to 8.5 years with equal numbers of boys and girls. The data were collected through semi structured interviews, the children were also asked to draw body parts on a prepared outline drawing of a body. The results showed that children as young as 4.5 years had a good knowledge of internal organs. The results provided show that the children were aware of a variety of organs, 98% of the sample recognised the existence of the heart, blood and bones, 90% were aware of the brain and muscles, 87.5% of lungs and 82% of the oesophagus. The study determined the children's knowledge of the position of the organs in the body from their drawings. The most accurately positioned was the brain (92%), and the majority of the children placed the bones (88%), muscles (82%), and heart (80%) in approximately the correct positions. Knowledge of body organs, their function, and positions with the body increased with age. Younger children showed more awareness of organs they had objective experience of such as, bones that they can feel under their skin and their heart that they can feel beating following exercise. Therefore in my opinion McEwing's results suggest a correlation between cognitive ability and an increasing ability to acknowledge the existence of body parts, their position within the body and their function, however more research would be necessary to verify whether there is a correlation or not.

2.2.2 *Children's concepts and understanding of illness.*

For more than twenty years research on children's understanding of illness has argued that children have different perceptions of illness depending on their age, and stage of development (Bibace and Walsh 1980, and 1981; Banks 1990; Hansdottir and Malcarne 1998).

Bibace and Walsh (1980) postulated that children's concepts of illness are consistent with Piaget's theory of cognitive development (cited in Flavell 1963). Within each of Piaget's stages of development Bibace and Walsh (1980) describe two explanations of children's concept of illness. Firstly within the preoperational stage (3 to 7 years) *phenominism* is described as the most developmentally immature explanation. Children in this stage are said to believe that illness is caused magically, by an external phenomena. The children are not able to explain the events that cause illness. Secondly more mature children in this stage attribute objects or people in close proximity but not touching them to cause illness, this is referred to a the *contagion stage*. The second stage of development is concrete operational (7 to 11 years), children in this stage are said to be able to solve problems providing they are concrete or real but as yet cannot handle imagined or hypothetical problems. The concept of *contamination* is thought to be characteristic of younger children in this stage; the child distinguishes between the cause and the effect of the illness. Older children are able to understand how illness is located within the body and that it may have originated externally, this is referred to as *internalization.* The final stage is the formal operational (12 years and over) within this stage the child can reason about hypothetical problems. The younger child understands illness may be caused by external events, but that the illness manifests within the body and is described as a nonfunction or malfunction of an organ or process, this stage is referred to as *physiological* explanation. Lastly a *psychophysiological* explanation represents the most mature understanding of illness. The child is able to describe an illness in respect of both physiological and psychological causes.

Banks (1990) found similar developmental progression in relation to children's concepts of illness causation. She suggested that as children develop their explanations of illness move away from magical thinking and become more consistent with scientific explanations influenced by cultural beliefs. Therefore can children's developmental progression of illness concepts be assumed to be universal, or is it indeed related to cultural beliefs, the following studies have used samples drawn from differing cultures in order to evaluate this assumption.

Hansdottir and Malcarne (1998) investigated the development of illness concepts among healthy Icelandic children within the context of cognitive development. Icelandic children were thought to be similar in socioeconomic status and race to children who had participated in American studies of concepts of illness (Bibace and Walsh 1980; Perrin and Gerrity 1981; Brewster 1982), however the authors identified some potentially important differences. In Iceland the health care is free, health terms are drawn for the Icelandic language, and finally the possible influence of the Icelandic climate with extreme cold weather, frequent storms and earthquakes. Sixty eight Icelandic school children and their parents participated in the study. The children were divided into 3 age groups: 6-7 years old, 10-11 years old, and 14-15 years old. These stages were chosen to represent Piagetian stages of cognitive development. The study used a number of different methods of data collection. The children's cognitive developmental level was assessed by administering a set of tasks based on Piagetian concepts of conservation, the interrelationship amongst parts, physical causality, and abstract thinking. Understanding of illness was assessed by four interview questions regarding the causes, symptoms, prevention, and treatment of illness. The parents were asked to complete a Child Illness Behaviour Questionnaire which consisted of 13 questions about their child's behaviour when ill. The parents were also asked to list illnesses their child had experienced as well as any family illnesses they thought may have influenced their child's understanding of illness. The study found that the effect of socioeconomic status on illness understanding was nonsignificant, and also that cognitive development was not found to be affected by gender or social class. The study concurs with the view that children's level of understanding of illness follows a progression that is consistent with Piaget's theory of cognitive development. The influence of the weather on illness causation was found to be consistent with other studies (Perrin and Gerrity 1981, Bird and Podmore 1990) in that children's concern with weather and the physical environment decreased as their age increased and they moved on to a more sophisticated understanding of illness causation.

A study by Peltzer and Promtussananon (2003) aimed to examine the understanding of health and illness in black South African children. The sample of children for the study was selected from a rural primary school, although the authors state this was a random sample there is clear evidence of purposive sampling as out of the 60 children who participated in the study 30 were 5 year old and 30 were 9 years old. It would seem that these age groups were intentionally chosen as the findings of the study compare the child's level of understanding in relation to age and developmental stage. The data were collected using tape recorded semi-structured interviews with open ended questions to allow the children to influence choice of the issues that were talked about. The results of the study showed that the older children (9 years) had more objective understanding of signs of disease such as colds, chicken pox and Acquired Immune Deficiency Syndrome (AIDS) than the younger group of 5 year olds. The study also found that there was no difference in the children's knowledge regarding avoiding illness. However the 9 year old children demonstrated more accurate knowledge regarding preventative measures than the younger children. The results suggest that children's understanding of health and illness is influenced by their age and stage of cognitive development. This was a small study drawn from a sample of children from a black South African community; therefore, the findings may not be representative of children from other cultures who may not have the same life experience exposure to diseases such as AIDS. This is supported by Walsh and Bibace (1991) who also concluded that children's understanding of AIDS reflected their level of cognitive development.

The conceptualization of healthy children about their bodies and illness causation is therefore thought to follow a developmental pattern in as much as children's understanding of concepts regarding the causes, prevention, and treatment of illness, parallel their development of concepts in other areas. However a further interesting concept is whether children with a chronic condition view their internal bodies in the same way as their healthy peers, and whether their concepts of illness differ from non affected children of the same age. Eiser (1989) put forward an alternative theoretical perspective which places greater emphasis on the role of experience. Crisp et al. (1996) state than expertise theories allow for, an indeed predict, that children will show varying levels of understanding in response to varying degrees of experience. This is in contrast to cognitive developmental theory that emphasises similar levels of understanding in all areas of cognitive understanding. This suggests that children with a chronic illness develop expertise about their condition due to their experiences that is beyond that expected for their cognitive level.

Crisp et al. (1996) compared healthy children (novices), and children who had a chronic condition (experts) understanding about the causes of illness. The findings indicated that experience with a chronic illness contributes to children's understanding of illness and that the complexity of symptoms, treatment and prognosis affects the child's comprehension of the disease. However other comparative studies by Perrin et al. (1991) and Vessey and O'Sullivan (2000) concluded that children with a chronic illness showed no statistical difference in either their understanding of body functions or illness causality. One reason postulated by Vessey and O'Sullivan (2000) for the similarity in findings between the two groups of children is the growing availability of children's books, computer software and television programmes for teachers and parents to use when instructing children about their bodies. Because of this they suggest, it is not unreasonable to expect that differences between healthy and non healthy children would be similar, even though children with chronic conditions are often exposed to programmes about anatomy and physiology of their condition.

I would argue therefore that children's nurses must not assume that mere familiarity with the health care environment is related to an increase in the child's understanding of health, illness, and treatment. It is also important to remember that for children with a chronic condition understanding of anatomy, physiology, and pathophysiology is a prerequisite for the child to assume responsibility for their own health and for managing their chronic condition. There are however methodological and conceptual problems that need to be considered in this area of research. For example the importance of the questions used to assess the children's level of understanding of illness, the type of measures of cognitive development and the definition of illness experience.

Within this theme I have identified the importance of understanding children's concepts of their bodies and illness. The dominant view within the literature (Walsh and Bibace 1991; Berry et al. 1993) appears to be that this follows a stage approach, and that children's level of understanding of illness follows a developmental pattern, and that cognitive development is a better predictor than age alone. However I have also shown there is evidence of an alternative perspective that emphasises the role of previous illness experience (Eiser 1989; Crisp et al. 1996).

2.3 LIVING WITH A CHRONIC ILLNESS

Due to the advances in health care the majority of children with a chronic illness survive into adulthood, this has led to a need to understand how children think about, and how they manage their illness within the context of their daily lives. Until recently much of the research on children's experience of chronic illness relied on parents reports of their child's illness with fewer studies capturing the child's own story of growing up with a chronic illness. However, there is a growing area of research that involves children as participants recognising their ability to provide accurate information about their own experiences. Within this section I have chosen to concentrate on research carried out with child participants to demonstrate that children can be self advocates, and act with agency in their own lives. I have also augmented this theme with studies that have used parental experiences of their child's chronic illness as I realise these provide a further perspective of living with a chronic illness.

2.3.1. *Children's experience of chronic illness*

A qualitative study by Christian and D'Auria (1997) utilised a disease specific approach to explore adolescents conceptions of their chronic illness. They interviewed a purposive sample of 20 adolescents (12-18 years) who had a definitive diagnosis of cystic fibrosis (CF). The study used a retrospective approach to capture the participants illness trajectory. The adolescents were asked to take the researchers back on a journey of what it was like to grow up with CF. Each childhood memory, as recounted by the adolescent was explored, and they were asked to describe how the experience made them feel. They were also asked to pretend to give advice to a younger child about growing up with CF based on their own experiences. Lastly a lifeline was used to visually represent and validate their perceptions of the course of their chronic illness. The data were analysed by using the constant comparison method (Glaser and Strauss 1967).

Three main themes are presented in the results of the study –

- *Keeping secrets*, the adolescents felt that telling others about their diagnosis threatened their chances of gaining social acceptance and forming friendships. They also described how they concealed their illness as they were afraid the other children would pick on them, see them as contagious and not want to be friends with them.
- *Hiding visible differences,* these were reported as the CF cough, taking medication and limiting activities; all of these were viewed by the adolescents as three outstanding behaviours which advertised their differences from their peers.
- *Discovering a new baseline,* during early and middle childhood the adolescents struggled with their self image and self esteem. As they matured they began to recognise that comparing themselves to healthy peers was the wrong standard for their lives.

Discovering a new baseline was an essential step in helping the participants to successfully reduce the sense of difference in their lives. These findings are supported by Kelleher (1998) who also found that minimising symptoms of illness 'allows feelings of being different from others to be pushed backstage' (p.41). Also, Bury (2001) stated that individuals often seek a way of keeping their pre illness identity intact by the maintenance of as many activities as possible, and also by disguising or minimising symptoms of illness. However individuals redesign their view of normal life by incorporating their illness into their lifestyle which signals a change of identity. This study by Christian and D'Auria (1997) has demonstrated the importance of social development during middle and late childhood and how much value children place on being accepted by their peer group as not being different. The presence of a chronic illness has the potential to inhibit socialising and interacting, and therefore adolescents may choose not to disclose their condition due to the fear of not being accepted by their peer group at a time when identification with their peer group is very important (Edwards and Davis 1997).

I feel it is important to note that the study by Christian and D'Auria (1997) was a retrospective study and that the maturation and life experiences of the adolescents could have influenced their perspectives on their childhood experiences. However studies that have used 'present time' to analyse experiences of chronic illness have also found similar findings. Woodgate (1998) found that adolescents described chronic illness as restraining often due to the extra effort of taking medication, controlling their diet and being different from their peers. Herrman (2006) also reported that adolescents feel different because of their diagnosis, and that essential daily care is seen as an interruption to normal life with friends.

Research studies that have included younger children as participants are less common, this may be due to difficulties in access to, and recruitment of younger children to research studies. However, Yoos and Mullen (1996) conducted a qualitative, disease specific study with children ranging from 6 years of age to 18 years. The study used a convenience sample of 28 children all of whom had at least moderate asthma which was defined by their daily medication requirements. The children were interviewed in their own homes using an open ended semi structured interview which was tape recorded. The interviews began with a grand tour question about the good and bad things about asthma. The children were also asked to complete a visual analogue scale (VAS) to assess how much they worried about asthma, and how much different their life was because of having asthma. A VAS is a self report paper and pencil scale that consists of a straight line that has extreme limits of the variable being measured at each end of the line. The respondent places a mark on the line to indicate the point at which their response best answers the question being asked (Dempsey and Dempsey 2000). The findings of the study were presented in five themes *'I can't', 'restrictions', 'symptoms and treatment', 'death',* and *'adaptation'*. The most prevalent theme was *'I can't'* where the children gave extensive lists of what they felt they could not do because of their illness, this was linked to the restrictions placed upon them by others. Daily treatment of asthma also dominated the children's stories and also the children's concerns over death. The study revealed patterns in relation to the age of the child participants, the younger children aged 6-7 years discussed asthma primarily in relationship to symptoms and treatment, whereas the middle age group of children were concerned with restrictions and what they could not do, and only during the adolescence stage did the concept of reconciliation to their condition and positive growth emerge.

Many of the studies regarding children and adolescents experience of living with chronic illness have demonstrated similar findings, the most predominant were, the children seeing their illness as a threat to physical well being (Kyngas and Barlow 1995), the need to be seen and to see themselves as normal (Woodgate 1998; Huus and Enskar 2007), the importance of support from family, friends and professionals (Berntsson et al 2007), and the opportunity presented by the illness to live a healthy lifestyle (Yoos and Mullen 1996; Christian and D'Auria 1997).

Research studies that have described parental experiences of their child's chronic illness provide a further perspective of how chronic conditions are experienced. These studies show how the lives of individual family members are touched by the presence of a person with chronic illness in the family. Research on parents experiences of living with a child with chronic illness highlights similar findings for example, parents see their child as normal and strive to give their child a normal life despite the illness, the illness although not seen as a dominant feature demands mastering of treatment and often technology, and family life is adapted to meet the needs of the child (Knafl et al 1996; Horner 1998; O'Brien 2001; Urquhart Law 2002; Immelt 2006). Therefore it is evident that the family both affects and is affected by their child's chronic illness, and that adaptation of the child and family are closely linked (Northam1997). The child's and family's adaptation to chronic illness is not a static phenomenon but a process that needs to develop and recognise the child's developing locus of control, capacity for self management of their condition, and the need to normalise their lives (Edwards and Davis 1997).

2.3.2. *Normalisation*

Being normal and getting on with life is a recurring concept within the literature (Taylor et al. 2008). Western culture values the notion of productivity and individuals strive to be productive social agents who function normally within society. Normalisation is the most common strategy utilised to accommodate and adjust to illness or disability this involves acknowledgement of the abnormality, but a denial of its social significance (Knafl and Deatrick 1986).

Woodgate (1998) investigated adolescents perspectives of chronic illness, 23 adolescents who had been diagnosed for at least one year with a chronic illness were recruited to the study. As the goal was to research common attributes, the researchers adopted a noncaterorical approach to the study, therefore adolescents with asthma, diabetes, rheumatoid arthritis, and chronic inflammatory bowel disease took part in the study. These different conditions were chosen as they all require daily treatment, have periods of stability and exacerbation, and are usually non fatal. The study used a qualitative design and data were collected using an open-ended interview which gives control to the participant with minimal guidance from the researcher. The study was given ethical approval by the appropriate institution and informed consent was obtained from both the participants and their parents. The data were analysed using the constant comparative method (Glaser and Strauss 1967). A dominant theme that emerged from the adolescents descriptions of their illness was '*it's hard'*. The adolescents stated that life was not easy because of their chronic illness. They were confronted by more obstacles on a day-to-day basis which included the following of treatment regimes, controlling their symptoms, and integrating illness experience into their everyday life. When the adolescents were experiencing fewer symptoms they described their lives as normal, they suggested that it was not '*really is bad as people think'* and they downplayed the illness experiences. However, during more unstable periods the adolescents referred to their experience of illness as '*hell*' or as a *'nightmare'*. The adolescents also expressed that the chronic illness should not become the number one priority in their life and, that it was important that they did not dwell on illness and attempted to '*get over it'*. A further concept identified was '*making the best of it'* this referred to the adolescents trying everything possible to fit the illness into their everyday life and attempting to turn a bad experience into a good experience.

This research demonstrates that the adolescents struggled to play down the difficulties of their chronic illness by relying on strategies that help to modify and influence their own subjective psychological state such as thinking positive thoughts, and trying not to think about the illness. Atkin and Ahmad (2001), Stewart (2003) and Woodgate and Degner (2003) also found that children with life threatening illnesses such as thalassaemia, and cancer describe their lives as routine and ordinary within the limits of unpredictable illness, and do not wish to be seen as victims of their illness, but to be accepted as the same person they were before their illness. However, during exacerbation of severe symptoms children define their lives as more difficult, and feel different from their peers. Symptoms are a big part of illness experience for children and their families, and when these become severe they make life more difficult.

Alternating between being normal and being different was also found by Herrman (2006). This disease specific phenomenological study included 25 young people between the ages of 8 to 15 years with type 1 diabetes. The participants were interviewed individually to elicit their stories of living with diabetes. The results showed the importance of being like, and being able to live like other adolescents. Normality was stressed in each of the themes that emerged from the data, in which the adolescents compared themselves with their peers and used their friends' lives to describe what they saw as normal.

This concept of normalisation in response to chronic illness has also been found in other studies for example by Dixon (2003) when conducting a case study of a child with type 1 diabetes and by Snethen et al. (2001) who assessed the perceptions 35 adolescents receiving renal dialysis treatment for end stage renal disease. A disease specific study by Protudjer et al. (2009) aimed to further understand how children perceive asthma. The children for the study were purposively chosen from a larger birth cohort study in 1995 as they had received a positive asthma diagnosis by a paediatric allergist. Twenty two, 11 year old children with asthma were included in the research, data was collected using semi-structured interviews, and the data was analysed using thematic coding. The results showed that the children viewed themselves as different because of their asthma and therefore developed various normalization strategies to facilitate their acceptance by their peer group. To do this the children emphasised their abilities and minimised the impact of asthma on their lives to stress the normality of their lives. This is echoed by Prout et al. (1999) who found that children with asthma and their parents stressed the ordinariness or normality of their daily lives, and that certain symptoms of asthma (wheezing and coughing) were accepted as normal occurrences. Guell (2007) also stresses that children with a chronic illness normalise the abnormal to take control over their uncertain bodies, as they want to be seen for themselves and not reduced to their illness. Therefore in order to successfully assimilate themselves into the everyday world, children with a chronic illness emphasise the abilities that are seen to be important to children without a chronic condition (Morse *et al* 2000).

2.3.3 *Locus of control*

A further concept evident within the literature is that of locus of control, also referred to as, taking responsibility (Woodgate 1998; Yoos and Mullen 1996), becoming responsible (Horner 1998), managing therapies (Kirk 2008) and taking care of one's self (Huus and Enskar 2007). These studies all suggest that the child with a chronic illness experiences a transition stage where the responsibility and locus of control for the daily treatment, care and management of the illness is transferred from the parents to the child.

Huus and Enskar (2007), conducted a disease specific phenomenological study. For this they interviewed 6 girls and 2 boys between the ages of 14 and 16 years using an open – ended interview to ascertain the adolescent's story of living with diabetes. The results showed the one of the most important issues for the young people was being able to take care of themselves. This was expressed as 'being in command,' the findings suggest this was achieved by the adolescents with help from family, friends and school. However there appears to be fine line between what the young people viewed as supporting and what they deemed nagging. Support outside of the family home was also seen as very important and help from a sports teacher in encouraging exercise and physical activity facilitated a process of liberation from their parents. This is a small study with only 8 participants. However sample sizes in phenomenological studies are typically 10 or less (Polit and Tatano 2006), the most important principle of sampling for this type of study is that the participants are able to describe their lived experience of the phenomena. The sample of adolescents for this study had all been diagnosed with type 1 diabetes for at least 3 years, therefore the sample was suitable for a phenomenological study that aimed to describe the reality of life for the 8 adolescents.

Horner (1998) also found that the transition from parental to child control is aided by parental support and guidance. In this qualitative study 12 families with a school aged child who had a diagnosis of asthma were interviewed. The results suggest that this transition is a gradual process, and as the children matured they took on more responsibility for managing their asthma. Wales et al. (2007) describes transition of responsibility from parent to child as an uneven, bumpy process that can take several years. The process is influenced by many factors such as the child's age at diagnosis, the cognitive and coping ability of the child, and also parental willingness to teach their child and relinquish control.

The majority of the studies I have analysed within this theme were from the qualitative paradigm therefore I recognised that the studies were relatively small and not generalisable to the population. However the qualitative research studies have provided an understanding of the phenomena from the *emic* perspective, which is from the individual experiencing that phenomenon. I have been able to explore children and young people's experience of living with a chronic illness because I focussed my literature search and analysis specifically to capture research that embraced children and young people as participants. I have shown that the literature suggests that children with a chronic condition feel different to their peers, and that they feel the need to be constantly vigilant in respect of treatment and medication. I have also highlighted how children with a chronic illness adapt to the constraints imposed on their lives by normalising their experiences, and by taking responsibility for their own health.

Implicit within many of the research studies on the children and young person's experience of chronic illness is the need for them to acquire self-care skills to allow them to be in control of their own health needs. Therefore I now move on in the next section to ascertain how the child and family facilitate the management of the child's chronic illness.

2.4 CHILDREN'S PERSPECTIVES ON THEIR HEALTH CARE NEEDS

Self management of chronic illness requires acquisition of self care skills namely, knowledge about the condition, mastering of treatment requirements, and the adherence to a healthy lifestyle. Children and young people with a chronic illness have identified several issues that can facilitate these skills namely, support, education, transition of responsibility, normalising their lives, and being involved in decision making about where they receive health care. Within this section of the review I have focused on issues I identified within the literature that facilitate children's management of their chronic illness.

2.4.1. Role of family, friends and health care professionals

Having support from family, friends and health care professionals for children with a chronic illness is a recurring theme within the literature (Herrman 2006; Berntsson et al. 2007; and Taylor et al. 2008). A noncategorical qualitative study conducted by Berntsson et al. (2007) aimed to describe the meaning of feeling good in daily life for young people between the ages of 12 years and 19 years. The adolescents had all been diagnosed with a long term illness or disability. The adolescents participated in an unstructured interview in which all the participants were asked the same open question about what was important for them to feel good in their lives. The results showed that the participants felt that in order to feel good they needed to accept their illness as part of their life, develop a feeling of personal growth, and have the support of family, friends, and health care professionals. An important issue for a feeling of acceptance was having an understanding of their body's physiology, their illness, and medical treatment. This clearly links to research highlighted earlier for example Hansdottir and Malcarne (1998), and Crisp et al. (1996). Support from family, friends, and health care professionals was said to be essential. The support from friends promoted a feeing of equality, liberation and spontaneity, linking to research reviewed earlier on a need to be seen as normal (Woodgate 1998; Protudjer *et al* 2009). Family support was a prerequisite for feeling good, and a good relationship with parents ensured they felt that there was someone on hand to discuss important issues with. Linked to this was also the need to feel trusted by their parents to manage different situations therefore building feelings of personal growth. The research shows that the professionals were seen as advocates for young people, and the school nurse was identified as an important professional who monitored health and was available to talk to them. This recognition of the school nurse as having a vital role to play in the provision of health care to school aged children and young people has been recognised by the Welsh Assembly Government within the Framework for a School Nursing Service for Wales (WAG 2009b) which set a target to introduce a named nurse for every secondary school by May 2011. The role of the school nurse is to promote the health and well being of children and also to support children with complex health needs so that they can remain at school. Egelke et al. (2008) found that school nurses make a positive impact on the health of children with a chronic illness by developing skills of case management to identify children who have a chronic illness that may limit their potential. The toolkit for school nurses (RCN 2008) echoes this by recommending that school nurses monitor children with long term problems and assess each child to determine their health care needs with the aim of improving their health.

Acceptance, encouragement, and the support of others are seen to facilitate the transition to autonomy for children and young people with a chronic illness. Woodgate (2006), in a phenomenological study, found that adolescents with depression wanted to be valued as a human being by health care professionals, that they found comfort and strength from professionals who respected them and were sincere in their relationship. A lack of respect or understanding resulted in non compliance with treatment. Qualities valued in professionals by adolescents include a focus on the individual and not the disease, flexibility, not giving up on their client, and a non judgemental attitude.

Karlsson et al. (2008) found that support from a specialist diabetes team strengthens self esteem in young adolescents. In a phenomenological study of adolescents (n=32) with type 1 diabetes Karlsson et al. (2008), aimed to capture the adolescents experiences of self management of their condition. The results suggest that transition towards autonomy in self management is complex, and is a process in which adolescents and their parents share responsibility and decision making to achieve well being. The study reports that the adolescents felt supported by the diabetes specialist nurse and other professionals who facilitated their decision making skills, and helped them arrive at their own decisions.

The support provided by health care professionals requires continual assessment and evaluation of each individual child's needs, as not all adolescents report that they feel adequately supported by health care staff. Participants in an earlier study by Kyngas and Barlow (1995) stated that rather that being supported they felt controlled, and disliked the constant enquiries about self care activities. Conflicts led to a lack of trust between the adolescents and health care staff and they felt this curbed their ability to become independent.

The transition of responsibilities and decision making, are clearly important issues for children with chronic illness and also for health care professionals. Kyngas et al. (1998) concluded in their disease specific study of 51 adolescents with type 1 diabetes that the relationship between the adolescent and practitioner is of vital importance in compliance to treatment and self management. The adolescents in this study described practitioners as motivating if they were perceived by them to be supportive. In relation to the action of nurses the adolescents described them as, either motivating, routine, or acting on physician's instructions. Nurses who utilised routine actions, or acted on instruction were said to ignore the young patients' opinions, and were deemed not to base their care on the needs of the individual patient, but followed routine practice dictated by the medical staff. Alternatively the nurses who were thought of as motivating, discussed self care with their patients and took notice of their opinions.

Characteristics children value in paediatric nurses have been identified as humanity, a sense of humour, and reliability (Pelander and Leino-Kilipi 2004), and that gaining children's trust is central to the development of partnership working (Bricher 1999). This is supported by Farrant and Watson (2004) who found that young people rate health care professionals high if they have good listening skills, good medical knowledge, are honest with them and respect their confidentiality. This is supported by Randall *et al* (2008) who state that children view good nurses as those who are willing to listen, are non judgemental and treat them with respect. Carter (2005) found that children used their parents as a benchmark when measuring levels of excellence and expected their nurse to be as 'good as mum or dad' (p. 56). Brady (2009) concluded that children's nurses were seen as delivering clinical excellence when they could combine technical expertise with personal characteristics such as being funny, cheerful, nice and helpful.

The concept of children as partners in their health care has been until recently relatively unexplored Gabe *et al* (2004) with the exception of Alderson (1993) who concentrated on children's consent in health care, and also Thomas and O'Kane (1999) who studied participation in decision making of children in the care of local authorities. Guell (2007) claims that treatment can only be successful if children are taken seriously and can act autonomously within the decision making process. She suggests that one of the greatest ambiguities for parents and professionals is one of protection versus autonomy, and that children with a chronic illness are often over protected, and the child's need for autonomy often takes a back seat. Coyne (2008) concluded that children are not always actively involved in decision making within healthcare, and that they occupy a marginal role in the information exchange process. However Coad and Shaw (2008) and Coad et al. (2008) found evidence that there has been an increased emphasis on the involvement and participation of children in decision making about issues that affect their health care. Parents and health professionals have a key role to play in consultation processes, and have the power to facilitate or constrain children's participation. The right of children to be consulted on issues that affect them has also been brought to the forefront by authors such as Alderson (2008) and Jones and Welch (2010).

The previous studies in this section have all related to older children or adolescents, however, Alderson (1993), and Alderson et al. (2006) state that younger children can also share in the decisions made about their care. Alderson et al. (2006) interviewed 15 children between the ages of 3 years and 12 years old with type 1 diabetes. Their aim was to investigate the ways in which the children shared the management of their medical and health care with adults. The results showed that even the younger children (4 years) understood how to control their diabetes by demonstrating their understanding of managing their diet, and insulin requirements. The children's ability and willingness to self inject with insulin and measure blood sugar was not found to be age related. Some children as young as 4 years were already taking responsibility with supervision, whereas other 11 year old children still relied on parents. This was a small qualitative study therefore generalisations are not possible, however it does demonstrate that even young children are capable and willing to take responsibility for their own health care needs.

This is supported by a case study by Sutcliffe et al. (2004) titled 'Ruby's story', a case study is a method of research that uses a single unit in a study (Dempsey and Dempsey 2000) and focuses on the complexity, circumstances and dynamics surrounding the case. It is a valuable method to use in exploratory research and for generating hypothesis. However although they contribute to understanding wider issues the results are not generalisable to the population (Bowling 1997). Ruby was diagnosed at 15 months with type 1 diabetes, her mother who is one of the authors of the paper states that gradually Ruby (5 years) began to know why she needed insulin, about not having too many sweets and controlling blood sugars. Ruby is said to describe a hypoglycaemic attack as 'feeing wobbly' (p. 25) she also tells her mother when she is hungry and if she feels sleepy to get her mother's attention. Ruby comments on managing her diabetes and is reported as saying (p. 25) '*You have to have injections every day, two times, at morning and tea time. It hurts quite a lot sometimes. And you have to do your blood, that doesn't hurt as much, I can do it myself, but not the injections. I can make that ready but not put it in my bottom. You have to wait until the insulin goes in to your blood and then you can have your snack',* (Ruby then aged 4 years). It is not possible to generalise from one child's experience and to suggest that all children can be as informed and responsible in relation to their health care needs as Ruby. However I concur with the authors that even a single example can challenge traditional thinking about children's ability to take responsibility for their health and treatment. It supports the theory that children with a chronic illness develop knowledge and understanding in relation to their illness that exceeds the level expected for their developmental stage (Eiser 1989; Crisp et al.1996).

2.4.2 Hospital or Home: Health care preferences of children with a chronic illness

Within the previous literature I identified issues important to children and young people in order for them to achieve mastery in managing their chronic illness such as support, maintaining control over their lives, and being able to live as normal a life as possible. I now move on in this next section to evaluate the literature on the health care preferences of children and young people, and highlight the need to involve children in decision making about where they want to receive health care in order to facilitate the development of their well being, and autonomy. Unfortunately many children with chronic illness require repeated hospital admissions, and frequent hospitalization has been demonstrated to impact negatively on children's emotional and psychological well-being (McClowry and McLeod 1990, Lansdown 1996,Thruber *et al* 2007, Salmela *et al* 2009).

Hospitalisation for young children was a rare event until the middle of the eighteenth century, and when they were admitted it was common for mothers to be resident with their children to help with the demands of caring. However during the nineteenth century the exclusion of parents from children's wards was prompted by new ideas about the spread of infectious diseases, the professionalization of nursing, the development of paediatrics and childcare nursing, and the growth of state and insurance funding for health care (Lindsey 2003). Between the 1930's and early 1950's parents had been effectively excluded from children's wards. During the 1950's a theory practice gap began to emerge between hospitals emphasising physical treatment, and the prevention of infection, and the emergence of new ideas around the emotional and psychological needs of children (Davies 2000 and 2010). The work of Bowlby (1953) on maternal deprivation was seen as being applicable to the hospitalised child; it was Bowlby's opinion that babies and young children require a continuous and unbroken relationship with one person to make healthy and secure emotional attachments.

The Welfare of Children in Hospital (MoH 1959) marked a watershed in the care of sick children both in hospital and in the community. This report more commonly referred to as the Platt Report recognised the potential psychological damage that could arise in children as a result of hospitalisation and stated that 'children should not be admitted to hospital if it can be possibly avoided' (paragraph 17), and recommended radical changes to the care of hospitalised children. These included the abolishment of strict visiting hours to be replaced by open visiting where parents were encouraged to stay with their children, and also the training of staff so that they could understand and respond to the emotional needs of hospitalised children (Burr 2001; Davies 2010).

There is no doubt that the care of hospitalized children has been transformed since the publication of the Platt Report in 1959, hospital staff now need to embrace parents as partners in care within a philosophy of family centred care (Darbyshire 1994, Coleman 2002). Today children's wards and departments are expected to provide engaging and aesthetically pleasing environments where play is encouraged (Soanes et al. 2009; Bishop 2010). However there is evidence that hospitalization remains psychologically challenging for children. Boyd and Hunsberger (1998), in a qualitative non categorical study on repeated hospitalization of children with chronic illness, found that children perceived the stressors of hospitalization to included, invasive procedures, surgery, fear of death, lack of independence, loss of control, isolation from peers, lack of activities resulting in boredom, and an environment that was noisy and lacked privacy. The study concluded that children who are repeatedly hospitalized develop coping mechanisms such as distraction techniques, seeking support from family and professionals, and gaining self control to help them deal with the stressors of hospitalization.

These findings were supported in a qualitative non categorical study by Sartain et al. (2000), who conducted semi-structured interviews with 6 children with a chronic illness between the ages of 8-14 years old on their opinions of being in hospital compared to being at home using grounded theory methodology. The findings of the study showed the children reported that being in hospital disrupted their usual routine, and that it was boring. The children were concerned about missing school and playing with friends. The children's opinions were not sought, and this annoyed some of the children who felt left out of the decision making process. Again the children tried to minimize the effects of being in hospital by bringing in familiar items from home such as a duvet, and setting up their own play areas. The children also reported that they got used to being in hospital but would rather have been at home. One child stated there was nothing positive about being in hospital except being able to leave the hospital ward with her family when they visited. By involving children as participants in this study Sartain et al. (2000) have shown that it is possible to give children a voice regarding issues such as their experience of hospitalization, and that their contribution as service users is as informative as that of adults.

A qualitative study by Salmela et al. (2009), described hospital related fears of children between the ages of four and six years old. Within the study ninety children were interviewed about their fears of hospital, sixty three children in the sample were interviewed in school and 27 were interviewed in hospital. The results showed that 48% of the hospitalised children expressed seven or more fears, where as only 24% their healthy peers in school expressed more than seven fears related to hospitalisation. The study also found that the most common fears expressed by children surrounded nursing procedures such as giving of medication, injections and taking samples. The study concluded that a major finding was that hospitalised children demonstrated more fears related to hospital that their healthy peers. However a level of caution is necessary here as the hospitalised children may have reported more fears due to being exposed to a strange environment, investigations and treatment which their healthy peers would not have experienced.

Thruber et al. (2007) concluded that hospitalized children suffer from homesickness which they defined as 'the distress or impairment caused by an actual or anticipated separation from home. It is characterised by acute longing and preoccupying thoughts of home and attachment objects' (p.2). They found that trepidation regarding hospitalization, expectations of homesickness, and distance from home were the strongest predictors of homesickness in children. The study concluded that in order to minimise homesickness it is vital to establish good orientation procedures to the hospital environment, give consistent messages regarding treatment and possible length of admission, involve parents in caring for their child, and encourage children to bring reminders of home such photographs or other personal comforters into the hospital environment.

All of these studies suggest that children dislike being out of control of their situation and environment, and that they miss the normalizing factors of being at home such as playing with friends and going to school. Angstrom-Brannstrom et al. (2008), state that children frequently rely on comforters, family and friends to provide them with security and comfort whilst in hospital. A further significant factor in reducing the effects of hospitalisation on children is to provide appropriate play facilities and staff within the hospital environment. Play in hospital helps children to cope with stressful experiences (Chambers, 1993), and suitably qualified play specialists can help children to prepare for painful procedures, provide diversion techniques and normalise a strange environment (Webster, 2000; Knight and Gregory, 2009). The National Service Framework for Children, Young People and Maternity Services in Wales (WAG, 2004a) state within Standard 1 that the provision of an appropriate environment with play and recreation facilities is an essential requirement for services that provide care to children and young people.

A further evaluation of children's perspectives on managing their chronic illness is to explore their experience of being cared for in hospital with being cared for at home. However although there is a body of research which describes the experiences and perceptions of parents regarding both hospital (Darbyshire, 1994) and home care for example (While, 1991; Kirk, 1998; Kirk et al. 2005; Wang and Barnard, 2008) there is less published literature on these issues in respect of children's experiences. Early studies on paediatric home care that have included children's level of satisfaction include (Jennings, 1994 and While, 1991, and 1992).

Jennings (1994) study aimed to evaluate a hospital at home scheme in an English health authority. The researchers sent out a questionnaire to 290 families from a random sample of families who had received care from the hospital at home scheme in the previous 18 months. They also sent questionnaires to 32 children who were over the age of 6 years these were accessed via their parents. Fifteen children (47%) responded to the survey, they concluded this may have been due to the time delay between the study and the home care visits. The results showed that 12 of the children who replied would have chosen home care again, and that the best things about being at home were having family, friends and familiar surroundings. The parental evaluations concluded that 79% of the sample would have chosen home care again and 60% felt that home care was less stressful than hospital care. These findings support the work of While (1991) who also found that children preferred home care.

While (1992), in a qualitative study of 40 families compared parents and children's satisfaction with hospital and home care. The results suggest that parents are more satisfied with home care than hospital care and express a preference for home care. The reasons given by parents for preferring home care are that they feel their children are more relaxed and happy at home, and that it provides normality for the child and family. This research also highlighted that parents require a great deal of information regarding their children's care, and that parents can feel pressurised into caring for their child at home. Children that participated in the interviews stated they found hospital a boring place, they disliked invasive procedures, and being woken up my medical staff. The children preferred home care and explained it that it was nice to remain at home with their family where they had their own toys and could do what they wanted. The children gave no negative reasons for staying at home and stated they would prefer to remain at home and receive care there if they became ill again.

This research recognised that the data they collected regarding children's experiences were very limited and out of the 40 families only a total of nine children were interviewed. While (1992) suggest this was for various reasons such as some of the children were too young to be interviewed, some were at school when the parents were interviewed and one child was too ill to be interviewed. These explanations however, do not demonstrate that this study was particularly focused on the views of the children, as a research study that has its primary interest in children's experiences would ensure that the researcher visited the family during an optimum time to secure an interview with a child participant.

A study that aimed to elicit children's experience of hospital and home care was that of Sartain et al., (2001), they conducted a qualitative research study that compared 40 families experience of hospital and home care. This was part of a larger randomised control trial with a population of 399 patients evaluating the clinical and cost effectiveness of a paediatric hospital at home scheme for children with acute illness. Within the qualitative study 11 children aged from 5 years to 12 years participated in semi-structured interviews (lasting 10-15 minutes), 6 children had been cared for in hospital and 5 by the hospital at home scheme. A drawing technique was chosen as a method of augmentation, these were completed whilst the parents were interviewed. The children's stated the best things about their hospital stay were the facilities such as the playroom, school, computers, and making friends. The negative aspects included boredom, taking medication and being woken up at night. When questioned about home care, the children explained that at home they felt more secure, they could play with their own toys, were not separated from their siblings and other parent. One child was reported as saying 'everything' was better at home. The parents offered more information on their satisfaction with nursing care both in hospital and at home. There was an overwhelming preference for home care as they perceived this as causing less disruption to the family, and provided a better environment for the child to recover from their illness. They also felt home care was less restrictive and less costly than hospital care. The parents also reported feeling reassured, and supported by home care which again echoes other studies (While, 1991, and 1992; Jennings, 1994; Peter and Torr, 1996; Kohlen et al., 2000). The limitations of this study include the small sample size and that the children had an acute illness. This would suggest their experience of hospital and home care to be qualitatively different to children with a chronic condition where their periods of hospitalization may be longer and recurrent, and that home care would include long term management of their illness.

There are few contemporary studies that focus on children's subjective experience of home care. However one Canadian study did explore the experience of home ventilation from the children's perspective. Earle et al., (2006) conducted a noncategorical study using case study methodology the aim of which is to provide an in-depth investigation of a single subject, family, or group (Dempsey, and Dempsey, 2000; Polit, and Tatano, 2006). The sample of 5 children aged 4 years to 17 years old was purposely chosen to represent a wide age range, the children had all been ventilated at home for at least 2 years, and were English speaking. The children participated in semi-structured interviews to explore their views on home ventilation. The data was thematically analysed and four themes are said to have emerged *'it's ok, it helps me breathe,* this theme described the children's acceptance of living with technology, and that this was not seen as a central issues for them but only one part of their lives. ' *the medicalization of childhood'* within this theme the children described their familiarity with medical equipment and procedures. The children were found to be very knowledgeable about their medical care, one child was observed reconnecting herself to her ventilator without any help. *'being a child'* even though their daily lives revolved around medical care and technology the children strived to be like other children, four of the children attended school regularly, friendships were important to all the children, and they took pleasure in participating in activities and hobbies with other children, and saw the technology as a small part of their lives. Within the themes the children demonstrated they had *' hopes for the future'* as the children all had a positive view of their future, however there was a focus on getting rid of the ventilator and ' *becoming someone'* was also dream for these children.

While Earle et al.'s, (2006) study does not specifically address the children's experience of home care, it does reflect many of the important issues for children with a chronic illness that have been highlighted in other studies. These issues include normalization of life experiences (Woodgate, 1998; Herrman, 2006; Protujer et al., 2009), as the children in Earle et al's, (2006) study defined themselves as ordinary active children who had no desire to focus on their need for ventilator support. Noyes (2000) in contrast found that medically stable ventilated children who remained in hospital did not wish to be there. The environment was shown to have a profoundly negative effect on the children who did not feel valued, and remaining in hospital reinforced feelings of loss of purpose and significance in their lives. This again was a small study however the findings suggest that children perceive their lives as far more positive when they can receive care at home. This is supported by Soanes et al., (2009) in a longitudinal exploratory study that aimed to gain an understanding of the health care experiences of children with a brain tumour. The research findings showed that being treated for a brain tumour affected all aspects of the child's and family's life, and that being able to have treatment at home was one of the key things the children reported would have made life better for them.

Improvement in quality of life between hospital and home care was also the subject of research by Speyer et al., (2009) who concluded that the children and parents scored their quality of life for home stay as being higher than when the child was in hospital. Speyer et al., (2009) compared parent and child agreement on Health Related Quality of Life (HRQoL) for children with cancer during a stay in hospital and a stay at home. This was assessed by the parent and child versions of the Child Health Questionnaire. The results of the research study showed that the parents had lower estimates of their child's HRQoL than the children themselves. Differences in reports by parents and children on issues such as health related quality of life (HRQoL) and their preferred methods of health care have been noted by authors such as (Guyatt et al. 1997; and Foster and Varni, 2002).

This again leads me to the conclusion that children should be seen as highly informed experts on their daily lives (James and James, 2004), and should be routinely consulted about their health care needs and experiences, as these will differ from those of the adults who care for them. Nevertheless as children are not seen as consumers of health care any choices about where they are cared for are almost always mediated by parents or other adults and therefore children are marginalised from the decision making process (Jones and Welch, 2010). Coad and Shaw (2008) concluded that giving choice to children about their health care still has not been fully realized. However, the United Nations Convention on the Rights of the Child (UNCRC, 1989) article 12 informs us that children have the right to express their views on all matters that affect them, and Alderson and Morrow (2004) remind us that children should be viewed as highly informed experts on their daily lives. Therefore, what is lacking from the literature are contemporary studies that build upon the work of authors such as While (1991, and 1992) and Jennings (1994) to explore children's views and experiences of home care. This reflects the dearth of research on children's experience and perceptions of health care, and particularly research on whether children with a chronic illness perceive the care they receive at home facilitates their management of their condition.

2.5 EVOLUTION OF HOME CARE

Within the previous section I have shown that children should be consulted about where they would prefer to be cared for when they are unwell. I now move on to examine the philosophy underpinning the development of home care for children and critically evaluate the reported availability of such services within the United Kingdom.

The benefits to children of home care as opposed to hospitalisation, has been evaluated in the previous section (While, 1991, and 1992; Tatman and Woodroffe, 1993; and Jennings, 1994). These classical studies were concerned with the development of home care schemes and evaluating the provision of a new type of service for children and families. They recognised that children were spending less time in hospital, and that transference of the care to community was becoming more common due to shorter hospital stays, an increase in day surgery, advancement in technology and changing patterns in child morbidity. This combined with a change in professional opinion regarding parental ability to meet the needs of their sick child (Callery and Smith, 1991; Darbyshire,1994 and 1995), and changes in health policy first recommended by the Platt Report (MoH 1959) which strongly advised that children's health needs should be met in the community and to this end stated that 'too few local authorities as yet provide special nursing services for home care of children – the extension of such services should be encouraged (p.5), led to the recognition that services that could support sick children in the home were highly beneficial.

The historical development of home care is multifaceted, and according to Lessing and Tateman (1991) it was originally a service that was provided to the rich within their own homes before the advent of scientific medicine. Hospitals however were originally charity institutions which cared for the destitute alongside the sick. The first home care scheme to be set up was in Rotherham in 1948 in response to an outbreak of gastroenteritis which led to a high level of infant mortality (Whiting, 1998), further services followed in Birmingham and Paddington in 1954. However, the next twenty years saw little development of such services and in 1970 there were still only 5 schemes rising to 7 in 1980. However an expansion began at the end of the 1980's and by 1991 there was reported to be 46 schemes in the United Kingdom (Lessing and Tateman, 1991).

2.5.1 Expansion of Community Children's nursing Services

Various factors have been attributed to the expansion of home care, policy documents such as Children First: A study of Hospital Services (Audit Commission, 1993), and the Health of Children in Wales (Welsh Office, 1997) recognised that investing in community children's nursing services would prevent unnecessary hospital admissions, promote earlier discharge home, and result in financial savings due to the growing cost of inpatient care. The average cost of caring for a child in a paediatric intensive care unit is now £2,067 per day which equates to £754,455 annually, in contrast the cost of a community care package for a ventilator dependent child would be somewhere between £100,000 to £250,000 per annum (Murphy, 2008). The RCN/Well Child (2009) campaign Better at Home found that the financial savings to the NHS of caring for a child requiring long term ventilation support at home as opposed to hospital are between £140,000 and £470,000 per year.

Recommendations from the National Service Framework for Children Young People and Maternity Services in Wales (WAG, 2004a), and the Community Nursing Strategy for Wales (WAG, 2009a) stated that a children's community nursing service should be available to meet local needs in every area of Wales and that community care must be seen as the norm with time spent in acute settings kept as short as possible, and that care and expertise must follow the patient, so that children can receive care as close to home as possible.

To reiterate recent recommendations I highlighted in the introduction of this thesis the RCN (2009a) recommended that for an average sized district with a child population of

50,000 a minimum of 20 whole time equivalent (Wte) CCNs are required to provide a holistic service, this is in addition to any child specific continuing care investment. The availability of such a service in Wales remains poor even though there is evidence to show the benefits of such a service to both clients and the NHS. Indeed a report by Davies (2010) on Community Children's Nursing Provision in Wales calculated that to meet the RCN target there should be 280 CCNs across Wales. To achieve this there would need to be a six fold increase in the numbers of CCNs that at present stands at 40-45 (Wte). Carter and Coad (2009) state in their review of community children's nursing in England that even though there has been an increase in CCN teams there are still children who are unable to access care from a CCN, and one of the recommendations from the review was 'access for all children and young people to community children's nursing services and a continuing shift in services from hospital to home' (p. 44).

The development and expansion of CCN teams was the focus of research by Eaton (2000) who over ten years ago commented that 'as yet not every child has access to a CCN scheme should the need arise' (p.41). The main focus of Eaton's research funded by the Wales Office of Research and Development for Health and Social Care was on the models of care provision for CCN services. Eaton (2000), and While and Dyson (2000) identified two predominant overarching models of home care teams. Firstly a community based model which provides care to sick children within a geographical area, and secondly a hospital outreach model, which is usually focussed on a specific client group such as children with diabetes or cancers. Eaton (2000), the Royal College of Nursing (2000) and Carter and Coad (2009) all state that community children's nursing services have evolved in an ad hoc way responding to local needs, because of a lack of national strategic planning and commissioning of such services.

While and Dyson (2000), conducted a quantitative research study to ascertain the characteristics of paediatric home care teams in England. They utilised a postal survey technique of all services in England (n = 137) listed in the 13th RCN Directory of Community Children's Nursing Services. They received an 85.5% response rate to their questionnaire. The results showed that 54.6% of the teams had been developed after

1990, echoing previous conclusions regarding a boom of development at this time (Lessing and Tateman, 1991). Almost half (48.6%) of the teams were funded by hospital trusts, and 72.8% were managed within acute directorates, and therefore not surprisingly over three quarters of the teams (77.8%) were based in hospitals. The teams varied in size from the smallest comprising of one member, to the largest comprised of 26 staff. The vast majority of teams offered a service during office hours from Monday to Friday, with a third (32.4%) providing a service at weekends and 16.7% of teams providing an evening service. However only a small number of teams provided a night service (5.6%), but 37% teams provided special arrangements for terminally ill children. The caseloads showed that care was provided for children from 0-16 years, with reported caseloads of between 20 children in some teams to above 100 in others, although caseload analysis was reported as unreliable due to constant change. The majority of the caseloads were acquired from hospital referrals (98.2%), with the remainder coming from community sources. The findings show that care and support was provided to children with a wide range of conditions by 86 teams, with 23 teams providing more focused specialist care. This research focused on the characteristics of the teams identified from the RCN directory, and therefore did not provide information about the geographical provision of CCN teams and whether there remained an unequal availability of home care services to children dependent on their post code rather than on clinical need.

Community needs assessment and community profiling are processes that can determine individuals and groups within the community who are in need of a particular service (RCN, 2000). Community children's nursing caseloads should take account of issues such as, the changes in child health with a rise in the incidence of chronic illness and life threatening conditions, that children are being discharged from hospital 'quicker and sicker' (Audit Commission, 1993), reduction in length of hospital in patient stay and the preferences of service users. This needs to be combined with an assessment of the geography and needs of the population to be served. While (1991), found that the scheme in her study provided more resources and support to families who were in the greatest social need. Cramp et al. (2003) found that CCN teams with predominantly acute case loads report a much higher annual case load than teams who care for a high level of children with a chronic condition. However, research or audit that concentrates on quantitative data often does not reflect qualitative issues for example, within acute case loads the children are more likely to have minor health issues, require less intense visiting and be discharged from the scheme much sooner than children with complex health needs. Therefore statistics alone can not reflect a holistic picture the workload of a community children's nursing service.

Research by Danvers et al. (2003) aimed to identify the strengths and weaknesses of a multi-professional service for children with life limiting illness As a memorial to the life and work of the late Diana, Princess of Wales, the Treasury in 1998 provided funding of 4 million pounds to set up ten Diana children's community nursing teams throughout the United Kingdom over a period of three years to provide palliative care for children with life-limiting illnesses, provide nursing care and practical and emotional support for children and their families at home. The study collected data from professionals and parents to address the overall aim of assessing the extent to which the Diana Team in Leicestershire were meeting the needs of children and their families. This study concluded that the team felt there was an improvement in inter-professional working, and that a number of links had been made with various hospitals. However there was concern over the way the service interlinked with pre-existing services in the community. Overall the research showed that the team was successful in meeting their identified objectives and partnership working was vital to ensure the continued development of CCN services in the UK. Although the research states that parents, children and professionals identified issues on the service, the paper only reports on the views of the professionals so it is impossible to evaluate how the children and their families evaluated the scheme. Many of these teams have now disbanded due to a lack of investment. They would appear to be a casualty of the lack of a national strategy to fund, to sustain, and expand community children's nursing services even though there is a wealth of evidence to support the view that children with a chronic or life limiting condition have a better quality of life when cared for at home supported by nurses with the relevant expertise.

The limited availability of a CCN service to children and young people was also identified more recently by Carter and Coad (2009) and Davies (2010), who both reported a lack of a twenty four hour service and Davies (2010) stated that there were no CCN teams within Wales who were able to provide a 24 hour 7 days a week service. The standard working hours between 9am -5pm Monday through to Friday were viewed as restrictive by Carter and Coad (2009) as it does not fit the needs of children and their families and often results in disruption to family life.

Studies that have been conducted outside the United Kingdom on the experience of home care for families include Kohlen et al. (2000), Fawcett et al. (2005) and Nuutila and Salantera (2006), although not exclusively focussed on community children's nursing identified important tissues for parents when their child receives care at home by professionals. These include the need for continuity of care, nurses who can adapt to the needs of the child, knowledge of the child and family, and the development of a collaborative relationship.

Fawcett et al. (2005) conducted a cross cultural study to examine the experience of parents caring for children with chronic conditions in both Hong Kong and Scotland. The study found that there were culturally different expectations between the groups regarding their child's health care. Parents in Hong Kong emphasised self reliance and had little expectation of any emotional support for the family, whereas the Scottish families had a greater expectation that the family's needs would be met by health care professionals. Both groups demonstrated a sense of loss of normal life, family conflict, isolation and uncertainty, they also highlighted that there were rewards associated with caring for their sick child. This study's findings are limited by the differences in health care experiences between the two cultural groups however it also shows that parental reactions to caring for a child with a chronic illness are similar wherever they live.

My evaluation of the literature on the development of the CCN service within the United Kingdom, and has shown how the service can be of benefit to children with chronic conditions and their family. Unfortunately I have also identified that the CCN service is still limited in many areas due to a lack of a national strategy for service development. Within the next section I have analysed the skills of the CCN and demonstrate that although there are a few exceptions this has been studied almost exclusively from the perspective of professionals, or parents of children with a chronic illness and again shows that the children themselves have not been included in the research process.

2.5.2 Role and Skills of the Community Children's Nurse

The delivery of nursing care to children within their own homes requires special and comprehensive nursing skills (Byrne, 2003; Pontin and Lewis, 2008a). The role of the CCN is complex and multifaceted, and includes facilitating independence in children and families, the maintenance of normality (Pontin and Lewis, 2008a), the building of a trusting supporting relationship with families, and maintaining continuity of care (Carter, 2000; Pontin and Lewis 2008a). The Nursing and Midwifery Council have continued to use the Standards for Specialist Education and Practice set out by UKCC most recently in 1998 as a requirement for CCN practice. These standards aim to ensure that CCN's are able to demonstrate high levels of judgement and decision making in clinical care, so that they can provide a skilled, specialist resource for children and their families (RCN, 2002). However the Community Nursing Strategy for Wales (WAG, 2009a) identified that the Specialist Practitioner Qualification (SPQ) is 'outdated, inflexible, and in need of modernisation to meet the changing health care agenda (p. 87)', thus demonstrating that community nursing, which embraces community children's nursing is high on the government's changing health agenda. In light of this the Welsh Assembly Government has introduced a flexible modular route of study for the SPQ that allows practitioners to achieve this qualification at a pace that is suitable for them and for the practice arena.

Work by Gow and Atwell (1980), described the role and function of the CCN within a paediatric home nursing service in Southampton as facilitating early hospital discharge, caring for physically and mentally handicapped children, providing medical care such as giving injections, managing children with a chronic illness, accepting GP referrals to avoid unnecessary hospitalization, and providing terminal care. Other functions identified included teaching, and liaison with other professionals. Contemporary community nursing practice requires CCN's to be flexible, skilled, and confident expert practitioners (Carter, 2000), who can demonstrate high levels of judgement and decision making in clinical care (UKCC, 1998).

Carter (2000), in a qualitative study examined the role and skills of the CCN, finding that although technical expertise and knowledge about a variety of conditions was seen to be important, the softer skills such as empathy, compassion, facilitation and listening were thought to be essential to CCN practice. This type of knowledge for practice is referred to as 'tacit knowledge' (Polanyi, 1962 cited in Rolfe et al. 2001), and is knowledge that is impossible to put into words. Benner (1984) argued that tacit experiential knowledge is the hallmark of expert practice. However, capturing expert performance is difficult as experts have a deep understanding of complex situations and know more than they can say. Byrne (2003), points out that the work of nurses who care for children in the community is largely invisible and that standard documentation does not capture the intricacy and breadth of nursing knowledge used to care for children with chronic and life threatening conditions.

Similar skills were described by Pontin and Lewis (2008a), in a qualitative action research study that aimed to generate an insight into CCNs' perceptions of workload. They found that helping families maintain their usual family life was a central feature of how the CCNs' defined what they did. Within the study, the CCNs' described achieving this by promoting family independence and by being proactive to ensure families maintained contact with the service. Getting to know the families was seen as vital to enable the CCN to act as an advocate for the child and family if needed, and lastly providing purposeful visits by articulating the reasons for the visit and anticipated outcomes, acknowledging that others may view the work of the CCN as nebulous. However the CCNs also recognised that actual events could supersede the original planned aim of the visit due to changed circumstances of the child or family. Within this research the CCNs' were able to demonstrate the invisible work of expert practice. Following on from this Pontin and Lewis (2008b) found that CCNs work to maintain consistency in care delivery by managing their case loads to maximise continuity of care for a child and family.

There is a dearth of research studies that have exclusively focussed on the experiences of children who receive care from a community children's nursing service. The research on the role of the CCN has almost exclusively been conducted either with the professionals themselves or with the parents of children who are receiving care from a CCN team which only provides two thirds of any story. A number of studies have documented issues that are important to both the professional and to parents when caring for a sick child at home such as, support and working in partnership with families and other professionals (Cummings, 2002; Danvers et al. 2003; McIntosh and Runciman, 2008), the development of trusting relationship between the professional and the family (Nuutila and Salantera, 2006), and the co-ordination of care by a key worker (Fawcett et al. 2005), however what is missing from the literature is whether these are issues that are also important to the children themselves.

The following research did include one child as a participant however there was no discussion in this article on this child's views regarding the service they felt they required. An action research study by Whyte et al. (1998) in which the CCN team brainstormed areas of concern within their practice identified a number of issues including fragmentation of care, an awareness of social problems, and gaps in the service provided. The study set out to enquire into the parents' perceptions of the service that was provided to them by the CCN team. A convenience sample of twenty six patients was randomly chosen from the CCN caseloads and 21 families were included in the study as four declined to participate and one was used for the pilot interview. The participants (mothers *n* =19, fathers *n = 2, child* = 1), were interviewed in their own homes and asked about the quality of the service and gaps in the provision. The parents gave detailed accounts of care provided by the CCNs this included, advice, support and listening, home visits, telephone contacts, monitoring of the child's progress and supervision of caring skills. Interestingly most of the participants felt they did not get enough information on hospital discharge, and would have liked more support when their child became unwell.

The mothers in the study most commonly saw themselves as the child's key worker, and only three named the CCN as the coordinator of the child's care. The findings of the study show that parents require information about their child's physical needs, the services and benefits available to them, they want a trusting relationship with a knowledgeable professional, and they also need one person to coordinate care and to be seen as part of a cohesive team. Although informative this research does not provide a holistic perspective of the consumers needs as there was no inclusion of the child participant's perceptions of the care they received or if the care provided met their individual needs.

One research study that focused exclusively on the feelings and experiences of children was that of Carter (2005) who explored children's perceptions of the Salford Diana Team. This research accepted that children can be co-researchers within a study demonstrating a respect for children as co-constructers of their world. Ten children between the ages of 2-13 years old participated in the study, and the data was generated by the children using a variety of methods including, audio tape, video tape, photographs and drawings. The results of this study showed that the children wanted the nurse to be competent to provide care and used their parents as their benchmark of excellence (Carter, 2005). The children expressed that they understood that the nurses made a difference to their family's life, as their parents were given time away from the responsibility of caring for their child. Clearly the children were aware of the complex skills identified in an earlier study by Carter (2000) of empathy, compassion, facilitation and listening as the children described the nurse as being-there as a support for their parents. The research also strengthens the argument for extending a care at home service as the children clearly showed a preference for being cared for at home as opposed to frequent hospitalizations. This study has demonstrated that young children have opinions about the care they receive, and are able to articulate their feelings when they are seen as active participants in a research project.

The role of partnerships in home care in two service evaluations was explored by McIntosh and Runciman (2008). Within their qualitative study they conducted in-depth interviews with parents (*n*=17), and professionals (*n*= *20*), the researchers did consider including children in the study however they concluded that the majority of the children receiving care were infants, therefore the number of children who could be interviewed was deemed too small. The results showed that in both services there was evidence of extensive partnership working, and that the development of partnerships involved sharing of knowledge and expertise, the development of trust and processes of negotiation. The data also suggests that trusting relationships between parents and professionals are characterised by critical listening, respect, sharing of expertise and empathy for parents and children. Partnership working requires knowledge and skills, and can prove to be resource intensive, however it is central to effective service delivery and not something to be taken for granted.

There is a wealth of literature on promoting partnership working in children's nursing, much of it influenced by the work of Ann Casey (1988, and 1995) and the development of the Partnership Model of Care, based on negotiation and respect for the wishes of the family. This model states that 'the care of children, well or sick is best carried out by their families, with varying degrees of assistance from members of a suitably qualified health care team whenever necessary' (p. 8). This model recognises the need for the child to receive continuity of care, and for the family to act as primary care givers whilst remaining as a functioning whole (Nethercott, 1993), and can encompass nurses who work in the community as well as in the hospital (Taylor, 2000). Partnerships imply the belief that partners are individuals who become capable by sharing knowledge, skills, and resources in a way that benefits all participants (Campbell and Glasper, 1995).

Partnership is one of the main concepts of family centred care (FCC) which has become a central tenet of children's nursing (Coleman, 2010). Ahmann (1994), suggests that FCC is underpinned by professionals recognising the central role of the family in the child's life, and that the family should be as actively involved in their child's care as they choose, which requires a collaborative partnership between the professionals and the family. A contemporary definition of family centred care is offered by Smith *et al* (2010) as '*the professional support of the child and family through a process of involvement, participation and partnership underpinned by empowerment and negotiation*' (p. 31).

According to Fradd (1994) the CCN is in an ideal position to ensure that parents are supported and encouraged to become actively involved in the child's care. Taylor (2000) comments that the main role of the CCN is to facilitate parents to care for their child by offering support, teaching and caring achieved by mutual goal setting and decision making. Similarly Sidey (1990), states that FCC at home in partnership with the CCN can extend normal parenting to embrace the needs of the sick child whilst maintaining family normality. Franck and Callery (2004) warn, however, that there can be tensions between the interests of children and other family members and that there may be important differences between the perspectives and objectives of children and that of their families, and that in some instances children are best placed to make their own decisions. Alderson (2007) points out that there are four levels of decision making, to be informed, to express an informed view, to have that view taken into account when decisions are made, and to be the main decision maker about proposed interventions if competent to do so and potentially subject to supervision of the courts (p 2277). Alderson (2007) argues that children are often left out of the highest level of decision making as it requires taking responsibility for the outcome of the decision, and that children are viewed as incapable of understanding relevant information and therefore cannot act in their own best interests. However this fourth level of decision making is enshrined in UK legislation if the child is deemed to be Gillick competent (Balen et al. 2006). Gillick competence is defined as having the 'sufficient understanding and intelligence to understand what is proposed' and, 'sufficient discretion to enable a child to make a wise choice in his or her own interests' (Alderson and Morrow, 2004 p.99). Government reports, notably Learning from Bristol (DOH, 2002), highlighted the need for children to be involved in decision making, and that they have a right to make choices about their care based on information provided to them which is sensitive to their level of understanding, and the National Service Framework for Children, Young People and Maternity Services in Wales (WAG, 2004) states that it '*supports the participation of children and young people in decision making at all level of service delivery*' (p.18). The report also states that parental views should be respected, and sought about their child's care and treatment however it recognises that as the child matures their wishes may conflict with those of the parent or carer.

In 2009 Carter and Coad were commissioned to review the community children's nursing service in England. The aims of the review focussed on what was already working well in CCN practice in England and how well it was meeting the needs of children and their families. The review also attempted to identify the future developments within CCN practice. The results showed that families valued the service and that the CCN was seen to work in collaboration with families. The participants reported that CCN's need to be friendly and approachable with good listening and communications skills and that they should demonstrate a non judgemental attitude echoing earlier results by Carter (2000). A further finding was that having access to a CCN helped families maintain normality in their lives which was also identified by authors such as Woodgate (1998), Herrman (2006), and Protuder et al. (2009). The professionals who participated in the review stated that they felt they were 'highly competent, autonomous, skilled professionals who gave high quality care delivery to individual and collective groups of children and families' (p. 19). The review also identified issues of concern to both consumers and professionals, these included, pressure on parents to provide care for their child due to a limited CCN service based around standard working hours, and CCN teams working at caseload capacity with not enough staff to care for children effectively. The professionals identified inequitable services to families fostered by a lack of government policy direction, and the CCN's expressed their concern at the lack of professional identity associated with CCN practitioners. These findings again strengthen the argument for providing a 24 hour comprehensive CCN service for sick children and young people. Carter and Coad (2009) chose a method for the project that would 'enable children and young people to contribute to the study' (p.7), and the methods adopted in the review included art based projects, interviews, an on line discussion group and involvement in a core advisory group. However Carter and Coad (2009) recognise in their findings the challenges of recruitment to the project as they had only been able to recruit five (n-5) children and two (n-2) young people to the study which they contributed to the time frame of the project which spanned school term time and good weather which may have influenced families to use their free time to do other activities. This reiterates how difficult it can be for researchers to recruit children and young people to take part in research even when the researchers have made every effort to ensure their research adopts an approach that would appeal to children and young people.

Within this section of the literature review I have evaluated the evolution of home care for sick children, and the development of the role of the community children's nurse. I have highlighted that the limited expansion of a CCN service to all children with the UK remains an issue both for professionals and the consumers of health care. The vast majority of the research conducted on CCN practice has been with either professionals or adult carers and this has demonstrated a gap in research in respect of children's views and experiences of care they receive at home from a CCN.

2.6 CONCLUSION

Within this chapter I have explored the literature on chronic illness in childhood. The first section aimed to demonstrate children's concepts and understanding of their bodies, health and illness, and the differences of opinion as to how these develop. The most dominant perspective was that of the stage/maturation model where the child's understanding is seen to be sequential, and governed by cognitive development. Alternatively there is now research evidence that emphasises the role of the child's experience, and that children who have a chronic illness may demonstrate a more mature understanding of illness than a healthy child of the same age.

Secondly I critically analysed the literature in respect of children's experience of living with a chronic illness. Important issues to emerge here were concepts of normality, locus of control, the need for children with a chronic illness to be accepted by their peers, and the need to take responsibility for their own health.

Thirdly I focussed the review on what children with a chronic illness feel they need to manage their condition. Implicit within this literature was that children need to be treated as individuals, have support from family, friends and professionals and be involved in the decision making about their care and treatment, and that children find hospitalization stressful and boring. Although the research is limited there is evidence to suggest that children with a chronic illness would prefer to be cared for at home.

Lastly within this the literature review I evaluated the evolution of home care for sick children within the UK. I identified within the literature a lack of resources and cohesive national planning to develop a nationwide comprehensive and equitable CCN service. However there is evidence to show that the CCN service is valued by parents of children who have a chronic or life limiting condition, and that home care is more beneficial to the child and family than repeated hospitalisation. This evidence extends to service evaluations that show home care can influence the cost of healthcare by shortening hospital stays, and preventing recurring hospital admissions. Finally I again identified a lack of research studies that have evaluated CCN services from the perspective of the most important consumers the children themselves.

In summary this review suggests that there is a need to build a body of research that recognises that children have vital information to give about their experiences of care and in particular home care. In the next chapter I have provided a detailed discussion on the methodological issues involved in my qualitative study where I have used children's stories to describe their experiences of managing their chronic illness at home and receiving care from a community children's nurse.

Chapter 3: Methods

3.1 INTRODUCTION

Within this chapter I discuss how I conducted my research with child participants. My rationale is presented for focusing this study on children's narrative accounts on managing their chronic illness at home. My reasons for choosing to use the Mosaic Approach (Clark and Moss, 2001) as a framework for this study, and my focus on first person narrative accounts are also discussed.

In this chapter I address the complex ethical issues involved in conducting research with children, including gaining ethical approval, conducting research interviews in the home setting, and obtaining informed consent. I also discuss the issues involved to recruit a sample of children for the study, and how access had to be continuously negotiated throughout the study. The chapter reiterates the aims and objectives of the study, and concludes with an overview of the data analysis chapters to follow.

3.2 REFLEXIVITY

Reflexivity defined by Davies (1999) as 'a turning back of oneself, a process of self-reference' (p.4), was a vital element to this research study from the formulation of the research question, through data generation and analysis and in the study's conclusion. Many research studies provide detailed accounts of gaining access to children, however what is often lacking is a discussion of the children's perception of the adult researcher, the extent to which he/she was accepted, and the impact the research has on the life of the child (Greene and Hill, 2005). On a personal level as a reflexive researcher I needed to reflect on my social construction of childhood and how this could affect the research process. The process of reflexivity has required me to examine my own experiences of childhood where I grew up happy and healthily. I am also a mother and more recently a grandmother, and have thankfully not had the misfortune to experience chronic illness in my own children or grandchildren. Holloway and Wheeler (2002) suggest that if the researcher adopts a self critical stance to the research then the study will be more credible and dependable. I was drawn to this quote by Alvermann et al. (1996) who state,

> *'Like it or not, the interpreting I do as a writer tells as much about me as it does about the others' whose stories are being told....I can never separate my own experiences from the experiences of those I write about'* (p. 117)

My aim was to be reflexive throughout the writing of this thesis which I feel helped to bridge the gap between myself and the children who participated in this study. Cocks (2006), suggests that reflexivity can widen the scope of the researcher to hear the voice of the child. I am aware that my writing has been influenced by the paradigm shift within the new sociology of childhood that recognises that children are active participants in the construction and determination of their own lives (James and Prout, 1997).

Until recently children were marginalised in sociology because traditional views on socialization ensured children were seen in a passive role (Corsaro, 1997). I am in agreement with James and James (2004) who maintain that children are no longer the passive output of child rearing practices, but social agents who take part in shaping their childhood experiences. I have tried to ensure that all aspects of this study have been based on these assumptions by engaging the children as co-constructors of meaning which is reflected in their own unique stories and drawings of their experiences of home care.

Using the Mosaic approach provided a framework for me as the researcher and the children to reflect together on issues, the children were not be left out of discussions but seen as central to the research process (Clark and Moss, 2001).

At times during the study I found the children's stories distressing and often marvelled at their resilience and courage. I hope that this study will be a vehicle for the voice for this group of children who courageously told me their stories of how they managed their chronic illness at home.

Conducting interviews in the family home carries a great deal of responsibility, the researcher is the invited guest and must respect the family's private domain. Evidence shows that children are highly sensitive to the context in which the research takes place (Hill, 2005), and that children may be more outspoken in their own home therefore I was aware that where the interviews took place was likely to influence the quality of the children's responses. As a community practitioner I was conscious that I was a guest in the children's homes, however after many years of community practice I felt comfortable within this research setting.

3.3 AIM AND OBJECTIVES

Aim

This study set out to explore children's stories regarding the management of their chronic illness at home.

Objectives

- To examine children's views on the skills they require to so they can manage their chronic illness at home.
- To determine images that children associate with home care.
- To identify children's perspectives of the care provided by the community children's nurse.

3.4 RATIONALE FOR THE THEORETICAL PERSPECTIVE OF THE STUDY

My theoretical perspective for this research was influenced by developments within the sociology of childhood which supports the view of children as 'beings and not becomings', meaning that children should be respected for who they are and not who they may or may not become as future adults (Quortrup et al. 1994, Daniel and Ivatts, 1998, James and James, 2004).

The new paradigm within the sociology of childhood questions ideas that children are naturally passive, incompetent and incomplete and instead promotes the perception that children are 'agentic' (James and Prout, 1997) meaning that children can take part in shaping their own experiences, and can take control of their own lives in interaction with adults. This view acknowledges children have important perspectives to contribute about their lives (Clark, 2004). It questions the traditional exploration of children's lives through the viewpoint of their adult caretakers (Christensen and James, 2000), and makes the point that children's lives are worthy of study in their own right, independent of the perspective of adults.

By conducting research with children I have acknowledged that they are individuals who can act with intention, and are 'experts in their own lives' (Clark 2010). I also feel it shows respect for each child and values their experience of the world. My belief in this philosophy guided this research study to focus exclusively on the children's experiences of receiving home care. I realise this is just one perspective in the multiple reality of a home care situation, for example parents, siblings and nurses caring for children at home can also offer their stories of their own unique experiences. However, from my review of the literature it was evident that there was an abundance of research focussing on the impact of caring for a sick child at home on both parents and nurses for example Knafl et al. (1996); Urquhart Law, (2002); Immelt, (2006). This echoes Scott (2000) who stated that research that does take children into account often focuses on the impact of children on adult lives instead of focussing on the lives of the children themselves. With this in mind for this research study I was motivated to find out more about children's experiences of managing their chronic illness at home.

Although my aim was to conduct this research study with child participants this did not necessarily mean I had to use any different or particular methods, as Christensen and James (2000) point out that children like adults, are capable of participating in interviews, filling out questionnaires and on their own terms allow participant observation of their daily lives. However, some techniques may be more appropriate for use with children and flexible and creative methods are becoming increasingly popular, for example, drawing, collage making, puppetry and drama to name a few (Tisdall et al. 2009). The most important factor I had to consider for this research study was that the method I selected provided the children with an opportunity to tell their own unique story of their experience of home care

As a researcher who wished to describe the experience of children in a particular context, I was looking for an underpinning framework for this study that would encompass the complex issues involved when conducting research into the everyday lives of children with a chronic illness. I feel passionately that children have value in the present, and not for just what they may become in the future (Daniel and Ivatts, 1998) that their voice should be heard particularly when they are the recipients of care or a service, and also that children should be active participants in the research process (Cocks, 2006). The concept of the 'child's voice' is according to Jones and Welch (2010) a metaphor as it is often used to describe how children are not listened to and sometimes silenced by adults who speak for them.

I did not naïvely think that conducting research with children was going to be easy or straight forward, and because of this I recognised the need to engage with the children during the study to ensure I was listening to them and was actually hearing their voices. From an extensive review of the literature on research with children and young people I chose to structure my research study using the principles of the Mosaic Approach (Clark and Moss, 2001). The Mosaic Approach was developed by Alison Clark and Peter Moss during a research project funded by the Joseph Rowntree Foundation to evaluate the Coram Community Campus, a model of multi-agency working which included early years provision, a parents' centre, and a homeless family project (Clark and Moss, 2001).

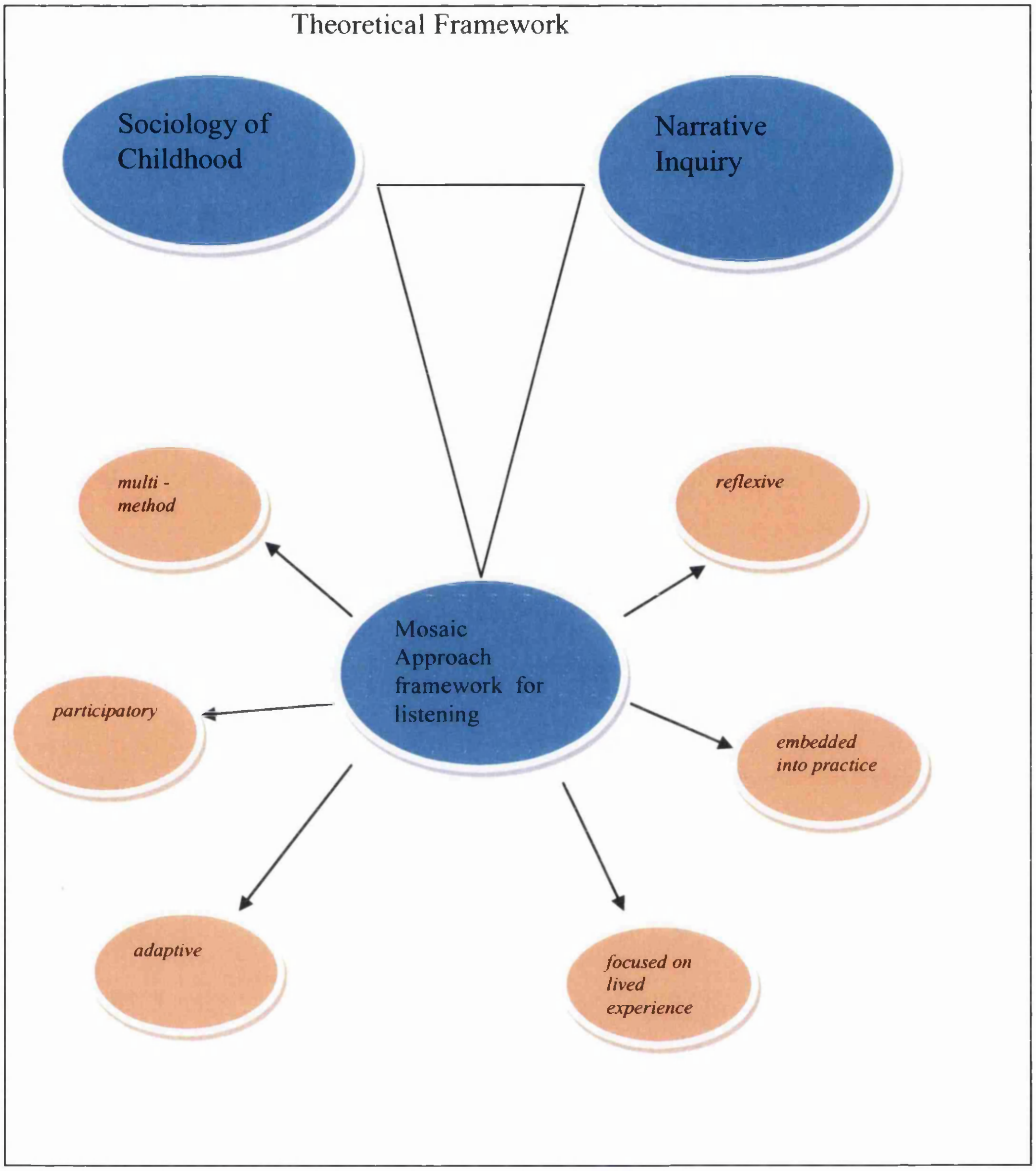
I chose the Mosaic Approach as it is a methodological framework for listening to children about important details of their daily lives based upon the previously described new thinking within the sociology of childhood which view children as 'beings not becomings' (Qvortrup et al. 1994). The Mosaic Approach also embraces the concept of listening to children's voices, and the notion of children's competency, which according to Cocks (2006) has resulted in research that directly explores and encourages children to become involved in the research process

Legislation such as the Children Act (DOH 1989; DfES 2004) places the welfare of the child as paramount, the Act emphasises that the child's wishes and views must be considered, taking into account the child's age and level of understanding. The United Nations Convention on the Rights of the Child (UNCRC) 1989 specifically Articles 12 and 13 promote the importance of ascertaining children's wishes and feelings. In 2012 the Welsh Government has set its proposal 'to "have due regard" to children's rights, when working on or developing proposed new legislation, proposed new policies and any review of, or change to, an existing policy' (WG, 2012b: p 3). The driving force behind these principles is the recognition that children are active participants regarding their lives and therefore have the right to be heard and to be involved in making decisions that affect their lives (Balen et al. 2006). Alderson and Morrow (2004) emphasise that listening to children is central to recognising and respecting their worth.

The Mosaic Approach describes children and adults as co-constructors of meaning and emphasises a way of listening that distinguishes between listening to children and hearing what they say. Roberts (2000) argues that some child focussed approaches may listen to children but the researchers and practitioners may not have heard what they had to say. Roberts also makes the point that theory and practice must link to ensure that the process and outcomes of research are of benefit and value to children.

The Mosaic Approach encourages children to communicate using a range of methods which allowed me to enter the children's inner lives as they shared their unique stories of living with a chronic illness. Children with different abilities and interests were able to be actively involved in the story telling as they used various means of expression such as drawing, using toys and even pets to make their story meaningful and personal. The children were treated as experts and agents in their own lives. This required me to not only see the question from their perspective, but also to recognise their right to their point of view or to remain silent. This participatory aspect shows that the child's views and also their silences were respected.

The framework encouraged and enabled me to practice reflectively as I worked with the children to interpret the meaning of their stories and drawings. Reflexivity is an important but difficult concept in qualitative research as it involves a process where the researcher reflects on their own preconceptions, values and beliefs and how they might affect the research (Monteith, 2004).



3.5 NARRATIVE INQUIRY

Narrative inquiry describes a qualitative research approach in which stories are used to describe human action (Polkinghorne, 1995). It is a way of understanding every day experience, routines, rituals and epiphanies through the stories people tell about their lives (Clandinin and Connelly, 2000). Children are avid story tellers and story listeners from an early age. The stories children tell about their day to day experiences, as well as their memories of specific and special experiences reveal the ways in which they are organising experience (Green and Hill, 2005). Telling stories is important to children as it allows them to express something that may be difficult for them to articulate. Their stories are the first person voice of what they are experiencing and feeling.

There is a growing focus in children's nursing research on using children's stories to articulate how children manage different aspects of their health and illness. Moffat and Johnson (2001) explored the meaning of nicotine addiction among teenage girls, more recently Angstrom-Brannstrom et al. (2008) examined children's experience of being comforted in hospital, and Huus and Enskar (2007) collected children's stories about how they live with diabetes. Carter (2004) warns us that we need to accept children as authentic and credible story tellers, and that listening and hearing their stories is a way of empowering children by giving their stories authenticity and credibility.

Narratives are described as stories with a beginning, middle and an end (Reissman, 1993) and that the stories follow a chronological sequence that order the events though time (Labov and Waletzky, 1967; Bruner, 1990), they involve characters, a setting where the action takes place, and a plot which is a term used to describe the theme or main point of the story (Polkinghorne, 1995). Holloway and Freshwater (2007) define narratives simply as 'continuous stories with connected elements that include a plot, a stated problem and a cast of characters' (p.4). Narratives are reflections and tales of people's experiences; and are a useful way of gaining access to feelings, thoughts and experience (Holloway and Wheeler, 2002). Sandelowski (1991) states that there is an increasing recognition in nursing that narratives affords nursing scholars 'a special access to the human experience of time, order, and change, and it obligates us to listen to the human impulse to tell tales'(p.165). However Atkinson and Silverman (1997) warn of a widespread assumption that personal narratives provide a privileged form of access to individual experiences. Nevertheless narratives are a particularly powerful tool for understanding the fullness and uniqueness of human existence (Oliver, 1998), as they are constructed through interpretation of multiple data sources for example, stories, drawings, observations and journal entries as a means to explore and make sense of individual experiences (McCance et al. 2001).

Polkinghorne (1995) distinguishes between two types of narrative inquiry based on Bruner's (1985) modes of cognition which are paradigmatic and narrative. Analysing data using paradigmatic processes results in themes that span a number of different stories to produce general concepts, where as the outcome of narrative analysis is an individual story built around a plot which gives meaning to the experience.

With the advent of scientific bio-medicine the importance of the patient story diminished to be replaced by objective interpretations of disease through clinical examination and pathology tests. The treatment of disease became dismembered from the individual and became located within body systems only understood by the experts (Bury 2001). However within the twenty first century patients are now referred to as clients and consumers of health care, information about illness is readily available through the media and on the internet which has disempowered medical authority and narrowed the gap between lay and professional knowledge (Gregory, 2010). Bury (2001) states that 'patient narratives, once almost silenced by a paternalistic if not overtly authoritarian medicine, suddenly find a new voice' (p. 268). The decline in infectious diseases on which the bio-medical model was founded and a growing prevalence of chronic illness has resulted in the re-establishment of the subjective patient view (Bury, 2001) as a mechanism for establishing what clients want from their health care professionals and whether they are satisfied with the services they receive. Patient narratives have gained importance as a means of understanding how individuals deal with chronic illness. They are a powerful means through which individuals can give voice to their suffering and experiences (Hyden, 1997; Bury, 2001). Frank (1995) makes the point that when people have a serious illness it is not just their body that is affected but also their voice and that they need to 'become storytellers in order to recover the voices that illness and it's treatment often take away' (p. xii). By listening to children's stories I feel we can learn from their personal experiences, identify what matters to them and provide qualitative evidence to inform health care providers.

Narrative research is often criticised as being journalistic in style and relying on anecdotal information and is therefore not evidence based or scientific (Holloway and Freshwater, 2007). Bruner (1985) observed that scientific and narrative ways of knowing are fundamentally different as science concerns itself with the establishment of truth, where as narratives are concerned with endowing experience with meaning. Hill Bailey and Tilley (2002) suggest that the qualitative researcher wishes to understand meaning and not truth, they cite an extract from Reed (1995) that describes the qualitative paradigm as challenging the modernist quantitative idea of a single, transcendent meaning of reality and the search for empirical patterns that represent the ultimate truth. Narrative accounts therefore can be unsettling as they question traditional thinking by providing multiple interpretations, create spaces for multiple possibilities, and require the acceptance that the world has no fixed rules for giving meaning to behaviour (Oliver, 1998).

Atkinson (1997) argues that narrative writing is only one of the ways of representing what is important in everyday life and that it should not be given priority over other research methods, he also emphasises that 'narrative does not provide a hyperauthentic version of actors' experience or selves' (p. 343). Atkinson (1997) also suggests that narrative writers such as Kleinman (1988) and Frank (1995) portray a romantic agenda that celebrate the story tellers as heroes of suffering, emphasising empowerment and insight into their own problems. Bochner (2001) argues that Atkinson is concerned with 'methodological purity' (p.139) which based on social facts, structural analysis and moral neutrality and it should not 'allow practical, ethical or moral concerns to interfere with the detached observation of sociological phenomena' (p.139). Bochner (2001) in his candid reaction to Atkinson (1997), and Atkinson and Silverman (1997) asserts that they privilege the story analyst over the story without recognising how the analyst becomes part of the story. I feel myself in agreement with Bochner (2001) when he wrote

> *'when I sit down to analyse a story, there's the story,*
> *and, there's me. The meaning of the story is not immanent*
> *in the text. The process of theorizing, analyzing, and categorising*
> *personal narratives is shot through and through with the imagination*

and ways of seeing of the interpreter'. (p.136)

This quote reminds me of how important it is to constantly reflect on the fact that I am the interpreter of the children's stories I have presented in this thesis and that my cultural frames of reference, for example nursing, motherhood and being a grandparent have all influenced my writing and analysis. Therefore I acknowledge that by listening to the children's stories and presenting narrative accounts of these stories I have privileged their voices above those of others. However I am also aware that as Atkinson (1997) points out that narrative writing is only one way of representation among many.

3.6 SAMPLE

Selecting the samples or groups to research is one of the first tasks of a research project. Within a qualitative framework the selection of participants is criterion based, this means that certain criteria are applied, and the sample is chosen accordingly (Holloway and Wheeler, 2002). The purpose of qualitative research unlike quantitative research is not to generalise the results of the research to the whole population (Dempsey and Dempsey 2000), instead the qualitative researcher wants to gain an in-depth understanding of the experiences of individuals or groups and so they deliberately seek out participants who can provide the necessary information. Therefore the identification of an appropriate sample is vital if the aim of the research is to be achieved (Holloway and Freshwater, 2007). Qualitative research adopts non-probability samples which are made-up of participants whose chances of selection are not known. For this research project the sampling method deemed to be the most appropriate was purposive sampling.

To ensure the aim and objectives of this study were achieved I had to ensure that the sample I selected would provide the necessary information. Therefore I utilised a criterion based or purposive sample this is also referred to as judgemental sampling and is a type of non-probability sampling in which participants are selected because they are identified as knowledgeable about the research subject. My sampling choice was based upon the fundamental principles of this research study which are that children are competent individuals who are experts on their own lives. I was interested in the children's perspectives about how they managed their chronic condition at home and I was committed to ensuring the children were active participants in the research project. I established certain criteria and deliberately selected the participants according to this (Holloway and Freshwater, 2007).

The sample for the proposed study were -

Children between the ages of 7 years and 11 years who had a chronic illness and were being cared for at home by their family and a Community Children's Nurse.

Criteria for inclusion in the sample included children who had experience of living with a chronic illness as defined by (Stein et al. 1993*),* and were receiving care from a community children's nurse.

3.6.1 *Sample Size*

The sample in narrative research can rely on a small number of participants as the aim is depth of information rather than breadth. In narrative research the researcher is not aiming to generalise the findings to the population but is concerned with meaningfulness and richness of the data (Holloway and Freshwater, 2007). Morse and Field (1996) state that the principle of adequacy should be applied, this means that the sample will need to provide enough data to develop full and rich description of the phenomenon.

During the early stages of this study the issues of identifying and selecting participants was a topic of discussion between me and my supervisors. We made a decision to aim for a sample of children who met the criteria for the study of between 25-35 participants. This decision was based on our knowledge of the community nursing services within the Local Health Boards, the time scale of the research project, and that as a novice researcher it would give me some parameters to work to. The final sample size was determined by a number of factors –

1 Initially I had planned to access the sample using the CCN's as gatekeepers, unfortunately this was not the most productive, as it was very slow to yield any prospective participants. The number of participants that were recruited for the research using this method was 12.

2 In order to increase the sample size I renegotiated how I would make contact with participants and still use the CCN's as the gatekeepers. It was decided that I should attend the children's outpatient clinics held in the local hospital where I was able to recruit a further 18 participants to the study.

3 When the sample of participants reached thirty my supervisors and myself decided that as I was not obtaining any new information from the participants and due to the length of time I had take to recruit to the study, that I would stop actively seeking participants to the study at this point.

Therefore for this study a sample of thirty children (n=30) who met the sampling criteria were interviewed. The narrative approach to sampling does not include data saturation as each of the stories is unique, however there will also be many examples of common experiences shared by the participants (Holloway and Freshwater, 2007). The following table provides a description of the sample accessed for this study.

Sample Participants

Number	Pseudonym	Age	Condition
1	Rhiannon	11	Diabetes
2	Blue	9	Leukaemia
3	Ellie	7	Leukaemia
4	Jake	10	Diabetes
5	Ruby	9	Cystic Fibrosis
6	Rhian	8	Diabetes
7	John Alumo	11	Diabetes
8	Penny	11	Diabetes
9	Ffion	10	Diabetes
10	Megan	9	Diabetes
11	Tores	12	Cystic Fibrosis
12	Barbie Girl	11	Diabetes
13	Zoe	9	Growth Retardation
14	Suzi	11	Diabetes
15	Vicky	10	Diabetes
16	Alesha	11	Epilepsy and Precocious Puberty
17	Scruf	11	Diabetes
18	Simon	8	Leukaemia
19	Zac	7	Cystic Fibrosis
20	Louise	9	Diabetes
21	Holly	8	Growth concern
22	Hannah Montana	8	Diabetes
23	Grace	9	Diabetes
24	Mattie	10	Leukaemia
25	Donna	11	Diabetes
26	Katie	9	Growth Retardation
26	Atlanta	10	Diabetes
28	Skye	9	Diabetes
29	Josh	7	Cystic Fibrosis
30	Rose	11	Diabetes

3.7 ACCESS

Gaining access to research participants requires approaching what are known as gatekeepers who are individuals or organisations that can allow or refuse access to researchers to groups or individuals However there is a tension between recognising children as active competent beings and the paternalistic tendencies of adult gatekeepers to view children as vulnerable and in need of protection (Balen et al. 2006; Carter, 2009). 'Gatekeepers are individuals or organisations who are able to grant or refuse access to a research setting, or who are able to influence such decisions' (Tisdall et al. 2009 p.225). To access children for this research study my first point of contact included professionals, organisations and the parents.

In order to access the child participants for this study I wrote to the managers of five Community Children's Nursing Teams within the geographical area to explain the nature of the research study and the involvement of the CCNs as professional gatekeepers. Once I had received approval for the study from the Multi-Centre Research Ethics Committee for Wales and Research and Development approval from each participating NHS Trust I visited all of the CCN teams to explain the study to the practitioners both verbally and in writing by providing them with information packs about my research project (CCN information packs Appendix 1) and I also explained their involvement in the sample selection process.

As the CCNs were the part of the professional gatekeeping process I asked them to give research information packs about my research project to the parents of children currently receiving care from the CCN team who met the sample criteria. The research information packs (Appendix 2) included letters of introduction for both the parents and the child, also included was a reply slip and a stamped addressed envelope. This ensured the parents and the child had received sufficient information to decide if they were prepared to allow me access to their homes as a researcher and to participate in the study. This is referred to as research opt-in (Alderson, 2005), where the researcher does not see a list of children's names and addresses. A professional, in this instance the CCN, informed the parents/guardians and children, and invited them to contact myself the researcher only if they wish to know more or join the project. I also attended children's out-patient clinics where many of the children who were cared for by the CCNs were followed-up in a clinic setting. During the clinic appointment the CCN was able to ask parents if they would be interested in hearing about my study. Interested parents were then provided with an information pack to take home and decide if they wished their child to take part in the study. Following several visits to local CCN teams and various clinics I was able to recruit a sample size of thirty (n=30) children who met the sampling criteria.

3.8 ETHICAL ISSUES

The ethical principles of this study are embedded in the ethos of children's rights, and that children are valued for themselves and not for their future (James and Prout, 1997; Jones and Welch, 2010). Alderson and Morrow (2004) and Alderson (2008) describe the Mosaic Approach as an example of how certain methods can include children actively and respectfully in research. However there is a tension between recognising children as active competent beings and the paternalistic tendencies of adult gatekeepers to view children as vulnerable and in need of protection (Balen et al. 2006; Carter 2009).

The recent wave of child inclusive research designs has highlighted a number of ethical tensions. On the one hand there is the move towards the inclusion and participation of children in research, and on the other the notion of children as a vulnerable group in society who are in need of protection (Alderson, 2008). According to Alderson and Morrow (2004) the important protective issues for excluding children from research include the idea that adults have more experience that will highlight any risks in the research, adults have more confidence and resilience to protect themselves from being hurt, are able to withdraw from the research if they wish to, and that researchers are more likely to respect this choice in adults than children. All of these concerns highlight children's vulnerabilities as seen by adults, however what is required is to give children the right to voice their opinion about issues that are important to them while ensuring they are respected and protected when they participate in research. Viewing children as vulnerable is, according to Carter (2009), one of the main reasons for the marginalization of children in research and the wide use of proxies to provide information about children's lives. She goes on to argue that a 'tick box' approach to ethics automatically identifies a research study with children as risky and forces researchers into defensive positions.

However it is possible to see child participation as a way of protecting children by enabling them to share in the responsibility of defining their rights and obligations within society. Children's rights can be identified within the UNCRC (1989) as either concentrating on provision, protection and participation or alternately by defining rights in terms of liberty and welfare (Alderson, 2008; Jones and Welch 2010). The children's rights agenda has been instrumental in recognising that children's experiences are worthy of consideration and that they should be active participants in decision making on issues that affect their lives. This requires children's perspectives and opinions to be viewed as different to those of adults but of equal value as it is children who are the experts on their own lives.

Alderson (2008) identified ten topics that researchers undertaking projects with children need to consider, the purpose of the research, costs and hoped for benefits, respecting privacy and confidentiality, decisions about selection criteria, funding, planning and revising research aims and methods, the information provided for children and adults involved, consent, reporting and use of any research findings and the possible impact on the children who take part and children in more general terms. I will discuss how these issues were addressed within this research study in the following sections.

3.8.1 *Ethical Approval*

Prior to the commencement of my research study I sought ethical approval from the Multi-Centre Research Ethics Committee for Wales (Appendix 5), I also gained research and development approvals from each participating NHS trust. This process although lengthy proved to be less arduous than I had anticipated and the study was approved with only very minor amendments.

Following ethical approval I was then able to contact other professional gatekeepers namely community nursing managers, community children's nurses and lastly parents of children who would participate in the research. These gatekeepers provided me access to thirty children to complete this study.

3.8.2 *Informed Consent*

Research ethics is about respecting the participants throughout the study (Alderson and Morrow 2004). The respect for autonomy means that the participants are allowed to make free, informed choice without coercion. Obtaining informed consent from children to participate in research is a fairly new issue for the social researcher (Morrow, 2005). It was important to negotiate informed consent with the children who participated in the study alongside obtaining consent from the parents who were acting as gatekeepers.

Within British law, minors over the age of 16 years can give legal valid consent; competent children under 16 years can also give consent. A child's competence is defined as having the 'sufficient understanding and intelligence to understand what is proposed' and 'sufficient discretion to enable (a child) to make a wise choice in his or her own interests' (Gillick v. West Norfolk and Wistbech AHA 1985 cited in Alderson and Morrow, 2004). The establishment of Gillick competence however does not mandate automatic bypassing of parental consent as advised by the Department of Health (2001) *'If a child under 16 is competent to consent for him/herself to a particular intervention, it is still good practice to involve their family in decision making unless the child specifically asks you not to do so'* (p.5)

Therefore to ensure good and safe practice as the children who were asked to participate in this research study were between the ages of 7 and 11 years, I obtained consent from both parents and the children. When gaining informed consent from the children it was necessary for me to ensure they understood all the relevant issues involved in the research, and that I valued their opinions regarding their experiences of home care. I designed informed consent forms (Appendix 3) for both the parents and children explaining the research aims and objectives. They were also informed of the demands on their time, that they would be free to withdraw at any time from the research, and that this would not have any effect on services or care they were receiving. Giving children clear information about the research can help parents decide whether to allow their child to participate as it reduces the risk of the parents feeling confused or unsure about their child's participation (Alderson and Morrow, 2005).

3.8.3 *Good versus Harm*

Good derived from the research must be weighed against possible harm, and the benefits must outweigh the risks (Holloway and Wheeler, 2002). The benefit from this research study is in the value given to the children's own views and opinions on their unique experiences of home care. Stafford et al. (2003) found that children do not regard the opportunity to be heard as a favour but something they see as their right. They are also more inclined to participate if the research serves some useful purpose such as improving their lives or the lives of other children. The children and parents were told that this research project may not bring any benefit to them personally, but that it may improve the service provided at home to children in the future. However it is hoped that the children enjoyed having a willing listener and gained satisfaction from engaging in other activities such as drawing and collage making.

I also recognised that the research may intrude into the lives of the children and the parents and could cause distress during or after the research. This could have been due to the children telling their stories of how they felt about their illness and care which may have also distressed the parents hearing these issues possibly for the first time. At any time during the research interview if the child or parent had become distressed then I would have stopped the interview and offered support from an appropriate professional. As the children were all living with a chronic illness the interviews only took place when the child was deemed well enough to take part.

3.8.4 *Confidentiality*

Children have many of the same rights to confidentiality as adults and they also have some extra rights in respect of protection from the media if they are involved in court proceedings (Alderson and Morrow, 2004). Access to this research was via opt-in which is more respectful of the participant's privacy than opt-out. Initially I was not provided with any names or addresses of children for this study, the parent information packs were given to parents either in their own home by the Community Children's Nurse or during a routine outpatient clinic appointment. The packs contained a reply slip and stamped addressed envelope which was returned to me only if the child and parents wished to be involved in the study.

Before the interview began I explained to the children that I needed to protect their privacy and that of other children who may also participate in my research study. This was an important concept for the children to understand as many asked if I had interviewed friends or acquaintances who they knew had similar health issues. This was done in a kindly way to try to help me recruit more children to the study. However being asked this necessitated me to reaffirm the importance of privacy and anonymity in research. To ensure the child felt comfortable with the idea of confidentiality they were each asked to choose a pseudonym for their interview which was only known to myself, the children and their parents.

The children were mostly interviewed in their parents' presence; however some of the older children chose to be interviewed on their own, when this occurred I ensured that the parents consented to the child being interviewed alone and they remained within close proximity.

3.8.5 *Safeguarding*

I am fully aware of my responsibilities towards child protection, I have an up to date Criminal Records Bureau (CRB) check. I clearly explained to the parents that I would have to report any safeguarding issues. I was also aware that this may have influenced the parents willingness to participate, however the welfare of the child is paramount and must be seen as the most important concern (DOH, 1989; Alderson and Morrow, 2004). This was never a contentious issue with the parents and indeed many parents stated they felt reassured that professionals were concerned about possible safeguarding issues. Prior to the child giving informed consent I discussed with them what I would need to do if I was worried about their safety. If a child had disclosed an incident of abuse during the study, then I would have explained to the child that this could not be kept secret and that I would need to tell a responsible adult who could help. I would have terminated the research interview and followed the Local Health Board protocols in relation to safeguarding.

The research interview data were kept as required by the Data Protection Act (1998) all material was kept in locked storage. The doctoral thesis, any future conference papers or journal articles will not contain any identifying material. I asked permission from the children and parents to include excerpts of direct text and images within my finished Doctoral thesis and the individual children have only been identified by their chosen pseudonym.

3.9 DATA COLLECTION AND GENERATION

Data were generated using the Mosaic Approach (Clark and Moss 2001) which allowed me to use a range of methods to engage with the child participants. These methods included listening to the children's stories of their home care experience, and discussing with them what they had drawn or created using the arts and crafts. These are discussed in the following sections.

3.9.1 *Children's Stories.*

The interviews were carried out in the children's own homes with children whose parents had made contact with me and made suitable arrangements for the date and timing of the interview. The context of the interview is particularly important when interviewing children as the expression of a child's personality is often context dependent. A child who is outspoken at home may be shy and reserved in school (Scott, 2000), therefore where the interview takes place is likely to influence the way the child responds.

Prior to commencing the interviews I introduced myself to the child and family members, I reiterated the purpose of my study and ensured that the child and consenting parent were still willing to take part in the research. I obtained written consent from both the parent and the child and explained that if at any time they wished to discontinue the interview process that they were free to do so. The parents and child were assured of their confidentiality and before the interview took place the child was asked to choose a pseudonym that I could use in the research study so that no one would know their real name.

The parents' attention was drawn to the declaration regarding safeguarding included in the parents' information pack to reiterate my professional responsibility regarding any disclosure of safeguarding issues. Researchers according to Alderson and Morrow (2004) must honour the confidentiality and anonymity given to research participants unless there are clear and overriding reasons not to do so for example, in relation to the abuse of children.

The narrative interview is a tool that allows the researcher to gain access to participants stories (Holloway and Freshwater, 2007). Within the narrative interview the researcher's responsibility is to be a good listener and the interviewee is a story teller rather than a respondent (Holloway and Jefferson, 2000). Good interviewers according to Morse and Field (1996) listen carefully and thoughtfully and stay 'with' the participant (p. 77). The narrative interview is more productive when the interviewer suppresses their own desire to speak as it helps the participant produce spontaneous talk (Holloway and Freshwater, 2007). The narrative approach allows for an open agenda which develops and changes depending on the experiences of the story teller.

I therefore made the decision not have a series of prepared questions as it was important for me to allow the child to tell their story. All of the children were initially asked the same grand tour question - '*please can you tell me your story in your own words what it is like for you to be looked after by your family and your nurse at home'*. However following an interview with a very quiet child I reflected on this and prepared a series of trigger questions based on previous interviews, these became a useful tool as it helped facilitate the stories of the more reserved children (Appendix 4). Some of the children also often consulted their parent during the interview to clarify something or to back up their story. This was an issue that I had foreseen, and as a nurse and health visitor who had experience of working with children and families I felt this was a natural occurrence within the interview process, and provided depth and normality to the experience.

The interviews were audio recorded with permission of the child and parents as this allowed for preservation of the child's words as accurately as possible. The children's stories varied in length from 20 minutes to over one hour in length. Holloway and Wheeler (1996), state that the length of the interview time depends on the informant. I was constantly aware as I was interviewing the children that they may find it difficult to concentrate for long periods of time. It was impossible to predict how long the interview with each child would last as this was dependant on variables such as the length of the child's story, interruptions such as the telephone or visitors, and the family's other commitments, although they had been advised prior to my visit that the whole interview process could take up to one and a half hours to complete.

The children were told at the beginning of the interview that they could stop at any time, however all the children completed the interviews with no obvious upset or fatigue. I was aware that all the children had a chronic illness and that his may affect their ability to participate for long periods. Arrangements for the interviews had on more than one occasion been changed due to ill health and on one occasion a period of hospitalisation. Some interviews were also changed to allow the children to carry on their day to day lives such as playing football or going out with friends.

I recognise that story telling has been described as unscientific, full of bias or entirely personal (Koch, 1998), and that it can be criticised for not being generalizable and writers of stories have been accused of fabrication. I have made every effort to provide an open and authentic account of the stories within this study and to represent the children who participated in this study as authentic and credible storytellers. Bleakley (2005) also warns that interviewing can be treated as a means to an end, rather than a social medium for active construction of knowledge. Mishler (1986) points to several potential issues with interviewing, such as stemming the flow of the participant's talk so that the narrative becomes fractured, and bias in the selection of which parts of the interview are reported.

It is important to recognise that the story told is constructed within the research and interview context rather than being a neutral account of pre-existing reality, however narrative research is participative and recognises that the listener makes an impact on the story as the storyteller shapes their story to make a connection with the listener (Holloway and Jefferson, 2000; Frost and Cliff, 2004). Therefore by asking the children to answer my *grand tour question* I realise I was already providing the context for the focus of the children's stories, but I was also conscious that the narrative interview was a powerful medium through which the storyteller can determine what is told, what is important, and what is unspoken.

3.9.2 *Play Materials*

During my visit to the home and prior to commencing the interviews I asked the children if they would like to have a look at the play materials I had brought along with me. My play bag contained variety of equipment, paper, pencils, felt pens, stickers, glitter, feathers, felt shapes, pompoms, Lego, fuzzy felt and a jewellery making kit. Most of the girls made a necklace or a bracelet which they were then able to keep. The boys were more interested in the Lego and the stickers. Another favourite was fuzzy felt from which some of the children made very entertaining scenes. The use of these play materials was not limited to the child participants and many siblings joined in the fun during my visits. Again I did not view this as a distraction from the process rather an opportunity to see how the children related to other family members. Some of the children introduced their own props to the scenario such as a favourite toy, and even a pet rabbit (who sat on my lap for the whole of the interview). Involving the children in these creative activities helped them to get to know me and hopefully feel more relaxed before participating in the interview.

I also I asked the children if they would draw a picture of their experience of home care. This proved to be a very popular pastime for most of the children and often took longer than the actual interview. In order to shorten my time with the families I soon learned to buy a smaller scrap book as most of the children felt the need to cover all the paper with colour and bits of sticky paper. I had envisaged that the children would develop an attachment or ownership of their drawing therefore I asked if I could take photograph of their drawing for my study and I was then able to leave the original with the child. However I do think that reproducing photographs of the original drawings has to some extent diminished their originality.

Using art based activities such as drawing and collage making with children allows them to express their views, and also enables them convey their feelings, fears and experiences without the need to verbalise (Coad et al 2009). Art work also promotes the rapport between the researcher and the child and empowers the child participant. Children's drawings are believed to reveal the child's inner mind (Grieg and Taylor, 1999), and are increasingly being used as a means of researching children's experience. Children as young as 7 years can master symbolic meaning of drawing and it can serve to transmit experience (Greene and Hill, 2005). Using drawing as a form of data collection has been used by a number of researchers who have conducted research with children for example, Sartain et al (2000) used drawing to the enhance children's ability to talk about their experience of chronic illness, and Brady (2009) used the write and draw technique to identify children's views of the good nurse, and Carter (2005) also used this technique to explore children and their siblings perceptions of the Salford Diana community children's nursing team.

However using a data collection tool such as children's drawings does pose challenges to the researcher when it is presented as data. The challenges faced in this study were that not all of the children wished to participate as some were too shy, or they told me they did not wish to draw, therefore not all of the children are visually represented in the data analysis chapter of this thesis. Although the use of children's drawings is viewed as a positive means of data collection it was of course crucial that the drawings were not falsely interpreted. I aimed to avoid this occurring within this study by asking the child participants to explain what they had drawn and why. I feel this also ensured I remained true to the principles of the Mosaic Approach as the children were involved as co-constructors of meaning (Clark and Moss, 2001).

Using such a variety of materials instead of just conducting interviews I feel helped to engage the children in the research process. Encouraging them to choose whether they wished to draw or play with the other materials gave them the opportunity to make their own decisions about what they wanted to do, embracing the concepts of the mosaic approach of adaptability and participation (Clark and Moss, 2001). The children were also reassured that they were not being tested at any time and that we were doing it for fun.

3.10 DATA ANALYSIS

Data analysis in narrative inquiry is a complex and often challenging process as there are many frameworks and structures available to the narrative researcher. However there is no agreed single neat way of analysing stories (Frost and Cliff 2004). Following extensive reading I made the decision to analyse the data using the framework described by Polkinghorne (1995). The complexity of using this framework is that Polkinghorne (1995) describes two types of analysis within narrative inquiry, paradigmatic analysis and narrative analysis. The first, paradigmatic analysis of narratives moves from stories to common elements or themes that cut across the stories, characters or settings to produce general concepts or categories. Polkinghorne (1995) refers to this as analysis of narratives which uncovers the commonalities that exist across stories and functions to generate general knowledge from a set of stories. This can be achieved in two ways, firstly deductively by applying theory to data, or alternatively inductively by allowing themes to emerge and concepts to develop from the stories (Oliver, 1998; Kelly and Howie, 2007). The strength in paradigmatic analysis is the capacity to develop general knowledge however, it can be abstract and formal, and often misses the uniqueness of each story as it relies on the researcher's preconceived categorization (Polkinghorne, 1995).

Secondly, narrative analysis that uses a plot to tie together individual experiences in order to create the context for understanding meaning. The work of narrative analysis is to produce an integrated story with a plot for each participant in the study using a case study. The outcome of this process is a narrative or set of narratives that provide insight and understanding about the people involved (Oliver, 1998).

How to analyse and present data is often a difficult decision for the researcher, and within this study I wanted to identify whether there were any common concepts or similarities between the stories of the thirty children I had interviewed. However I was also very interested in presenting the data as a storied account of an individual child's experience of managing their chronic illness at home. Therefore I came to the conclusion that the best option was to use both paradigmatic analysis, and narrative analysis as described by McCance et al (2001). Firstly I analysed the data inductively to discover general themes from the data using paradigmatic analysis, this was not a straight forward process as many of the concepts within the stories overlapped, and to begin with I found the process almost overwhelming. I conducted the data analysis during a three month sabbatical therefore I was able to fully immerse myself into the process of analysis. I recognise that one of the most important lessons to learn when analysing stories is not to make premature decisions about the data, and to almost welcome a state of uncertainty, although the temptation is to want to show how organised you are as a researcher by providing clear cut concepts and themes in the data analysis chapters. I was also very aware during both the data collection, and analysis stage of this thesis how important it was for me to actively listen to the children's stories. I hope I have been able to show that I made a conscious effort to present the children's stories not just as clinical data but with humanity, and honesty.

For the narrative analysis I focussed on two individual narratives, I am aware here that the choice of whose complete story has been told was my own. I was guided in this decision by Polkinghorne (1995) who suggests the researcher should select narratives that illustrate different kinds of experiences. So guided by this I chose narratives from two of the children from the study sample who were receiving care at home for different health needs. When I had completed all thirty interviews and listened to and transcribed the children's stories I made a conscious decision about which of the two stories I would present as complete narratives. When I was reading *Blue* and *Rhannon's* stories I became aware of how they coped with their chronic illness at home, and the relationship between themselves, their family, and the CCN. I recognise that all of the children had their own stories to tell, however as in any research study some participants provide more in depth data than others. This may be due to individual personality, and also the rapport that develops with the researcher. I interviewed *Blue* and *Rhiannon* early in the data collection phase of my study, during both interviews I felt the children were very open and relaxed and offered their stories without the need for too much probing on my part. What constitutes a 'good' story is ambiguous (Carter 2007), as stories may be described as being good if they provide the researcher with rich data to fulfil their academic needs. Therefore I recognise that my decision to use these two stories was based on my novice status as a narrative researcher, and that my choice was heavily influenced by my need to provide clear credible stories which I could interpret, and demonstrate faithful description. There were other stories that I could have introduced that gave a more fractured or fragmented account of the child's experience of managing their chronic illness. These stories were captured during often chaotic interviews where there were many interruptions from family members, telephone conversations and unruly pets. I recognise on reflection that I may have chosen the most useful stories and not necessarily the best stories.

However by using a combination of paradigmatic and narrative analysis I feel I have been able to elicit general themes from the stories, and also capture the uniqueness of two individual stories.

3.10.1 ***Analysis of Narratives***

In chapter four the data are analysed under four themes which were inductively derived from the children's stories using paradigmatic analysis (Polkinghorne, 1995) to seek out common elements and to identify instances of general concepts. Paradigmatic analysis is a way of examining data to identify and locate common themes among stories (Polkinghorne, 1995). By using paradigmatic analysis I have been able firstly to theme the storied data into particular occurrences, and secondly to demonstrate how the themes link to one another by noting the relationships between the concepts. The strength of paradigmatic analysis is its capacity to develop general knowledge about a collection of stories (Casey 2002). The process of analysis followed certain stages:

- *Transcribing* - To begin with I transcribed the children's stories verbatim. Each transcript was coded using the child's chosen pseudonym. The front sheets of the transcribed interview contain data relating to the date of the interview, age of the child, and the chronic condition presented. The transcribing was very time consuming and working on an average of 8-10 hours per story the transcription took in excess of 300 hours, but it did allow me to immerse myself into the data and become sensitive to the important issues. The interview transcripts were stored on a computer which was password protected.

- *Ordering and organising the data* – During this stage of the analysis I read and re-read each individual story to discover common elements that cut across each of the 30 stories. I decided to use a manual approach to the data analysis adopting the colour coding approach described by Morse and Field (1996) as I had previous experience of using this technique whilst completing my Master's dissertation, and it is reported to be a fast method of identifying and organising data.

  Firstly each individual interview was colour coded in the left margin using a different colour for each participant. This along with keeping a master copy of each complete individual interview ensured I could retrace the original source of the text. I then identified the common elements from the 30 individual interviews by using different coloured pens to highlight passages of text that appeared to me have similar meanings. When this was completed I used the cut and paste technique which involved cutting all of the stories up depending on the colour code and reassembling pages containing the same colour to represent a category.

- *Identification of themes* - The next stage involved the identification of themes which involved reading and re reading the colour coded text and spending time considering what the children had been trying to say to ensure I did not draw conclusions from the data too quickly. From the pages of colour coded text I identified four themes that emerged from the data.

The four themes identified were:

1. *Memories of diagnosis*
2. *There is no place like home*
3. *That's my community children's nurse*
4. *Taking control*

3.10.2 *Narrative Analysis*

Within chapter five I have presented the full storied accounts of two children to capture a holistic explanation of their experience of managing their chronic illness at home. Narrative analysis is the procedure through which the researcher organizes the data into a coherent and developmental account (Polkinghorne, 1995). The development of narratives as case studies is a difficult process and requires more than simply recounting the events of the story. According to Polkinghorne (1995)

> *'the problem confronting the researcher is to construct a display of the complex, interwoven character of human experience as it unfolds through time' (p18)*

I conducted the narrative analysis of the data using the criteria described by Polkinghorne (1995):

- *Description of the cultural context in which the story took place*
- *The nature of the protagonist (chief person in the plot of the story)*
- *Identification of significant others affecting the choices and actions of the main character*
- *Choices and actions of the main character in pursuit of their goals*
- *Attention to previous experiences as they manifest themselves in the present*
- *Production of a story with a bounded temporal period that is a beginning, a middle and an end*

- *The provision of a plot or story line that configures data elements into a meaningful explanation of the characters responses and actions*

My intention here was to synthesise the data to discover and develop a plot to give meaning to the children's stories as they described their experiences in their own words. I followed the following steps to ensure I was able to capture all of the issues described above in Polkinghorne's (1995) approach to narrative analysis.

Step 1: *During my home visit I encouraged the child to share their story which I audio recorded and transcribed verbatim.*
Step 2: *I listened to the audio recordings and read the story transcript to gain a sense of the story.*
Step 3: *I arranged the data in chronological order.*
Step 4: *I identified the outcome of the story by analysing what events and actions contributed to the outcome.*
Step 5: *As the plot of the story became apparent I looked for connections, causes and influences, such as periods of exacerbated illness, treatment, and also how the supporting characters in the story influenced the outcome.*
Step 6: *I composed the data elements into a story with a beginning, middle and an end and presented the characters in sufficient detail to ensure the stories were unique to the child's particular situation.*

3.11 TRUSTWORINESS AND AUTHENTICITY

Trustworthiness and authenticity in narrative inquiry are focussed on the original stories told by the participants and the representation of these stories in narrative form by the researcher. By choosing to use a narrative approach to this study I have taken into account that the children's stories may have been affected by issues such as the children failing to remember certain events, becoming confused over certain issues, and also the possibility of them over-dramatising their story. However my epistemological assumption is that there are multiple subjective realities and therefore my aim for this study was for children with a chronic illness to describe the reality of their lives from their perspective.

It was also important for me to be honest to the theoretical perspectives and values I have been committed to during this study. I have proclaimed that my ideas are embedded within the sociology of childhood that views children as social actors who are able to act with intention in their own lives. Therefore it was vital that I accepted the children's stories as authentic and valid and that their perspective was as worthy as those of adults. The stories were entrusted to me as the researcher therefore my aim has been to ensure I have preserved the worth and dignity of the story tellers. Blumenfeld-Jones (1995) writes that 'the narrative is believable when it can be credited with conveying, convincingly, that the events occurred and were felt in ways the narrator is asserting' (p. 25).

It has been my intention within this thesis to draw out the authentic stories of the children, to do this I had to acknowledge my own role in both the construction and analysis of the narratives I have produced. Therefore a vital element to the trustworthiness and authenticity of this thesis has been my commitment to being a reflexive researcher. I have attempted to reflect on how I built up a relationship with the participants by using the Mosaic Approach (Clarke and Moss, 2001) to listen to what the children said was important about their lives. I have also explored and discussed how my theoretical assumptions, my clinical background and interests influenced this research thesis.

Dependability is linked in qualitative research to the consistency of the research instrument. Because the stories of the participants are unique (Holloway and Freshwater, 2007) and the researcher is the main instrument in qualitative research, narrative research could never be said to be wholly replicable as other researchers will have other backgrounds and ideas which would influence and direct the research (Holloway and Wheeler, 2002). The issues of whether the research could be repeated or replicated at another point in time is problematic as children develop so rapidly that repeating the study with the same children would not be feasible (Mac Naughton et al. 2001). However findings in a particular context are transferable to similar situations with similar types of participants (Lincoln and Guba, 1985), as although the stories in narrative research studies are unique the findings can be applied to different settings and conditions to produce knowledge (Holloway and Freshwater, 2007).

3.12 CONCLUSION

Within this chapter I have discussed the fact that this thesis was influenced by the new sociology of childhood that recognises children as social actors who can take control of their own lives and participate in decision making about issues that affect them (Quortrup, 1994; James and Prout, 1997; James and James, 2004). The research was guided by the Mosaic Approach (Clark and Moss, 2001) which as I have shown in this chapter is an adaptable framework that was developed to listen to children about the complexities of their daily lives. Even though the original framework was designed for early years teaching and research I felt it was adaptable enough to be applied to the discipline of children's nursing research.

I have also discussed that Polkinghorne's (1995) approach narrative inquiry was used as a method of generating and analysing children's stories for this study. I have given my rationale for using two modes of analysis for this study, firstly paradigmatic analysis and secondly narrative analysis. Within this chapter I have also discussed how I gained ethical approval and access to the sample of participants who were recruited for this study. I have also discussed the importance of reflexivity and how this has been achieved throughout the research process. I have provided an analysis of the ethical issues involved in conducting research with children and demonstrated that by using inclusive methods I have given children with a chronic illness the opportunity to tell their own unique story.

The findings of the study are presented in the following two chapters. Firstly chapter four moves on to the analysis of the data collected from the interviews I conducted with the children. The findings were analysed using paradigmatic analysis (Polkinghorne, 1995) and are presented under four themes - *memories of diagnosis, there's no place like home, that's my community children's nurse,* and *taking control.* Chapter five presents the narrative analysis of two complete stories. Firstly the story by *Blue* a nine year old girl suffering with leukaemia and secondly, *Rhiannon's* story of living with diabetes

Chapter 4 Analysis of Narratives

Within this chapter I have analysed the findings using paradigmatic analysis (Polkinghorne, 1995) which enabled me to uncover common themes across the children's stories. I used an inductive approach so therefore I allowed the themes to emerge and general concepts to develop from the stories. As I had chosen to utilize a noncategorical approach to this research study I was interested to discover whether children with differing chronic illnesses would have the same or similar experiences of managing their illness at home. The findings are presented in four themes which captured the commonalities from the stories of thirty children.

THEME ONE

4.1 MEMORIES OF DIAGNOSIS

4.1.1 *Introduction*

Within this theme I begin my analysis of the children's stories of managing their chronic illness at home. At the start of the interviews I asked the children to tell me their story of what it was like for them to be looked after by their family and CCN at home. However, many of the children began their stories by reflecting back to their initial memories of their diagnosis. As my aim was to encourage the children to tell their story in their own words I was mindful that Mishler (1986) stated, that if the interviewer does not suppress the interviewee's responses by limiting the answers to what they see as relevant to a specific question, then a storied answer will be provided. Therefore, although my main focus was on the child's experience of how their illness was managed at home, I was aware that the children needed to recount their individual stories in a way that made sense to them. A narrative recounts events over time (Bruner, 1991), and a vital element of a narrative is its use of diachronic data which contains temporal information about the sequencing of events. The storied narrative describes when events happened, and the effect they had on subsequent happenings, the stories are emplotted accounts with a beginning, middle and an end (Polkinghorne, 1995).

Therefore I have analysed excerpts from the children's stories where they talked about their initial diagnosis. This seemed for many of the children a truly significant event that emerged from their stories, and held the key that unlocked their stories of how they were able to cope with their chronic illness. Some of the children were too young to remember their diagnosis themselves, however they recounted tales told to them most often by their mothers, others who were older when they were diagnosed gave vivid first hand accounts of their experience. Following on from this my analysis will show how vital it is for children with a chronic condition to be knowledgeable about their illness and treatment if they are to successfully manage their condition at home.

4.1.2 When I was first ill

The diagnosis of a chronic illness is itself experienced as a significant crisis. It is a threat to the child and family's life, and a time when they feel they have lost control over their routines. Temporarily children diagnosed with a chronic illness can feel that their world does not make sense to them as a major diagnosis often requires fundamental changes to all aspect of their lives, and they become afraid of the world around them. Frank (1995) suggests that serious illness results in a loss of the 'destination map' (p.1) that had previously guided an individual's life, and that telling and sharing their stories helps them to learn to think differently. The diagnosis of a chronic illness disrupts the relationship between the body, self and the surrounding world so the individual needs to reconstruct their life so that they can understand issues that have disrupted and changed their lives (Hyden, 1997). Following diagnosis children with a chronic illness have to assimilate vast amounts of information about their bodies and their condition. Many of them will need to master skills, and learn how to manage their chronic illness to ensure they maintain a healthy lifestyle within the constraints of their illness.

When telling their stories some of the children told me they that they did not remember the initial diagnosis as they were too young and, others did not remember a time when they did not have their chronic condition. However the following children all began their story with recollections of their diagnosis which would suggest this was major event in their lives. *Alesha* an eleven year old girl who lived with her mother and grandmother had been diagnosed with epilepsy and precocious puberty and *Torres* a twelve year old boy with cystic fibrosis explained.

> *"I don't really remember I was only eighteen months old mammy gave me Calpol and I had a fit" (Alesha age 11: Epilepsy and Precocious Puberty)*
>
> *"since I was a baby yes 3 months I think" (Torres age 12:Cystic Fibrosis)*

Alesha is describing something she has no memory of herself however she is recounting a story that has been told to her. Although it is only one sentence it portrays a vivid story line of a baby having a fit and of her mother caring for her by administrating medication. *Torres* told me he had had cystic fibrosis since he was a baby and after some thought decided he was three months old, again this is hearsay knowledge has been passed to him through his family. Engel (2005) writes that children begin listening to stories before they can tell stories of their own. Young children are avid listeners of their parents' stories about experiences that have shaped their lives. Bury (2001) suggests that the telling of stories whether about oneself or about others is universal and that they create the fabric of our lives. Story telling within families generates local knowledge and binds its members with collective stories that have shaped their lives. *Suzi* an eleven year old with diabetes explained that she did not remember a time when she did not have the condition and but that she remembered her mother caring for her.

> *"I always remember having injections my mother used to do it and I remember she used to do my blood and write it in the book but I can't remember much from the beginning because I was so young" (Suzi age 11:Diabetes)*

Suzi's story shows that like many parents whose child has been diagnosed with a chronic illness her mother become involved in treatment regimes to alleviate symptoms and manage her condition. This involves parents combining the role of being a mother or father with the provision of skilled care on which their child's wellbeing depends. Learning and adapting to their child's needs following a diagnosis of chronic illness is a stressor for parents as they may have to master new skills such as, administering medication, maintain treatment regimes and make complex clinical decisions (Kirk, 2001; Meleski, 2002; Kirk et al. 2005). Parents are also aware that in order for their child to be managed at home they need to take responsibility for their care. Marshall et al. (2002) reported in a critical review of the literature on adaptation and negotiation with families whose child has been diagnosed with diabetes that, successful management depends on the parent's ability to provide the required care. In recent years there has been a shift towards home management for children with chronic illness therefore it is the parents who shoulder the responsibilities of care, and in order to do this successfully they require support and education from the community children's nurse (Fradd, 1994; Taylor, 2000; Kirk et al. 2005; Carter and Coad, 2009). I will return to these issues in theme three.

Megan was also able to recall her first memories of how diabetes affected her life and she even corrected herself as to what school year she was in during the time which seemed really important to her. *Megan* is attempting here to provide what she remembers as a true story and as the story teller she is determining what is important, as getting the details of their story correct gives the author authority to speak and can aid credibility.

> *"I remember Year 2 no actually reception I can remember my blood used to go low and they used to give me milk" (Megan age 9:Diabetes)*

Megan is clearly making a connection between having low blood sugar levels and the need to drink milk. *Megan* seems to have shaped her story to connect with me as the listener, she did not question whether I understood the complex issues involved in maintaining a stable blood glucose level for diabetic patients because she knew I was a children's nurse and therefore she assumed that her story would have significant meaning for me. For many of the children like *Megan* their earliest memories involved their symptoms or how they were feeling at the time. These experiences were told in graphic detail by some of the children and their stories were given a certain amount of drama and excitement. By giving details of their experiences and prioritizing events the children were demonstrating that as the author of their story they were able to decide which issues they wanted to talk about. Frank (1995) explains that telling stories about illness is how individuals can give voice to an experience that medicine cannot describe. The following passages from the children's stories highlight their individual experience of their illness.

> *"It was a bit hard I was frightened because I was on holiday in Florida I felt really thirsty and sick and I was thin and everything I was eight nearly nine when I went to the toilet I was thirsty again and I was going thin and pale I could not eat because my throat was kind of thin and everything but then we called the Doctor in I had to wee in a thing and the Dr told us I was diabetic so I had to go to hospital in Florida I was there for three days" (Vicky age 10:Diabetes)*

> *"I was nine I was really ill was feeling sick and sore I had to go to the Dr they did a urine test that came out bad so I had to go to hospital and they had to take blood out of me and I was frightened a lot for it" (Barbie Girl age 11:Diabetes)*

> *"I felt really shaky and I drank a lot I did not feel frightened because my brother is diabetic my mum knew I had to test my blood sugars mum took me to the hospital in the night I stayed in overnight" (Penny age 11:Diabetes)*

> *"I was four and a half I think I remember having some sort of blood tests that's all" (Jake age 9: Diabetes)*

> *"When I was first diagnosed I did not have a clue I was 6 and I can remember I hated the injections" (Simon age 8: Leukaemia)*

These children are all telling their unique story of their first encounter with their chronic illness, and their most vivid descriptions surround their symptoms, for example feeling sick, thirsty and needing to use the toilet. *Vicky* described how she looked thin and how her throat hurt, and by using the adjective *"thin"* it seemed to me she was attempting to explain how her throat felt in a way I could empathise with. *Vicky's* story described how a family holiday was interrupted by her illness, Bury (2001) refers to this as a 'biographical disruption' meaning that *Vicky* and her family's lives were interrupted and changed forever by the onset of her condition (p.271). *Vicky* and *Barbie Girl* also described how frightened they were by the unfolding events. *Vicky's* fear may have been exacerbated by being away from home as she clearly sets the scene of her diagnosis on holiday in Florida. However *Penny's* story suggests that her fears were alleviated because her brother had diabetes and her mother recognised the symptoms and so was able to deal with the situation. For *Barbie Girl* her fear was linked to having her blood taken '*they had to take blood out of me and I was frightened a lot for it'*, and *Jake* who had diabetes told me quite categorically that he only remembered the '*blood tests'*, and *Simon* an eight year old boy with leukaemia explained that when he was first diagnosed he did not understand, all he could recall about this time in his life was that he disliked having injections. All of these children are demonstrating one of the main stressors of hospitalization invasive procedures such as having blood samples taken, the insertion of intravenous needles and taking medication (Boyd and Hunsberger, 1998; Sartain et al. 2001; Salmela et al. 2009).

One young boy chose *Jonah Lomu* as his pseudonym after a famous rugby player as he was a big rugby fan, I however had no idea who this person was and *Jonah Lomu* found this highly amusing. *Jonah Lomu* was an entertaining character who told his story with some aplomb and he began his story as had many others with his initial experience of his chronic illness.

> *"Yeh I felt really sick and my blood glucose was really high and I needed the toilet a lot...well after a couple of days my dad noticed I was not right so my dad took me to the doctors after about half an hour they sent me to the hospital for a check up and then the doctor said to stay in overnight. My blood glucose was extremely high and in the danger zone and I stayed there for three nights"*
> *(Jonah Lomu age11: Diabetes)*

Within this section of his story *Jonah Lomu* is describing the unfolding events accumulating in his having to stay in hospital for three days. He begins by describing how he felt sick and needed to go to the toilet more than usual, he states that it was his father who realised there was something wrong with him and made the decision to take him to the doctor. It is often parents who recognise there is something wrong before diagnosis and is one of the most difficult periods parents have to experience (Meleski, 2002) as a diagnosis of a chronic illness causes strong emotional upheavals and the permanent nature of the child's condition can generate feelings of sorrow and hopelessness.

Jonah Lomu has also shown in this excerpt from his story how he has synthesised the knowledge he had during the time of his interview about diabetes with past events. For example *Jonah Lomu* explained he was feeing sick and that his '*glucose was very high*' however at the time of his diagnosis it is unlikely he would have known about blood glucose levels, he even elaborates on this possibly for dramatic effect and states that his blood glucose was '*extremely high and in the danger zone*' which again is not something he is likely to have understood or recognised at the time. However this newly attained knowledge of his condition is so embedded within him it was impossible for him to exclude it from his story. Bury (2001), comments that respondents' stories move back and forth between lay concerns and perceptions as they develop a familiarity with medically based concepts and that at times it can be difficult to identify where lay and expert modes of thought begin and end. Therefore the story becomes a new whole where it is impossible for the teller to disentangle the separate spheres of lay beliefs and medical knowledge.

Scruff a young girl with diabetes again tells a graphic story of how her tongue went white and she was being sick, in this section of *Scruff's* story she refers to the events as happening to all of her family '*they told us we had to go to the hospital*' when the doctor admitted her to hospital and again '*they said we had diabetes*' when given the diagnosis of diabetes. However *Rhian* distances herself from her parents and in her story the sequence of events is clearly happening only to her as she uses the first person and her parents are portrayed as characters in the scenario.

> *"I have had diabetes for 4 years I was going to the toilet and was thirsty all the time my tongue went white and I was being sick we went to the doctor's and they told us we had to go to the hospital they said we had diabetes I stayed there for a few weeks" (mum said no a few days) (Scruff age 8: Diabetes)*

> *"I went into hospital because my mum rang the Dr and I went to the Dr's and then they said to take me to hospital I was in for 4 nights, they had an Nintendo wii that was nice but the food was not very nice" (Rhian age 11: Diabetes)*

The literature suggests that locus of control is a transition process where the responsibilities for self management and care are transferred from parent to child (Woodgate, 1998; Kirk, 2008). This suggests that as *Rhian* is older than *Scruff* her locus of control was stronger and she was able to see herself as an individual within her family scenario. However, *Scruff* may have used the word 'we' simply because her mother was present in the room during her interview and she wanted to include her in the story. The transfer of responsibilities for self management is something that needs to occur gradually and requires continual parental involvement and is a concept I have discussed in theme four.

Within this theme I now move on to show that the children's stories demonstrated that the children were aware that their chronic illness was often the cause of hospitalisation.

4.1.3 Causes and Consequences of chronic illness

The children's stories continued with many of them describing their experience of hospitalization. The children associated admission to hospital with diagnosis, exacerbations and complications associated with their condition. Within contingent narratives individuals frequently link the onset or an exacerbation of their condition with events occurring at the time, demonstrating a life event approach to illness occurrence (Bury, 2001). In the following excerpts the children talked about what they saw as the life event that precipitated their admission to hospital.

> *"I went low a few months ago I collapsed and could not speak properly I was in hospital for a few hours... (pause)..I think it was because I did not have enough of a snack before bed" (Vicky age 10: Diabetes)*
>
> *"I started going into hospital more 'cause I was getting bad throats" (Rhiannon age 11: Diabetes)*
>
> *"If I don't feel well I go to the hospital to see whether something has gone wrong" (Mattie age 10: Cystic Fibrosis)*
>
> *"Once or twice a year I have to go in to hospital and have my IV'S mostly because I am not well" (Ruby age 9: Cystic Fibrosis)*

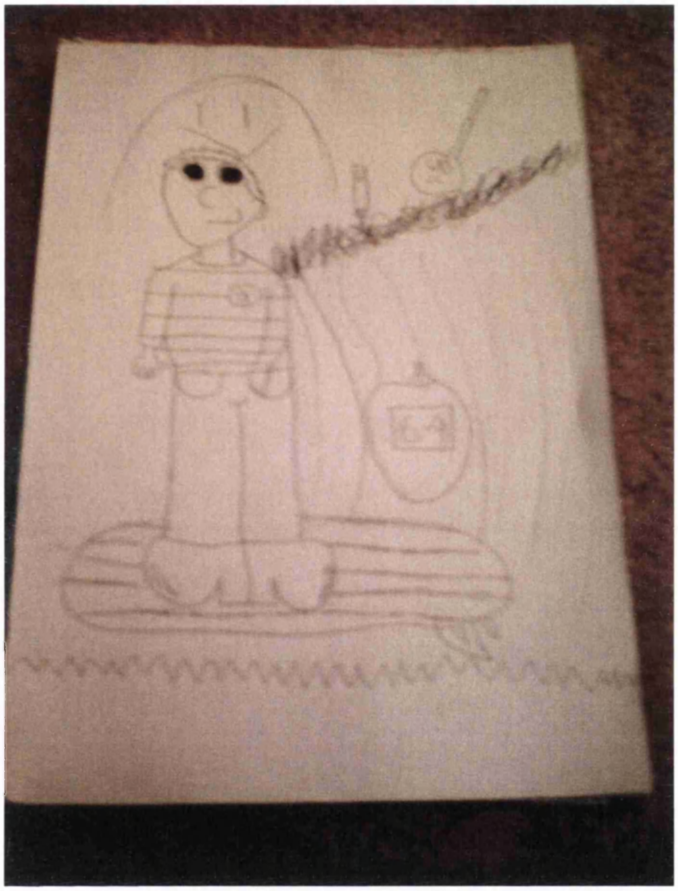
> *"I have been in hospital with stomach bugs and not being able to eat"*
> *(Donna age 11: Diabetes)*

These excerpts provide examples of how the children were able to relate the development of illness symptoms, provide possible causes for the exacerbations and relate them to life events. They have associated hospital admission with periods of ill health and also with treatment. Illness narratives therefore allow the teller to weave their symptoms and the consequences of their illness into their surrounding life events and shape how their illness impinges on their life. This was evident in *Vicky's* story where she was able to link a lifestyle choice to her emergency hospitalisation. When she told me her story she thought through what she felt was the reason for her acute reaction and realised it was probably due to a lack of food.

Jonah Lomu explained that he needed an emergency admission as his blood sugar was too low and he could not take any more sugar as it was making him sick.

> *"Overnight yeah last summer I went camping with my friend for my birthday we had a joint party a couple of friends each and at nine I had to leave because my blood sugars were not rising I got to the house and I could not have any more sugar so my mother rang an ambulance and I went to A and E because I had so much sugar I was sick and they had to monitor me all night and I was in the sea all day surfing (pause) well you have to have snacks and the amount of time I can spend in the water surfing because you have to come out after a certain time because you just can't stay in there all day like a normal person your blood sugars will drop an awful lot and you will have to have dinner so you are in and out its quite frustrating you have to come back out then the tide goes out and you have to walk nearly a mile to get back in" (Jonah Lomu age 11: Diabetes)*

Within his story he stressed that he knew he had to limit his time in the water surfing and that he could not do the same activities as his friends because of the constraints of his chronic illness. Here *Jonah Lomu* has firstly attempted to normalise his life by keeping his pre-illness identity and lifestyle intact, but he has also redesigned his life to contain his illness and incorporated it into a changed lifestyle (Bury, 2001). *Jonah Lomu* also realised that he could not compare himself to his healthy friends who were able to '*stay in there all day*'. This is reflected in his drawing as he chose to draw himself surfing however he also said he had to include his insulin injections and his blood sugar monitor as they were always part of his life.



Jonah Lomu - a self portrait of surfing

Christian and D'Aura (1997) also found that as they mature, children with a chronic illness realise that they can not compare themselves to their healthy peers, and that they need to develop a new baseline that describes normality in their lives.

The following section analyses the excerpts from the children's stories as they talked about their understanding of their illness.

4.1.4 What I know about it

As the children's stories continued to unfold in temporal sequence their talk moved almost seamlessly from their memories of diagnosis to how they found out about their illness and what they knew about it. The thinking surrounding children's concepts of illness has been dominated until recently by cognitive developmental theory which asserts that children progress along a well established developmental continuum (Bibace and Walsh, 1980; Vessey and Mebane, 2000). There is however an alternative position put forward by Eiser (1989), and Crisp et al. (1996), that children's understanding of illness is influenced by their unique experiences and that those children with a chronic illness demonstrate a more mature understanding than would be expected for their developmental stage.

Ellie explained that she knew that she had cancer and that she had been given this information by some of the doctors and nurses in the hospital.

> "*well some of the doctors and nurses explained to me.. she (CCN) tells me lots of things when I was first poorly I learned that I had cancer and um... now I feel better that I know and I am going to get better soon and I am so excited*"
> *(Ellie age7: Leukaemia)*

However it is clear from her story that the CCN was the professional for whom *Ellie* gained most of her information. Within this passage of her story *Ellie* also expressed that she felt better because she knew what was wrong with her. One of the greatest dilemmas for parents and professionals when caring for a child with a chronic illness is finding a balance between protecting the child whilst allowing them to develop their own autonomy. Parents often feel the need to protect their child from the realities of the illness and may conceal a diagnosis as they assume the child would not be able to cope with the consequences. However unless children are seen as experts on their own lives they will remain marginalised in the decision making process about issues that affect their health and the care they receive (James and James, 2004; Guell, 2007). Edwards and Davis (1997) stress that giving information to children in a helpful and supportive way makes the situation more manageable for them. Also if they are not given information they may gather it in more ad hoc ways which can lead to misconceptions and the development of fantasies about what is happening to them which could be more frightening than the reality. Horstman and Bradding (2002) and Salmela et al. (2009) also found that one origin of children's fear manifests from uncertainty about what is going to happen to them usually due to a lack of information. Steward (2003) described uncertainty as one of the major stressors for children with cancer.

Ellie is using what Frank (1995) describes as restitution within her story, the plot of the restitution narrative has a basic story line of 'yesterday I was healthy, today I am sick but tomorrow I will be healthy again' (p. 77). The telling of the story gives the story teller an opportunity to knit together the split ends of time, to fit their illness episode into a temporal framework and provide a context where illness events and other life events are created in a state of interrelatedness (Hyden, 1997).

Zac a nine year old boy with Cystic Fibrosis remembered asking his mother about his illness when he was five years old, however it seems as if the information was repeated on several occasions during *Zac's* contact with the medical profession. It is important to recognise that information giving should be seen as a process and not a one off event and it should be updated at regular intervals to meet the changing needs of the child (Edwards and Davis, 1997).

> *"I remember asking mum when I was about five what it actually was and she explained but I don't remember it but I remember asking that one question but whenever I used to go to the doctor's or the hospital they would tell us too. .. It's something about my pancreas and so I can't digest food and my lungs"*
> *(Zac age 9: Cystic Fibrosis)*

Many of the children made links between their understanding of their bodies how their illness affected their bodies, and what they had to do in order to maintain their health. The excerpts below show that these children were able to give fairly detailed and accurate descriptions of diabetes. All of the children made a connection between the pancreas and insulin production and some also recognised the link between food intake and their blood glucose levels.

> *"Um my pancreas does not work I have to put more insulin in it and I don't eat a lot of sugar, I eat more carbohydrates" (Rhian age 11: Diabetes)*

> *"It's your pancreas that does not produce insulin so you have to have insulin injected into you instead and insulin keeps your blood at a regular level"*
> *Megan age 9: Diabetes)*

> *"My pancreas does not work and after a while it will stop developing insulin and I will have to do my injections even when I am older" (Barbie Girl 11: Diabetes)*

> *"I am not allowed to eat sugar because if you do you go hyper but if you do not have enough then you go into a hypo and the insulin if you have too much sugar in your blood stream balances it out" (Ffion age 10: Diabetes)*

> *"Um your pancreas does not work it stops producing insulin so you need to inject to let insulin get in your body" (Louise age 9: Diabetes)*

Jake, told an elaborate story of what he understood about the function of the pancreas. However he then told me that his did not work properly because in his words it was '*snapped in half*'. *Rhian* and *Barbie Girl* can be described as in the formal-logic stage of development (Piaget, 1952 cited in Flavell, 1963) and as they have just entered this stage their explanations are said to be physiological where children ascribe the cause of their illness to a non-functioning internal organ or process, but see the trigger of the illness as external. It is clear to see that *Jake* who is 10 years old also connects his diabetes to sugar an external source which he sees as the reason he becomes in his terms '*hyperactive'*, however he also recognises that he needs a snack to ensure his '*sugars don't drop'*.

> *"if I eat sugar I get hyperactive and that's going to lead me to go too low I could fall asleep for a couple of hours there are tablets to make me go back up and I need to snack in between every few meals if I don't eat then my sugars drop. The pancreas it pumps insulin into the body so it works with the sugars to keep my energy right but mine does not do that it's snapped in half"*
> *(Jake age 10: Diabetes)*

However *Torres* and *Zac* were unable to elaborate on their understanding of their illness although *Zac* was able to explain that he thought that his problem stemmed from his pancreas which affected his lungs and his inability to digest food.

> *"I have got Cystic Fibrosis all I know is that it's an illness"*
> *(Torres age 12: Cystic Fibrosis)*
>
> *"It's something about my pancreas and so I can't digest food and my lungs"*
> *(Zac age 9: Cystic Fibrosis)*

Jonah Lomu adds a further consequence of his illness. In his story initially he told me very similar things to the other children but he also recognised that if he did not take insulin he could die. As previously mentioned, *Jonah Lomu* was a colourful character who I feel enjoyed employing some shock tactics into his story line. However he has obviously internalised the risk to his health posed by his diabetes. *Scruff* also makes the connection between maintaining a healthy blood sugar control and staying out of hospital, and *Ruby* a nine year old girl with cystic fibrosis associated having a portacath with maintaining her health and also recognised that without it she would become unwell.

> *"I have to take insulin because my pancreas does not work , I think its down there (points to abdomen) the insulin makes my blood sugar drop stops it from going high and keeps my blood stable without it I could die"*
> *(Jonah Loma age 11: Diabetes)*
>
> *"If I do running around I have to have something to eat and I have to control how my blood sugar is all the time if my blood sugar is low and I just left it I would be in hospital and if it was high and I left it I would be in hospital as well"*
> *(Scruff age 11: Diabetes)*
>
> *"I have a portacath because I have a lung disease otherwise I will become ill"*
> *(Ruby age 9: Cystic Fibrosis)*

Children with a chronic illness often recognise they feel different to their peers this can lead to self comparison with others reported in studies by Woodgate (1998), Herrman (2006) and Protudjer et al. (2009).

> *"because my pancreas does not give out insulin it makes my blood sugar high and where as a normal person their blood sugar would be normal because insulin would cancel the sugar" (Penny age 11: Diabetes)*

> *"Its my bones and my height...well there is this girl and she is a bit higher than me I don't think my mum was worried um my dad was a bit because he thought I was not growing they don't think there is much wrong with me and that I am going to grow" (Zoe age 9: Growth Retardation)*

> *"I have injections because I am growing older than I am since I was 6 I think I went to see the health visitor and then saw C (Nurse) its puberty I think (laugh) and epilepsy" (Alesha age 11: Epilepsy and Precocious Puberty)*

The above excerpts from stories by *Penny*, *Zoe*, and *Alesha,* all explained what they understood about their condition by comparing themselves to what they viewed as normal for children of their age. Children who compare themselves to their peers illustrate the desire to fit in which is an important issue for all children but particularly for children with a chronic illness. Herrman (2006) found that adolescents compared their lives to those of their friends to describe what they saw as normal.

Children with a chronic illness are constantly exposed to physical and psychological stress, physical stressors include painful or unpleasant procedures which were described in many of the children's stories and discussed earlier in this theme. The story extracts show the children were also conscious of psychological stressors associated with their conditions these included hospitalization, restrictions associated with their illness and real or imagined fear of death (Kyngas and Barlow, 1995; Northam, 1997; Huus and Enskar, 2007). It is unusual for healthy children to think about their mortality until they become adolescents when they develop the ability to think abstractly, however experiencing chronic illness may force younger children to confront issues such as the life threatening aspect of their condition (Edwards and Davis, 1997).

Therefore literature surrounding children's concept of illness is still open for discussion, however it seems that it is multi-factorial and results from a synthesis of the child's cognitive ability and their life experience (Yoos, 1994; Rubovits and Siegel, 1994). The theory that children with a chronic illness have more understanding of their bodies and illness is also controversial and contradictory. Crisp et al. (1996) found that having a chronic illness had a facilitating effect on children between the ages of seven and ten although they were not able to define what type of experience accounted for this effect. Conversely Perrin et al (1991) and Vessey and O'Sulivan (2000) found no significant difference in understanding of body functions or illness causality in children with a chronic condition. This uncertainty has been again demonstrated within the passages from the children's stories above, although there was not a vast difference in age *Jake* who was 10 years old when he told his story was able to give a more detailed description than *Torres* who was 12 years old. Therefore I feel this remains a topic that warrants further research as Wilson Vacik et al (2001) found that health professionals lack basic knowledge about children's concepts of illness.

4.1.5 Conclusion

Within this theme I have recounted and analysed excerpts from the children's stories that have shown similarities in their talk about a critical period in their life, their initial diagnosis. Most of the children began their story at this point in their lives demonstrating that being diagnosed with a chronic illness was seen as a disruption to their lives (Frank, (1995). These stories can be described as contingent narratives (Bury, 2001) because they have been concerned with the onset of a chronic condition, the symptoms and the effects of the condition on the body and everyday life. The stories have also shown that the children had different levels of understanding about their illness, many of the children demonstrated they knew a great deal about their condition and what the consequences would be if they ignored their symptoms. It is not possible here to make any claim to either a cognitive development approach (Bibace and Walsh, 1980; Vessey and Mebane; 2000) or a life experience approach (Eiser 1989; Crisp et al. 1996) to explain children's understanding of illness. However I feel these findings highlight that more research is needed on children's conception of illness. I am also mindful that these children were only a very small sample of children with a chronic illness and I was aware that some of the children in this study may have been more reticent than others to talk to a stranger about their knowledge and feelings.

Within the next theme I have shown the how the children perceived the care they received and drew comparisons between hospital and home care.

THEME TWO

4.2 THERE IS NO PLACE LIKE HOME

4.2.1 *Introduction*

In this theme I have analysed the children's stories where they talked about their experiences of hospitalisation and also of receiving care at home by the CCN. Being admitted to hospital can be a stressful experience for children as there is evidence to show that they can suffer from homesickness, boredom, also they are fearful of invasive procedures and the uncertainty about what is going to happen to them when they are in hospital (Boyd and Hunsberger, 1998; Stewart, 2003; Thruber et al. 2007, Salmela et al. 2009). My analysis shows that the children's stories gave detailed accounts of their experiences of both hospitalisation and home care, and provided valid reasons for their preferred choice of care environment.

In order to capture the children's experience and to remain true to their narratives the children continued their stories by telling me about issues that affected them when they were in hospital the most dominant being boredom and homesickness. However being at home and receiving care from their CCN generated positive feelings of comfort, support and normality.

4.2.2 Hospital it's just boring

It has been shown that children find hospitalisation a boring disruption to their lives (While, 1992; Boyd and Hunsberger, 1998) and their main desire is to return home (Sartain et al. 2000; Sartain et al. 2001). *Ellie* explained that her hospital experiences were boring because every day seemed the same to her, and there appeared to be very little variation in her activities.

> *"It's (hospital) a bit boring because every time I wake up I have got the same things to do all day so I don't go different places in the day" (Ellie age 7: Leukaemia)*

Sadly all of the following passages of the children's stories expressed feelings of boredom when they were in hospital. They clearly highlight that as far as they were concerned the hospital environment was more suited for babies and young children and therefore they had to manage their own entertainment by taking in distractions such as games, books and computers.

> *"I was ill I had to have IV's it was boring I only had my play station, there were only baby toys there I would like to see a play station and books to read" (Torres age 12: Cystic Fibrosis)*
>
> *"I take my games (DS) and book and stuff most of the stuff is for babies I would be bored without my things they need more things for older children like computers and games" (Mattie age 10: Cystic Fibrosis)*
>
> *"Sometimes I nose around a computer, there are lots of things for little people to do but no magazines, colouring books but no colours and its not very comfy" (Josh age 7: Cystic Fibrosis)*
>
> *"When I am in hospital they test my blood and weigh me then I read my book" (Zac age 9: Cystic Fibrosis)*
>
> *"it was ok because they had play nurses and things to keep you occupied but it was quite boring really" (Blue age 9: Leukaemia)*

The children explained that they took toys from home in to occupy themselves when in hospital because they felt the play facilities were not suitable for them, and also taking familiar possessions from home can help to alleviate home sickness, and provide comfort and security in a strange environment (Thruber et al. 2007; Sartain et al. 2000; Angstom-Brannstrom et al. 2008). Although play specialists are employed specifically to organise play and activities for hospitalized children (Knight and Gregory, 2009), these findings show that children do not always feel their needs are met in relation to their psychological care.

There are similarities in the children's evaluation of the play facilities available to them as they comment on the fact that the hospital environment was aimed at young children and babies. There appeared to be a lack of age appropriate activities for school aged children to participate in. Also *Josh* thought it was an uncomfortable place that lacked good quality play materials. These findings concur with Soanes et al (2009) who found that children who were being treated for cancer praised hospitals that provided entertainment such as play and school rooms, organised activities and television. The National Service Framework for Children, Young People and Maternity Services in Wales (WAG, 2004) stated that children's wards and departments that cared for children should provide an appropriate environment with play and recreation facilities. However, the stories above tell us that the facilities provided do not always meet the needs of older children.

4.2.3 Home comforts

Thurber et al. (2007), state that hospitalised children suffer from homesickness. Here *Suzi* talks about a time when she was ill but really did not want to go to hospital as it was Christmas Day and she felt she would have missed out on the traditional family festivities.

> *"I have been in hospital a few times like this Christmas I went into a fit and the ambulance came because I was not coming around I did not really want to go in to hospital on Christmas day so they left me" (Suzi age 11: Diabetes)*

The following extracts captured the difference the children saw in their lives when they were at home compared to when they were in hospital.

> *"when I am home I have got different places to go after school and do stuff and that's what I like about being home and staying with my pets a fish and cat but she never comes in ..the cat is scared of daddy and she is not allowed upstairs because she goes to the toilet and she was sick" (Ellie age 7: Leukaemia)*

> *"I was excited about coming home and seeing my family um being able to pick your own food(laugh) um getting up and playing going to bed in a comfy bed um just being around your family really" (Blue age 9: Leukaemia)*

> *"It's better than going into hospital because... because when you go in its like boring although it's good to take time off school" (Rhiannon age 11: Diabetes)*

Ellie explained that she liked the fact that she could go out when she was home and do '*stuff*'. Speyer et al. (2009), state that paediatric oncology patients have limited contact with other hospitalised children and have few visitors other than their parents. *Ellie* and *Blue* expressed the comfort they experienced by being surrounded by their family. Speyer et al. (2009) found that children rate their quality of life as better when at home rather than in hospital. Hospital life is more restricting for children as they often cannot see their friends and do not have the same leisure activities available to them. However it must be remembered that during hospitalization the child's quality of life will be influenced by their level of ill health and the effects of any treatment. Research that produced similar findings included While (1991), Jennings (1994) and Sartain et al. (2001) who found that children preferred home care because they were in a familiar environment, had friends and family around them and could play with their own toys.

4.2.4 Supportive of family life

Home care has been found to be less restrictive and costly for families compared to care in hospital (While, 1991, and 1992; Jennings, 1994; Peter and Torr, 1996; Sartain et al. 2001). Interestingly the following excerpts demonstrate that these were felt to be important issues for the children within this study. The children explained that their CCN visited them at a convenient time so as to fit in with their family life. The maintenance of normal family life has been demonstrated as a positive outcome of home care in other earlier studies for example (While, 1992; Sartain et al. 2001).

> *"If the nurses did not come I would have to go to C for a finger prick. Yes I think that is what I would have to do it would be bit of a pain every week as its 1 hour, it's better they (CCN) come here it would be a pain just to go once a week to hospital. It is better if the nurse comes so I don't miss out on school... when it's a school day she comes to school and takes it" (Ellie age 7: Leukaemia)*

Ellie explained how having the CCN visit her at home to take blood samples made life easier and less stressful for herself and her family. *Ellie* lived in a rural location therefore hospital appointments and treatment visits would take up a great deal of their family's life. Stevens et al (2004) also found the provision of home chemotherapy for children with cancer resulted in less disruption of daily life, and a reduction in psychological stress. *Ellie's* story shows how important it was for her to return to her everyday life such as going to school, or just getting back to what she was doing before the CCN visited. Getting on with life and being normal was a recurring theme found within the literature (Woodgate, 1998; Taylor et al. 2008; Guell, 2009).

Helping families maintain their usual life patterns is a significant aspect of the role of the CCN (Pontin and Lewis, 2008a and 2008b). Carter (2000) found that CCN's view one of the major aspects of their role is to enable 'family life to carry on without the child's health care needs creating major disruption and chaos' (p. 69.). This is of vital importance as caring for a child with a chronic illness at home can lead to a diminished a sense of normality within family life due to increased isolation and conflict (Fawcett et al 2005, Kirk et al 2005). *Ruby* even though she recognised that being at home gave her mother extra responsibility still preferred being home to being in hospital.

> *'It's better because I don't have to stay in hospital mammy has to stay up late sometimes but it's better than being in hospital' (Ruby age 9: Cystic Fibrosis)*

Many of the children valued the continuity of care that was provided by the CCN service, and for some of the children this extended to periods of hospitalisation. Both *Jake* and *Ruby* emphasised that the same nurse was there to support them when they were in hospital and when they returned home. Kohen et al. (2000) also found that families with a child with a chronic illness said it was important that the same nurse visited them on a regular basis as it led to the development of a trusting relationship. A permanent relationship between the health care provider and family has been shown to be essential for the development of trusting relationships between families and health care personnel (Nuutila and Salantera, 2006).

> *"I have been looked after at home mostly I see Y she comes every few months I was in hospital with food poisoning last year and she was there too" (Jake age 10: Diabetes)*
>
> *"My nurse taught her (mum) in the hospital the same one that comes to the house" (Ruby age 9: Cystic Fibrosis)*

Ruby also demonstrated that she recognised that the CCN played a vital role in preparing her mother to care for her when she was at home, demonstrating that she was aware that the CCN was not just her nurse but a support and educator for her family. The excerpts show that both of these children understood that the CCN influenced their care and promoted their wellbeing without using hands on skills, or invasive procedures.

Within this theme I have given first hand accounts through the children's stories of their experience of hospital admission, and what they saw as the reason for this admission. Demonstrating agency in their own lives (James and James, 2004) the children have shown they have their own opinions about the environment in which they are cared for, and that they were able to provide valid reasons for preferring home care to hospital care. The children's stories show that an admission to hospital is an unwelcome and stressful intrusion into their lives. The majority of them recognised that their admission was due to complications or treatment associated with their chronic illness. None of the children described their stay in hospital as a positive intermission to their lives, however their stories about being at home and receiving care was much more positive. The findings show that the children demonstrated they recognised the role of the CCN in facilitating their care at home. The children's perceptions and of role of the CCN in managing and facilitating their care will now be explored in the next theme.

THEME THREE

4.3 THAT'S MY COMMUNITY NURSE

4.3.1 Introduction

In the previous theme the children gave accounts of their experiences of hospital and home care, and through their stories they expressed a preference for home care for reasons such as home comforts, being with their family, and receiving care from the CCN that was convenient for the family.

Within this theme I move on to analyse the children's stories about what attributes they saw as desirable in their nurse. The children explained how their CCN facilitated their understanding of their condition, provided support and advice, taught them the skills they needed to become self caring, and when needed delivered skilled nursing care based on expert clinical decision making.

4.3.2 The best things about having a CCN

Within their stories the children demonstrated what they saw as the best things about having their own CCN, some of the children talked about what they felt their nurse was like, and what attributes they valued in their CCN. There has been little evidence of children's perceptions of what constitutes a good nurse as most of the literature has been derived from an adult perspective. However more recently research has been conducted with child participants notably, Pelander and Leino-Kilpi (2004), Carter (2005), and Brady (2009), who all found that humanity was the most valued personal characteristic for a good nurse, with children expecting nurses to be nice and kind. *Ruby* and *Alesha* described their CCNs as a kind and happy people. Brady (2009) also found that being cheerful and friendly are positive characteristics of a children's nurse.

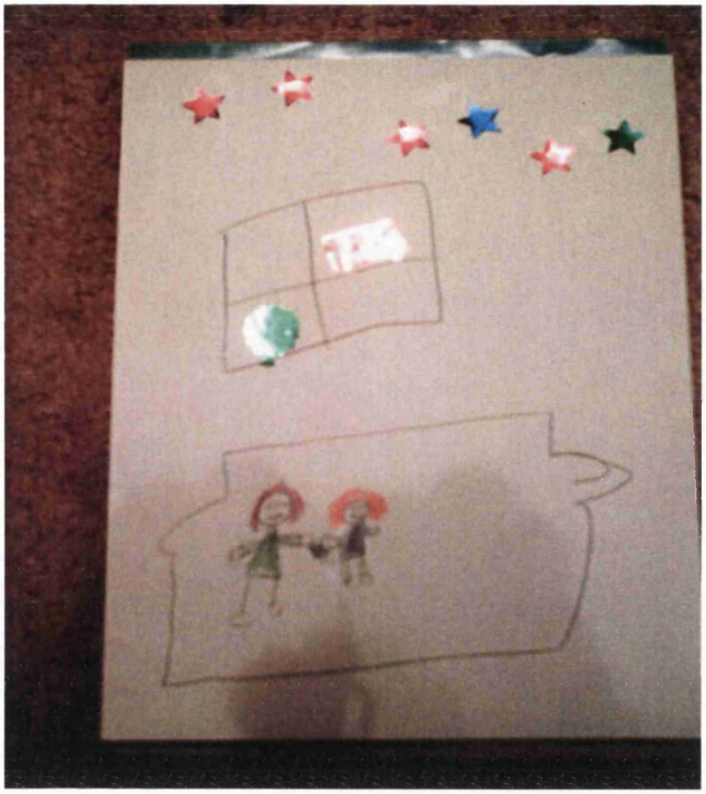
> *"I like her (CCN) she is kind and happy" (Ruby age 9: Cystic Fibrosis)*

> *"she (CCN) is happy when she comes she asks me how my gran is and how is Tiny (dog) (Alesha age 11: Epilepsy and Precocious Puberty)*

These excerpts demonstrate that the CCN's talked to the children about aspect of their daily life which were not always directly connected to their health. *Alesha's* story shows how the CCN was aware of her extended family by enquiring about her grandmother, and *Alesha* seemed particularly happy that her CCN was interested in her pet dog Tiny. Carter (2005) found that one of the essential criteria for a CCN stated by children in her study was not to be frightened of dogs, and liking cats. In order to deliver care and treatment that is effective and acceptable to the child it is vital that the CCN develops a relationship with the child and family. It is important that the CCN demonstrates that he/she values the child as an individual, and shows them respect and courtesy by utilising positive communication skills (Carter and Coad, 2009).

Holly and *Ellie* portray the CCNs within their stories as professionals who were interested in their lives because they asked them about what they had been doing since they last met. A willingness to listen has been shown in other studies to be a positive virtue of a children's nurse (Pelander and Leino-Kilpi, 2004; Randall et al. 2008).

> *"She talks to me like what am I doing this week and stuff' (Holly age 8: Growth Concern)*
>
> *"I get all sorts of nurses every week so I have got different names of them (names CCN's) they come once a week sometimes Monday or Tuesday if they don't come on a Monday they go to other people… they talk to me say like if it was after Christmas they would say did you have a nice Christmas and what did you have" (Ellie age 8: Leukaemia)*



Elle's picture of a visit from the CCN

When asked if she wanted to draw a picture of being visited by her CCN *Ellie* designed the picture above. She explained to me that outside the window there was a tree and from her house she could see the CCN's car when she came to visit her. *Ellie* told me that she would sit on the settee with the CCN and they would talk about issues that were happening in her life. *Ellie* was able to give Christmas as an example of what her CCN talked to her about during a recent visit in December, and although *Ellie* was being visited by many different nurses she was able to give me the names of all of the nurses showing she recognised each of them as individuals.

4.3.3 The worst things

Although the majority of the children's stories described the CCNs visits as positive, some of the children told me there were times when they did not care for the advice or treatment that was given to them. *Jake* described the CCN's visit as an inconvenience to his daily routine as he told me that he did not really like Y visiting him because he would prefer to watch the television. Herrman (2006) refers to this as a cost of taking care of diabetes as children feel that management of their condition interrupts and inconveniences their lives.

> *"Y (CCN) comes to see me every few months she asks me what have I been usually high or low she asks about weight and height and what I eat in the mornings and all that oh and my nails (does not elaborate) she asks questions about how I have been I don't really like it because I like to watch telly (laugh) she has a machine to take my blood pressure I don't like it much" (Jake age 10: Diabetes)*

Some of the children explained that they did not like the CCN reminding them about having to do their blood sugars on a daily basis and *Atlanta* told me she had made up her blood sugar recordings and had been found out by the CCN who had told her to in her own words to *'stop lying about it'*. Conflict with health care staff regarding treatment can lead to a lack of trust as the child and adolescent may feel their ability to become independent is being curbed (Kyngas and Barlow, 1995).

> *"Do your numbers (refers to blood sugar) I don't like needles they are horrible" (Ffion age 10: Diabetes)*

> *"When I see them (CCN) they do your numbers (referring to blood sugars) I don't like needles they are horrible and I show my diary where I keep my finger prick blood sugars" (Grace age 9: Diabetes)*

> *"To test my blood sugar more than I used to and stop lying about it" (Atlanta age10: Diabetes)*

Torres was very clear about what he disliked most about his CCN's visits and he was able to sum it up in one word.

> *"Blood" (Torres age 12: Cystic Fibrosis)*

Jonah Lomu explained that he had been given a booklet about diabetes written in English and at the time he could only read in Welsh. He also told me he was not pleased when he was told he could no longer eat sweets.

> *"She (CCN) gave me this booklet to read and I could not read it because I was only reading welsh you don't learn English until you are in juniors my mother read it to me and I was ... I did not know what to do and I was confused I was not upset but she (CCN) said I was not allowed to have sweets and I like sweets" (Jonah Lomu age 11: Diabetes)*

These children were demonstrating that they wanted to live what they saw as a normal life, and *Jonah Lomu* wanted to be able to eat sweets because he liked them. Doing the same things that friends do is very important for children and adolescents as it brings a sense of normality into their lives (Herrman, 2006; Guell, 2009)

However, other children viewed procedures in a more positive way because they felt it gave them a baseline from which they could plan their lives.

> *"To help me she takes blood so I know where I can go if my bloods are high or low and she has to do it to help me get better" (Elle age 7: Leukaemia)*
>
> *"I like it when they (CCN) come to the house and not the hospital and I like to know what my bloods are so I can go out with my family" (Zac age 9: Cystic Fibrosis)*
>
> *"I feel happy if I have got new blood so I know what I can do this week if they are high or low I get excited over what I can do and if I can go to different places if they are high and stuff but if they are low I don't like it because I can't go to school and I like going to school to see my friends" (Simon age 8: Leukaemia)*

The personal burden of chronic illness affects how a child lives their life. However they do not want to be seen as victims of their illness, but to make the most of life within the limits of unpredictable illness (Stewart, 2003; Soanes et al. 2009). So although the children demonstrated that at times they disliked contact with the CCN because they associated her visit with a painful procedure or advice they did not wish to hear, the findings also show that they children were aware of the importance of investigations and treatment to the maintenance of their health.

4.3.4 Advice and support

The children's stories showed that they were aware of the advice and support given to them and their parents by the CCN and that a vital aspect of the contact the children have with the CCN involves talking about their health in relation to their chronic illness. Professional support has been shown to be an important factor for children and adolescents with a chronic illness (Kyngas et al., 1998 Karlsson et al., 2008). The following excerpt from *Suzi's* story highlights how the CCN showed interest and concern about her health and wellbeing.

> *"I see X and talk to her for a bit she asks if I am eating properly and how my sugars are just making sure everything is normal really... I don't see X very much I either forget to go to clinic or forget to be in when she calls" (Laugh)*
> *(Suzi age 11: Diabetes)*

Suzi recognised that the CCN was checking to make sure everything was as she described '*normal*', by this she is referring to her own state of normality where her diabetes remains well controlled. Children with a chronic illness will often normalise the abnormal and minimise the impact the illness has on their lives to successfully absorb themselves into the everyday world (Guell, 2007; Protudjer et al., 2009). *Suzi* also portrayed here elements of non-compliance by not keeping appointments made with the CCN. Non compliance with treatment can result in poor health outcomes and hospitalisation. *Suzi* was eleven years old at the time of her interview and therefore still developing her ability to make appropriate decisions about her health. Children at this stage often view health care staff as enforcers of health related regimes and the child can feel controlled by the constant questioning about self care activities and management of their chronic condition. The process to successful self management occurs gradually and the development of autonomy requires the support, encouragement and guidance of professionals and parents, however the transition process is often fraught with conflict and is a bumpy and uneven process (Horner, 1998; Huss and Enskar, 2007; Wales et al., 2007).

Katie and *Josh* recognised that their CCN gave them advice and monitored their health. For *Katie, Zoe,* and *Holly* young girls who were under surveillance for growth retardation being measured was one of the highlights of their contact with the CCN. *Katie* also explained that she enjoyed discussing her health issues with her CCN and felt that by doing this she was learning about her condition.

> *"I like I don't know probably seeing if I have grown or not I like talking to her (CCN) to see what her views are on it I ask questions back otherwise you are not going to learn much" (Katie age 9: Growth Retardation)*
>
> *"C (CCN) measures me and weighs me and sees how much I have grown since last time" (Zoe age 9: Growth Retardation)*
>
> *"Um just weight and height to see if I have gone up and that and to see how healthy you are" (Holly age 8: Growth Retardation)*

For *Josh* who had been diagnosed with cystic fibrosis being under weight had been an issue for many years, he recognised that he needed to gain weight and said that his CCN talked to him about his diet and encouraged him to eat more fruit and vegetables. Although from the look on his face when he told me this I felt this was one piece of advice that had fallen on stony ground, and *Atlanta* did not seem too pleased that she had to give up her toast. It is vital that the CCN has the skills to support and educate children so that they can develop the skills to become self caring. However children are able to determine what advice they value as supporting and what they see as nagging or unwanted advice (Huss and Enskar, 2007).

> *"She (CCN) talks to me about my weight I need to be heavier she talks to me about eating more fruit and vegetables sometimes I do a cough swab and lung function" (Josh age 7: Cystic Fibrosis)*

> *"She (CCN) found out I was eating too much toast which has loads of carbohydrates in it I cut that out and my thing (refers to blood sugar) just went down then" (Atlanta age 10: Diabetes)*

Rose also told me that her CCN gave her diet advice, and she seemed to think that the CCN went to a shop and wrote a list of food suitable for her. I felt this explanation was very innocent and naïve, but demonstrated how important *Rose* felt she was to the CCN that she would take time to do this specifically for her. Woodgate, (2006), and Berntsson et al. (2007) also found that children value professionals who are sincere, and respectful, and treat them as individuals.

> *"She has a bit of paper with all the food I can eat and stuff she goes to a shop and writes down all the stuff I can eat and my mum buys some stuff then" (Rose age 11: Diabetes)*

Penny and *Hannah Montana* explained that their CCN gave them support in relation to their blood sugar levels. They told me that they felt they could contact X at any time even at home if they had a problem. This was also echoed by *Josh* who told me that his mother had contacted the CCN, and that her support had been in his words '*helpful'*.

> *"It's because of the support from X and she says 'that's too high for you" (Penny age 11: Diabetes)*
>
> *"We have got access to X we can ring her at home but we don't need to do that" (Penny age 11: Diabetes)*
>
> *"The best thing is that it helps if there is something wrong we can say to her or like um... if I am really low and it won't go back up or something like that we can just ring her" (Hannah Montana age 8: Diabetes)*
>
> *"Mum has rung her a couple of times she (CCN) was very helpful then" (Josh age 7: Diabetes)*
>
> *"It's good they (CCN) come especially in the beginning I have been well that's because of all the support" (Rose age 11: Diabetes)*
>
> *"X (CCN) was there to help straight away she came to the house she helped me with injections gave me a new pen and everything. "(Vicky age 10: Diabetes)*

Maintaining contact and providing support with families in a proactive way is an important aspect of the role of the CCN (Pontin and Lewis, 2008a; Carter, 2000; Carter and Coad, 2009). The children's stories demonstrate that they thought that their CCN was a knowledgeable practitioner who they could rely on if they had a problem. They have also shown that they recognised aspects of the role of the CCN other than technical or practical skills. The findings suggest that the children recognised the more complex skills which Carter (2000) referred to as the real expertise of the CCN (p.68). These skills are softer and more emotionally based and include support, enabling, facilitation and empowerment. Caring for children with a chronic illness in a community setting requires skills of a higher order than caring for children with short term problems. CCNs are a skilled, specialist resource for children and their families who require exceptional interpersonal skills and insight to work effectively with children and families in the community (Whyte, 1992; Carter, 2000; RCN, 2002).

> *"Once I was throwing up a lot I was not having anything to eat and the nurse was coming to see me she sent me to hospital and I stayed there for one night" (Mattie age 10: Cystic Fibrosis)*

> *"Whenever they (CCN's) give me a bag of stuff they always tell me how much I have to have because I might put on weight or loose weight so they have to tell me how much I have to have they tell mammy as well as she has to measure out the medicine" (Ellie age 7: Leukaemia)*

> *"Well she (CCN) just comes and checks me over and makes sure I am ok and sometimes she has to put a needle in because I have a portacath, because I have a lung disease otherwise I will become ill, she puts all the things ready, she put a needle in my port, she puts antibiotics in it, she sees if I am ok. When I am in hospital she checks for bumps, when I am not well she (CCN) comes to listen to my chest to see if there is anything in there, then she can sort it out. She takes a swab and sends it to the pharmacy, then the results come back and they see if I have to have anything and if I do they give me some antibiotics, and then if it comes back fine I don't have to have anything" (Ruby age 9: Cystic Fibrosis)*

> *"I have injections she (CCN) comes from B (place) she checks me every month, she takes my blood pressure, it helps her to know how I am when she is not here" Alesha age 11: Epilepsy and Precocious Puberty)*

> *"I can tell her anything and she will give me solutions of how I can get around doing the solution" (Rhiannon age 11: Diabetes)*
>
> *"I tell mum my mum rings the nurse (CCN) we take my temperature we go straight to C" (hospital) (Blue age 9: Leukaemia)*

The excerpts from the stories above show how the CCN was relied on as a source of expertise. The CCN is portrayed within the stories as a problem solver as *Ruby* explained her CCN would be able to *'sort it out'*. In this part of her story *Ruby* has demonstrated that she has quite a detailed understanding of the role of the CCN as she describes how the CCN assesses her condition on a continual basis as on more than one occasion in this excerpt *Ruby* talked about how the CCN *'checks me over and makes sure I am ok', 'she sees if I am ok'* suggesting that *Ruby* has recognised that part of the skill of the CCN is to assess and monitor their patient's condition. The findings highlight the technical expertise required by CCN's to provide skilled complex care so that children with chronic conditions can be cared for at home.

4.3.5 Bridging the gap

The following excerpts show that the children saw the CCN as someone who bridged the gap between themselves and the medical profession. Here *Megan*, *Grace* and *Holly* said that their CCN was there for them either during a consultation with their doctor, or was available to discuss and explain issues to them. *Grace* expressed this very clearly as she talked about the doctor using *'big words'*, however her perception of her CCN was someone who was able to explain issues to her at a level she could understand. This was also echoed in *Holly's* story. The need for the CCN to portray good communication skills has been highlighted in previous studies, Brady (2009) reported that communication is a vital attribute for a good children's nurse and Randall et al. (2008) and Carter and Coad (2009) maintain that good nurses have good listening skills and are non judgemental, approachable and helpful.

> *"She (CCN) talks to me about how my bloods have been, how my diet has been and if I have been having any bad lows or any high ones. Every 3 months I have my weight and height checked, X (CCN) comes in to all the doctors she gives mammy and me advice I need with injections. If things need hiring or lowering, she is the one who talks to mum through things and with me and if there are any problems she explains that if its like to do with my diet, or if it's just to do with because I am growing and I need more to counteract it" (Megan age 9: Diabetes)*

> *"she (CCN) talks to me about stuff, she explains it better than the doctor, he speaks in big words" (Grace age 9: Diabetes)*

> *"a nurse or doctor on the ward explained it, but I did not get it so C (CCN) told me then I understood" (Holly age 8: Growth Retardation)*

4.3.6 Social contact

Torres a young boy with cystic fibrosis thought that the best thing about his CCN was that she arranged a trip to Anfield where he had been able to meet his favourite football team, and the fact that it snowed seemed to make it all the more exciting. *Vicky,* expressed her enjoyment of attending a diabetic holiday camp, which was arranged by her CCN. Also *Blue* explained that her CCN arranged caravan holidays for her and her family close to where she lived on the coast as she was not well enough to travel very far. Carter (2005) found that children being cared for by a Diana Team said that trips outside the home make a big impact on children with long term health issues. So although being a travel agent is not necessarily a skill usually associated with CCN practice, it is important that the CCN recognises that a special treat or holiday can make a huge difference to a child's quality of life, and is highly valued and appreciated by patients and families.

> *"T (CCN) gives mum the information and she gives it to me. T is ok though I had a wish I met all the football players I went to Anfield and it was snowing" (Torres age 12: Cystic Fibrosis)*

> *"I went to LL (diabetic camp) that was really fun it was great, I was sharing a room it was great to make new friends" (Vicky age 10: Diabetes)*

> *"they give us breaks, I went to meet the Prime Minister at Christmas and I went to decorate his tree, they give us breaks we had a caravan holiday in T". (Blue age 9: Leukaemia)*

This theme has analysed excerpts from the children's stories where they talked about their relationship with the CCN, they described their CCN as someone who they thought was friendly and kind. The results show that the children not only recognised the concrete clinical skills performed by the CCN, but that they had an awareness of the more complex skills embedded within expert CCN practice. The children described the CCN as a knowledgeable practitioner who supported and empowered them, so that they could become responsible to manage their chronic illness themselves.

In order to empower children to successfully manage their chronic illness at home the CCN needs to be an expert practitioner who is able to demonstrate the skills of assessment, clinical decision making, planning and evaluation. Along with these clinical skills an expert practitioner needs to be flexible, confident and have the ability to communicate effectively with both children and their families. However it is also vital that the need to do something for a family does not result in disempowerment.

Within the next theme I have discussed how the children demonstrated they were able to take control and gain independence and the necessary agency to manage their chronic illness at home.

THEME FOUR

4.5 TAKING CONTROL

4.5.1 Introduction

Within the previous theme the findings have shown how the CCN supported the children in partnership with their families to achieve the skills necessary to manage their chronic illness at home. This theme is concerned with the children's stories as they moved on to give accounts of their journey to becoming self-caring. The stories demonstrated that initially the responsibility of managing their illness had resided with their parents (usually the mother). However the children also provided evidence of how they had been able to take responsibility for their own health with the help and support of their family and the CCN.

4.5.2 Developing Agency

Enabling children with a chronic illness to develop agency in relation to their own health thereby facilitating independence is a major role of the CCN as transition of responsibilities from parents to the child is an important issue for children with a chronic illness (Woodgate, 1998; Yoos and Mullen, 1996; Kirk, 2008). The children's stories show how their agency was encouraged and supported by their parents and the CCN.

The findings suggest that level of self care the children undertook mainly depended on the complexity of the treatment and the severity of their illness. *Ellie* and *Blue* were being treated for leukaemia and as their treatment was complex the locus of control had remained mainly with their parents. They were also the two of the youngest children within the study, and therefore the most developmentally immature, and according to Bibace and Walsh (1980) may be categorised as being within the concrete operational stage of cognitive development where children are able to solve concrete or real problems, but have not mastered the ability to deal with hypothetical issues. My feelings however from conducting the interviews were that both of these children had a thorough understanding of their condition and treatment as I have described within theme one, and therefore the reason for strict parental supervision of medication was due to the complexity and toxicity of the drugs the children were being treated with. A further example of parental management was provided by *Alesha,* when I asked her about her medication. Indeed she thought it was quite funny that I had asked her this and proceeded to tell me in detail how she took her tablet.

> *"my mammy puts it (medicine) into a bowl and I take it once a night and some are morning and night" (Ellie age 7: Leukaemia)*
>
> *"My mum and dad look after me at home my mum gives me my tablets on a Wednesday and every night before I go to bed" (Blue age 9: Leukaemia)*

> *"I take my tablet mammy gives it to me (mum says she put the sachet out and A takes it herself), I pop a tablet put it on my tongue, get a glass of water and drink it sometimes I forget. Sometimes I have a fit in the night I wee and poo and mammy cleans me up, I have bad dreams" (Alesha age11: Epliepsy and Precocious Puberty)*

Ruby's story demonstrated that parents often assume a great deal of responsibility for the care of their child, which can be a frightening experience (Nuutila and Salantera, 2006), as for parents one of the most distressing aspects of providing care is to carry out clinical procedures that may cause their child distress (Kirk et al., 2005). Therefore parents require information and support from a knowledgeable practitioner to enable them to care for their child at home (Cummings, 2002; Danvers et al., 2003; McIntosh and Runciman, 2008). CCNs need to embrace the philosophy of partnership in care, which is based on mutual trust, negotiation, and respect, as one of their main roles is to facilitate parents to care for their child through teaching, support and shared decision making (Taylor, 2000; McIntosh and Runciman, 2008.).

> *"I have physio every day mum does it (pause) sometimes I use my pet mask it's a machine designed to help me. I have to breathe into it and it gets all the phlegm off my chest, I lie on mammy's knee and she has to smack my chest and my sides and my back" (Ruby age 9: Cystic Fibrosis)*

Scruff described how her mother helped her to make the decision about whether to have an insulin pump fitted, she explained that X (CCN) had discussed this with them and had provided written information, following which her mother had conducted her own research by using the internet. *Scruff* went on tell me that once the device had been fitted both she and her family found the maintenance of her diabetes much more convenient. Their decision making was facilitated by the CCN who provided information about an insulin pump, however this excerpt also shows that parents will often seek other sources of information to verify the information provided by professionals. *Scruff's* story demonstrated shared decision making between herself and her mother, and shows how children can be actively involved in the process and that they can act as agents in their own lives.

> *"X gave mum a few books about it. Mum was looking on the web site and it looked really good because you don't have to have injections all the time. We went to the hospital to put it in the first time and then we went home and were doing it on our own. Because I have this pump now if it's high I just type in my number and then it will tell me how much insulin to put in myself. I don't have much chocolate stuff only on special occasions or I will go high all the time" (Scruff 11: Diabetes)*

To gain independence children require education about their condition, and to learn the skills necessary to maintain their health. This is a gradual process that moves from full parental responsibility though a period of shared responsibility, to the child becoming self caring (Horner, 1998; Wales et al., 2007; Kirk, 2008). As these extracts show the parents were very involved in their child's transition to become self caring by supporting and helping them.

> *"my mother helped me do it, she helped me keep my hand steady and then I started on my own" (Jake age 10: Diabetes)*
>
> *"mammy and daddy help me they make sure I don't eat stuff and make sure I don't forget to take my snacks to school" (Hannah Montana age 8: Diabetes)*
>
> *"mum was showing me most of the stuff how to set up and everything and when she showed me I was doing it in school on my own" (Rose age 11: Diabetes)*

Many of the children had diabetes in this study which requires daily insulin injections and monitoring of blood sugar levels. *Suzi* described how her mother would hurt her whilst recording her blood sugar levels. She explained that her mother's technique was not correct, and that when she followed the advice of her CCN she found the procedure much less painful. *Megan* was also reluctant to allow her mother to give her the insulin injections, she explained that she felt safe when U (CCN) was doing them but was unsure of her mother taking over the procedure. Bricher (1999) states that gaining trust requires time and patience on behalf of the practitioner, and here *Megan* demonstrated that she trusted U to give her injections but that she needed time to accept her mother had the competence to carry out the procedure. Also children often do not want to associate a parent with painful procedures as they would prefer to associate them with caring and comforting. Both *Suzi* and *Megan* had moved on to become self caring and had incorporated their need for insulin injections into their daily lives.

> *"She (mother) would pinch the skin and taking my blood from the tip of my finger would really hurt so when ever I was doing it in the middle of my finger like X (CCN) showed me it was better. I do it now it's (BM Monitor) by the side of the bed" (Suzi age11: Diabetes)*
>
> *"I can remember U (CCN), I used to let her do my injections but would not let mum do it but then I had to in the end when I was 8 I started doing them myself" (Megan age 9:Diabetes)*

Jake said that his CCN explained to him about his diabetes, he was convinced that it was due to Y that he understood so much about his condition.

> *"Y (CCN) told me about me about diabetes and about carbohydrates, pasta, rice. Carbohydrates is what I should eat at every meal, I like everything except sprouts and cauliflower. I understand things better because of Y (CCN) I would only know half of what I know" (Jake age 10: Diabetes)*
>
> *"because when we were in Florida they did tell us a bit but I did not understand so much. It was more X who explained when she helped me inject and everything. But then I got used to it I learned to do it myself. Because when X came she showed me how to do it. The best thing was that we would not know what to do she explained more than anyone she knew more, and then it was much easier like if she was not there we would probably struggle more, we would be ok but not great" (Vicky age 10: Diabetes)*

This is echoed in *Vicky's* story were she recalled that as she had been diagnosed whilst on holiday and said she had not really understood about her condition until she met X. She saw X as the professional who was able to explain to her about diabetes in a way she could understand. *Vicky* told me that she thought that her CCN knew more about diabetes than anyone else, and had taught her how to inject herself, and that that without X she would have found life more difficult. This excerpt demonstrates the complexity and almost simplicity of an expert practitioner who was able to empower her patient thus facilitating the transition to becoming self caring. Karlson et al. (2008) and Kyngas et al. (1998) also found that children with diabetes are motivated by nurses who discuss self care with them and that they rely on health professionals as they feel they can learn from them.

4.5.3 Mastering Skills

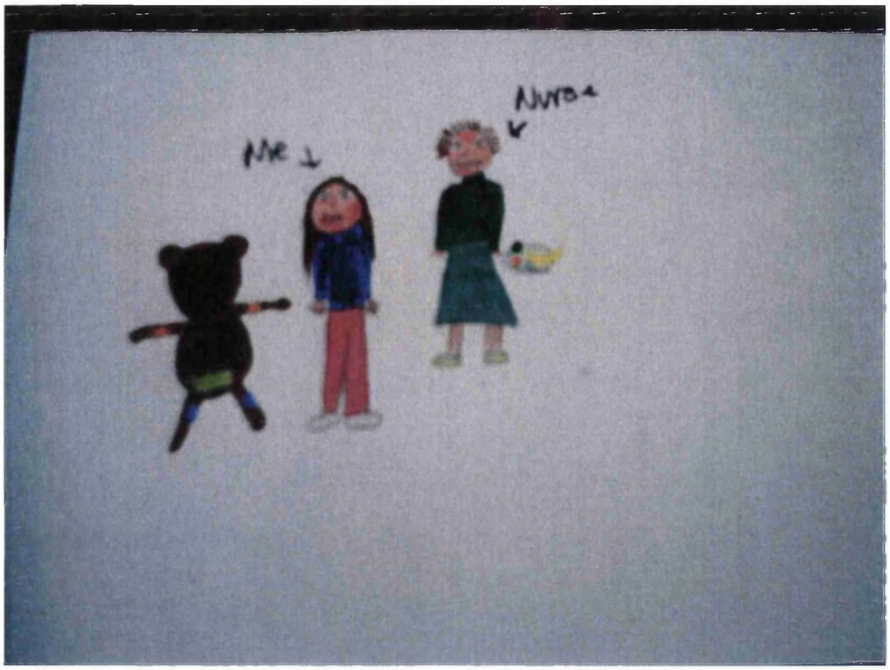
Being able to attain the skill necessary to be self caring was a recurring theme within the children's stories. The findings showed that the children recognised and valued the skills of the CCN who supervised and supported their learning through demonstration and teaching.

Ffion, Rhian and *Penny's* stories show how they mastered the skills they needed to become self caring. The use of a teddy bear to demonstrate the correct injection sites and technique seemed common practice for the CCNs caring for children with diabetes. Many of the children showed me their teddy bear which they had lovingly cared for over many years. *Ffion* explained that she felt able to give herself the insulin injections because she had been able to practice on Ruby bear as practicing on an orange was not very successful, as she explained it did not feel at all the same as real life. *Ffion* brought Ruby bear for me to see and seemed very proud when I asked if I could take a picture. Sutcliffe et al. (2004) state that even very young children can cooperate with distressing treatment as *Ffion* has shown here. When she talked about her father's poor health and compliance to treatment, she was demonstrating a further point made by Sutcliffe et al. (2004) who describe a child's acceptance of daily injections as being linked to their understanding of the complications that can arise from non compliance, and that the benefits of treatment outweigh the harm.

> *"I have done my injections since I was 5. I practiced on a bear called Ruby, she had patches on her leg, on her bum, and on her belly, and on her arms, and that is where you can inject, and she has hearts on her paws so that's to test your finger and because I could do it on her I could do it on myself then. They (CCN team) showed me on an orange it was funny (laugh), but an orange is not like your leg though the teddy bear feels better she (CCN) explained it to me and to you (points at mum) and well we all done it, I learned slowly how to do it on myself. Dad is a diabetic so he knew but he is naughty he does it through his clothes and he has kidney failure and is going on dialysis" (Ffion age 10: Diabetes)*

Picture of Ffion's Ruby Bear

When asked to draw a picture of a visit by the CCN *Rhian* designed a picture of herself with her CCN and the bear with the injection sites clearly drawn on the arms, legs and tummy of the bear. She explained how she was taught to give her own medication by practicing on the bear and stressed that she had been able to achieve this from the onset of her diabetes showing that the CCN provided *Rhian* with the skills necessary to become self caring.



Rhian's picture of herself with her CCN and the bear.

> *"I do my injections since the start X (CCN) taught me and she had this bear and um...I was squirting water into it... in the morning I do it in my tummy and in the night when I am having tea I do it in my leg" (Rhian age 11: Diabetes)*

Penny also told me she learned how to self medicate by practicing on a bear, she said she felt less afraid because she had seen her brother doing his insulin injections and he was also willing to help her. Children often find the process of transition to self caring is aided by family and friends (Horner, 1998; Huus and Enskar, 2007)

> *"She (CCN) had a bear and she was showing me all the injection sites and explaining. But because my brother is diabetic I knew so it was easier. Yeah it was sad but I found it exciting but I had books to explain and J (brother) was explaining" (Penny age 11: Diabetes)*
>
> *"(CCN) showed me how to do my injections she had this bear, and um I was squirting water into it" (Grace age 9: Diabetes)*
>
> *"At the start W (CCN) would watch me do my insulin I don't think I would be doing so well without her" (Skye age 9: Diabetes)*

> *"She (CCN) told me to put it straight in and don't bend it or wobble it. After a couple of days or a week it just came and the pain just went as your skin gets used to it" (Louise age 11: Diabetes)*
>
> *"Well W (CCN) showed me how to do it, but every day mum would show me where to go or what to do" (Skye age 9: Diabetes)*
>
> *"X (CCN) she explained what diabetes was she was teaching me how to do my injections. She was really helpful with everything with my mother and father" (Barbie Girl age11: Diabetes)*
>
> *"She (CCN) came to the house telling mum what happens if I go low or high and she was telling me about how to do the injections and telling me what to give myself when I am low. Then she gave us a CD for the computer and that tells us everything about what happens when your blood sugar is high or low"*
> *(Scruff age 11: Diabetes)*

All of these passages from the children's stories show that the children needed to master a technical skill in order to maintain their health. The stories reflect very similar experiences of how their CCN taught them the skills of administering an insulin injection. *Scruff's* extract however shows that the care provided by CCN included far more than demonstrating a technical skill. In order for her to become self caring *Scruff* needed to assimilate knowledge and understanding about normal blood sugars levels, and how to manage her diabetes in the event of a hyperglycaemic or hypoglycaemic attack. These stories show that the CCNs recognised the children as partners in care which is vital if they are going to successfully manage their chronic illness and make autonomous decisions about their health care needs (Alderson et al., 2006; Huus and Enskar, 2007; Guell, 2009).

4.5.4 Recognising their needs

The children's stories also show that they felt their lives were different to those of their friends because of their illness. *Jonah Lomu* and *Suzi* explained how their diabetes restricted their ability to do the same things as their friends, *Jonah Lomu* started by telling me he could eat almost anything but then as his story continued the reality of his restrictions were clear to see. By minimising symptoms and restrictions imposed by chronic illness the children are attempting to bring to attention to their capabilities rather than their disabilities (Bury, 2001).

> *"I can eat a bit of everything I have a treat every week but not a chocolate bar or ice cream or anything maybe a little pizza every about 2 months.. if we go out to a restaurant for someone's birthday I can have a little chocolate bar or lolly" (Jonah Lomu age 11: Diabetes)*

Suzi was less enthusiastic about her inability to join in with her friends when they have treats and seemed resigned to the fact that she would not be choosing a dessert like her friends. *Ruby's* story again reflected the constraints of having a chronic illness as she explained how her school day was organised around her medication needs. The stories show that the children's lives were restricted by their chronic illness a finding that is supported in research studies by both Woodgate (1998), and Hermann (2006).

> *"I know for myself if I am allowed to or not and its kind of awkward because, say I am going out somewhere for a meal and drinking coke and I have to have diet coke or everyone is having ice cream or desserts I won't have anything"*
> *(Suzi age11: Diabetes)*
>
> *"I have to take tablets every day, the school looks after them instead of looking after them myself I give them in to the office and every break time and lunch time I go down to take them. I take them because otherwise I would not be able to digest my food" (Ruby age 9: Cystic Fibrosis)*

Children with a chronic illness can feel they need to keep their illness a secret as it minimises the difference between them and their healthy peers, and lowers the risk of loss of social acceptance and allows them to fit into their peer group (Christian and D'Aura, 1997). *Rose* and *Jake* said they thought the fact that their CCN visited their school to talk to their friends was very helpful as they felt it helped their friends understand their condition and accept them.

> *"She (CCN) came to school and told everyone about my diabetes and gave me a disk for everyone to see. She came in the beginning" (Rose age 11: Diabetes)*

> *"Y (CCN) went in to teach the school and one of the teacher's father is diabetic" (Jake age 10: Diabetes)*

Penny's story shows that her friends were a source of support, and that she felt completely accepted by them. *Penny* has also shown in her story that by becoming responsible for her own medication she had been able to foster her own independence as she was now able to visit friends straight from school. Maintaining emotional support from peers makes it easier for children with diabetes to integrate their condition into daily life (Karlsson et al., (2008), indeed support from friends has been shown to promote equality, and facilitate the acceptance of illness by the sufferer (Woodgate, 1998; Berntsson et al., 2007; Protudjer, 2009).

> *"at first I could not go over my friends houses and now especially since I take my injections to school to do it I can go over from school, and most of my friends know about it so they would know if anything was wrong they look out for me but it does not bother them" (Penny age 11: Diabetes)*

4.5.5 Keeping Vigilant

The children's stories also showed that they needed to be vigilant to maintain a normal life. All of these excerpts demonstrate that the management of their condition was very much the responsibility of each individual child. These children have shown that they were able to recognise and treat the symptoms of their condition, and take control of their illness by following medication routines, checking blood sugar levels and eating a healthy diet. Clearly these children with a chronic illness had to make an extra effort which was often time consuming and restricting to maintain a healthy life. Children with a chronic illness to need to plan ahead, and according to Guell (2009), have to arrange their life around their illness so as to live the same lives as other children. All of these stories show that the children had to take time out to manage their illness on a daily basis and that they were able to demonstrate they were capable of managing their chronic illness themselves. These children were demonstrating their understanding regarding the risks posed to their health by their chronic condition and how competent they were at minimising these risks.

> *"I take my blood sugar and see what it says, if it's low I have Lucozade and a biscuit if it's high if it's really high I have more insulin if its 12 or something I just leave it" (Grace age 9: Diabetes)*
>
> *"I take my blood sugar and see what it is" (Rhian age 11: Diabetes)*
>
> *"I eat a lot of fruit and vegetables, but I have a little treat once a week I test my blood sugars and if they are low I have something sweet, but if they are high I can't unless it does not have sugar in or its low in carbs"*
> *(Rose age 11: Diabetes)*
>
> *"If my bloods are high I either have extra insulin or exercise, if its low and I know because I go sweaty and I shake and my tongue tingles I drink Lucozade and have a biscuit" (Ffion age 10: Diabetes)*
>
> *"I take Lucozade and biscuits whenever I go to school and if I have a hypo I ask teacher and then just eat in class" (Atlanta age 10: Diabetes))*
>
> *"I have got to do physio and I got medicine. My mother she pats me on the back and stomach, then I have to do breathing exercises. I do my tablets myself mum puts them ready I take tablets before every meal and my medicine is the morning and the night" (Tores age 12: Cystic Fibrosis)*
>
> *"I have to have physio and having lots of calories and take the tablets"*
> *(Josh age 7: Cystic Fibrosis)*

Jonah Lomu's story shows that he understood the need to be vigilant in his management of his diabetes. This is a complex section of his story where he is describing how he would treat a hypoglycaemic attack in a hypothetical situation. By using an imagined account *Jonah Lomu* was able to incorporate the drama of needing to telephone for an ambulance if his hypothetical situation became critical. However this shows that he was voicing his concerns about his illness and as the story unfolds he described how important it was for him to be vigilant in his insulin maintenance as he was very aware of the complications that could befall him in later life if he did not control his diabetes.

> *" if my bloods were low I would have this thing called hypogel you rub it in your gums and its really fast acting, but say now your bloods keep dropping and the hypogel was not working and you put in too much insulin in by accident well I have not done it but say you have the only thing you can do then is phone an ambulance. Sorting out my insulin dose so it's literally perfect otherwise something could go wrong keeping my blood sugars right which is part of my*

> *insulin um.....(pause) watching out for my diet because if I eat wrong I could loose a leg or something when I am older and um...(pause) not eating too much sweets or chocolate, because if my bloods go too high I go into a coma and then I won't be happy. Well some of my friends in school say you will be really fit when you are older because you can't have any chocolate"*
> *(Jonah Lomu age 11: Diabetes))*

This last sentence of *Jonah Lomu* story "*well some of my friends in school say you will be really fit when you are older because you can't have any chocolate"* shows facets of automythology (Frank, 1995) a metaphor derived from the myth of the phoenix a supernatural creature that is able to reinvent itself from the ashes of its own funeral pyre and live for another thousand years. *Jonah Lomu* is not just portraying himself as an individual who has survived his illness but as someone who will be reborn as a healthier version of himself and it is his destiny to become someone his friends will think of as a role model.

4.5.6 Independence

Many of the children described their lives as normal the excerpts below show how they had redesigned their lives to incorporate the illness into their changes lifestyle. *Donna* told me about her morning routine and how she included the management of her condition into everyday life.

> *"I can just do my injection get dressed come down stairs before I go to school I have breakfast and just leave" (Donna age 11: Diabetes)*

When individuals tell stories where they disclose their illness rather than disguising it they are demonstrating a changed identity which incorporates their symptoms and treatment this was reflected in the stories by *Megan* and *Zac.*

> *"I am on 4 injections a day I do my blood sugars and look after my diet and exercise" (Megan age 9: Diabetes)*
>
> *"In school I go to the hall and take my tablets before my food" (Zac age 7: Cystic Fibrosis)*

Suzi told me that it was so routine for her to inject herself that sometimes she could not remember whether she had given herself her insulin injection and would have to look for tell tale signs of a recent injection site.

> *"I do it so often like every morning I can't remember if I done it because I am thinking about yesterday morning or something I write my sugars down every night before I go to bed if I forget its weird.... I am looking for little marks on my belly or legs I end up panicking in case I have not done it"*
> *(Suzi age 11: Diabetes)*

Tores and *Alesha* explained that they could do everything and gave examples such as rugby, exercise and swimming. *Jake* told me that he was the healthiest in the school because his diet was better that all his friends and he knew what he should eat. Again *Jake* is portraying himself as a hero who has gained health rather than ill health from his chronic condition. Children often talk about their abilities in a positive way as a means of expressing their normality and according to Prout et al. (1999) this adaptive spirit enables them to 'maintain and produce their own ordinariness' (p.156).

> *"I get up have breakfast take tablets go to school I do everything rugby football tennis athletics and swimming" (Tores age 12: Cystic Fibrosis)*
>
> *"eat healthy and do everything loads of exercise swimming and rugby" (Alesha age 11: Epilepsy and Precocious Puberty)*
>
> *"I know what I am meant to eat its easy I am the healthiest in the school" (Jake age 10: Diabetes)*

Within their stories the children are all talking about how healthy they see themselves, they have depicted themselves as healthy normal children who just get on with their lives who are capable of making the necessary adjustments to ensure they maintain their health. The children's stories show how their independence was fostered through the support and education provided to themselves and their parents by the CCN.

4.6 CONCLUSION

Within this chapter I have has analysed the children's stories using paradigmatic analysis which revealed the common elements of the children's experiences of managing their chronic illness at home. The findings show that the children felt they were knowledgeable about their condition mainly because they were given support and guidance by their community children's nurse. The stories demonstrated the children preferred home care to being in hospital and they gave valid reasons to support their choice. The stories also showed the role of the community children's nurse from the viewpoint of the children who were the consumers of the health care. The children described the CCN as the professional who taught them the skills necessary to be able to manage their chronic illness themselves. The stories also highlight the importance of parents who were recognised by the children as supporting and guiding them through the process of gaining their own locus of control. The findings suggest that the children were capable of being included in the decision making process in respect of their health care needs, and that they were able to assimilate their chronic illness into their everyday lives.

This chapter has developed general themes from the children's stories and in doing so has highlighted the most common elements of the children's stories. Within the next chapter I have presented two whole stories which have been set in the context in which they were generated and told. Passages of talk that formed the narrative have been used with the aim of describing the world created by the narrator.

Chapter 5: Narrative Analysis

Within this chapter I present two of the children's stories that I have analysed using narrative analysis (Polkinghorne, 1995) the outcome of which is a narrative with a beginning, middle and an end. Within the stories I have used a plot to give meaning to the children's experience. When reading the literature surrounding story telling in qualitative research it soon becomes apparent that there are many different types of narrative forms. For example Bury (2001) distinguishes between three types of narratives, firstly contingent narratives which are concerned with aspects of stories that deal with beliefs and knowledge that influences the onset of illness and the effect of the illness on the body. Secondly moral narratives that are about the changes between the person, the illness and social identity, and core narratives that reveal connections between personal experience and the cultural meaning attached to suffering and illness. When analysing the elements that construct narratives I became aware that there are many commonly identified plots or genres, these include stories that focus on heroism, tragedy, comedy, irony, disembodiment, didacticism, and romanticism (Gergen and Gergen, 1983; Kelly, 1994 cited in Bury, 2001).

However I found the most useful exploration and explanation of the genres of illness narratives in the work of Arthur Frank in The Wounded Storyteller (1995). Frank (1995) proposed three basic narrative types firstly, the restitution story which is the most culturally preferred story in the westernised world as it is about health and recovery rather than illness. Secondly the chaos story which depicts deep illness and is hard to listen to. The teller cannot really tell their story as they are so consumed by their illness and cannot see an end to their suffering. Lastly the quest story is about meeting suffering head on, accepting illness and gaining something through the illness experience. However stories often contain element of all three types of plot as the story teller narrates their illness experience. The types of narratives described by Frank (1995) for me encompass all of the genres identified by Gergen and Gergen (1983), and Bury (2001) and therefore I chose to use the genres of Frank (1995) to present and analyse the two following stories. Firstly *Blue's* story which is based around a plot of restitution and secondly Rhiannon's story based around the plot of a quest.

5.1 *Blue's Story*

Blue a 9 year old girl with leukaemia told me her story one afternoon in late December. I had arranged to visit *Blue* and her family in their home, and *Blue's* mother welcomed me into their living room which was adorned with Christmas decorations. *Blue* was lying on the settee watching television when I arrived and seemed pleased to have a visitor. The family had been provided with information about my research project by their community children's nurse, however I explained to both *Blue* and her mother in more detail about my research project and what participating would entail for *Blue*. Both of them were happy to participate and following consent from Mum and assent from *Blue* I asked *Blue* to tell me her story.

Blue's story is dominated by the plot of restitution which has a basic storyline of "yesterday I was healthy, today I am sick, but tomorrow I'll be healthy again" (Frank, 1995 p77). Frank (1995) suggests however, that in any story there will be examples of all three of his proposed narrative types. This is evident in the following story as *Blue* moved from restitution to chaos, back to restitution, and at times used elements of quest. *Blue's* story began with a vivid account of how she had been admitted to her local hospital, and following tests was transferred to a regional unit which was seventy miles away from her home where she and her mother were given her diagnosis. This is typical of a restitution plot where the story teller explores their experiences, investigations and treatment. *Blue* is talking here of a very stressful event in her life, she did not refer to her illness by name at this point in her story and indeed she never did. However as her story unfolded it was clear to me that *Blue* knew a great deal about her condition.

> *"I went to C (local hospital) and they rushed me up in an ambulance to C (regional unit) and they took lots and lots of blood and then and then they came back and told me and my mum what I had really"*

Hospitalization is a stressful experience for children and can impact on their emotional and psychological well-being, *Blue* demonstrates in her story classic concerns that have been shown to affect children during a period of hospitalization (McClowry and McLeod, 1990; Lansdown, 1996; Thruber et al., 2007; Salmela et al., 2009).

> *"I stayed in hospital for about 2 weeks it was ok because they had play nurses and things to keep you occupied but it was quite boring really and you were quite scared because you did not know what they were going to come at you with"*

Blue described feeling bored even though there were play specialists available to her, boredom has been found to be a significant issue for hospitalised children in many research studies including While (1992), Boyd and Hunsberger (1998), Sartain et al. (2000). *Blue's* fear is clearly linked to the fact that she felt she did not know what tests or procedures she would require or when these would occur. This concurs with Stewart (2003) who also found that children with cancer live with uncertainty which is most evident during initial diagnosis. The main consequence of living with uncertainty is fear, the most common fears expressed by children in hospital relate to nursing procedures associated with medication, injections and taking samples, therefore it is vitally important that children receive information about what is going to happen to them whilst they are in hospital (Salmela et al., 2009; Soanes et al., 2009).

As I was listening to Blue's story I was mindful of the relationship between the protagonist and the supporting characters and how their actions influenced the story line (Polkinghorne, 1995). *Blue* carried on her story by telling me how the doctor explained to her and her mother about her illness, and what treatment she would require, Z the community children's nurse (CCN) appears as an important supporting character in this story as she is a professional who influenced *Blue's* thinking, feeling and actions. *Blue* explained that Z had given her an explanation about her illness whilst she was still in hospital, however here *Blue*'s story jumps from her initial hospitalization and diagnosis to saying that Z went to her school to explain her illness to her friends and ends with "*and that I would be better*". Frank (1995) would describe this as a metaphoric phrase and the core of a restitution narrative as such phrases are reflexive reminders that the story is about health.

> *" my doctor up in C (regional unit) she explained everything and that was going to happen and the things they would give me and Z explained everything to me as well and she went to my school and told all my friends what I had and that I would be better...yea I was in hospital and she (Z) came to see my mum and said that she would come and take blood from home and things like that and we see her in C (local hospital) when I go to have my Vincristine"*

For *Blue* and her mother this first meeting with Z was the beginning of a long relationship with both Z and other CCN's who would visit and provide care for *Blue* within her own home. The initial contact with a CCN is vitally important for children and their families with a life threatening illness as is provides the foundations for the development of a trusting, supporting relationship between the family and the CCN. Getting to know children and their families and developing a relationship with them however requires the CCN to provide individualised family centred care, promote independence and advocate for the child and/or family if required. Carter (2000) refers to this as '*entering the tapestry*' (p.68) of family life as the care provided by CCN's requires them to become involved in the complexity of the illness experience of the child and family.

I asked *Blue* how she felt when she was told that she could go home, she replied by saying

> *"I was excited about coming home and seeing my family... um being able to pick your own food (laugh) um getting up and playing going to bed in a comfy bed um just being home with your family really"*

That *Blue* had felt excited about going home from hospital that first time was still evident as she was able to recall her emotions and what being home would mean for her very easily. *Blue* had experienced many changes in her life because of her illness, such as long periods of intensive treatment, and repeated hospitalisation which disrupted her normal lifestyle. She explained that at the beginning of her treatment before the insertion of a Hickman line her medication had been given to her via what she described with the help of her mother as '*syringes*'. *Blue* felt she had missed out on family life and had been very upset at being in hospital. Hospitalization can be psychologically challenging for children as they can suffer from homesickness (Thruber et al., 2007), as a result of separation from home and attachment objects. However receiving care in the familiar surroundings of their own home supported by family, and friends improves children's quality of life (While, 1991 and 1992; Sartain et al., 2001; Speyer et al., 2009).

> *"they used to give through (what they called asks mum) syringes then I was in for a long time and it was Christmas you miss things such as Christmas dinner, being home on my computer, school, and when we plan something my brother had a football party and the day and the day before I had a temperature and I could not go and I was really upset, my dad brother and sister went and me and my mum were in hospital"*

Blue went on to talk about her relationship with Z and what she felt Z's role was in the management of her illness.

> *"She makes sure there is no bruising on me she would check if I am alright, mum would check that she was giving the right doses of things and then she would just take my blood, she just says how have you been this week um and I just say fine and she asks me if I am weeing and pooing ok she takes my blood and says I will see you next week sometimes if my mum has problems she rings her up and she tells mum what to do"*

This section of *Blue's* story is very complex, she is demonstrating what Frank (1995) describes as disassociation where the person within the body is affected by it but remains detached from it. Within a restitution story the teller insists they are fine and it's just their body that's sick. This is evident here as when asked by Z how she had been feeling during the previous week *Blue's* answer was '*fine*' even though when reading her story it is clear that *Blue* is not fine but is dealing with a serious life threatening illness. *Blue* describes almost casually how Z assesses her well being, undertakes a technical skill, and provides information and support to her mother when necessary. I would suggest *Blue* has in fact described Z as an expert practitioner who demonstrated a deep understanding of a complex situation. CCN's who care for children with complex needs require special and comprehensive nursing skills to enable them to recognise the level of support required by the child and their family at a particular time whilst acknowledging the potential for disempowerment and the development of dependency on the service (Carter, 2000; Byrne, 2003; Pontin and Lewis, 2008a). Interestingly *Blue* went on to explain that if Z could not come then she would be visited by one of the other nurses within the CCN team all of whom she could name, and that when they visited they provided the same care as Z. It is vital that a community children's nursing service is able to maximise continuity of care without families becoming dependent on one CCN who they rely on to make decisions with (Pontin and Lewis, 2008a, 2008b).

> *"If she can't make it then one of the county nurses that comes B, J, TE, AM and S .. it's the same really they ask me about what I have been doing in the week it's just the same really as when Z comes"*

During the next part of *Blue's* story she became consumed with talking about how her life revolved around her illness and I feel demonstrated what Frank (1995) describes as being "sucked into the undertow of illness" (p.115). *Blue's* story is dominated by chaos as the story line loses coherent sequence and she stacks all of the events rapidly in this section of her story. Frank (1995) suggests that the teller of a chaos story is in fact the wounded story teller who must be able to remove themselves from the chaos so that they can look back on events so they can tell their story. Chaos stories are hard to hear as they are threatening and reveal the vulnerability of the story teller. Until *Blue* began this chaotic section of her story I don't think I had appreciated the full impact of *Blue's* illness on her and her family.

> *"My nurse comes and takes blood from my line every Tuesday. My mum and dad look after me at home, my mum gives me my tablets on a Wednesday and every night before I go to bed. I have weekend medicine which I take, I take it before I go to bed and when I wake up in the morning. I used to have medicines but I started taking tablets um ..it's quite hard when I go to school because if I don't feel well I have to come home and rest um ...I go to C hospital every couple of months and I go and sleep and they take samples from my back um.. my mum gives me my tablets, when we go to the hospital they give the tablet I need and then my mum puts them in a tablet box and I take them every night before I go to sleep. My mum went to the pharmacy to get my sicky medicine ..(pause) it's like when I feel sick I have this medicine and it stops me from being sick.. there was tube was in to my nose and down to my stomach and a bit around my ear it was not very nice because you could taste the plastic, and when you had the feed*

> *going through it you could feel it going down your throat it was not very nice. Sometimes I went out with mum and dad, one night and I came in and I was sick and the tube came up and they I pulled it out and I was too scared to put another one down just in case it came out again, but then when I was sick I used to hold a tissue by my nose and it would stop it coming out".*

This part of her story depicts *Blue* at the mercy of her illness as she was unable at this stage in her story to concentrate on one aspect at a time. Her sentences were strung together jumping from the past to the present, she described things that were done to her by professionals *'the nurse takes blood from my line every Tuesday', 'they take samples from my back' 'they give me the tablet I need',* suggesting that *Blue* did not feel she had any control over these events and appears to be engulfed by her illness. Within a chaos story the teller describes themselves as being swept along without control and this can be exacerbated by the inability of medical science to control the disease (Frank, 1995). For me as the listener *Blue's* graphic description of how the naso gastric tube felt and the experience of being fed in this way was very emotive, and I feel showed her vulnerability as in the telling of her story there is rawness and agony associated with someone living with deep illness.

The extra burden of caring for a sick child can have physical and social implications for parents such as tiredness, stress and social isolation (Soanes et al., 2009; Woodgate and Degner, 2003). As *Blue* was only 9 years old her mother is a vital supporting character within her story as she assumed a major role in providing treatment and care for *Blue.* When caring for a child with a life threatening illness parents need to acquire the expertise to provide skilled care and to make complex clinical decisions which they have to assimilate with being just mum or dad (Kirk et al., 2005). For *Blue* her mother and father seemed to take on very different roles, her mother is depicted as the manager of her care, organising her medication *"mum gives me my tablets" "mum went to the pharmacy to get my sicky medicine".* However *Blue* described her father as the person who made her laugh and stopped her being bored.

> *"my dad's funny if I am bored my dad has a singing kit and we sing or we go out in the car"*

I asked *Blue* if she thought life would be different for her and her mother if they did not receive care at home from a community children's nurse. *Blue* was quite clear about the benefits of receiving care at home and what she felt the CCN was able to do for them. *Blue* explained that she had spent a great deal of time in hospital and recited the reasons for her admissions one after the other. During this part of her story I did not feel *Blue* was consumed by the chaos of her illness symptoms, indeed she almost seemed proud of how many things she could remember to tell me, and seemed very relieved that she had not been hospitalized since the previous August. Children who are being aggressively treated for cancer or leukaemia often develop complications or reaction to the drug regimes (Woodgate and Degner, 2003; Soanes et al., 2009). *Blue* talked about her many admissions to hospital which she produced like a list so that she could tick them off as she went through them. She later explained that her *spikings of temperatures* had become one of the symptoms she looked out for as this was indicative of her becoming unwell.

> *I have been in hospital a lot I had a reaction to chemo that made me paralysed I could not talk or walk I could not do anything I was in bed for about 2 weeks in C.. I have had spikings of temperatures I have had teeth out and had my Hickman line in I had pneumonia shingles broken foot I went to the fair and hit my leg on a ride, but I have not been in since August" (Blue age 9 Leukaemia)*

Here within *Blue's* story she has arranged her symptoms in a temporal order and related them to other events such as having a Hickman line inserted and going to the fair, ensuring that a unified context is constructed and coherence has been established. The telling of her story provided her with a medium for her to articulate and transform her symptoms and the disruption they cause to her life into meaningful events and relate them to her life course (Hyden, 1997).

Receiving treatment at home for children with cancer improves children's quality of life (Soanes et al., 2009; Speyer et al., 2009) because it reduces disruption to family life due to less time spent travelling to hospital, and the psychological stress of receiving treatment is minimised as children feel more secure in their own environment (Stevens et al., 2004). Children are more relaxed and happy at home and lead what they would describe as a normal life (While, 1992; Jennings, 1994; Sartain et al., 2000, Speyer et al., 2009). *Blue's* perception of having to attend hospital for all her care was that it would be very time consuming, and that it would detract from the normality of her life. *Blue* explained that because they knew when the CCN was going to visit it was easy to fit her treatment into her day, and then family life could resume as normal. Children with cancer emphasise the ordinariness of their daily lives despite their diagnosis which is only disrupted by unpredicted side effects of treatment which could interfere with their routine (Stewart, 2003).

> *"she rings my mum and says I am coming or I am going to be 5 minutes it (going to hospital) would tire us out a lot we would not have time to do anything we would have to go in the car go to hospital a lot more now we can stay home and the nurse can come and take your bloods and then you can get back to doing what you were doing before the nurse came"*

The role of the CCN is complex (Carter, 2000; Pontin and Lewis, 2008a), however in her story *Blue* has been able to make visible what Byrne (2003) described as care that is largely invisible as it is difficult to document the intricacies and knowledge required to care for children with life threatening conditions.

> *"because she has taken a bit off mum as well because my mum does not have to worry about taking my bloods and she does not have to worry about asking me these questions. Yes well my mum would have to take all my bloods and things she would have to know well she does know but without the nurse mum would have to know all my medicines my mum would have to come to school to take my bloods"*

Blue describes the CCN as someone who is able to support and take over some of the responsibility of her care from her mother. She recognises that without the support of the CCN that her mother would need to provide much more of her care, and be even more knowledgeable about her medication. The most commonly referred to aspects of the role of the CCN are support for families (Carter, 2000; Pontin and Lewis, 2008a), providing clinical care such as medications (Gow and Atwell, 1980), giving advice and teaching parents clinical skills (Whyte et al., 1998), and maintaining consistency of care for children and families (Pontin and Lewis, 2008b). However these role attributes were all identified by the parents of children who were being cared for at home by a CCN. There is as I have identified previously a dearth of research that has concentrated on how children perceive the role of the CCN. One exception is the work of Carter (2005), who explored children's perceptions of a CCN team. The results showed that the children like *Blue* recognised that the CCN relieved their parents temporarily from the constant burden of care, demonstrating that children have important perspectives to contribute about issues that affect their lives (Clarke, 2004; Christensen and James, 2000).

Research has shown that children value certain characteristics in nurses who care for them. These include a sense of humour, honesty, respectfulness, being nice, funny, helpful and non judgemental (Farrant and Watson, 2004; Carter, 2005; Randall et al., 2008; Brady, 2009). Blue demonstrated her displeasure with her CCN when she described how she had wanted to go to the fair with her family but the advice from the CCN was that it was not safe for her to go based on the results of her recent blood test. Within this section of her story I feel that *Blue* and her mother are making an attempt to control their lives as they seek the predictability of *Blue's* body prior to her illness rather than concentrating on the unknown element of her mortality (Frank, 1995).

> *" we went to the fair and my neutrophils were not very high and my mum rang her and asked if we put a scarf around her mouth and she (nurse) said NO I was not allowed to go and all my friends went but mum got an operation mask and I still went"*

I asked *Blue* why she thought Z has told her she could not go to the fair with her friends she replied.

> *"To help me but it does not feel like it at the time, nasty Z" (laugh).*

Demonstrating that *Blue* understood that the Z was giving advice based on evidence from her most recent blood results, and that the advice was in her best interests. Working in partnership with parents and children is one of the main goals for nurses caring for children, and one of the main roles of the CCN is to facilitate parents to make decisions about their child's care.

I was interested to know whether *Blue* knew what neutrophils actually were or if it was just a word she had heard used by her doctor and CCN.

> *" they are things in your body that keep bugs and things away and mine was very low and if I went out or into very big places then I could catch something then I would be in hospital"*

It could be argued that *Blue's* understanding of illness was more advanced than expected for her cognitive developmental stage due to her experience of illness. According to Piaget (1929 cited in Flavell, 1963) *Blue* can be categorised as being in the concrete operational stage of cognitive development and would be expected to be able to solve problems that are real but would find hypothetical problems difficult to handle. *Blue* is demonstrating her understanding is more advanced than would be expected of a child within this stage of development. Her description of how *neutrophils* should protect her body is quite detailed and demonstrates a physiologic explanation of illness where the cause is attributed to the non function or malfunction of an organ or process within the body. This level of understanding is usually associated with children who are eleven years old or more and therefore within the formal-operational stage of development (Bibace and Walsh, 1980).

Whether experience of illness has an effect on children's concepts of illness remains a disputed issue. Crisp et al. (1996) found that for children between the ages of seven and ten years having a chronic illness did influence their understanding, however Perrin et al. (1991) and Vessy and O'Sullivan (2000) found no statistical differences between healthy children and children with a chronic illness, suggesting that more research is needed about whether living with a chronic illness influences children's concept of illness.

However *Blue* seemed to think that having leukaemia had given her some advantages. This is reminiscent of a quest narrative (Frank, 1995) where individuals believe that something useful has been born out of their illness. *Blue* told me about things she felt she would not have known or achieved if she had not had leukaemia. Blue explained that she felt she had an advantage over her peers as she knew more about her body because of her illness

> *"yes I know a lot more because when we have PSE they ask you things about parts of your body and they don't know and I am there putting my hand up because I know more about my body than they do"*

She was also very excitedly told me about meeting the Prime Minister and helping to decorate the tree and going on holidays that were organised for the family by the CCN. These aspects of the quest narrative are representative of a memoir which synthesises the illness story with events in the teller's life that demonstrate they have achieved things they would not have done if they had not suffered from their illness.

> *"I went to meet the prime minister at Christmas and I went to decorate his tree they (CCN) give us breaks we had a caravan holiday in T (local holiday resort)"*

Blue's story however rests on a plot of restitution. At the beginning of her story Blue made it clear that *"she would be better"* and indeed the ending of her story captures the desire to return to a time when life was 'normal'. *Blue* explained that she had been having treatment for "2 years" but that she would finish her chemotherapy treatment *"on the .... date (laugh)*". That Blue was excited about this would be an understatement, she was laughing and smiling as she told me this final part of her story. Blue's story has captured the themes of a restitution narrative as she began with health, moved on to talk about her sickness and ultimately returned to looking towards a healthy future.

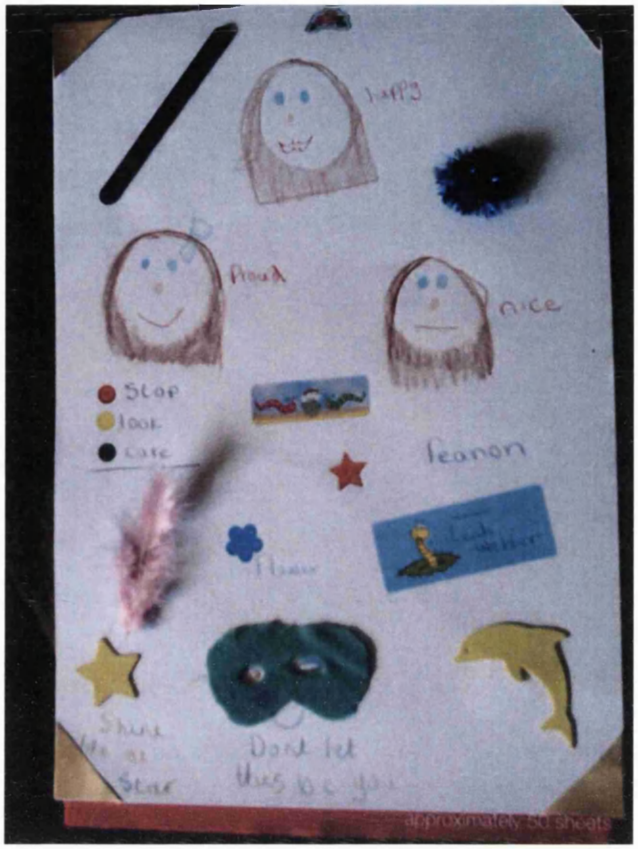
Blue has told her story by exploring her experiences of tests, treatment and care she received both in hospital and at home. Two main characters came to life in her story firstly her mother who *Blue* recognised as the parent who took on the main responsibility of caring for her. Secondly Z the CCN who *Blue* describe as the professional who supported both herself and her mother and made it possible for her to receive the majority of her care at home where in *Blue's* words she would be enjoying

> *"playing, going to bed in a comfy bed and um just being with your family really".*

5.2 *Rhiannon's Story*

Rhiannon an 11 year old girl lives with her mother, two sisters and her step father in a close community within the Welsh valleys. *Rhiannon* was diagnosed with type 1 diabetes when she was 7 years old. I visited the family home where following an explanation of my research project *Rhiannon* and her mother consented to the interview. *Rhiannon* and her two sisters were very interested in the play materials I had brought with me. Both of *Rhiannon's* sisters were soon happily making jewellery and *Rhiannon* decided she was going to make a collage.

Within her story *Rhiannon's* depicts herself as someone who needs to find in her own word "*solutions*" to the challenges of her diabetes, to accept it, and to use it. This underlying plot of *Rhiannon's* story can therefore be described as a quest (Frank, 1995) as through her story we can see how she was transformed by her illness journey. Quest stories depict individuals as beings who "meet illness head on; they accept illness and seek to *use* it" (Frank 1995 p. 115). When *Rhiannon's* picture was completed she began her story by explaining to me what she had made.



Rhiannon's collage

> *"I've a star on the left bottom hand corner and it says shine like a star and I got a mask a green mask saying don't let this be you and I got a dolphin and three lights a red yellow and green one saying stop look and care and then up the top I have got three faces saying how I feel when V(CCN) comes here and stars then and a bauble a label and a name badge with my name on it".*

Rhiannon's design was very detailed and so I felt I needed to ask her some questions to clarify her meaning as I was very aware that I could falsely interpret her drawing (Greig and Taylor, 1999), *Rhiannon* explained

> *"I done the star because people because some people say they do say they are in school and they do a nice piece of work they don't like to go and show people so that's why I done shine like a star that (mask) means say you're scared don't hide tell someone and then they will help you then"*

Rhiannon picture is about having the courage not to hide but to ask someone for help and face their fears. She also recognised that some people may be too timid to show their capabilities, I do not know however whether *Rhiannon* was actually referring to herself in this picture as her explanation was not personal but generic. Certainly the three faces Rhiannon had included on her picture related to her, as when I asked her about what she had drawn she told me they represented how she felt when V the CCN came to visit her.

> *"I feel happy and I feel proud and it's nice"*

I then asked *Rhiannon* to carry on and tell me her story. Illness stories often begin with the symptoms or signs that there is something wrong with the body, to begin with the symptoms are often ignored or not recognised as being the onset of deep illness. Here *Rhiannon* shows in her own words how in the beginning she did not understand the necessity of "*sticking needles in*" and then she explains how she began to "*grasp*" the reasons for her hospitalization. The teller of a quest story is said to be on a journey of transformation and that they will gain something by the illness experience. This section of *Rhiannon's* story can be described as the "*departure"* (Frank, 1995 p.117) stage of her illness journey which began with the onset of the illness symptoms. To begin with these may be ignored as a way of expressing denial, however eventually the symptoms can no longer be denied and the first stage of the journey may be completed when the story teller requires hospitalisation and treatment for their illness.

Rhiannon's "initiation" (Frank, 1995 p.118) stage of her illness journey began here as she was initiated into the world of diabetes where she was required to learn a new set of skills in order to successfully manage her condition. *Rhiannon* described how she practiced her injection technique on an orange and how after two weeks she began to give herself her insulin injections. Children with a chronic illness experience a period of transition from dependence to independence (Kyngas et al., 1998), however this is not a linear process but one that one that swings back and forth on a pendulum as shown by *Rhiannon* who takes responsibility for her medication unless she is ill then the locus of control reverts back to her mother.

> *"I have had diabetes for 4 years…yes I had to go into hospital and they had to stick all needles in to me and they couldn't find veins so they had to stick more needles in me then. It was… I did not like it because they were hurting when they*

> *were sticking the needles in... I started to go into hospital more cause I was having bad throats, and that I started to grasp then why they had to stick all the needles in me ..um well I first went into hospital with my diabetes this nurse the nurse before V (CCN,) she helped me before V when I first went in. They let me stick my needle into an orange to see what it was like. Then when I come home the first time I had diabetes my mam done it for the first 2 weeks and then I started to do it, and I have done it ever since except when I have been bad"*

Rhiannon went on to tell me that her CCN should have visited her two weeks before the interview, however she was unable to call as she needed to visit a child who had been newly diagnosed with diabetes. *Rhiannon* said that she understood and did not mind that this child's needs were prioritised over hers. I feel this shows that *Rhiannon* was capable of empathy and was able to recognise the need of others as well as her own. Again *Rhiannon* describes a visit from V as something she looked forward to and showed a clear preference for home care as opposed to attending a hospital which reiterates earlier findings from this thesis (theme 2) and other research studies such as (While, 1992; Sartain et al., 2001; Earle et al., 2006; Carter, 2005). Interestingly *Rhiannon* was able to find a positive aspect of going to hospital which was to take time off school, this could be seen as depicting the belief that she had gained something from her illness a characteristic associated with the quest narrative. However this was said is a rather tongue in cheek way as *Rhiannon's* sense of humour was apparent throughout her story. Humour is one of the genres that can be used to underpin a narrative and can be a means by which the story teller distances themselves from the pain and discomfort of the story to focus on a positive outcome of the experience (Bury, 2001). The positive side of treatment was also found in a study by Soanes et al. (2009) where children reported they felt they could get away with more things such as missing school when they had to visit the hospital.

> "V (CCN) *has been here for about 2 years, she was supposed to come 2 weeks ago but she had to go and see this other kid because they had just been diagnosed with diabetes and I didn't mind I didn't. When she does it's extra special it's better than going into hospital because...because when you go in its like boring although it's good to take time off school like"*

Quest stories are about illness leading to new insights where the individual is not seeking recovery from illness but rather emphasise positive change through difficult circumstances (Frank, 1995 and 1998; Thomas-MacLean, 2004). Managing diabetes type 1 during childhood is physically, psychologically and cognitively challenging as it requires a lifelong process of self care. A crucial element in ensuring the child becomes self caring is the relationship between the child and the practitioner. Here *Rhiannon* explained how she was taught by V how to manage her diabetes helped by a bear called Rosie. *Rhiannon* was very attached to Rosie bear and she seemed to have a good camaraderie with her due to the fact they were both able to have injections. *Rhiannon* described the story book that accompanied Rosie bear and thought it was a really nice story. I was shown all of Ruby bear's injection sites some of which made *Rhiannon* laugh. The fact that *Rhiannon* took Ruby bear to bed with her every night demonstrates her attachment to a much loved companion. Again the story reflects elements of the quest narrative as *Rhiannon* expresses her bravery and reflects that that is the reason why she was given Rosie the bear.

> *"at first when I first had diabetes it was S but it was too much travelling for her so then I had V and she helped me as well and so it was easy she gave me a bear called Ruby and for the boys is a teddy bear called Rufus, and I have got the book somewhere it's about this boy called Tom and has diabetes and his mum goes out to buy him a bear and she sews patches on and sews his name Rufus on to the bear and it's a nice story. Rosie used to have a top on with juvenile diabetes on but I lost it. I don't inject insulin into her I don't do it but you can stab needles into her and she has got one by there and one by there (site) and one on her belly on her finger, on her arm and she has got one on her bum (laugh). She goes to bed with me in the nights she does she has even got her own pillow and she sleeps on my bean bag pillow V gave her to me because I was brave. This one is a cartoon series 5 (shows me a book) it shows the blood cells and where the blood goes and how people inject and that it teaches you about the pancreas"*

Rhiannon at this point in her story also brought out a book she wanted to show me she explained that is was from a series of books given to her by V so she could understand how her body functioned. *Rhiannon* use words such as blood cells, and pancreas and I was keen to know if she really understood the complexities of her diabetes management.

> *"it's not producing enough insulin for me for it to work through my entire body so I inject insulin into my legs I done my bum once but it hurt. The insulin goes to my pancreas, say I ate a bar of chocolate after I had done my BM after a hypo my mam says what amount of insulin to do it takes the sugar out of the blood and it sends it around the part of the body were I need it. My bear has got a diabetes thing (shows bracelet) if you look at the back it says juvenile diabetes I need to get a new chain for mine ...yes and it will help me when I go down to the comp because when you go down the comp they do this one girl told me they dissect a frog (laugh)"*

From this section of *Rhiannon's* story it is evident that she had a fairly comprehensive understanding of her condition. She was able to describe how the insulin she injects regulates her blood sugar levels by giving an example of how she and her mother would deal with a hypoglycaemic attack. *Rhiannon's* story soon flits back to the subject of the bear's bracelet and that her bracelet was broken. This shows that *Rhiannon* as the story teller was in command of her story and I was only able to guide her talk as far as she permitted. *Rhiannon* was also convinced that because she knew so much about her body and her illness that this would be an advantage to her when she transferred to the local comprehensive school. Here again we see elements of the quest narrative, *Rhiannon* is depicting herself as someone who has changed because of her illness and that she has gained knowledge because she has diabetes that she would not have if she was to return to her pre illness state. This can be described as the final stage of the illness journey that of "*return*" (Frank, 1995, p.118) where the story teller becomes someone who is no longer ill but has been scarred by their illness which has offered them access to different experiences and knowledge.

Rhiannon continued her story by explaining how she felt that having a CCN visit her at home was much more convenient for her and her family because V would call at a time that was suitable for the family. This again was a finding from this thesis (theme 3) and has also been described s a positive outcome of home care by Woodgate (1998), Taylor et al (2008), and Guell (2009).

"V comes at the best time for us. So it's not awkward it's easy so say I am going with my dad and V says she was coming into my house tomorrow I just call my dad because V is

more important she like talks to me and sees how my BM's are and when I was in the hospital about a week ago she gave me 2 new BM meters and I liked them it was a black one that glows in the dark.. she always lets me know so then I can have one then if I need one if its broke then my mam can give her a ring and she will post us a letter so we can go down the doctor's down the road cause if we just go there we would have to pay thirty pounds for one meter.. out the board out by there we got her number and we have got the child ward number as well so if we need any help or anything we can just give her a ring say my BM's are high and my mam is not quite sure what to do cause they might be going up down up down she gives V a ring and V tells what to do for the best.. the best thing about it is because she understands me and if we need her we only have to give her a ring we can talk to her and when we go into hospital she is nice all the time"

Rhiannon explained that her CCN talked to her when she was inquiring about her blood glucose levels, she seemed very happy with her new monitors that she described almost as a special present from her CCN, she particularly liked the one that could glow in the dark and even wanted her mother to close the curtains so she could show me how it 'glowed'. *Rhiannon* went on to tell me that the visits from her CCN (V) were extra special for her as she had known her for two years. Although an initial relationship between a CCN and a child can be established quite quickly, it will only continue to develop into a deeper relationship with prolonged contact with the child (Edwards and Davis, 1997). *Rhiannon* depicts the CCN as a professional the family can rely on for help in getting the equipment they require, and as the person the family turn to when they require information about managing *Rhiannon's* diabetes. The literature has shown that parents who care for a sick child at home want information about their child's needs, to know about the services that are available to them, and they also want someone who can be the coordinator of the child's care (Whyte et al., 1998; Fawcett et al., 2005). Very little research has been conducted that describes what the children themselves expect from the CCN. Carter (2005) found that children want their nurse to be competent and that they recognise that they made a difference to their family's life by supporting their parents.

Rhiannon told her story as an interrupted biography (Frank, 1995, p.120) she has given a story about her life into which her illness has been interwoven. Her story was not told in chronological order but was linked to everyday occurrences and events in her life, for example in the next part of her story *Rhiannon* talked about how she was able to care for herself and how her mother would provide her with a snack to prevent a hypoglycaemic attack.

> *"I do the injections myself if I am not well then my mam does them then but if I am well I do them.. say I wanted a banana and a snack when I got my breakfast before school and before we had a tuck shop my mum gave me a banana or a cereal bar to go to school because so lunchtime so I don't get a hypo"*

Rhiannon also felt that by understanding her condition she was able to work out with her mother whether she could have a snack. This shows that *Rhiannon* was still dependent on her mother to aid her decision making demonstrating that developing independence and agency in her life was still a process the *Rhiannon* was going through. This is supported by the literature that shows that the process of gaining independence develops slowly over time (Wales et al., 2007; Kirk, 2008). *Rhiannon* is also suggesting here that here is a hidden benefit to her illness as she told me that her friends will have dental problems due to their poor diet. This suggest that *Rhiannon* is attempting to show how she copes with the intrusive symptoms and the need for constant self control, Bury (2001) would suggest that this is how individuals maintain some sense of worth.

> *"knowing about it (diabetes) helps me especially with the food because when I am out with the girls and they are having chocolate I phone my mam and ask if I can have a packet of crisps and but don't follow the girls because they are going to have bad teeth and they will fall out and I can't have none of it so I just have a packet of crisps or a bottle of diet cherry coke"*

V the CCN is portrayed in *Rhiannon's* story as an important supporting character, here she talked about how she felt that V was always available to her and would help her in her quest to find the "*solution*" to her problems. *Rhiannon* talks about one of her problems in this section of her story. She explained that she was worried about going out in public as she had experienced a hypoglycaemic attack and felt that people were staring at her because of this. Bury (2001) makes the point that chronic illness is linked to identity and that some changes brought on by illness are not visible and can clash with culturally accepted behaviour. Donoghue and Siegel (1992) refer to invisible chronic illness where the individual feels humiliated and ashamed and to deal with their illness they must learn to accept their illness and to share their feeling about it with others. *Rhiannon*'s story shows that she has been able to conquer her shyness because of the help she received from her CCN. She also describes the CCN almost as a saviour someone who has been instrumental in ensuring that her illness did not engulf her life. From this section of *Rhiannon's* story it is evident that the work of the CCN should not be underestimated and demonstrates that they have a vital role to play in supporting, educating and empowering children and their families to be able to manage their chronic illness at home.

> *"V is always there if I need her I can give her a ring I know she is there whenever I need her I can give her a ring and I can tell her anything and she will give me solutions of how I can get around doing the solution like when I go out in public I am having the shakes in the middle of the street or something I feel shy and I was having a hypo in the middle of the street I was shy to do a BM because everyone was staring at me but I am not as shy because I have had help.. yes I do feel that because if I did not have V I probably would be in a coma now because I would not have had anyone to help me or to adjust me because at first me and my mam when it was new we was a bit unsure what to do and its frightening when I go into hospital once or twice I had to go in because I had ketoacidocis its frightful it is"*

During this next stage of the interview *Rhiannon* clearly shows who was in charge of the process as she explained to me that she was being picked up by her father to go to a party and so needed to spend time getting ready. Again I feel this shows how *Rhiannon's* story can be described as a memoir as she was able to tell me her illness story and synthesise this with events happening in her everyday life.

> *" my dad's (name) picking me up at 3 to go to a friend's party her 1st birthday (names a local pub) and we need to be down there 20 past three"*

This chapter has provided an in depth analysis of two complete stories. I have attempted to show from these stories how living with a chronic illness affected the children and the lives of their families. The stories have been told through the narrative types described by Frank (1995), whilst I was aware that this is only one way of analysing the children's stories it has provide a framework to guide my analysis and show how these children lived and coped with deep illness.

Within the next chapter I have drawn together the threads of the argument of this study. The chapter discusses and evaluates how far the aim and objectives of the study have been achieved. I have evaluated the contribution this study has made to the body of knowledge of children's nursing, and returned to the value of reflexivity within a qualitative research study conducted with child participants. The limitations of the study are explored and possibilities for future research are presented.

Chapter 6: Discussion

6.1 INTRODUCTION

This thesis has been based on the theoretical perspective that children are social actors who are competent to make decisions regarding their own lives (Christensen and James, 2000; James and James, 2004). However this study has shown that historically children's lives have been described and evaluated almost exclusively from an adult perspective. Recognition that the voice of the child regarding issues that affect their lives is as valuable as those of the adult population has evolved from legislation such as the Children Act (DOH 1989, DfES 2004), the United Nations Convention on the Rights of the Child (1989), and the commitment of the Welsh Government to putting the rights of the child and young person at the heart of policy making and administration (WG 2012b). These together with sociological theory (James and Prout, 1997, Christensen and James, 2000; Jones and Welch, 2010) advocate that children are not passive, incompetent individuals who are in the process of becoming competent adults, but are individuals who can act with intention in their own lives. The aim of giving children a voice is to gain a better understanding of childhood and to disseminate this to the rest of the world (Spyrou 2011).

At the beginning of this thesis it was identified that the epidemiology of childhood illness has changed from acute infectious illness to long term chronic conditions (WHO, 2008) which means that chronic conditions are increasingly becoming important causes of child morbidity and mortality. The increasing life expectancy for children with a chronic illness means that they are more likely to be hospitalised due to complications or exacerbations of their condition. My findings have indicated that young children are capable of providing evidence to support their choices in respect of their health care preferences. The stories showed that children with a chronic illness do not wish to be cared for in hospital and prefer to be cared for at home by a community children's nurse. The children in this study have shown they were knowledgeable about their condition, wanted to be involved in decisions about their lives, and were capable of managing their chronic condition with the support of their parents and CCN.

Chapter two of this thesis identified that there was very little research that had been conducted with child participants on their experience and preferences of managing their chronic illness at home. The majority of research had been conducted either from the perspective of the professionals, for example (Carter, 2000; Pontin and Lewis, 2008a, and 2008b) or of parents who were caring for their children for example (Wang and Bernard, 2008; Nuutila and Salandera, 2006). More recent research identified that children should be seen as active consumers of healthcare, and that they should be consulted about the services they receive (Coad and Shaw, 2008).

Within this chapter I address the extent to which I have achieved my original aim and objectives. I also provide a discussion on the findings of the study of how children with a chronic illness develop the skills they require so that they can manage their chronic illness at home. I address my choice of research method and evaluate the strengths and limitations of the study. I also return to the value of reflexivity and whether this had been transparent throughout the study. The implications and contribution of this study to the lives of children with a chronic illness and to children's nursing practice are evaluated, and I argue that this study has shown that children have their own set of ideas and expectations of the health care they require to facilitate the management of their chronic illness within the home setting.

6.2 RETURNING TO THE AIM AND OBJECTIVES

Aim

This study set out to explore children's stories regarding the management of their chronic illness at home.

Objectives

- To examine children's views on the skills they require so they can manage their chronic illness at home.
- To determine images children associate with home care.

- To identify children's perspectives of the care provided by the community children's nurse.

This study set out to explore the experiences, feelings and impressions of children about their chronic illness and how it was managed in the home setting. As a children's nurse with experience of managing a community children's nursing education programme I was aware of the growing demands on the National Health Service by changes in the patterns of child health (WHO, 2008), the evidence base surrounding the effects of repeated hospitalisation for example (MOH, 1959; Lindsey, 2003) and also the policy drivers for example (RCN, 2002, 2009a, 2009b; WAG, 2009) that were advocating for services to be moved from secondary to primary care. However what I was unsure about, and could find little evidence of in the literature was whether services were actually meeting the needs of children with a chronic condition based on evidence from the children themselves. The following sections discuss how far this study has met the original aim and objectives.

6.2.1 *Objective 1: Children's views on the skills they require so they can manage their chronic illness at home.*

Within this section I evaluate how far I have achieved the first objective of my thesis. The findings have shown that the skills required by the children to manage their chronic illness themselves developed over time. This reiterates finding from previous research that identified that the transition of responsibilities from parents to the child develops slowly over time, and that it is of vital importance to children with a chronic illness (Woodgate, 1998; Yoos and Mullen, 1996; Kirk, 2008). The findings showed that achieving agency and independence was facilitated through teaching and demonstration by the CCN and the support of parents.

The children's stories highlighted how knowledgeable they were regarding their conditions, and how they felt this knowledge helped them become self caring. The findings showed that by gaining knowledge about their condition the children felt they had an advantage over their peers as many of them transferred this knowledge into the wider context of their lives such as school, or being healthier than their counterparts due to their understanding of the importance of a healthy diet.

Many of the children who took part in this study had been diagnosed with diabetes, and the findings show that these children were able to give an almost textbook account of how diabetes affected their body, and how vigilant they needed to be to maintain their blood glucose levels. It could be said that the children's stories reflected a scripted account of their illness and treatment. However this it could also suggest that it demonstrates the skills of the CCN's who were caring for these children as they had been provided with information based on evidence in a way that they could understand, and use this knowledge to underpin the skills they required to manage their condition themselves. All of the children who had diabetes in this study were capable of giving their own insulin injections, monitoring their blood glucose levels, and they were also aware of the dangers posed to them of not eating a healthy diet. The stories reflected that the children were supported in managing their diabetes by their parents (mostly their mother). However the findings showed that the daily routine of self management was primarily the responsibility of the children. The work of Alderson et al. (2006) also concluded that even young children understand how to control their diabetes and Karlsson et al. (2008) found that support from a diabetes team enhanced self management in children and young people.

The children's stories have shown that they needed to recognise that they were different from their peers and although they could maintain a normal life they realised that their lives were at times restricted by their illness. The children discussed how they absorbed the need to maintain often daily treatment regimes, and also minimise their symptoms so that they could enjoy life with their peers and family. Many of the children highlighted the restrictions they felt their illness posed on their life, for example not being able to eat the same foods as their friends, take part in vigorous exercise, and go on spontaneous days out with their friends. However they were also able to find positive aspects from having a chronic illness such as being more knowledgeable about their body, being healthy and also being a role model to their friends. The notion of gaining something through living with deep illness suggests these children were telling a quest story as individuals find they gain something through their illness (Frank, 1995).

The ultimate goal for children is to become self caring and independent and the findings show that the children were able to achieve these. Independence appears in the findings as the children showed how they assimilated their chronic illness into their everyday lives by being in control of their own medication, diet and social life. The children saw themselves as normal individuals who because of their chronic illness had to be more vigilant than their peers to ensure they maintained a healthy lifestyle.

6.2.2 *Objective Two*: *Images children associate with home care.*

This study has shown that children with a chronic illness are able to determine where they wish to receive care. They are also able to give valid reason as to why this care should be provided at home. The effects of hospitalisation was clearly articulated within the literature review of this study for example (McClowry and McLeod, 1990; Lansdown 1996; Thruber et al., 2007; Samela et al., 2009) and include a fear of invasive procedures, fear of surgery, lack of independence, loss of control, boredom and an environment that lacks comfort and privacy. The findings from this study highlighted the main concerns for the children was fear of procedures, boredom, and a lack of age appropriate games and equipment for the school aged child. Many of the children reported that the ward was only appropriate for babies, demonstrating that although there have been improvements in hospital environments they do not always meet the needs of all age groups.

Home care however engendered much more positive responses from the children's stories. Improvement in the quality of life for children when cared for at home was identified by Speyer et al. (2009) and was also a finding of this study. The comfortable feelings that come with being at home were identified in the findings reflected in the children wanting to be with their family, eat family food and have their own things around them, echoing earlier work by (While, 1991; Jennings, 1994).

Being cared for at home was previously identified in the literature as being less stressful, more conducive to family life and providing a better environment for children to recover. However although there was an abundance of research studies conducted with parents regarding their views on home care (While, 1991; Kirk, 1998; Kirk et al., 2005; Wang and Bernard, 2008) there was less evidence based on the views and preferences of children other than (Jennings, 1994; While, 1992; Sartain et al., 2001) and none of these studies focussed exclusively on children's perspectives. Within the UK the availability of the CCN service is mainly limited to a 9am-5pm service from Monday to Friday (Carter and Coad, 2009), which does not reflect a service that is responsive to the needs of children with a chronic illness and their family. Children with a chronic illness need and want to maintain normality in their lives which includes attending school, going out with friends and family. To do this they require a flexible CCN service that ensures the least disruption to their lives and that of their family.

I have shown in this study that has exclusively focussed on the experiences of children that they recognised how much more convenient it was for them and their families to receive care at home at a time that fitted in with their daily routine. So although evidence suggests that the CCN service remains limited (Carter and Coad, 2009, Davies, 2010), the children in this study felt their needs had been met by the service available to them. However the findings reflect that the CCNs made themselves readily available to the children on their case load, the children reported that their parents had access to telephone numbers so that they could contact the CCN with any queries or problems. As this study did not include the CCNs as participants it is not possible to say whether the practitioners were providing this service out of their contracted hours. Nevertheless whilst recognising that this was a small study from which the findings cannot be generalised I feel I have been able to show that children have their own opinions about the care they receive and that these should be given the same legitimacy as those of adults.

I now recognise that when I first commenced this study I had assumed that receiving home visits from the CCN for children with a chronic illness would be a major factor in their lives. However I have come to realise that although the CCN is a significant professional in facilitating children's agency and self caring skills the actual visits only represented a small portion of the lives of the children in the study. Indeed one of the children I feel really put this into the context of his life when he said *"I don't like it I like to watch telly"* (*Jake aged 10 years).* The intensive needs of some children can result in a lack of privacy in the home particularly when the child is reliant on technology. Therefore even a CCN who provides care in the patient's own home can be seen as an intrusive and disruptive influence in the child's life.

6.2.3 *Objective Three: Children's perspectives of the care provided by the community children's nurse.*

The skills of the CCN have been described in the literature as complex and multifaceted incorporating practical nursing skills, for example giving injections, wound dressings, teaching and also the more tacit skills of support, empowerment and listening (Pontin and Lewis, 2008a; Gow and Atwell, 1980; Carter, 2000). The literature review of this study highlighted that there was very little evidence regarding the role of the CCN other than from the view point of professionals or parents. Work by Pontin and Lewis (2008b) described the CCN as a proactive practitioner who promoted family independence and other studies such as Cummings (2002), Danvers et al. (2003), and McIntosh and Runciman (2008) recognised the importance of support and working in partnership with families. There appeared to be only one significant study that had exclusively concentrated on the experiences of children regarding the role of the CCN and this was the work of Carter (2005). Carter was able to demonstrate that children want competent caring nurses who in their interpersonal interactions with the children were funny and nice.

The findings from this study have shown that the children described their CCN's as kind and happy. Children want the CCN to do more than just provide clinical care they expect them to be interested in their everyday lives, and to talk about aspects of their lives such as their family and pets. That the CCN showed an interest in the children's daily lives was evident in the findings and suggests that as the children incorporated this into their stories demonstrated the importance they put on to this aspect of the CCN visits. This suggests that children want to be valued for who they are, that they want to be seen as individuals in their own right, they want to be cared for by professionals that respect them and not provide care that is solely based on their nursing needs. The children in this study were all able to relate to the CCNs who visited them by name suggesting that they had built up a relationship with the CCNs which is an essential element in ensuring the provision of care is effective and acceptable to children. A further finding highlighted that children want continuity of care as many valued the fact that they had seen the same nurse for many years at home, or that they had seen the same nurse in hospital and at home. The geographical area in which this study was conducted has a stable nursing workforce. Many nurses who complete their pre registration education locally continue their professional development within the Local Health Board. Therefore it is not unusual for children and their families to be cared for by the same team of nurses for many years both in hospital and community settings. Continuity of care is important for children with a chronic illness as they need to be cared for by CCNs who can recognise how the chronic illness affects the child and family and adapt their care to meet their needs.

The findings also demonstrated that there were times when the children would have preferred not to have had contact with the CCN as the children disliked having injections and having blood tests. The findings highlighted that the children were not always happy to be reminded to take medication, test their blood, and be honest about their diets. This reiterates the work of Kyngas and Barlow (1995), and Herrman (2006), who found that conflict can occur when children are asserting their independence. However the stories also showed that the children understood that the CCN's were providing them with the appropriate advice to maintain and improve their health, even if this was not the advice they wanted to hear. An example of this was evident in *Blue's* story where she recounted that the CCN had warned her and her mother that it was too dangerous for her to go out to a fair ground based on her blood results. *Blue* described the CCN as "*nasty*" however, her story also demonstrated that she was aware that the CCN was providing her with the best evidence available to her, and that her intentions were not to be unkind but to protect *Blue's* health.

The CCN was described in the findings as the professional who taught the children how to master the technical skills required so they could manage their chronic illness at home. This was often done by the CCN's with the use of a bear who the children with diabetes could practice their injection technique on. Many of the children included the bear in their stories and the findings also provided pictorial evidence of the children's special bears.

Mastering technical skills is of vital importance to ensure that children are able to successfully manage their condition and gain independence. However children need to do more than just master clinical skills to ensure independence, they need to assimilate knowledge and understanding about their condition to ensure they can make autonomous informed decisions about their health and health care needs. The findings show that the children recognised that the CCN provided care that was more complex than just teaching them clinical skills and that the CCN was a professional who was able to assess their individual needs and provide holistic care. Attaining the knowledge and skills to become independent has been described previously as important to children with a chronic illness. The children were able to demonstrate in their stories how the CCN facilitated this independence, and empowered them to become self caring individuals. The CCN's were described as problem solvers, someone who would find "solutions" and help the children work out how to deal with their chronic illness. The children recognised that the CCN was a professional who had the skills and knowledge to give advice and information to themselves and to their parents. The findings highlighted that the children were aware of clinical decisions made by the CCNs as they talked about the CCN checking their health status for example, recording their blood pressure, taking blood samples, and examining them. The findings suggest that the children were able to recognise the skills embodied within an expert practitioner which was also identified by Carter (2005).

6.3 EVALUATION OF THE RESEARCH STRATEGY

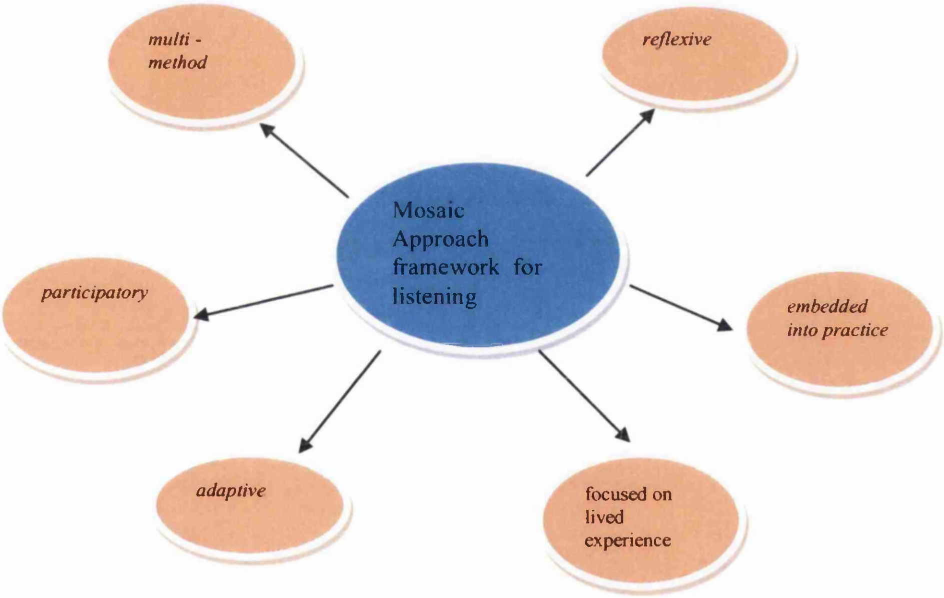
6.3.1 *The New Sociology of Childhood*

This research study developed from my interest in the sociology of childhood's position of recognising that children are 'beings and not becomings' (Quortrup, 1994) and the acceleration in the movement towards children's participation and voice (Daniel and Ivatts, 1998; James and James, 2004; Alderson and Morrow, 2004). As the thesis developed more contemporary work was also influential for example Alderson, (2008); Jones and Welch, (2010) who further developed the principles of involving children in research and decision making about issues in their lives that are important to them. Adopting the values and principles of children as social actors who can act with intention in their own lives I made the decision to focus this study solely on the views of children. I was aware that this might prove to be a more complex thesis as directly researching the experiences of young children has been viewed as too difficult and often results in tokenism (Darbyshire et al. 2006). Reasons for not conducting research with children vary from the perceived complications involved in being granted ethical approval to involve children in research, gaining access to an adequate sample, and the traditional ideas that children may not provide the thesis with credible results.

However as a nurse lecturer with a clinical background in children's nursing my intention was to capture the experiences of children regarding their stories of being cared for at home by a CCN. Also from conducting a preliminary literature search I was aware that research regarding the lives of sick children who were cared for at home was mainly focussed on parental experiences, the development of the CCN service, or the experiences of professionals. Although such research studies included evidence surrounding the lives of sick children the focus of the research was on the impact of caring on parents, professionals, or service delivery. Adopting the ideology of the new sociology of childhood which has re-evaluated the role of children in research from passive responders, to active participants in the process has allowed me unique access into the lives of the children that participated in this study who had their own stories to tell.

6.3.2 *Mosaic Approach*

I chose to adapt the principles of the Mosaic Approach (Clark and Moss, 2001) as it was a framework that was based on the principles of the new sociology of childhood, and it also adopted the ideas of listening to children's voices and that children are competent individuals. The framework of the Mosaic Approach allowed me to make the link between the new sociology of childhood and narrative inquiry and was used to guide my data collection and analysis.



The multi-method approach of the framework allowed me to incorporate play materials and children's drawings into my data collection methods. I realise that I was not able to fully incorporate all of the methods of the framework. However, I do feel that the activities I included aided my data collection. I was interested in incorporating play into my contact with the children and I chose to use a variety of play materials that included a kit for making jewellery, Lego, stickers, and fuzzy felt. These were used before the interviews with the children to allow them time to settle down and for me to build up a rapport with them. These proved to be very popular and often the children were joined by brothers and sisters who also wanted to take part in the fun.

Using the framework allowed the children to choose how they wished to participate in the research. All of the children wanted to take part in playing with the materials I had brought to the homes. However not all of the children wished to draw pictures as some were too shy, and others told me they did not like to draw. Some of the children were very interested in the camera and were very keen to have a picture taken of their favourite Ruby or Rosie bear. As the framework was adaptable it gave the children the opportunity to participate or not in the activities on offer. It also helped me to recognise that interviewing children was not going to be a straight forward process and I conducted one interview with a pet rabbit on my lap which pleased the child no end.

As the aim of the Mosaic Approach is to focus on children's lived experience I feel that it complemented the use of narrative inquiry that uses stories to understand every day experiences (Polkinghorne, 1995; Clandinin and Connelly, 2000). Using the children's stories allowed me to describe and analyse their experiences of managing their chronic illness at home. I was aware that the Mosaic Approach was not originally developed for use in nursing research, however as the framework focuses on children's views and experiences I feel it adapted well to the discipline of children's nursing research.

6.3.3 *Narrative Inquiry*

I chose to use narrative inquiry methodology for this thesis because it is an approach that uses stories to describe human action (Polkinghorne, 1995), and I was interested in using children's stories to try to understand how children with a chronic illness managed their condition within the home setting. I made the decision to use a noncategorical approach to chronic illness (Stein and Jones Jessop, 1989) for this study which allowed me to focus on the children's experiences of living with a range of chronic illnesses and not limit the finding to one specific chronic illness. However this meant that I needed to be aware that some illnesses pose more of a burden on individuals than others, and this was evident in the findings. The findings reflect that for children with life threatening illness for example leukaemia, or long term conditions such as diabetes, daily management was a major aspect of their lives. However for others with less severe conditions for example growth retardation, the management was confined to regular assessments from the CCN to monitor growth patterns.

Narratives are stories with a beginning, middle and an end, they follow a chronological order and describe events over time (Reissman, 1993), they also include characters and a story thread referred to as a plot (Polkinghorne, 1995). During my research journey I have become aware that there are many different approaches to narrative analysis and indeed as Reissman (1993) pointed out there is no standard set of procedures compared to other forms of qualitative analysis. I became interested in the two forms of narrative analysis identified by Polkinghorne (1995) firstly paradigmatic analysis in which the analysis cuts across stories with the intention of identifying common themes. Secondly narrative analysis where the outcome of the analysis is an individual story told through the medium of a plot. I made the decision to utilise both of these methods of analysis within this thesis.

Within chapter four of this thesis I presented the findings and analysis of the children's stories using paradigmatic analysis. The strength of using this method of analysis was that it allowed me to uncover the similarities of the children's stories with the aim of identifying the most common aspect and develop general concepts from the data. These were presented in four themes in which the children described from their own perspectives the most important aspects of managing their chronic illness at home. The thematic analysis identified that the children were knowledgeable about their conditions, and were capable of managing their condition themselves, and wanted to receive care at home by a CCN with support from their families. The children attributed their knowledge and skills to the education and support given to them by the CCN. By using paradigmatic analysis I have been able to highlight how the knowledge and skills (identified by the children) of the CCN enables children through education, empowerment and the teaching of self caring skills to become social actors who are able to act as agents in their own lives. However, I was also conscious that this form of analysis could mean that I would miss the uniqueness of individual stories as they became broken down into my thematic categorization. Therefore in an attempt to analyse the data as fully as possible I took the decision to use narrative analysis to analyse two complete stories.

Using both paradigmatic and narrative analysis of the same data could have been problematic, in that how would I ensure that the analysis did indeed bring out different elements of the data. I was conscious therefore that through the narrative analysis of the data I needed to use a different focus on the children's stories. I was very interested in the idea of a plot that Polkinghorne (1995) suggests is the main thrust of a story. However, his writings do not give any indication of what a plot may involve. When I first began to read stories particularly patient stories I became aware of the different types of genres on which stories are based including, heroic, tragic, ironic, romantic and didactic (Gergen and Gergen, 1983; Kelly, 1994 cited in Bury, 2001). However for me the most compelling narrative plots came from the work of Arthur Frank (1995) in the Wounded Storyteller where patient stories of living with deep illness are told though plots of, restitution, chaos or quest. Indeed Frank (1995) also suggests that stories may contain all of these elements, but the foundation of each story will be based predominantly on one of these types. I did however recognise that using this form of analysis had been criticised for romanticising illness (Atkinson, 1997) and that narratives only provide one view of what is important within everyday life, and that it should not be assumed that narratives give researchers a privileged access to individual experience (Atkinson and Silverman, 1997).

Using the work of Frank (1995) in chapter five of this thesis to structure the narrative analysis of two stories I have been able to attempt a critical exploration of the stories and the social context in which they occurred. The first story presented was that of *Blue* an eleven year old girl with leukaemia, her narrative depicted a plot of restitution as her story was focussed on how she was soon to return to a healthy state. Restitutions stories are also about tests and treatment and the story teller becomes less visible as these take precedence. Although Blue's story focussed on her return to health the analysis also identified elements of chaos where it was difficult for *Blue* to measure her life other than in the turmoil of hospital stays, treatments, exacerbations of her condition and the constraints her illness imposed on both her and her family. To witness Blue's story and to analyse the extent to which her illness affected her life was at times a harrowing experience, however I feel that unless I had used this form of analysis to complement the paradigmatic analysis of the findings from this thesis I would not have been able to show how living with a deep illness affects a child and family.

Within the second story *Rhiannon* was able to use her diagnosis of diabetes to highlight how it enhanced her life. Quest stories are about individuals embracing their illness and using it to transform their lives. *Rhiannon's* story showed great courage and determinism to succeed in managing her diabetes. She drew a comprehensive picture (page 161) which she described to me in detail. Her message to other children was not to be afraid and to meet illness head on. Individuals who tell quest narratives not only feel they can learn something through their illness they also feel this learning can be passed on to others (Frank, 1998). However the quest narrative can highlight feelings of loss for example *Rhiannon* had lost the ability to eat the same foods as her friends but she portrayed herself as healthier because of this, however this may have been to hide the pain of having diabetes. Using this type of analysis I have been able to show that *Rhiannon* story represented a memoir as she readily combined the telling of her story with other events that were happening in her life.

Using narrative analysis I was also able to show how the children related to the CCN on a more individual basis. This form of analysis allowed me to focus on the supporting characters within the stories for both children the main characters were their mothers and the CCNs. *Blue's* restitution story with elements of chaos showed how her family had been changed by her illness, the fact that the family lived in a rural location affected how much time was spent on travelling to hospital for appointments and how by providing care at home the CCN was able to minimise the disruption to family life. Rhiannon's story showed that she felt '*extra special* 'when she was visited by her CCN and again the nurse was portrayed as a knowledgeable practitioner who was relied upon by *Rhiannon* to help her make decisions regarding her wellbeing.

By analysing two complete stories using narrative analysis I have attempted to show the unique relationships that develop between the CCN and their clients. The stories again reinforce the findings from the paradigmatic analysis that showed that the CCN is a knowledgeable practitioner who supports and empowers children to manage their chronic illness at home.

6.4 LIMITATIONS OF THE STUDY

It is possible to identify a number of limitations of the study. Whilst recognising that generalisability is difficult to achieve in qualitative research it is possible that the findings from this study could be usefully transferred to similar situations with similar participants (Holloway and Wheeler 2002). The limitations to narrative research have previously been alluded to in this thesis and include a warning by Atkinson and Silverman (1997) that, narratives should not be seen as giving researchers a privileged form of access to research participants, and it should be seen as only one of the methods that can be used to represent important aspects of the lives of individuals (Atkinson, 1997).

This study was conducted within a relatively small geographical area of the UK where the political and nursing policy climate may not be representative of the UK as a whole. However to conduct a study on a larger scale on a part time basis whilst carrying on a full time job would have been an impossible task.

Gaining access to a purposeful sample of children for this study was challenging. By using gatekeepers whilst they provided protection to participants to avoid any possible coercion this did mean that I needed to keep on being proactive to ensure I recruited sufficient children to the study.

Although narrative inquiry enabled me to explore the experiences of children regarding managing their chronic illness at home I also think that I could have used an ethnographic approach to the study. This would still have given me the opportunity to use the interview as a data collection tool, but I would also have combined this with non participation observation of the visits conducted by the CCN. However I also feel I need to reflect on what observing the visits would have achieved. If I am to stay true to the theoretical position of this study of hearing the voice of the child, then the children's stories should stand as a true representation of their experiences without the need to verify them through observation.

6.5 ON BEING A REFLEXIVE RESEARCHER

Within chapter three of this thesis I stated that my aim was to demonstrate a reflective approach to conducting and analysing my research. Narrative research demands a high level of reflexivity both in the analysis and interpretation of the findings and in its writing (Holloway and Freshwater, 2007). Cocks (2006 p. 262) wrote that 'reflexivity is an approach researchers can apply to bridge the gap between themselves and the researched'. Taking a reflexive stance aims to incorporate the subjectivity of both the researcher and the participants into the data, and redresses some of the power imbalance and enhances the transparency of the findings (Claverole 2004). I have strived to demonstrate all of these wherever possible throughout this thesis. I feel therefore that as reflexive researcher it is important for me now to reflect on the personal and professional values and experiences that have guided and influenced this study.

6.5.1 *Personal knowing*

As previously discussed in chapter three I have been constantly aware of my own feelings and experiences that have derived from my own socialisation as a child, the change in my life when I became a mother and more recently becoming a grandmother. I have been fortunate enough not to have had the experience of caring for a child with a chronic illness. However, just over one year ago my nephew who was then four months old was seriously ill with meningococcal meningitis. As a family we were 'prepared' by the medical and nursing profession as he was not expected to live. Sitting by his cot for days on end waiting for a change in his condition was very distressing. I felt helpless to both my nephew and also to my grieving family. My nephew survived and is now a healthy and happy child, but through this experience I have reflected on what parents of children who are diagnosed with a life threatening condition must experience, and that for many of these parents the joy of seeing their child recover is a long process and for some something that is never realised.

6.5.2 *Professional experience*

I have also been aware that my role as a researcher in this study was influenced by being a children's nurse. Being a nurse can in some situations provide credibility with participants and initiate a feelings of safety. When I introduced myself to the children and their parents I explained to them I was a researcher who was also qualified as a children's nurse, however, I reinforced that during my contact with them I was acting as a researcher. I was also constantly aware of my responsibility as a children's nurse in safeguarding children and before any interviews took place I clearly explained this to the parents and the children.

I also realise that my professional experience and interests have influenced and shaped this thesis and by reflecting back to the grand tour question I initially asked all the children *'please can you tell me what it is like for you to be looked after by your family and your nurse at home'* I realise that I deliberately focused their answers to my research interest. However the children's stories revealed far more than I had initially anticipated and I now recognise that my question which was devised at the start of this study was very passive as it is about being cared for and not self management. The findings have demonstrated however that rather than talk about being looked after the children showed how they were the managers of own care. So although I aimed to recognise children as social actors and agents in their own lives initially I fell into the trap of seeing patients as passive recipients of care.

6.5.3 *Reflecting on the ethical principles of this study*

Reflecting on the ethical issues involved during this study I have made every attempt to ensure they reflected an ethos of children's rights and that it was my intention to value the children for themselves and not for who they may become in the future (James and Prout, 1997; Jones and Welch, 2010). When I first commenced this study I was aware of the ethical debates on including children in research and how they are often viewed as vulnerable and in need of protection (Alderson, 2008). However unless researchers are prepared to take the decision to actively involve children in research their opinions on issues that affect their lives will not be heard and evidence will be still be produced that relies on the opinions of proxies.

Reflecting on my journey through this thesis I have made every attempt to demonstrate that I remained true to the ideals of children's rights and that the voice of the child should be heard. The research study was presented to the Multi-Centre Research Ethics Committee for Wales, and I received approval from each participating NHS Trust. The parents and the children were sent information packs explaining the research and requesting they contact me if they wished to participate. Prior to the interviews taking place in the home I explained the study again and sought consent from the parent who was present and assent from the child. I also explained to the children the importance of confidentiality and asked them to choose a pseudonym so that they would not be recognisable in the actual research findings. This was an important aspect of the ethical process for the study as some of the children who were eager to help me asked if I had interviewed their friends who they thought would be able to help me. I was able to explain again about the need for confidentiality but thanked them for their help.

I conducted the interviews for this study within the children's homes. As an experienced community practitioner I was aware that I was a guest in the home. However entering a child's home as a researcher and not primarily as a health visitor or children's nurse was a new experience for me. As previously discussed I prepared myself for the interviews by putting together play materials for the children to use to help them settle prior to the interviews taking place. I feel these also helped me to break the ice with the children and the parents and gave me time to discuss the study with the parents and ensure they were still prepared to consent to their child taking part.

To ensure that the children's drawings were presented accurately within this thesis I asked all of the children to describe to me what they had drawn so they became co-constructors of meaning ensuring I was reflecting the principles embedded within the Mosaic Approach (Clark and Moss, 2001).

I made the decision to present the finding from the perspective of the children as it was my intention to bring each child's story to life within my writing by making them as visible as possible to the reader. I feel this was helped by using the children's chosen pseudonyms and by describing their individual characters that came through during the interviews. Some characters made considerable impact for example *Jonah Loumu, Rhiannon and Blue* are three children that for different reasons will always be memorable to me, and I hope I have been able to share their extraordinary resilience, courage and sense of humour with readers of this thesis. By mentioning these children it was not my intention to suggest other children were not recognised as individuals, indeed I do not think I will ever forget conducting the interview with the pet rabbit on my lap.

Antaki et al. (2003) highlighted that there can be a tendency for writers to refer to quotations rather than analyse them and also to show sympathy for, or solidarity with respondents. However Claveirole (2004) argued that the value position and the life experience of the researcher are important dimensions of the researcher as a research instrument. Therefore as a professional who has practiced in the nursing profession for forty years I feel that it would have been ethically impossible for me to have given a voice to children who were managing their chronic illness at home without becoming immersed within their stories. Indeed Frank (2000) stated that 'any good story analyst has both an ethical and an intellectual responsibility to enter relations of storytelling (p.355). Representing children requires wisdom and insight on the part of the researcher (Spyrou

2011) and a reflexive approach accepts the messiness and the multi-layered meaning in stories that narrative research produces. As I reflect on my research journey I am mindful of how indebted I am to all of the children who participated and also to their parents who were prepared to allow me into their homes and interview their children.

6.6 IMPLICATIONS OF THIS STUDY

This study has implications for the delivery and research into the care of children with a chronic illness. The introduction of this study highlighted how policy has strived to ensure that sick children are not admitted to hospital unless there is no other alternative (MOH 1959), and policy drivers such as (Audit Commission, 1993; Health of Children in Wales Welsh Office 1997; RCN 2009a; WAG 2004; WAG 2009) have all advocated for an expansion to the community children's nursing service. However Carter and Coad (2009), and Davies (2010), reported that the service was woefully inadequate and that some children were unable to benefit from this service. This study has provided evidence to show that children with a chronic illness want to be cared for at home. They want to be in an environment where they can participate in family life and enjoy the comforts of home. The study was also able to show that being visited by a CCN empowers children to become self caring individuals who can manage their condition themselves with the help and support of the CCN and their family.

Davies (2010) calculated that there was a requirement for 280 CCN within Wales and to achieve this there would need to be a six fold increase in the numbers of CCN's in Wales that currently stands at somewhere between 40-45 (Wte). To increase the numbers of CCN's to meet this target would need commitment from the Welsh Government to ensure that there was sufficient investment into recruitment and education for children's nurses to gain the knowledge and skills required to care for children within the home environment. Local Health Boards however will also need to be committed to the expansion and provision of this service to ensure that children's nurses feel that by focussing themselves on a career in CCN practice there would be a service available for them to practice in.

There is a need for children's nurses to engage in research that involves children as participants in the process. This study has highlighted several areas for potential research including research into at the development of children's concepts and understanding of illness, and whether this differs in children with a chronic illness. It may also be possible to conduct a research study to test a hypothesis such as whether children who receive care from a community children's nursing team have better health and social outcomes than children who do not have access to a CCN service. A further area for possible research development is how far children with a chronic illness are involved in decision making about their health care. This study provided some evidence to show that children are involved at the level of care delivery within their own homes. However it would be interesting to discover whether children are involved in decision making on a more strategic level.

6.7 CONCLUDING REMARKS – THE CONTRIBUTION OF THIS STUDY TO THE CARE FOR CHILDREN WITH A CHRONIC ILLNESS

By answering the aim and objectives of this study I have been able to provide some evidence to support the care of children with a chronic illness within the home setting. This study was committed to the principles enshrined within the United Nations Convention on Children' Rights specifically articles 12 and 13, the belief that that researchers and practitioners need to listen to the voice of the child (James and James 2004) and that children should be valued for who they are and not for who they may become in the future (Quortrup et al., 1994).

The overall aim of the Doctorate in Nursing Science programme was that 'students will demonstrate the ability to make an original contribution to knowledge in the discipline' (p.5). To achieve this aim within this study I have assimilated knowledge from different disciplines, the theoretical position of the new sociology of childhood on which this study was founded, the principles of the Mosaic Approach (Clark and Moss 2001) and narrative inquiry particularly the work of Polkinghorne (1995) that provided this study with the research methodology. This has produced an original approach to conducting research with children with a chronic illness. I have also provided the discipline of children's nursing with an original insight into the lives and expectations of children with a chronic illness who manage their care at home.

I cannot conclude this study without returning to the writings of Arthur Frank in *The Wounded Storyteller* (1995) who wrote that '*seriously ill people are wounded not just in body but in voice. They need to become storytellers in order to recover the voices that illness and its treatment often take away'* (p. xii) his work was very influential in my analysis of the children's stories and I feel provided an insight into their lives that without I would not have been able to capture.

To ensure that the voices of the children that participated in this study are heard it is my intention to disseminate the finding of this study through publications in academic journals, and presentations at professional conferences. My ultimate aim is to produce a booklet for children who have been newly referred to a community children's nursing team. This would provide the children with information about the role of the CCN, and encourage children to become active and discerning users of health care.

To complete this thesis I have chosen a quote from a book I read when I first began my research journey. This book is entitled *A voice for the child: the inspirational words of Janusz Korczack edited by Sandra Joseph (1999).* This book contains a compilation of quotes from a famous doctor who dedicated his life to helping the Jewish and Catholic children of Poland. During World War II he chose to accompany the children from his orphanage in the Warsaw Ghetto in 1940 to the extermination camp in Treblinka. Even though he had been offered sanctuary by the German army he chose to board the trains with the children and was never heard from again. The most likely reported reason for this was that along with the children Janusz Korczack was killed in a gas chamber on their arrival at Treblinka. The quote I have chosen to end this thesis eloquently expresses what I hope I have been able to portray through my original writing which is that -

Children are not the people of tomorrow,
but are people of today,
they have a right to be taken seriously.
and be treated with tenderness and respect.

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APPENDICIES

APPENDIX 1

Letter of introduction – Community Children's Nurse Version 1.0 30/04/2007

Mrs M Bodycombe-James
Lecturer
School of Health Science
Swansea University
SA2 8PP
Date

Name Community children's nurse
Address
Date

Dear Community children's nurse

I am a lecturer within the School of Health Science at Swansea University. For my PhD thesis I am exploring 'the experience of children of being cared for at home by their family and community children's nurse'. This study has gained ethical approval from the Multi-centre Research Ethics Committee for Wales.

In order to do this research I require access to purposive sample of children. I have chosen to use an opt in method of sampling procedure which requires that as the researcher I have no contact with the prospective participants unless they decide to participate in the study. I am therefore requesting your assistance as a professional gatekeeper to invite children and their families to participate in this study.

What do you need to do?

I have prepared information leaflets for both parents and children who could be included within my study. These together with an introductory letter will be provided to you in a sealed envelope.

These letters should be given to the parents/guardian of children on your case load who meet the following criteria

Children who are between the ages of 7 years and 11 years who have a chronic illness and are being care for at home by their family and community children's nurse.

Your only involvement in this study will be to give these letters of introduction.

To participate in the study the parents/guardian of the child will be required to contact me directly.

I have included a short description of the study, however if you wish further information or want to discuss any issues in more detail please do not hesitate to contact me on the number provided.

Yours faithfully

Marie Bodycombe-James
Lecturer

<u>**Letter of introduction – Community Children's Nurse Version 1.0 30/04/2007**</u>

Information About The Research.

Study Title – Children's experience of being cared for at home by a community children's nurse

Purpose of the study

The purpose of the study is to elicit the experiences of children with a chronic illness of being cared for at home by their family and community children's nurse. This study is being undertaken to fulfill the requirements of a PhD study.

The study will include a purposive sample of 30 children who receive care from community children's nursing teams located in various geographical areas.

This study has been reviewed and given favorable opinion by the Multi-centre Research Committee for Wales.

This research study is sponsored and supported by School of Health Science, Swansea University. As the researcher for this study I will receive no extra payment as I am employed as a lecture within the university and conducting research is seen as part of my role.

All information which is collected about the children's experience during the course of the research will be kept strictly confidential, and any information about the children will be anonymised.

The theoretical perspective of the research study is based is based upon the new sociology of childhood which views children as beings and not becomings, the concept of listening to children's voices, and also the notion of children's competency. The purpose of this research is to understand the social world from the point of view of the child living it and to enable the voice of the child to be heard. As the aim of the research is to capture the experience of children a qualitative approach to the research has been chosen.

The children's stories/narratives will be elicited through an unstructured interview. The interview will take place within the child's home in the presence of the parent/guardian. The children will be asked to tell me in their own words what it is like for them to be cared for at home by their family and children's nurse. This story will be tape recorded.

The information will be kept as required by the Data protection Act 1998, the information will be kept in locked storage, only myself as the authorised researcher will have access and any published work will not contain any identifying material. Following completion of the study all information will be destroyed.

During the study the child will be free to withdraw at any time. During the interview process if the child feels they do not wish to continue the interview will be stopped and any collected information would be destroyed.

Results of this study will be published as part of my PhD thesis, within academic journals and as conference presentations. Any information specific to the participants will be anonymised. The study results will also be available to the parents/guardian. The findings will be available in a child friendly format which it is hoped will eventually be provided to all children who receive care from a community children's nurse.

If you have a concern about any aspect of this study please contact me on 01792 518590. If you remain unhappy and wish to complain formally, you can do this through Dr Deborah Fitzsimmonds, Assistant Dean Post Graduate Faculty, School of Health Science, Swansea University, (contact number 01792 602226).

APPENDIX 2

Information letter for parent/guardian Version 1.0 30/04/02007

Mrs M Bodycombe-James
Lecturer
School of Health Science
Swansea University
SA2 8PP

Date

Dear Parent/Guardian

Further to our discussion in clinic on I have enclosed the information about myself and my study.

I am a lecturer in nursing within the School of Health Science at Swansea University. I am also a qualified nurse, health visitor, children's nurse and teacher. Prior to becoming a lecturer I worked as a health visitor and children's nurse.

For my PhD thesis I am exploring 'the experience of children on the management and treatment of their chronic illness at home'. This study has gained ethical approval from the Multi-centre Research Ethics Committee for Wales.

I have enclosed information for both you and your child about my study. If you would be interested in participating, or would like more information before you decide please contact me directly via the following routes

Reply Slip (attached) Please return in the stamped addressed envelope provided.
Direct line telephone number 01792 518590
Mobile number 07816222187

Email M.Bodycomb-James@swansea.ac.uk

Yours faithfully

Marie Bodycombe-James
Lecturer

Information letter for parent/guardian Version 1.0 30/04/02007

Reply Slip

I would be interested in my child................................ participating in the study

Preferred method of contact –

Telephone number

Address

....

Signature of parent/guardian.

Parent Information Sheet Version 2.0 14/07/2007

Information about the Research.

Study Title – The experience of children on the management and treatment of their chronic illness at home.

I would like to invite your child to take part in my research study. Before you decide you need to understand why the research is being done and what it would involve for your child. Please take time to read the following information carefully. Talk to others about the study if you wish.

Part 1- this tells you the purpose of my study and what will happen to your child if they take part.

Part 2 - this gives you more detailed information about the conduct of my study.

Please ask if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish your child to take part.

Part 1 - Purpose of the study

The purpose of my study is to explore children's experiences of managing their chronic illness and their perceptions of the care they receive. This study is being undertaken to fulfill the requirements of a PhD study. It is seen as important to include children in research so that they can tell professionals what their experience is really like.

Your child has been invited to take part in this study because they receive care from a Specialist Children's nursing team.

The study will involve your child (in your presence) telling me their story of how they manage their chronic illness and their experience of the care they receive. This interview will be tape recorded on a child friendly recorder. I envisage this interview to last for approximately 30 minutes. Your child will not be able to be identified from the tape recorded information. Your child will also have the opportunity to draw a picture of their experience of home care and use other creative resources available from a play package.

It is up to you to decide whether to let your child participate in this study. I will describe the study and go through the information sheets with you and your child. I will then ask you to sign a consent form to show you have agreed to let your child take part. You and your child are free to withdraw at any time, without giving a reason. This would not affect the standard of care that your child receives.
Participation in this study may provide no direct benefit to your child but information I get from this study may benefit other children and families in the future.

Although I am visiting you and your child as a researcher for this study I am also is a qualified nurse (RN), children's nurse (RSCN) and health visitor (RHV). I am bound by the NMC Code of Professional Practice (2002) and therefore I have professional child protection responsibilities. It may be necessary for me to discuss with you and your child what would happen if I was concerned about your child's safety. The research interview would be terminated at this stage and if necessary appropriate child protection procedures put into place.

To comply with child protection procedures I have undergone a recent police (CRB) check.

I will follow ethical practice and all information about you and your child will be handled in confidence. The details are included in part 2.

If this information from Part 1 has been of interest to you and you are considering allowing your child to take part please read the additional information in Part 2 before making any decision.

Part 2

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect you and your child's safety, rights, wellbeing and dignity. This study has been reviewed and given favorable opinion by the Research Ethics Committee for Wales. This research study is sponsored and supported by School of Health Science, Swansea University. As the researcher for this study I will receive no extra payment as I am employed as a lecture within the university and conducting research is seen as part of my role.

All information which is collected about your child's experience during the course of the research will be kept strictly confidential, and any information about your child which leaves your home will have his/her name and address removed so that they cannot be recognized.

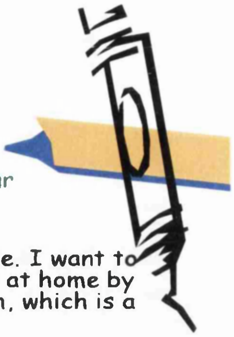
I will collect information for the study from your child through the story they tell me during the interview process. This story will be tape recorded. Before the interview takes place I will ask your child to choose a secret name for themselves. This secret name will then be used to anonymise the information given to me by your child ensuring any data will not contain any identifying material.

The information will be kept as required by the Data protection Act 1998, the information will be kept in locked storage, only myself as the authorized researcher will have access and any published work will not contain any identifying material. Following completion of the study all information will be destroyed.

During the study you and your child are free to withdraw at any time. During the interview process if you or your child feels they do not wish to continue the interview will be stopped. It would be possible to continue if desired at another convenient time or you may decide to withdraw from the study and any collected information would be destroyed. If you decide to withdraw from the study it will have no effect on the care your child receives from the community children's nurse.

Results of this study will be published as part of my PhD thesis, within academic journals and as conference presentations. . Any information specific to your child will be anonymised. The study results will also be available to you and your child. The findings will be available in a child friendly format which it is hoped will eventually be provided to all children who receive care from a community children's nurse.

If you have a concern about any aspect of this study, you can ask me about it and I will do my best to answer your questions (contact number 01792 518590). If you remain unhappy and wish to complain formally, you can do this through Dr Deborah Fitzsimmonds, Assistant Dean Post Graduate Faculty, School of Health Science, Swansea University, (contact number 01792 602226).

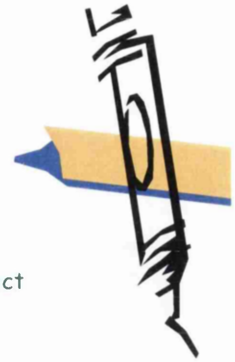


Research Project

Your story of what it is like to be looked after by your family and children's nurse.

- Hello my name is Marie, and I am a children's nurse. I want to find out what it is like for you, to be looked after at home by your family and your nurse. This is called research, which is a way we try to find out the answers to questions.
- I want to ask you this, because I know that you have a nurse that comes to visit you and your family.
- Before I could ask you this question, I had to get it checked by a group of people called a Research Ethics Committee. They make sure that the research is fair.
- You do not have to take part in this project if you do not want to. No one will be cross with you if you do not want to do it.
- The only other people who will know that you have been part of this project, will be your family and myself. I will not use your name, or address on anything, so no one will know who you are. I will only call you by a secret name that you can chose for yourself.
- I can not promise you that being part of this project will help you. But it may help other children who are also looked after at home.
- If you do not like doing the project, then you can tell your family, or me and we will stop straight away. No one will be cross with you if you decide to stop .

Thank You
Marie



This is what will happen if you take part in the project

- I will come to visit you in your house three (3) times.

- I will come to your house to meet you with your family. I will tell you about the project, and what my plan is for us to do. You can ask me questions about the project, or about myself. If you want to take part in the project, I will come back and see you with your family on another day, when we would start the project together.

- I will ask you to tell me your story of what it is like to be looked after by your family and your nurse. To do this you will need to talk to me. Your mummy, daddy or another relative will be with you. I will bring a tape recording machine with me so that I can record your story, because I will not be able to remember everything you tell me. I will give you pencils and crayons, so that you can draw a picture if you want to. I also have other things that you can use to help you tell your story, like stickers, glitter, glue and fuzzy felt.

- When you have finished telling me your story, I will take the tape recording with me . If you have drawn a picture I will take a photo of it so that you can keep your picture.

- After I have listened to your story. If you think I have not understood your story then you can tell me.

APPENDIX 3

Parent Consent Form Version 1.0 13/04/2007

Consent Form

Children's experience of being cared for at home by a community children's nurse

Researcher – Marie Bodycombe-James

Please initial box

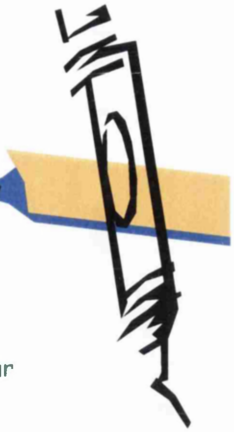
1. I confirm that I have read and understand the information sheet dated..............(version......) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2 I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason, without their care or legal rights being affected. ☐

3 I understand that relevant selections of data collected during the study May be looked at by individuals from Swansea University. I give my permission for these individuals to have access to the data. ☐

4 I agree to let my child take part in this study. ☐

....	....	....
Name of parent	Date	Signature
....	....	....
Name of person taking consent	Date	Signature

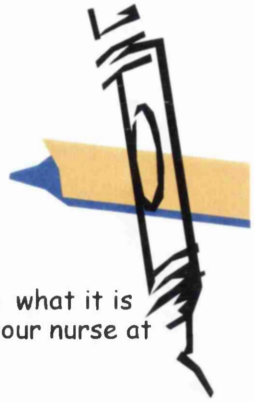


Project Title - Children's experience of care from a community children's nurse

Assent Form for Child (to be completed by the child and their parent/guardian)

This project is your story of what it is like to be looked after by your family and children's nurse.

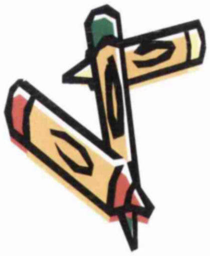
- Child (or if unable, parent/guardian on their behalf) to circle all they agree with
- Have you read (or had read to you) about this project? yes/no
- Has somebody else explained this project to you ? yes/no
- Have you asked all the questions you want to? yes/no
- Have you had all your questions answered in a way you understand? yes/no
- Do you understand it's OK to stop taking part at any time? yes/no
- Are you happy to take part in this project? yes/no
- If <u>any</u> answers are no or you do not want to take part, don't sign your name
- <u>Sign your name below to show that we have talked about this project, and that you are</u>
- <u>willing to take part in this project.</u>
- Your name.. Date....................................
- The researcher who explained this project to you needs to sign too
- Print Name.. Sign..
- Date...

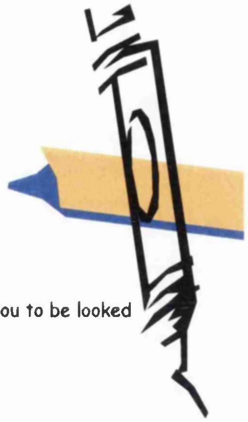


Interview Schedule

- Please can you tell me your story in your own words what it is like for you to be looked after by your family and your nurse at home.
- Would you like to draw a picture of how it feels to be looked after at home.

Child Interview Schedule
Version 1.0 13/04/2007





Interview Schedule

- Please can you tell me your story in your own words what it is like for you to be looked after by your family and your nurse at home.
- Trigger questions -
- Does your nurse visit you at home?
- What does she do when she comes to see you?
- Who explained to you about your condition?
- How do you look after yourself?
- Who taught you about these things?
- What is the best thing about your nurse's visits?
- Have you ever been to hospital because of your condition?
- Do you think you need to go to hospital less now that you know how to look after yourself?
- Would you like to draw a picture of how it feels to be looked after at home.