

**An exploration of mothers' experiences in
caring for children with complex needs**

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**A thesis submitted in fulfilment of the degree of Doctor of
Philosophy of The University of Dublin, Trinity College**

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Declaration

This thesis is submitted in total fulfilment of the requirements of the degree of Doctor of Philosophy. I declare that this thesis is entirely my own work, unless otherwise acknowledged, and has not been previously submitted as an exercise for a degree at Trinity College Dublin or any other university.

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SUMMARY

An exploration of mothers' experiences in caring for children with complex needs

Background

The diagnosis of a chronic childhood illness or disability is a major crisis which can bring about irreversible change for the family. Unlike parents of children with acute illness where the focus is on cure, parents of children with chronic illness have a focus on care that may be prolonged and of unknown duration. Within the literature on care-giving for children with chronic illnesses it is reported that mothers must attend to a significant range of responsibilities and activities that places multiple and ongoing demands on them. The consequences of this have been categorised as stressors experienced at the time of diagnosis, during developmental transitions, those related to ongoing care needs and when the child experiences illness, exacerbations and hospitalisation.

In children with chronic illnesses many specific stressors have been identified. However, little is known about the needs of children with rare, progressive and potentially life-limiting disorders and the impact of caring for these children at home. Knowledge of the mothers' experiences of providing this care in Ireland is currently limited at a time when services are being developed in response to meeting the complex needs of these children.

The aim of the study

The aim was to explore mothers' experiences of caring for their child with complex needs at home. The nature of these experiences, and specifically mothers' care-giving, was investigated. The focus was to seek rich in-depth descriptive and interpretive information to provide a greater understanding of this particular phenomenon.

Methodology

This qualitative study utilised the philosophy of hermeneutic phenomenology based on the approaches of Heidegger and Gadamer. Seventeen mothers from The Republic of Ireland and Northern Ireland provided the data collected through multiple interviews and diary recordings. Forty-eight in-depth interviews were undertaken and eleven mothers each submitted three diaries. Approval to undertake the study was provided by Trinity College, Dublin and ethical and methodological issues were addressed throughout.

Findings

The mothers' experiences of caring for a child with complex needs are framed by dimensions that exist in an inside world at home; in the world outside the home and in a going-between world. The complexity of caring involves eight dimensions for mothers. These are care-giving that comprises normal mothering, technical care-giving, pre-emptive care-giving and individualised care-giving; paperwork and administration; constant instability; constant observation; a 'no-choice' situation; knowingness; unknowingness; and constant communication.

Conclusion

The mothers' experiences of caring for children with complex needs have been explicated and these are bounded in three worlds. The eight dimensions provide a greater understanding of the experiences of caring for children with complex needs at home in Ireland. The findings have implications for health care professionals, and policy makers, who need to ensure that services for these children develop from the perspective of the service user.

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FORMAT OF THIS THESIS

This thesis is presented in three sections. Section one covers chapters one and two. Chapter one provides the background and contextualises the study. Chapter two addresses the literature on mothers' experiences of caring for children.

Section two contains chapters three to six. In Chapter three the research framework is reported. Chapter four outlines the data collection methods. Chapter five contains the study design, ethical issues and quality and Chapter six the data analysis.

In section three, chapters seven, eight and nine focus on the findings. Chapter ten provides a discussion of the findings and contextualises them within the literature. Chapter eleven provides the limitations, implications and recommendations.

CHAPTER 1 - INTRODUCTION AND CONTEXT

1.1 Introduction

Within this chapter the background to the study will be provided. This includes a discussion on terminology, the current situation and statistics on children with complex needs.

1.2 Background

Children with complex needs including those with life-limiting or life-threatening conditions, disabilities and chronic illness are emerging as groups of children with specific needs and service requirements (While, Citrone and Corish, 1996; Emond and Eaton, 2004). Progress in technology, medical advances and drug treatments means that these children are increasing as a group of service users who require health care at home by multidisciplinary community based teams (Olsen and Maslin-Prothero, 2001). Figures reported in the United Kingdom (UK) suggested that approximately 50 children per 50,000, that is 1:1,000 will suffer from a life-limiting condition (ACT&RCP&CH 1997/2003). The Association of Children's Hospices (2005) suggest that 12 in every 10,000 children have a life-limiting/life-threatening condition and approximately half of them will require palliative care at any one time. In Northern Ireland (NI), there are approximately 860 life-limited children which is 360 more children than would have been predicted using the ACT&RCP&CH formula (Maguire, 2000).

Home care services are continuously expanding as more children are discharged home where care is provided by their parents (Kirk, 1998; Noyes et al, 1999; Kuster et al, 2004), though debates around service provision continue. In 1991, While suggested that parents viewed the provision of home care for these children as an acceptable and welcome alternative to hospital, but Noyes et al (1999), amongst others, suggests that it is unknown if parents' needs are being met as there are variations in services provided, the children's needs are more complex and the care-giving is more technical in the home.

For many families the reality of caring for their child is a complex world where heavy demands are placed on the family, often for protracted periods of time, has historically been reported as exhausting and insurmountable (Burton, 1974; Voysey, 1975). A range of literature reports on the psychological, physical and financial burden under which families are living and identifies the stressors involved (Burton, 1974; Coyne, 1997). The needs of families for support in home care delivery are emerging (Kirk, 1999; Olsen and Maslin-

Prothero, 2001). Coyne (1997: 122) has described children's complex needs for physical and technical care at home as "a constant daily round of caring procedures," which includes frequent hospitalisation for acute management of chronic conditions. Parents, however, while wanting to care for their child at home have been found to be fearful of being unable to cope with the child's symptoms (Chambers and Oakhill, 1995; Noyes et al, 1999). They face limited and inconsistent nursing care support at home, no consistent approach to funding and "an ad hoc system of patient management" (Noyes et al, 1999: 439). Several studies have identified a cost benefit to the management of children at home (Vick, 1996), while others suggest that these studies do not cost the real implications to the family (Noyes et al, 1999).

As the complexity of caring becomes clearer there has been an increase in service provision that has resulted in the implementation of various models of home care delivery. These include specialist community teams, palliative care services and children's nursing services. Community children's services are being developed as the needs of the families for nursing interventions become recognised. In Ireland, and NI, advances in hospice and home care services are ongoing. Nursing practice initiatives include the implementation of models of care that focus on negotiation and parental involvement in their child's care and family centred care approaches with an emphasis on primary care (Whyte, 1994; Coyne, 1995; Coyte and McKeever, 2001; Maguire, 2001). Collaborative multi-agency approaches have been promoted in child health care (Townesley, Abbott and Watson, 2004) while partnership with parents as a philosophy pervades all current strategic policy documents (Department of Health (DoH), 2002; 2004). Nurses are also focussing on the skills required to help parents deliver care to these children (Hewitt-Taylor, 2005). Yet within this changing context the everyday experiences and concerns of maternal care-givers remain under investigated.

1.3 Research purpose

The purpose of this study was to explore the experiences of a group of mothers of children who were caring for their children with complex needs at home in an Irish context. The phenomenon of the mothers' experiences was to be described, analysed and explained in order to illuminate and generate a greater understanding of this phenomenon. The aim was to provide rich, in-depth descriptive and interpretive evidence by uncovering these experiences, and subsequently to provide direction to professional children's nursing practice and to inform and contribute to the evidence base for service delivery.

1.4 Phenomenon of interest

The phenomenon of interest was mothers' experiences of caring for a child with complex needs at home in Ireland within the contemporary health care context (2002-2008).

1.5 Focus of enquiry

The focus was the exploration of mothers' experiences of caring for a child with complex needs at home. My aim was to explore the mothers' life worlds and from this to develop a greater understanding of the nature of their experience and to identify potential interventions that may support mothers. Data were collected from seventeen mothers in Ireland (both North and South) using a series of unstructured in-depth interviews and diary recordings. Forty-eight interviews were completed, each lasting a minimum of one hour, and eleven mothers submitted three diary recordings.

1.6 Rationale for the study

Within the health sector, the needs of these children and young people is a developing area of care and attention, as evidence about the needs of children with complex needs and life-limiting conditions is emerging. In relation to life-limiting conditions specifically, it is well recognised that the complex needs of children differ, that the conditions often have a familial nature and that the nature of the illness means that predicting a prognosis may be quite difficult (Department of Health and Children (DoH&C), 2005). Historically, different agencies and services have been developed to help meet the needs of these children with the emergence of paediatric palliative care as a specific specialist area. UK Government policy documents provide a framework of guidance for these children including The National Service Framework for Children (NSF) (Department of Health (DoH), 2004b). The numerous policy directives, changing demands and increasing needs, have caused an emphasis to be placed on the palliative care needs of children particularly with the publication of the NSF for Children, Young People and Maternity Services, Commissioning Children's and Young Peoples Palliative Care Services (DoH, 2005). This initiative, which forms the health and social care development, identifies standards for services to children and young people by 2014.

In relation to palliative care, particularly in the UK, developments in the delivery of specific children's services are occurring. In Ireland, as in the UK, provision of services for children with complex needs is being given priority in policy and service developments. The Programme for Prosperity and Fairness (Department of An Taoiseach, 2000) highlighted the development of disability services as a priority area, while The National

Children's Strategy (Government of Ireland, 2000) recognised the need for increased collaboration in relation to children's health and welfare. It suggests that there is a need for increased public awareness of childhood disability and that prevention of disability is a key area. A national physical and sensory disability database is being established to complement the existing national intellectual disability database, to improve the ability to identify children with disabilities and to plan services to meet their future needs and requirements.

Emond and Eaton (2004) however, report that while our capacity to manage children who are technology dependent at home increases steadily, the evidence base on which to plan care packages is patchy. Often, they suggest, paediatricians and children's nurses have to develop care plans based on limited evidence and experience. There is little evidence from an Irish perspective of the experiences of families of children with complex needs where service provision is currently under development. Nursing research in mothers of children with complex needs in an Irish context is sparse and little is known of mothers' care-giving experience from a contemporary Irish perspective in which children's palliative care needs are only now being investigated (DoH&C, 2005). The care given by mothers to a child with a complex care pathway requires skilled practice that can make physical and psychological demands on them (DoH, 2004). Yet these demands and their consequences from the mother's perspective are unidentified. It is timely that appropriate services are developed from a user perspective. The intention is therefore to enhance children's nurses' knowledge in relation to mothers' needs in this current situation and to develop an evidence base. A conceptual framework in children's nursing that accurately depicts the nature of mothers' experience, or effective nursing contributions to this, has not been found.

1.7 The research design

This study was guided by the philosophy of hermeneutic phenomenology, using the approaches developed by Heidegger (1962) and Gadamer (1975). This offers a way to investigate subjective phenomena, and is based on the belief that essential truths about reality are grounded in everyday experience (Van Manen, 1990). Phenomenology examines the meanings that lived experience has on people's lives. The ultimate purpose is the study of the individual's experiences with a major concern focussed on the person and their views. The focus throughout was on the subjective experience of the world as it was experienced by each mother and attention was given to their detailed perceptions of their experiences. Phenomenology is discussed further in Chapter Three.

1.8 Complexity in terminology

In this section an introduction to the complexity of this terminology is included to provide a contextual and relevant background to the mothers' experiences as language and definitions are essential to effective communication. Terminology is also used in the criteria for service development and delivery. For example, if a young child is identified as disabled, then disability services can be accessed. However if a child has 'no diagnosis' the case for services is less clear. Terminology is discussed as it has a direct impact on how mothers were recruited and it will contextualise the literature review. This is relevant as children with complex needs require high levels of support and are therefore likely to be in contact with many different agencies and services for support (Cass et al, 1999), where commonality in terminology is not evident. The mothers in this study had children whose complex needs spanned diagnostic groups and the range of services that were not always recognised by service providers. This discussion provides a perspective on one of the difficulties faced by the mothers in the study which occurs when professionals, and others, use a range of disparate terminology for the same situation. Mothers do not necessarily attach a particular label or use this professional terminology in respect of their child. They indicated throughout the "specialness" of their children, rather than a diagnosis or label.

The terminology that surrounds the care of life-limited children and those with life-threatening illness and complex needs includes multiple definitions and terms. These can vary depending on the age of the child involved, their diagnosis and need and also depend on the author and their professional perspective. Terminology varies across the lifespan and can change as the children grow, when needs develop or when a diagnosis is made which redefines the situation. Seligman and Darling (1997) provide a discussion about terminology and use the term 'special children' in their text on disabled children.

In non-professional literature a complexity of terminology also exists, perhaps as a response to the lack of clarity parents have faced. Sources including family support groups use a broad range of terms that add to this situation. These include, for example, ACT, the Association for Children with Life-threatening or Terminal conditions; Scope, an association for children with cerebral palsy or Headway for those with neurological injuries.

This ongoing confusion may account for some of the findings in this study about service provision and mothers' difficult experiences of finding help (Section 9.4). It also impacts

importantly on the research that surrounds these groups of children who have a variety of diagnoses and a range of needs who do not neatly fit into groupings. Emond and Eton (2004:195) report that “significant robust clinical studies have not been conducted in this area because of the complexity and rarity of many conditions, the many variables involved with these vulnerable children and difficulty in assessment”.

1.9 The reason for complexity in terminology

The complexity of terminology that exists in the literature and among professionals has been a dilemma throughout this work. In this study there were children whose diagnosis was unknown or unclear and the complexity of terminology that surrounds these children causes professional confusion when their needs are not immediately identifiable by their diagnosis. In the UK The Royal College of Paediatrics and Child Health (ACT&RCPCH, 2003) adopted a medical diagnostic model to clarify terminology. They outlined four broad groups of children likely to require palliative care whose needs can change over time. Using diagnostic groupings, however, may not necessarily be appropriate particularly given the changing nature of disease outcomes and treatments. Tritter and Calnan (2002), for example, suggest that cancer has been defined as a chronic illness and that cancer can be disabling. Generic terms that emerged after this study commenced may be more appropriate. The National Service Framework (DoH, 2004), refer to children more broadly as those who are disabled and/or those with complex health needs, including physical impairments. In the UK these may include the 15,000 (at least) children who require palliative care and a wide range of conditions render their need for this type of care (Price and McFarlane, 2006).

A lack of clarity in terminology is evident in palliative care which is relevant to children in this study. Praill (2000) and Payne, Sheldon and Jarrett (2002) report that definitions and terminology are poorly understood and not agreed in palliative care and the development of hospice type services have historically focussed on terminal care at end of life, particularly for those with cancer. In the UK they suggest that terminology, particularly related to end of life care, has undergone several transitions between the 1960's and 2000 from hospice care and terminal care to palliative care. More current health policies have broadened palliative care out to include both palliative and supportive care, which needs to be introduced much earlier into the illness trajectory (DoH&C, 2005).

Sutherland et al (1994) consider that caring for children may be further impeded by a lack of an agreed set of working definitions for such basic terms as child, life-limited and palliative care. This is similar to the situation found in this study where children were not

viewed as in need of some services as they were not clearly defined by diagnosis and because of their unclear and changing needs.

Within children's nursing this confused situation surrounding terminology is also evident. Watson, Townsley and Abbott (2002) indicate that the lack of clarity impacts on the delivery of care, communication and the provision of services, funding and equipment. Multiple interpretations may further impact on the development of collaborative partnerships and family centred care approaches which are fundamental aspects of contemporary children are nursing (Casey, 1995). Unclear terminology, and a lack of common understanding between professionals, may influence current complex developments of children's and family services as professionals adopt their professional perspective on the situation.

The use of a range of terminology creates a complex picture without common definitions and understandings. A lack of common understanding between care-givers, professionals and recipients of care added to the mothers' experiences of caring for children. It added to mine when I was trying to clearly identify children to include, and in explaining the diversity in the range of children to others. With hindsight, selecting children with a specific diagnosis would have been easier, but much less interesting.

1.10 Confirming the terminology used in this study

The ambiguity in terminology provided the focus for an initial quantitative study in which the language used by children's nurses and nurses caring for children with life-limiting conditions in Ireland was explored (Nicholl, 2006). This provided information that helped to contextualise the research and to recruit mothers. This was imperative as language used in the initial recruitment phase needed to be understood and simultaneously show sensitivity. In my experience, mothers never referred to their child as life-limited and the term is not commonly used amongst nurses. This preliminary study, as well as professional discussions with other experts, led me to decide to use the term 'complex needs' in this study.

This term is used to refer to children who had a range of disorders including rare, congenital, genetic, metabolic and neurological conditions, which were mostly of a degenerative nature, and no specific diagnosis.

1.11 The children

All children, aged between infancy and nineteen, had complex needs as determined by the gate-keepers at the point of recruitment and all were cared for by their mothers at home.

This was confirmed at my initial contact with each mother. The range and complexity of the children's needs is described in Chapter 7.

1.12 Statistical complexity

Complexity in terminology has made statistical data on infants and children with life-limiting conditions, disabilities and complex needs difficult to determine and the data are very limited and vary across countries. It is also influenced by how and by whom the data have been collected and the definitions used. The difficulty in identifying and diagnosing disorders with less defined aetiology, for example, children with no diagnosis or having 'pervasive developmental delay,' impacts on the accuracy of the data. This all-encompassing term is used in rare and genetic disorders, if a diagnosis is unclear, or if there is a delay in determining it. Improved identification of disease profiles and newly emerging diseases (for example, autistic spectrum disorders) all add to the evolving nature of terminology, understanding and service provision and add to the complexity of collecting accurate statistics for children with complex needs. The same situation applies to data on chronic illness where estimates vary internationally and again depend on the definition used. This is not a homogeneous group of children and there is diversity in terms of the nature of the disorder, its progression and severity, and the ability of the child, and family, to adapt (Cooper, 1999). Children with no known diagnoses, or whose diagnosis is not made until post-mortem, are other influencing factors in statistical accuracy.

1.13 International disability statistics

In the United States and Canada, national estimates of childhood chronic illness (that is a prolonged illness or disability that interferes with daily functioning) indicate that approximately 31% of children under the age of 18 years have one or more chronic illnesses (Newacheck and Taylor, 1992). In the UK there are around 150,000 families caring for a severely disabled child under the age of sixteen, but again definitions vary (Roberts and Lawton, 2001). Contact a Family (CAF) – a support group for parents of disabled children indicate that 75 children in the UK are born, or diagnosed with a serious disability or rare syndrome daily, and the vast majority of these children are cared for at home (CAF, 2007). Again, only information from parents known to this support group is collected, which leads to a potentially inaccurate picture of data. Similar issues emerge when data are collected from voluntary agencies.

1.14 Disability statistics in Ireland and Northern Ireland

In Ireland, statistics on children with an intellectual disability are reported in official sources including the National Intellectual Disability Database (NIDD, Health Research Board (HRB), 2004) but less is known about children with both physical and intellectual disability. Hospital statistics or family support groups in the field of developmental disabilities and in children with metabolic disorders or muscular dystrophy provide limited data. Other figures emerge from reviews of service provision but these too are influenced by definitions used. Data vary and the exact statistics are very limited in both NI and The Republic of Ireland (RoI). The NIDD (NIDD, HRB, 2004) indicates that 34.2% of those registered on this database are less than 19 years of age. They report that the prevalence rate for the 0-4 age group is 0.78 per 1000, but that this is underestimated (NIDD, HRB 2004). In explaining this they suggest that “respect is also given to situations where parents are reluctant to allow information about their young child to be recorded on the database” (NIDD, HRB 2004: 21), which influences the reliability of the data. The Disability Federation of Ireland (2006) estimate that 10% of the population have a disability and that no less than 360,000 Irish citizens are affected, but the numbers of children are not identified. In NI, 3.5% of the child population (14,600 children) are disabled (Duffy, 1995).

Few reliable statistics are available for children with complex needs receiving services at home in Ireland. A family support group for babies, up to age four, born with severe developmental delay reports that they are supporting over 190 children and their families from all over Ireland, and that, on average, 10 new babies join them each month. They note that “most people are not aware of this distressing age gap in health care services. These tiny and forgotten babies and their parents could be the forgotten people of Irish Society” (The Jack and Jill Children’s Foundation Information Website, 2007).

1.15 Children with complex care needs at home

Within the literature, data are emerging of “subsets” of children who fall into specific disability, palliative care and life-limited groupings. This may result from the changing focus on the service requirements needed to meet these children’s complex care needs at home (DoH, 2004b). Glendinning (1999) indicates that there may be up to 6,000 technology dependent children living at home in the UK. These may be over-cautious estimates, and if children were distributed evenly across the UK, they suggest that there would be at least 500 such children in each region with an unequal distribution. Some regions, such as NI, may contain over twice the numbers of some other regions and they

suggest that the children appear to be disproportionately young. Glendinning et al (2001) report on specific types of technological dependence required by 6,000 children in the UK, including 2,800 children receiving artificial tube or intravenous feeding. They report on the potential number of children receiving home intravenous antibiotics and state that one specialist regional hospital is supporting over 60 children with cystic fibrosis who receive this treatment at home; another regional centre estimates that there are 1,000 children with haemophilia receiving intravenous Factor VIII at home. They extrapolate figures based on the experiences of a specialist regional centre, which suggests that 800 children depend on home oxygen therapy and indicate that the number of children likely to receive this treatment following discharge from local district hospitals is unknown. Jardine et al (1999) report that about 100 children are likely to be dependent on long-term ventilation at home in the UK, although this too may considerably underestimate accurately the numbers of children using assisted ventilation, leaving an unclear situation. Additionally statistics on children with non-malignant life-threatening diseases, though limited, suggest that this is a significant group of children. The RCP&CH and ACT (1997) reported on the lack of accurate morbidity statistics on these children.

It is recognised that these figures are dependent on a number of factors, including the definition criteria and the information source and their accuracy could be questioned. However, they suggest that these children are becoming more visible in health care as their need for service provision becomes identified.

1.16 Children with complex care needs at home in Ireland

In the initial stages of this study, Irish children with life-limiting conditions were not identified as a discrete group for statistical purposes. The need for accurate national data was identified by the DoH&C and consequently discussion of a needs analysis was ongoing. Definitive epidemiological data relating to diagnosis, numbers and place of death at a national level are currently being collated. The Irish Hospice Foundation and the DoH&C (2005) has attempted to establish the number of children with life-limiting conditions but reported difficulties due to inappropriate inclusion, duplication and omission of data. They indicate that the total number of deaths in children in Ireland from life-limiting conditions for the years 1996-2001 was 2,222 (mean 370, range 354-398 deaths per annum). The average death rate is 3.6 deaths per 10,000, which is significantly higher than was reported in 2001 by the National Advisory Committee on Palliative Care (DoH&C, 2001). In relation to mortality, the total number of deaths from all causes in children less than 18 years of age between 1996 and 2001 was 3,308. In this period, 83% of the deaths occurring

in children less than one year were from life limiting conditions. For all childhood deaths the majority (66%) were from life limiting conditions. An assessment of the numbers of children in RoI requiring palliative care services was formulated from estimated figures from the UK of 12 per 10,000 children aged 0-19 years (ACT and RCP&CH, 2003). Based on Irish population data in 2002, and, using the UK approximate figures, a national prevalence in Ireland was estimated to be 1,369 (DoH&C, 2005). This report however cautions against using these figures as accurate and estimates are provided. It is suggested that the incidence in Ireland may be higher than in the UK, given the current situation regarding the legal and constitutional position against termination of pregnancy in Ireland (DoH&C, 2005).

The identification of specific groups of children who are life- limited, disabled, chronically ill, have complex needs, disability or who are technologically dependent, who require palliative care or children's services is influenced by unclear definitions and overlapping groupings. Literature published in 2006 during the later stages of this study indicates that children are emerging as a specific group within health care and they have been "the subject of growing interest, particularly within the field of paediatric palliative care and the hospice movement" (Price and McFarlane, 2006: 770). These children with complex rare conditions, who require high levels of technological and support at home, are becoming a significant group within children's community and palliative care services.

1.17 Emerging need for home care - rationale

Patterns of home care have been fuelled by factors other than an improvement of survival rates of seriously ill children. Most children with chronic conditions and, increasingly, children with complex and long-term needs (as in cerebral palsy or metabolic disorders), currently live at home where their care needs are met by their parents (ACT&RCPCH, 1997/2003; Katz, 2002). Technological advances and the development of mobile portable devices have enabled children with serious physical limitations and technology dependence to live safely at home in the comfort of their family (Kirk, 1999; Glendinning et al, 2001). Simultaneously, it is reported that the survival rate of children with long term disabling conditions and life-limiting illnesses is increasing and their resulting complex needs require management in the community (Emond and Eaton, 2004). In Ireland the number of families caring for children at home is not known though Roberts and Lawton (2001) UK estimates that 150,000 families in the UK care for a severely disabled child could be used to provide an estimate.

Longer survival rates have resulted in the need to develop alternative models of delivering treatments in community settings for children with complex needs. Children's nurses and community support services are therefore required and personnel need to become skilled at caring for these children, who have complex care needs, require intense complex treatments and who experience frequent exacerbations of their conditions. The children may additionally require end-of-life care involving complex nursing interventions.

1.18 Increase in community-based care

Fradd (1994) suggests that the ongoing situation with changing patterns of hospital care, shorter admissions and day surgery that have resulted in growing numbers of children with more complex problems being supported by the delivery of community care services is likely to continue. It is now recommended that children should receive care in hospital only if that care cannot be delivered at home (House of Commons Health Committee, 1997; Kirk, 1999; DoH&C, 2005) and the emphasis has been placed on the delivery of health care in the community rather than in secondary based care in hospital (Middleton and Sidey, 2000). The increasing costs of hospital care, a concern for the development of children who experience prolonged institutionalisation (Patterson et al, 1994) and hospitalisation (Shields, 2001), preferences for care at home and improved outcomes at home (Tatman and Woodroffe, 1993) all underpin the current changing emphasis in the delivery of care within community care services.

As policy developments are occurring, the right of the family to be involved in the care of the child is being increasingly recognised in practice. Family centred care, which is "the professional support of the child and family through the process of involvement, participation and partnership by empowerment and negotiation" (Smith, Coleman and Bradshaw, 2002: 22), has been developed as a nursing response. This concept is now central to children's nursing as parents are encouraged to be active participants in all aspects of the care process (Ahmann, 1994) and is being implemented in policy directives on health (DoH, 2004). Family centred care emphasises that while health care providers may change, the family is the constant in a child's life (Ahmann, 1994) and central to this are the beliefs that families want to participate in their child's care and parents should be viewed as equal partners and ultimately experts in their child's care (Sidey, 1995). What is lacking in these developments, however, is the reality of the expectations that this may place on parents who may be required to deliver highly complex caring in the home situation that, for many of them, goes well beyond the bounds of normal parenting (Roberts and Lawton, 2001). It is expected that services available to families should

provide care and support that focuses on family/professional collaboration to help with the delivery of care (Watson, Townsley and Abbott, 2002). The concept of collaboration in care with parents in care delivery at home (Watson, Townsley and Abbott, 2002; Lee, 2004) has been incorporated as a basis for best practice and has been incorporated into the philosophies of care for many agencies involved in the delivery of care to children (Sloper and Turner, 1992; DoH, 2002).

1.19 The current service provision

It is within these changing philosophies of service delivery that the focus of attention is being placed on the development and implementation of hospice care facilities to support these children and their families. Respite care, either in home, or out of home, is emerging as an instrumental part of palliative care for children and young people. Caring for a child with life-limiting illness has been found to be both emotionally and physically draining for the family and parenting a sick child may involve 24 hour devotion (Maguire, 2001). In order to meet the children's and families needs in Ireland, services for children with "severe/profound and life-threatening intellectual disability" (Redmond and Richardson, 2003) including The Jack and Jill Children's Foundation, Suzanne House, The Sunshine Home, as well as services facilitated by statutory services, voluntary federations, volunteer organisations and parental support groups have been established. In addition, a range of other services are being developed. Voluntary agencies provide some funded domestic and nursing support to families to meet the care requirements of children with complex needs. In NI services for children are provided by health and social services and some voluntary organisations.

1.20 Conclusion

It is within this background of complex language, unclear common understanding and rapidly developing service provision for children that this study is set. Models and practices in nursing are currently being developed, which are underpinned by partnership and collaboration between parents and service providers. In NI, the children's hospice service is being further developed and at the outset of this study, plans and funding were being sought for the first Irish Children's Hospice in Dublin. At the same time, a review of palliative care needs of children in Ireland was being undertaken.

This chapter has provided the context to the study. It is relevant and timely to investigate the mothers' experiences of caring in this current developing situation.

The literature review is presented in the following chapter.

CHAPTER 2 - THE LITERATURE REVIEW

2.1 Introduction

In this chapter the literature related to the study will be critically discussed. This includes care-giving in children with disability, chronic illness, complex needs and life-limiting illnesses.

2.2 The place of the literature review in this study

Within qualitative research there is a debate about the timing and completion of the literature search that forms the basis for ideas before, or during the study to identify the aim and the research question. Researchers use the literature to contextualise the study in what is already known about the subject but Parahoo (2006) suggests that these functions apply mainly to quantitative research. Others suggest that qualitative researchers should not generally begin with an extensive review as this will reduce the possibility of the researchers' suppositions or biases about the topic developing (Speziale and Carpenter, 2007) but Creswell (2003) accepts that an initial review may help provide an orienting framework to focus the research. I completed a literature review up to the point of recruitment as I was influenced by methodological literature that suggests that developing preconceived notions from the literature should be avoided. This will protect the researcher from being influenced during interviews and leading the participants in the direction of their own beliefs (Speziale and Carpenter, 2007). Previous research findings could influence the data analysis and I wanted to adopt a holistic view of mothers' experiences rather than investigate, or confirm, particular facets of it. However, I needed to identify literature known about the topic and confirm an absence of similar studies to convince others of the need for the study. This literature review confirmed an absence of studies, including nursing studies, on children with complex needs in Ireland up to 2002. Generally the literature retrieved for the review was left until initial data analysis was completed. Methodological literature was sourced and used throughout to assist with the research. During data analysis a further in-depth literature search was undertaken to confirm the emerging findings with those reported in national and international studies. A final review was completed towards the end of the work to contextualise the findings and demonstrate how they fitted into what is already known about the phenomenon. Studies reported between 2002 and 2008 are included in the discussion.

2.3 Completing the review- benefits of this approach

Using this flexible approach allowed me to let findings emerge, without any potential contamination with those in other studies. This enabled me to seek literature at appropriate points and to confirm, and contextualise, emerging findings in recent literature as data were analysed. This was used to develop an understanding of the mothers' experiences by adopting a holistic focus without external influences or using pre-existing structures from others work.

2.4 Sources of information

A systematic search of the literature was undertaken using databases including Cumulative Index to Nursing and Allied Health Literature, Cochrane Database of Systematic Reviews, Medline, PsychLit and PubMed. Proquest and Synergy databases provided by specific publishers were used. Searches were undertaken of major texts and publications from the UK and Irish Government. Literature from voluntary organizations, including ACT, Association of Children's Hospices and Contact-a-Family (CAF) were sourced. Web sites and search engines including Cancerbacup, Paedpalit, Google and Google Scholar were used. Key search terms included care at home, chronic illness, community care, complex needs, disability, diagnoses, hospice care, home care, impact of chronic illness, life-limited, mothers' experiences, palliative care and terminal care. Generally literature from 1998-2006 was sourced though earlier seminal literature was used if appropriate. Other sources included radio and television programmes. Non-English material was not used. The advice of specialist librarians was sought. Personal experiences and those of professional colleagues were also used.

2.5 The literature - an overview

Many studies have been undertaken on the complex impact of disability and chronic illness that offer a range of professional perspectives including nursing, psychology, sociology and related fields. These include studies that focus on the experience of the person involved, the family and carers. This literature includes research focused on stress, coping and adaptation and role restriction in disability and chronic illness (Wallander et al, 1989; Seligman and Darling, 1997). Nursing studies generally have adopted a focus on the individual or family experience of a specific disease including asthma, cardiac conditions, cancer, cerebral palsy, cystic fibrosis, diabetes and metabolic disorders (McCubbin and Svavarsdottir, 1999; Gupta et al, 2001; Yeh, 2002; Han, 2003; Read, 2003). Others nationally and internationally adopt a broader, less diagnostic approach and focus on

children's complex needs or technology dependence (Kearney and Griffin, 2001; Katz, 2002; Kirk and Glendinning, 2004). The impact on care-giver's physical and psychological health has been studied in mothers of children with complex needs and technology dependence (Kuster et al, 2004) and on stress levels in parents of children requiring specific aspects of care-giving including enteral feeding (Pederson, Parsons and Dewey, 2004). Studies recently focus on the experiences of the individuals including mothers (Grinyer, 2006) or fathers (Ware and Raval, 2007), while others investigate parents or family members with few studies on sibling and grandparent experiences. Studies focus on care-giving in various situations including the home, while others focus on interventions to assist parents in their care-giving responsibilities or the duration of the care-giving experience. Caring experiences at points during the illness trajectory (Barrera, Fleming and Khan, 2004), or the changing care perspectives that emerge as the children move through adolescence, are reported. The experience of affected children and siblings are beginning to be explored (Irish Society for the Prevention of Cruelty to Children (ISPCC), 2006).

Given these many perspectives this review will focus on literature on the impact of disability, chronic illness and complex needs on the family, particularly the experiences of caring for children and their consequences. A categorical approach on the impact of specific diseases is included. A non-categorical approach is adopted on studies that are related to complex needs, rare, life-threatening and progressive disorders.

2.6 Disability studies

Disability studies form the basis for many studies on children with complex needs and terminology used in the literature varies widely and many culturally determined definitions are used. There is a significant volume of literature on the types of disability and their impact on the mother, family and child. These are also studies that focus on children with named disabilities including autism (Shu and Lung, 2005); cerebral palsy (Mackie, Jessen and Jarvis, 1998); Down Syndrome (Van Riper, 1999) and spina bifida (Pit-Ten Cate, Kennedy and Stevenson, 2002). Others adopt recognised disability classifications, or broader terminology, including severe intellectual disabilities (Hoare et al, 1998) and developmental disability (Milo, 1997). The impact of disability, using broader terminology in children at particular stages or ages, is reported. Rosenberg and Robinson's (2004) work, for example includes young children with developmental and medical conditions while Redmond and Richardson's (2003) Irish study involved children with severe/profound and life-threatening intellectual disability. Studies focus on the impact of

getting the diagnosis (Seligman and Darling, 1997), on care-giving, the impact on family functioning and coping mechanisms. The emotional, physical, social and financial consequences of disability in care-givers in a range of settings and at points in the disease process has been investigated from a range of perspectives in qualitative and quantitative studies, through large clinical trials or comparative studies are not apparent.

The negative impact of disability on families' lives is evident and chronic sorrow has been reported as a maternal emotional response to disability (Phillips, 1991). This negative impact is assumed by most researchers (Kearney and Griffin, 2001) and these studies include those focussed on parental stress, the burden of care, the invisibility of caring (Chisolm, 2000) or the impact on quality of life (QoL) of care-givers. Others have demonstrated the stages parents go through when they have to cope with a child's disability from the point of diagnosis and have produced sequential models that are time bound with denial, grief, anger and acceptance being identified. Historically, Voysey (1975) however has noted that in research findings parents' optimistic and positive experiences are sometimes dismissed as methodological artefact, statistically insignificant, and interpretations can be influenced and explained by the researcher's pre-existing assumptions. Others however report on positive outcomes of parenting a child with disability and have shown the positive impact of the value of home care for the child and family (Stutts, 1994).

Kearney and Griffin's (2001) study, for example, using an interpretative methodology informed by phenomenology, focussed on the experiences of parenting children with a significant developmental disability. Data were collected by personal interviews completed over an eighteen month period from six parents, two couples and two single parents. Post-interview telephone discussions were used to clarify the emerging findings. Major themes that emerged following analysis using Van Manen's analytical processes and reflection showed that the parents' experiences were of joy and sorrow. Parents were "torn by the joy in the survival of their children, but at the same time, questioned the cost" (587). The parent's emotional states were found to be held in tension and were mediated by feelings of confusion, ambiguity and doubts about their parenting situation. Parents reported having entered a world in which they had no knowledge and experience and they acknowledged and confronted their sorrow. Positive outcomes included that the children were great sources of joy and that parenting experiences were also strengthened. This study is limited by its sample of six parents caring for four children and the variation in the duration of their experiences of care-giving (2years, 3years and five months, 6years and 3years). The range and variation in the children's abilities and care dependency levels were not clearly

reported which is relevant to the utility of the findings. There was no specific measurement of the child's needs and inclusion criteria were broad. The variation in the children's diagnosis (four children had acquired developmental disability who were normal before brain damage, while two had congenital impairments) was not explicitly addressed. The study does however offer some new insights into the positive aspects of being a parent of a child with a developmental disability which is missing from many similar studies. These findings are similar to other earlier positive reports from parents about home care (Ray and Ritchie, 1993).

A lack of definitions, complexity in terminology and the variation in the children's needs and service provision to families can influence the interpretation of data in many studies. This is a common flaw in much of the literature on children with disability and complex needs where the inclusion criteria are broad, or undefined, which may account for diversity in the parent's experiences of getting the diagnosis and providing care. Service provision, cultural variations in expectations and the context of care delivery can impact on the generalisability of the findings from international studies. Large quantitative studies are not evident.

2.7 Psychological impact of disability

In the literature on disability in families the psychological constructs of stress, its causes, consequences and depression are reported (Seligman and Darling, 1997; Olsson and Hwang, 2001; Olsson and Whang, 2003). Many stressors have been identified and outcomes of stress including physical and psychological damage are widely reported in families of children with disabilities. As a consequence of the identification of many stressors in care-giving, coping models and strategies have been developed and widely investigated. Within the literature an emphasis is placed on cognitive appraisal, internal and external coping resources in parents and families and studies have focussed on types of coping behaviours. The concept of resilience is also reported. The development of a social model of disability (Oliver, 1990), rather than a medical model has influenced the literature on disability and many studies investigate the impact of social factors on disability. There is some evidence in the literature that suggests that families are disabled by the same social barriers, prejudices and poorly conceived services as disabled people themselves (Dowling and Dolan, 2003). Studies investigate those affected by disability, and their involvement in the decision-making processes about their care (Cavet and Sloper, 2004), while others focus on what disabled children and their families say about their lives (Connors and Stalker, 2003).

Qualitative and quantitative disability studies include those that focus on care needs and the aspects of care that disabled children require and the extra care parents provide. Roberts and Lawton's (2001) study, for example, comprised of quantitative analysis of records of 40,000 records from the Family Fund Trust database. This independent UK charity provides financial grants and information related to care for severely disabled children. The study involved the exploration with parents of disabled children's extra care needs and Trust staff. Parents from 11 families were recruited for consultation purposes from a small stratified sample of 60 families known to the Trust. The data base records of 4,500 infants aged < 1 year and 35,000 children aged 1-16 years were analysed. Descriptive statistics were used to identify the prevalence of extra care needs for daily activities. Computer analysis using SPSS enabled a cluster analysis to identify homogenous groups or clusters within a sample, with further analysis of families with technology-dependent children or families with more than 1 disabled child. The findings reported indicate that five distinct clusters of care emerged where children required additional care. These care needs were likely to occur in combinations, (for example, care because of 'fits' and during the night). Care clusters included extra assistance with many daily activities and pain (average of 8), behavioural problems and help at meal times. In the study infants' requirements for extra care were particularly common at meal times and at night and almost 90% of the children experienced medical crises. The authors report that the validity of the five clusters was largely supported by Trust staff. Focus groups with 11 sets of parents were also recorded and subsequent data analysis provided examples of extra care needed for severely disabled children. This study explicitly identified and attempted to quantify the specific care and extra attention parents provide. Washing, meal time care, dressing, keeping occupied and care during the night was needed by >70% of the children. Distinctive combinations of extra care needs were associated with certain conditions and technology-dependent children had additional extra care needs.

This study is limited in that Trust records were used for sampling and only families known to the charity between 1992 and 1998 provided data. Data therefore depended on the accuracy of records, like other studies of this type, and only parents applying for assistance to the charity were sampled. The authors suggest, however, that over half of all the families with severely disabled children were on the database though a lack of definitions and accurate statistics on these children reduces the relevance of this statement. The data were collected from a small sample and missing data in 3,276 cases from the original sample of 35,810 children affects the results. The study does, however, make explicit the dimensions

of caring that families deliver and the complexity of clusters of caring activities in which parents are involved.

Other studies on disability include those that investigate roles and family functioning where children have a specific type of disability or medical diagnosis (Adams, Gordon and Spangler, 1999; Manuel et al, 2003). Family functioning has been identified in disability but there are few comparative studies that compare this with family functioning in a normal family (Bower and Hayes, 1998). However, the findings do indicate the impact of disability on the family which are similar to those identified in literature on chronic illness. Others have investigated coping, personal coping characteristics, parenting skills and parenting by family members (Pelchat, Lefebvre and Perreault, 2003).

The experience of disability has been researched from a range of perspectives including individual accounts and studies with small samples. Large comparative studies are limited. The use of varying definitions of the term disability results in the findings from studies on its impact often not being generalisable.

2.9 Chronic illness and its impact on carers

Studies on the impact of chronic illness on the family similarly focus on the point of diagnosis, particular aspects of care needs and coping. The diagnosis of a chronic childhood illness is reported as a major crisis that can bring about irreversible change. Davies (1993;1) suggests that “the sudden need to adapt to dreadful circumstances is forced upon the parents, their child and indeed the whole family...their vision of the world, their values, their ambitions, their whole philosophy will be altered by this one event”. Others suggest that the point of diagnosis marked the end of a previously known world of the parents. The diagnosis requires a period of adaptation to a new way of life; which included both “physical adaptation and adjustment to performing time consuming therapies in addition to normal parenting” (Fisher, 2001:601). The stress caused, and the consequences of stress of care-giving, have been the focus of many studies on children with a range of chronic conditions. Stressors investigated in chronic illness, as in disability, include those at the point of diagnosis including antenatal studies, during developmental transitions, those related to ongoing health care needs of the child and during illness exacerbations and hospitalisation. These place demands and stressors for parents (Canam, 1993; O’Brien, 2000) which are said to be multiple and ongoing (Diehl, Moffit and Wade, 1991; Cohen, 1995; Jerrett and Costello 1996). Many studies have been undertaken to identify specific stressors and the impact of chronic illness in families of children in specific diagnostic groups including cerebral palsy and thalassaemia (Atkin and Ahmad,

2000; Manuel et al, 2003) while others have focussed the consequences of stress on carers and on burnout (Burke and Greenglass, 1995).

Studies, similar to those in disability, have shown the impact on the whole family and family functioning (Svavarsdottir, McCubbin and Kane, 2000). Peri, Molinari and Taverna (1991) found that having a child with asthma may lead to tension in the family due to disagreements over approaches to treatment, the anxiety it provokes, and the effects that it has on other family members. Sullivan-Bolyai et al, (2003), amongst others, suggests that parents must attend to a wide range of day-to-day responsibilities and activities. Parents of children diagnosed, and being treated for cancer, have been found to live with uncertainty of the future and the fear of the child's potential death (McGrath, 2001). The physical and financial responsibilities and economic costs involved in care-giving all contribute to the stress experienced, which impact on mothers' ability to work. This is similar to findings in disability studies.

2.10 Care-giving work

Researchers have explicated the actual work of care-giving involved in children with a wide range of chronic illnesses (Deatrick and Knafl, 1990; Jerrett, 1994; Holmbeck et al, 2002) and linked it to the changes needed to accommodate chronic illnesses within families. Jerrett and Costello's (1996) qualitative study using a constant comparative method explored parents' perspectives and experiences of caring for a child with asthma. Data from thirty families in which at least one child age 2-13 years had asthma were collected and analysis used grounded theory methods. The primary issues identified were coming to grips with the child's illness; making changes that were incorporated into family life over time and integrating its management into family life. A lack of understanding undermined the parent's sense of control which is similar to stress theories in which control is a coping strategy. It was found that if the child was acutely ill parents often preferred to hand over control to professionals and considered this to be a management strategy. The parents also wanted health professionals to acknowledge their abilities and appreciate their role in managing the child's disease, which for the parents enhanced their feelings of competence. Other studies have investigated chronic illness from the perspectives of mothers and fathers and identified the commonalities and differences in that experience.

Dalheim Englund, Rydstrom and Norberg's (2001) Swedish qualitative phenomenological study involving 12 mothers and 12 fathers and using unstructured interviews, investigated what it meant to be the parents of a child with asthma and the impact on the family. They

found that the mothers felt isolated and alone, and that the child's condition requires a great deal of time and reduced the time available for socialising. Being a mother of a child with asthma was accompanied by feelings of sadness; it is a time for isolation, guilt, sorrow and fear for the future. To be the parent, they reported, was to live a strenuous life; the mother protects her child; she is constantly watching for an incident to occur and she is afraid of leaving her child with anyone else. Team work between parents and complementing each other in care-giving was important. The families reported on the need for good partnerships between parents and nurses in which the nurses understood the situation, knew about the disease and had open communication with parents. The researchers suggest that this places demands on the nurses who meet these parents. Like other studies investigating the impact of episodic chronic illnesses this research is limited by the lack of information on the severity of the child's illness and family circumstances which all mediate parental responses. The culture, and context, of the study impacts on the utility of the findings in other countries, where health services and support for parents differ.

Many chronic conditions lack clear, and internationally accepted, definitions. Conditions can be episodic with acute crises that can impact on experiences investigated. In many studies inclusion criteria are not reported, except that the child fitted the diagnostic group. These factors can limit the findings from many studies on chronic illness which often use small samples and qualitative approaches. Parents' experiences are influenced by support, information and the severity of the child's illness, which in turn is influenced by the services availed of. This impacts, at times, on the generalisability and utility of the research findings across countries.

2.11 Psychological impacts

Care-giving demands in families of infants and young children with many chronic illnesses, and the moderating variables, have been investigated in many studies. The experiences of care-giving from the mother's perspective, the father's perspective, or from both have been investigated while others have compared parental coping. Post-divorce families' experiences of chronic illness, including cystic fibrosis (CF), a life-limiting disease, have also been studied (Ganong, Doty and Gayer, 2003). Gender based studies identify the mother as the main care-giver and mothers report different concerns in care-giving. Research studies on the impact on the mental health on parents and children with chronic illness, as in disability, exist. In a study of 76 families (75 mothers and 62 fathers) of young children (infant to six years) with asthma, Svavarsdottir, McCubbin and Kane

(2000) identified the most time-consuming and difficult care-giving demands experienced by parents. Using a cross-sectional research design the relationships of family demands, care-giving demands, sense of coherence (SOC) and family hardiness (FH) with parent's well-being were evaluated. SOC and FH are considered resiliency factors that buffer the effects of stress and are considered stress resistance resources. A range of tools, including The Care of My Child with Asthma 24 item questionnaire (McCubbin and Svavarsdottir, 1996) and the General Well-Being Schedule (GWB: Dupy 1977) were used. For mothers the most time consuming task was providing emotional support for the child. Others included managing behaviour and discipline problems, handling an acute episode and planning and structuring family activities. Mothers' difficult care-giving tasks related to her own fatigue, getting up at night and managing work when caring for the child but for fathers the two most time consuming care-giving tasks were providing developmental and emotional support. However, SOC and FH were not found to moderate the relationships between family systems demands, care-giving demands and mothers' and fathers' well-being. This study is limited by its sample size which causes a lack of power to reach significance level in the measurement tools used, and the demography of the families in the study, who were primarily white middle class. As with other studies in chronic illness and its impact, the variable nature of the disease process in individual children makes it difficult to generalise the findings.

The unpredictable onset of symptoms in chronic illness has been studied in a range of disorders including epilepsy (Oostrom et al, 2001) and asthma (Weintraub and Wamboldt, 1995) which identify upheaval and uncertainty, increased parental concerns about the child's health and increased demands on the time needed to provide care-giving. In asthma, Weintraub and Wamboldt (1995) suggest that these, as well as the complex self-management drug regime needed, can stress marginal families of children beyond their levels of coping. Stress can exacerbate dysfunctional family dynamics and lead to increased difficulties in the child. There is a risk of secondary psychiatric problems in children and families which can challenge normally competent families, and occasionally stress them beyond their limits. These families, similar to those with other chronic illnesses and disability, also face financial and emotional burdens that can cause secondary stressors which, in turn, adversely affect the illness progression and the child's response to treatment.

Other literature links chronic illnesses, including diabetes and epilepsy, with family stress, adaptation to the new and unfamiliar situation and developing new skills. Within a relatively short space of time parents of diabetic children, for example, have to acquire a

knowledge base, develop the practical skills needed for disease management and learn how to respond to acute episodes (Lowes and Lyne, 1999). Parents are required to adapt their working life as well as their family life to cope with diabetes, which can result in changed family circumstances (Gallo, 1990); with the fears, anxieties and frustrations brought about from their interactions with the affected child and changes in established family routines (Ingersoll and Golden, 1995). In epilepsy, behavioural problems may be caused by the side effects of medications that add to uncertainty, though Oostrom et al (2001) found that 52% of parents in their study (n=69 children) in the Netherlands perceived themselves as coping well with epilepsy in their children. They (33% of parents) indicated that they had not been “thrown off balance” since the onset of epilepsy (p.1452). However 15% of parents perceived themselves, and their child, as not adapting adequately to the situation. Like others they also indicated that adolescents with epilepsy became vulnerable behaviourally. Studies have investigated family support and help available for mothers of children with chronic illnesses. Help is influenced by the child’s disease and the care needed. Lowes and Lyn (1999) suggest that working parents of children with asthma are often dependent on relations, childminders or after school clubs to care for their child during working hours and may face additional stress if carers are fearful of coping with the aspects of the disease management. This is similar to mothers of children with complex needs and disabilities where the effects of disability on family poverty, and caring responsibilities, are recently reported (McKay and Atkinson, 2007). Other themes that emerge from the literature on care-giving by parents identify key areas of responsibility (Kirk, 2001). The management of direct care includes the day-to-day activities that are needed to manage the child’s care. Indirect care activities are identified and include the coordination of care, making sure the home environment is safe, and addressing both personal needs and those of other family members (Schoenfelder et al, 2000).

There is a substantial amount of research on parental stress in a range of chronic illnesses which includes psychological testing of coping strategies and adaptation to the disease (Hatton et al, 1995; Faulkner, 1996). Over time these stressors change, as studies of adolescents and their parents’ experiences of children with health care needs identify new stressors during transition from childhood to adulthood (Sparacino et al, 1997; Betz, 2004). The parent’s reality of coping with the daily demands of the diagnosis, the management of the illness, and adjusting their lives to meet the care-giving demands presents major long term stressors for parents which have psychological consequences including depression (Manuel et al, 2003).

2.12 Life-threatening disorders/technology dependence

Within the literature on care needs and the consequences of care-giving, studies are emerging that focus on children who have technological dependencies which often overlap chronic illness, life-threatening disorders and disability (Woodroffe et al, 1993; Draper, 1995). The specific needs of technology-dependent children for specialised nursing care that is being carried out by parents at home, its impact and the service provision to support parents has been investigated nationally and internationally (Wang and Barnard 2004). Other studies demonstrate the complexities and variability of the parents' caring work in children with chronic diseases including those that are life-threatening and often require technological dependence to ensure survival. Increasingly these children, often referred to in the literature as technology-dependent, are becoming the focus of research, though definitions of terminology vary. In the UK increasing numbers of children who depend on medical technology are being cared for at home, many of whom may be very young (Glendinning and Kirk, 2000). They indicate that it is currently unclear if the children will have less technological dependence as they age. This adds to the uncertainty that parents face and the duration of their care-giving. In Ireland no specific statistics are available on technologically dependent children.

Chronic and life-threatening inherited diseases poses severe, physical, psychological and social problems for the child and the family and can result in technology dependence on a range of equipment in the home. The impact of respiratory, genetic and congenital disorders has been the focus of numerous studies in which particular aspects of care-giving, its impact and the economic benefits of having these children cared for at home have been investigated. Caring for these children often requires ongoing dietary management, care-giving and extensive medication (Foster, Byron and Eiser, 1998) to meet these children's needs in the home setting. This has resulted in the development and subsequent evaluation of service provision.

Kirk and Glendinning (2004) explored the experiences of families caring for technology-dependent children at home using data collected by in-depth interviews with parents of 24 technology-dependent children and 44 health, social care and other professionals. They examined parents' needs for practical and other support and explored how far current services met parental needs. Their findings indicated that parents assumed responsibility for the performance of highly technical procedures that would have only been undertaken previously by qualified professionals. Parents also performed multiple roles in caring including managing the child's condition, organising services, advocating for their child

and performing clinical procedures as well as “the more usual elements of parenting” (Kirk and Glendinning, 2004: 212). Parents felt that the emotional aspects of caring were ignored by professionals, who emphasised only the acquisition of technical competencies when teaching parents. Other issues that parents reported included the medicalisation of the home, restriction of social activities, financial impacts, accessing support services and disputes over funding responsibilities. They included the impact on family lives and routines that caring imposed though parents indicated that their desire to have their child discharged home had dominated their actions. This study is significant because it not only provides parents’ perspectives, but also those of professionals involved in service provision, which are limited in the literature. The professionals in the study were concerned that hospital staff had not discussed parents’ responsibilities for clinical procedures explicitly with them but had unquestioningly “expected parents to continue participating in their child’s care as they had done in hospital” (Kirk and Glendinning, 2004: 212). They confirmed a lack of time being given to order the equipment needed for discharge of the child from hospital staff and problems in supplying equipment. Nurses reported that they had not been adequately involved in discharge planning and identified a lack of clarity about their responsibilities for the different aspects of care to the family. This is similar to Kirk’s (2001) study which found that roles in care-giving undertaken by parents were not always negotiated. Kirk and Glendinning’s findings suggest that the development of appropriate community based services has not kept pace with the advances that enable children with complex, intensive technological needs to be discharged home from hospital. Limitations to the study include the small sample size of parents (n=24) and the findings only record the experiences of parents within a specific location in the North of England. Only four of the families were headed by lone mothers so it offers a perspective mainly from a two parent family. The duration of the parents’ experience of caring at home is also not described which is a relevant factor in their interpretation of the experiences of caring. Additionally technology dependency is commonly undefined. For some children the dependency may vary significantly in type, duration and nature and so impacts differently on the experiences within the family.

Wang and Barnard (2004) provide an empirical review on the literature on children who are technology-dependent and its impact. Similar to Kirk and Glendinning (2004) they report on the literature on practical and emotional issues and implications associated with the long term care of technology-dependent children and their families in homecare settings. The studies included in the review include Noyes et al (1999) and Roberts and Lawton (2001) who both have reported the extra physical and emotional burden of care-

giving on parents. These studies, like many others, are limited by their use of self-report measures for data collection that provide a subjective view. However, they do explicate parental responsibilities and their impact.

Within the literature on care-giving the term ‘technology-dependent children’ is further divided into subsets depending on the technology used; for example, ventilator dependent. This adds to the complexity of the literature and the utility of findings from small studies in which clear acceptable definitions are missing. These include studies on those who require mechanical ventilation, tracheostomy and oxygen therapy, enteral and parenteral feeding, intravenous drug therapies, and peritoneal and haemodialysis at home. Kuster et al’s (2004) quantitative study, for example, focussed on thirty eight primary female care-givers of ventilator–assisted children and used a range of stress measures. Data collection tools included the Social Support Index, Personal Lifestyle Questionnaire and The Impact on Family Scale. The high demands placed on care-givers delivering care at home impacted on their nutrition, exercise, relaxation and general health. Maternal coping and the child’s functional status were found to be positively correlated with the mothers’ participation in health promoting activities and were found to be significant predictors of mothers’ participation in healthy activities. They suggest that the demands of caring for a child who is ventilator dependent with poor functioning can be a significant risk factor for mothers not participating in their own health promotion activities. This study is relevant in that it is one of few found that investigated health promotion activities in care-givers but its significance is limited by a small population (n=38), recruitment from a single hospital site and lack of a pilot of the tools that were translated into Spanish for use by some mothers. The variability in the child’s need for ventilator support impacts on the utility of the findings.

Technology-dependent children form a diverse group and their needs vary according to the cause of the disease, the duration of the dependence (which may vary from months to life-long dependency), the incidence and severity of associated disabilities and the frequency of using technology which influences the utility of research findings. Defining the children and their needs in inclusion criteria is problematic given the changing nature of the needs of children for the technology and the fact that it may be needed only intermittently, when the child is deteriorating, or as the disease progresses or improves. International definitions are commonly adapted within studies which can limit them.

2.13 Rare and potentially life-threatening disorders

Within the literature on children and their families there are research studies on care-giving in families with children who have specific, but rare and/or potentially life-threatening medical diagnoses. These include children who are medically fragile (Leonard, Brust and Nelson, 1993). Children with congenital heart disease, for example, face temperamental disturbances as infants and toddlers, learning difficulties, a feeling of being different, social problems, nutritional problems and increased risk of feeding difficulties (Marino & Lipshitz, 1991; Lobo, 1992; Morris et al, 1993; Van Horn et al, 2001; Lowoko and Soares, 2002). These extensive problems impact on parents and Svavarsdottir and McCubbin (1996) found that feeding the infant proved to be the most time consuming care-giving task. Studies in older children with congenital heart disease include Sparacino et al's study that investigated eight parents of adolescents and young people. Among the seven themes identified as parental concerns from the semi-structured interviews in this study were the dilemmas of normality, the challenges of uncertainty and dilemmas in the illness management. This study is limited by its small size, its recruitment method that was from one cardiology centre and the variation in the range of parental experiences of congenital heart disease. Evidence about the concerns the parents of these children have about their child's illness, treatment and the effects on the child's daily functioning and well-being exists. The degree of uncertainty about the prognosis and its challenges continued to be stressful for parents over time (Sparacino et al, 1997).

The extent of the cardiac abnormality however, has been found to make little difference on the parental impact. Morelius, Lundh and Nelson's (2002) study of parental stress found that parents of children with less severe cardiac malformations experienced as much stress as parents of children with more complex cardiac conditions. Data were collected from 101 parents who completed the Parenting Stress Index. They conclude that the severity of the child's congenital heart disease is of no distinct importance to the degree of parental stress.

2.14 Quality of life (Qol) studies

Studies have focussed specifically on the impact of Qol in families with children with a range of diagnoses, disabilities and conditions including cerebral palsy (CP) (Eker and Tüzün, 2004) which they view as a chronic and disabling condition. In this comparative Turkish study 40 mothers of children with CP were compared with 44 mothers of children with minor health problems including fever, cough and diarrhoea. Data were collected from personal interviews, a background questionnaire and The Medical Outcomes 36 Item Short Form Survey (Turkish version). The severity of the child's motor ability was also

assessed using the Gross Motor Function Classification System. Mothers of children with CP were found to have significantly lower scores on the SF 36 subscales, with the exception of the physical functioning subscale, than mothers in the comparison group. Scores were lower in mothers of children who had the least independent motor function. This study provides a quantitative measure of the differences in the Qol in mothers of children with CP as compared to children with minor illnesses. However, it does indicate the greater the severity of the child's motor disability, then the greater the decrease in psychological and physical well-being of the mother. It is limited by the small sample size, the lack of detail of those in the comparison group and the recruitment process using one hospital site.

Other studies on Qol include those that have examined the Qol in children with a range of physical, sensory and neurological disorders that show these children are at risk of psychological adjustment problems and decreased self-esteem (Lavigne and Faier-Routman, 1993) which can impact on experiences of care-givers.

Studies that investigate how rarer diseases affect parents offer a different dimension because of the rarity of the condition. This is important, as there is the potential that health professionals may lack an understanding of, or misunderstand the disorder and the family, because of limited experience and knowledge of the disease. This may also occur in children with complex needs due to rare illnesses and is relevant for this reason.

Bernehall Claesson and Brodin (2002), in a Swedish study, reported on the living conditions of thirty families with children and adolescents with brittle bone disease and focused on the families' need for support. Using questionnaires with thirty families and interviews with ten families they found that the parents seemed to have had no influence on treatment; the parents listen to the doctor and accept what is recommended and many parents do not know if they get optimal treatment. This study raised other interesting issues. Many parents lacked information about the disease and when information was given it might not be at the right time or at the right occasion. The families emphasised difficulties in finding information on the technical devices available, the disability itself and the support services available. Almost all families in the study stated that there is a shortage of experience and knowledge of brittle bone disease by professionals. This is one of few studies on rare disorders that have a moderate sample size considering the rarity of the disease.

Within the literature studies of children who do not have a named cause of their chronic illness, or have no diagnosis, are reported. They can be termed complex needs and within this review it is therefore relevant to include literature on children without a specific

medical diagnosis but who have specific care needs for feeding difficulties, failure to thrive, developmental delay and seizures from known, and unknown, causes.

2.15 Unspecific medical diagnoses

Studies have investigated parental experiences in children with less specific medical diagnoses where the findings are similar to those already reported but the lack of a clear diagnosis also has an impact, causing fear in parents' lives. Tomlinson (2002), for example, interviewed a purposive sample of twelve families of children who had failure to thrive for multiple known and unknown reasons. The sample included mothers, stepmothers, fathers and grandfathers. Seven themes emerged from the data. Families talked of living with an all encompassing fear which affected every aspect of their lives. This fear of the possible causes of failure to thrive, of the illness itself if a diagnosis had been made, and fear that resulted when a diagnosis was not, or could not, be made were reported. A lack of diagnosis caused fear to be an ongoing constant in family life and as a consequence parents became exhausted and felt physically ill from lack of sleep. The comparisons of the children made by others, and themselves, also affected them. The families described how their concerns were not heard by the professionals when they sought care for the children. Additionally, parents felt blamed for their children's growth failure that added to a sense of isolation and helplessness. Maternal adjustments to illnesses, disability and chronic illnesses have been investigated across a range of diseases, disabilities and symptoms.

2.16 Parental responses

Within the literature there is a significant amount of research on the identification of specific stressors that are caused in chronic illness, disability and parental responses to these (Fagan and Schor, 1991; Oostrom et al, 2001). One response that is well recognised is the uncertainty that exists in the experience of caring in disabled children (Craig and Scrambler, 2006) and in children with sleep disturbance (Gelman and King, 2001). Literature focuses on the causes of uncertainty, coping responses to it and the implementation strategies to reduce uncertainty. This includes studies on information-giving to help develop parental control as a coping mechanism. Psychological impacts related to uncertainty include mental health problems, particularly depression, which is more common in mothers caring for children with cystic fibrosis (CF) and many other specific chronic diseases. This is related to the never-ending routine of treatment, uncertainty about the future, the symptoms of CF and fear of future pregnancy (Mullins et al, 1991). Hodgkinson and Lester (2002) explored the stresses, coping strategies and

relationships with health professionals of 22 mothers of children with CF who were attending a children's hospital in Birmingham. Three main themes arose from the data that were collected through semi-structured interviews. These were the perceived cause of stress, which was the stress of feeling in the middle, the burden of responsibility and coping with a changed identity. Being 'in the middle' was a feeling described by the majority of mothers. This was an issue in decision making, particularly concerning aspects around the genetic implications of the disease. A number of mothers believed that they had lost their individual identity, and a sense of sacrifices that had been endured as a result of their child's diagnosis was frequently reported. The careful advance planning that was required was identified. Disease management had to come first in everything.

Many studies focus on other chronic and potentially life-threatening illnesses including cancer, despite its relative rareness (Grinyer, 2006). Parents are faced with prolonged periods of uncertainty about the outcomes which transform the everyday life of families (Eiser, 1993). Uncertainty has been explored in parents of children with cancer including Cohen's (1995a) study which explored how families come to experience and manage the sustained uncertainty concerning their child's illness. A grounded theory approach and three sources of data were used. These were the literature, an existing set of data from interviews from ten parents of children with cancer and interviews from a cross-sectional sample of parents of children with a variety of chronic, life-threatening illnesses. The analysis identified a process whereby parents reported passing from a secure, taken-for-granted world to an uncertain reconstituted world. In the study undertaken over a five year period involving ten families, Cohen identified a perceptual-interpretive-behavioural process that showed the emergence and intensification of the uncertain state that occurred during the pre-diagnostic period. Cohen suggests that this process follows three stages; lay exploratory, legitimating and medical diagnostic stages which commence when the parents become aware of cues about the child's illness and finish when at the point of the diagnosis. Cohen suggests that the management of uncertainty is important and recommends strategies including time, information, awareness and social interaction that can be used to reduce this in parents.

Others have studied situations where parents need to live with the intense demands of the child's treatment, the uncertainty of the child's prognosis and the fear of the child's impending death in cancer (McGrath, 2001), in reports on AIDS (Williams, Berrien and Trubey, 1997) or epilepsy (Ostrom et al, 2001). Hans' Korean study (2003) identified factors that influence maternal psychosocial adjustment to childhood cancer and reports that adjustment is influenced by a range of factors including the self-reported level of

stress, coping, social support and time since diagnosis. Mothers who consistently employed more coping strategies tended to adjust better and increased coping was significantly associated with better adjustment. The findings are limited as a non-random selection of the sample of 200 mothers was used. The use of self-report measures that were collected during hospital visits may have influenced the mothers in completing these. Data collection could be influenced by situational determinants, mothers' psychological state at the time and the fact that coping can change over time, and during the illness trajectory.

Predictors and mediators of psychological adjustments have been investigated in mothers of children newly diagnosed with cancer and compared with mothers of children with acute illnesses. In one of few comparative studies Barrera, Fleming and Khan (2004) compared mothers of children with a recent cancer diagnosis and mothers of children with acute illness. The focus was to examine specific correlates of psychological adjustment in mothers and to test two models of psychological adjustment. A series of measurement tools were used including the Beck Depression Inventory (BDI), the State-Trait Anxiety Inventory for Adults and one global measure of mental health (Symptoms Checklist-90-Revised: Derogatis, 1992), The Ways of Coping Questionnaire, The Child Behaviour Checklist and The Family Stressors and Family Strains subscales of the Family Index of Regenerativity and Adaptation-General (FIRA-G: McCubbin and Patterson, 1983). Mothers of children with cancer (n=69) showed more symptoms of depression, greater use of emotion-focused coping strategies and received more social support when compared to mothers with children with acute illnesses (n=22). Mothers of children with a diagnosis of cancer showed no more anxiety than mothers of children with acute illness. Limitations in this study include a high rate of refusal to participate and, like many other studies in which stress and coping are investigated, the heterogeneity of the children's diagnoses, which can affect the experience of caring and coping, are not accommodated in the findings.

2.17 Mediators of stress

The findings in disability, chronic illness and specific diagnostic group studies are similar to those reported in the international literature surrounding children with unspecified life-threatening disorders. Others have measured stress mediators including social support, information and service provision as mechanisms implemented to help families cope. Katz's (2002) Israeli study, for example, on the impact on parents of children who have life-threatening illness and non life-threatening illness, measured satisfaction with social support received, perception of impact of the child's illness and coping behaviours. Eighty fathers and 80 mothers of children completed a range of questionnaires, including the

Coping Health Inventory for Parents. Parents reported significant differences in social support, perception of the impact of the illness and coping behaviours. No significant differences were found using ANOVA, MANOVA and Doubly multivariate analysis between fathers and mothers related to social support. Limitations of this study include the definitions used for life-threatening and non life-threatening illness, which were determined by the physician involved in the child's care and a subjective judgement about the anticipated death of the child within a year. The sample, although large, was a convenience one and the questionnaires were completed in the child's home in the presence of the researcher, which can influence results and their generalisability.

2.18 The impact on parents of the care-giving activities

Many reports exist of the impacts on parents of care-giving including sleep deprivation and feelings of exhaustion (Hodgkinson and Lester, 2002) and marital discord (Petr, Murdock and Chapin, 1995). These include studies on the well-being of mothers of children with sleep disturbance (Gelman and King, 2001). Emotional turmoil has also been reported and includes responses of stress, anxiety, anger, guilt, frustration, sorrow and chronic disappointment (Patterson et al, 1994; MacDonald, 1995; Seligman and Darling, 1997; Gupta et al, 2001). Many other studies report on the experiences of families caring for children at home, including the duration of caring. Quint et al (1990) reports on parents with ventilator-dependent children and found that those who had been caring for their children for more than two years had lower coping scores and were burnt out and exhausted.

Wilson, Morse and Penrod (2001), in a Canadian grounded theory study of mothers (n=16), identified absolute involvement as a core variable in caring for ventilator-dependent children, though the differences in the children's abilities impacts on the findings from this study. Others have linked caring to fear (Kirk, 1998; Gupta, 2001), and a lack of knowledge also impacts on parents (Hodgkinson and Lester, 2002). However this literature is complicated by various factors including the small number of studies that investigate mothers' experiences only, the complexity of the terminology, the lack of specific inclusion criteria and the duration of the experience is not always reported.

2.19 Irish Studies

The mothers' experience of caring for a child with complex needs at home has not been explicitly examined from either a nursing perspective or the cultural setting in Ireland. Service provision for family carers of children with disability/severe/profound and life-

threatening illnesses has been the focus of a social policy study undertaken by Redmond and Richardson (2003). This study investigated the expressed needs of 17 Irish mothers of children with severe/profound disability and their views on the efficacy of services being offered to them. The mothers were the primary carer and the children were under four years of age. The study involved a mixed method approach using semi-structured interviews and The General Health Questionnaire to measure respondents' perceptions of their physical, mental and emotional well-being. This questionnaire uses positive and negative questions with four possible responses per item to assess whether full time care of a young child with severe intellectual disability increased the likelihood of mothers' experiences of psychological distress. The findings identified that mothers were under considerable emotional and psychological distress relating to the care of their child. Mothers also reported on the extent of their daily care and expert skills they used, the complicated regime provided, and the fragile and uncertain nature of their child's life. There was a lack of uniformity in all aspects of service provision and service quality. Quantitative data indicated the mothers were experiencing levels of strain (77%), had encountered high levels of unhappiness and depression (71%) and 94% felt themselves less able to enjoy normal day-to-day activities. However, like other studies in which positive outcomes are reported, the results indicate that some mothers were quite positive about certain aspects of their lives, with 59% feeling that they played a useful part in things and 47% perceiving that they were able to face up to problems. Mothers wanted reliable, comprehensive and coordinated services and reliable information on practical services to help them to manage and meet their children's needs. This study provides an interesting perspective from the RoI but is limited by the fact that all children in the study were under four years old, mothers were recruited from one organisation and a single interview was used to collect the data. It also focussed on service provision and, like others, inclusion criteria were limited to mothers known to one specific organisation. However, it does offer valuable insights into how well these mothers were functioning as they undertook difficult caring roles, and the services that they would like developed.

Another perspective from the RoI is described in a small study by Hartrey and Wells (2003). Using a phenomenological approach they explored the experience of two mothers of respite care for their children who had learning disability. Data were collected using a diary of events and recording a taped narrative reflection of life with their child. This study provides an interesting perspective and identifies three themes that emerged from mothers' experiences. These were emotional meaning and how parents conceptualise their attachment to their child with learning disabilities as different to their attachment to other

children; how the demands of caring socially restrict parents and sibling activity was the second theme and physical meaning was the third theme identified. This study is limited in that its interpretation is based on the experience of two mothers, one of whom did not complete her diary of events. The method of recruitment of these mothers, (one was known to the researcher) and the fact that mothers volunteered because they “wanted their stories told” limit the utility of this study, but it does provide an insight to the carer’s experience.

2.20 Summary

Within the literature on children being cared for by parents at home both quantitative and qualitative studies have been undertaken in many groups of children with a range of needs. Studies have approached the experiences from the perspective of physical, psychological, financial impacts on family functioning, care needs and service provision and at different stages of the disease trajectory. These include studies of families with disabled children, chronic conditions, a specific diagnosis and those who are defined by their need, dependency and requirements for service provision rather than diagnosis. Studies adopt a psychological or sociological perspective with some studies emerging from nursing. Quantitative studies have focussed on the psychological and physical impacts of caring including the measurement of stress and depression, adaptation and coping and mediating variables in the stress response and interventions (Seligman and Darling, 1997). Recent studies focus on the delivery of care to children at home and its impact, perhaps as a consequence of the current focus on community care, rather than a hospital-based specialist model (Emond and Eton, 2004). Others focus on the concept of the home, the scope of responsibilities of professionals and parents, and altered relationships between the child, parents, professionals and society (Wang and Barnard, 2004). However, many studies are limited by their sample size, a lack of definitions and clear inclusion criteria. They are situationally limited as services and care provision, as well as cultural acceptance of diseases differs in diagnostic groupings, and across countries, which can influence experiences and impact on findings. What are not evident are studies on the totality of the experiences of care-giving on mothers who are the main carers, and phenomenological studies from an Irish perspective.

2.21 Linking the literature to the aim of this study

The literature provides an overview of the impact of caring on families. Quantitative studies have resulted in the development of measurement tools that reduce the mothers’ experiences to a level, number or statistical significant entity. Qualitative studies that focus

on the perspective of mothers caring for children within groups do identify some of the experiences of caring, though many focus on investigating individual aspects of caregiving, rather than its totality. In Ireland two studies have been sourced. This literature does not give a full picture of the experience that a phenomenological study would do, nor does it provide the total reality that I see in my practice when nursing children at home, such as the complicated intricacies of care giving when a child is intellectually and physically disabled, has complex physical and technology needs and is life-limited. Beresford (1995: 128) indicates that families' experiences are "compounded when professionals do not understand what it is like to care for a disabled child". The care of children by parents with complex needs warrants further investigation from a nursing perspective in this current context. My intention is to use a phenomenological approach to develop a greater understanding of mothers' experiences from the perspective of a children's nurse. This will be achieved by enabling mothers to talk about their experiences of caring for children with complex needs to a nurse experienced in this field of practice.

CHAPTER 3 - THE RESEARCH FRAMEWORK

3.1 Introduction

The aim of this chapter is to outline the rationale for the choice of hermeneutic phenomenology as the form of enquiry used in this study. The focus will be on the underpinning epistemological position that is “coming to know and the nature of knowledge” (Munhall, 2001: 15). The focus will be on the philosophical framework selected and the use of the ‘self’ in the generation of knowledge and understanding.

In the literature choosing a methodological approach appears a simple straightforward process. However, the complexity of the decision making processes involved, the influence of the self and the use of reflexivity need to be recognised. Understanding, in my view, requires engagement between the researcher and those being researched and that developing understanding needs to be “participative, conversational and dialogic” (Schwandt, 2003:302). The purpose of this study was to gain an understanding of the lived experiences of mothers caring for children with complex needs. My view of the mothers’ worlds was not based on a single interpretation but a diverse range of interpretations referred to as “relativist ontology” (Willig, 2001: 13). The philosophical approaches of phenomenology and its focus on the meaning of lived experiences were therefore appropriate. I sought to understand, describe and interpret the meaning of mothers’ experiences while recognising that I was not separate from them, but I was implicated in the research process. My understanding is lived, or existential, and my view is that understanding mediates everything and is mediated along with ourselves by understanding (Gadamer, 1979); one impacts on the other.

3.2 Influences on the choice of research design

My choice of approach was influenced, not only by theoretical issues, but also by personal and professional values, and expertise. I have an interest in the real life experiences of mothers who are caring for their child or in some cases, children, at home. Mothers face an emotionally and physically demanding experience in which they report having limited support. One mother has described the experience of ‘being a prisoner in her own home’, caring when every day could potentially be the child’s last; others are facing the death of more than one of their children and caring for children with ‘no diagnosis’. The findings in the literature do not report these experiences with the intensity that I know mothers experience. I recognise the psychological, emotional, physical and financial impacts of

caring, models and scientific measurements of stress of coping, adaptation, anxiety and depression reported in the literature. These, in my view, do not capture the intensity of the mothers' experiences or explicate the totality of what I know of mothers' experiences in caring for their children at home. To achieve this, a qualitative phenomenological approach was appropriate to understand this phenomenon fully. It was also professionally and contextually appropriate to explore these experiences from a holistic perspective so that they might be better understood.

Shih (1998) reports that the decision to study a topic in a particular way involves a philosophical choice. The decision to use phenomenology is influenced by my personal beliefs, values and attitudes about the nature of reality, truth and my belief in a particular research paradigm. I believe that the discovery of knowledge that is *verstehen* (understanding) cannot be attained by the empirical-analytical sciences (Van Manen, 1977) but is achieved by sharing a common meaning. Phenomenology offered the opportunity to illuminate the mothers' experiences, to understand the context of these and how they were described. The improved understanding that would result from mothers' disclosure is capable of contributing in a special way to the broadening of our human experiences (Gadamer, 1989). It is the language that mothers use, and the phenomenological text that is collected, that have the power to disclose the world, as we live it (Van der Zalm and Bergum, 2000). It is this human experience that I am interested in.

3.3 The place of phenomenology within qualitative research

Phenomenology, of which there are many interpretations and approaches, is situated within the qualitative paradigm. Its focus is to challenge existing beliefs but not to infer predictions (Easterby-Smith, Thorpe and Lowe, 1991) and to use the knowledge gained to improve understanding of lived experiences. Phenomenology involves adopting an interpretivist approach in which the perspective of the other as well as the researcher is important. The researcher develops and acquires an insider understanding of the situation or individual being researched and identifies their definitions of the situation (Schwandt, 2003). This approach is underpinned by three beliefs; firstly, that reality is complex and is based on subjective interpretation; secondly, I am not separate from the research subject, and thirdly that truth is best achieved by conducting the research process openly with subjects in their natural environments and without prior theorising (Lincoln and Guba, 1985). The phenomenologist's view further accepts that life events are ever changing, and an outcome with knowledge as set of given laws or developing law-like statements is not therefore of concern. The focus of phenomenology is on the experience as lived and on

revealing meanings rather than developing abstract theory or on arguing a point (Koch, 1995; Van Manen, 1997(a); Van der Zalm and Begum, 2000). The objectives are to explore unknown, or to re-examine existing phenomena and to contribute to a greater understanding of its nature and meaning in the natural environment. Phenomenological studies do not attempt to provide an answer, and in fact there may not be one, but what it can do is provide a greater understanding of the issues. In using phenomenology designs are therefore flexible and emerging during the research process as the complex life-world does not remain static and the interpreter will also bring himself to bear on the text (Van der Zalm and Bergum, 2000; Munhall, 2001).

3.4 The methodological approach

Phenomenology therefore provides a research method that utilises both descriptive and interpretive elements to examine lived experiences to give voice to human experience just as it is (Heidegger, 1962; Husserl, 1965, Jardine, 1990). The subjective experience involving the world is based on the belief that essential truths about reality are grounded in everyday experience is the essence in the phenomenological method (Van Manen, 1990). This truth “appears at the intersection of epistemology and ontology, at the point where knowing and being co-determine one another” (Di Censo, 1990: 146). In phenomenology the focus is two fold; firstly is the investigation of understanding (Gadamer, 1979; Heidegger, 1962) and the second involves the interpretation of text in which the understanding is reported (Gadamer, 1979; Geneallos, 1998). The interpretation of text involves an attempt to grasp and create meaning to enable different or more complete understandings of the phenomenon under investigation to occur and new insights to be developed. This understanding of understanding (Verstehen) is assumed as an epistemological position in phenomenology (Schwandt, 2003).

Within the literature multiple approaches to phenomenology and the use of description and interpretation within different approaches are reported (Caelli, 2000). My aim was to uncover the experiences of caring for children with complex needs and to provide a rich in-depth description, which in turn provided greater understanding of this phenomenon in a current contextual situation. The ultimate purpose was to study the mothers’ experiences so that the integrated totality of these experiences could be explored rather than one dimension, or particular aspect of caring. The rich detail uncovered could be used to discover the common meanings and underlying empirical variations of a given phenomenon (Baker, Wuest and Stern, 1992), if they were present. If commonalities emerged in these experiences these would then be added to my interpretation of an already

interpreted experience. My view was that mothers' experiences had already been interpreted by them, rather than ones described in a primordial form (Caelli, 2000). Since language is an interpretative medium the primordial form has already been interpreted if it is reported. Understanding is always bound up with language. My aim was to focus on what it is like for the mother to care for her child and to identify and revealing essential meanings of this experience in my interpretation of the data.

3.5 Phenomenology and nursing

There is a growing tradition towards the use of phenomenology in nursing research as quantitative methodologies are beginning to be questioned as adequate approaches for the study of human life experiences (Geneallos, 1998; Van der Zalm and Bergum, 2000; Munhall, 2001). Nurse researchers have increasingly used phenomenology as a philosophical base for enquiry, and Caelli suggests that phenomenological studies allow the "person's experience to speak so that it may be understood and stresses the importance of the individuals' own lived experience" (2000: 370). There is evidence that attention to the life world descriptions, that is phenomenology, is also currently entering mainstream health care (Todres and Holloway, 2006) where it can be used to begin to understand many of the perplexing and complex conditions "in which humans find themselves and thus address nursing's central concern, which is caring for people" (Caelli, 2000: 370). Developing nursing knowledge was central to my methodological choice as there is a need for an understanding to improve empathy and this knowledge is an essential adjunct to technical efficiency if a holistic approach is to be implemented. Such kinds and levels of knowledge, where a greater understanding of the world of the patient is explicated, may help to provide a template for the development of more uniquely person-centred practice (Phillips, 2007). The knowledge generated when the mothers' real life world is investigated can be used to create a greater understanding of the totality of their situation and to expand evidence based practices and education focussed clearly on the patients' point of view and perspective (Todres and Holloway, 2006). Phenomenology offered me the opportunity to explore and understand more of mothers' holistic experiences in caring for children with complex needs by expanding my horizons of this topic. It was also necessary, and appropriate, to explore all the dimensions of the mothers' experiences, rather than to confirm what was already known as these did not represent, for me, the totality of what I knew of the phenomenon of mother's care-giving. It offered a way of exploring the intensely personal and hidden aspects of these mothers' lives that may remain hidden in quantitative studies and to contextualise the mothers' experiences.

3.6 The 'I'

In investigating the lived experiences of mothers caring for children with complex needs I have adopted the perspective of a professional nurse. Nursing, for me, deals with the experience of distress as it is uniquely described by people (Phillips, 2007) and this uniqueness should be investigated. If I am to be an active participant in the process of understanding the mothers' experiences when I work with them in caring for their children, I am not an uninvolved observer. I need to attempt to understand their experiences in their lived world by striving to understand this, rather than by providing causal explanation of it (Van Manen, 1977). I am influenced by current philosophies including partnership models and family centred care that underpin child care service delivery, yet often interventions are focussed on technical and not emotional support. There is a need to explicate the reality of the mother's perspective in greater detail so that appropriate children's nursing interventions could be developed. Evidence of 'I' is included in Appendix 15.

3.7 The history of phenomenology

Phenomenology has its origins in the philosophical perspectives of Husserl who, with others, explored the structures of consciousness in human experiences (Polkinghorne, 1989). Its history is based on the paradigm shift away from the world of the hard sciences and mechanistic view offered by Descartes and Galileo. The term was initially used in the contexts of religion and philosophy. Cohen (1987) reports that phenomenology was first described by Immanuel Kant in 1764, in a scientific study of the study of 'phenomena' and 'noumena'.

Hermeneutic phenomenology is said to have originated during the 16th and 17th century Protestant Reformation in Northern Germany when it was viewed as offering a method of interpreting theology from the classical religious and biblical texts. The original focus of hermeneutics was on how to derive the word of God accurately from these texts that had undergone many translations over time, which had resulted in changed meanings. Multiple interpretations meant that biblical meanings and understandings no longer always corresponded with each other in these texts, resulting in confusion. In an attempt to reconstitute the ancient world as accurately as possible, hermeneutics, as a way of understanding, was introduced into aesthetics and philosophy where the study of texts, through a reflection on the language used in them, was needed for clarity of interpretations and to improve their meanings, and subsequent understanding.

Early founders of phenomenology were Schleiermacher (1768-1835) and Dilthey (1833-1911) who proposed a shift in how science was perceived as an alternative to Cartesian dualism, which was the dominant philosophical approach at the time. Phenomenology explored the subjective interpretation of experience with a focus on relativism as distinct from a scientific objectivism. Schleiermacher developed the initial hermeneutic approaches of textual interpretation and went on to recognise hermeneutics more broadly as a general method of understanding the interpretive mechanisms that characterise knowledge. The phenomenological movement developed thereafter and early in the twentieth century phenomenology emerged as a discrete philosophical tradition that eventually extended into the social sciences, including nursing. However, over time the understanding of phenomenology has changed and the use of the term has changed. As a result there are variations in the methods used within the approaches. Alternative interpretations and new approaches are continually emerging internationally, and within disciplines (Crotty, 1995; Caelli, 2000; Denzin and Lincoln, 2003; Rapport, 2004). Current approaches include transcendental, descriptive, interpretive or hermeneutic phenomenology and phenomenology of practice (Willig, 2001; Van Manen, 2002; Todres and Holloway, 2006). Despite these varying approaches phenomenology can always be distinguished from other qualitative methods in that it adopts a clear focus on describing and/or understanding the meaning of the participants' lived experiences.

3.8 The foundation of phenomenology and work of Husserl

The foundation of phenomenology as a science is said to be based on the work of the German philosopher Edmund Husserl (1859-1938) who is often reported as the central founder of transcendental phenomenology. It is recognised that he built on the work of the earlier philosophers who wished to describe human experience as a valid starting point in philosophy. Husserl sought to make philosophy "a rigorous science" by returning its attention to things themselves as it made no sense to view the world of objects and subjects as separate from the individual's experiences. He rejected the notions that objects exist in the world which could be objectified and interpreted through scientific fact. These beliefs were developed from his experiences in mathematics to a position where he viewed phenomenology as equally objective and subjective (Reeder, 1987). Uncovering the essential structures of reality is central to Husserlian transcendental phenomenology and his concern was the uninterpreted world of the everyday experience. According to Husserl, an individual's consciousness structures what is experienced and the appearance of an object is a perceptual phenomenon that can vary with time and orientation (Willig, 2001).

Husserl used the term “*lebenswelt*”, the concept of the lived experience or life-world, which was viewed as the world as lived by the individual. This was not an entity that was separate or independent from the person. Centrally therefore, is the need to recognise the experience as the meaning of knowledge. He supported the idea that to return to the things themselves, and to re-examine what is already known, was needed. By bringing to awareness that which has been taken for granted, the familiar, and the essences that constitute the consciousness and perception of the human world, were central (Koch, 1995). Husserl’s view was that pure subjectivity was the foundation for both scientific knowledge and the life world of everyday experiences (Johnson, 2000).

3.9 The developments by Heidegger

Heidegger later developed Husserl’s description and explanation of consciousness and argued that understanding “is always ahead of itself” (*sich vorweg*), projecting expectations that interpretation then makes explicit. According to Heidegger inherent in understanding is a “forestructure” (*Vorstruktur*) of assumptions and beliefs that guide the individual’s interpretation of the individual situation (Johnson, 2000). This interdependence of understanding and expectations is in part a reformulation of the classic idea that interpretation of texts is a fundamentally circular process in which changes can occur. Any interpretation therefore is always necessarily based on assumptions about the whole to which it belongs. This theory of understanding reflected Heidegger’s personal assumptions about human existence which he viewed as a process of projection. As humans, we are always outside of, and beyond ourselves as we direct ourselves toward the future. This differed from Husserl’s epistemological focus on a way of knowing or understanding (Heidegger, 1962: Johnson, 2000). The initial position in hermeneutic phenomenology in Heidegger’s view was that *dasein* (the mode of being human) and “being there”, with a focus on ontology, was distinct. The presence of an anticipatory structure of understanding is important for later versions of phenomenology that focus on interpretation and reading. Heidegger focussed on the structure of being, and the task of hermeneutic phenomenology was to understand the mystery of being and the structure of being human (Lavery, 2003). His focus was on “being-in-the world”, the structure of being and being there. Todres and Holloway (2006), however, suggest that within the literature the distinctions between the two types of phenomenology described by Husserl and Heidegger have been over emphasised. They suggest that there are common features to both, in that they both start from life world descriptions; they use bracketing, or sensitising

as a reflective analytic method to isolate the individual researcher's experience; and arrive at 'essences' or fusion of horizons to characterise the experienced phenomena.

3.10 Ongoing developments – Gadamer

The research design used in this study was based on the Gadamerian hermeneutic phenomenology as described by Hans George Gadamer whose work was influenced by Heidegger and Husserl. He advanced Heidegger's early work, having been a student of his at Marburg and Freiberg Universities. Gadamer (1976) offered valuable insights into how an individual may develop a deep understanding of texts (Fleming, Gaidys and Robb, 2003). Hermeneutic phenomenology developed by Gadamer, and later by Ricoeur and others, further explores the role of presuppositions in understanding. They investigated how different literary works are understood differently by audiences with different interpretative conventions. Gadamer developed hermeneutics as a means to clarify further the conditions in which understanding occurs, rather than investigating how understanding takes place. Gadamer was concerned with how understanding is possible and emphasised the notion and importance of historical awareness which he valued as a positive condition for knowledge and understanding to occur (Fleming, Gaidys and Robb, 2003). Gadamer's view of hermeneutics suggests that understanding is a mode of being as well as a process (Heidegger, 1962; Ricoeur, 1981; Gadamer, 1996). He emphasized the fact that we are all part of history and consciousness and identified the fusion of the individual's horizon within the prejudices of history, including those provided by people and texts, in the creation of knowledge and understanding. Central to Gadamer's approach are the concepts of the hermeneutic circle of understanding, prejudice, historicity, linguisticity of understanding, fusions of horizons and lived experience. Language and the non-conscious processes of socialisation and a person's consciousness are not independent of history (Gadamer, 1992) and traditions and understandings are therefore inherited through these mechanisms. He argues that an individual's orientation to the world is acquired through language and by learning to speak which is closely linked with their history and culture. For Gadamer language is fundamental to understanding and that it "is the universal medium in which understanding occurs: understanding occurs in interpreting" (Gadamer, 1989: 389). Human, cognitive and linguistic abilities enable the individual to reflect on and to interpret experiences in a dialogical process. New experiences are checked against those previously encountered which consequently influences and shape any future experiences. Understanding therefore derives from the individual's involvement in reciprocal

interpretative processes that are inextricably linked with being human and being in the world.

Simply put, the ‘mothers’ being in the world’ and ‘my being in the world’ were different because of our different history, experiences and interpretations. My focus was to develop a greater understanding of the other. I wanted to understand the mothers’ interpretations of their experiences so that my existing experience (or preunderstandings) would be expanded and new knowledge generated to create new understandings for me. Mothers were informants in the study, rather than subjects of it as their role were to inform me of their experiences.

Gadamer’s approach includes the notions of practical wisdom (phronesis) and intentionality. He conceived understanding and interpretation as a practically orientated mode of insight that has its own rationality irreducible to any simple rules that cannot be taught and which is always orientated to the particular case in hand. This involves adopting a clear focus or intentionality (Gadamer, 1989). Understanding and interpretation are not separate entities but are inextricably linked and indissolubly bound up in each other (Annels, 1996). Since interpretation is therefore an evolving process, and fusions of horizons are always changing (or have the potential to change depending on one’s intentionality), for Gadamer a definitive interpretation is not possible (Gadamer, 1989). Interpretation is impacted upon by the individual and the individual situation and consequently there is always the potential for multiple interpretations and understandings that are influenced by the preunderstandings and intentionality of the interpreter in the situation. Understanding is also bounded by time or historicity and can change over time. Phenomenology is therefore the study of the phenomena, or the appearance of things, that involves interpretation and understanding. In a phenomenological study an attempt is made to understand another person’s subjective experiences and feelings by studying their field of expression. The researcher emphasises the value of describing and interpreting human experiences and attempts to do this credibly and with insight. “The promise of phenomenology was that human beings could be understood from ‘inside’ their subjective experience” (Todres and Holloway, 2006: 224), which could not be adequately explained by any external analysis. They, like Gadamer, reject the quantitative notions of a single truth and suggest that a view from within a person’s perspective is needed for any comprehensive understanding of human behaviour.

Within phenomenology, as explicated by Gadamer, there are a number of concepts that can further enhance an understanding of hermeneutic phenomenology.

3.11 Fusion of horizons and prejudice

Gadamer (1996) uses two terms, fusion of horizons and prejudice, which influence the individual's interpretation and therefore their understanding. Horizons comprise preunderstandings that enable us to make sense of the events or people (Gadamer, 1976). These preunderstandings, like prejudices, are individual, subjective, culturally and historically produced and are not static. In understanding, therefore there is always the continuous possibility of developing new understandings as an individual's horizons change and develop. Gadamer (1996: 270) defines prejudice as "a judgement that is rendered before all the elements that determine a situation have been fully examined". He challenges the negativity associated with prejudice and argues that adequate understanding requires considering both its positive and negative meanings. There is a frequent tendency to focus on unfavourable negative connotations in prejudice, which is viewed often as an unfavourable opinion with a negative meaning. If prejudice is viewed like this, and interpreted as a dichotomy, I am not prejudiced or I am prejudiced, priority is given to negative interpretations and there is a tendency to ignore the existence of multiple and contradictory dimensions of the term. If I, for example, interview mothers and think that their experience is related to only physical care, based on incorrect preunderstandings and prejudice, then I would search only for the physical aspects of caring and see the negative consequences. If I do not see the other aspects important I do not look for them. Gadamer (1996) suggests that there is a need to remain open to these hidden prejudices and that unexamined prejudices may impact on, or limit, the horizon of understanding. According to Gadamer prejudice involves the individual having a limited horizon which results in not seeing far enough, or overvaluing the familiar and known, which results in the individual not seeing, or closing off to what could be known by assuming it is already known. An individual's horizon may be limited by prejudice. However, the horizon is not fixed in an individual who is prepared to reflexively engage with different understandings to develop new horizons and pre-understandings.

Interpretation using Gadamer's approach therefore recognises the potential for understandings to change and increase as prejudices are examined and explored. This requires being open, non judgemental and compassionate, immersion in the process and "becoming phenomenological" (Munhall, 2001: 134). Within this study I intended to look for new understandings of an experience I already knew something about, but needed to be open to new interpretations of this throughout. The horizon, preunderstandings and prejudices that the researcher brings to the research study are therefore influential on the

process of understanding and require reflection. This concept is relevant to using a Gadamerian approach as I believe, like Munhall (2001), that researchers cannot eliminate, or ‘bracket’ their experience, which is inextricably linked to interpretation. Bracketing, or suspending as much as possible of the researcher’s pre existing meanings, understandings, experiences and interpretations, which Husserl would advocate, is not required within Gadamer’s approach. Rather, my preunderstandings, including my interest and clinical experiences are used within the research. Following this, readers too, as interpreters themselves, participate in the process of interpretation by bringing their own horizons to the work. The themes emerging from the text may therefore differ for each reader but, critically, although readers may not share my interpretation, they should be able to follow the pathway that led to the interpretation given (Benner, 1984). Reporting the ‘I’ within the study will help achieve this.

3.12 The hermeneutic circle and reflexivity

Within the Gadamerian tradition interpretation constitutes an inevitable and fundamental structure of ‘our being in the world’ and involves the hermeneutic circle. Interpretation is not an additional procedure in understanding, but each phenomenon is perceived differently by each individual, and in understanding “each brings to bear his, or her, lived experience, specific understandings and historical background” (Finlay and Gough, 2003:107). In this context the hermeneutic circle can be understood as a cycle of fore-understanding, meeting a ‘resistance’ when interrogating experience and the interpretative revision of the fore-understanding. Gadamer (1975) identifies the reflexive part of the hermeneutic circle. He argues that the method of interpretation is to challenge fore-understanding through addressing the ‘thing’ itself (initially accessed through the fore-understanding). The process intrinsically involves a self-critique and an ongoing revelation of individual assumptions - now found to be partial or wrong- built into the fore-understanding. Simply put this means that I “see” things in a different way if I look at them differently and if I choose to look for different interpretations. A circle is complete but never ending. Writing, reading and dialogue are all processes in this hermeneutic circle. Writing and rewriting that is shaped by reading and rereading interview texts is required. With each reading there is a rethinking which may change, reaffirm or enhance the written interpretation. Having once written and reread the interpretation, it can be rewritten again as new interpretations emerge. Writing is not a technical activity but the written word gives voice to interpretations as they are at that time and in that situation. The situation and historicity are relevant. The researcher attempts to identify thoughts as they emerge and to

use language that is common and connecting. The language used needs to evoke thinking. These activities are all interrelated and the report of a hermeneutic research study is consequently not a report of what has been found; rather it is giving voice to the researcher's interpretation. Phenomenology additionally resists grouping responses, categorising or placing responses in stages as would occur in grounded theory. Rather the researcher is interested in the meanings of an experience as it is interpreted by the individual experiencing it. Commonalities of experience may exist or be found, by the focus is not on the structure of the phenomena but in its interpretation.

3.13 The application of hermeneutic phenomenology

Within this study the research design selected is hermeneutic phenomenology as described by Gadamer, influenced by Heidegger. The aim of the method, underpinned by the philosophy of phenomenology, was to uncover hidden phenomena and meanings, by interpreting frequently 'taken for granted' shared practices and common meanings, or what is not immediately manifest in our intuiting, analysing and describing (Omery, 1983). The philosophical insights of Heidegger and Gadamer are that researchers are not successful in suspending their preconceptions or isolating their experiences from the phenomenon under investigation. They believe rather that the researchers should use their preunderstandings positively, making them explicit so that the readers of the research can understand the strengths and limitations of the interpretations provided. My focus was to develop a philosophical understanding, to see what is otherwise concealed. Understanding the mothers' experience was found in the hermeneutic circle. This means that I bring my personal preunderstandings to the text created in the experiences and that these cannot be set aside (Lincoln and Guba, 2000). Consequently, I participate in the interpretation process and making the data. This approach is in contrast to the scientific method, where the researcher passively receives knowledge and is unconnected (or as unconnected as possible) with the object under investigation.

3.14 Flexibility in this approach- The 'I'

In selecting a philosophical approach within research study it is essential that the methodology chosen matches the question asked (Cormack, 1991). In this study the focus was on the mothers' lived experiences and the interpretation of the individual life world and the importance of understanding and interpretation of this. Exposing hidden meanings in the mother' experiences and questioning those things that we take for granted (Jardine, 1990) was important. Moules (2002) suggests that this approach enables the researcher to

peer behind the language into the contextual worlds of words and silence. In this study these were the mothers' experiences. At the outset I wanted to know if the totality of mothers' lived experiences was more than the physical, emotional, financial and social impacts of caring described in the literature. The findings from this qualitative phenomenological study were not expected to provide me, or the reader, with the absolute truths about the phenomenon being explored. It was only intended to provide greater insight into the mothers' experiences of caring for children with complex needs as described by mothers in Ireland at the time, and in the situation in which the data were collected and analysed by a children's nurse.

Finally hermeneutic phenomenology offered a realistic, flexible approach, rather than adopting a Husserlian approach of reductionism. However, I was aware at the outset that there is reluctance on the part of phenomenologists to focus too much on the specific steps in the research method (Hycner, 1999) which offered the flexibility I required. Keen (1975: 41) similarly reports that "unlike other methodologies, phenomenology cannot be reduced to a 'cookbook' set of instructions. It is more like an approach, an attitude, an investigative posture with a certain set of goals." This flexibility was appropriate as I felt that the research method should arise out of trying to be responsive to the phenomenon as it was being investigated. In adopting this approach, therefore, I was offered an opportunity to make sense of the mother's experiences by recognising that the world of the mothers is interpretable and it is my interpretation that exists. Reflexivity is part of the investigative procedure.

3.15 Reflexivity in this approach

Understanding is a dynamic process and we are already within a hermeneutic circle by virtue of already having a history, language and culture (Phillips, 2007). For Gadamer (1989) the key concept of *Bildung*, or openness to meaning, is essential in all human understanding. This involves processes of reflexivity and making visible preunderstandings and presuppositions that impact on interpretation. Within this study a process of reflexivity was used to develop interplay between my preunderstandings, based on my experiences, fore projections and the hermeneutic circle. Using reflexivity requires an awareness of the researcher's contribution to the construction of meanings during the research process and an acknowledgement of the impossibility of remaining outside the subject matter while conducting research. This focuses attention on the conditions (or situatedness) in which understanding always takes place (Phillips, 2007).

Within qualitative research Speziale and Carpenter (2007) identify significant characteristics that are linked to reflexivity including a commitment to acknowledge participation of the researcher in the research process and recognition of the researcher as instrument. It is therefore accepted within this study that all research is conducted with a subjective bias and, furthermore that there is potential for the researcher, through their participation, to add richness to the collection and analysis of data. Munhall (2001) suggests that this requires the researcher to explore the ways in which their involvement with a particular study influences, impacts upon, and informs such research.

3.16 Types of reflexivity

Within the literature there are two types of reflexivity described (Willig, 2001). These are personal reflexivity, which involves reflecting on the ways in which our own values, interests, experiences, beliefs, political commitments, social identities and wider aims in life have shaped the research. It involves thinking about how the research may have affected and possibly changed us, as people and researchers. Epistemological reflexivity, the second type, requires the researcher to engage with questions about the design of the research question, how the research question could have been defined differently and to what extent alternative thinking during the research processes could have resulted in different understandings of the phenomenon being investigated. Willig (2001) suggests that this type of reflexivity encourages researchers to reflect on the assumptions (about the world, about knowledge) that have been made in the course of the research. This helps researchers think about the implications of such assumptions for the research, and its findings.

In this study I am, therefore, unable to avoid bringing my own self into it. All my understandings are based on my fore-understandings and prejudgements, which are part of me. Finlay and Gough (2003: 108) suggest that it is these prejudgements that are both “our closeness and our openness to the world-they are our basis for experiencing.” While we may attempt to identify, explicate or ‘bracket’ our perceptions and understandings from the phenomenon studied, this is not possible using hermeneutic phenomenology. We need to recognise that our “interpretations and the ongoing revelation of the thing under scrutiny are one and the same” (Finlay and Gough, 2003: 108). They further suggest that, by virtue of description and the use of language, once we experience a thing as something, it has already been interpreted through our own words and language. In Heidegger’s and Gadamer’s view ‘being-in-the-world’ involves interpretation.

Given the way in which my perceptions are necessarily entangled in interpretation, the intrinsic role I played as researcher must be acknowledged. Within the study I have attempted to make myself transparent to ensure an understanding of ‘otherness’ and to make clear facets of ‘I’ that influenced my interpretation using both personal and epistemological reflexivity. This flexible process involved an examination of past preunderstandings to enable new understandings to emerge “from a complex dialectic between knower and known, between the researcher’s past understandings and the present research process, between the self-interpreted and the present research process, between the self-interpreted constructions of both participant and researcher. Between and beyond” (Finlay and Gough, 2003: 108).

In order to explicate my beliefs, ideas, thoughts and presuppositions, I have provided an outline of these at the outset, and include others during the study in data analysis and at its completion. The function of this activity was to bring to consciousness my beliefs to make me more aware of the potential judgements that may occur during the study. It will also make me visible to the reader. I have used a number of strategies to demonstrate reflexivity including keeping a research journal in which my notes, feelings and emerging issues were recorded. Before each interview I used pre-reflective preparation, where time was set aside to heighten my awareness of specific issues, and reflect on situations, and methodological progression. A research diary was kept in which records were recorded of meetings, negotiations, discussions, issues that emerged from my clinical practice and ongoing discussions that impacted on my thinking and decision making. Reflexivity involved openness and honesty when undertaking and completing the work, when reporting and considering the difficulties encountered in the research process, the ongoing decision-making and in acknowledging the limitations of the research.

Lewis (2000) argues that the self-reflexivity process is not the achievement of introspection. It is not an isolated, private contemplation process, but involves processes of vibrant tension between oneself as a subject and an object. During the study reflexivity was enhanced by the use of external support and advice from an academic supervisor. Advice was sought from others on the research methods used and interpretations of the data. This helped with developing openness to and awareness of, other points of view and created opportunities for clarifying interpretations. It helped to challenge me to identify and acknowledge my own taken for granted values and their impact on the interpretation of the data.

3.17 The 'I' - an exemplar of existing presuppositions and prejudices

At the outset (2002) my views of mothers' experiences of caring for children with complex needs include the following:-

Mothers will cope if they have family support. My clinical experience and decision making up to this point has been influenced by judgements I make on the mother's ability to cope with her child on discharge from hospital. I presume that good family support helps mothers adjust to the daily demands of caring. I presume family support is available and that families rally round to help mothers in the transition to caring for a child with complex needs.

The following is an exemplar of reflexivity and developments in my thinking over time

In 2006 (July 24) I recorded the following:-

Mothers do not always have family support. Others are 'scared' to help and initial high levels of support, if ever present, dissipate as the situation continues. Payback is sought if help is given by others. Family support is not always there for mothers. Families and friends do not always rally round to help mothers and the reaction can be impacted upon the mothers' response to help offered. The "big house, big car" view from those in the outside world impacts on how others see the family. The giving of care by others from the outside world is an issue. Respite care impacts on the mother causing practical and emotional problems, and concerns.

In 2007 (January) I recorded developments as new horizons emerged:-

The world of the mother is a complex one, which involves constant care in three worlds. Not only does this place physical demands on the mother but other roles in care-giving are evident. There is a no choice situation. Finding respite care causes mothers dilemmas; doing by self is easier. Reactions to and from others impact on the mother's experience of caring.

It can be seen from these exemplars that journeying has taken place between the start of the study and the analysis of data. It is evident that some of my preunderstandings have changed and developed. Initial understandings have changed and I no longer see family support as present in these mothers' lives. The reactions from family members and carers include a "scared reaction" to the child, maybe due to the complex nature of their demands for care, which has an isolating effect. I understand better the mother's care-giving roles and the difficulties faced on care-giving in three worlds. This example (from many) demonstrates the differing views I have of the mothers' worlds as I come to understand, in a different way, the mothers' experiences of caring.

3.18 Final comments - The 'I'

In using phenomenology I have confronted a complex range of issues that were particularly challenging. My decision to use an eclectic approach was the result of a realisation that neither one nor another of the many approaches in them was appropriate. Using hermeneutic phenomenology as a methodology and achieving reflexivity was not a straightforward endeavour. It required me to operate on multiple levels at times simultaneously using description, interpretation and analysis. I found it reassuring as it offered a flexible and changing paradigm and an orientation rather than a fixed position. Fluidity in the emerging data, returning to it time and time again during the process of gaining understanding through a process of reflection did not sit comfortably at times as I felt that analysis was never complete. Every day potentially offered a different interpretation. Acknowledging the researcher involvement has been difficult to describe in full. This personal self awareness and an awareness of the relationship between myself, the researched and the research environment (Mason, 2002), and self inspection entailed within it, has caused me tension throughout.

3.19 Conclusion

Within this chapter I have outlined my choice of hermeneutic phenomenology as a theoretical framework. The historical background to phenomenology has been described and a discussion on hermeneutic phenomenology has been provided. The importance of preunderstandings, prejudice, fusion of horizons and the hermeneutic circle have been outlined. Given the importance of these concepts and reflexivity to an understanding of hermeneutic phenomenology, my presuppositions and the nature of their ongoing changing development have been reported. In the following chapter research design and data collection methods are discussed.

CHAPTER 4 - RESEARCH DESIGN AND DATA COLLECTION

4.1 Introduction

Within this chapter the study design and methodological issues will be discussed. The research aim, design, the evolving nature of the research question, researcher intention, recruitment and methods of data collection will be reported.

The phenomenon of mothers' experiences of caring for children with complex needs was explored using a hermeneutic, phenomenological approach focussed on understanding. The objectives focussed on uncovering the meanings of this experience are described to provide rich, in-depth descriptive and interpretive information to provide a greater understanding. Interviews and diaries were used to collect the data.

4.2 The sample

In undertaking this study I decided to focus on mothers' experiences only. It is recognised that many children are brought up in households with two parents but mothers are the main carers for children of sick children and those with chronic needs and undertake most of the caring activities which has impacts on them (Hassiotis, 1997; Heller, Hsieh and Rowitz, 1997; Seligman and Darling, 1997; Porter and McKenzie, 2000). At the outset I explored my decision with professional colleagues, experts in sociology, psychology and in family support groups. The gate-keepers, and colleagues experienced in community children's nursing, also reported that, in their experience, that for many of the children receiving health care at home, mothers are either lone parents, or the mother is involved as the main carer, who takes most of the decisions about the child. At this stage I gained ethical approval from Trinity College, Dublin (TCD) to undertake the study on mother's experiences only.

4.3 Recruitment strategy

Following approval, a recruitment strategy was implemented to identify mothers for the study. In order to obtain a sample from across Ireland three organisations/service providers from NI and three from the RoI were identified as gate-keepers, that provided support and care services for mothers of children with complex needs. In NI one organisation initially agreed to support the study but following further discussion this support was withdrawn and this site was not used. The organisation provided names of other potential gate-keepers in NI statutory services who were subsequently contacted. However, it emerged from

discussion that each service provider/Trust required individual ethical approval and these mechanisms were undergoing procedural changes that had not been fully implemented at the time. This posed unacceptable significant delays, and access via these organisations was excluded. The final recruitment strategy involved contact with four specific voluntary organisations in NI and the RoI that provided care, funding and information to families of children with complex needs and disabilities. These organisations required no further ethical approval other than that from TCD.

Negotiating access to mothers through four organisations was implemented. This process commenced with an informal telephone call to key personnel in each organisation in which the study was outlined and possible recruitment processes discussed. One organisation withdrew at this stage. An introductory letter outlining the study was sent to the remaining three organisations, and follow-up meetings were arranged. At these, details of the proposed study were presented, ethical approval discussed and questions about it answered. Following these meetings I decided to use the three services for recruitment. In one organisation subsequent meetings were arranged at their facility with those who would be involved and initial support was confirmed. A further meeting was arranged at which the inclusion criteria, potential participants and the method of recruitment were agreed. The service manager agreed to personally approach mothers to inform them of the study, after which individual mothers would contact me if they wished to become involved. Four weeks later the manager indicated that no mothers wanted to participate. This included a member of staff, herself a mother who met the inclusion criteria but would not be involved because of her role. This organisation was thanked for their potential help and not involved further.

A second meeting was arranged with staff in the two remaining organisations (which included nurses) at which a final presentation was made about the study and inclusion and exclusion criteria were confirmed. Ethical approval was clarified and it was confirmed that TCD ethical approval satisfied their Board of Management/governing body. Each organisation was assured about indemnity and safe practices in research. Before recruitment commenced further meetings were arranged for clarification of outstanding issues. The ACT&RCPCH (1997) framework and diagnostic groupings that met the inclusion criteria were discussed but no specific diagnostic or age grouping was sought and this was confirmed. The term 'complex needs' was agreed for use in the inclusion criteria and recruitment literature thereafter. It was agreed that each organisation would contact 30 mothers. The duration of the mothers' experiences was not stipulated but it was envisaged that this would be at least six months.

The two organisations subsequently accessed their information databases to identify mothers who met the inclusion criteria. Information packs containing details of the study were sent to each organisation. These were then distributed by post to 30 mothers known to them. Mothers' personal details were known to the organisations and I had no access to these at any stage until the mothers contacted me. The two organisations were asked to keep a temporary record of those who had been contacted. Each organisation sent a follow up reminder letter four weeks later to those who had not replied. At this stage they would have known who had been invited to participate but did not know who had agreed, not replied or declined the offer to become involved or who withdrew from the study. No further follow up was undertaken. After this stage anonymity was maintained and I did not make either organisation aware of the mothers who agreed to be in the study. The coded lists set up by the organisations of potential participants were subsequently destroyed. In recruiting sixty potential participants it was intended that 20-25% response would be achieved. As a final recruitment strategy snowballing was also used when participating mothers were asked to refer any others who would be interested in involvement. The technique can be used when no sampling frame exists and it cannot be created. No mothers were recruited this way.

4.4 The mothers recruited

I needed to recruit mothers whose children had complex needs, but without a specific data base or clear terminology this was problematic. The population was mothers of children known to services providing care, support, information or respite to children with life-limiting conditions and complex needs. Recruitment was conducted across the RoI and NI as I presumed that the experiences recorded would be richer in this mix. In doing so it was recognised that service provision differs but the aim was not to investigate services but to explore the experiences of mothers. I decided to include mothers from both rural and urban environments, as the Regional children's hospitals are centred in Belfast and Dublin, which may impact on the mother's use of services. The organisations selected as gate-keepers provided services on a regional basis and it was appropriate to use these in recruitment.

4.5 The responses

Of the sixty mothers invited to participate, twenty returned reply slips in the stamped envelopes provided indicating their interest in the study. One mother indicated that, in her view, her child did not have complex needs and was not interested in contributing. One

mother indicated that she did not have a child with complex needs. Ten mothers returned replies indicating no interest in the study. Thirty mothers did not reply.

Table 4.1 Responses

| Organisation | Letters sent out | Responses | | | Withdrawn after recruitment | Final |
|-----------------------|------------------|------------|----------------|----------|-----------------------------|-----------|
| | | Interested | Not Interested | No reply | | |
| A | 30 | 11 | 6 | 13 | 1 | 10 |
| B | 30 | 9 | 4 | 17 | 2 | 7 |
| Total in study | | | | | | 17 |

4.6 Subsequent processes

After receiving written replies I telephoned each mother. During this contact I ensured that the child/ren had complex needs and met the inclusion criteria. I answered any questions and attempted to allay any anxieties or concerns expressed about the study, the methods of data collection and confidentiality. Twenty mothers who verbally agreed to proceed were sent information and consent forms to sign and return.

Of the twenty mothers who gave written consent, two mothers who initially agreed to participate dropped out, one before the first interview and the second after agreeing a convenient interview date. This mother did not respond to my arrival for the prearranged first interview at her home. She subsequently telephoned to explain her difficult circumstances and withdrew at this stage. A second mother who needed to defer the interviews for some months withdrew due to family illness and the pressure of caring.

4.7 The respondents

Data were collected from 17 mothers of at least one child with complex needs thus providing a depth of experience. Mothers came from rural and urban locations and received varying levels of support, and service provision. Fifteen mothers were interviewed on three occasions; one mother agreed to be interviewed only twice and one mother was available for only one interview because her children's conditions had deteriorated significantly. I felt it was unethical, unnecessary, inappropriate and intrusive to pursue further contact with this mother for research purposes. Forty-eight interviews were completed and eleven mothers submitted diary recordings.

4.8 The children

The children had conditions that clearly fit definitions of life-limiting conditions and included children with no diagnosis. The children underwent a range of treatments, interventions and periods of deterioration during data collection that impacted on the interviews. They were aged from under 1 to 19 years.

4.9 Challenges in recruitment

It was important to access those who had experience of caring for their child at home and from whom the nature of the experience could be elicited. From the outset, accessing mothers was problematic. The most appropriate way to access mothers was through gate-keepers. In agreeing to contribute gate-keepers are likely to have concerns before agreeing to involvement in research. These include issues about the value of the research, its political sensitivity, the time and resources needed and the reputation of the researcher and organisation (Lincoln and Guba, 1985; McCracken, 1988). I was also conscious that the organisations would have concerns about confidentiality, their reputation and trust. Staff in one organisation alerted me to their previous experiences of research in which they had felt poorly treated. This increased my need to demonstrate confidence and credibility in my work.

There were challenges in establishing inclusion criteria. I was conscious of the sensitivity of the study and knew that finding a sample, given the complexity of terminology used to identify these children, was an issue (Nicholl, 2006). I invested time in deciding how to exclude specific groups of children, including those with progressive diseases, for example, cystic fibrosis, or potentially treatable ones, including cancer. I wanted to include children of all ages with complex needs, not necessarily those with a specific medical diagnosis. I did not want to include only mothers who had specific experiences of specific hospitals but also those who had a range of service provision, or none, which excluded recruitment via hospitals. I wanted to include mothers who were remotely located from regional centres. The study includes the mother of a child aged 19 and another whose child's needs were non physical, except when injured, as they were in receipt of children's services and had complex needs as defined by their mothers. These may, in other studies, be negative cases but for me they added to the realities of the complexity of defining a specific group of children and in undertaking research in children's nursing. I felt this variation would add to the study, given that many of these children have rare disorders who do not lend themselves to large studies of diagnostic groups. Older children also continue to receive children's services into early adulthood.

4.10 Challenges in sample size

Qualitative research uses samples that focus on providing information-rich cases rather than a specific number of people *per se* (Sandelowski, 1995a). Qualitative studies are usually based on small samples and sampling techniques range from convenience, purposive, theoretical and snowballing. In qualitative research there are no clear published guidelines on the sample size required to achieve saturation and recommendations include between thirty five and fifty interviews (Morse, 1994) or a minimum of twenty five (Sandelowski, 1995b). Oberle (2002) suggests a less prescriptive approach and indicates that a sample size cannot be specified before the study begins and is reached at a point when no new concepts, themes or discursive constructions emerge from the analysis. The representativeness in qualitative research, Sandelowski (1986) indicates, is in the data and not in the sampling unit. Oberle (2002) further suggests that samples will often not be inclusive, and this lack of inclusiveness should not be taken as detracting from the value of the research, especially as generalisability of the findings is not a concern within the qualitative tradition.

Dilemmas in determining an appropriate sample size emerged. The sample size was not initially determined but it was envisaged that including between fifteen and thirty mothers would provide a depth of data. Using this flexible approach and purposive sampling helped and mothers were recruited on the basis of their experience of caring for a child with complex needs and the aim was to investigate information-rich sources. At this stage I was influenced by Mason's (2002; 27) approach to "sampling as an organic practice" that would develop as data were collected and findings emerged. I used mechanisms to review my sampling size throughout and to make informed decisions about further data collection. These included discussion about recruitment, peer review of data and discussion of commonly emerging themes. I maintained records of all decisions and tracked emerging themes, identified when commonalities were emerging and when data were becoming repetitive. This occurred when I had interviewed twelve mothers. I wanted, and needed to stop data collecting before I was going into homes to hear what I wanted to hear, thus potentially influencing the interview situation. In selecting a sample size pragmatic issues related to the volume of data collected and the time constraints on data collection. These issues will be further discussed in the limitations to the study.

4.11 Challenges and the changing nature of the enquiry

Current challenges in qualitative research include the ability of researchers to discover truths or to represent the realities of another. I have implemented a qualitative study that was strategically conducted while simultaneously enabling flexible, contextual decisions to be taken on the basis not only of research techniques, but also on sensitivity to the changing contexts and situations. To demonstrate this flexibility I have included an example of how the focus of enquiry shifted as mothers provided insights into their world and how the research questions developed during the study. At the outset I wanted to know more of the mothers' experiences that were reported in the literature and I wanted to understand the finer details of this and to explore this further in an Irish context. Using a flexible approach enabled me to adapt the focus of enquiry as data emerged. This necessitated that the research questions were influenced by the changing context and the emerging data. In Table 4.2 I have outlined the range and development of questions that were asked at stages during the study to provide an example of how the focus of enquiry developed as I came to understand aspects of the mothers' experiences better.

Table 4.2

Questions asked at stages during the study

| | |
|--------------------------------------|--|
| <p>At the start 2002</p> | <p>I asked a broad question:</p> <ul style="list-style-type: none"> • What is the mother's experience of caring for a child with complex needs really like? |
| <p>2004-2006 Data Collection</p> | <ul style="list-style-type: none"> • What is the experience of being a mother caring for a child with complex needs? • How do mothers describe and explain their experience? • What are the realities and consequences of this situation? • What can I learn from hearing these experiences reported? • Is the experience similar or dissimilar to other mothers in similar situations? • In what ways? |
| | <p>Evolving questions asked during the interviews:</p> <ul style="list-style-type: none"> • What is the experience really like to care for a child with complex needs at home? • What is the mother's experience of this situation? • What are the key issues emerging? |
| <p>2004-2007 Data Analysis</p> | <ul style="list-style-type: none"> • What are the key emerging issues in the nature of caring for a child with complex needs? • What the essences of the experiences are as reported? • Are there similarities / differences being reported? • What has been unconcealed about the experience? |
| <p>2006-08 Study reporting</p> | <p>Following analysis the following questions were posed:</p> <ul style="list-style-type: none"> • What are the key elements of the mothers' experiences of caring? • Are all the elements reported? • Are the messages from mothers' experiences as they have reported them exposed? • Is my understanding of the mothers' experiences different to my understanding at the onset of the study? • Are the experiences of the mothers similar to those reported by other mothers in different contexts and times? • What have I learned from the study? • What can others learn from the study? |
| <p>Nearing the end (2007)</p> | <ul style="list-style-type: none"> • What are the key elements of the mothers' experiences of caring? • Are all the essences, elements and dimensions reported? • Are the messages from mothers' experiences as they have reported them exposed? • How do these experiences link to findings from literature? • Where are the similarities or differences? • Does my understanding of the mothers' experiences different to my understanding at the outset of the study and if so, how? |

4.12 Methods of data collection

Within this section the methods of data collection will be discussed.

4.12.1 Data collection - interviews

In undertaking research investigators need to adopt the most appropriate research methodology for the subject that they wish to investigate and openness is critical (Koch, 1996). To understand the mothers' experiences I needed to use data generation methods consistent with a phenomenological approach and the underpinning epistemological and ontological position. Unstructured in-depth interviewing was appropriate to my ontological position, which "suggests that people's knowledge, view, understandings, interpretations, experiences, and interactions are meaningful properties of the social reality" (Mason, 2002: 63). The social reality that I planned to explore was mothers' experiences of caring. Interviews enabled me to develop a conversational relationship with the mother in which we could explore the meaning of an experience (Van Manen, 1990).

4.12.2 Interviews: a discussion

Within qualitative approaches there are a number of methods of data collection including in-depth interviews, often involving tape recording. There are variations in style and tradition, and qualitative or semi-structured interviewing is referred to synonymously (Mason 2002). In phenomenological studies, the process of collecting information involves primarily the in-depth interview, which is an interactive dialogue in which silence, listening and comfort play a part (Munhall, 2001). Interviewing clearly fits with the hermeneutic phenomenological approach that studies the subjects' perspectives on their world and attempts to "describe in detail the content and structure of the subject's consciousness, to grasp the qualitative diversity of their experiences and to explicate their essential meanings" (Kvale, 1996: 53). My role was not to put things into someone's mind (for example, my preconceived categories for organising the world; my preunderstandings) but to access the perspective of the person being interviewed and to explore the context of the participant's life-world (Munhall, 2001). Using interviews was also based on my epistemological position. Mothers' experiences could only be constructed or reconstructed in interviews and this fitted with my view of "knowledge as situational and evidence as contextual, situational and interactional" (Mason, 2002: 64). Interviews offered a meaningful opportunity to generate data by talking interactively with mothers and to listen and ask questions to gain access to their experiences in a discourse (Mason, 2002). Dialogue was essential to find out about the mothers' experiences and to understand their

context. The interview could not be separated from the social interaction in which it was produced in the mother's homes and that it was inappropriate to see social interaction as 'bias,' which potentially can be eradicated, or a situation in which variables could be controlled.

My role in data collection was that of a research tool and I needed to develop a relationship in which data were created. I needed to acknowledge the relationship between the philosophical tradition of phenomenology and method. Munhall (2001) suggests that this distinction is clearly seen in the reflective relationship between the researcher and the participant in phenomenological research where they come together to attempt to understand meaning in the experience being explored. Interviewing enabled me to be the instrument and participant and this acknowledges that I am an important component in the research process.

4.12.3 Unstructured in-depth interviews

I was clearly interested in exploring and understanding the mothers' experiences in context, wherever or whatever that context was and to use myself as the data collector was appropriate. It was appropriate to use in-depth interviews that are repeated face to face encounters that are directed toward understanding informants' perspectives on their lives, experiences or situations as expressed in their own words (Taylor and Bogdan, 1988). This interaction is modelled after a conversation rather than a formal question and answer exchange that involves a non-directive, unstructured, non-standardised and open-ended approach. In-depth interviewing allowed me to enter the mothers' life world, to understand their view of their world, and the context and content of their experiences. In interviews I created opportunities for mothers to talk candidly and comfortably, and to share their experiences with me. I was genuinely interested in what they had to say and I was concerned that they understood I would respect this data. I felt certain that, once they had been recruited, mothers would talk to me. I felt that my background helped demonstrate confidence during data collection. McCracken (1988) identifies the long interview as one of the most powerful tools of qualitative enquiry and suggests that this method enables the capture of data needed for penetrating qualitative analysis. The duration of an interview can vary and some suggest that it should last no longer than two hours as it may be difficult to maintain participants' interest for longer than this. Berg (2004), however, maintains that participants' interest is dependent on how interesting and exciting they find the interview. Others do not distinguish differences between the in-depth, the long interview or the qualitative interview. Maykut and Morehouse (1994) suggest that qualitative interviews

take between one and a half and two hours, which allows for prolonged engagement to occur. This also enables the interviewer, if they are competent, to create a rapport and to promote a climate of trust while also allowing for the tiredness that concentrated effort causes.

4.12.4 Interview approaches considered

In deciding to interview models of structured interviewing were considered. It was feasible to use the first interview to obtain demographic data, a “medical type” history and personal information about the child’s needs and progress. I considered focussing in the second and third interview on specific issues that impact on mothers; for example, the physical impact of caring. This structured approach, however, offered my pre-constructed perspective and was contrary to the phenomenological approach. Asking a same series of pre-established questions did not fit with my focus of enquiry and using questions that were based on a pre-decided coding scheme and controlling the interview was inappropriate and offered my predetermined perceptions of the mothers’ experiences. This type of data could have been gathered by quantitative means using a questionnaire, for example, in measuring mother’s depression, or coping scales. Given that a phenomenological approach was adopted, I considered that the interviews should have an open focus with each mother being enabled to tell her story, as she construed it, and not as I perceived it. The choice was made to follow the path of unstructured interviews of an unspecified duration that would facilitate the collection of a greater depth of data.

4.12.5 Using multiple interviews

Within this study each mother was interviewed on three occasions. This initially may have appeared to be intrusive, onerous and time consuming for an already potentially busy mother. This approach was based on the literature on the development of relationships and trust. In order to gain information about the personal experience of caring for their child it was recognised that some mothers may initially be hesitant about the researcher and the research despite volunteering to contribute. Counselling literature indicates that descriptions of experiences occur in early stages of a relationship and greater exploration occurs only when the relationship is developed and trust attained (Nelson-Jones, 2002). Using three interviews enabled me to develop increasing rapport and familiarity with the mother, demonstrate competence, knowledge and credibility and thus increase trust in the relationship. Maykut and Morehouse (1994) report that where multiple interviews are used the resulting persistent involvement makes it more likely that a deeper understanding of the

phenomenon will be developed. Using multiple interviews enabled me to pursue emerging issues in subsequent interviews. I was able to develop an in-depth exploration of the mothers' experiences which would not be possible in a single unstructured interview, no matter what its duration. Munhall (2001) suggests that two to three interviews with the same person may be helpful as this approach means that respondents can reflect on the issues between interviews, and therefore the material that is forthcoming in the second or third interview is a more detailed interpretation of what was said previously. This was evident in this study as mothers recalled previous interviews, or indicated that they had been thinking about what we talked about last time. Using this approach, however, has the potential to lead to tensions in relationships when the research is completed, due to some respondents being unwilling to relinquish the relationship that had developed. This was also difficult for me as relationships were formed, that were deep and meaningful.

Using multiple unstructured interviews was appropriate and their duration was restricted by the mother's availability and willingness to engage further on each occasion. Interviewing multiple informants was viewed as useful in providing depth and variation in the nature of the phenomenon of caring for a child with complex needs. In the first interview, each mother was asked to tell her story so far that provided valuable contextual information to their current situation, thus setting the scene for further exploration. It was recognised that exploring this background may be less threatening for the mother than commencing the first interview by attempting to explore potentially very sensitive issues in a limited time frame with an unknown researcher. In the second and third interviews the mothers' experiences were focussed on in greater depth. In the third interview each mother was given the opportunity to discuss other issues not outlined previously. Ongoing analysis impacted on the interview in that the later interviews were modified and linked with previously related material to explore it further. To this extent it may be argued that the subsequent interviews were structured. This, however, was only to the extent that some issues that had emerged previously were further discussed.

Each recorded interview lasted between 45 minutes and one hour on average, though the actual time spent in the home varied depending on the mothers' availability. All interviews were similarly recorded, apart from part of one in which the mother was extremely hesitant about this. In this situation interview notes were taken and the last part of the interview was recorded with the mother's consent. Notes from all visits were recorded. Unstructured interviewing seemed to fit well with mothers, though I was asked by one mother if what she was talking about was relevant and another asked "is what you want?" The mothers appeared to need (or were used to) a structured approach, perhaps due to their previous

experiences with health care interviews that are often very focussed on getting information in a short period of time.

4.12.6 Planning the interviews

It was recognised that planning was required before the interviews were carried out.

The main issues that were considered related to scheduling the interviews, the setting, interviewing skills and relationship development. These were viewed as crucial to successful interviewing.

Interviews were carried out at a prearranged convenient time in each mother's home or an agreed venue. They were scheduled to suit mothers for whom care needs were their priority (Nicholl, 2007) and were organised around mothers' availability. Interviews were completed at all times during the day into the very late evening. All interviews were confirmed by telephone one week beforehand. On the day before each interview, arrangements were normally confirmed by telephone if requested. If this date was then unsuitable, another arrangement was made. Most interviews were planned at least a week in advance, though some took place at short notice depending on the mothers' availability. Sometimes final arrangements were confirmed on the morning of the interview if the child was unwell. Subsequent interview arrangements followed a similar pattern. Interviews with 16 of the participants were conducted in each mother's home, as this was the most convenient place. One mother was interviewed outside the family home.

4.12.7 The interview setting

The setting was important as preparation for uninterrupted interviewing was needed. It was initially envisaged that the interview environment would be quiet, private, comfortable and not intimidating (Oppenheim, 1992) and anything that might upset or disturb the mother, within my control, was to be avoided. It was intended to do what was possible to ensure confidentiality, a lack of interruptions and to find free time for uninterrupted discussion. The setting was sometimes constrained by events and circumstances without the mothers' control. In most interviews, steps had been taken to avoid or reduce distractions for the interview, as mothers had been advised to enable them, if possible, to give uninterrupted focussed attention to the interview without having to provide care. If the setting was other than the mother's home, over which I had no control, I suggested that this should also be suitable. The one mother who was interviewed outside her home complied with this.

Where family members were present in the house it was hoped that they might be asked not to be present during the interviews; this was managed with each mother. I attempted to

do everything in my control to create a relaxed atmosphere for the interviews. Wengraf (2001) theoretically suggests that the setting should be free from interruptions by telephones, outside noise or from other people as this can interfere with the recording. However, many interviews were unavoidably interrupted.

Ideal interview situations were not always achieved though mothers mostly tried to arrange times when other family members were absent. For the most part, the interviews took place in the family kitchen, or lounge, during the day but some interviews were undertaken late at night, or during weekends. During most interviews the child (or children) was usually present, or returned home from school during them, which often interrupted the situation. Mothers seemed keen that I met the children and their siblings during the interviews. Unavoidable distractions occurred in all interviews with mothers frequently having to provide care simultaneously. Mothers were generally caring, cuddling and talking at the same time, or carrying out other tasks, including PEG feeding and caring for siblings. On occasions, children required active seizure management during the interviews due to their instability. This provided the 'real' context for exploring mothers' experiences and I had to interview around difficult and emergency situations, as well as facilitate care-giving and normal family activities, during them. Understandably, interviews were suddenly terminated on occasions, and many times the recording was paused and continued later depending on the interruption and situation. The constancy of caring and observation was evident, and multi-tasking was very obvious. Fathers, adult family members, siblings, friends and carers were occasionally present in the home and they were asked sometimes, but not always, by the mother to leave. The interviews were interrupted by telephone calls, other family members or health professionals visiting. In one interview two elder siblings had been invited by the mother to meet me and they stayed during the interview and contributed to it; in others the father and grandfather were present. Siblings, if not at school, were sometimes around the house, often displaying much interest in who their mother was talking to. To placate siblings, sometimes they were recorded singing and playback was given which was fun for them and seemed to help ease their concerns. These recordings were destroyed. However, despite these problematic situations everything was done to create an unhurried, comfortable and relaxed atmosphere. Tea and biscuits were commonly provided by each mother. Mothers often displayed non-verbal cues indicating a need to conclude the interview as they had to get on with care-giving routines.

4.12.8 Interviewing - The researcher as tool

Interpersonal skills used were seen as crucial to successful interviewing. Oppenheim (1992:69), however, indicates that “formal training or academic qualifications in one of the social sciences are no guarantees of competence in this field”. This is supported by current evidence in communication in health care where Brown, Crawford and Carter (2006) suggests that interactions with health and social care professionals have left many service users feeling “oppressed and humiliated, rather than cared for” (107). Within the interview, I was able to use a range of interpersonal, counselling and social skills to ensure success and to ensure that the mothers were not damaged by the experience and interaction. I demonstrated a real interest in the situation and in what was being said, using a range of skills including those needed in palliative care, sensitive counselling and qualitative interviewing (Munhall, 2001; Mason, 2002; Nelson-Jones, 2002; Brown, Crawford and Carter, 2006). The verbal and non-verbal skills used in beginning, continuing and ending the interviews included giving attention to space, adopting an open posture and using appropriate eye contact and appearing relaxed (Perry and Burgess, 2002; Sully and Dallas, 2005). A non-judgemental attitude was displayed, and listening skills employed carefully. It was important to establish a relationship of substance and a relationship with the mothers to ensure that their experiences were explored, and not just described. I used skills to develop the interview to promote discussion of the experiences of each mother and their meaning including open questioning, verbal prompts and reinforcement to encourage the mother to go on talking and to encourage the development of depth in the interviews. Skills used appropriately included reflection, double attending, mirroring, pause and silence. I gave mothers time to think through their answers and I avoided interruptions during silences when I used non-verbal skills to indicate attentiveness (Wengraf, 2001). This was particularly important when sensitive issues were being reported. At times strong emotions were exhibited, including anger and sadness, and I used interpersonal skills to manage these situations. Some mothers became visibly upset and cried. Empathy demonstrated an understanding of the mother’s emotions and I tried not to “rush in” or move the conversation on by asking another question. I provided verbal support and reassurance using non-judgemental statements, for example “this seems difficult for you”.

One of the most problematic issues, both in accessing a sample and in interviewing, was the use of appropriate language and terminology. It was important that I was seen as credible during the interviews and I felt that this was checked out by mothers, when they could not pronounce drugs or medical procedures, for example “you know what I mean

don't you?" I adopted non-medical language unless the mother used this in the interview (Nicholl, 2007). Mothers' expertise in medical jargon was evident throughout. Fontana and Frey (2003: 64) suggest that the interview cannot become so technical and the procedures so standardised that interviewers can ignore these contextual elements. To do so would have been inappropriate in this study. I also learned about cultural interpretations of language as mothers reported "there's not a bother on him", a common Dublin colloquialism, and the difference between "going down to Dublin" and "down the country".

4.12.9 Developing the researcher – researched relationship

In phenomenological approaches the nature of the researcher/ respondent relationship that is developed is important. In phenomenology close involvement between both is expected and trust is essential to the relationship (Fontana and Frey, 2000). The interview requires that a complex relationship develops. McCracken (1988: 25) suggests that "this semiotic exercise can dramatically influence whether and how the respondent responds to the questions they are asked". Massarick (1981) suggests that in the phenomenological interview, the relationship is one where the "interviewer and the interviewee become caring companions, mutually committed to the enhancement of understanding, their respective humanities richly and actively revealed" (205). The meaning of the mother's experiences was the result of a co-creation between each mother and me, in which I attempted to understand better their experiences without forcing any prior categorization on the data that might restrict the area of research (Fontana and Frey, 2003). In developing this relationship one issue relates to the respondent's understanding of the research role and who does the respondent think the researcher is? Denzin (1978) suggests that the respondents judge the institutional affiliation of the investigator, the project description, and even his/her appearance, mode of dress and patterns of speech. If these cues are not carefully controlled by the researcher in the interview, they will confound the nature of the respondent's participation and the data provided (Stebbins, 1972). I tried to strike a balance between formality and informality and adopted informality in manner, demeanour and speech, which I thought would help the mothers cast me in the role of an interested nurse researcher, which is someone who could ask very personal questions, not out of a personal but a professional interest in them and their experiences.

This posed challenges in the use of language and in professional role conflict throughout the interviews (Nicholl, 2007). By doing this I intended to assure mothers that I could be trusted to maintain confidentiality while still demonstrating a need to understand their

experiences. I adopted a relatively informal, yet professional approach to assure the mothers that I was not a distant creature unacquainted with, or indifferent to, the complexities and difficulties of her life situation (McCracken, 1988).

Throughout all contacts with mothers I presented a genuine interest and friendly, yet professional manner. My professional background was explained at the outset, both in written information and at the start of the first interview, providing credibility that appeared to increase mothers' cooperation throughout. McCracken (1988) suggests making the respondent a kind of collaborator has the merit in encouraging fuller disclosure. I attempted to develop mothers' understanding of my relationship as researcher and nurse. Initially, I think mothers viewed me as an academic researcher and had some concerns about this which were noticeable in the initial telephone conversations and first meetings. I had a sense that they held research in either awe, or as irrelevant to them. Others were interested in getting their story told it seemed, and used me as the mechanism of doing so. My impressions were that once they had met me, mothers viewed me as a nurse with a research interest who could help get their experiences better understood by health professionals.

Good qualitative interviewing is hard creative work (Holstein and Gubrium, 1995) and undertaking the interviews was complex and exhausting. A skilled flexible approach was adopted in the interviews to ensure that the focus was maintained on each mothers' perspective.

4.13 Data collection timeframe

Data were collected between January 2005 and July 2006. Interviews took place over approximately three months, though on occasions the interval between the first and final interview was over 12 months. Diaries were normally completed in the same timeframe. A research diary and notes were maintained from the outset until 2008.

4.14 Diaries as a data collection tool

The second method of data collection was self-report diaries completed by the mothers on three occasions. Diaries have been considered as documents of importance in historical research and are often used for data collection (Corti, 1993). However, they have been relatively neglected in sociological and applied qualitative research (Elliott, 1997). In nursing the use of diaries is becoming increasingly common as data collection tools. Odenrats, Ehnfors and Grobe (2005) used them to investigate patients living with chronic obstructive pulmonary disease. Butz (2004) suggests that there is a growing interest in

recording aspects of health in health diaries such as chronic pain, or symptoms of chronic illnesses. Diaries have been used in studies of wheeze symptoms, medications adherence and parents' post-surgical experiences of children's care (Hughes and Callery, 2004). Butz indicates that the ongoing interest in diaries for data collection is due primarily to their use in reducing the recall bias of health events that is associated with questionnaires.

The use of diaries to create data is consistent with hermeneutic philosophy. Diaries offered a way to comprehend, perceive and know what the experience of mothers was like at episodic intervals between the interviews; to describe experiences without my influence, and they facilitated access to very personal information that may not emerge in face-to-face interviews. They added another dimension to the data to identify, clarify and contextualise the mothers' personal recollections without the problems of retrospective reporting, that can easily be coloured by the respondents' present circumstances, retrospective interpretation of events or simply forgetting of details. Willig (2001:28) suggests that, when used successfully, diaries provide information that is otherwise very hard to obtain and the data generated are "temporarily ordered; that is, they reveal how events unfold prospectively in real time." Burns and Grove (2005) similarly suggest asking participants to record events shortly after they occur, believing that this is more accurate than acquiring these data at an interview, through possibly inaccurate recall. In this way, they feel the participants' perceptions of situations are recorded and a higher level of reporting is achieved. They further suggest that diaries can be used to collect data that might not have been accessible through other means, and that participation in studies using health diaries has been good and attrition rates are reported as low, especially when diary keepers are recruited face to face (Burns and Grove, 2005).

Within the literature on diaries there is a suggestion that diaries are especially prone to errors arising from respondent conditioning (Corti, 1993). This, she suggests, is also observed in other types of behaviour and the effects are termed the "first day effects". They may be due to respondents changing their behaviour as a result of keeping the diary (conditioning), or becoming less conscientious than when they started keeping the diary. In order to maintain a diary it was recognised that the respondents would need to be literate to a reasonable standard. In this study where the lived experience was the focus, it was important that the mother's language and phraseology was captured to give a sense of their experiences.

Problems intrinsic to diaries include different response modes, cost, respondent cooperation and complex data analysis (Butz, 2004). She suggests that respondent cooperation varies by age, gender and ethnicity. Sensitisation and fatigue cause

methodological issues if the respondents, for example, become more aware of their health because they are using diaries when participating in health-related studies.

Diaries would, however, be familiar to these mothers as, in my experience, they are used to keeping reports about their children in school diaries, health records and care plans, for example.

4.14.1 Using diaries – practical issues

In the diaries mothers were asked to record their experiences of what they perceived to be a “good day,” a “bad day” and a “normal day” and to report detailed information about each situation. In this study, where lived experience was being investigated it was important that the mother’s language and perceptions were captured. This added personal, subjective experiences and obtained reports in the mother’s language to add to the richness of the data. It was recognised that a mother may be willing to explore a particularly “bad day” in privacy at the time, but at an interview sometime later the recall of these events may be forgotten. I was aware that I was asking each mother to reflect on issues that ordinarily she would not have done. Keeping a diary may increase sensitivity to these situations; for example, by recording a bad day the mother was required to think more deeply about this than she would otherwise have done, thus providing depth in the data. It was recognised that mothers would keep diaries in different ways that would differ in their intimacy in reporting good, bad or normal days, so a structured format was provided. To provide reassurance, adequate instructions related to completing the diary were viewed as critical (Burman, 1995). Each diary was prepared in this structured way using headings for guidance (Appendices 8 and 9).

Under-reporting or incomplete recording of information were potential issues, so advice and guidelines were provided. Some mothers would be more predisposed to completing diaries so verbal reinforcement was used to encourage mothers to write and submit them. The potential onerousness caused by recording three diaries was identified and it was recognised that this may increase pressure on the mother, particularly during a stressful time and may affect the mothers’ daily routine. However, only three records were required and it was envisaged that each recording should take no more than thirty minutes. Diary recording, and the time needed to do this, was discussed with mothers at the outset, and in ongoing interviews. Encouragement and advice was provided during written and telephone contact during data collection, and by referring to their content in ongoing interviews as a method of positive reinforcement. Three stamped addressed envelopes were provided for their return. Personal collection has been found to increase the completion rate (Butz,

2004) so completed diaries were collected as they were recorded. This enabled any issues in them to be discussed as they arose. Some mothers indicated concerns about writing and style of presentation and the time needed. I offered reassurance, support and advice when these issues were raised. The mothers were assured that all data were confidential and no details about them or their child would be identified in the transcripts of the diary recordings. Pseudonyms were explained. No incentives were provided to complete the diaries, but the value of the information gained from them was discussed to provide intrinsic motivation for mothers to continue with them. Diaries can be prone to inadequate recall and insufficient cooperation, but as they were not the primary source of data, this was not perceived as problematic. The use of totally unstructured diaries can increase the costs of data analysis in time and transcription. However, these costs were balanced against the superiority of the diary method in obtaining important data on the mothers' experience. Once each diary was forwarded to me it was transcribed in full.

4.14.2 Issues in diary recording -The 'I'

Diary recordings did help achieve collection of important data on the lived experience of the mothers that were not always captured in the interviews. Consequently, greater understanding of the experience of caring for a child with complex needs resulted. Structuring and writing instructions for the diaries was problematic as it was recognised that this would significantly influence what was written. The headings and structure ("good, bad and normal") were initially difficult to determine as I felt I was providing my framework in which the mothers had to report their experiences. I had some dilemmas in providing specific guidelines but recognised that a framework had to be used for guidance.

This dilemma is made obvious in Imelda's normal day diary;-

Unfortunately I really feel that there is never any such thing as a "normal" day in this house. It goes from one extreme to another.

And in Emer's good day diary:-

I've sat for the last months waiting for a good day in order to complete my trio of diaries for this study. It's only in the last few weeks that it has dawned on me that every day I have child* is a good day.

I also suggested that mothers may want to include artefacts or supporting information, which some mothers did do. These, because of the potential breach of confidentiality of family details cannot be used, which is a pity as they do provide a pictorial representation of the experiences. The diary excerpts provide a personal and subjective interpretation of the mothers' experiences and add to the richness of the data collected. While I have

structured their focus, and applied my framework and perspective on mothers' experiences, which may be contrary to a phenomenological approach, I felt that to give completely unstructured diaries could cause concern, and need greater written and verbal explanation that could take considerably more of mothers' time. I also knew that "good and bad days" were how mothers talked to me about their experiences in clinical practice. Given the mothers' reports within diaries a normal day should have focussed on a "not so bad" day.

4.15 Other sources of data

Other methods of data collection used included field notes, written narrative and a research diary. In these ideas and thoughts that emerged during the study provide a rich resource. Meetings were recorded; pre and post interviews, and thoughts and comments on the experiences were noted. Post-interview notes were recorded to provide a source of supporting data. Wengraf (2001) identifies their functions. The first is to record some non-linguistic data that are not captured on the tape recording; the second is to avoid the situation in which the recorder malfunctioned, or if the tape is lost which, fortunately, did not occur. The third important function is that making such notes enables the researcher to record events and incidents contemporaneously, rather than some time later when memories may be distorted, or issues forgotten. These notes enable material about emotions and feelings to be recorded and to complement the tape recording with the immediate and ongoing interpretation.

Following each interview I took an hour on my own for instant debriefing, which is central to understanding the interview and developing professional competence (Wengraf, 2001). My notes included information about the interview structure, process and content as these can be lost after the researcher leaves the interview, talks with others, and gets on with other issues. Wengraf (2001:143) suggests that "you have only one opportunity to get maximum benefit from the data from your brain: immediately after the interview before you do, or think about anything else". It is suggested that the researcher should stay in the same room to record notes but they were compiled when I arrived back at my car after each interview. The data were used in the subsequent analysis and helped in developing my skills for subsequent interviews. I needed to record, for example, family names and specific details that that needed to be referred to, or followed up, in subsequent interviews. This attention to detail indicated listening and attention. I later recorded ideas and emerging issues in a research diary as I experienced them. A data management software package (NVivo) facilitated me in recording research memos during data analysis.

The study has been informed by reading, listening to radio interviews, doing presentations, watching television programmes, personal clinical practice, peer discussion and expert discussion about methodological issues and the emerging findings. Notes from these have been similarly recorded.

4.16 Summary

Unstructured interviews, diary recordings, notes, memos and research records were used to develop a richer and deeper understanding of the mothers' experiences. It is important to recognise, however, that within hermeneutic phenomenological approaches it is necessary to accept the impossibility of gaining direct access to the participant's life world (Willig, 2001). It is also necessary to recognise that the exploration is from my perspective which, of necessity, implicates my own view of the world, as well as the interview interaction between me and the mothers. Consequently all methods of data collection and subsequent analysis produced are always an interpretation of the participant's experience.

4.17 The 'I' in research design and data collection

I am conscious of the simplistic approach that may be portrayed in the complexity that surrounds data collection and that this chapter in no way fully represents the complexities involved in arranging and undertaking interviews, or the work that went into creating letters, diaries and information sheets in the study. Additionally, I was always aware of the need to demonstrate trust, credibility and a professional approach throughout to gain access and to collect data. How this was achieved is hard to describe, but evidence of success is that all, but one of the seventeen mothers agreed to be recorded fully in her first interview, and fifteen of them completed all three interviews. I was aware that during the data collection period some children became progressively more ill and was conscious of the time I was taking from mothers' care-giving for research, and particularly when paperwork and administration emerged in the findings. Asking mothers for their continued involvement was, at times, finely balanced between beneficence and non-maleficence.

The ethical issues and quality mechanisms will be discussed in the next chapter.

CHAPTER 5 - ETHICS AND QUALITY

5.1 Introduction to ethics

In this chapter the ethical issues pertaining to the study and the mechanisms used to demonstrate quality will be discussed. These issues pervaded all aspects of the study and are reported prior to data analysis and the findings.

In any research study that involves human subjects, safeguards need to be included for their protection. In Ireland nursing research principles are outlined in the An Bord Altranais (ABA) Code for Professional Conduct for each Nurse and Midwife (ABA, 2000) and in the UK by an equivalent professional document from The Nursing and Midwifery Council (NMC). ABA clearly states the nurse's responsibilities:-

“in taking part in research, the principles of confidentiality and the provision of appropriate information to enable an informed judgement to be made by the patient must be safeguarded. The nurse has an obligation to ascertain that the research is sanctioned by an appropriate body and to ensure that the rights of the patient are protected at all times. The nurse should be aware of ethical policies and procedures in his/her area of practice.”

I was registered on the Nurse's Register in both jurisdictions as this is a requirement to undertake research. My background was checked by An Garda Síochána, The Police Service (NI) and the Criminal Records Bureau to ensure that no criminal activity was recorded. This is necessary to ensure that legal requirements for working with potentially vulnerable children are met. Within this study I adhered to the principles of beneficence, non-maleficence, autonomy and respect for persons, which influenced my practices throughout the research process. I was aware that I was working with a potentially vulnerable group of mothers and their families and implemented a number of strategies to ensure their protection.

5.1.1 *Formal ethical approval*

Researchers have to adhere to regulations and guidance from the University, professional bodies and the law which identify standards to promote good quality research and to reduce potential adverse events and poor performance in their work. Each Irish University currently provides its own ethical framework and approval mechanisms. Approval was obtained from the Ethics Committee in The School of Nursing and Midwifery Studies, University of Dublin, Trinity College. Minor amendments and points of clarification required by this Committee were provided before the study commenced (Appendix 2).

Indemnity was provided by the University. At the outset no similar approval system applied to the voluntary organisation in NI but staff in its UK headquarters confirmed their approval of the study and their involvement in recruitment, provided I had no direct access to client information. It had no further ethical concerns or need for formal written agreements. They also offered to access mothers using their website and news letter had I wished to recruit mothers from the remaining parts of the UK.

Before recruitment commenced, the gate-keeping organisations were sent a copy of the ethical approval letter. These organisations are not identified in the study. My supervisor was informed of any unexpected ethical issues throughout the study and her advice was sought on managing them. These discussions were recorded in a research diary and supervision records.

5.1.2 Informed consent

A central feature of all research is that participants should be fully informed about a project before they assent to take part (Oliver, 2003.) This principle of informed consent is closely linked to the principle of autonomy. Informed verbal and written consent was sought from each respondent. At the outset the study consent was explained in the written recruitment information sent to each potential respondent. The benefits or risks of contributing to the study and the contact details of my research supervisor were included, in line with good practice (Willig, 2001; Gerrish and Lacey, 2006) (Appendix 7.). At the initial contact each mother was given the opportunity to ask questions and to discuss any of their concerns. I advised mothers that non-participation, or withdrawal at any time, would have no impact on their child's care or service delivery, and this would be only known to me. Informed consent was enhanced by providing written information, explanations and verbal discussion. The information sheet that accompanied the consent form provided details of the study and included a series of questions that the mothers might have had about becoming involved, and any possible consequences that could occur.

One ethical issue that had to be addressed was to decide the limits of the information that was provided for each mother. It appeared initially that there was a large volume of information needed for recruitment, which was a concern and required me to be selective at times. Mason (2002: 81) suggests that "many interviewees may not be interested in the detail and may not be familiar with the disciplinary skills and conventions which are needed to understand these issues". I was very conscious of the volume of paperwork provided about the study and its potential impact on already busy mothers, especially as they received it in the post without prior notice. Retrospectively, I think less written

information would have been appropriate at the outset that could have been further developed in the initial meeting. One mother reported “wading through the paperwork”; another said “it nearly put me off”. Given the findings of this study about the mothers’ administrative role, I appreciate that they took the time to read the recruitment information and become involved.

Having provided the facts for the mothers I left them to form a judgement about their involvement, thus enhancing autonomy and their right to self-determination.

5.1.3 Formal written consent

Formal written consent established that the mothers consented to being involved in the study (Appendix 7). A written consent form that included information on risks and benefits, confidentiality of the data and withdrawal without prejudice and their contribution to the study was signed by each mother at the outset. By signing the consent form, mothers indicated that they understood the information and their contribution to the study. A copy of the signed consent form was given to each of them.

During data collection, ongoing consent to continue was discussed with each mother at the beginning of each interview and during telephone conversations. I viewed the period of study as “an ever changing field and viewed informed consent as an ongoing process” (Munhall, 2001:544) and ensured informed consent throughout. No formal written consent was given by the children whose care is reported. However, when the child was present during interviews I discussed this issue with each mother. I ensured that, if appropriate, the child was informed and affirmed that the mother was agreeable to proceed. Fathers and siblings were similarly advised and were included in the interview if verbal consent was given, and with the mother’s agreement. In one interview the father’s contribution was included in the recording. In others their contribution was noted in my research diary.

5.1.4 Confidentiality

The confidentiality of mothers, children and families needed to be protected throughout and I took steps to ensure that this was not compromised. Given the potential vulnerability of the children, the rarity of the medical diagnoses, the complexity of their needs, their medical circumstances, each child’s and their family’s identity had to be protected as others could readily identify these families given their unique situation. The personal details and circumstances of each mother’s situation are not identifiable in the work, or in publications related to it. No child is identifiable by name, location or medical diagnosis. Pseudonyms have been used for mothers, children, siblings and any named health care

personnel and sites. Where data were collected, which if used, could link findings to a particular mother or site, this information was not included. The recruiting organisations are known only to me and are not identified in the text, or in publications.

5.1.5 Control of information

Strict controls were placed in access to all data. Original interview recordings were stored in a locked cabinet and transcripts and other hard data were stored in a password protected computer, to which only I had access. My supervisor signed a confidentiality agreement that required her to maintain information about the study in a professional manner (Appendix 12). In data analysis, discussions and presentations all identifying markers were removed. I discussed with the transcriber the sensitive nature of the data and the importance of confidentiality. She signed a confidentiality agreement (Appendix 11) and agreed to keep all research data safely, and to delete data from her computer after completing the work. Others who supported the data analysis had no access to raw data from which they could identify the respondents or families. The psychotherapist who was available to support mothers had no access to confidential information. Copies of original data will be kept as required by University regulations in a safe manner until it is destroyed after five years.

5.1.6 Trust

Trust is important in studies where sensitive personal information is potentially being investigated and divulged. In the recruitment phase I needed to develop and demonstrate a trusting relationship with each of the gate-keepers and subsequently, with each mother. At the outset, developing and maintaining trust was recognised as an important component for successful recruitment. The mothers, thereafter, were required to trust me sufficiently to enable them to explore personal issues during the three interviews and in diary recordings. Trust was achieved by providing information on confidentiality and how this would be maintained. My professional and personal background was provided in verbal and written information to demonstrate credibility in the study (Appendix 1). Professionals and organisations contacted in the initial phase of the study were made aware of the rationale for the study and the University involved.

In the literature there are a number of factors that promote interpersonal trust. These include greater perceived mutual interest, clear communication, less risk of unfulfilled trust, less perceived difference in power with the person being trusted, an expectation of a longer term relationship and a higher cost for not trusting (Gambetta, 1998). In this study,

mechanisms to demonstrate these characteristics were implemented. Mutual interests were emphasised in verbal communication with gate-keepers and mothers, and my experience in caring for children at home were discussed. Initial steps were used to build a relationship and demonstrate trust; for example, I took a long time in the first telephone call with each mother to display interest in her situation and demonstrated empathy non-verbally during the interviews. I checked mothers' understanding by asking if anything needed to be clarified in telephone calls and by giving the mothers the opportunity to ask questions throughout. If I was asked to do something by a mother then it was done; for example, in follow up telephone calls or requests for information. Mothers were given the opportunity to ask questions about the emerging findings.

In developing relationships and trust with mothers, I attempted to reduce potential power differences in the researcher-researched relationship which initially proved difficult with mothers who seemed to have some concern about meeting an "academic from Trinity" and who were perceived to hold the researcher, a university lecturer, in some esteem. One mother commented at the first interview that I was not "as she had expected". I developed and demonstrated equality in our relationships, for example by using our common language and by recognising mothers' expertise in care-giving throughout (Nicholl, 2007). At one period (2006) trust became particularly important when there was negative national publicity about parents of a child with autism who "whistle blew to the press" about the lack of services. This impacted on mothers who knew and talked about this family and this publicity. One mother was seriously concerned about her anonymity if she similarly complained of a lack of services during the interviews. At this point I reassured her about confidentiality. At the same time another mother had no hesitation in allowing her family situation to be identified "if it would improve the services at all".

Throughout I used interpersonal skills and behaviours to demonstrate a trusting relationship including listening carefully, asking thoughtful questions, never interrupting, answering questions clearly, explaining situations and getting to know the mother (Nelson-Jones 2002). Friendly caring staff who took the time to develop rapport, used personal introductions and took the time to explain information in a timely manner are also identified as trustworthy by parents in hospital (Thompson, Hupcey and Clark 2003). These behaviours underpin my nursing practices and were applied throughout. Their success has not been measured, but agreeing to multiple interviews suggests that mothers did trust me. As this study finishes, I have been contacted by five mothers, including one who withdrew from the study early on, for feedback on progress, which may add to this sense of trust and interest in my ongoing work.

5.1.7 Autonomy

In any research study that involves the collection of data from vulnerable individuals I needed to justify their inclusion in the research study. Given the nature of this study, I considered it appropriate to involve mothers, and that protection of their rights and those of their families was a key component. Consent and withdrawal from the study was fully discussed. In my view the mothers were adults and capable of making an informed choice to contribute or not, as the case may be, to the study. If a mother withdrew then this decision was fully respected. This is part of the informed consent process and is linked to the other ethical principles outlined.

5.1.8 Non-maleficence and psychological distress

Involving vulnerable groups and the collection of data that involves sensitive information is reported in the literature where it is recognised that contributing to a project where emotional issues are discussed can potentially cause psychological distress (Addington-Hall, 2002). Researchers may often deal with matters that are deceptively ordinary such as relationships or the family (Oliver, 2003), yet many sensitive issues may be uncovered in such situations. Mothers were considered a vulnerable group, and the principle of doing no harm was important. From the outset I recognised that I would be engaging with mothers who were dealing with complex life situations, and that there were many sensitive issues that could emerge during the interviews and in diary recordings. This information might be divulged when the mothers were recollecting how their life was, or had been impacted upon by the child's diagnosis or demands of caring, and that their awareness of these feelings might be heightened by contributing to the study. I consequently arranged for confidential psychotherapeutic support to be available for all mothers that could be used as required at any stage during the study. The psychotherapist signed a declaration of confidentiality and was not aware of the mother's details unless they made themselves known to him. His contact telephone number and details were provided at the end of the first interview. No mother used this service.

I outlined the potentially sensitive nature of aspects of the study at the outset and during each interview gave every mother the opportunity to pause, stop, or terminate the interview if she appeared to be, or reported being, uncomfortable with the situation. There is evidence however, that emotional release can be cathartic and beneficial. During the interviews some mothers became tearful and upset which was sensitively managed. Before the second interview one mother reported that she "felt like she had been hit by a truck"

after the previous interview, and that issues which she had forgotten had been recollected. After the final interview she reported that the interviews had helped her “resolve some family issues that had been remained unresolved had she not thought about them during the interview process.” This experience heightened my awareness of this impact on other mothers which I discussed with them when appropriate.

5.1.9 Child protection

Child protection needs to be considered in any research where child care practices may be discussed or observed. There is a legal and professional requirement for all nurses to ensure issues related to child protection concerns are made known to an appropriate authority in law and as required by professional Codes of Practice or policy guidelines. Within the interviews and diaries there was a potential for issues of child safety and protection to emerge. My requirement to adhere to child protection guidelines was identified in the initial information for mothers and gate-keepers. My responsibility to report any concerns should they arise, was subsequently discussed when mother’s signed their consent form. Where protection or child safety issues were raised I discussed the situation fully with the mother. No incidents were reported to others. In one situation a mother asked about an unexplained injury to her child and I gave professional advice indicating the need to investigate and report the situation to the appropriate authorities. When I followed this up subsequently these steps had been taken and the situation had been resolved. Where mothers identified unsafe nursing practices these were fully discussed and the mother advised to contact professionals working directly with the family for advice. I will highlight these situations in presentations related to this study to alert others to the need to explore the consequences of a lack of equipment.

5.1.10 Researcher safety

Guidelines and good practice recommend that researchers review potential risks to their safety when considering their procedures for collecting data. It was recognised at the outset that there would potentially be physical and emotional risks to me that required cognisance of health and safety legislation. Interviewing mothers in their homes placed me at potential physical risk. Conducting interviews in remote locations, and the potential of physical threat or abuse, though very unlikely, still had to be considered given the potentially sensitive nature of the interviews and that I had no awareness of the family background. There was also the risk of being placed in a compromising situation in relation to child protection, given that I was involved with mothers and children. A risk assessment was

carried out at the outset and at stages during the study and was assessed as low. However, I was cautious and implemented strategies to ensure my physical safety. I am a practising nurse, often working as a lone worker, and always adhere to this policy. I carried a fully charged mobile phone and planned my routes in advance. Particular care was taken in night-time interviews, which were avoided where possible. I ensured that another party was aware of the venue, proposed start and finish time of each interview. They had to contact me at a specified time after the interview was completed to ensure I was fine. If they failed to contact me as agreed they were to immediately inform the police /Gáarda and my supervisor. I adhered to this policy at other times when my safety potentially could be jeopardised, for example, in overnight stays in hotels.

It was envisaged that interviewing mothers about sensitive and emotional issues as well as ‘becoming immersed’ in the study could potentially harm me psychologically. The nature of what was disclosed in the interviews could have put me at risk of psychological upset, particularly as prolonged engagement with the data was necessary. Appropriate support mechanisms used included peer debriefing and discussion, confidential discussion with counsellors, physical activity and relaxation therapy. During various stages it did become difficult to handle some of the data, particularly as children were deteriorating. At these times, I took ‘time out’ and data analysis was interspersed with other less emotionally demanding activities.

5.1.11 Comment on ethical issues - The ‘I’

The ethical complexities that emerged during this study were resolved using the mechanisms reported. Unexpected ethical issues did emerge; for example I had to negotiate access to mothers through gate-keepers who were in a protective position towards mothers, and their service provision, which took longer than expected. I was also asking mothers to give time to interviews and recording diaries for a research study when their lives were already busy and their experiences of health professionals were not always positive. I was well aware of the potential emotional impact of the words “life-limited”, which is similar to the term “palliative care,” reported by Addington-Hall (2002) and of the sensitive nature of mothers’ situations and the emotions involved. I recruited mothers using the term ‘complex needs’ and the use of the term “life- limited” remains a dilemma for me despite its use in professional literature. This tension was overcome by asking mothers, in my initial conversation, if they would describe their child as having complex needs, and if the response was affirmative, their child was included.

Throughout I have been conscious of the fine line between doing good and doing harm. In a study of this nature, one should expect ethical issues to emerge, and ethical decision-making and resolution should be viewed, I suggest, as an ongoing process. It should be expected that mothers may use the opportunity of interviews to seek advice on treatments or service provision, for example, and you cannot expect them to understand the role conflict between researcher and practitioner that this causes to the researcher. Researchers need to be aware of the dilemmas that can arise during data collection and take decisions on their management before they occur (Nicholl, 2007).

In the following section the issues related to the quality of this study, which are closely related to ethical issues, will be discussed. The achievement of quality impinged on all aspects of this study.

5.2 Introduction to quality

In traditional research studies in the quantitative paradigm, the notions of reliability and validity are reported. Within the qualitative paradigm, where the researcher is the instrument of data collection, the issues that need to be addressed include those that demonstrate quality and trust in the study. These involve “giving attention to and articulating the researcher bias (explicitness) and adopting an emic perspective (vividness), as well as to explicate a very specific phenomenon in depth (thoroughness)” (Whittemore, Chase and Mandle, 2001: 524).

Quality is a means by which the integrity of the study and researcher competence, and the legitimacy of the research process, is demonstrated. In the extensive literature on quality in qualitative research (Willig, 2001; Rapport, 2004), Sandelowski (1993:1) suggests that “evocative true to life and meaningful portraits, stories and landscapes of human experience” can be threatened by an over-emphasis on scientific methods, as opposed to the art and creativity of interpretation. Adopting inflexible and rigid approaches to rigour in qualitative research removes the sensitivity to meaning that is essential in phenomenological studies where Gadamer’s notions of historicity, intentionality and the interpretation of language that is bounded by social situations, context and time play a part. In qualitative research the notion of validity, as applied in the quantitative paradigm, where the positivist idea of one fixed and essential truth is the focus, cannot therefore apply because of this different ontological and epistemological position. In the interpretive and constructionist traditions of qualitative research researchers are working with socially situated truths (Green and Thorogood, 2004). Denzin and Lincoln (2003) more strongly

suggest that the very idea of ‘scientific criteriology’ (including validity, reliability and generalisability) is irrelevant to, or an anathema in, the qualitative research endeavour.

This does not mean, however, that the researcher does not have to justify their methodology, analysis and interpretation of the data in qualitative research. To do otherwise results in many criticisms including anecdotalism in which the findings are not supported by analysis, and exoticism, where the most exciting findings are reported (Green and Thorogood, 2004). It is necessary therefore, to use technical procedures throughout the research to demonstrate its quality. Procedures are essential to prevent the researcher from developing concepts and theories that do not authentically represent the phenomenon under investigation or reporting findings that can be erroneous, unsubstantiated or which reflect bias (Hammersley, 1992; Miles and Huberman, 1994; Whittemore, Chase and Mandle, 2001; Rapport, 2004).

There are a number of processes offering different approaches and techniques that can enhance the quality of a qualitative study. Munhall (2001), amongst others, identifies tenets of qualitative research and suggests that studies should be evaluated on their significance, which includes their relevance, importance and transferability. Some approaches focus broadly on the evaluation of quality and offer “signs” of a good piece of work, while others produce specific guidelines for enhancing the quality of the work, or suggest the use of verification strategies to ensure rigor (Sandelowski, 1986; Denzin and Lincoln, 2000). This includes producing an audit trail, analysing deviant cases and member validation, analysis of the whole data set, comparing between and within cases and accounting for the role of the researcher within in the study. Green and Thorogood (2004), suggest that transparency is also necessary and reflexivity should be accounted for. Rolfe (2006) has identified three distinct positions in the debate on quality, using Hope and Waterman’s (2003) work as a basis. The first position is the adoption of positivist validity criteria in qualitative work; the second is to adopt separate criteria from those used in quantitative work, and the third is the rejection of all predetermined criteria in the quantitative paradigm. Hope and Waterman, Rolfe further states, conclude that the application of criteria, however defined, is not clear, and confusion exists as to how judgements should be made about whether, or not, a standard has been achieved.

Cognisant of this ongoing debate I will report on the steps I have taken to ensure quality within this work which was based on the work of Munhall (2001). She suggests that the features that should be evident in qualitative research are adopting a “a holistic approach, a focus on human experience, sustained contact with people in their natural environments, a high level of researcher involvement and the production of a descriptive and narrative

data” (Munhall, 2001:67-8). In doing so I recognise that this approach has been criticised by Rolfe (2006) as all aspects may not be applicable to all approaches in qualitative research. Within this study, therefore, a number of approaches were incorporated.

5.2.1 A holistic approach

The phenomenon investigated was the mothers’ experiences of caring, not a part of it, but the totality of the experience. The research question was broad, which recognises that human realities are complex (Munhall, 2001) and changed throughout the study as the mothers’ experiences emerged from the data. The focus throughout was the experience of caring and I did not focus during the interviews and diaries on preconceived notions of technical physical aspects of care, or on stress or coping as others have done. In the study, mothers reported these issues to me as part of their experience. A holistic approach was also achieved by interviewing mothers on more than one occasion and collecting data from multiple diary recordings.

5.2.2 A focus on human experience

A second feature outlined by Munhall (2001) is the focus on the investigation of human experiences. In this study, the focus is evident from the aim of the study, the methods of data collection and the findings. Data were collected through human interaction and multiple interviews enabled the mother’s experiences to be explored in depth and the focus was on the mothers’ interpretation of her experiences. There is a clear focus on the description and exploration of the mother’s experiences of caring for her child, or children, in the naturalistic setting of the mother’s home. The methods of data collection were appropriate to this focus on experience.

5.2.3 Sustained contact in the natural environment

Evidence of sustained contact was achieved by the use of prolonged engagement (Lincoln and Guba, 1985; Creswell, 1998) or sustained contact, which requires and demonstrates contact with people in settings where those people normally spend their time. Sixteen mothers were interviewed in their home, and the interviews and diary were spaced out over time, that provided for prolonged engagement on the phenomenon under investigation. Throughout the study (2002-8) I was continually engaging with the data collected in voice data files, written notes and interview transcripts. I was constantly mulling over information and connecting it with other sources of data to confirm the findings. Prolonged engagement was achieved by connecting the findings to my clinical practice situations and

seeing if what was emerging happened in reality during my observations and the delivery of care. During the study I attended study days, parent's fora and meetings where the topic of children with complex needs was discussed which were recorded in my research diary. Following meetings I recorded the confirmation, discussion and affirmation of findings, or any new ideas for investigation or application (Appendices 1 and 14). The discussions I had about the findings are recorded. The data management package (NVivo) records show my constant engagement with the data for prolonged periods of analysis and the programme enables this to be fully documented so it could be audited. Records of this were provided for my research supervisor. Issues and emerging findings and discussions throughout the period of the study (2002-2007) have been recorded in NVivo and in my research diary. Annotations and memos have been used to record my thinking during data management to provide evidence of my decision making trail.

Gibbs (2002) outlines possible threats to the quality of qualitative analysis and suggests that there are a variety of threats during data analysis. These include bias that can occur in biased transcription and interpretation, using vague or inconsistent definitions and unwarranted generalization. It includes overemphasising positive cases and ignoring negative cases, or focusing on the unusual. He suggests that using the data management software makes it easier to complete an exhaustive analysis and that there are ways for "ensuring that the text has been coded in consistent and well defined ways" (2002:14). NVivo was used to record the processes of analysis that were provided and discussed during the study to confirm my findings.

5.2.4 Persistent observation

Sustained contact (Munhall, 2001) and prolonged engagement was supported by persistent observation (Lincoln and Guba, 1985). This was achieved by identifying and focusing on the issues being investigated which "adds a dimension of salience to what might otherwise appear to be little more than mindless immersion" (Bryman and Burgess, 1999:410). This enabled me to be open to the multiple influences that impinged upon the phenomenon being studied, which provides depth to the characteristics and elements of it. The use of voice data, written text files and files in NVivo enabled me to be in constant contact with the data during its collection and analysis. I was constantly listening and looking for what, and how, mothers were describing their experiences. NVivo allowed me to label and group data as they emerged from the text, to code them in nodes and to constantly be in contact with the original and analysed data. Using computerised annotations and memos, supported by my notes enabled me to record, track and note observations during a

continuous physical and psychological state of contact with the data. This persistent observation of, with and in the data was achieved by becoming immersed in the research process, and thoughtfully and creatively considering all possible meanings in data (Atkinson, Heath and Chenail, 1991). Multiple interpretations and negative cases were sought and conflicts and similarities were reported. NVivo codes and coding, as well as interview transcripts, were made available to, and discussed with, my supervisor to support and explain my ongoing interpretations. Strategies included a search for alternative interpretations of the data during analysis by use of external verifiers, peers and exploring and documenting these discussions. The self was also examined and reported and my preunderstandings were recorded before and throughout the study. Potential ambiguities were explored. Using NVivo and supervision, with ongoing discussion during the study, ensured that in depth analysis occurred.

Analytical thoroughness was achieved by prolonged immersion in the data. Each recording was listened to, read and listened to again and again, even when familiarity had been achieved to ensure nothing had been missed. Codes were checked and rechecked, and questions were asked of the text manually and using NVivo, and the outcomes are recorded. This persistency enabled the development of the hermeneutic circle as ideas, themes and issues emerged during my questioning of the text, thus enhancing prolonged contact with all the data. I used persistent observation additionally to source other relevant material and collected radio and television recordings, journal cuttings and publications that were relevant to the topic of mothers' experiences.

5.2.5 High level of research involvement

The level of research involvement is evidenced by the processes reported. Data were collected over an eighteen month period using methods that required close, continuous involvement with the mothers, the data and findings and in the write up of the work. This study was undertaken during 2002-8, but pre study work commenced in 2000. During this time I have amassed information relevant to mothers' experiences of children with complex needs. I have been recently recognised as knowledgeable in this field of practice with involvement in educational training for those involved with children with complex needs in Ireland. In relation to methodological expertise I have a been involved in research training within the School of Nursing and Midwifery where I am a recognised expert in phenomenology and ethical issues in research involving children and mothers. My high level of research involvement has been recognised by others and in peer review article publication which adds to credibility.

5.2.6 *Verification- descriptive and narrative data*

The final characteristic reported by Munhall is related to the production of data. She suggests that “the data produced provides a description, usually narrative, of people living through events or situations” (2001:68). To demonstrate how this was achieved, I used verification strategies that are focussed on descriptive, interpretive and theoretical validity (Sandelowski, 1995a; Silverman; 2000). Descriptive validity refers to validation in relation to interview content and the resultant transcript. This was achieved by audio taping interviews and reproducing verbatim transcripts. Original transcripts and journal recordings were kept. All researcher notes were kept in notebooks throughout the study. The decision trail is evident in written and computer notes and NVivo.

Theoretical validity refers to the degree of accuracy between the researcher’s interplay of data and theory. In relation to interpretation of the data, Polit and Hungler (1999) support the use of an audit trail to document clearly how a researcher comes to decisions during the research process that demonstrates adherence to the data and the emergence of the findings from the data. This is achieved through the process of auditing, and to achieve it researchers are responsible for ensuring that the process of the research is logical, traceable and clearly documented (Schwandt, 2001). It is demonstrated through a clearly visible audit trail where I made clear to the reader the decisions that have been made (Appendix 14). A clearly reported account for the choices and decisions made during the study has been kept. I have reported on the researcher and the researched by using exemplars from my notes, interview notes and transcripts. I have been honest about the apparent lack of clarity at times and the dilemmas and decisions that faced me during the process.

A key issue in the conduct and analysis of data is also related to error, which may occur at any stage and can compromise the outcomes and limit the utility of the data (Morse, 1991). This error compromises the truthfulness of the research results. In relation to interpretative validity in this study, rigour is “less about adherence to the letter of the rules and procedures, than it is about fidelity to the spirit of qualitative work” (Sandelowski, 1993: 2). Schwandt (2001) refers to the notion of credibility, which addresses the issue of “fit” between the respondents’ views and the researcher’s interpretation of them. It focuses on the question of whether the description and explanation of the data fit the description and whether the description is credible. Assuring the credibility in this study refers to the efforts I made to establish confidence in the accurate interpretation of the meaning of the data collected and analysed. Within this study, each transcript was listened to when various questions were asked of the text as reported. This process continued throughout the data

analysis as the experience reported by each mother became clearer and exemplars that described the mothers' experiences became apparent in the data. I have reflected the experiences of the participants in a believable way (Lincoln and Guba, 1985) using direct quotations from the interviews and excerpts from research diaries. This evidence substantiates my interpretations and reduces distortion and conjecture. However, it will always remain my interpretation.

Interpretative validity refers to the participants' experiences and the meaning that those experiences have for the participants. In this study interpretive validity was achieved by obtaining each participant's individual perspective and discovering the meaning that this experience had for her (Sandelowski, 1995a). The interview data identifies meaning and interpretation of the mothers' experiences.

Another verification strategy partially used in the production of findings in this study was member checking. Holloway (1997) refers to this as respondent validation, where participants are involved in the process of checking out interpretations in analysis to clarify, or seek clarity on, any issue. During the interview phase of the study themes, hunches and findings emerging between the individual mothers, and other mothers in the study, were discussed during subsequent interviews. This was recorded in researcher notes and coded in research methodology nodes in NVivo. All mothers were given an opportunity to clarify emerging issues during the interviews. I introduced statements, for example, "other mothers in the study have told me that.." as prompts for discussion and at the end of the final interview each mother was asked to report any issues that she felt were central to her experience that had not been discussed. This provided ongoing opportunities for clarification and exploration of the key issues.

Member checking, often suggested as a mechanism for verification of findings, (Lincoln and Guba, 1985), raised two major dilemmas for me. It potentially offered a philosophical contradiction between philosophy and method and was ethically improper in this type of study. I had considered returning the emerging findings to the mothers as is recommended within the literature after data analysis. However, given that what had been produced was my interpretation and that readers will add their own interpretation to the data, I would have had to send the findings to every mother which was not possible. The alternative was to send it to some mothers, but which ones? This philosophical dilemma was eased when one mother emailed me in March 2007 asking for the findings. Her response to my initial findings indicated that these made sense for her. Professional colleagues, at the time, suggested that what they heard sounded right and fitted with their experience.

It was also not ethically correct, in my view, to return data to mothers from interviews that may have taken place up to 18 months previously. During this period one of the children sadly died, which alerted me to the ethical difficulties, and psychological dangers of doing this. Mothers' personal circumstances and the children's illnesses had also changed and, in some cases, deteriorated. I believe that it was inappropriate to return to ask the mothers to verify my interpretations, given that what had been collected as data was influenced by time and situation.

I was very aware of the changing nature of the mothers' experiences and their child's illness so I selected to use other methods to affirm my interpretations of the findings. I discussed this issue with colleagues and experts at methodological presentations, after which I decided that mothers would be provided with some general findings when the study was completed, and that further use of member checking after interview completion was not appropriate for verification. This decision was agreed with my supervisor. The findings have been subsequently verified by professional colleagues and others at ongoing conference presentations related to this work.

5.2.7 Peer debriefing and review

Conscious of my decision, but still keen to ensure that the findings made some sense to others, I used a number of other methods to affirm my interpretations of the data. I used peer debriefing and review to demonstrate the 'fit' between the respondent's views and my representation of them (Schwandt, 2001) and to ascertain whether or not the explanation given fitted the description of the phenomenon. Thorne, Kirkham and McDonald-Emes (1997) suggest that there is a need for assurance that interpretations are trustworthy and reveal some truth external to the investigator's experience. At the outset, peer and expert discussion was used to clarify the terminology that was used to recruit mothers. Peer debriefing with my supervisor included discussion on emerging themes and issues. She reviewed interview transcripts with two mothers in full, and excerpts from others to discuss my understanding of them, the codes used and my interpretation of the themes. This functioned to ensure that my confidence and decision-making was challenged by an expert in this research method.

I was also part of the School's formal research group and used this peer review forum to discuss emerging issues in data analysis, interview methodology and terminology and to be challenged on my decision making and to justify my decisions during the research process. This included presentations on issues in interviewing and how data emerges in qualitative studies in which I had to defend my decision-making. Anonymous data were discussed and

my coding explained which provided critical scrutiny by academic experts of my decision-making in analysis. Presentations have subsequently indicated that the findings do demonstrate an understanding of the mothers' experiences that is recognised by others. I utilised the expertise of visiting professors to the School for advice and critical discussion over the period of the study and I met regularly with professional colleagues with relevant clinical, social science and research backgrounds for peer support and advice at critical junctures during the study.

During the interview period, I met with professionals, professional groups, research colleagues and representatives from service providers to learn of their views on the emerging issues (Appendix 1). I was also part of an academic team in which subject specialists from psychology, sociology, children's nursing, disability nursing and counselling were available. During discussions I was challenged about the study, aspects of the methodology and the findings. These discussions and decisions are recorded.

This review by methodological and clinical experts enabled discussion, clarification and exploration of decisions made. It facilitated a critical approach and served as a debriefing opportunity, exposing me to questions about the emerging dimensions, potential biases in interpretations and "blocks" in analysis. The themes and understandings were recorded and added to memos in NVivo which recorded all searches made in the data. Using these methods I followed Thorn et al's (1997) suggestion that there is a need for assurance that interpretations are trustworthy and reveal some truth external to the investigator's experience. Later discussions also enabled me to test and confirm the "fittingness" of emerging themes (Lincoln and Guba, 1985).

Finally, these discussions provided emotional support during the study which helped psychologically. Undertaking qualitative research can be emotionally challenging and peer debriefing enabled me to clear my mind of emotions and feelings "that may be clouding good judgement or preventing the emergence of sensible next steps" (Lincoln and Guba, 2000: 413).

5.2.8 *The "phenomenological nod"*

A final approach in ensuring fittingness of the findings involved using the "phenomenological nod." This concept has been outlined by Van Manen who suggests that it this can indicate affirmation by others that they can identify, recognise and relate to the experience that is described (1999:b). Within this study, this became evident at various times and in different situations. It was apparent in colleagues and experts at presentations and in experienced fellow researchers and was recorded in comments in evaluation reports

following presentations. It emerged during periods of clinical practice as I cared for children with others, and when I began to look for the findings from the study in practice. I saw the importance of the mobile phone. I heard mothers' talk of their experiences with the health system and their child's physical needs, as examples. These incidents were anonymously recorded in outline in my research journal and exemplars of similar situations are included in this work (Appendix 14). I found myself confirming findings when I heard local radio interviews in which mothers reported their experiences of caring for children with rare disorders, and in newspaper articles on parents' experiences of caring for children with autism, for example, as this is currently topical in Ireland.

Towards the end of the study, professional colleagues sought me out as information about the study emerged. They expressed the nod and confirmed the findings from their experience. These situations established my confidence in an accurate interpretation of the meaning of the data.

Finally, the creativity of the study and its findings must be preserved but not at the expense of the quality of the science. Patton (1990) suggests that it is essential that qualitative work should be highly creative at the same time as it is analytically rigorous and explicit. The decision making process throughout the study is recorded and available. The use of 'I' has been recorded to demonstrate the processes and decision-making. This includes a self-critical account of some of the dilemmas and challenges faced in the study and in this real world research.

5.3 Conclusion

Within this chapter the processes that underpinned recruitment have been reported and how quality was achieved discussed. The principles that enhance good ethical practices and trustworthiness of the findings have been reported to facilitate an understanding of how the experiences of mothers emerged from the data and the interpretative processes used. Throughout this study I have been aware that, not only did the results of the study need to reflect the experience of the participants in a believable way (Lincoln and Guba, 1985), but that the mothers recruited into the study who contributed to the work needed me to portray their experiences accurately. Within this study, assuring this credibility refers to confidence in an accurate interpretation of the meaning of the data. In order to assess the quality of a research study Punch (2005:195) indicates that "a key question in assessing a piece of research is: how did the researcher get to conclusions from these data?" This has been achieved by using the mechanisms outlined. I am aware of the philosophical contradiction on the appropriateness of using some of these methods of confirmability and

that others were not used. I have approached quality flexibly, while at the same time attempting to ensure that steps were taken throughout to ensure that the processes I have used in completing this research are clear to others, and I have adopted an open, transparent approach to this.

5.4 Final comments- The ‘I’

The issue of rigour in qualitative studies has been challenged by Van Manen, amongst others, who suggest that this term does not fit within the qualitative paradigm (Van Manen, 1990). Ritchie and Lewis (2003) report that the concepts of reliability and validity were developed for the natural sciences, and because of this, and the very different epistemological basis for qualitative research, there are significant concerns about whether these concepts have any value in determining the quality, or sustainability, in qualitative studies. I have used numerous strategies as outlined to ensure that this study fulfils the requirements of a good piece of qualitative research and meets the “criteria of vividness and methodological congruence” (MacIntyre, 2001: 444). Like Sandelowski (1986) I believe that a study is credible if it reveals an accurate description of an individual’s experience. This has been confirmed by using the strategies reported. The steps taken to ensure quality in this study have been reported before data analysis as quality was viewed as ongoing throughout the whole study. This decision will enable the reader to confirm the steps I have taken in subsequent chapters.

Within the following chapter the processes of data analysis will be outlined.

CHAPTER 6 - DATA ANALYSIS

6.1 Introduction

The aim of this chapter is to outline the processes of data analysis used within the study. The focus is on the processes of phenomenological data analysis using a model of analysis based on those of Koch (1993/1995) and Smith (1993/1997/2004). The analysis of data is drawn from the philosophies underpinning the work of Heidegger and Gadamer.

6.2 The purpose of the research

The purpose of the study was to explore mothers' experiences so it was imperative from the outset that the method of analysis was integrated into the other steps of the research process. The aim was to uncover and describe the mothers' experiences and to represent this in such a manner "that a person who had not experienced this might understand the phenomenon" (Thorne, 2000: 69). The aim of data analysis was to provide descriptions that captured the meaning of the mothers' lived worlds in which they cared for their children with complex needs.

6.3 Data analysis: the challenges of no single approach

Punch (2005) suggests that there are multiple practices and perspectives in the analysis of qualitative data. Different techniques are described that are often complementary, frequently interconnected or overlapping, but that are sometimes mutually exclusive (Punch, 2005). This diversity in approaches underlines the fact that there is no right way to do qualitative analysis and no single methodological framework available. Coffey and Atkinson (1996) indicate that the variety in techniques exists because there are different questions to be addressed and different versions of social reality that can be investigated and elaborated. Some qualitative approaches are also not designed to find commonalities or patterns in the data, as is the aim in constant comparative analysis (Thorne, 2000). In phenomenological research, the aim is to explicate parts of the underlying structure, or essence of the participants' experiences, by intensively studying individual cases and that it is this movement, or an ongoing conversation, which sets hermeneutic phenomenology apart from other approaches (Koch, 1995; Thorne, 2000). What links all approaches to data analysis is a central focus on transforming and interpreting qualitative data in a rigorous way, in order to capture the complexities of the studied worlds (Coffey and

Atkinson, 1996). Whatever method is used in analysis, it needs to be systematic and visible.

6.4 The process of data analysis

For most mothers data were collected over approximately three months, though on occasions this was over 12 months for unavoidable reasons. Analysis was ongoing continuously from January 2005 when the first interview was completed until July 2006. Initial analysis of each interview occurred before the second or third interviews and between interviews. Further analysis was ongoing until April 2007. Diaries were collected over the same time frame. Other data were recorded throughout the duration of the study and thereafter.

The aim of data analysis was to orientate me toward the detail and depth of understanding that can only be appreciated through a systematic, exhaustive, and reflective investigation of the experiences as they are experienced (Thorne, 2000). In order to assist with the analysis a number of the frameworks found in the literature were considered. I investigated a number of models including Colazzi (1978), but recognised that the data validation stage he recommended was not possible. The death of one child during the study highlighted to me that it was totally inappropriate to return to the mothers' worlds, which had moved on and were different from the time of data collection. Koch (1993) reported a similar problem when investigating the experiences of older adults using this framework. It was therefore decided to adapt Koch's six stage framework to assist with data analysis. This framework involves:

- reading through the entire subject descriptions for a sense of the whole
- extracting significant statements that directly pertain to the investigated topic
- continue extracting significant statements from each interview
- developing clusters by comparing the whole data set, grouping significant statements into clusters to represent commonalities of experiences
- developing the clusters into themes to produce exemplars.

This model was adapted and further changes were included that were based on the work of Smith (1997), Smith et al (1999), and Willig (2001) who provide frameworks for interpretative phenomenological analysis (IPA). This model uses processes of interpretative engagement with the texts and transcripts to attempt to unravel the meanings contained within them (Smith, 1997). Philosophically this model was useful as it involves seeing the person as experiencing and making meaning in these experiences (Eatough and Smith, 2006). It offered a flexible and non-prescriptive approach which could be adapted

as necessary to suit this study. Willig (2001: 54) further suggests that this method takes “an idiographic approach whereby insights produced as a result of intensive and detailed engagement with individual cases (for example, transcripts or texts) are only integrated in the later stages of the research”. These processes, and those outlined by Koch, Smith and Willig, were therefore helpful as an approach. They were also suitable for analysing multiple interviews and diary data in this study. Figure 6.1 provides an overview of these models.

6.5 Koch and Smith’s models –an overview

The following offers a summary table of the steps used in analysis.

Table 6.1 Koch and Smith’s models

| Stage | Koch, 1993 | Smith,1997 Smith et al, 1999 Willig,2001 | What? | How? |
|-------|--|--|--|--|
| 1 | Read through the entire subject’s descriptions for a sense of the whole-making sense of them | Read and reread individual texts | <ul style="list-style-type: none"> ▪Make wide ranging and unfocused notes ▪Write comments, descriptive labels | <ul style="list-style-type: none"> ▪Ask questions ▪Reflect on original thoughts and observations ▪Identify associations, questions, |
| 2 | Extract significant statements that directly pertain to the investigated topic | Identify and label themes that characterize each section of the text | <ul style="list-style-type: none"> ▪Identify themes | <ul style="list-style-type: none"> ▪Look for essential qualities in what is being represented in the text |
| 3 | Analysis of individual transcript – continue to extract significant statements from each interview | Attempt to introduce structure to analysis | <ul style="list-style-type: none"> ▪List themes and think about relationships between them. ▪Label themes to capture their essence | <ul style="list-style-type: none"> ▪Go back to original data to connect themes with original data. ▪Ensure themes are connected with original data |
| 4 | Develop clusters – compare whole data set | Produce a summary table of structured themes | <ul style="list-style-type: none"> ▪Use quotations from each theme to illustrate them | |
| 5 | Develop themes | Integration of cases (A) | <ul style="list-style-type: none"> ▪Integrate summary tables for individual participants with the experiences of the group | <ul style="list-style-type: none"> ▪Generate master themes, lists of |

| Stage | Koch, 1993 | Smith,1997 Smith et al, 1999 Willig,2001 | What? | How? |
|-------|-------------------|---|--|---|
| | | Integration of cases(B) | <ul style="list-style-type: none"> ▪Use the summary table from first participant in the analysis of subsequent cases ▪Full integration generates a list of master themes which captures the quality of the participants' shared experience of the phenomenon under investigation | superordinate themes and constituent themes |
| 6 | Produce exemplars | | | |
| 7 | | | <ul style="list-style-type: none"> ▪Write up findings using examples of text | |

The processes outlined by Smith and Willig differs from Koch in that each text produced by participants is analysed one-by one, which was appropriate as three interviews were undertaken with each mother, and three diaries were recorded. The individual cases are integrated only in the late stages of analysis as the ongoing interviews and diaries were completed. Later integration was important as ongoing data collection meant that the whole would have been out of date by the end of data collection. This adapted model was used flexibly which fitted with my approach of collecting data over time. In using the model, diary recordings were considered text and added to NVivo and analysed with the interview transcripts.

The first stage of the model used involves reading and rereading each text to produce wide ranging and unfocused notes that reflect original thoughts and observations. These included associations, questions, summary statements, comments on language use and absences or descriptive labels. My initial impressions from the transcripts of the interview data were recorded in my researcher journal, and later in NVivo memos. In stage two, emerging themes were identified and labelled. This involved note taking, manual colour coding of text and creating nodes in NVivo.

In stage three, structure is introduced into the analysis. The researcher lists the themes identified in stage two and thinks about them in relation to each other. Clusters of concepts and themes that share the same meaning are developed that are given labels to capture their essence. These can be in vivo terms used by the respondents, brief quotations or descriptive labels. At this stage it is important to ensure the clustering of themes make sense in relation to the original data. To ensure this the researcher has to move “back and

forth” between the list of themes and the text that generated them in the first place to ensure the connections between the themes are reflected the detail of the respondent’s accounts. This involves constant questioning.

The fourth stage of analysis involves the production of a summary table of the structured themes, together with the quotations that illustrate them. Within this process, only those themes that capture something about the quality of the participant’s experiences of the phenomenon under investigation are used. This means that some themes developed earlier will be excluded, either because they are not well-represented in the text, or they are marginal to the focus of the enquiry and the phenomenon.

It is at this stage that the researcher reviews the corpus of data (all cases) to obtain a more generalised understanding of the phenomenon. At this stage the process of integration is carried out in a cyclical manner, whereby any emerging higher order themes are checked against the transcripts. This ensures that integrative themes are grounded in the data just as much as the lower level conceptual themes are. The aim of the analysis was to identify elements, themes and sub-themes in descriptions of the human experience and to find language that captured the themes and sub themes. This was achieved by following the series of sequential steps described.

6.6 Application of the analysis frameworks to this study

An overview of how Koch and Smith’s models of data analysis were used within this study is reported. The analysis framework developed by Willig (2001) was applied to each of the interviews and then to all the interviews in totality.

6.7 The manual phase

Step One: Read and reread the individual texts

- Following each interview I downloaded the data and saved it as a data voice file on personal computer and compact disc. (Recordings were sent for transcription during this phase). Word files were similarly saved. Each was individually labelled and saved in named folders.
- Each interview was printed when it was transcribed.
- I listened to each audio recording immediately after each interview and made notes on my initial impressions and key issues.

During this phase I was asking questions of the texts. These questions included:

- What is the mother describing?
- Is this relevant to the focus of enquiry?

- What is relevant?
- Why is it relevant?
- Is it similar to other mothers' experiences?
- Have other mothers reported this?
- Is this usual?
- Is this unusual?
- Does this fit emerging patterns?
- I checked the data emerging with each audio recording and the written transcription, constantly going between them.
- I made wide ranging, unfocused notes and jottings in a research diary. Initial descriptive labels were identified.
- I also reflected on my original thoughts and observations. I recorded emerging associations, themes, commonalities and questions within the texts.

This process continued with the data collected from each mother. Emerging themes and key issues were confirmed by reading and rereading the texts, and listening to the audio recordings. Emerging issues were clarified during subsequent interviews with mothers as necessary.

Step Two: Identify and label themes that characterise each section of the text

- This process continued throughout the data collection phase. Key issues were identified by asking the same questions as described in Step 1 and one additional question:
 - Is this a key issue?

Emerging themes and key issues from individual interviews, and between interviews, were further confirmed by rereading, listening and making associations.

Step Three: Attempt to introduce structure to analysis

- Each participant's interviews were analysed and clear associations between all interviews were sought.
- Similarities between mothers' experiences were identified and documented.
- The questions asked at this stage were:
 - What are the mothers describing?
 - Is it similar to other mothers' experiences?
 - Have other mothers reported this?

- Is this usual?
- Is this unusual?
- Does this fit emerging patterns?
- What emerging themes are appearing?

Step Four: Produce a summary table of structured themes

- Once structured themes began to emerge these were recorded in researcher notes.
- Questions were again asked of the texts, both by reading and listening to the recordings.
 - Is there similarity/commonality in other mothers' experiences?
 - What are the commonalities/key themes?
 - Does this fit emerging patterns?
 - What emerging themes are appearing?
 - Are new themes emerging?

At this stage, given the nature of data collection, I was able to clarify and confirm emerging themes with mothers during ongoing interviews. I consulted with peers, experts and my supervisor to confirm the identified themes.

Step Five: Integration of cases

- This was achieved by cross checking each mother's data with the findings emerging from other mother's data. Questions asked included:
 - What are the common issues emerging in other mother's experiences?
 - What is common between the mothers' experiences?
 - What is less common /uncommon in the experiences?
 - Are new emerging themes appearing?
 - Are identified themes converging /coalescing?

Again, in this stage I was able to discuss emerging themes with mothers/peers/experts for clarification and confirmability. Key and common dimensions were identified.

Step Six: Writing up

- This involves presentation of the themes including quotations from respondents to illustrate the themes. Reflexivity should be addressed. The discussion should link the emerging themes with those in the literature.

In this phase I spent a significant period writing and rewriting my findings, having them confirmed, and developing a clear and coherent report which accurately represents them.

The use of this framework encouraged prolonged engagement and immersion in the data and enabled the development of a clear understanding of the complexity of the mothers' experiences. It helped identify the commonalities and differences in these experiences, and offered a flexible, analytical and coherent framework for data analysis. I did not, however, use line numbers for clusters and themes and summary table was not created, except in outline form, as NVivo can do this automatically. I also identified all the themes in the data in stage four and proceeded onwards with all themes, rather than, as Smith et al suggests, where only those themes that captured something of the phenomenon under investigation should be used. Culling data at this stage was not appropriate in my view and remained a dilemma in the ongoing data analysis. In this study data was culled in the write up. The model was, therefore, flexibly applied and adapted. Manual coding was replaced by computer management of data in July 2006.

6.8 The computer management of data

There was a significant volume of written data amassed at this point, that included interview transcripts, diary recordings and researcher notes. In order to manage these data it was necessary to use a software package for management and retrieval. At this stage of the study (July 2006) a data management package (NVivo V7) was introduced to handle the data analysis. This computer assisted software package encourages an exploratory approach to data analysis. Fundamentally, the software supports the storing and manipulation of texts or documents, and the creation and manipulation of codes, known in NVivo as "nodes". It was selected as it was reputed to be relatively simple to use as I was familiar with Windows, which is compatible with it. It also encourages researchers to develop "a constant playing of ideas and data" (Gibbs, 2002: pxxiii). It was easy to ask question after question of the data and to follow up hunches about interpretation, using many of its functions. It enabled me to create and examine new ideas about the data by searching and linking ideas (Gibbs, 2002:16). The model explorer included in the package, that can be used for diagrams, initially offered a flexible way of expressing ideas, though I found this cumbersome, a distraction and time-consuming. Modelling was not used for reporting results, though it offers great potential for visual presentations.

This software enabled bulk data records to be moved swiftly into a project (Richards, 2005). In it my emerging ideas and results of my thinking were recorded rapidly, however trivial they seemed. This was helpful, but given the changing and developing nature of thinking in this type of study, it is very difficult to record all insights, which were sometimes jotted in a research diary.

At this stage I had already ‘opened up’ the data, and emerging themes and commonalities had been identified (Appendix 10), but the software enabled complex memos and annotations to be recorded as data were further analysed. I recorded my ideas in this way and noted questions about what was emerging. Gibbs (2002:11) suggests that software can “help the researcher to keep good records of their hunches, ideas, searches and analyses and give access to data so they can be examined and analysed”. It enabled me to link my research notes and data as emerging themes became evident. Making connections between one piece of datum with another was made easier. Using models and diagrams was possible as themes and links emerged, though drawing ideas on paper was much easier.

Whatever the software tool selected, and however helpful it may be with the management of data, it cannot do the analysis, nor can it do the reading and thinking for you (Gibbs, 2002). All software will only do what you ask of it, so care is needed as there may be a danger of asking too much, and over-dissection of the data may occur.

There are further disadvantages in using management software that I was aware of and there was always a concern that by using this programme, I would become distant from the data. I had a feeling that by using a paper based approach I would be closer to the mothers’ words, and to my research notes. Listening frequently to the audio recordings kept me grounded in how things were being said. It was easy at times to lose the sense of the data and I found analysis much easier from the recordings rather than having to read masses of written text.

The NVivo software also emerged from grounded theory approaches so, while appropriate in this study, it may be better used in theory generation, as its functions enable this with ease, with case and cross case connecting, which is not appropriate in a phenomenological study. In this study data management software was utilised after data collection and after the initial coding of the emerging themes, unlike the process in grounded theory. Following manual coding of the data, NVivo was used to manage the data. Again, the model used in manual coding was applied.

6.9 Data management using NVivo

6.9.1 Step 1: Read and reread individual texts and research notes

Using NVivo, individual texts were read and coded to free nodes. Significant statements that captured the essences of the mothers' experiences were identified and coded into free nodes (similar to files). This enabled me to bring parts of the data together so that they could be reviewed, and that my thinking about the emerging themes could be developed. NVivo also enabled me to inspect, interrogate and interpret the data (Richards, 2005). It helped to identify and report, not just the texts as described by mothers, but to give the results of analysis deriving from my work with the data.

When coding the data a number of strategies were used. Questions were asked of the text, dimensions of the themes were sought, patterns were looked for and analytical coding was used. This is central to attempting "to unravel the meanings contained in...accounts through an interpretative engagement with the texts" (Smith, 1997:189). At stage one, descriptive coding and topic coding were used, and questions identified previously were used to interrogate the text.

At the end of stage one coding, 179 free nodes were present. Each free node related to a concept, area or common theme that was emerging from the data, which would be further developed in analytical coding subsequently. Examples of free nodes at this stage included mother's descriptions of their child, getting the diagnosis, and care related to seizures and breathing. Initial diagrams of the findings were attempted in NVivo, but were abandoned in favour of paper ones. The technical aspect of this seemed so time-consuming and removed me, I felt, from the focus of enquiry.

Before moving to the next stage this initial free noding was repeated in its totality. This gave me an opportunity to revisit the interview data and to rethink, if necessary, the emerging free nodes and to ensure recently created free nodes captured all relevant data as ongoing analysis occurred. With hindsight I am not sure if this was necessary but it helped with confidence building in the use of the software.

6.9.2 Step 2: Identify and label themes that characterise each section of the text

In stage two creating categories (forming tree nodes in NVivo) enabled free nodes to be categorised and grouped together. Those with shared commonalities were moved and arranged into themes and hierarchies using tree nodes. Connectedness and similarities in mothers' experiences were sought which were documented in NVivo memos and annotations. At this stage the previously outlined questions were asked. This questioning enabled the management of rapidly expanding data by facilitating the expansion of my

ideas, and by enabling me to organise, support, and record emerging themes. This enabled early ideas to be built up, or ignored, as firm constructs were developed (Richards, 2005) and helped with speed, reliability and efficiency of data management. Using tree nodes had the advantage of enabling the exploration and demonstration of relationships between data in free nodes. Searching between nodes and trees to create relationships between the data within them was easy. NVivo enabled the review and strengthening of ideas, and to the clear identification of major dimensions in the data in a traceable way.

6.9.3 Step 3: Attempt to introduce structure to analysis

This was achieved by identifying key issues and similar themes that were emerging and trying to make links between the mothers' experiences. Initial free nodes were printed, read and re read in an attempt to identify patterns and to begin to identify the key issues and commonalities. Tree nodes were used to group similar themes together into the three emerging worlds. 'Coding on' was used in NVivo to demonstrate these structures.

6.9.4 Step 4: Produce a summary table of structured themes

In this step, free nodes and tree nodes with original content from transcribed interviews were created and a summary of the tree nodes developed. This was managed in NVivo, which facilitates a summary report of analysis, and data can be moved and copied between nodes and trees as themes emerge. Further initial coding and coding on to new tree nodes was undertaken in this stage.

6.9.5 Step 5: Integration of cases

This stage involves the integration of cases and identification of master themes. In this phase, clusters were integrated into the main themes emerging; that is that mothers' experiences are bounded by an inside world, an outside world and a going-between world. Within each of these worlds themes were identified. Smith's model suggests that these worlds are the superordinate themes and master themes, which I suspect could be used for theory generation, if this had been the research approach. I used key themes at this stage as the three worlds emerged. There were themes common to each of these worlds, which were evident. Constant communication and other themes also emerged and were linked together in the data.

6.9.6 Step 6: Writing up

In this stage excerpts from NVivo were moved to a Microsoft Word programme and write up continued. Coding was used to provide a framework for the written report.

6.10 Summary

In data analysis, the model outlined was used flexibly and NVivo was used to assist in data management. NVivo enabled me to identify key content, and to link this with my interpretations. New ideas and changing interpretations were recorded easily by the insertion of annotations, memos and researcher notes in the data and analysed texts. It helped to record levels and processes of analysis, and emerging patterns within the data. Annotations and memos record questions I asked of the text and record my ideas and emerging issues. It forms part of an audit trail in data analysis.

6.11 Challenges in the analysis of data

6.11.1 Using NVivo

Within this study it was two years before I implemented the use of a data management package to handle the huge volume of data that had been collected. I used NVivo with some trepidation, as technical expertise is not my forte and technical support, though excellent, was limited by not being readily at hand. However, once this apprehension was overcome, the package became relatively easy to use. NVivo did however, cause me some concerns. The first was the time needed to acquire the skills to use it, which for me removed me from the data and meant that ideas and thinking were sometimes lost. At times I felt that I was over-dissecting the data in my search for meaning, and depersonalisation of the data became evident as I analysed it. At times analysis was all consuming, ever growing in nature, and increasingly complex as I tried to look at the multiple texts in various ways to check the emerging themes. The manual data management, while consisting of huge amounts of paper was, by comparison, relatively familiar and reassuring as highlighted colours appeared from cut sections of paper text. I found it difficult at times to think in a hierarchical three-dimensional way using NVivo and often reverted back to paper to make diagrammatical representations of my findings. NVivo did enable me to jump back easily to the data and to examine the context of coded or retrieved data. This is still easily done as I am asked questions about particular aspects of the findings. NVivo has been criticised in that its functions seem to be too influenced by grounded theory (Gibbs, 2002) and at times I was conscious of this. I sometimes felt the pressure to connect nodes, to trees to hierarchies and to develop a theory, to the extent that in November 2006 my diary recording indicates:-

Am I doing grounded theory or phenomenology? There is a tension in moving from free nodes to trees to form a theory-a theory could be generated about the constancy of caring and its dimensions using the free nodes...I need to remember the focus of enquiry and to stick to it....phenomenology.....get inside the circle and see what's there...How does this compare to what I knew before, to clinical practice? Stick with it.

This dilemma was discussed with colleagues and my supervisor at the time.

6.11.2 Analysing and interviewing simultaneously

Initial plans to undertake all three interviews with each mother before starting the next set of data collection was not feasible given the constraints of arranging interview times (Nicholl, 2007). This made the process of data analysis problematic at times, as many interviews were ongoing simultaneously. However, I was able to use this opportunity to verify emerging findings. The initial manual phase of analysis proved to be very important in identifying emerging key issues and themes early.

6.11.3 Using software, multiple interviews, models of analysis and anonymity

I have no doubt that NVivo, despite its flaws, made analysis possible given the volume of data collected, but I would caution against its use without adequate preparation, understanding and practice. As Richards (2005:33) notes “making qualitative data is ridiculously easy. The challenge is not making too much data, but rather making useful, valuable data, relevant to the question asked”. NVivo was helpful in managing the quantity of data but the analysis caused me concerns and some unease at times. Within the literature, models for data analysis may be appropriate for a single interview technique, particularly if using a structured approach, but for multiple interviews they need adaptation. Dilemmas also surround the culling of data during analysis and deciding what makes data irrelevant; is it because it does not fit in? Is this not worthy of attention? In this study data included discussions, for example, about family pets, school activities and other intimate family details. To cull this, when I felt it was all part of the mothers' experiences, remains a dilemma.

I was further concerned about the micro and the macro aspects of analysis and a tendency to code the data line by line, rather than analysing “the whole”. The issue of decontextualising the data and totally dissecting the experience was managed by continually returning to the audio recordings. This constant re-engagement with original data enabled understandings to be checked and rechecked. This gave me a sense of security by reminding me of the real experience being investigated. Finally, the written data and

report, particularly when data was made anonymous, did not have the same sense of realness or humanness as the original data. Using numbers to protect mothers' anonymity did not feel comfortable so all have been renamed and identifying markers removed. I feel, however that in this text, Breige is not the same as Bridie, nor Karen the same as Carol and some loss of identity and personal characteristics has occurred. I am not sure if this is over-involvement with the data, or is a consequence of undertaking human research, where a connectedness between the researcher and the researched needs to be developed.

6.11.4 Hermeneutics and data analysis

From its introduction, hermeneutics indicates that “the meaning of a part can only be understood if it is related to the whole”; that is, a Biblical text can only be understood if it is related to the whole Bible (Alvesson and Sköldbberg, 2000: 53). The basic concern of hermeneutics is the revelation of something hidden. Alvesson and Sköldbberg suggest this type of hermeneutics is “alethic” in that it is derived from the Greek *aletheia* or “uncoveredness”. One of the criticisms of hermeneutics, they suggest, is that rules for interpretation are rejected, and that efforts to establish general rules have always faltered when it comes to application and to specific areas and cases. They further suggest that the process of interpretation and sub interpretations should be permeated by the whole and the part, and by the researcher's preunderstandings and understandings. The interpretation of the whole text is successfully developed by the interpretations of its parts, and conversely the views of the parts are illuminated by the view of the whole (Alvesson and Skölbberg, 2000:66). Retrospectively I found the analysis process difficult in that dissection of experience, in my view, may lead to a new understanding and interpretation, but in doing this the original meaning can be lost in places, given the volume of text being analysed. At the same time alternation between preunderstanding and understanding is taking place during the interpretive process, which can lead to dilemmas and choices in interpretations. The understanding of the new text demands preunderstandings or prior understandings; yet at the same time, preunderstanding, if it is to be developed, demands understanding of the new text. Yet this is also bounded by the situation existing on the day and at the time of analysis. Understanding must continually refer back to the earlier preunderstandings, which must be developed by the new understanding, leading to a constantly fluid and moving situation, that can be difficult to explain and describe. What was a theme one day in the data seemed not to be the next.

A criticism of this approach to analysis is that it implies openness to multiple interpretations. Alvesson and Sköldbberg (2000:66) suggest that “if the scales are tipped in

favour of a certain interpretation, there is nothing to stop new arguments from appearing the very next day”. They suggest that a “polyphonous” account of different interpretations, or at least of possibilities for interpretations, is moreover, a form of honesty towards the reader. It is, however, hard to make this visible and the different interpretations that occurred throughout are not reported. What is reported is the interpretation that had to be fixed so that the study was completed. On another day, or with another year, other interpretations may emerge.

6.12 The ‘I’ in analysis

My understanding of the data was continually changing. Continual rethinking occurred and, my interpretation activities were inextricably linked in the analysis, but the complexity of the processes was, at times, difficult to explicate and fully describe. In a study of this nature the final report is not consequently a research report of what has been found; rather it is giving voice to my interpretation at a particular point in time; this provided an ongoing challenge. Having once written and reread the interpretation, it was always possible to rewrite it again as a new interpretation emerged. Within qualitative phenomenological studies, therefore, a key issue is when does understanding between the researcher and the researched merge and end. In this study the horizons were constantly changing with time and further reflection. Issues that at one point seemed central became background, and the foreground was continually changing. My understandings, as I engaged with the data, the literature and clinical experiences were constantly changing as the real life world of the mothers emerged.

I used a framework for analysis, which appears linear and uncomplicated. For this reason, Smith’s adapted model was used but it, too, does not make explicit the link between the researcher’s preunderstandings and the data. It is suggested that any model needs to have a stage where preunderstandings, and the interplay between these and the data, is made explicit. From a philosophical perspective this framework does not, I feel, fully acknowledge the interplay between the researcher and the researched, or between the preunderstandings and data emerging from the mothers’ stories. The process of analysis, for me, dissected the whole into smaller parts, though the model does accurately identify the stages of analysis. It offered a framework that enabled me to build up a detailed picture of the phenomenon under investigation, that is mothers’ experiences of caring for their children, as it is embedded in the narrative of their individual life world (Eatough and Smith, 2006).

However, there appears to be a lack of integration between the fusion of horizons that is a philosophical concept in this method, and the analytical processes that identify the changes in understanding that occur. This play and interplay is demonstrated by exemplars, but the total process of cognitive change is difficult to fully report. The processes of analysis, I feel, cannot be derived from the specific application of a particular model and the processes of sense-making need explication. Wolcott (2001) suggests that we should allow for intuition, recognition of past experiences and emotion, basically the personal attributes of the researcher and these need incorporation. Dey (1995) suggests that there are three 'I's' involved in this process, and lists them as insight, intuition and impression. For me, the explication and exploration of the three 'I's' in the study, and the need to demonstrate them in the written word, was a challenge throughout.

6.13 Conclusion

Within this chapter details have been given of the processes of analysis undertaken in the study. It has provided an understanding of how the description and interpretation of the mother's experiences of caring for a child with complex needs emerged from the data and how this emergence was impacted upon my preunderstandings and fore-structures. Smith's adapted framework has been outlined and its application to this study discussed. The complex processes undertaken have been reported and the 'immersion in the data' and 'being in' the analysis have been discussed.

In the following three chapters the findings from the study will be reported and discussed.

CHAPTER 7 – THE FINDINGS AND THE INSIDE WORLD

7.1 Introduction

Within Chapters 7 to 9 the findings will be reported. The aim of the study was to use a hermeneutic phenomenological approach to gain a greater understanding of the nature and meanings of the experiences of mothers caring for children with complex needs. This chapter includes a description of the mothers and children and outlines the three major sections of the findings: the inside, outside and ‘going-between’ worlds experienced by the mothers. The details of the mothers’ inside world are explicated and excerpts from the data are used throughout to support the findings.

7.2 Alteration to transcripts

Within this submission identifying markers have been removed. Pseudonyms have been used for the mothers and all mothers are represented in the findings. Personnel and sites have been anonymised. This is indicated by #. Impersonal pronouns have replaced other names throughout to help with clarity in reading; for example, father’s name is replaced with dad*, the child’s name with child*. I have removed some text and this is indicated by...(3 dots). Brackets indicate the addition of my text to provide context and the removal of other potential identifiers. Quotations are indented without parentheses.

7.3 The mothers

Ten mothers who provided data were from the RoI and seven from NI. Each family’s biographical background did emerge during the study but cannot be explicitly reported for reasons previously outlined. Fourteen mothers had one child with complex needs and three mothers had between two and four children with complex needs. One had young adults with unrelated complex needs. One mother had experienced the death of a child prior to the study. Two children are known to have died before the completion of the study while others were deteriorating throughout it. One mother herself had complex needs. Four mothers were working outside the home in education, health care and in their own businesses during the period of data collection.

Background information on geographical location is provided in Table 7.1 and marital status in Table 7.2.

Table 7.1 Geographical location

| Geographical location | | | |
|-----------------------|----|------------------|---|
| Republic of Ireland | | Northern Ireland | |
| Co Cork | 2 | Co Antrim | 2 |
| Dublin | 2 | Belfast | 2 |
| Co Limerick | 2 | Co Tyrone | 2 |
| Co Louth | 1 | Co Fermanagh | 1 |
| Co Meath | 1 | | |
| Co Wicklow | 1 | | |
| Co Westmeath | 1 | | |
| Total | 10 | Total | 7 |

Table 7.2 Marital status

| Marital status of mothers | | | |
|---------------------------|------------------------------|------------------------------|-------|
| | In a two parent relationship | In a one parent relationship | Total |
| Republic of Ireland | 9 | 1 | 10 |
| Northern Ireland | 4 | 3 | 7 |

7.4 The children's needs and diagnoses

The children had a range of complex conditions which, for some, had a diagnostic label but for whom deterioration of their illness meant that they needed respite care, if this was available. Diagnoses included rare, metabolic, cardiac, chromosomal, connective tissue genetic and neurological disorders, rare syndromes and 'no specific diagnosis'. To name their diagnoses would identify the children involved, as many of the conditions were very rare, so broad descriptors have been used.

Table 7.3 Examples of medical diagnoses similar to children in the study

| Type | Similar diagnoses |
|---|---|
| Metabolic disorders* | Galactosaemia Hunter's syndrome Hurler's disease Mucopolysaccharidoses Phenylketonuria |
| Neurological disorders** | Cerebral palsy Cerebrovascular accidents Hydrocephalus Lissencephaly Microcephaly Neurodegenerative disorders Spina bifida |
| Genetic disorders** / rare syndromes | Chromosomal deletion syndromes Collagen storage disorders Complex cardiac disorders West syndrome |
| No diagnoses*** | Developmental delay Pervasive developmental delay No known diagnosis Suspected unknown genetic disorder Undiagnosed metabolic disorders |
| *In some families more than one child had a metabolic disorder ** In some families there were children with both rare and neurological disorders *** In some families more than one child had no specific diagnosis | |

The children had a range of complex needs and requirements for care. These varied but most had previously or currently, required assistance with feeding including using alternative mechanisms including percutaneous gastrostomy (PEG) or nasogastric (NG) tube. They needed assistance with mobility, personal hygiene and bladder and bowel management. The children required regular and intermittent medications for specific symptoms associated with seizures, progressive deterioration and acute illness. The children needed care to manage individualised symptoms, including abnormal startle

responses, unremitting crying, self-harming behaviours and hypersensitivity. They required ongoing hospital admissions for diagnosis, symptom management, preventative treatments and recurring illnesses including infections and seizures. The children had undergone a range of surgical interventions, some of which occurred during data collection.

Table 7.4 Children in study

| Age range of children in study | |
|--------------------------------|-----|
| Under 5 | *10 |
| Five -19 | *10 |

* In three families more than one child had complex needs. These figures do not include other adults with complex needs in the families.

There was one more girl than boy described in the study. Some children had more than one condition/diagnosis as is common; for example a child might have a chromosomal abnormality and epilepsy, or a neurological disorder as a result of progression in metabolic disease. Some children had learning and physical disabilities. No children of ethnic groups, other than white European, were included. All but one child was under 19 years of age.

7.5 The children

Mothers gave very comprehensive pictures of their children and their needs, which provided an initial reference point from which to explore their experiences of caring. Mothers often selected to talk from the point of diagnosis, or from the first suspicion that something was wrong, to the present. For mothers, noticing that something was different about their child was the beginning of their experiences of caring in three worlds, in which eight key dimensions were found to be present.

Imelda's experience sets the scene.

Imelda:

He* is now 4...doing exceptionally well...at a stage where we would not have dreamed he would be at...(He) was born looking fine...my husband* ...felt he 'wasn't right'...I took a look at his hands to see was he Down's Syndrome?...Dad* said to me 'his head'...'you're wrong'...His dad*...knew straight away something was wrong...head size, the gap ...between his brows and his hairline was too short. So...we got a paediatrician to have a look at him and he agreed '...there is major, major brain damage...he is severely, severely damaged...has a chromosome disorder.'

7.6 Findings

7.6.1 Overview of mother's experiences

For most mothers the delivery of a healthy baby is a happy event. They know their babies will require clothing, feeding and nappy changing and that they need to protect them. Mothers expect their children to emerge relatively unscathed into adolescence, perhaps apart from minor childhood illnesses. However, in this study mothers' experiences were dissimilar when they, either at time of birth or soon thereafter, found that their baby was exceptional or different in some way. For them motherhood was very different and the normal progression from dependence to independence that occurs through childhood was not part of their experience. Mothers are confronted by complex, unremitting care-giving that occurs in three worlds and comprises eight dimensions.

7.6.2 The emergence of three worlds

Mothers provide care in three complex worlds and their experiences of caring are bounded by the environment. These experiences are contextualised firstly within an inside world, within the home, where the child and the family are present. It is a physical space bounded by the walls of the home, and is a world that others, including the extended family and carers, enter at times. Secondly, there is an outside world external to the home, where the child may, or may not be, present. It includes the world of the hospital, health care facilities and the social world of the mother and child. Thirdly, there is a 'going-between' world of travelling between the two other worlds; this involves car journeys and travelling outside the home with the child to any venue outside the physical walls of the home. The mother may be on her own or with other family members.

7.6.3 Common dimensions

Within the worlds, eight common dimensions emerge. All exist, to a greater or lesser extent, in each of the three worlds. The dimensions permeate all three worlds but for clarity they will be presented under the world where they are most evident.

The inside world

1. Care giving

This is care giving in which the mothers are involved and comprises of:

- Normal mothering; that is, care delivered by all mothers.
- Technical care-giving; that is, care requiring specialist skills and information.

- Pre-emptive care giving; that is, care that has a preventative component.
- Individualised care giving; that is, care explicit to meet the child's particular needs.

Care giving is most obvious and most time-consuming in the inside world, but it spans all worlds as wherever the child is, care must be given.

2. Paperwork and administration

This is a time-consuming role in the mothers' experience and is related to getting physical, financial, educational and technical services and assistance for her child. It occurs mainly in the inside world, although it straddles all three. It frequently requires the mother to leave the inside world.

The 'going-between' world

3. Constant instability

This constant situation occurs because of the child's unstable condition, progressive deterioration or susceptibility to recurring illness. It requires the mother to be constantly alert, and responsive to potential problems requiring further immediate intervention.

4. Constant observation

This is the constant state that is required in mothers because of the complexity of the child's needs and their ongoing changing and unstable condition.

These two dimensions are present in all worlds but are more apparent in the 'going-between' world as the mother has the added challenge of travelling whilst maintaining her constant watch and dealing with emergencies as they arise while on the move.

5. A 'no-choice' situation

This is a component of the mother's experiences as she finds herself in a situation in which there is no choice but to do what she has to, to ensure that her child's needs are met, no matter what the circumstances. As the child's mother she has no choice but to do what she has to do to care for and protect the child.

This dimension permeates all three worlds equally as it is an ever-present facet of the mother's life, but is most apparent in the 'going-between' world as she is forced to make journeys despite the difficulties of travelling.

The outside world

6. Knowingness

This is mother's expertise in all aspects of their child's care. It includes mothers' constant alertness of, and reaction to, any change in their child's needs that impacts on their delivery of care. The mother develops knowingness to manage the child's care in the

absence of help from others. Although this knowingness is present at all times, again it is more noticeable when the mother goes into the outside world and meets others. Her in-depth knowledge and understanding of her child and her child's condition are highlighted in comparison with the 'unknowingness' of others.

7. Unknowingness

This is a lack of understanding by others. Mothers face, confront and have to manage unknowingness when she meets others who, because of a lack of awareness of the child and their needs, do not fully understand the situation. Others do not necessarily want to develop knowingness of the mothers' situation which can result in avoidance, isolation and poor relationships with them.

8. Constant communication.

The mothers' experiences include the need for constant communication to meet their child's needs. There is an 'always connectedness' with the mother that is facilitated by the mobile phone that ensures she is always available to respond to, and for, her child's needs. This is vitally important for her when she enters the outside world on her own, leaving her child in the care of others. It is also common for others to use it frequently to communicate with the mother, about the child's needs.

These are specific and core dimensions of the experiences of caring for a child with complex needs that are common to all mothers and occur in varying degrees in each of the three worlds. Each mother's situation differs in the way these dimensions influence her experiences and depend on the child's individual needs and situations. Each of these worlds will be individually explored and the dimensions explicated.

7.7 An inside world: an interpretation

The mothers' experiences of caring for their child occur within an inside world at home that is bounded by the physical space. Depending on the family formation, membership includes the child, the mother and siblings and father/partner. In this inside world of confined and adapted space mothers deliver normal mothering, and technical, pre-emptive and individualised care, that are influenced by the child's condition. It is a fragile, unstable world in which constant observation plays a significant role; where the mothers continuously make decisions and problem solve. It is a world where sudden deterioration in the child's condition can occur, progressive deterioration becomes apparent and end of life care, with all that this entails, may be required. Adaptations and medicalisation alter this space and can confine movements around the home for both mother and child. Where

the child is placed at any time inhibits the mothers' movement about the home and her ability to undertake normal household tasks or personal care. Using complex equipment is part of care-giving in this inside world. Mothers perform normal mothering tasks, for example, nappy changing, but the duration of this type of care is prolonged as independence does not occur. Significant skills are used in technical care-giving and to reduce its physical impact 'turn-taking', where limited care is sometimes provided by the father instead, occasionally provides help. Mothers are unable to undertake some aspects of care and needing two people was identified when the father or others were needed to assist with care-giving. In this world mothers attempt to meet the competing demands of caring for other family members, while meeting her child's complex needs. She manages normal mothering tasks for siblings, family activities and maintains her relationship with her partner. Everyday household tasks need to be undertaken but are influenced by how and where the child is. It is a 'no choice' situation where the child's needs are given priority as the mother tries to maintain normal family life. The child offers much to that family life where all is not sadness. The inside world is a private world of the mother, child and immediate family. It is also a world, for some mothers, where sudden worsening of the child's condition occurs frequently and progressive deterioration is common. The two main dimensions identified in this world were "care-giving" and "paperwork and administration."

7.8 Care-giving

All the mothers were involved in care-giving for their children that included 4 components of

- Normal mothering
- Technical care-giving
- Pre-emptive care-giving
- Individualised care-giving.

7.8.1 Normal mothering

Mothers' care-giving includes normal mothering related to the activities of daily living including dressing, bathing, and toileting and maintaining child safety.

Rachel explains:

Needs help with just about everything, dressing, feeding...very determined, lovely nature...demands a lot of attention...enjoys one to one. She enjoys ...role

play...things that don't need...fine motor skills...she can finger feed a little bit
...you need to sit with her for everything.

However, as normal developmental milestones do not occur, mothering is challenging, prolonged and develops over time. Mothers consequently provide ongoing care as most children's needs became increasingly complex with age. Children's dependency also increased as the children deteriorate or complications occur. This was evident in relation to all activities including feeding, toileting and mobilising.

Imelda:

He doesn't want to take the bottle as much as he was...he's just not able for the bottle.

Weight and height increases impact on the mothers when caring becomes more complex and maintaining mobility and safe positioning becomes an important facet of care-giving. Needing larger nappies and mobility equipment as the child gets older, for example, adds additional aspects to normal mothering.

Anita:

I couldn't bath her on our own. We had to have two people to bath her. She was so wriggly and you had to have two hands to hold her.

Initially, when the child is an infant, normal mothering skills are managed, usually with limited help from others, including the family. In some families fathers, family members and carers do offer some help, but, generally, mothers manage this type of care for the child. Asking for, and finding help with care is problematic as the child grows and their care needs become more complex and do not follow the normal developmental path. Normal mothering of infants is quickly added to by the need for technical care as the child's needs become complex.

7.8.2 Technical care-giving

Mothers' care-giving involves providing highly technical aspects of care. The changing and ongoing nature of the technical care-giving was evident and additional care demands were common to the children.

Rachel explains:

Cerebral palsy...quadriplegic...dystonic ... changing tone...very little balance...all 4 limbs are affected...her facial muscles...speech...drilling, very limited hand function...doesn't walk,...very bright ...understands everything...sleeping pattern is very mixed...Sometimes she'll be up several times...with pains or needing to be turned...I do her oxygen therapy... sick now if she had a trigger food...Every winter

she's had like a chest thing and she's been admitted...She needed a nebuliser...have one for her at home, so when she's ill this winter she didn't need to be admitted...She gets the usual bugs...now been diagnosed with asthma.

Technical care-giving included management of children's airways, shunts, bowel washouts, urinary catheterisation, dressings and medications. Mothers are skilled in simultaneously managing technical equipment and multiple procedures including oxygen saturation monitoring and using suction and feeding pumps.

Niamh:

She has a PEG tube...can't have anything orally...requires suction and physio...very chesty.

Paula: [from her normal day diary excerpt]

Prepare the mixture for (child's*) bowel washout...inject 800mls through her ACE procedure ...diarrhoea...catheter time...shower time...physio.

For most children physiotherapy, occupational therapy and speech and language exercises were undertaken by mothers to improve and maintain progress. They deliver alternative therapies, including conductive education. Mothers are regularly involved in post-operative treatments and interventions in the children following a wide range of surgical procedures undertaken to prevent complications. Mothers consequently delivered additional technical care including the management of children with Plaster of Paris, PEG tubes, hip spicas and the associated therapies and treatments. In providing technical care, mothers identified their role in the early detection and management of any changes in the child's conditions. They were skilled in monitoring their children for signs of deterioration, changes in normal patterns or behaviours, the onset and management of associated illness, including respiratory and urinary infections, neurological symptoms, vision, communication and hearing disorders.

Brenda:

He's actually been very chesty for the last week and a half...he hasn't needed more oxygen...He's needed more nebs but he hasn't needed an extra antibiotic.

Mothers were skilled in detecting and managing other symptoms indicating deterioration or the onset of seizures or illness. They reported, and during the interviews demonstrated, a heightened sensitivity to their child's physical needs and any deterioration or improvement in the child's condition, no matter how slight.

Denise:

She...woke up screaming...it was clear that there was something wrong. Her neck was very distended.

This involved highly technical assessment, observation, problem solving and decision making skills.

Dara:

It kind of depends; in the winter time, I think you probably need to use it (suction machine) more. Like I've used it more or less every night.

Mother's care-giving experiences included technical feeding, seizure and medication management skills which included using a range of technical equipment and support devices. They included mobility equipment, walking and standing frames, wheelchairs and gym equipment, special beds and bathing equipment. In no homes, however, were lifting devices seen which is relevant given the potential for back injury and that mothers reported difficulties in moving the children.

Helen:

She is...a great size...very long. So mm that is getting a little bit, I actually pulled a muscle in my back a few weeks ago lifting her as well.

Using technical equipment meant that mothers were involved in ordering and maintaining it to ensure adequate, appropriate supplies were maintained. Mothers had the responsibility for getting updated or larger versions of the equipment needed as the child grew and often had to travel outside the home to get essential equipment and to complete the paperwork needed to ensure it was received on time. The child's need for technical care required this essential equipment always to be at hand and the need to use it at speed limited the mothers' mobility round the home, particularly between downstairs and upstairs. If the child was downstairs then the mother was downstairs or if she moved between rooms then the child and any equipment had to follow. Technical care-giving always had to be available and mothers were in a state of constant preparedness to deliver care

Imelda:

I mean to go to the bathroom out there literally you've to wheel him out the door so he can watch you going to the loo, because you can't leave him.

In addition to physical and medical care mothers had to ensure that their child's social, psychological and educational needs were met through a variety of services, both in and out of the home. Mothers reported needing to advocate for their child for health care and service provision. A further key issue were the dilemmas in care-giving which the mothers constantly faced due to the unpredictable changes during the child's illness. Constant instability was a feature of the inside world.

7.8.3 *Technical care-giving explicated in feeding management*

A significant volume of data related to many aspects of care-giving required by the children so, to explicate technical care-giving, only data related to feeding management will be used.

Feeding is very much part of mothers' technical care-giving experiences and its nature changed and became more complex over time as the children developed complications, deteriorated and could no longer swallow. Technical care-giving included the challenges of spoon feeding children with poor swallowing and using alternative methods including NG tubes and PEG feeding for those with neurological impairment. The time taken to feed, feeding regimes, overnight feeding and the technical issues associated with ensuring nutritional requirements were met and weight maintained in the children were significant issues. For many mothers help and advice with this aspect of care was often limited and unhelpful and they frequently had to manage to do their best in difficult situations. Early feeding difficulties and the lack of advice about how to manage technical care-giving were well remembered. Karen, whose child had a rare disorder including an oral deformity, explains;

Karen:

Very poor feeder...got her home...like a wee mouse; drops of milk...not putting on weight at all...What we didn't know...she had a sub mucus cleft palate...Trying to get her to feed, that was the biggest, biggest battle... didn't put on weight, very puny and tiny...She cried for about the first year...constantly...She was probably hungry all the time... One lovely doctor did say to me... 'we never made you any promises, you know feed her anything. I don't care, iron bars. Whatever you want to feed her, to get weight on her'.

Weight gain in children was an obvious marker of growth, development and normality and caused mothers concerns that were reinforced by unhelpful comments or advice. The importance attached to weight gain by health professionals added to these concerns and to the attention mothers gave to feeding and weight gain in their children. Tube and PEG feeding was initiated without education and advice being available, often leaving mothers to do what they felt was best to maintain feeding and weight. Technical care-giving often involved battling and struggling for prolonged periods, in the presence of unhelpful advice and with a lack of specific help or planned management. Anita explains the difficulties:

Anita:

Brought her home...feeding difficulties continued...a struggle...a complete aversion...I fed her for 5 weeks...traumatic for her...traumatic for me. I said 'this

isn't fair...put her onto the bottle feeding'...We wouldn't even get a mil into her...We struggled on...struggled on...She was tube fed...no matter how you tried...she just was not able to do it...For the first year and a half...pretty horrific....Then she would be aspirating...refluxing...vomiting, eh rings around her...5 or 6 seizures every single day ...for the year and a half...It was decided to get the NG...And he (neurologist)...said 'this cannot continue...I don't know how you have kept the child alive for as long as you have'...They decided on the NG tube feeding because they felt at the time she was quite frail.

Finding appropriate help and advice with feeding was problematic. Anita, like other mothers, indicates that interventions to help were opportunistic, in her case based on a change in doctor, rather than a decision following formal assessment. If this child had not been admitted it is difficult to know how much longer her mother would have struggled without help. For many mothers finding help to manage all aspects of technical care-giving occurred opportunistically, or through luck, rather than as a planned approach. For mothers luck, rather than planning, was an influencing factor in implementing alternative feeding methods.

Brenda:

NG tubes...for...his first year...It got blocked ...We were on holidays in Spain...rang the doctor...He said 'there's nothing really you can do but just try your best'. So we took the tube out and started orally feeding him and we've been doing that ever since...They were threatening to put...one of those PEGS into, but they said that if he's doing well...then leave it the way it is.

Mothers did not explain why planned interventions and help were not implemented but it may be related to the unknown trajectory of the children's illnesses. Mothers felt that the professionals were often adopting a cautious 'wait and see' approach with the children, rather than active intervention. Given the problems mothers encountered, this lack of help and advice in feeding management was significant and caused emotional concerns and practical difficulties, with an obvious impact on mothers' well-being. This results in difficulties in relationships between mothers and health professionals who provide incorrect information and demonstrate a lack of planning for the children who have significant, ongoing difficulties with feeding. Conflict between mothers' knowingness and unknowingness in professionals of the actual difficulties mothers have was apparent.

There were psychological and practical impacts of changing to, and managing alternative methods of feeding on mothers. Changing to tube feeding was significant and added a dimension of tension in normal mothering, and to conflicts between mothers and family

members. The removal of oral feeding adds emotion to this situation. Tensions in normal mothering between feeding to develop the normal sucking responses, emotional bonding and the practical realities of having to tube feed add to the complexity of technical care-giving. The conflict between the impersonality of tube feeding and the pleasure of giving her child a 'food treat' adds to the mother's dilemmas.

Helen:

I just couldn't do it anymore...so I just said... 'She's going to be tube fed' because it was just easier for me. My husband tried for a bit longer...I'd go to the shop because I just couldn't watch it. It was too hard. He'd try her with the bottle and I would come back...all over the floor...so disheartening, and it still is a little bit because some days you give her, her spoon feed there, and you think, 'oh that's great now'. Now it's not for the nourishment at all obviously. It's just for the novelty for the taste so we give her all the nice stuff like the strawberries.

In relation to changing to tube feeding their children, mothers recalled their reactions to this and 'no choice' situations that were encountered in their desire to get the child home from hospital. They did not report on any discussion on discharge about feeding management except their keenness to get their child home and a lack of help. At home mothers identified pragmatic difficulties with managing the tube itself. Unhelpful advice again resulted in difficult relationships between mothers and professionals, with a conflict between mothers' knowingness and others' unawareness of the need for help, information and the practical issues mothers faced in managing tube feeding at home when they were alone or at night. Difficulties in technical care-giving included the replacement of the NG tube and the steps taken to avoid its removal by the child, and illuminate the dimensions of pre-emptive care giving (Section 7.8.4) and constant observation (Section 8.4). Some mothers were willing to persevere with bottle feeding, and all that this entails, rather than manage overnight tube feeding.

Brenda:

It frightened the life out of me...I'd rather stick to my guns with the bottle...than have him feeding over night on a nasogastric tube because one night we woke up and the tube was half way out...And I thought 'oh my god...he could have choked in the middle of the night and we wouldn't have known'.

For some mothers passing a NG tube on their child was beyond their practical capabilities, despite their ability to manage other technical care-giving activities successfully.

Ciara:

I could probably have done it to another child but not my own. So, no. I couldn't.

Technical care-giving was therefore complicated at times particularly when two people were needed. Tube changing frequently required a second person, which was problematic and required either the child's father to help or someone else had to be found. The need for two people applied to many other aspects of care including physiotherapy, bathing, moving and transporting the child and heavy equipment. This often left mothers in a difficult position of having to arrange care needs around father's schedules or on occasion to do the best they could in a 'no choice' situation. One mother described how hospital advice was that she should be able to change a NG tube 'easily on her own' and that wrapping the child in a towel was a solution. This advice was unhelpful and unrealistic. Such disregard of the realities of the mothers' difficulties results in them being dismissive of those who demonstrate a lack of understanding of their situations at home.

Within any study of this nature, events can be captured serendipitously. Two children had PEG tubes inserted during the study, which provided an illuminating perspective on this feeding method that is common in children with complex needs. These data add to the nature of technical care-giving, decision making and the emotional aspects of mothers' experiences and illuminate the practical and emotional difficulties this causes. Other mothers reported similar experiences and deciding to change to this type of feeding was difficult. A lack of support, advice, help and the emotional impact of PEG feeding was evident.

The decision to have a PEG inserted is a difficult one for mothers, adding dilemmas to their care-giving when their normal mothering is challenged.

Frances:

...And I probably have a bit of a problem up here (pointing to head) about a PEG because I don't think it's a picnic either...I don't think it's going to be the answer to our prayers...It's several things. First of all, I think it's a mother thing...right from the beginning I have fed her myself...I think attaching her to a machine...is something that I have a problem...a block about that...the coldness of attaching her up to a pump, it's true.

However, knowing the child was getting the correct volume of feed, and a reduction in vomiting and medications that could be easily administered helped reduce the mothers' concerns and improve their knowingness (Section 9.3).

Imelda explains:

We were left roam around ourselves which was absolutely appalling ... after braving it out...doing an NG tube...Now he's PEG fed for most of his feeds. Mammy still tries...because I love to give a bottle...he loves a bottle but you have

to have him very upright for it... all his medication goes in through the PEG and that's great... We know what he's getting. We know it's staying down.

When problems arose in PEG management mothers frequently had to manage on their own, seemingly without help or appropriate advice. The need for additional equipment added to the stress of mothers' caring experiences. Mothers' technical and problem solving skills are rapidly developed in no choice situations (Section 8.5). Helen, whose child also had a PEG inserted, explained the complex situation faced by mothers. A Foley catheter acted as a temporary PEG tube in her child, and the lack of information and local support is apparent and the necessity of having to travel for three to four hours to find help in a regional hospital was not a choice.

Helen:

They put her on Zoton fast tabs...They told us you could put it through the Foley catheter and it blocked it. So I was here. Could not feed her, couldn't give her drugs. There was no one that would touch it. I rang the hospital (local #)... 'You can bring her in ..' I said 'what will you do?' ...They said they would be trying the same as I was, fizzy drinks and stuff to try and clear it. Mm, other than that it was go to (city#)...The last thing we wanted to do was to head up to (city#), so... I said 'oh what will I do?' We were going to take her in the next morning if I couldn't clear it. So last option, I got a chop stick and...I went poking at it...and I got it clear. I kept on drawing back and pushing...I tried every sort of drink...She was covered in Coke (laughing) so I was drawing back and pushing in Coke and going at it with the chop stick...I must have been at it for...an hour or two...I got it cleared so we were delighted.

Having a PEG inserted did improve feeding in some children but it added to mothers' problems and work in finding carers or family members who were skilled in undertaking this task or who had to be taught the procedure. Mothers often opted to manage themselves as it was easier for them than teaching others, including fathers, to be competent.

All aspects of technical care-giving, including feeding, impacts not only on the mother but also on the other caring responsibilities that they have in relation to siblings and husbands or partners in the inside world. Mothers reported on practical issues they faced in meeting the competing demands of caring for the child and others. The dilemmas faced in caring for siblings were reported. Helen explains:

Helen:

But, the hard part is putting sibling* to bed. Before with sibling* we read her a story every single night from the bed, while that's gone. Now sometimes I would

get to do it but she'll have to, it had to be on the couch because I can't go upstairs and leave her (child) down here. Maybe for a split second, I run up and I tuck sibling* in, and sure if I stay any few minutes you can hear her below (child) having a seizure, so I'm back down again, so it's like 'night, night, ok', close the door...I feel bad doing that to her because she just got so much attention before.

Within the inside world turn-taking is used as an attempt to share the child's complex caring demands of care where parents take turns to provide care; this is further explicated in the outside world (Section 9.2) and the consequences of this response are discussed.

7.8.4 Pre-emptive care-giving

A third dimension of care-giving is that of pre-emptive care where mothers identified care they provided in addition to highly complex technical care-giving. Pre-emptive care-giving was provided in all three worlds. It was used commonly by mothers in many situations, for example, when children were being discharged from hospital, when planning the equipment needed for home, or when going to hospital. It is identified from mothers' reports of care-giving in which they indicated the preventative steps they took in all aspects of care. Prevention of accidents or injury is part of normal mothering but the uniqueness of the children's needs and the rapid deterioration that occurred added to the pre-emptive dimension of care-giving. This was needed to manage symptoms including the children's poor mobility, reflux, cold, hypersensitivity and risk of serious haemorrhage that added to the complexity of caring. Mothers are required to be proactively involved in assessing changes in the children's conditions, identifying their severity and possible consequences, adapting treatments, problem solving, decision making in very difficult, rapidly changing and tense situations with often, apparently, little support.

Mothers reported on using pre-emptive care-giving, like technical care-giving, in a very matter of fact way; as if it is a natural part of their everyday experience that they accommodate without question. They just seemed to know what to do and reported using a range of options in managing these issues, including watchful waiting, altering medications and using comfort measures. They demonstrated high levels of 'knowingness,' and asking for help or advice from others about what to do in these situations was a late measure, perhaps due to previous unhelpful experiences with 'unknowingness' in others. Whatever the reason, mothers' responses indicated that this was a 'no choice,' unstable world. The physical and emotional impact of the experiences on the mothers was evident. Pre-emptive care-giving is implemented to prevent things happening or 'just in case' and is linked to knowingness (Section 9.3) and constant observation (Section 8.4). It includes the actions

mothers take, because of their knowledge of the child's needs and their awareness of changes in their child's condition. Mothers reported altering normal caring activities to attempt to prevent complications or deterioration from occurring. This is the mother's response to difficult situations, for example, when she has to take the child out of the home where she knows the child's normal routine will be interrupted and the consequences of this. Pre-emptive care-giving included changing feeding volumes and times and altering medication regimes to ensure that the child did not vomit or was seizure free during journeys. It included taking steps to prevent problems arising, for example, constipation or weight loss.

Janet:

He can't go to the toilet himself even still and we had him on medication for it...And we could go 5 or 6 days... when he would go then he would burst himself... he is on milk now and it didn't make the constipation worse. I don't think it did, his weight flew up again, thank god. But we had to watch his weight because he has a tendency to lose weight.

Pre-emptive and technical care-giving were closely linked as mothers described constantly looking for clues as to what might be wrong with the child and using processes of elimination to identify the cause and to manage it.

Helen:

You know you were constantly watching it...her little MICKEY button... was a little bit sore when she came home after getting it done. We put her on an antibiotic just in case there was a bit of an infection and she is getting cream on it and a little dressing...

7.8.5 Pre-emptive care explicated in seizure management

There was a large volume of data related to the many aspects of pre-emptive care-giving provided by mothers, so only data related to seizure management will be used to explicate this type of care. In mothers' reports of seizure management they described managing highly complex skills and ongoing decision making about the child's care. Their 'knowingness,' and the steps taken to help develop their knowingness of how to manage situations, emerged. Mothers whose children had epilepsy, which was common to children with complex needs, described many experiences of life-threatening situations in the three worlds, where pre-emptive care was provided. In describing the care needed by children with seizures, mothers described pre-emptive care-giving in rapidly changing and difficult situations, often when little or no help was available. They described their experiences of

hospital admission for management. Some children were relatively stable while others were completely unpredictable and unstable, despite medications. Mothers identified the sense of instability that pervades their lives and the complex care-giving in which they are involved. Many of the eight dimensions, including constant observation and technical care-giving coalesce in these descriptions. The issues and dilemmas mothers face, their experiences with health professionals and carers, the changing situation during the deterioration of the child's condition and end of life situations were reported.

Anita's daughter has epilepsy. Pre-emptive care is identified in the explanation of her child's difficult to manage epilepsy.

Anita :

36 hours old...going floppy and unresponsive ...having threshold attacks...She stopped breathing while I was changing her nappy...I started blowing into her mouth to get her going again...I took her home... eye rolling episodes...twitching at the side of the mouth, the hands used to go...They were quite subtle but they were obvious...5 or 6 seizures every single day...Mm, she is good...her seizures are well under control. I don't expect it to last too long, it never does...She has had two seizures before you came today...they were just the eye rolling episodes...very mild...hysteria attacks...I have Diazepam in the fridge...we were using this 3 or 4 times a week...very volatile even if she had a very small elevation of temperature, slight...if she was tired...if she got upset, if her nose got blocked she would take a seizure.

Pre-emptive care-giving in medication management often involved altering dosages particularly to prevent and manage seizures. Mothers identified managing medications based on the child's responses during seizure management and using drugs that they knew needed to be used. Brenda reports:

Brenda:

If he gets 2 or 3 in a row I'll give him a Stesolid to try to pull him out of it.

In relation to pre-emptive care mothers also reported weaning children off drugs when they felt they were no longer of benefit or if the child appeared to be better off without them. Their knowledge in drug medication and seizure management was evident.

Frances:

We started to withdraw her off the medication and she became like a different child. Her seizures reduced, she still had them but she was having them anyway on the huge doses and the interaction that we got back from her and still do

now...seizures can be very bad one week and...can be very good...So her drugs are obviously having nothing to do with it...

Complex medication management, problem solving and decision making thus form part of the mother's care-giving in unstable situations. Pre-emptive caring emerges from Dara's description of her experiences. Like other mothers she developed knowledge of what to do based on her previous experiences. She identifies the matter of fact way in which mothers cope with very difficult situations:

Dara:

He was about 2 weeks old and we started noticing funny patterns. I didn't know anything about epilepsy so I didn't know what it was...burst suppression seizures...patterns of jerks...40 of those, say 30 sets of 40 seizures. After a lot of to-ing and fro-ing he ended up in hospital for about 3 months...he was diagnosed...went on a whole diet of drugs...one drug to another...He went through Diazepam...all various kind of seizure suppressors...but he settled on Epilim and Seconal and they more or less brought him down...Stopped having seizures about 2 years ago...He hasn't actually had any seizures since unless we try to mess with the medicines...He was seizure free for a year and he started again. It wasn't exactly the same sort of seizure...his eyes were rolling...to the back of his head that you'd know that a seizure was coming on. He was starting to do that again, so we just bumped it back up to normal and it was fine.

In weaning children off medications and altering dosages mothers made significant decisions, often apparently in the absence of any specific advice. Medication management involved high level decision making as mothers attempted to try to establish some stability. They discussed medication management knowingly and without concerns; it was part of their responsibilities to do this. Mothers were aware of what worked for their children and what did not and used this knowledge in pre-emptive care. The complex processes of decision making and mothers' knowingness was evident.

Orla, for example, describes her child's seizures which commenced when the child was 11 months and their impact as the child's condition changes.

Orla:

She was on Epilim and now we've tried her on Tegretol and now we're weaning her off Epilim to see whether the Tegretol is the better... and we tried the oral Diazepam and Respiradol.

Pre-emptive care, similar to other aspects of care-giving, was ongoing, evolving and long-lasting with physical consequences for the mother and the family:

Helen:

... she was getting probably around at least ten, thirteen seizures a night so we weren't getting a lot of sleep.

The potential side effects of the medication complicated the child's care needs further and added to care-giving. There are also dilemmas in seizure prevention that mothers have to face as they are aware of the implications of medication dosages on their children.

Helen:

She gets Diazepam...up to maybe twice a week...She needs way more than that but we just can't give it to her all the time because; Well one thing is she's totally whacked off her head then all the time...We tried to wean her off Epilim because her Epilim levels were way too high and I don't know whether it's that, or whether it's having a bad effect on her, or maybe it's just her.

The complex nature of pre-emptive care mothers are involved in delivering, including that related to feeding, drugs and seizures, adds to the constant complexity of technical caring and the constant observational state that mothers need to be in at all times. Night time causes mothers to be in a state of heightened awareness, and disturbed sleep, with its physical sequelae, is part of the mothers' experience, even when others are caring for the child.

Helen:

(child*) sleeps up here at night time because I can hear the seizures through the wall otherwise. Even when dad's minding her I can hear the seizures sometimes, but I just roll over and go back to sleep. But we get up for every seizure she gets...I can't leave her for a minute.

Pre-emptive care can include the use of additional technology and mothers described many steps that they took to ensure early interventions to prevent deterioration.

Frances:

Well we have the baby monitor down here but I can hear her in her room... So it's very rarely at night when she has a seizure which is great.

In addition, technical caring and pre-emptive care-giving is impacted upon by the practical implications of the high levels of medications needed to control seizures. Consequently, the children needed frequent investigations, examinations, hospital admissions, blood tests for drug levels which add to the uncertainty that is part of the mothers' experiences. They cause mothers to need to go into the outside world, as no alternative is available. The degenerative nature of some of the children's illnesses impacted on the complex nature of both seizure and medication management.

Mothers described how they tried to identify possible causes for any deterioration in their children and when pre-emptive care was needed. Mothers tried to develop their knowingness by looking for the reason for the seizures, or changes in behaviour that could guide them. Again unhelpful advice is reported:

Brenda:

... and we had to increase it back up and he's now back up at his maximum dose... he's starting recently to get more seizures... When he developed the seizures first it was very strange because we'd always been told you'd know it when you see it but at first I hadn't a clue, all he was doing... a jerk... is it his chest infections? or is it his seizures? And if he has an infection his seizures get worse so it's kind of a mix really... It is a vicious circle and then he's teething... That causes seizures too and I noticed that from the very start, his seizures got very bad one time and then I realised gosh he's teething.

Pre-emptive care-giving changes over time as new challenges in care-giving and dilemmas emerge during the deterioration in the child's condition requiring the mother to constantly develop new skills.

Imelda:

We're just kind of going into another area that it's kind of just a bit, can't say a bit unknown but just it seems a bit different again at the moment... so we're just concerned ourselves, ..He's sleeping a bit more than he would be normally which is always, for us is more concern because you know when he's sleeping he's worn out with something so we'd just be watching the 2 of those things very closely. The doctor that we're dealing with... her recommendation to try this because we go as high as we can with 2 other drugs and we'll have to introduce a 4th drug now which sounds fine to somebody else but we kind of feel it's an awful lot like that he's on, you know.

7.8.6 Pre-emptive care and ethical challenges

In care-giving mothers faced difficult ethical choices in relation to the children's management, particularly in the late stages of the disease. They reported the pre-emptive steps they took and the technical care-giving needed in very challenging situations.

Helen:

We don't rush into the hospital... when she goes into constant seizure. We deal with it at home, because ... as far as we are concerned there's nothing they can do in the hospital that we can't do here, bar stick needles in her, which we don't want. I was

giving her IM injections for her infantile seizure spasms...They put her on ACTH injections... I gave her those at home... and I pass her tube myself and there really is nothing I don't feel that I can't do for her at home...that they do in a hospital. So, we also have decided that she has the DNR (Do Not Resuscitate) done up so she will not get IV antibiotics if she gets pneumonia or she's not to be resuscitated. She's not to go on life support anymore...she can be in constant seizure or she can get one seizure an hour or maybe one every two hours...We give her either Diazepam suspension, Diazepam, Stesolid, Midazolam or for emergency, Chloral hydrate, but really you might as be well giving her water (laughter) ...sometimes they work, sometimes they don't.

These ethical challenges were particularly difficult when mothers knew what their child needed when others were less knowing.

Frances:

I told him that in the past she gets even worse on medication and he mm he is actually very good but he is old school but he is very funny really, whatever he does can't offend me anymore but he said mm – "... It's like this, I see her having a seizure in front of me, it's very severe, I am offering her this medication, if I don't put her on this medication and she has a seizure and she is dead in the bed in the morning and you have a very good solicitor I am for the high jump"...She has been up to 2 days ago on ...medication and since her PEG has gone in but I am weaning her down off it. I see no improvement in her seizures, you know, so what is the point...it's all to be expected. This is like a plan, and actually you can see, not that the doctors know, but you can see that the paediatrician and the neurologist she is just fulfilling the prophesy of the doom and gloom that they painted in the beginning, that she will deteriorate, and this is the beginning of the e.n.d. (word spelt out).

Seizure management and ethical decision making impacts on the difficult relationships that mothers have with health professionals involved in their child's care. Unknowingness in others impacts on the mothers and complicates relationships with others in the outside world (Sections 9.3 and 9.4).

7.8.7 Individualised care-giving

The fourth aspect of care-giving that mothers provide is individualised care which is closely linked to technical care-giving and pre-emptive care. The mothers described a wide range of less complex, but equally important, individualised care needs which required

their attention. Individualised care resulted from caring for children whose needs changed over time, and added to the complexity of caring. Individualised care was needed for a range of symptoms, which added to the complexity of caring in the mothers' experiences, and is additional to technical care-giving and pre-emptive care. It was required to prevent physical or psychological injury in the children, which added to the constancy of observation needed. It impacted on the child and family leaving the inside world as mothers tried to prevent, or pre-empt difficult situations.

Rachel reports on a "startle thing" that her child has and its impact.

Rachel:

She* can't cope in crowds of people or indoors...she gets upset...can't do social situations at all...just screams...uncontrollably...just the sudden change in tone, it shocks her... it would happen constantly...It's a dreadful thing because she* wants to go and integrate in certain situations and she can't. She just has no control over it...It's very limiting, it's the most... it's the most disabling thing for her.

Mothers identified many other specific aspects of their children's needs, including unpredictable startle responses, continuous, unexplained, incessant crying, self harm from constant sucking and finger chewing, and other self-injurious behaviours. Episodes of aspiration, unpredicted deterioration, and hypersensitivity to heat and cold add to the complexity of care-giving needed to meet individualised children's needs. These needs varied in intensity and duration; some were episodic or ongoing, and some resulted from deterioration in the child's condition.

Orla:

Just a cry, she's just screw up her face and open her mouth and cry and she wouldn't be nursed. She wouldn't watch the, just as if, you'd think there was a wee worm wriggling over her brain really annoying her...

Individualised symptoms included unexplained unusual weight loss, constipation, behavioural changes and the onset of new symptoms of no known cause, which mothers quickly tried to identify. These needs resulted in the mother having to provide technical, pre-emptive and individualised care in many situations in the three worlds. The individualised nature of the children's needs impacted on the mother and child's ability to go out from the inside world (discussed in Section 7.8.7).

Mothers described many experiences of situations where individualised care was delivered. It was associated with technical and pre-emptive care-giving and normal mothering, as the mothers tried to balance the child's physical, social and educational needs, while also managing these individual needs. Managing to find clothing, for example, for a self-

conscious adolescent with progressive scoliosis, or finding outside activities where others are not present to startle the child, add to the uniqueness of the child's needs and the complexity of the mothers' experiences. They added the need for interventions and constant observation to ensure the child's safety and comfort. Instability, knowingness and unknowingness in others of these individualised needs impacts on care by others and the ability of the mother to leave the child with anyone else.

Imelda, as an example, describes the family reactions to her son and the impact of this:

Imelda:

They're all a little bit nervous of him...They mean well but they're all very apprehensive...They stand back really.

Mothers become so accustomed to care delivery that they often do not recognise its complexity. Paula, for example, was not sure at the outset if she met the criteria to be included, or if her child had complex needs or not. When I explored the care requirements of the child in an initial phone call, she told me that she catheterised her child every three hours. Mothers frequently minimize their care-giving skills. The individualised nature of the children's needs change over time, and as the sequelae of hospital admission. The ongoing constant observation, care-giving, instability, knowingness and unknowingness in a 'no choice' situation become evident.

Some individualised care is apparent to others, while other aspects are little understood by anyone other than the mother, including close family members. This added to the difficulty in finding carers who understood these situations and the uniqueness of the child's needs. Paula explains the constant worry, instability, unpredictability and rapid nature of deterioration in her child's condition, common to mothers:

Paula:

...born with spina bifida...developed hydrocephalus...lesion repair...a shunt inserted 2 weeks old...And then at 3, 3 ½ the shunt broke down completely out of the blue with no...No warning...was her usual happy, happy, clappy self ...and she fell asleep on the floor which in itself wasn't like her...I wonder what's...is she coming down with something, never thinking it would be the shunt...she'd been so grand...up to the hospital...her shunt had snapped...put a complete new shunt ...they'd found was that it had all disintegrated and had wore away...She actually came home like a different child...she went into hospital you know my lovely natured wee girl...as perfect...and came out like a monster, just never stopped crying...cried right through the night, stopped eating, just was horrific, was like a split personality.

The individuality of the children's needs and the instability of the situation mothers' face was apparent. The instability and rapid deterioration, that is common in these children, becomes evident in the mothers' experiences. The unremitting nature of individualised caring, described as a "vicious circle" adds to the understanding of this experience. The unpredictable, deteriorating nature of the children's conditions often meant that unexpected and urgent hospital admissions are needed, with all that this entails; and having to manage life-threatening situations are frequent experiences.

A final dimension to the individualised nature of caring is reported by Frances. Her child had no specific diagnosis, was blind and had epilepsy. She also had a PEG procedure carried out because of deterioration in swallowing, between the second and third interviews. For this mother, as with others, constant crying was a really distressing symptom. It added to the unknowingness of the mothers' experiences as its cause was unclear and it was apparently irresolvable, no matter what technical, pre-emptive or individualised care was used.

Frances:

She has been in and out of palliative stages...it's just a question of when, she rallies and improves and it's great...She is good for a while...you feed her up again...get her great again and then something will knock her back...She is progressive really...drooling the whole time and seizing, you had no interaction...at all...She was just like a vegetable. Your classic, in the chair...her gag was very poor...her medical condition just fluctuates...Her breathing was rapid and she was sweaty...as white as a sheet...Her condition just changes within a few hours...but I don't mind the physical aspects of caring for her, the feeding, anything, but it would be crying I cannot, I cannot bear the crying.

Brenda:

He'd only give you about 5 minutes of a warning to say I'm getting hungry, now I'm really, really hungry...He'd start screaming...he'd start to scream the house down and the only way to calm him down is to feed him but because he's so irate he tends to cough and then choke until he's actually got a little bit of food in him and then he'll calm down.

The complex and individual requirements of these children has significant impacts on the mothers and families and on finding, and keeping, carers to help mothers care for the child. The competency, knowingness and reactions of the carers' impacts on the mothers and, conversely, the impact of having a child with complex and individualised needs also impacts on carers. This, the carer's reactions, and the practical difficulties of finding carers

to help in this unstable situation, adds to the complex nature of caring. For 'policy' reasons, for example, many untrained carers were not allowed to give medications, which can have a significant impact on the benefits of having respite at home. Mothers expressed concerns about the competency of carers in seizure management, and in meeting the child's individualised needs.

Paula:

No, she wouldn't be able to feed or medicines. You see even the home help the odd time I might pop out for a pint of milk but if child* took a seizure or needed medicines they wouldn't be allowed to distribute them. It would be against mm, they wouldn't...not procedure...No, it's not. They would just be afraid of her.

Trusting carers and leaving them alone with the child caused mothers concerns. Unknowingness in others and their inability to demonstrate pre-emptive reduces their practical capabilities and the trust the mother has in them in all aspects of care-giving.

Frances:

...Now it's the seizures. They are very anxious about them.

The anxiety displayed, in turn, reduces the trust mothers have in others in caring for the child and a negative feedback loop is established.

Brenda:

...but it's just...you know, if he was having seizures. Like you know trusting them all...

The complex nature of individualised care provided by mothers in situations in which instability is obvious, constant observation a must, unknowingness is evident, deterioration is common and the future uncertain. The nature and impact of this will be further explored later in the outside world. The inside world of the home for mothers of these children is a world of normal mothering, technical care-giving, pre-emptive care-giving and individualised care-giving. Some further examples are also included in mothers' diary reports in Appendix 10.

Within this inside world, the work of care-giving is added to by the need for the mothers to be involved in paperwork and administration.

7.9 Paperwork and administration

A second dimension in the inside world is related to the administrative roles that mothers have to undertake as manager of care, administrator and advocate for their children. In the inside world of the home mothers reported their experiences of the health care, education,

benefits and social services systems that surround children and how this adds a significant part to their experience of caring and to the instability in the inside world.

The inside world of the home comprised care-giving but additionally mothers also need to navigate many support systems and to take on a significant administrative role in meeting the child's needs for equipment, service provision and care services. These experiences, and their impact on mothers, were evident. The changing demands for equipment and services as the child grows and develops add to the need for ongoing administration. The unstable, deteriorating and changing nature of the child's illnesses adds to this as demands for equipment change over time. Mothers reported on the administration needed to find, and employ carers, and help with their child and the paperwork that this entailed. They clearly identified a significant role in advocating for the child to ensure care services were delivered which added to their responsibilities.

The emotional, physical, social and financial consequences on mothers emerged as they took on this administrative, advocate and management role in the absence of others, or outside help. Mothers' experiences identify the fluidity and instability of their inside world and how, what would seem to outsiders to be simple tasks, proved for these mothers to be a significant role taking much effort and time.

Paperwork pervaded all aspects of the child's care needs from getting equipment, medications or appointments to finding babysitters and carers. Mothers reported the difficulties in accessing services and the problems that arose when care provision changed usually as a response to annual budget or service provision reviews. Difficulties in obtaining services from health boards were common and mothers reported the lengths they had to go to get their case for services understood. Unknowingness by others of the mothers' situations and their needs emerged.

A significant factor in administration was ordering equipment, getting it and going out to collect it, which were major issues for mothers. Delays in equipment deliveries caused mothers much frustration and anxiety. One mother reported unsafe practices that resulted from a lack of equipment. What appeared to be, from the outside, not a significant issue in delivering supplies, was in fact for these mothers an ongoing and persistent problem. Mothers had to spend time and energy continually following up on equipment and services. Getting financial allowances and benefits proved problematic and required constant attention. Niamh described this additional aspect of care:

Niamh:

It is because there is always something else, you could be doing without it, you know.

Mothers reported on having to 'chase things', including simple equipment, drugs and allowances. There was no organised effective delivery system for top-up deliveries of essential equipment except for occasional, unreliable or ad hoc local arrangements. One mother, for example, had supplies delivered by a nurse locally; for another, a helpful pharmacist sometimes delivered drugs but this was unusual. Most mothers had actively to follow up deliveries of supplies and administer restocking, often well in advance of need.

Janet:

That's the only hassle, the same with the nappies...Now I had to put in my order there 2 months ago so that I might have them by July...I think they're too slow at getting the equipment, the equipment is ridiculous.

The range of administration varied from the need for new equipment as the child developed; for essential equipment needed for everyday caring, as well as forward planning for the future. Mothers were very forward thinking, and needed to be for all aspects of the child's needs, as little future planning was evident in service providers. Janet explains the difficulty and lack of knowingness by others of her difficulties:

Janet:

Shoes, like we've made his order now because it could be Christmas they might have them...Yeah, at least 6 months I know it's going to be, which means I have to order a size bigger than he really needs because he's going to need...you never know. Like that's crazy, it's crazy to be that long waiting for something that they've grown out of it.

Administration and paperwork surrounded extensions and adaptations to homes needed to meet the child's changing needs for space and equipment. Delays, obstructions and unhelpful suppliers frequently added to this dimension of the mothers' experiences and caused more work in their already busy schedule of caring. It added to the paperwork that mothers had to undertake, often at the end of the day when the child was settled in bed. Mothers reported on a lack of understanding of their situation by others within care systems and a difference in the systems of ordering and delivery between health services and boards. Unknowingness by others in the outside world thus impacts directly on the mothers' inside worlds.

Martha:

Now I really am tired, I am tired, exhausted, physically, mentally, mm and I don't know what the system, how do they, I mean how and what can I say or do to make them see? I mean, do I have to break into a crumble for the system to understand what I am going through, or are they just going to leave me?

This administration is ongoing and relentless. It forms part of mothers' day-time activity and is also undertaken late in the evenings, which has an impact on family relationships and time for relaxation. Asking for much needed equipment frustrated other mothers as did delays, and little understanding by suppliers was apparent. Chasing and waiting becomes part of the mothers' experiences. It was viewed as an unnecessary battle caused by a lack of understanding in others and is not solely related to health needs.

Rachel:

Then her wheelchair, I was battling about that as well because she'd outgrown her wheelchair and there's a waiting list... I don't know if the word is fight, I don't know another word for it but that's the way I felt...It seems to be what you have to do to get anything....there was all these hurdles then because she had to have a classroom assistant...You had to go then to different bodies belonging to the educational and all the different things and then start all over again.

The constant need for resupplies or replacements for faulty equipment added to the mothers' frustration with little evidence of a proactive approach from health care providers, suppliers or services. Delays in ordering equipment by health staff needed follow up with little recognition or understanding of the impact of the delay on the child's care and the unnecessary paperwork this caused for the mother. Often failures in these outside systems were reported, which compounded the administrative role and the technical care-giving in the inside world. It added to the mothers' physical difficulties in care-giving.

Anita:

But she (therapist) didn't put in an order for the child...I couldn't bath her on our own. ...so eventually I just said 'look we have to get something for the bath for her'. So she had been assessed and the order didn't go in for 8 months...So I rang the suppliers who gives you the sanction and they hadn't received the request at all. I said 'you know I have been told the request had gone in' so I didn't go to the OT and say 'look you haven't sent it in...' I said that I had rung the suppliers and they haven't got the request. I said 'would you re-issue the following month?' and then I rang again and I said to her 'I will be ringing', I said, 'every Friday...until it's sanctioned...' 9 months waiting for it, maybe 10 months. It was ridiculous but that shouldn't have happened, that should not have been the case.

This administrative role was added to by a constant moving of the "goal posts" in provision which added further instability to an already unstable situation.

Rachel:

The one that the (health services) was offering her... the wheels weren't big enough so she couldn't reach them. So I went to price them... about 2,500 (money) and it was just luck that..., one of the reps...said 'this one here is being discontinued'. So I'm getting the actual chair for 950 (money) and I just thought that's great and I went back to my board and they found some way to pay.

This lack of stability and planning causes the mothers to contend with unpredictable situations over long periods of time. Instability and unpredictability are evident in many of the services that mothers require. This concerns them.

Paula:

No, the (nurse) calls once or twice a year. If they need something...It used to be they would collect the syringes and she told me there a few months ago they won't pay for syringes anymore...It's just one thing after the other. Like at the minute now I have no 5 ml syringes. I have to wait for the prescription... Just at times you just feel like saying 'what are we expected to do?'

Not getting equipment on time was common. In some cases this required mothers to reuse disposable equipment or to "make do". This had consequences for the safe delivery of care to the children, and additionally reduced the time mothers had available for normal mothering.

Anita:

It was so bad that we were actually sterilising our syringes to reuse them. One of the nurses came in and we were like fools standing at the sink washing them and putting them into the steriliser... Could you imagine the length of time washing them?...No wonder the nurse said... 'You're the only family that sterilises syringes'. What could we do?...I said 'yeah this is just not on' and this was taking me away from the child. I'd have her up beside me at the sink and I'd be washing these syringes (laughter) and it was taking time away from her... I said 'this is just unacceptable'. I could be half an hour at the sink washing these things. I could be sitting doing a bit of work with her...Eventually I just said 'I'm not doing this anymore, I am not.'

The mothers' experiences demonstrate a clear lack of understanding by outsiders, including health personnel and suppliers of the children's needs for equipment and medications. Unknowingness in the outside world is evident and significantly impacts on mothers' workload by increasing their administrative role.

Dara:

Like the (health service supplier)...can be quite awkward for wanting new prescriptions every single time you want something. So it can be quite a slow process but the doctor... she's well on top of the ball now. Whenever we ring up...What would you like?' She'd type it up straight away. I would go down and collect it.

Mothers additionally reported on their administrative role with getting help in caring for the child. This included sourcing nursing help from service providers, and finding and employing carers and babysitters. For some mothers funds were available from voluntary agencies. One voluntary organisation directly funded pre-school children with donations that were administered and accounted for by the mother. This organisation withdrew services after this, which caused a gap in service until the education services took over. To use any funding provided to them, from any source, mothers had to find, and employ, staff to help care. Other mothers, who had been unsuccessful in getting funding, had to source and fund services themselves, and pay for carers in the home. Accessing appropriate services for the children required paperwork. For other mothers receiving help from one service meant that other providers did not become involved, often leaving the mothers to negotiate services from multiple agencies, with the subsequent administration this entailed. Rachel describes her role as employer, and how she had to advertise for help when no help was forthcoming:

Rachel:

I phoned (services) because, really, I didn't have the time or the inclination to put an ad in and interview people and so... they weren't interested in helping me find anyone, you know...Just put an ad in the local paper...Got a load of sort of applications.

Within this inside world the child's care needs impacted upon mothers finding and keeping carers who could help them with their child's management. Mothers reported the impact of having a child with technical needs on getting carers and the difficulties experienced with carers in the management of the child. The technicality of the care needed has an obvious impact on the mother in finding help from alternative care-givers but it caused the mothers to be involved in administration. Janet's child's carer, for example, would not ensure her child was fed because the carer perceived this "enforced" feeding as unnecessary and making the child sick. Unknowingness in carers is not helpful to mothers, nor is it readily accommodated by them. This carer was not employed for very long given this unhelpful

response, further adding to the instability in the situation and the need for more administration.

Janet:

I thought she was going to be great but he* had a problem feeding at that time, he was being moved on from liquids to liquidised and he used to throw up a lot. But she kept saying to me 'I am not forcing a child to get sick'.

In their administrative role in the inside world, mothers had to adopt an advocacy role to ensure service provision for their children. Reducing the unknowingness of those in the outside world was part of the mothers' experiences and frequently included advocating for their child. This applied to their children's needs for education, health care, financial and respite services. Mothers gave many examples of how services changed and needed regular review. This lack of constancy created an unending insecurity as well as a constant round of paperwork, as services provision to the families were frequently re-evaluated and changed. Mothers reported on their experiences of lobbying for services, and the significant steps they had to take to get help. This was an ongoing issue as service provision changed on a frequent basis for some mothers due, they indicated, to annual budgetary review. The lack of future planning adds physically and emotionally to the demands of caring, and to the complexity of the mothers' experiences. The mothers' perspectives on how she, and her child, are viewed by service providers add to mothers' concerns and have an emotional impact.

Rachel:

Em so I was very annoyed about this and basically I went to, the principal said to speak to the board and I spoke to the board... Next year I've no guarantee and she's going to be possibly staying in to the same time and I could be coming back in September with a fight on my hands next year. So I thought about it and I phoned the (Commission#)... so I've been up to my eyes...doing that at the minute. I've taken legal action against the...She's being discriminated against because of her disability...We seem to have a very strong case.

Funding, like other services, was under constant review, which left mothers in difficult situations, and there was no awareness in others of how this lack of planning impacted on mothers. Mothers had to contend with services that stopped and started, that were constantly reassessed, and which were often not delivered, despite promises to do so. Funds frequently had to be accounted for and that led mothers to use them no matter how they felt or how useful the service purchased actually was to them, or to face the prospect

of losing the money. Assessments and reviews of services were difficult situations for mothers.

Emer:

They cease to fund her because that is more or less the rules. They don't look after kids forever. So I was left then fighting on my own and I go to (politician*) ... Just say no, we can't afford it like. And I got letters from the (health service) saying, mm the physio is costing too much and there is a budget for kids in care and there is a budget for kids at home... it quoted 40,000 or 50,000(money). So I realised because I had choose to keep her at home that I am making other areas in the (health services) suffer.... Like I didn't choose... In a letter from top dogs you know in the health board. Like I didn't choose...Like, I chose to have a child, but I didn't choose for all of this to happen...Oh I was like a mad woman. (laugh)...Really, really because I said 'if I murdered someone I wouldn't be told how much it's costing to keep me in jail' ...You know, they never say to prisoners 'do you realise because you robbed you are costing the country so much?' ...Like again, if she was in care she would be costing a hell of a lot more... Oh I was mad now, I really was. It's appalling in this day and age getting letters like that.

Asking for help and the practical realities of getting extra help is fraught with practical and emotional issues, as mothers challenge the outsider's unknowingness. Mothers reported on many experiences of trying to get their child's needs understood by others and to find services that would help. For some mothers this involved telephone calls and rejections. For others who managed to get services or funding, this had to be fully accounted for by keeping reports and time sheets, or by recruiting their own help from family members, to fill the hours allocated to them.

Emer:

But it might be stopping now at the end of the month. It's from the (Service#) for the past two years and they give me...(money) and I have used it to pay a carer ...Yeah, I have had it for 2 years. I used to have it from the (health service) and then they stopped it and then...different people have paid for it...But the... money now is gone as well, so I don't know where I am at.

This feeling of not knowing what future plans are made for the child warrants further investigation as a response from health providers. It identifies a lack of planning and it will be linked to not being believed that mothers' experience in the outside world (Section 9.4). For other mothers, delays and procrastination were common responses. Mothers reported 'falling between two stools' when they attempted to find care services. There is a sense, in

the mothers, that services were offered in order to placate them, at least temporarily, rather than as a right for the child. Platitudes by others are not helpful, and a lack of understanding of the mother's situation is evident.

Helen, for example, explains the impact of funding issues and the challenges faced in relation to respite care:

Helen:

We get a week in the summer so far yeah... for the first time last year now. We had to fight to get it... the health board they still haven't paid up ...The (service#) had to step in and pay for the respite... The (health service), it took them six months to, I had to go to (politician*) and everything. I actually put her in the car and went down to him...She was actually at her worst when I went in and he sort of (laughter). 'You shouldn't have to come here. You shouldn't be here at all. What are you doing here? You shouldn't have had to come here'. But I did have to go there... we still had to battle out, send letters after letters to fight to try and get respite for her. They wouldn't pay for the respite, and then they gave out a once off payment for the year, and said they couldn't guarantee anything ...so we were writing the letters again.

Mothers' experiences of service provision are fraught with tensions. Getting services is difficult, keeping them is problematic, and getting the right service to meet their child's needs is equally important to them. They feel that their situation is unrecognised, and that their contribution is often overlooked in others, who the mothers look to for help. There is a tension between saying little and being grateful for what is given, and demanding services that they know should be available to them. Imelda explains:

Imelda:

And we don't want 24 hours a week, you know, care, 24 hours a day... but we do want a small bit of recognition that we are doing the best we can. ...I mean I was on to the (service) this morning which we are entitled to get 3 hours a week from and she said 'you know you are top of the list' .., but I said 'we are top of the list for a year, we have been told that now for the last 3 months, but we are not going anywhere, we are not,..' I wonder, I just wonder if we had, God forbid, a case like MS or one of the other, would we be treated the same way? Is it because he is a baby? Is that the whole scenario? That wait till he is big and old enough and he will shout, you know.

A final dimension in this inside world is related to additional administration roles that mothers undertake in response to being given help from any source. As if care-giving was

not be complex enough, mothers reported on the administration that they undertook as part of their support for voluntary agencies that they had used for advice and support. Within the data a sense of “payback” mechanism emerged in situations where mothers had received help or services from either an individual or a service provider. Mothers reported on giving gifts to carers and helpful professionals, and fundraising for service providers. Given that this was not reported by all mothers it was not further investigated, but it did add to the administration many of them undertook. The reason for it was unclear but I did get a sense that keeping carers “sweet” was an issue, and that gratitude for any help given evoked a need to repay this, even if it was provided by close family members. This is worthy of greater investigation and discussion. It may be due to the fact that these outsiders have demonstrated some knowingness of the mothers’ situations which evokes this response. In my experience this is an issue for families who use respite facilities, who appear to be so grateful for any help that they go to great lengths to repay by fundraising. For me if the services are required for children they need to be available and not dependent on families who need them to fund them.

Imelda:

No, and anything that we can do, I mean anything that they’ve had a few fund raising events. We will go all out to bring family on to support them, anything that we can, you know because you’re hanging on their wish in another way. Do you know that if you don’t get the help from them, you’re out on your own.

The final excerpt summarises the impact of chasing and waiting, which ultimately reduces the time available for care-giving or “time out” for mothers. The frustration paperwork and administration causes, as well as the time it takes are clear. It contributes significantly to the mothers’ experiences of caring and adds a dimension to it. It impacts on the mothers and the children.

Rachel:

From about lunch time I started on the phone to do something and I was on the phone till 4 o’clock doing just different things that needed done... whatever is priority at that stage. I’d be on and off the phone and something else will get left. Things just continually move around the pile so whatever she really needs at that time, that’s what I’m on about. But other stuff... will get left...until I get back to it when whatever is sorted and then maybe it becomes urgent...You spend a high percentage of the time... fighting for things.

Mothers outlined situations surrounding the navigation of the systems they needed to access to ensure their child's needs were met and reported on the additional and sometimes duplicated paperwork, this entailed. These included carer's notes, school reports, school health diaries and medical reports for allowances. For mothers this frequently repetitive, administration not only had consequences in the time this took, but it must have added to the financial and physical costs of caring. Additionally, paperwork was required for house adaptations, negotiation of funding and car replacements. Challenging and managing the impact of outsiders' unknowingness of their child's needs for services is part of the mothers' experiences.

7.10 Conclusion

Care-giving experiences occur in each of the three worlds, but are most obvious in the inside world of the home. The findings indicate that the experiences of caring are not just those of technical care-giving, but involve many other facets including normal mothering, technical care-giving, pre-emptive care-giving, meeting the child's individualised needs and dealing with paperwork and administration. These experiences have physical, emotional and financial consequences for the mothers. These data explicated the children's complex and individualised needs, and the mothers' experiences of caring and administration in the inside world.

In the following two chapters the six remaining dimensions will be explored.

CHAPTER 8 - THE 'GOING-BETWEEN' WORLD

8.1 Introduction

In this chapter the mothers' experiences in a going-between world will be discussed. Mothers' care-giving responsibilities and activities for their children at home involve more than care-giving in an inside world. A going-between world is entered when the mother has to leave the inside world of the home for any reason to travel into the outside world. This is the world of car journeys and travel and the eight dimensions previously outlined also pervade this world. These dimensions are common to all worlds but are impacted upon by the context in which mothers have to deliver care. Mothers' experiences in the going-between world, including constant instability and resulting constant observation required by themselves as care-givers, will be explicated.

8.2 The going-between world – an interpretation

In this second world key issues emerged in the mothers' experiences of caring for their children that were similar to the other two worlds but they differ in that the context of the delivery of all care is difficult as the mother has to maintain the child's physical safety while travelling. Significant pre-emptive care and planning is involved in care-giving. Journeys that mothers face in the going-between world are always problematic due to the child's instability and individualised needs. The going-between world involves situations when mothers have to manage their children's needs in difficult circumstances. In journeying out of the home mothers face situations that can be out of their control, which concerns them when they leave the home with the child. Mothers described their concerns in making the decision to go out, which was not an easy choice unless the reason for the journey was essential for the child. Mothers described the significant planning that was involved in getting ready to go out, and travelling in, this going-between world. Sometimes the journey was with the child on their own, sometimes with siblings and /or the father and other children may have been present.

Transporting the child with complex needs is avoided but, if undertaken, always involves planning, constant observation and difficulties in the car arise due to the child's instability. Journeys always involve difficult choices if the child is to be transported safely. Mothers frequently face situations where they have little, if any, choice but to travel despite their concerns about the child's wellbeing and the significant impact on the child of changes in routine. Often there is no choice but to enter this going-between world, which causes

mothers practical and emotional concerns during the journey and at their destination. There are practical and emotional consequences for mothers, the child and the family in this going-between world.

8.3 Constant instability

This dimension pervades all aspects of the mothers' experiences. Normal mothering in a going-between world for most mothers includes the school run, driving children to social or after school activities that is part of family life. However, for the mother of a child with complex needs, these journeys differed in many ways with care-giving, instability and constant observation evident throughout. The constant instability added to the time pressure of journeys. As well as practical challenges, each mother faced dilemmas and conflict in normal mothering and normalising her situation by taking her child to the outside world. Mothers faced significant challenges in going into the outside world for themselves, the child with complex needs and other children.

8.3.1 Constant instability – the child's needs

These challenges of travel for mothers include managing constant instability which is closely linked to constant observation. Instability was caused by specific issues including seizures and choking but also by the child's susceptibility to respiratory, urinary and other infections, as well as symptoms caused by their specific disorder, and the sequelae of deterioration. The sudden onset of symptoms including episodes of diarrhoea, pain or vomiting added to the constant instability that is a limiting factor for mothers in their decision-making to leave the inner world. Mothers often, however, have no choice because of the child's needs but to go to the outside world for services and help. Constant instability resulted from the children growing and developing, which meant that mothers constantly faced fresh challenges in care-giving as needs changed. Getting into the outside world caused mothers significant practical and emotional difficulties.

Emer describes visiting an outpatient appointment, the instability of her child's needs and the physical, emotional and social impact of managing these in the going-between world.

Emer:

This was the worse day of my life (laughter)...so I asked the (health service) for a taxi to go up to hospital...We couldn't get the buggy into the taxi for starters...we juggled the buggy, got in and me and her got into the back of the car...I hadn't time to eat breakfast between packing and getting her dressed...I was getting sick...I looked and she had poohed all over, all over me...her clothes and everything... The

taxi driver was going to kick us all out... Oh, it was the worst experience I ever went through in my life. I had to just literally change her and put as many poohy clothes into bags and wash my trousers because I was going into a consultants in the hospital with trousers...dreadful experience...and I says never ever again am I leaving this house without breakfast with her...when I go anywhere I have to bring a spare trousers...just to be sure you know.

As the children got older their physical needs changed, adding to mothers' difficulties. Neurodegenerative changes, or other progressive features of their disease, caused the children to lose their standing and sitting ability. This added to the size, weight and volume of equipment needed which increased the difficulties in travelling. These increased when children developed new symptoms or complications of treatments including headaches and cerebral irritability that appeared without warning adding to the instability during travel.

Dara:

It was just horrendous...going out to a party and half way there in the car; in the back seat...just screamed and grabbed her temples and threw up...you know so there's just no kind of warning to it.

Over time, constant instability resulted in increased isolation for mothers in similar situations and caused her to stay in the inside world if possible. Its impact on the mother is closely linked to the other dimensions of care-giving in all worlds. Instability further compounds the mothers' ongoing and changing situation by adding to the paperwork and administration described in the inside world.

8.3.2 Constant instability and being prepared

The complex nature of travel anywhere outside the home with the child required technical care-giving to be provided in difficult, uncontrolled circumstances. The constant instability in the child's condition resulted in mothers having to physically prepare for every eventuality during the journeys and when outside the home. This meant that journeys were avoided if any choice was available, or if they were undertaken they had to be planned in exacting detail. It required that some very complicated journeys were undertaken that had difficult consequences for the mothers, the children, siblings and, occasionally, the children's friends. To travel anywhere outside the home, mothers had to make significant preparations to ensure that the entire range of the child's care needs were met.

Gretta:

Before I go out I have to stand there have I got this, this, this, this for him...his pyjamas...medicine crusher...medicines...Thick and Easy,... spoons...special cups...everything before I go out the door...buggies.

The complexity of entering the going-between world required physical effort and lifting, as the child and their equipment was mobilized into and out of the car. For mothers, the preparations needed were exhausting and they sometimes had to manage more than one child with PEG tubes or multiple physical difficulties as well as siblings. The nature of the child's care needs change over time and transporting the children has a prolonged negative physical impact on the mothers.

Brenda:

But he's harder to manage now because he's bigger... and it's more tiring. Whereas when he was small...he was lighter, easier to manage.

Preparation was complex as mothers had to move the children around the home while maintaining constant observation and moving the equipment to the car. Time pressure was evident and the instability of the child required mothers continually to work around meeting all the child's care needs while simultaneously preparing to leave and move heavy and bulky equipment.

Imelda:

I've a ramp...the chair...a ramp out of the house, a ramp into the vehicle...strapped to the floor. Strap him in, strap to the floor...That's it, and then go. You are taking a fierce chance.

Such preparations were needed on a daily basis for very short journeys if the mother had, for example, to meet the travel needs of her other children including school runs. Often no help was available to mothers for these trips, as fathers were usually working, leaving the mother with no choice but to undertake this journey with the child alone.

Anita:

It takes 5 journeys to the car before I can get behind the wheel and drive. I've counted, just out of curiosity...If I'm planning...to pick her (sibling) up...at 10 past two, I will start...packing the car at maybe half 1...He's only 5 minutes away...With her in my sight at all times...Then you have to plan...when the suction machine goes in because the suction machine must always be beside her. Because she'll unexpectedly, she will unexpectedly (start seizing).

Very occasionally other mothers from the school would help by collecting siblings with their own children and driving them home, but for many such help was never available or

offered. Going into the outside world for longer periods including visits and holidays necessitated significant planning and these types of outside trips were often limited because of instability of the child's situation, despite the mother's wish to normalise the child and family. If undertaken, these trips were planned with much precision and 'just in case' requirements were added to the equipment needed.

Imelda:

The car was laden because you didn't know what you were going to encounter on the day...There is an amount of preparation and there's just so much to bring, to physically bring with you.

This complicated preparation required time, effort and organisation, often the night before travel. Entering the going-between world meant that mothers required two sets of equipment; one suitable for the car and another for the home and outside use. This added to the storage space needed in the home and car, the size of the vehicle and the need for frequent changes and updates of mobility equipment. Mothers needed to be, and were, adept in managing all this, often on their own, while often getting other siblings, and themselves, organized at the same time.

8.3.3 Constant instability and pre-emptive care

The preparation that occurred before journeys involved mothers in implementing pre-emptive caring. They needed to ensure that the child was stable, or as stable as possible, throughout every journey. Mothers always attempted to maintain maximum stability and to avoid potential complications. To achieve this they implemented pre-emptive caring and preparedness. Mothers packed all the necessary equipment that they knew from experience might be needed to manage the child's instability, ready for whatever happened.

Imelda:

In the last week now I've used...8 to 10 Stesolid...So you definitely wouldn't go anywhere without a Stesolid... Everything, you just wouldn't go, you just couldn't like...You're bringing an amount of stuff for a very short journey.

This involved getting extra supplies, drugs and equipment to ensure that everything needed was available in the quantities potentially required. There was no room for forgetfulness, or running out of supplies, and mothers made significant preparations for all journeys to ensure the child remained well and fit to travel.

Gretta:

You'd think you were going away for 6 months...I just took all his medication and all his extra medication, just in case, just in case.

Mothers used pre-emptive care-giving and took steps to avoid and to control the child's symptoms for the duration of the journey. Travel was, therefore, often planned around the child's feeding routines, seizure patterns and medications if possible. This limited mothers' travel at times or put them under pressure to alter the child's normal regime to accommodate travel into the outside world as they knew the consequences of not doing this.

Ciara:

You couldn't go out within an hour of feeding him because he'd just throw up all over the car and wherever you were going... It happened many, many times, all in the car.

Alteration to normal routines included making changes in medication management, giving drugs early, preparing them in bulk, or taking them to administer in the car, which in itself added difficulties for mothers. It further added to the child's instability and mothers were concerned about the impact of changes in all routines for their children. Pre-emptive care had to be maintained during the journey as mothers indicated the risk their children were at because of enforced immobility which concerned them. As part of pre-emptive care-giving mothers took steps to prevent the complications of immobility adding to the equipment needed.

Imelda:

If it was you or I, we'd get up out of the car and we'll walk around and move our legs. (Child*) will be in the same seat, so you're very aware that you've another car seat, or maybe an ordinary buggy to move for 10 or 15 minutes.

8.3.4 Constant instability and the child's individualised needs

Mothers described the need to take equipment as a precaution, that might be required 'to be on the safe side'; to cope with the child's individual needs particularly if the duration of the stay in the outside world was unknown, the venue was new or delays during travel were possible.

Brenda:

I still have to bring the oxygen just in case...a small cylinder just in case...I'll bring a change of clothes...because he can have very bad bowels...Like 2 changes of clothes...his nebuliser and his suction machine...Especially if I'm going anywhere that's...more than 15 minutes away. I wouldn't like to not bring it..., just to be on the safe side...I haven't gone long distance yet without it, so I don't think I will either, you know.

This not only added to the amount of equipment needing to be transported but to the free space available in the car, which consequently impacted on siblings and having others with the mother and child. It limited the distances mothers travelled and the venues visited. Part of the mother's extensive preparations, related to the instability of their child's individual situation, involved checking out the place that they were travelling to, and locating the emergency services available there. This was needed for all new venues.

Martha:

And the nearest emergency service and how far it would be from here to here. It just isn't easy...you know. I don't know what it's like to get into the car and say 'where will we go?'

The child's needs for urgent treatment meant that mothers had to prepare for accidents, emergencies and sudden hospital admission, in visits to the outside world. Mothers were prepared and kept emergency bags packed, and had medical information explaining their child's disorder, and emergency treatment for use in unfamiliar hospitals, with them.

For mothers with other children trips into the outside world were a necessary part of their experiences but were not undertaken with any pleasure. Finding anyone to care for the child with complex needs was difficult and mothers avoided all unnecessary trips.

8.3.5 Constant instability during travel

Entering the outside world for any reason involved significant dilemmas and decision making for mothers as the unstable nature of their child's condition impacted on all journeys. The child's instability required mothers to undertake journeys as speedily as possible which had potentially serious consequences for them and the child. Mothers often reported taking chances in many situations in the hope that the journey was uneventful. Anita outlined her experiences of a journey to a birthday party with her child and their sibling. The instability and the dilemmas involved and how technical care is delivered in dangerous circumstances are evident.

Anita:

It was horrendous...took a chance...She took a seizure on the back seat..., ...had to pull in, on the (motorway)...the hard shoulder...get out ...fly around...suction her a bit because she was spewing...and give her a little bit of sedation...I knew I couldn't turn and go back...She was hysterical...I knew I had to give her the Diazepam...I knew I couldn't do it on the back seat of the car...she'd have hit her head. I just knew it wasn't safe to do it...Yes...I had to do it, I had to do it...I'll never forget it and then the thoughts of driving.

These difficult journeys, in which constant instability was part, is similar to the situations mothers experienced in all three worlds. Mothers, as they did in the other worlds, indicated the natural acceptance with which they treated these situations; they just reported dealing with things and getting on in a 'no choice' situation. They had to manage instability as part of their everyday care-giving experience and were accepting of this, despite the physical and emotional demands it placed on them, and the danger in which it places them.

Martha in her bad day diary reports:

Drove 10 miles...(child) still in the car, bowels has moved again, half way there.

She is now asking me to stop she's feeling sick, she's been sick.

Mothers' care-giving skills were highly adapted to individual circumstances and coping with these unstable situations was common.

Helen:

She is...in the back on her own...if I'm driving...I see her and she will start retching straight away. So it's a matter of pulling over, go back, let her vomit and then get in and drive off. Then she would probably get a seizure. You have to pull up again.

Mothers indicated the time pressure during their journeys and the practical realities they faced in getting to places, and hospital appointments, on time. Instability was managed by preparedness, making early starts, getting equipment ready, dressing the child the night before and altering the child's morning schedule. Pre-emptive caring helped maintain stability and control.

Mothers referred to the need for investigations requiring frequent hospital attendance. These, and many similar essential journeys, impacted on the whole household, as preparations were undertaken that limited the time available for siblings. Journeys to get supplies of equipment were further complicated by limited opening hours, which required essential journeys to fit around these.

Imelda:

I have to go to the other end of the city to get nappies. They're only open certain hours...I was sitting outside in the car thinking what else I'd to get and didn't the flipping door close...I might have been there 20 minutes so I couldn't get the nappies... I had to either sit there for the hour ...or...to go away and come back; but it drove me to the point of desperation. I mean that I was crying and as (my other son*) said again 'you cry a lot'. I cried all the way home.

Car journeys for social activities were fraught with similar problems. The child's level of instability and wellness resulted in altering or cancelling arrangements at late notice, or not accepting invitations. Mothers consequently missed many social events which resulted in

isolation of the mother, child, and sometimes siblings from activities. The instability is constant, ongoing and ever-changing and results in longstanding emotional concerns for mothers.

Imelda :

You will do nothing without planning and forward thinking and I don't think your brain actually stops...but what will happen in the next 10 minutes or, I honestly think it's like a tornado waiting and moving around your brain because you don't know what...

Staying at home, rather than travel, becomes an easier option for mothers if any choice exists. Turn-taking, identified previously, where one parent stays at home while the other goes out on their own, or with siblings, is an alternative which is practically but not emotionally acceptable.

Imelda:

We've also discovered that going anywhere extra is too hard...Like going to the hospital was a major, it is a major ordeal. Going to Mass now, just in the last 3 or 4 weeks, has been almost impossible. We've now opted 1 go on Saturday night and 2 go on Sunday which is dreadful.

8.3.6 Constant instability and time pressure

The mothers knew of the physical consequences for their child of delays in this going-between world, the instability this caused and the importance of getting there speedily. This time pressure pervades all worlds but is less controllable for mothers than the inside or outside world, as external factors, including traffic delays or parking difficulties, play a part. Delays in travel had serious consequences for the children that add to the physical and psychological impacts of travel in the going-between world. Other journeys, including those related to paperwork and administration were frequently enforced on the mothers. Speeding to places to meet closing times or appointments placed mothers, children and others in significant danger at times.

Martha describes a day in which she had arranged to meet a social worker to get a form signed. This was similar to other mothers' reports and gives a real picture of the conflicts and dilemmas mothers faced.

Martha:

I was a bit later getting up in the morning...got her up...dressed and rushed...She...was so incontinent by her bowel...Got out of the car...out to my own house, got out the wheelchair, put it all together. Got her out, put her into the

wheelchair...What a wrong thing to do. I should have gone in and got a sheet, you know, but your time...I have got my hands so messed up...Got her all sorted...everything, the wheelchair...Come back round here...see the social worker driving out... away off like bloomers after her. I...missed her. We came home...back in...got her dressed again...into the car again...I was stopped by the (police)...speed...and he kept on and on telling me...and here was my daughter. She just had passed this awful (laugh) in the middle of the whole thing...He still kept going on and on and on.

Responses to mothers from others in the going-between world was sometimes perceived as less sympathetic but mothers, though they realized that speeding was illegal, often felt that they had no choice but to do this, despite police warnings and its dangerous consequences. Time pressure has serious consequences in the going-between world. Delays in travel impact on the physical health of the child that concerned mothers.

Martha's bad day diary includes this excerpt:

On our way home...there was diverted traffic. I had a further three mile added to my journey. When I got (child) changed again her skin is now red and sore. This is another added thing to be cared for.

In addition to the instability in this going-between world not only were the journeys difficult but mothers faced challenges when they arrived at their destination. Finding parking space added complexity to the going-between world and to the time pressure that mothers were under to get to where they needed to go quickly. Mothers expressed significant concerns about their experiences and the difficulties that they faced after getting through the journey itself.

Paula reports in her 'normal day' diary:

Once the three of us are ready, we go shopping. As usual the parking bays are taken.

This seemed to be the 'last straw' for many mothers as their difficulties with their child and the instability of their situation was little recognised by others, which caused much frustration. This difficulty further reduced mother's journeys to the outside world.

Imelda:

I would have had to get the ramps out so you need the two spaces. So people don't, they don't think at all. I have a sign which I haven't had to use because I don't take her in and out often, but that you can stick up saying please do not park within...I guarantee you, you put that up, they will still park there, you know.

Some children were ineligible for disabled parking permits, because the complexity of their needs were not understood, or they did not fit neatly into a specific category of disability, adding to the mothers' difficulties in travel.

Lorna:

I had no disabled sticker so it means I couldn't get parked which I had to carry her the whole way.

The extra physical activity, the child's instability and the need to maintain constant observation all added to the mothers' difficulties in getting to the outside world. This going-between world and its complicated nature was added to when mothers had other children. The consequences of this for the mothers were often that they avoided going out for this very reason- it was easier not to go or not worth it.

Imelda:

You can't park outside the door so it means you can't leave (him) on his own. You can't just...Zip in and zip out...

8.3.7 *Constant instability –respite and hospital trips*

Despite the child's instability and the difficulties mothers faced journeys are a necessary part of the mother's experience. Journeys to hospitals and respite care, for example, were a familiar component of this going-between world. Mothers reported some additional specific preparations needed for out of home respite care and hospital trips that frequently involved long journeys. Additional preparation for out of home care was needed.

Emer:

So we would go up in the evening... a 3 to 4 hour return journey you know, to get her there, pack all her stuff...We have to take obviously all her clothes, all her feeds, all her medication, her nappies, everything. Like they don't supply...any of that. So I would have to be running around for a day or two before...checking to see if all the labels are right and not going off the medicines and all because they won't distribute them. Getting the doctor to sign all the medicines, even that is work...Then she is home with a bag full of washing...

The consequences of this planning and preparation require the mothers to use extra effort to make these trips to respite, which were often some distance from the family home, safe and comfortable. Mothers often had to make these journeys on their own as it was too difficult for them to organize the whole family for such trips. Admissions in the evening, for those with other children, required mothers to travel with the child alone while the father looked after siblings.

Helen:

It's just from a Monday evening until Wednesday evening where I have to take her up and collect her on my own which means bags, baggage.

For some mothers the consequences are that only journeys, including those to respite, that are absolutely necessary, are undertaken. The going-between world becomes so difficult that travel, even to respite, is avoided at times. If there was no choice mothers made brief, time limited and well organized trips into the outside world if possible.

For some mothers, brief and short ventures were possible but, more commonly, hospital or respite visits entailed significantly longer journeys that were often undertaken under pressure of time.

Helen:

An appointment for 9 o'clock... So we had to get up at min 5 o'clock in the morning and get her ready and go. Leave here at quarter to 6 to be up in (city#)... stressed out the whole way up....Yeah, I packed it the night before... you would swear we were going to America for a week...everything just for a day.

For mothers living in rural locations the duration of the journey to Regional children's hospitals were often more than three hours away, and these journeys were problematic. Delays in appointments, or the time taken in appointments and investigations, that were outside of the mothers' control added to their concerns and to the time pressure they were under to get there and to get home again.

Dara explains in her diary:

I was due in...hospital...review...a chest x-ray...I wasn't looking forward to the trip... I was on my own and couldn't find anyone to look after the baby... I...began preparing bags...bottles...things I had to remember...He is the most awkward to load into the car...already having passed my absolute latest leaving time. I had less than an hour to make it...and so was beginning to feel stressed...Hurried as I buckled him in, accidentally trapping his foot...It twisted slightly, causing fresh tears... and a new bout of roaring...I pulled out of the drive to the chorus of screaming children and felt my heart pound and blood pressure rise....

8.3.8 Constant instability and siblings

The nature of travel was so difficult that some mothers avoided going out with siblings and stayed at home when possible with the child with complex needs. However, this was not always feasible and mothers had sometimes to undertake journeys to maintain normal family life for them and their siblings. For mothers with other children it meant that trips

with their friends in the car were not feasible, which resulted in mothers depending on the friends' families at times to transport their other children. Social visits, other than those which are really unavoidable, were limited, or if the mother did choose to attend, caused emotional and physical challenges to all involved. This resulted in few non-essential visits being undertaken, which in itself further isolated the child, siblings and family.

Ciara:

They did get out but there was huge planning went into doing that. You know a trip to the park#...was a big...a big outing...Like you didn't just decide in 5 minutes, oh well here, get into the car and we'll go... It wasn't like that".

In some situations mothers opted to go with siblings without the child with complex needs if someone was available to care for them at home. This required organisation, scheduling around available help and, because of this, these were rare journeys. Occasionally the child was left with their father, but this too had to be accommodated within work schedules, and father's availability during daytime to help was often limited. If the child was left in the home, mothers needed constant reassurance that the child was well while they were away from home. This will be further discussed in 'constant communication' in the outside world, but it meant that often the mothers had to take the child with complex needs and their siblings together. If siblings were of school age mothers tried to time visits into the outside world with the affected child during the school day. They often had to curtail these journeys, or they were undertaken under time pressure, as the mothers had to work around school pick-up times. Any delays in appointments, which were common for mothers, resulted in them needing to undertake journeys in the going-between world under significant time pressure. School holidays were particularly problematic as school services for the affected child, which provided some free daytime for some mothers, were no longer available. Journeys during school holidays and over the summer break with the child with complex needs were not easily planned and mothers found holiday times particularly problematic unless the siblings could be cared for by neighbours or family. Mothers, consequently, often had to include all children in journeys, either because of the wish to include them, or because they had no choice. The unavailability of care services at short notice, or having no service available to help care for the child, was evident.

Mothers subsequently reported many journeys when they had no choice but to go and that this often involved taking a chance that nothing untoward would happen. Occasionally there were real consequences for the child's potential well-being that had an emotional impact on the mother. It curtailed long and unessential journeys for the child, the siblings

or family. What resulted was a tension in normal mothering and the need to normalise and socialize the child and siblings in the outside world.

These difficulties were part of everyday life for mothers that had a significant impact on normal social activities for everyone in the family.

Gretta:

We wouldn't go shopping or anything. Because it's just too awkward.

8.3.9 Constant instability and development

The physical challenges of travel were added to by the changing and ongoing nature of the child's requirements, which impacted physically and financially on the mother. The child's development and increasing instability of needs that changed over time raised other practical concerns in travelling. This included the need for larger cars, car adaptations and more travelling space for larger equipment which, unless provided, further restricts mothers and siblings from entering the going-between world. It adds to the paperwork and administration (Section 7.9) and mothers' concerns.

Imelda:

We'd to change our car to accommodate him...my car was too low down. I couldn't get his seat and all his belongings and if I did get it all in there was room for nobody else...A chair, a special seat.

This practical need for a bigger car adds a dimension to the reactions to the family from others, which are further discussed in the outside world, and additional administration results from instability and changing needs.

8.4 Introduction to constant observation

Constant observation, one of the eight dimensions, forms part of mothers' experiences and is an essential requirement of care-giving in all three worlds. It is related to the other dimensions, particularly constant instability, that requires the mother to be in a situation where she can constantly see the child at all times. In the home, technical devices are used to help with this, including closed circuit television and baby alarms. The home was often adapted so that the child was in close proximity to the parents at night-time if monitoring equipment was not used. When the mother was separate from the child, constant communication was used as an alternative to constant observation by mothers to ensure that the child was well and was being constantly observed. The need for constant observation was clearly evident to the mother but was not apparent to all others, causing the mother concern when she was not the caring for the child herself.

In this world, constant observation was required for many reasons; to intervene to protect the child's airway, during seizure management or because of the child's individualised needs.

Janet:

No, we kind of keep an eye on him... We were afraid he'd choke.

Constant observation is needed in all three worlds and is a constant in the mother's experiences of caring. It was used by mothers to maintain the child's physical and emotional wellness at all times during both day and night-time and during travel. The instability of the child's situation was difficult for mothers and the need for constant observation was reinforced by particular past experiences.

Brenda:

One time I got an absolute fright. I went in to give him a kiss...to say good night and he was fast asleep and I got the fright of my life. He felt so cold. I thought 'oh my god'. I really, my heart, I just froze... I could feel myself, my stomach just churning ...I couldn't hear him or feel him and all I felt was cold and I thought oh it was horrible, it was absolutely horrible.

Mothers needed to use constant observation continuously and were aware of the danger their child was in if this was not maintained in all worlds.

Helen:

She has given me a few frights. She has literally gone black when she has been trying to get sick, yeah. She always, like she's good, she comes out of it herself but you have to catch her and sit her up and shake her and stuff you know.

These types of experiences were common to many mothers and reinforced the mothers' need to be always available to manage their child's instability. Being in control of situations was important for mothers and they managed instability by using constant observation. The child's needs impacted on mothers in all aspects of their daily activities in the inside world and on family life and siblings. It impacted on mothers and children leaving the home to enter the going-between and outside worlds, including the family garden.

Orla:

Saturday, they were outside running about and sort of had to sort of keep child* in because she would go out there running and then she's down... If she falls on the grass outside she'll sit there until somebody goes and lifts her back up.

Constant observation, similar to that in the inside world is required, as mothers have quickly and competently to manage children who are being sick, having seizures, bleeding

or choking in the rear seat of the car. This constant observation has physical and emotional consequences for mothers as they faced the challenges of leaving the inside world. For the mothers, few alternatives existed when car journeys were needed and any journeys undertaken involved the mothers driving, while simultaneously maintaining constant observation of the child, using whatever means possible. Mothers of children with rare metabolic disorders, had less technical care-giving during journeys but still had to observe them constantly to prevent them eating ‘dangerous foods’ that could be given to them by unknowing friends and strangers in the going-between world.

Situations in which the children needed immediate care varied from the minor “she choked on a crisp with me in the car one day,” described by Orla, to more significant life-threatening episodes which required urgent life-saving actions in situations where conditions were less than optimal. Constant observation is added to by the dangerous context of journeys. Mothers took pre-emptive steps as well as using constant observation of the child throughout all journeys. In some situations this resulted in event free travelling but on many occasions mothers faced, and managed, very difficult situations. Many steps were taken to ensure that constant observation was maintained while preparing for the journey and during the journey itself:

Brenda:

He’s in the back seat but...I have a little mirror you know in the front so that I can see him.

Mothers’ knowledge of what could happen, and how to manage such difficult situations was apparent, and constant observation was a necessary preventative tool. Mothers constantly observed for situations in which their child could come to any harm, physically or psychologically. Mothers of more than one child with complex needs additionally had to observe all children simultaneously.

Anita explains:

When you’re driving as well you’re listening for sounds.

The difficulty in maintaining constant observation during essential journeys often resulted in not taking the child out unnecessarily, despite the dilemmas this caused for mothers. Night-time visits were avoided because of the difficulties in travel and observation. Fathers who could have helped were often involved in caring for siblings and were not available. In the home mothers were able to use equipment to maintain constant observation at night but during travel this obviously was not possible. Night-time visits were therefore very restricted and day-time trips ended early so mothers could get back home before dark.

8.4.1 Constant observation and individualised needs

The child's individualised needs that required constant observation caused avoidance of the outside world and travelling into it at times. It limited mothers in where they went, the time they left, and returned, and whether they went alone, or with the child.

Anita:

I can't go outside the door. Child* is so volatile that even to put (her) into the buggy... We could go as far as the path and you could see 'oh today is not a good day for a walk with her' and then you're back in immediately.

The time spent outside the home was controlled and limited if the mother could do this. This, and the instability of the children's needs, creates situations where mothers are under pressure to get where they were going, or back home, as quickly as possible. Having unlimited time in the going-between and outside worlds is not part of the mothers' experiences

Orla:

She can hack the car for a wee while... I would need to be going at say 9 o'clock in the morning when things are quiet when she'd be like that... but it's really not worth the hassle.

Constant observation during travel, as elsewhere, was needed as mothers had to prevent the children's self harming behaviours:

Dara:

He can chew on his finger or chew on his thumb. He hits himself quite a lot.

Janet:

He's biting his hands very bad still... I notice the skin is starting to get very rough and he gets sore every now and again, I have to watch him.

Mothers similarly reported how the child had to be always kept within their view, to ensure that they were physically safe, as many of the children were unaware of dangers in any of the worlds.

Orla :

If the back door was open she'd be out there like a shot... Em and I can't let her outside anyway unless I'm out with her...

Mothers used constant observation to prevent their children's individual responses and behaviours, including crying and screaming, being evoked by strange and unfamiliar situations. Constant observation was particularly difficult in the going-between world and adds to the pressure of time and planning needed.

Mothers had particular concerns about long trips and maintaining the constant observation required. There were specific issues for mothers who were often undertaking these journeys without the help of another adult. Being alone added difficulties for them as there were many situations where two adults were needed. This is similar to situations described in the inside world when carrying out aspects of technical care-giving, but for many mothers these difficult and unstable situations had to be managed single handed, adding to their practical and emotional concerns. Journeys were limited by the availability of help from others that was often not forthcoming.

The need for constant observation impacted on mothers' decisions to take the child out of the familiar inside world where they were able to control most situations. Observation was needed at all times to maintain the child's safety in the presence of other children, including siblings and their friends anywhere inside, or outside, the family home, including the garden where siblings were at play.

Lorna:

You had to be very careful with children about because at that age children will run into children. So it was very hard to keep an eye on her.

Mothers were very conscious of the child's individualised behaviours and their potential to unknowingly harm, or be harmed by, other children who did not understand the child's needs and situation. This adds to the instability in the mothers' experiences.

Orla:

...but she is not normally, you know, she is not an aggressive...It would only be if she is starting to get a wee bit frustrated...and they went to do something she didn't want...She would give them a shove out of the way. But it wouldn't be intentional and it doesn't happen very often.

8.5 Situations of 'No choice'

The final dimension explicated in this chapter is the 'no choice' situation that mothers face in their experiences of care-giving. This has already been alluded to in the descriptions of constant observation, and instability, in the worlds previously explored. In caring for children with complex needs mothers face a 'no choice' situation. There are no alternatives open to her but to do what she has to do, in the way she does, in all three worlds. In the inside world no choices exist in care-giving as there is often an absence of anyone, other than the mothers to deliver the care the child needs. In the absence of help, advice and support mothers undertake care that they know their child needs and do what they think is best, often in the absence of help from family, friends or professionals. In the going-

between and the outside world ‘no choice’ forms part of the experiences and requires mothers to negotiate, and advocate, to ensure services are provided for their children. This involves the administration described, but also required the mother, usually with the child, to travel outside the home, in the absence of any alternative. ‘No choice’ journeys are part of the mothers’ experiences and are necessary to navigate the systems that surround their child’s needs. These include visits for medical appointments, investigations, treatments and for follow up. They were needed for physiotherapy, speech and language and occupational therapy for the child and to prevent complications. For mothers these were viewed as situations in which they had ‘no choice’ but to attend, and to accept and manage as best they could all that this entailed for them. They were highly committed to attend frequent appointments, which often entailed long journeys. For social visits, the mothers had a greater choice but often did not attend, which will be discussed later.

8.5.1 No choice journeys to hospital

Car journeys in the in between world were associated with ‘no choice’ medical visits and mothers described the measures they had to take to meet the many appointments needed for their children. The mothers’ difficulties of getting to the hospital, and the journeys entailed, were little understood by others who were often dismissive of the mother’s concerns and demonstrated little knowingness of the difficulties they faced in getting to see health professionals. Others demonstrated little understanding of the ‘no choice’ situations that mothers were in when it came to meeting the health care demands of their child. Mothers had to accommodate these visits and there were few reports of where health professionals made any attempt to prevent multiple visits or where home visits were provided. One mother did report on attending an early intervention service where visits were coordinated and most services could be visited during a single visit. Some children with metabolic disorders were seen at a single site for its management, but for other issues mothers had to travel extensively. The complexity of the children’s needs often meant that mothers had multiple visits to be seen by a range of professionals, at different venues, which they viewed as imperative to attend. They had to accommodate visits for siblings who required genetic screening or advice, which were ‘no choice’ situations. For some parents this required visits to centres in the UK for treatment and genetic testing, which were problematic.

There was no recognition of the ‘no choice’ situations mothers were in and mothers perceived that no one really understood their situation or what caring for their children really entailed. Mothers perceived that others were dismissive of their concerns and did not

recognise that mothers needed help, often leaving mothers with no choice but to find out information themselves.

Rachel:

At 6 months we saw... (a doctor) in the baby clinic and we said we were concerned about these clenched fists and so on...(Doctor) said 'she's fine'...I said 'you know doesn't clenched fists mean anything at all and she just said 'no, not to worry about it'. Em and we took her home and we were still worried ...We needed more information ..., we left lost. So we went to the library... just hunted through medical books ...we were just lifting medical books and reading them.

In these visits when mothers concerns were dismissed or others do not help, they often became emotionally upset as others' unknowingness was demonstrated. This makes it difficult for mothers to face the prospect of hospital visits adding to their emotional reactions in going to the outside world. The reactions of others will be further explicated later, but at the end of a difficult journey the last thing the mothers needed was to be met with limited understanding.

Imelda described the need to leave home for a "two minute" interview, a 'no choice' situation for her, to be assessed for benefits. The practical difficulties and emotional responses are evident.

Imelda:

To bring him for an assessment...4 years on...the greatest insult. The health board# sent me this letter to appear at 9 o'clock... in their offices in the middle of the city with him...and I thought how am I going to do this?...which I don't like to do. It's like going to the hospital with no medication...They wanted...a doctor to interview me because they were going to refuse giving me (an allowance for care)...I thought Jesus...what do they think has changed?... It was so maddening to have to go...I showed the letter to (his dad) and...he says to me 'well you better go in...you know it all helps, it pays.' ...I don't know what time I got up that morning... but I went without the ramps for his chair... so much to bring now, couldn't get a park anywhere near...It was pouring rain... I wrote a letter, put it up on the dash along with his wheelchair sign...How was I going to get him out of the car on my own because I couldn't lift the chair down...so I saw a man coming out...and I went up to him as near as I could ...Would you mind helping me?...and he gave me a hand lifting it out...The minute the doctor inside saw him she said to me, 'I don't believe... we called you in...The minute she saw him...she said 'how did we bring you in here?'.... 2 minutes, literally 5 minutes later I was back in the car and I

couldn't get him back into the car. It took me a half an hour to get someone to carry the seat back in. So I spent longer getting parked and getting him in and out than I did with the doctor.

Mothers were faced with many similar situations in which there was no choice. They had to manage the child, siblings and family life and did what they felt was necessary to accommodate the child's needs while attempting to maintain normality. This resulted in mothers having no choice but to learn how to manage all aspects of care-giving, often in the absence of help or advice. Additionally it had consequences for the mother's physical, emotional and social wellbeing as isolation was used in an attempt to maintain stability in the child's and family's life.

8.5.2 No choice and the impact on siblings

The going-between world, and the journeys in this world, had an emotional impact for mothers that resulted from the negative reactions of siblings to the need to travel and their experiences of difficult journeys. Mothers often had no choice but to take siblings with them on journeys with all that this entailed. Siblings reacted badly to these difficult journeys, which added to the emotional complexity of caring in this going-between world.

Emer, for example, records in her bad day diary:

They* (siblings) start. They don't want to go to (city#). "It's too long. It makes me feel sick".

8.6 Conclusion

The constant observation, instability and 'no choice' situations, common to mothers' experiences in this going-between world are apparent in all three worlds. These dimensions and their effects impacted physically and emotionally on the mother and also impacted on others within the immediate family, including the child and their siblings. Preparedness was necessary at all times. Turn-taking and going out separately, while one partner remained with the child resulted. This preparation adds to the time pressure, planning and preparation that is the mothers' daily life. Entering this world is often a 'no choice' situation for mothers, and others in the outside world lack an understanding of, or are dismissive to, the mothers' experiences and the difficulties that journeys cause them. Mothers and children, as well as siblings, responded to the challenges these dimensions posed them by only entering the going-between world, and subsequently the outside world, if absolutely necessary. Contact with family and friends by mothers, and vice versa, are consequently reduced, adding to the isolation of mothers.

Constant observation is time-consuming, hard to maintain at all times, limits mothers' activities within the home and impacts on the feasibility of travel outside the home. It impacts on the physical structuring of the home and warranted consideration when deciding where the child slept at night, and when house adaptations were being planned. Leaving the inside world limits the mothers' ability to maintain constant observation during travel. Journeys are not undertaken without significant planning, which provides mothers with some control of difficult situations. The journey itself is difficult as mothers face challenges of trying to maintain constant observation while driving. Mothers face dilemmas as they know the consequences of not going for them and the family, but they equally know the difficult consequences if the choice is made to leave the inside world.

Imelda:

And I wonder will your report make that clear, that like it's just such a difficult journey that you don't want to bring him places, which is wrong, isn't it?

The final dimensions of knowingness, unknowingness and constant communication will be fully explicated in the outside world in the next chapter.

8.7 The 'I'

Car journeys and the mothers' experiences of travelling were not part of my horizon at the outset of this study, an unknown, until the mothers began to report the issues they faced in getting to the outside world with, or without, the child. What emerged was that caring for a child with complex needs involved more than caring at home, and a significant component of care-giving is delivered by mothers in a 'going-between' and 'outside' world.

In the following chapter the final world of care-giving, the outside world and the remaining dimensions will be discussed.

CHAPTER 9 - THE OUTSIDE WORLD

9.1 Introduction

This chapter will focus the findings related to the outside world that forms part of the mothers' experiences in caring for a child with complex needs. The eight dimensions are confirmed but they are contextualized in the outside world that the mother experiences when she leaves home. In this chapter the dimensions of knowingness, unknowingness and constant communication will be developed.

9.2 The outside world: an interpretation

Mothers' knowingness of their child, their needs, and the instability of their child's situation, was evident in all worlds but is reported in the outside world as mothers' knowingness, and others' unknowingness was clearly evident in this world.

This world is the one outside the home and includes situations in which the child gets care with, or without, the mother. In this world the mother and child can be together; sometimes siblings and fathers are present; at other times the mother is separated from the child who is with others. Experiences outside the home include family events and outings, when the mother is undertaking normal family activities, and in hospital and health care situations. In the outside world the mothers were impacted on by the responses of others. Mothers' knowingness of their child's needs was apparent and others were less understanding, which resulted in practical and emotional concerns for the mothers, the children and siblings. Constant communication connects the mother with others in the outside world.

9.3 Mother's knowingness-an overview

Mothers' knowingness in care-giving, that involved high levels of technical care-giving and individualised care, was evident in all worlds. Mothers explained how they 'knew' what care their child needed, and the steps they took to deliver this care over prolonged time periods. The skills were influenced by the changing, unstable nature of the child's condition which required mothers to adapt and deliver care in, sometimes, very difficult situations in the three worlds. Their knowingness of what to do, and how to do it, in whatever situation they found themselves, was evident. Others in the outside world, however, did not demonstrate similar levels of knowingness, which concerned mothers and influenced their decision making about who cared for their child. This, in turn, influenced whether or not mothers entered the outside world and which services they used. Those in

the outside world, including carers, were limited in their understanding of the child's needs which the mothers readily recognized. Mothers found situations outside the home, with or without the child, equally challenging. If the child was present mothers continued their technical care-giving; if not, mothers had to ensure that the child's needs were met in her absence by those unfamiliar with them and the technical care-giving the child required. If the child was being cared for by others, whether in the home or in out of home situations, mothers were always concerned about the knowingness of those who cared for the child; this included health care professionals in hospitals and respite care.

In the outside world a significant part of the mothers' experiences are the reactions to, and from, others including those known to her, and family, and those who are unknown. Reactions from others influence mothers, and in many situations they chose not to leave the family home, partly because of the difficulties this entailed, but also because of practical and psychological issues that mothers knew they would face in situations where the child's needs were little understood by others, including health care professionals.

Mothers knew how, and when, to leave the security of the inside world; when the child could manage this, and when going out was impossible. They knew when it was as safe as possible to take the child, and their knowingness always influenced their actions. Mothers knew if venues were suitable for visits and times when they could visit when they would meet few outsiders. Mothers' knowingness was challenged at family events as well as in unfamiliar situations.

Despite these difficulties and dilemmas mothers did make decisions to attend family events and outings with the child and siblings. In all families, events such as weddings, birthdays and funerals are part of normal social occasions that the mothers tried to attend. First Communion and baptisms are important cultural and family occasions that have a significant role in religious traditions in Ireland. Mothers' experiences at all events, including other outings to eat or shop with the child and siblings, were influenced by reactions from others. In the outside world maintaining technical, pre-emptive and individualised care during the outing, while at the same time trying to enjoy it, impacted physically and psychologically on the mother, child and siblings. Deciding to go out was influenced by the help available for the family, but negative reactions to the mother and child from others, including relatives, neighbours, children and unknown outsiders played a part. Mothers knew the reactions that they, and the child, would face and that the child could react negatively to others' reactions to them. Mothers reported on some helpful and, more frequently, not so helpful responses that varied from sympathy to curiosity. Frequently mothers' knowingness, and others' unknowingness, were in conflict in this

outside world. The unknowing reactions also impacted on siblings, causing further concern for the mothers, as they tried to protect all their children from adverse reactions.

9.3.1 Development of mothers' knowingness

At the outset of the child's illness neither mothers, nor health professionals knew much about the individual child's condition. Emer explains the challenges faced in caring for a child with complex needs, and the unknowingness that pervades the future for many children with complex needs, making outcomes difficult to predict. Mothers face this unpredictability and unknowingness and often look to others to help advise them, which for some children is not possible, leaving mothers in a search for knowingness.

Emer:

I was called... 'Come in quick. She mightn't make it much longer.' ...They turned off all machines. She just kept seizing and seizing...She was put into my arms...'She was going to die'...So mm...maybe a week or days...I asked about taking her home and mm they suggested I put her into care, that that was an option...She was going to be hard to manage and I discussed it...They reckoned...that I wouldn't have her home for very long anyway...She would probably get a chest infection or pneumonia or some childhood disease and it would take her anyway, that she wouldn't survive too long...That was four years ago.

For children with no clear diagnosis, or unknown future, this issue of unknowingness may be compounded as mothers face attempts by medical staff to find a diagnosis. Not knowing was difficult for mothers who made significant attempts to find information. When they found that no answers were forthcoming from those that they thought should know, mothers became very frustrated. In some situations, however, no firm answers could be given which reduced mother's knowingness and caused long-term concerns.

Helen:

I ended up with a list of questions...Every time he (doctor) came I'd say he was saying; 'Oh, here she goes again'. I mean I had to write down. They might sound like stupid questions but to me I just didn't, you don't understand...I got to the stage I was saying, 'do you think is there a chance she's gonna spend the rest of her life in hospital...Will we ever be able to take her home?' And he said; 'Yeah, it's a possibility'. This was the answer I got all the time...I'd say; 'do you think she will be able to walk?...Do you think it's this?...It's that?'... (Doctor said) 'It's a possibility'...You're left then...They walk away then and you're still...scratching

your head. What was he saying? So you have to really drag it out of them...No one will tell you and not knowing one thing what it is, not knowing how long she will live...So not knowing I found difficult.

The lack of information, and particularly being given bad news, constantly had a significant emotional impact on mothers and again a negative reinforcement cycle was established between mothers and health professionals.

Martha:

I never remember any time going either to hospital# that I got good news. So I have my body and my mind sort of accepting and not getting into a real panic...You know it seems as if you're always crushed and torn.

Attempts by professionals to reduce their unknowingness that prove incorrect can have significant consequences for mothers and their relationships with professionals.

Ciara:

CAT scans...doing blood tests...sub-dural fluid. Asked permission to bring...x-rays to a conference...On her (doctor's) return she did suggest non accidental injury...In hindsight now I could look back and say they could have easily accused us of it and it would be very hard to prove you were innocent.

Mothers tried to increase their knowingness by searching the Internet as well as asking questions from others. Some sourced information from nurses who visited, but mainly mothers viewed this as their responsibility in the absence of help.

Karen:

A diagnosis, I think about a year, maybe a wee bit more, of (named) syndrome which I had never heard of...It's not a specific thing. It's just a whole host of things; a list that may or may not affect the child. So you know you could have 50 or 60 things and you may have 2 of them or you could have all of them, some of which would never affect you very deeply and others that will. So we sort of lived by ticking off little things on the list for a long time.

9.3.2 Mothers' knowingness of the child's individualised needs

Difficulties in the outside world were clearly illuminated in the mothers' experiences. Choosing to take the child outside was influenced by many factors including mothers' knowledge of the child's physical health state, their individual behaviours and their current needs for technical care-giving when outside the home. These difficulties, and the complex planning required, caused mothers to venture outside with the child only if the trip was essential and if there was no choice. Mothers knew the significant planning required and

the potential instability of the child's condition that required mothers to be fully prepared to meet all the child's needs in an unfamiliar environment and to know how to manage serious and life-threatening situations.

Mothers tried to develop knowingness in situations where they did not have this. They were constantly looking for reasons for the causes, and explanations, of unfamiliar, and new symptoms, or changes in their child's needs. On many occasions mothers worked out what the new problem was by trial and error. Knowingness is linked to coping and mothers' ability to manage their situations.

Helen:

Not knowing anything really is very, it's sort of, well for me, the more knowledge I have the better I can cope.

Difficulties in providing care in situations other than the familiar inside world of the home influenced mothers. Their knowingness of what might happen in the outside world influenced them and leaving home with the child was not an easy decision to make as Imelda explains.

Imelda:

If he* is having a bad morning the last thing you want to do is take him out.

Leaving the inside world required making choices, each of which had its own implications for the mother and child. Mothers knew their child needed to be socialized, but they also knew of what could potentially happen in the outside world, and were aware of the issues they would face in care-giving there.

Emer:

If you did bring her into a shopping centre and she dirties. It's just so hard to change.

The children's individual needs impacted on the mother's decisions to enter this world where protection, comfort and safety of the child are important to mothers. In their protective role mothers attempted to reduce the onset of individualised behaviours by avoiding trigger factors in the outside world. Mother's knowingness was linked to constant observation needed to protect their child from serious, life-threatening injuries. Lorna's school age child had a very rare disorder that demanded continuous close observation. She explained her experiences at a family wedding.

Lorna:

The hotel...Getting ready was a nightmare. You know trying to watch her and get ready...We were late...Even sitting in the chapel...If (she*) misses and hit a seat, she's split...and...the kneeling thing...her foot stuck in it. Her foot, and ah

God...Started swaying...started crying. We just had to throw off the shoe to see was she O.K. Thank god...just swelled a bit.

In the uncontrolled outside environment mothers constantly knew of what could, and would, happen to their children and the seriousness of their situation. They were also concerned of the emotional impact and having to manage this in addition to their other responsibilities.

9.3.3 Knowingness of changes in routine

Mothers were always aware of the consequences for their child of changes in routines and this, in turn, influenced their movements in all worlds. Mothers knew that the child's individualised needs were exacerbated by strange situations which they needed to prevent or minimize these by taking pre-emptive steps. Mothers knew how even minor changes in routine, circumstances and situations impacted negatively on the children, which added to their care-giving.

Imelda:

He's not able for weather, like he's not...He likes everything exactly regular, the same smells. Nothing changed...everything the same... Don't surprise him.

The outside world was consequently difficult when children faced unfamiliar challenges, or situations which mothers knew would upset them. This frequently meant that situations were avoided as mothers knew that unfamiliarity could have short or long lasting repercussions for the child. They knew how the children's various reactions would cause further difficulties for them, the child and siblings, if present.

Paula:

Take her out to somewhere she has never been; it's a hassle for her, because she has to overcome that fear factor...Fear that there might be a dog or a cat...a bird...a butterfly. I mean you are coming into summer season where you get flies. She is terrified of anything that moves.

The mothers were always in a state of constant observation and preparedness to manage serious physical injury that often required urgent hospital attention. Mothers' knew that they had to be prepared to manage these difficult situations amongst others who would not. They knew that others had little understanding of the individualised behaviours that were not always physically obvious, or easily explained.

9.3.4 *Knowingness and separation*

Mothers' knowingness of the child's needs caused them practical and emotional concerns when they had to leave their child in the care of others, either at home or elsewhere. The impact of changes in the child's care routines impacted on mothers when they chose to leave their child for any reason. Mothers were equally concerned that they knew exactly the care that their child needed, and was used to, while others did not. Mothers knew of the consequences that any separation had for the child and their previous experiences added to the conflict they have when they leave their child with others to be cared for. Mothers recognised that others did not have the same level of knowledge which concerned them through all separations. The duration of any separation from the child was consequently very controlled and limited.

Orla:

I know there's (respite*)...but...I can't ever see that being a big thing for us...I never see me taking (child*) there and going 'bye, bye pet, see you in so many days'...She knows to a degree who she can trust, who she feels comfortable with...Because she's special needs I don't see why I should take her somewhere. Who has a stranger coming in looking after her for 8 hours and then another stranger coming in? You wouldn't do that with a normal child.

Additionally the children are affected physically and emotionally by separation which mothers were aware of and consequently tried to avoid.

Dara:

And then that (changed behaviours) generally just ebbed away; so we just put that down to insecurity really...He just wasn't happy about being put into a place, a strange place.

Mothers additionally had to manage the sequelae of separation, which alters their normal routines, and they have physical and emotional difficulties in settling during absences any from the child.

Frances:

The first night I am away from (child*) I can't sleep. And I think I can hear her and everything...We were away for 2 nights, and the first night I slept really badly.

If any choice was available, visits to the outside world were not attended by the child and they were often excluded from many social occasions. The mothers recognised the impact that exclusion had and leaving the child in 'at home' or 'out of home' respite was a difficult decision for mothers to make. If care was provided by others mothers had to undertake significant planning to ensure their child's many needs were met. This proved

really challenging and leaving their child with others caused mothers significant psychological concerns before, during and after the separation.

Orla:

You know, at the end of the day you have to build up your own trust in somebody and at the end it's your child. Couldn't just go out the door and leave your child with anybody.

Separation added to mothers' responsibilities as they had to be constantly available to the alternative carers if they left the child.

9.3.5 Knowingness reinforced

Mothers' knowingness is evident to others and is reinforced when they contact mothers for advice about the child's needs, or when the child is deteriorating and needs additional care. Mothers were, and needed to be, a constant information resource about their child's needs when they were apart for any reason. Mothers additionally have to manage reports of difficult situations in which others have difficulty coping with their children which further reinforces mothers' knowledge and others' lack of knowledge.

Helen:

She was puking up in the respite at the weekend and she (carer) said 'she went black...She couldn't get the oxygen out'...She thought I had the valve off in case it would leak. She (carer) was in an awful state.

The need to be always available for advice creates a negative feedback loop in which the carer's lack of knowledge of what to do in particular situations is made apparent to the mothers which in turn reinforces the care-givers' unknowingness in the situation. This leads to constant communication and interrupts any periods of respite that the mother is having from the child. Mothers' knowingness is continually reinforced by comments from others who little understand that the mother has to do what needs to be done to ensure her child remains safe and well. There is no choice and mothers know this.

Karen:

'I couldn't do it', that's what people used to always say. 'I couldn't do what you do'... 'You're so brilliant at it'... I used to say 'Well...what do you do, lie down and die or get on with it. I mean you have to do it. You have to survive'.

9.3.6 Knowingness and siblings

In making decisions to enter the outside world for any reason, mothers are concerned about the impact of this on their other children. Mothers had a knowingness of the issues the

siblings faced in the outside world which impacted on them. Mothers knew that going to family events with their sister or brother directly impacted on them and children reacted to their sibling's presence in different ways which mothers have to manage. Mothers know they will have to deal with the consequences of others' reactions to the children and siblings which add to care-giving. Siblings, too, were affected by the responses of others to the child's individual needs which further compound the mother's situation. Mothers know it is safer if they remain in the inside world where these difficulties, if they emerge, can be controlled. Mothers knew of these negative reactions and their consequences when they take their family into the outside world. They adopt a protective role for all their children, thus adding to their difficulties and reducing their enjoyment of activities. Siblings were often given a say if decisions were being made to attend family events and some were more positive about their sibling's presence than others. Siblings too, faced decisions and choices and, like mothers, they sometimes chose to avoid the outside world because of negative reactions. Anita described how her child explained the dilemmas children faced.

Anita's child:

'Yes mammy, I would like her to come very much but we'll have to make sure that she doesn't scream, mammy'.

These situations added to the mother's concerns and she had to know how to handle these situations. Mothers have a role in protecting well siblings from the unknowingness of others which can be experienced as hurtful comments or bullying. Emer recalls reactions to the child from her sibling's friends:

Emer:

I just hope it's not hard on the other 2...but I just hope they're not ever being...said things to...Like her sibling* has gone through a thing at school where 2 girls, 2 girls in her class who both have horses...They says 'we'd rather see child* dying than our horses because child* is sick anyway.' Her sister was...in a bad way about it and...told her teacher and like the teacher wasn't great. She says 'ah just pass no remarks on them'... whereas that's a very big deal in a child's life.

Managing these reactions and preventing them from impacting negatively on the child, and siblings, causes mothers to adopt a protective stance which can isolate her and the family further from the outside world. Imelda explains.

Imelda:

I suppose...you wrap your other children in a bubble because you don't want them to be affected by it...And that's it really, that's what you try and do. You protect yourself, you know.

Siblings have to manage comments from their friends, and unknown other children, and mothers subsequently have to teach their children, and sometimes the affected child, how to manage these situations. Mothers sometimes avoided taking the affected child out with their brothers and sisters because of negative reactions from and to siblings. At other times mothers, however, actively pursued attempts at providing normality for the whole family. Tensions are created when mothers have to manage their knowingness of situations in which harm to the child and siblings is possible, and knowing that going out is an important part of family life.

Anita:

I believe she* should be at it. She's part of our family...I really don't...I don't know what to do. I feel my daughter should be there... it is a family day.

9.4 Introduction to unknowingness

The second dimension to be explicated in the outside world is unknowingness which is linked to mothers' knowingness. Unknowingness is the demonstrated lack of understanding of others of the mothers' situation and the child's needs. It is apparent to mothers and influences the support that is available for the child and family. The mother has to develop skills to manage unknowingness in others who, because of a lack of awareness of the child and their needs, do not fully understand her situation. This dimension is explicated in the outside world as it is here that mothers mainly face the unknowingness in others. However, unknowingness, like the other dimensions, is present in the inside world when others, including professionals and carers enter the home to provide care, or to meet with the mothers to discuss the child.

Frances in her bad day diary explains:

Even the RGN is very nervous of caring for her (child). We have an RGN here for 8 hours today but I can't really go out.

9.4.1 Unknowingness in the extended family

Unknowingness is evident in some family members who do not frequently enter the mother's world. Others demonstrate a clear lack of awareness, or understanding, of the mother's situation, either by choice, or a lack of experience or interest. Relatives, or those in the outside world, do not necessarily want to develop knowingness of the mothers' situation which results in avoidance, isolation and poor relationships with them. Mothers' experience unknowingness in all worlds, but control unknowingness in the inside world by limiting and controlling those who enter the home. Mothers are aware of others'

unknowingness and it has a practical and emotional impact on them. It directly influences the help available for mothers.

Anita:

Leaving (child*) with other people, that's an impossibility. You cannot leave her with other people such as family or friends...because they don't have the capability. They're not competent to deal with nasogastric tube feeding... with suction, tubing or...machine. If (child*) takes a seizure and needs...rectal medication...you could not expect family members or friends to do that.

Unknowingness, and the mother's response to it, results in others distancing themselves physically and psychologically from the situation. It causes the mother concerns when her child is being cared for by others when their unknowingness is reinforced.

Mothers expressed concerns about how they, and the child, were viewed at family occasions and often felt that at these situations, where support from relatives could be expected, they did not receive it. This influenced mothers' choices in attending events, considered to be important social milestones in family life, including birthday parties or funerals. Family reactions were often negative and unknowingness of the mothers' experiences was demonstrated. Mothers knew of these negative reactions beforehand which impacted on them deciding to attend.

Frances:

With the family Communion next week...and mm? Am I am bringing her with me...I am trying not to because...but it might not even go down well.

As a consequence mothers often avoided even important family occasions, or they made last minute decisions to attend if they felt emotionally able to handle the negative reactions. There was a constant tension between the challenges of normalizing the child, family involvement and managing the reactions of relatives. Family occasions were subsequently emotionally and physically challenging for mothers as the expected support was not forthcoming and pity and a lack of understanding was apparent.

Imelda:

We had one Communion...They are very hard to bring your child...You want to bring your member of your family along but...they're looking on at you saying 'oh God...how are they managing or why are they doing it?'

Relatives were not always supportive of the child's presence at events. The decision to attend was consequently influenced by the mothers' past experiences- if she had faced negativity previously she was less likely to go; or if she went to subsequent events the child was often excluded. Consequently the child became isolated completely from the

extended family which added to the mother's concerns as she was aware of the consequences of exclusion for her family.

Emer:

Like even at...(relatives*) funeral...she was the only (family member) that wasn't there. At the wedding...she was the only child that wasn't there and always will be the only child that wasn't there. You know...They wouldn't mention her...They take it for granted that she won't be there...No, they never say anything much about her to be honest.

Anita:

So I think she will be left out on Holy Communion day somehow or other. Family occasions how are ye?

Unknowingness in relatives that is reinforced by being isolated, or isolating themselves from the child, impacted on mothers who indicated support from them was not forthcoming. This consequently reduced their knowledge and understanding of the family situation when the mother and child did not attend family occasions.

Niamh:

Some people see, but sometimes they don't believe you...like people see but they don't really see. You know what I mean.

A negative feedback loop was created between the mothers and the relatives (mothers avoided events, relatives in turn did not meet the child), which reduced their support and interest in the child. Emer explains:

Emer:

Mm, like she has been sick for the past two weeks but none of them have called... 99% of them haven't even called to see her.

For many mothers, the lack of family help for the child with complex needs caused emotional concerns.

Anita:

I resent that em. She's her* godmother and never once has she ever...Never once has she said 'would you like me to take the child* for an evening?'

Unknowingness in relatives was further reinforced by the fact that mothers often viewed relatives as busy in their own lives. As a result, mothers had concerns about asking family members for help as they recognised the demands this placed on them when they had their own families to manage.

Emer:

There is actually no one, well I suppose one of my sisters would be the only one that myself or dad would phone and say look we need somebody to mind her...But...she has...young kids as well and she works fulltime so the time she can give is limited. But she is the only one we wouldn't be afraid to ask.

At the very early stages some relatives offered support but they reduced contact soon thereafter. Family support that is provided dissipates over time and becomes limited to enquiring phone calls rather than practical, or emotional, help.

Helen:

No, at the end of the day, it is down to yourself. No matter how much people offer anyway, and they all do. I remember when I was bringing her home from the hospital, 'Oh, we'll do everything we can; We'll do this...that and'. They don't because they're busy with their own lives. Everyone's life is so busy; they just don't have time.

Some help was occasionally available to help mothers go into the outside world on urgent business, or if the child was in hospital when relatives, if they lived locally, cared for siblings. Grandparents' sometimes helped the family but more so with domestic chores, shopping and caring for the other children. Additionally, as the child grew up, older relatives were not physically able to help with the increasing complexity in the child's needs, particularly with lifting and moving.

Mothers linked this lack of help to others' unknowingness which caused them to avoid the family. Where help was provided mothers reported on a need to reciprocate this help and that 'pay back' was sometimes required, which added to the mothers' caring responsibilities rather than reducing them.

Imelda:

One of my (extended family) then came and said 'Look I did you a turn yesterday, would you mind helping us out now we want to go out? Would you mind if we left 2 of ours (children) with you?' And that was very fair because it was more than square, but you're all the time owing back.

This payback mechanism is similar to that reported when mothers receive help from outsiders. Mothers learned that help was not forthcoming and felt that their situation was little understood by even close relatives. This isolation may result in the mothers being unable to handle others' reactions to the family situation and avoiding discussion within the family and confronting others' unknowingness.

Frances:

(Child's father#) feels that, I think very deep down, he is kind of shocked. I know my mum and dad are shocked but we don't talk about it...And actually how I feel about my sister in law now is that she came 6 months ago here and I was feeding my daughter and she had such a look of disgust on her face. I said to (child's father) 'I don't want her visiting us anymore'.

Unknowingness in the extended family is a persistent factor for mothers and it conflicts with their knowingness. Unknowingness may be the result of lack of exposure to the family, a lack of interest in their situation, or a lack of understanding in the difficulties faced.

It may also be a coping reaction in family members.

Imelda:

Family support would be great for the others; for him* no. They'd find it hard, very hard...Some can't cope with seeing him...with the idea of what has happened.

It is evident from the mothers' responses that improved knowingness in family members was not developed within the extended family for many reasons. These include not enquiring about the child, the child's constant absence or their emotional difficulty in handling any discussion about the child and their needs. Others may presume, wrongly, that because the child is not present at family events that either all is well or that the family is getting help, without recognizing the real issues involved. A negative reinforcement loop was being developed between mothers and families. The result is that family support is limited and conditional.

Given this lack of help and others' unknowingness, an alternative arrangement to caring for the child within the home was used in two parent families. Going out as a couple was replaced by turn-taking; in which each partner took turns to provide care to enable the other one to go out alone. This was not an option for one parent families where support was limited and older siblings were sometimes used to help.

Gretta:

Then trying to be somewhere to get a drink. He is so...it's just too awkward...So if I have anything to do (child's father) will sit here with him. Or if (child's father) had anything to do I would sit here, you know...go out separately.

Dara:

We take turns, we go down the pub say for an hour and then dad* would come up... I'd go down for an hour and then I'd come up.

Turn-taking has an obvious impact on the family social activities but the alternative was to avoid going out at all.

9.4.2 *Unknowingness in friends*

Mothers reported on similar reactions in friends in whom unknowingness is also evident. These reactions varied across the span of the child's illness from the diagnosis to the current situation. Some, like relatives, were initially supportive but became less so as the duration of the illness continued.

Helen:

We've had friends that don't call to us anymore. They've just disappeared off the face of the planet.

These reactions are a consequence of unknowingness and a perceived lack of understanding of the need for help. Mothers however, identified behaviours that indicated to friends that they were managing. Mothers' dismissive comments such as "things are fine", if accepted at face value, further reinforced others' unknowingness. Mothers were frequently unwilling to explain fully what was going on in their experiences and to tell of their situations to anyone else.

Karen:

My friend used to say 'oh my god you are not wise. You should have somebody coming in to do your housework... and you should be doing this and you should be doing that'. But I just, I couldn't see the broader picture, you know at all. Maybe I've just grown up unable to accept help in a way which keeps you locked up, I don't know. You know I don't know why I'm like that, but that's how I cope.

Dismissing the difficulties mothers faced results in further isolation from friends and relatives as they do not wish to disclose the full nature of the reality of their experiences. Mothers often feel that there is little about the child that others would understand and frequently avoid discussion about their experiences.

Imelda:

I suppose friends took a back seat...maybe it was me now...I often think I'm a hard, cold person at this stage, I wouldn't have thought I was but I think I am now...No, most of them took a back seat.

Tensions are created for mothers by these reactions. Others' unknowingness may be reinforced as the child does not go through the normal developmental stages they expect. The helpful reactions reported initially following the diagnosis are reduced over time as the complex nature of the child's needs become evident and the situation becomes different

from the normality friends expect. Mothers perceived that avoidance was used with them and the family. A negative feedback loop created by the mother may be part cause of these reactions in friends.

Other verbal responses to mothers from friends and neighbours included quasi religious responses. These are dismissed by mothers but they do, however, impact on the contact that others have with the family.

Karen:

A very close friend...used to say 'Jesus you are a saint'...People just were always telling me how brilliant I was...and 'I don't know how you do it' and all that. You know for years and years and years and 'I couldn't do it'...People used to always say, 'I couldn't do what you do'; or 'you're so brilliant at it'.

Such responses further isolate mothers from friends who view them as having special virtues that help them cope with their child and the situation they face.

Imelda:

Then other people...look upon you. 'Well, you know, it's your cross, you have to get used to it' which is the very last thing you want to hear because, sure you're not a cross...(speaking to child).

9.4.3 Unknowingness in those less well known

Mothers faced physical and emotional challenges as they encountered the reactions of others. Some helpful responses with physical aspects of the child's care were reported, but many less helpful reactions were identified. Ignoring the child and the situation becomes part of an unknowing response from others that mothers have to face and manage.

Imelda:

Very hard...very hurtful...People ignore...people just pretended that they didn't..., that we didn't have him and still don't. I mean I met someone yesterday evening; I was really surprised; I'd gone for a walk and they just pretended he wasn't there.

Mothers continually faced a lack of awareness of the child's physical needs that raised practical and emotional concerns.

Emer explains:

I brought her to...a dentist meant to be for disabled kids and she dirtied her nappy...I asked the receptionist 'Is there anywhere I can change her nappy?'...She said 'Oh no, we've no facilities for that'...I went into the dentist...he let me into their toilets.

Outsider's unknowingness has a direct practical effect on how the mother managed her child's care in the outside world and on the development of emotional and social support mechanisms. In children with obvious physical disability mothers faced the challenges of these reactions to themselves but had to manage the impact of stigma on the child and siblings.

Martha:

They would be staring...with this wheelchair coming along and they'd be staring. Child* would say to me 'I wonder why they're always looking at?' ...It rips every emotion and feeling out of you, you know.

However, mothers also perceived that many outsiders viewed them and their family as "grand", in receipt of financial help, often having big cars and big houses and receiving significant levels of physical help to assist with their child.

Emer:

I suppose anyone could say 'god you are grand. You can go away shopping'...No, I have to make sure I have enough money at the end of the month to pay them...You have to do the books right...I still have to be home or pay, you know.

From the mothers' perspective this was an incorrect view but it was one that they felt impacted on the provision of help to them at all times. Mothers felt this view influenced outsiders, including health professionals and neighbours, and potential help from all sources was consequently limited.

Martha explains how others respond to her situation and how they perceive that her needs are met and finances available. Their unknowingness is evident to mothers.

Martha:

And what about all the things around the house? Ach sure, they get (services, equipment) for my child* because you know that is free. You get an extension, toilets. They get all them wheelchairs. Sure they could get a car if they wanted to, everything is free. Sure they are grand. Aren't they well off...Great...But what they don't realise.

This view was developed by incorrect assumptions about the situation and potentially by mother's physical and psychological isolation mechanisms. These, and negative feedback mechanisms, potentially further isolate mothers from sources of help.

Helen:

Whereas, I think, after a while people think; 'Ah, they're grand now, you don't have to ask anymore'. Which, I don't want people asking all the time either; it's a very hard balance to strike, I suppose.

Being provided with services adds to the perceived interpretation of “grandness” by outsiders and the extended family. Emer reports on getting a home help and how this is viewed by others, including relatives.

Emer:

A lot of people think I just spend my life up here, rarely doing housework, but they don't realise...it's only the basic housework is done. I have to do beds, clothes, you know a lot of different...you still have to try and do yourself.

The reactions of others to them in this outside world were further impacted upon by the child's individualised behaviours and their 'differentness'.

Dara's bad day diary includes this excerpt:

Almost every pedestrian on my walk to the front door (of a hospital) shot me an unreadable look, especially the group of young boys on their way to lunch from the nearby...school.

These reactions impact on the family and add to the mothers' difficulties as Helen explains:

Helen:

Into the shopping centre with her, she roared. Everyone was just looking at us.... I mean there is nothing we can do and dad* was like a dog. All we wanted to do was go home...we said 'just forget it, take her home'...I was literally crying because it was like our little day out, it was just a total disaster. So I said I will never take her anywhere again. That is it.

Some mothers responded to unknowingness by isolating themselves within the local community, where they felt there was some understanding of their situation that offered some protection from negative reactions.

Orla:

I suppose we do live a lot in our sort of community, and in our own wee world, it's just easier that way.

Mothers perceived that others in the outside world, like those who helped in the inside world, were nervous and scared of the child. This reaction is noticed and increases mothers' practical and emotional concerns. It identifies unknowingness.

Dara:

They just look a little bit scared. Like, they kind of sit on the edge of the seat and it just takes a little bit of getting to know.

This reaction was also caused by specific individualised behaviours, including seizures.

Brenda:

Now she (carer) would be more nervy. You know she would be more nervous if he started having seizures and what not, of what to do.

Scaredness is a reaction that mothers expect and accept. However, mothers avoid people who exhibit this reaction, if possible, to protect their child from their negative responses.

Imelda:

But I think people are just, are scared you know...People...would be very wary of how to cope with things or how to deal with things.

The complexity and individuality of the child's needs, the instability of the situation and unknowingness may cause similar reactions in family members. Within nursing I have seen this response with nursing students who are unfamiliar with these children and who "stand off" from expert parents. Wariness not only results from the child's physical situation but others find it difficult to handle the mother's reactions. They do not know how to manage the subject of the child in a conversation, leading to reticence on the mother's part in opening any discussion.

Orla:

There's times I can talk about it, and I can talk about it...It's not a positive subject, there's nothing positive about it.

Mothers notice this hesitancy in discussions about the child and the difficulties others have in handling the mothers' emotions. Mothers respond in different ways.

Orla:

They (friends and strangers) don't know whether... 'Do we talk about the subject? Do we ignore it? Do we not say anything?' Which some of them did do...I suppose they didn't know how to approach the subject...I suppose maybe they thought, 'Mum* will then go into a lot of tears, and should get upset'.

Outsiders demonstrate little understanding of the mothers' experiences and are unaware of the 'no choice' situation that they face. Mothers recognise this and further isolation results.

Niamh:

But at the end of the day they can walk away from it but we can't...It's sympathy, but at the end of the day they walk away and don't give it another thought.

Unknowingness results in physical and emotional isolation. Mothers, as mothers, have no choice in what they do; unless they care no one else will, which is little understood by others.

Rachel:

I mean people just don't really understand that. They think they do but they just don't.

9.4.4 Unknowingness in health care

Unknowingness in those working in health was a common factor in the mothers' experiences of caring, and their need for support from these services was frequently not understood. This was evident during discussion about service provision in all three worlds and in health care settings. Mothers reported that others had limited understanding of their situation or their child's needs. Mothers initially perceived that they would get help from such services but, over time, they learned that their needs for help were not understood by those who they would have expected to understand. They identified similar reactions in their reports of health and social care experiences, including unknowingness and avoidance.

Imelda reports:

The (health service) came...the first time to analyse us..., 4 of them came and we sat around the table...4, imagine... I mean they didn't believe us really you see. ...Like everyone they drove down the drive and they thought 'this is a lovely house now and these are grand people down here. Why would they want help?' I mean it's grand if we were in a (council/corporation house)...we'd have been fine but because we were both self employed...We both worked to get here, that really was against us...They felt why would you want help?...So the (senior person in the health service#)...and I sat down over there with my son* and she must have got off that chair, I'd say 7 or 8 times, because as he was seizing. She lost it, she couldn't take. She was a nurse by profession...They went away... came back about 2 weeks later with 3 hours a week for us...Some very, very sad, very sad individuals...I suppose they don't know what to do, so they ignore him.

When health professional's unknowingness was demonstrated to mothers it had a significant impact on them physically and emotionally.

9.4.5 Unknowingness in care services

In some situations mothers avoided taking the child to the outside world and the child was left at home in the care of others or in out of home respite care. In these situations, finding help was problematic and caused mothers physical and emotional challenges. Finding alternative carers who knew of the child's needs was difficult. If the mother was leaving

the child with others at home there was a need to find someone who was competent and who demonstrated knowingness to a level that satisfied the mother. Given the technical care required, mothers needed to have competent carers whom they trusted. The unknowingness in carers limited the help for many mothers and only a small number of people were available. Mothers' experiences of going out and leaving the child in the care of others at home did not lead to a relaxing time out. Impromptu and planned visits were often curtailed due to the instability in the child's condition. Instability required the mother to be constantly on call during the absence to provide advice and support. Contact with, and by, mothers throughout the absence was common. Mothers were concerned at all times about the carer's unknowingness. Where mothers did go out and leave the child at home, the child had to be settled. Consequently nights out for mothers started late and were frequently interrupted by the child's need for attention at home as the carer needed advice or assistance.

Anita:

We didn't arrive till say quarter-to-eleven... We didn't leave here till about quarter-to-ten. So like I had everyone settled before I left. We got a call then at twenty-to-twelve to come home. Little rascal.

When help was found, mothers were very appreciative. However, even those who were employed to care were left with as little care to deliver to the child as possible in the mother's absence. Mothers were concerned about the consequences of asking for 'too many favours' from those who did help, including paid carers. This is linked to 'pay back' described in the inside world when help is given.

Emer:

Now the odd time we would ask the nurse, you know. We...sort of say 'would you come a bit earlier like a quarter to nine' and you don't, like, ask even once a year. You have to pluck up the courage to ask them ...but you still don't like taking advantage and I feel they are good enough to work and come. I would be afraid of losing them.

For some mothers out of home respite was provided either in a carer's home, or in dedicated respite facilities. Mothers who availed of this service appreciated it as it provided an essential break for short periods for them but at the same time all mothers remained concerned about the child. Leaving the child in respite for any period of time caused mothers significant unease, emotional strain and an inability to enjoy the separation. They knew they needed a break but also knew of the consequences this had for them. Mothers living in rural settings had to undertake long journeys, as described previously, to avail of

these services and the respite stay always had to be planned well in advance, which limited impromptu outings for mothers.

Imelda:

I mean they have asked us at the beginning of the year...”What have you on this year? Have you communions or weddings or do you want a weekend off?”

Mothers reported on the impact of respite which had consequences when the child returned home, adding to their reluctance to use this service as Dara explains:

Dara:

That was the longest stint he’d ever been away from home ...when he came home he went through a phase of ... night terrors. Every single night he’d wake up...screaming crying and then we’d settle him down ...taking him into our bed would work.

Mothers attempted to reduce these effects by undertaking pre-emptive care and by constant communication with the care provider; this was not always reassuring and added to the mothers’ emotional concerns and anxiety throughout all separations.

Emer explains:

I would ring up and...some of the nurses would say ‘she is unsettled and she is crying’...One of the nurses said ‘she just cries and cries and cries’. ...I have nothing against respite homes, or services, for kids but I find it very hard, I feel very guilty leaving her there.

The dilemmas between knowingness in the mother and unknowingness in others in care delivery are apparent and the physical and emotional consequences on the mother and the child are evident. For outsiders, however, the use of respite was viewed as the expected solution to the mothers’ situations, no matter how temporary, which caused mothers concern. Others’ lack of understanding and unknowingness of their situation was apparent and mothers’ concerns were unrecognised when this solution was offered.

Emer, for example, explains the dilemmas mothers faced about respite care and leaving their child in the care of others.

Emer:

It’s hard...people, they all say ‘sure she will be grand (in respite#)’ but I said to the social worker ‘but, like she cries. But like if you had a child would you leave them with someone that you thought they wouldn't settle with overnight and like if this was a normal healthy child, no. Then why am I expected to do it?’...They just couldn't answer me.... I said ‘at the end of the day ‘she* is my child, she* is a

person and I have the same feelings for her that I have for those two'. So why should I be expected to say just turn off when she is not about.

The unknowingness, anxiety and concerns for some mothers reduces over time as they became used to the separation and valued the time for themselves, but there is always a significant tension in this situation.

Imelda explains:

We used to be very, very lonely...we'd bring him at 7...and collect him at 7... the boys* found it very hard to begin with...He* goes for a weekend every 4 to 6 weeks now and it's absolutely fabulous...It's a real normal weekend. Now we miss him...but it's just, it's the break really.

Out of home respite provides some relief for some mothers but this is a situation in which she continues to have physical and emotional concerns about her child, and the level of care they are receiving. The unknowingness of others who are providing care for their child is always an issue.

9.4.6 Unknowingness and hospitals

The children had significant contact with health care services, in both local hospitals, tertiary level paediatric centres and with community services that formed part of the mothers' experiences in the outside world. A significant amount of data focused on such experiences, which may have been related to the fact that I was a nurse and mothers may have felt that, by telling me of their experiences I could change things for them, or that they wanted others to hear of their experiences of health care.

Despite being cared for at home most of the children continued to need prolonged periods in hospital for diagnosis, interventions and follow up services. Mothers outlined their experiences in getting their child's diagnosis, investigations, genetic screening and the consequences of this for them. Other experiences included caring for children having pre and post surgical care for a wide range of surgical interventions common in children with complex needs, and the management of respiratory and urinary infections, as well as deterioration in their condition. These were in addition to routine developmental assessments, screening for drug levels and ongoing health issues. Health services were provided by a wide range of medical, nursing and allied professions.

Karen:

It's swings and roundabouts. It goes from absolutely nobody for a few weeks to everybody one after the other. You would be running every day of the week.

Brenda:

The first year and a half gosh...the first almost 2 years we were in and out of hospitals like yoyos, every couple of weeks.

Mothers reported their experiences of unknowingness in others including those involved in attempting to make an initial diagnosis, and during episodes of unexplained deterioration. Mothers outlined the issues they faced in getting a diagnosis for the child and the importance that was attached to this. Facing and managing unknowingness adds to the challenges of caring for children who have rare diagnoses and complex needs that may be little understood by the professionals involved. The mothers' experiences of being given their child's diagnosis, the unknowingness and the communication that surround this were apparent. The impact of the diagnosis and results from investigations was graphically described by the mothers.

Orla explains:

I got a phone call here one day to say that her* blood results had come through...and Dr* would like to see me...I said 'that's no problem, how soon?'... 'Today'... 'Will you make sure you bring your husband with you?'... Me, naïve as I was, thought they're going to turn around and tell me she's severely epileptic but that's ok we can cope with that... 'She has metabolic disorder*, its life limiting' and that was just like shell shock, total, absolute. You might as well have planted a bomb between the 2 of us.

Mothers explained how they tried to develop knowingness in the absence of help from others, particularly at the point of diagnosis or when a diagnosis could not be found. The emotional impact of the diagnosis was clear. Other mothers whose children did not have a diagnosis faced different issues. These included the medical search for diagnosis, living with a child who had no diagnosis, difficulties in service provision as the child did not clearly fit into specific service criteria and discussions about post-mortem investigations to find a diagnosis.

Frances:

Last year we said 'we don't want the diagnosis'. They (medical staff) are really quite persistent in doing two things...They can't believe she is still alive first of all and secondly she is so severe that we should be able to give a diagnosis on this child, we must do...We were sent for genetic testing ... 'We (neurologist) would like a repeat the MRI to see what her brain looks like now.'... 'If she was to die how would you feel about, you know, a bit of a post-mortem? '

In this situation whether the exact words were those that are recalled is difficult to understand but “a bit of a post-mortem” indicates how mothers interpret others’ search for knowingness in children with no known diagnosis.

9.4.7 Conflict between mothers’ knowingness and others’ unknowingness

Mothers described incidents in which they felt they were not believed by those involved in health care in their concerns about the child’s needs and where conflict existed between their knowingness and others’ unknowingness. Mothers reported when they used their knowingness to confront others’ unknowingness and the consequences of this. Not having their concerns believed within healthcare situations caused frustration for mothers. Not being believed occurred in communication with medical staff and nurses, amongst others, and demonstrated a lack of knowingness that is similar to those who did not recognize the mothers’ need for supplies and services in the inside world.

Janet explains her experiences of her concerns about her child’s deterioration. Knowing that something was wrong was not believed.

Janet:

The neurosurgeon...said ‘ach it’s a habit, its nothing but a habit’ and I said ‘...it wasn’t something that she ever had and it’s only started from she’s developed these headaches’...And she just wasn’t right,...It was such a hard time to get the neurosurgeon to listen...and by now I was at the end of my rope and I was saying ‘please’. I was almost on my knees begging this guy ‘please, you know do something’ because there was clearly something wrong... (Neurosurgeon)...said ‘she’s maybe just a headachy child’ and I said ‘I don’t believe that there should be such a thing, headachy children you know, I’m not a doctor but I don’t believe’...This neurosurgeon really intimidated me, really and I couldn’t fathom why...but he made me feel about knee high you know...The shunt was all disintegrated and it was broken in 3 places and he said ‘you know she should be dead’.

Given the nature of the children’s illness it was not unexpected that those inexperienced with the complexity of some of the children’s conditions are unknowing. However, for mothers the impact of a lack of acceptance of their knowingness is difficult for them to understand and it caused disruption to their relationships with many health professionals. Dismissive responses of mothers’ concerns during difficult situations related to the diagnosis and deterioration in the children impacts on them. Mothers can react by taking situations into their own hands, taking on more responsibilities, or avoiding those who

have treated them in such a way. There is an obvious emotional conflict for these mothers at times between their knowingness and the unknowingness of others and vice versa.

Paula in her bad day diary explains:

I have just phoned the (secretary*) to get (child *) seen before October...I am stunned and angry... it seems October is the soonest my child can be seen... (Child*) really needs to be seen earlier. I am so mad my superhuman patience is failing me. Can they not see that this is my child's life they are playing with?

Mothers face significant challenges with others' unknowingness in situations where their child deteriorates significantly. For some children this occurred frequently due to the nature of their condition. In some situations the mother, and others, tried to reduce the unknowingness, but the difficulty in doing so may be a real concern for those who work with children with complex needs, given the unpredictability of the disease trajectory. However, unknowingness in health care is ongoing and frequent in the mothers' experiences, and not believing a mother when she expresses concern about her child is difficult to explain.

Other incidents demonstrating unknowingness in nurses had similar consequences for the mothers.

Frances:

And when I ring up (the hospital) in the morning and say 'how is my daughter*?' Oh 'she was very good all night'. Like, it's like you are lying about what is going on at home.

Unknowingness in health care is significant in mothers' experiences. Many mothers commented on a lack of understanding of others of their situation and an unknowingness of the child's needs. These negative experiences had significant, long-lasting physical and psychological effects, and mothers were frustrated by inappropriate responses.

Rachel:

I don't expect people to understand it; I mean I wouldn't have understood it before I experienced it. But when...they've seen it once or ... I've explained or said why I can't do something I wish people would just take it at face value and not say 'Ach you can; you will; you know, it will be grand' because they don't know, you know. I know her limitations and if I say 'she's not going to be happy with something then she's not going to be happy with it'.

Within the outside world mothers spent much time in the health care where mothers' knowingness and unknowingness in others can be in conflict. Getting the diagnosis, the unknowingness of the diagnosis by the mothers, and sometimes the professionals, adds to

the complexity of the mothers' experiences. The inappropriate reactions of staff, the care given, and care situations experienced, all impact on the mothers. Being believed was an issue within health care for them. For professionals, the unknowingness in the situation is demonstrated by unknowing responses that mothers identify. In health care a clear diagnosis adds to the knowingness of professionals.

9.4.8 Responses to the outside world-negative reinforcement

Mothers reported on a range of verbal responses they made in answering questions about their child. One response was not quite telling the whole story, "she's grand", which in turn compounds the issue of improving knowingness in others as mothers avoid explaining the complicated situation that faces them, and the realities of this. For mothers it is easier to be dismissive than to explain what is really going on. This results in reinforcing others' unknowingness, which for mothers is at times problematic and avoided. Mothers responded by not telling the whole truth.

Helen:

They say; 'well, how's the baby', or whatever...and I say; 'ah, she's alright, she's grand or'. I mean I would saying sort of 'oh, she's much the same'. And it's very hard... to answer them because bar saying; 'well, she's the bloody pits. That actually I was up all night and she's puking like'...I don't want people asking all the time either. It's very hard balance to strike, I suppose.

Mothers additionally reported how they became frustrated at having to tell their story on numerous occasions, especially in relation to health care. They found it difficult to have to report on their child frequently, particularly as there was often little change in progress.

While their responses can be fully understood, the "I am grand" type response may further isolate mothers from those who are accepting of this statement at face value. Others, including family, friends and those in health care may accept this and not investigate further the underlying reality of the situation.

9.5 Constant communication between the worlds

A final dimension explicated in the mothers' experiences which links the three worlds and all dimensions is constant communication. It is explicated in the outside world as it acts as a mechanism that is used to connect the mother with those in the going-between and outside worlds. Constant communication was achieved between the mother and others frequently to provide a link between the mothers' knowingness and the unknowingness of others. The mobile telephone was a source of constant communication in the mother's

experiences. This dimension and its importance emerged early in the study when I noted the number of times mothers asked me to call back as they were busy, or when they wanted to be contacted only at specified times. I noted the number of telephone calls that interrupted the interviews (Nicholl, 2007), and the great speed with which the mother always answered the telephone, but especially when she was separated from the child. Mothers were always waiting for calls during interviews, which caused interruptions, as they were always viewed as important. This observation is recorded in my diary: The mobile telephone is a constant between the mother, the outside world and the inside world, when she is separate from the child or to connect with services - a constant (11 02 2006). Telephone contact was needed to get advice about the child's condition, for equipment, to follow up on supplies, and to communicate with hospitals. The frustration unanswered calls and telephone experiences caused and their impact on mothers was vividly described. This constant communication was part of the world of caring for a child with complex needs and has an emotional component.

Rachel:

I started on the phone...I don't know, just everything, chasing things,...but it's because you ask a question and it takes a fortnight to get an answer unless you sit on the phone.

It is time consuming and requires the mothers to be constantly available to respond, no matter where the mothers are. This method of communication is a constant, and frequently used, link between those in the outside world and the mothers, often impacting more than any individual caller to the mother would know or understand.

Emer:

I might be grand when I am on the phone and I will just come off the phone and I will put it down and cry for 10 or 15 minutes before I will come back to myself then...But I have to be prepared for that when I do make phone calls to several people...Nearly every phone call I make concerning my child* it happens.

Mothers additionally reported on their experiences with telephone calls during the past and recounted many examples of being given diagnostic information or the results from tests by telephone. The mothers recounted the impact of this which, again, may have been unrecognized by the unknowingness of the caller of the mothers' situations.

Ciara:

It was an awful shock at the time because the hospital said 'they had the results'. They phoned to say 'we have the results, we want you to come in tomorrow'...I felt if the news was bad they would have told us over the phone.

Mothers reported on the frequency with which they had been requested by service providers to telephone for help, information, to book carers, arrange respite, for results from tests and investigations or to make appointments. Little recognition seems to have been given by outsiders to the 'doing of this'. There was no recognition of the impact that this constant connectedness causes the mothers as they manage their child's physical needs while meeting the competing demands for their time.

Janet:

Somebody called and you would stop (physiotherapy) and you would say 'I will come back to you' but you don't... and the phone is taken off the hook.

The interruptions that these calls made and the demands that this constant communication placed on mothers was significant. Equally for mothers the frustration caused by others not returning their calls demonstrated little understanding by others of their needs. The frustration felt when not getting replies to telephone calls is part of the 'chasing and waiting' described in the inside world. It adds financial and time pressure for the mothers but is emotionally challenging.

Martha:

I am waiting on the fellow who deals with disability to ring me and I have to wait on him to ring me... You really do get very physically and mentally exhausted, you know... The other thing... is the time, the time that you have to wait to get things moving... how much ringing does one need to do?

It was apparent that when the mother and child were separated, for whatever reasons, the constant communication strategy between the two was needed. The telephone provided a constant two way mechanism for communication about the child's care to, and with, others. This channel was always open and was important to both the mothers and service providers at all time including when the child was in out of home respite or separated from the mother for any reason. It linked mothers' knowingness with others' unknowingness and provided a source of knowingness for the carer and the mother at all times.

The telephone was used as a mechanism of checking in and checking out between the knowingness of the mother and the unknowingness of carers. This emerged when mothers reported on how they made and received calls when separated from the child during "time out" from their caring activities, when their child was separated from them, for whatever reason. This included occasions when the child was with their father, in school, respite or with other carers. The telephone not only provided constant communication to reassure the mothers that all was well, but it also caused constant interruption to the mothers when they

were getting a break from care. When the mother was separated from the child the telephone was a constant method of being connected with the child.

Helen:

One weekend I went to (city#)...a weekend away and I got a phone call up in the shop and she had pulled her tube out, and I had to tell dad (how to put it back in)...inside a shop.

Mothers used the telephone as a checking out mechanism when she was separated from the child. This adds to her knowingness of the situation from which she is separated and provides essential reassurance. The reasons for receiving telephone calls included the child being unwell, the carer needing advice about aspects of care or to tell the mother to return home because the carer could not cope.

Frances:

When I was in Aldi...shopping. She (carer*) rang me...‘I just rang to let you know I think her breathing is not good’.

Mothers telephoned frequently to check on many aspects of care being given to the child in her absence even if the care is being provided by the child’s father. For some mothers, texting was used in addition to telephone calls.

Anita:

Dad* texts me. I text him at every break, em and then he texts me when she* is settled and how she is, yeah I find it extremely difficult being away from her.

The time apart from the child could vary from a few hours to a short break but, no matter the duration, constant communication is maintained. If the child is in out of home respite and the mother is not present the need for this constant communication is reinforced by the mothers.

Gretta:

Yeah.....Every hour on the hour... I ring morning, afternoon and evening and then when he’s in bed.

Mothers use the mobile telephone as a mechanism to ensure all is well, just as they use constant observation within the home. It is a constant in their life in all three worlds and results in the mother never being fully separated from the child in any situation.

Helen:

but I always tell them ‘if anything happens her that they are to ring me, not to ring the doctor. They are to ring me first before they ring anybody else’. So they do...they ring me first.

Mothers consequently are never removed from their care-giving responsibilities, even when the child is being cared for in respite, or in the mother's absence, in the home. They are constantly aware of their child's needs no matter where the child is. The mother wants to be the first to know if there is any change, however slight or significant, in the child's condition. She knows what to do if this happens and needs to be informed and is constantly available for advice. She knows others do not have the same understanding of her child.

Imelda:

No I'd be very worried. I would ring every day. Would I go around with my mobile not on? No. I'm going everywhere with my mobile... Turned on. Yeah... definitely they know now that to try the mobile if there was anything urgent. They'd leave messages because they know it's always something with him* if I don't answer. But if I hadn't him* with me I guarantee you 99% of the time I'll answer... He's your red alert, you really are very aware that like.

Mothers additionally reported on using the telephone in the inside world to keep in contact with the outside world of family, friends and for support. Others also used a telephone call to provide support for the mother. However, the constancy of communication impacted physically and emotionally on mothers who, at times, reported either not answering the telephone, or taking the telephone off the hook, if the child was with them. If this was known to outsiders they knew to ring back but in other situations these avoidance responses further reinforce the isolation that mothers experienced.

Helen:

My friends, my two best friends...ring me a lot. But I got to the stage that I have to take the phone off the hook, because they ring me and she gets a seizure in the middle of a call or she starts puking and I have to say, 'hang on a minute, they're there with the...'. I have the phone down and they're,...all they're listening to is (made a vomiting noise) in the background.... And I end up picking up the phone saying 'I have to go, I have to change, or whatever'. So like I have to ring them now... but mm I just, I've got into the habit now of not even trying to answer it because it's not fair... I can't leave her for a minute.

Interruptions caused by telephone calls, from whatever source that impacted on the child's care which mothers avoided if at all possible.

While telephone contact offered a significant potential support mechanism for mothers to their family and friends, and an opportunity to reduce their isolation, some mothers reported how they avoided telephone contact at times.

Brenda:

Sometimes I wouldn't bother ringing anyone... There's no one really that you could ring and say; 'oh, Jesus, I'm having a really bad day'. My friends will, they'll be very understanding to a degree, but they really don't understand. They might hear him crying. They're like 'oh', you know. I'm like; 'oh, my arse' (laughter), 'take him', you know. 'Oh' just doesn't cut it... it's nice and it's sweet and everything else but they can hang up the phone and they're gone.

The response of not answering calls or taking the telephone off the hook, as mothers get on with technical care-giving and perceive that others are unknowing of their experience further negatively reinforces attempts by others to offer support.

The mothers' experiences are characterized by constant communication between all worlds. This constant adds to the constancy of observation and connectedness that characterise the mothers' experiences and has many practical and emotional consequences. The constancy of caring is consequently not reduced when the child is separated from the mother because of a two way communication and mutual support mechanism that is clearly established between the mother and the carer. This reinforces mothers' knowingness; for carers it reinforces their unknowingness. This mechanism is put into place by outsiders who advise mothers to 'If there are any problems please call us'; 'I will ring you if there are any problems or if he doesn't settle' or 'ring us if you are worried or need anything' type conversations that I know are made when children are discharged from hospital, or respite. It is implemented by mothers who ask carers to call them if there are any difficulties and expect this to be done. It adds to the constancy that pervades the inside, the going-between and the outside worlds and offers a connectedness to knowingness in mothers. The use of the telephone for mothers' support in the inside world is limited if it impacts on the delivery of the child's care.

9.7 Conclusion

In the previous three chapters the findings have been reported. This exploration of mothers' experiences of caring for a child with complex needs has identified that caring occurs in three worlds. These are an inside world, a going-between world and an outside world. The experiences comprise eight dimensions that are central to the mothers' experiences of caring for a child with complex needs. Four are related to care-giving and comprise normal mothering, technical care-giving, pre-emptive care-giving and individualised care. The remaining dimensions are paperwork and administration, constant instability, constant observation, a 'no choice' situation, knowingness and unknowingness

and constant communication. The findings indicate that these dimensions impact physically, socially and emotionally on mothers, the children and family. Mothers' knowingness of their child's needs influences them as they find themselves in a 'no choice' situation that is little understood by others including health professionals, family and friends.

9.8 The 'I'- a comment

During data collection the dimensions emerged at various stages and were verified during subsequent interviews and in presentations related to the study. As the data were analysed the three worlds and the eight dimensions became evident. Fitting the dimensions together when writing the findings was a real difficulty. It was only as I wrote, and rewrote, the many drafts of the work that the eight dimensions and the three worlds became obvious and the link between mothers' knowingness and unknowingness in others became part of the mothers' experiences. Gadamer is correct when he describes the need to write and rewrite. This also adds evidence to the fact that analysis is not a staged process, but is ongoing and ever changing.

The findings from the study will be discussed in the following chapter.

CHAPTER 10 - DISCUSSION OF THE FINDINGS

10.1 Introduction

The focus of this chapter is the discussion of findings from the study, the link between them and what is currently reported in the literature.

10.2 The outcomes

The data collected, and the use of a phenomenological approach, has enabled the lived experiences of mothers to have been illuminated in a detailed way. Mothers' experience of caring for children with complex needs at home involves care-giving in an inner world of the home, a going-between world and an outside world. The data provided by mothers offers additional knowledge and a different perspective to the phenomenon of caring for a child with complex needs. The findings reported mostly concur with those from previous studies and bring together concepts and findings from literature on caring by mothers of children with disability, life-threatening illness, complex needs and children receiving palliative care. Additional perspectives on care-giving at home by mothers, which have not been previously reported in the literature, have been identified.

10.3 Care-giving

10.3.1 Normal mothering in care-giving

Within this study four components of care-giving have been explicated. The findings support contemporary views that the major part of caring for children with chronic illnesses tends to be borne by mothers (Porter and McKenzie, 2000) and a division of labour frequently occurs in two parent families when one parent, usually the mother, is the primary care-giver for the ill child (Orloff et al, 2004). Care-giving involved normal mothering which is provided by all mothers by meeting the child's needs in relation to activities including washing, dressing and feeding. Normal mothering is prolonged, becomes more complex and physically difficult as the child grows and develops, and mothering roles and responsibilities persist. Mothers must develop new skills and roles and have to manage themselves, the child, siblings and normal family life around the needs of the child. They face the challenges of normalising the family and the tasks of balancing the demands of parenting and care-giving simultaneously (Section 7.8). In the literature on mothering children, the physical and psychological consequences of chronic illness, technology-dependence and illness on mothers, the family and the home have been

identified (Twigg, 2000). These include maternal role ambiguity and conflict, care-giver burden, stress, loss of privacy and the impact on siblings and marital relationships (Kuster et al, 2004; Hewitt-Taylor, 2005; Heaton et al, 2005; Kuster and Badr, 2006; Green, 2007). The need for technical equipment means that homes are often transformed into miniature intensive care settings (Sudia-Robinson, 1998) that mothers need to manage as part of care-giving. Green (2007) has indicated that mothering a child with disabilities is no different from ordinary parenting in that this, too, is time consuming, expensive and physically exhausting, though Greer, Grey and McClean (2006) in a small study (n=36) report on positive perceptions of mothering a child with intellectual disabilities in Ireland. Raina et al (2005) report that care-giving is a normal part of being the parent, but that this role takes on a different significance entirely when a child experiences functional limitations, as in cerebral palsy, for example, and when the possibility of long term dependency occurs. Mothering is complicated by the child's needs for complex procedures and treatments, and a reliance on technical equipment (Gatford, 2004). In this study roles, including normal prolonged mothering, was undertaken to ensure that the children's needs were met, no matter what the physical, emotional, financial or social consequences to the mothers or their family (Section 8.5).

10.3.2 Technical care-giving

Mothers were involved in highly technical care-giving in addition to normal mothering (Section 7.8.1). The range and complexity of skills delivered are similar to those reported in mothers of children with disabilities (Green, 2006); technology-dependence (Thomlinson, 2002; Wang and Burnard, 2004); a motor impairment (Warner, 2006); and medically fragile children (Hodgkinson and Lester, 2002). It is evident in literature in children with specific diagnoses (Ganong, Doty and Gayer 2003); cerebral palsy (Raina et al, 2005); mitochondrial disease and biochemical genetic disorders (Read, 2003); brain injuries (Guerriere and McKeever, 1997) ; spina bifida (Zipidis and Paschalides, 2003) and in literature on children requiring particular aspects of care, including feeding by gastrostomy tubes (Hunt, 2007) and ventilator-dependence (Wilson, Morse and Penrod, 2007). The range of problems exhibited by these children included high levels of medical, nursing and psychological needs (Kirk and Glendinning, 1999; Lenton et al, 2001) and the evidence suggests that daily routines and continual responsibilities result in physical and emotional overburden on the carer (Wang and Burnard, 2004).

The technical care-giving delivered by mothers in this study are similar to Redmond and Richardson's (2003: 219) findings, of a 'quasi-nursing' role where Irish mothers met the

children's specific medical needs including complex medication administration and Himmelstein et al's, (2004) study in children's palliative care that identified constant, round the clock care-giving and complex medical tasks, from which parents have little relief. Wilson, Morse and Penrod's (2007) Canadian study of mothers of ventilator-dependent children similarly found absolute involvement in mothers' care-giving.

Care-giving for children with complex needs is time-consuming, requires extra work and all aspects of the mothers' lives are affected by caring, monitoring their child and fulfilling care-giving activities. Technical care-giving activities that placed additional demands on mothers in this study involved delivering multiple aspects of care including enteral feeding, seizure management and individualised behaviour management in one and sometimes more children simultaneously (Section 7.8.2). The mothers' experiences of enteral feeding and its impact are similar to Hunt's (2007) reports of tube feeding in disabled children and the stress involved in PEG feeding and the enormous time needed identified in Spalding and McKeever's (1998) work. However, in my study mothers had simultaneously to manage additional complex aspects of care, including seizures and behavioural problems.

The complexity of skills mothers need to use, including managing sophisticated equipment in sometimes life-threatening situations, are similarly reported in technology-dependent children (Heaton et al, 2005); chronic conditions (Sullivan-Bolyai, 2003) and severe disabilities (Pain, 1999). My findings, however, identify how mothers adapt care-giving to their child's unstable, individual situation and the uniqueness of their child's needs (Section 7.8.7). McKeever and Miller (2004) similarly indicate that care-giving not only requires considerable skill but also knowledge, and responsibility, by mothers. My findings illuminate the ongoing and continuous physical and emotional demands of technical care-giving and how mothers manage their situation around the demands of care-giving in three contexts. These aspects of care-giving in other contexts are not identified in many studies that focus on care-giving within the home, with no recognition of the care-giving that is required in the outside, or going-between worlds. Additionally the impact of technology, and the need to ensure that the child's essential equipment is appropriate, stocked and replaced, and how this adds to care-giving, has been revealed. The impact of technical care-giving on the mothers' physical, emotional and social functioning is evidenced.

What is additionally identified is that technical care-giving proved difficult when two people were required to undertake some aspects of the child's care (Section 7.8.3). Little is reported on technical skills that require two carers including NG tube changing, mobilising or bathing, or how mothers manage in similar situations in the absence of partners, or

family help. This is not reported, for example, in studies of gastrostomy feeding (Craig and Scrambler, 2006) where the need for skill, time and patience is noted; or in studies on care negotiation in technology-dependent children (Reeves, 2006). Yantzi, Rosenberg and McKeever's Canadian (2006) work has highlighted the lack of carers who are available to single parents, but the difficulties either lone mothers face, or situations in care-giving that require two people, are not evident. My finding that those who deliver the child's care require intensive training and knowledge which limits the help available to mothers, is also supported by Yantzi, Rosenberg and McKeever (2006). In my study, mothers frequently reported managing on their own in mobilising the child for example, which sometimes placed them, and the child, at physical risk, particularly in the going-between and outside worlds. It meant that care had to be scheduled around others' availability.

In the literature on alternative feeding issues of stigma, normalisation and decision-making are identified but there are no reports of the specific practical difficulties that can occur. In this study, fathers did help occasionally with some aspects of care-giving but this was limited by their availability and skills (Section 7.8.3). Adams, Gordon and Spangler (1999) similarly found that fathers lacked confidence in managing children with feeding difficulties. Taking turns in care-giving, identified in my study, had an impact on family functioning and social activities. Paternal involvement has been found to buffer the effects of stress, role strain and family burden in chronic disease in children (Gavin and Wysocki, 2006), yet this was limited in my study where fathers' lack of availability, and mothers' unwillingness to involve them at times, was apparent. Pederson, Parsons and Dewey's (2004) Canadian study found that parents of enterally fed children had higher levels of stress that were associated with a lack of support from spouse, family and friends, which supports my findings in relation to technical care-giving and feeding.

The current expectation in health care is that children who require long-term technological and medical support will be discharged home (Noyes, 2000), yet little is known of the long-term impact of this. Wang and Burnard's (2004) review of technology-dependent children and their families identify barriers to community care delivery and the impact of technology-dependent children and their families in paediatric home care, but do not consider the specific situations faced by lone parents whose children require care needing two people. Given the range in the age of the children this study identifies the impacts on mothers over time and how they manage which is not always evident in others' work.

Mothers identified the range of technical skills needed to ensure that their child remained well and their responsibility for providing care (Section 7.8). Mothers delivered complex skills, often on their own, in difficult situations in, and outside, the home, with little help

from relatives, friends and carers. In the literature on the impact of technology-dependence, it is reported that families assumed responsibility for performing highly technical skills at home that would previously have been undertaken only by qualified professionals (Kirk and Glendinning, 2004). The findings reported here concur with this and the mothers' role in care-giving at home was generally assumed by others which are also reported by Lewis and Noyes (2007). The child's complex needs impacted on the help available to mothers as others were not able to offer technical practical help as they could not undertake some of the procedures that mothers were performing themselves. Hewitt-Taylor (2005:b) identified the need for education for nurses caring for children with complex needs at home but similar literature on the needs of parents for education is not available, though Lewis and Noyes (2007) report on the need for training in specific skills for parents of children with complex needs, but no details are provided.

In my study the lack of knowledge and understanding of technical care-giving by others resulted in limited help being available and created concerns about competence, and trust, in alternative carers. Yantzi, Rosenberg and McKeever (2006) support the finding that there is a misconception that others in the family, friends or relatives are able to help mothers by providing respite care. Mothers provided care-giving in a 'no choice' situation where little negotiation was undertaken with them about their technical care-giving role, and the support needed for this. This is similar to findings in other studies (Reeves, Timmons and Dampier, 2006), but differs from the recommendations in guidance for discharge planning where it is reported that roles and responsibilities, and ways of working, should be negotiated with parents (Lewis and Noyes, 2007).

Mothers' graphic descriptions of the situations in which care was delivered in the three worlds contextualises technical care-giving and its physical, and psychological, impact. The unstable and fragile nature of the child's condition and the constantly changing, challenging and ongoing nature of their needs are evidenced. Yantzi, Rosenberg and McKeever (2006) suggests that the extraordinary care required by children is often taxing physically, mentally and emotionally, yet mothers in this study had no choice but to do what needed to be done; to learn what care their child needed and to deliver it as best they could. This included caring during travel (Section 8.3) and in the outside world, which is unreported in the literature though Yantzi, Rosenberg and McKeever (2006) do identify similar findings in the preparation mothers need to make to travel outside the home with children with long-term needs.

Technical care-giving included complicated drug management. In Ireland, management of drug regimens is a doctor's remit, yet mothers identified altering drugs and treatments

without any discussion in order to improve their child's condition, particularly in relation to constipation, infections and seizure management (Section 7.8.5). This was not daunting for the mothers but was a normal role for which they reported no specific training. If they did not manage situations, and make decisions based on what they thought was needed, no one else was readily available to help, or advise them. In this study those that could help were, for some mothers, at least a journey away, which was not any help to mothers in frequent, urgent situations, given the difficulty in travelling with the child (Section 8.3).

Other findings related to technical care-giving, and its consequences, including time pressure, planning and navigating barriers in the environment in the outside world are similar to those physical, social and service challenges reported by Yantzi, Rosenberg and McKeever (2006). They are reported in UK literature on disability, and mothers' experiences in going out into public places, with learning disabled children. Ryan (2005), for example, reports on structural obstacles in the outside world and their impacts, but does not provide details of journeys that this study does. Lewis and Noyes (2007) give examples of factors to consider when discharging children with complex needs home, and refer to the need to work with parents so that they can transport equipment, which was a significant difficulty for mothers in this study, but was unrecognised by others.

10.3.3 Pre-emptive care-giving

Care-giving has a pre-emptive care component which requires mothers to be constantly alert to changes in the child's condition and to implement care to constantly ensure the child's physical and psychological safety in all worlds (Section 7.8.4). In the literature on technology-dependent children, parents have reported experiencing concerns about their child's illness and particular fears about deterioration, or finding their child dead (Kohlen, Beier and Danzer, 2000). However, the steps mothers take to pre-empt deterioration, and managing these fears, are not clearly identified. In this study, in the absence of support, mothers undertook pre-emptive care-giving to ensure that their child remained well which required constant forward planning and pre-emptive care. Tonks et al's (2005) work on chronic illness reports that exacerbations of chronic illness increases families' vulnerability to relatively minor events but does not examine how vulnerability is managed. In this study, pre-emptive care is a strategy used to manage instability and vulnerability as the mothers attempt to maintain stability in the three care-giving worlds.

10.3.4 Individualised needs

Within this study the individualised nature of the child's needs and their impact on mother's care-giving, and social activities, have been explicated (Section 7.8.7). The stigma associated with the children's individualised behaviours, including communicative and sensory problems, on the child, and family, in the outside world are evidenced. These behaviours, that are known to the mothers but which are unrecognised by others, impact physically, and emotionally, on the mother, the child and siblings. Caring for children with complex needs includes the prevention, and management, of these behaviours, and mothers undertake pre-emptive care-giving to attempt to prevent them, and manage them, by maintaining the child's routines where possible (Section 7.8.4). Raina et al's (2005) study on children with cerebral palsy indicates that non-clinical behavioural issues impact on the care-giver's psychological health, but the social impact is not reported. The child's individualised needs had an impact on the mothers by restricting them within, and to, the home, during travel and in the outside world. Mothers, additionally, require carers to acknowledge, and successfully manage, these individualised behaviours if they are to leave the child (Section 7.8.7). This is similar to Yantzi, Rosenberg and McKeever's (2006) findings in children with long-term needs. In this small study (n=11 mothers) they report that few others have the expertise to care for the child which results in social, and spatial isolation, for mothers that is unrecognised, which is similar to my findings. The impact of individualised behavioural problems, as well as the physical aspects of the child's needs is significant, and supports Pederson, Parsons and Dewey's (2004) findings that parents of enterally fed children had greater social isolation.

Studies of parents of children with learning disability suggest that individualised behaviours, including being intolerant of loud noises, or being unaware of dangers, make going out problematic. In Ryan's (2005) qualitative study (n=17) mothers reported on children's behaviours similar to those I have identified. Many of the problems experienced in Ryan's study were caused by the non-visibility of the behaviours. The findings related to the disapproval that mothers face in the outside world are similar to those reported by Ryan. However, the isolation that is a response to stigma associated with their child's behaviours in public in this study (Section 9.4) was not the response Ryan found. She reports that "on the contrary...mothers make persistent efforts to maintain a public life for their children" (p71). Some of the mothers in this study expressed their desire to maintain a public life by bringing their children to family occasions and events despite the emotional and practical realities they face. There was, however, always a tension for mothers in this study in taking children out into public situations.

The impact of social stigma in children with specific diagnoses, behaviours and complex needs includes a negative impact on family integration, in epilepsy (Mu, 2008), in HIV (Chuang and Liu, 1997) and in chronic renal disease (MacDonald, 1995). Individualised behaviours, including seizures, and their physical impact, have been examined in ten couples of young children (aged 3-6.8years) with epilepsy by Mu (2008). Parents in this study faced unstable patterns of seizures that exhausted them and caused the family to be in a state of chaos. American mothers of children with asthma similarly reported on unending illness, and its impact during acute episodes, which resulted in them feeling frightened, frustrated and helpless especially during night-times (Horner, 1997). Horner reports on mothers trying alternatives to resolve the children's situation, which is similar to pre-emptive caring used by mothers in my study, when they consider a range of options to avoid situations deteriorating.

In this study individualised care-giving is illuminated as the mother's response to their need to manage the particular, and individual, needs of their child in the three worlds.

10.4 Paperwork and administration

Managing paperwork and administration is a significant role for the mothers that added to their caring responsibilities. Mothers reported on the tasks they had to undertake to ensure their child's care needs were met by those in the outside world who appeared to have little understanding of the situation (Section 9.4). Kirk, Glendinning and Callery (2005) similarly describe this in parents of technology-dependent children, whose roles were described as multi-faceted, that not only includes managing complex unpredictable situations, but also organising support services in the home. All the mothers reported their role in finding and getting help, advice or support in their care-giving that added to their administrative role. The ongoing, and changing, needs of the children were unrecognised and planning for the future was the mother's responsibility. A lack of service planning was evident and budgetary constraints impacted on mothers, adding to the administration they needed to undertake. These findings are consistent with the literature in families of children with complex needs and technology-dependence where confusion in responsibilities for service delivery is reported. Mitchell and Sloper (2001) indicated the confusion families face in how to liaise with providers, with eligibility criteria, and the disparate roles that professionals have. Mothers reported on the difficulties in accessing services due to their children not meeting particular eligibility criteria (Section 7.9) and on their role in getting services and the paperwork involved. The complexity of the children's care commonly created difficulties in locating services. A number of mothers had to take

action with their councillors and politicians to get their case heard. Jordan, Eccleston and Osborne (2006) report similar findings in parents fighting for resources to manage their children's chronic pain and that one parent indicated the need to be "bolshy" (p52) as the only way to gain mastery in the situation. In the literature 'battling the system' is documented and issues reported include the unavailability of services, unmet needs, bureaucratic barriers, and a lottery of provision (ACT, 2003; Audit Commission, 2003). Accessing services was similarly difficult for mothers and depended on where they lived and how hard they were able to push to access support. The provision varied and included voluntary organisations that provided funding used to 'purchase' services by the mothers. For others, the services depended on the particular diagnosis of the child and the consequence of getting help from one service, for example disability, meant that other services were unavailable. Mothers were unaware of services and funding available to them; accessing them was difficult and services were often provided opportunistically rather than being delivered in an organised approach. There were gaps in delivery between services between hospital and community. In Ireland the lack of outreach support services has been identified by Redmond and Richardson (2003) and may be the result of lack of interagency support (Watson, Townsley and Abbott, 2002). Respite services in Ireland are seen as poorly structured with a lack of central and local policy emphasis (Kiernan, 1997) and there is a focus on respite in intellectual disabilities (Mulvany, 2000). Children with complex needs do not fit neatly into diagnostic groupings or known medical categories, which made them difficult to place in a medically focussed system. Mothers identified difficulties though, that are similarly reported in intellectual disability services for children in the RoI and accessing services was also highly prized (Redmond and Richardson, 2003). In NI, children's community nursing is further developed and mothers there were slightly better informed, even if services were not always provided for them because of the child's diagnosis. The difficulties and the administration this causes is similar to findings in studies of parents of disabled children that indicate the frustrating, time-consuming, repetitive and distressing processes involved (Audit Commission, 2003). Maunder (2006) similarly identifies the need to implement services that meet the changing demands as the child grows and matures, which was not evident in this study, perhaps because of the lack of statistics related to these children.

Though this study was undertaken in Ireland, where community services for children are currently under development, the administration and paperwork mothers reported is supported in international studies. Peter et al's (2006) Canadian study of children with special needs children at home indicates that services are unequally distributed and

fragmented and there are few policies related to specialized services needed to meet their medical needs.

Mothers identified the difficulties that they had in the outside world and navigating the system to lobby for services, equipment and resources (Section 7.9). This needed persistence, time, problem-solving and decision-making that added unnecessary travel and administration, yet Lewis and Noyes (2007) identify the importance of purchasing equipment, servicing, breakdown management and on call support in discharge planning for children with complex needs. The Audit Commission (2003) reports on unacceptably long waits for equipment, adaptations and interventions and their impact on children and families. The impact on the mothers in this study identified the need for administration that resulted in time pressure and frustration. The time wasting caused by poor coordination is similar to results from Read's (2000) work in which families reported finding the systems confusing and impermeable. Mothers faced changes in service provision at particular times of the year, including summer holidays, when education services were reduced and when changes in consultant or health care staff occurred. Service planning did not feature in the mothers' experiences, and a maze of uncoordinated, unreliable services compounded their administrative role. Decisions about the child's care by others were unplanned and happened by luck, using a 'wait and see' approach or when mothers "had had enough" and wanted things changed.

Fighting for services, the time pressure and stress caused to parents is a common finding in the paediatric literature (Jordan, Eccleston and Osborn, 2006; Van Riper, 2007). There was no organised approach to the child's care between the hospitals and local providers, for even the most fundamental equipment, that added to mothers' administrative roles. This frequently resulted in unnecessary travel in the going-between and outside worlds, entailing car journeys like those described. There was limited understanding in service providers that children grow and develop, and that the complexity of their diagnosis may cause deterioration over time and that their needs change. There was no future planning for the children who would clearly deteriorate, and whose needs would obviously become more complex over time. Yet care planning, multi-agency planning and partnership in caring with parents are identified as principles valued and promoted within children's nursing nationally and internationally (DoH, 2004). Within this study the service provision of any nursing contribution was fragmented and difficult to obtain (Section 9.4). Services were sourced for some mothers by luck, or opportunistically in the initial stages of their child's illness. There was an uncoordinated approach, yet care coordination and partnership with parents are highly recommended in discharge planning and community

care (Sloper, 1999; Lewis and Noyes, 2007; McIntosh and Runciman, 2007). Mothers reported on their vulnerability in relation to keeping nursing services, particularly at home respite. This may be due to a shortage of experienced, and technically able, nurses and carers, whose availability is limited and unpredictable, particularly in rural areas. For other mothers, sourcing nursing respite at home involved forward planning, administration and paperwork, which added to the demands of caring. Receiving grants and financial help to fund private nursing and care arrangements impacted on the complexity of caring as mothers then had to account for funding by keeping “books”, or use it to find services themselves, which meant recruiting or employing their own staff, with all that this entailed for them (Section 7.9). Finally, mothers’ responsibilities included advocating for their children’s services and they viewed this as their role in the absence of other help (Sections 7.9 and 9.3). This is similarly reported by Green (2006) in mothers of disabled children, who indicates the limitations this places on mothers’ social and leisure activities. In my study, mothers’ roles were complicated by the paperwork and administration needed. However, studies have shown that when parents feel in control of events and can obtain appropriate help for their child and family, they are less likely to have high levels of distress (Seligman and Darling, 1997; Porter and McKenzie, 2000). This may account for the ‘just getting on with it’ and the ‘no choice’ approach adopted by mothers in my study (Section 8.5). This may also be linked to the development of resiliency that acts as a coping mechanism (McCubbin and Svavarsdottir, 1996) and empowerment.

What is new in this study in relation to mothers’ administrative role is that mothers who received payments or services reported on a “pay-back” mechanism (Section 7.9). This meant that mothers felt under some real, or perceived, pressure to do some fundraising for the organisations or services that provided help, and to ‘pay-back’ for help given by services, nurses, family and friends. This is not reported in the literature, but has been described by professional colleagues in respect of parents getting support from organisations that provide life-limited children with holiday opportunities, who then feel under compliment to support these organisations. The pay-back mechanism reported in this study adds a new dimension to the phenomenon of care-giving. It was noted that where care was available, either at home or in out of home respite, mothers perceived the need to keep service providers ‘sweet’ and to accept others’ lower standards of care delivery. In home care, when it was provided, mothers were in a relatively powerless position in relation to having carers in their home, and had to manage around the carers’ activities and availability. Mothers reported having to comply with carer’s expectations and the carers’ routines and practices, rather than their own (Section 9.4). This led to mothers concealing

their concerns, or putting up with things, as keeping any help was better than none in some situations. The reasons may be similar to Coyne's (1995) findings with parents of hospitalised children who conceal anxieties in order to be seen as a good parent. Waterworth and Luker (1990) suggest that patients 'toe the line' as they do not want to be labelled as 'difficult' by health professionals. There may be a link between being a "good mother", and attracting a nursing presence, as reported by Darbyshire (1993), where being a compliant parent had the potential to increase the nurse-patient contact. The difficulty in finding carers who could help may add to this difficulty, and the need to do whatever it takes to keep them, was identified by the mothers.

10.5 Constant instability

The instability that occurs in children with complex needs, and its impact on the mother, has been explicated in detail (Section 8.3). The continuous instability of the child's condition adds significantly to the complexity of mothers' care-giving over time. This is in addition to the management of symptoms that cause life-threatening situations as well as managing new symptoms, treatments, drugs and interventions. In the literature on epilepsy Mishel (1988) has identified that parents and families experience high levels of stress due to the unstable patterns of seizures and uncertainty. In a similar study, parents of children with epilepsy also reported on their experience of long, unstable patterns of unpredictable and uncontrolled seizures, which exhausted them and "placed the family in a state of chaos" (Mu, 2008:547). Guerriere and McKeever (1997) present similar findings in mothers of brain injured children who report their lives to be precarious and unpredictable, but were accepting of this, as the alternative did not bear consideration. Mu (2008) reports how parents rarely discussed the child's diagnosis of epilepsy outside the family because of the stigma attached to the disease. One mother in this Taiwanese study noted how her family avoided the topic, which is similar to findings from this study that identifies how family and friends avoid discussing the child with complex needs, and the family situation. Constant instability, and its impact, was little recognised by others outside the immediate family. Additionally mothers had to identify alterations in behaviours, the onset of illnesses and deterioration, to interpret the situation, to decide and implement the identified interventions (Section 7.8.4). Roberts and Lawton (2001) suggest that this interpretation requires a multi-faceted decision-making process that is complex and daunting for parents new to illness-related management. The constant instability identified as a dimension of care-giving impacted on the mothers at all times in every situation. Its implications are closely linked to constant observation.

10.6 Constant observation

Constant observation emerged as a key aspect of mothers' experiences of care-giving in three worlds (Section 8.4). Kirk (1999) reports on the vigilance required by children with complex needs and the inability for the children to be left alone unsupervised, even for short periods. Constant vigilance in caring for children with asthma and diabetes is needed for managing and controlling the condition (Palmer, 2001; Sullivan-Boylai et al, 2002). In my study, mothers had to observe the children for similar reasons, but also to prevent complications or deterioration, or to identify improvement so that appropriate interventions could be taken (Section 7.8.4). Nickel and Desch (2000) report similar findings in children with myelomeningoceles in whom constant vigilance was needed to prevent complications including contractions, shunt malformations or urinary tract infections. Mu (2008) similarly indicates that the "essence of parental coping is vigilant parenting" (2008:548) in parents of children with epilepsy. Constant observation is a key dimension in my study and was required because of the nature of the child's needs and the instability of their condition. It may be part of a coping response for managing instability, as Mu suggests, but it is essential for maintaining the child's wellbeing. Constant vigilance is assisted by using alarms, video cameras and monitors. This technology, which is so readily available, further increases the financial and practical complexity of care for mothers, as it costs to use and has to be maintained. In this study, constant observation impacted, not only on mothers' sleep, but on their day to day activities within, and outside, the home. Heggarty (1994) suggests that families of life-limited children are emotionally shattered, which is similar to mothers in this study who rarely, if ever, got a break from their caring responsibilities as constant observation is essential (Section 8.4). Within the literature the potential risks of managing ventilator-dependent children have been identified (Chestnut, 1998) but what is not apparent are the specific needs of children with complex needs for constant observation inside and outside the home, and during travel, and the physical, social and emotional impacts that this has on mothers (Section 8.4).

The need for constant observation was in addition to providing the daily, hands on, direct care (Sullivan-Boylai, 2003) and adds to the demands made on mothers in the three worlds. The constant observation limited the mother's physical ability to move around the home and into the going-between and outside worlds (Sections 7.8.5 and 8.4), which has not been explicated elsewhere. In studies of technology-dependent children at home other problems identified include sleep disruption in parents who similarly report the impact on sleep of alarms, disconnections and leakage from feeding pumps (Heaton et al, 2005a).

Similar issues in this study are reported by mothers who maintained constant observation to prevent such issues occurring and to manage them early if they did. Heaton et al (2005b) further suggest that sleep deprivation limits parents' ability to socialise, a finding that is similar to my study, but mothers are significantly more limited by the child's need for constant observation during travel (Section 8.4). The isolation, and the potentially dangerous sequelae, of having to travel with children who need constant observation has not been previously reported, though the physical activities of moving and transporting children with care needs is documented by Yantzi, Rosenberg and McKeever (2006).

10.7 A 'no choice' situation

Within the literature the demands and stressors of care for parents of children with chronic conditions have been identified and the psychological effects of chronic illness on families are evident (O'Brien, 2000; Orloff et al: 2004; Tonks et al, 2005). There has been a growing recognition of the consequences of cancer, disabilities and technology-dependence on mothers (Kirk and Glendinning, 2004) which includes depression, fatigue and sleep disruption and deprivation (Heaton et al, 2005b; Meltzer and Mindell, 2006). However, despite these well recognised consequences being ill, tired or feeling unable to cope for mothers in my study was not a choice available to them. Often they were a single carer, or their partner was working out of the home, and family support was unavailable. Mothers were in a 'no choice' situation and had to continue their caring role no matter how tired, or ill, they felt at times.

The emotional impact of care-giving is identified in the literature. Seligman and Darling (1997) for example, suggest that families go through a grieving process from the time of diagnosis as they change their lifestyles and accept the disease. The literature indicates that the diagnosis of chronic illness has a devastating effect and constitutes a major family crisis (Broster and Warner, 2006). However, mothers in my study found themselves in a 'no choice' situation where they had to provide care. There was little time for other activities but caring for the child, and other needs within the family had to be accommodated (Section 8.5). This stoic response is reported by Tonks et al (2005) in a cross cultural study of chronic illness and parental responses in Scotland and Hong Kong. They report that the Scottish mothers of children responses may reflect "Scottish reserve and stoicism in the face of difficulties" (p13) that was not apparent in Hong Kong mothers. This stoicism was evident in Irish mothers who faced a 'no choice' situation in caring for their child. Mothers, in the absence of help, had to accept their situation and manage it. Mothers had little time for grieving or worry about themselves as they immediately had to

face the challenges of care-giving. These mothers accepted their situation, and its complex nature, despite the physical activities and emotional consequences, including hurt and guilt it caused, as this was part of their role as a mother (Section 8.5). Their “just getting on with it” is similar to findings reported by Ganong, Doty and Gayer (2003) in mothers of children with cystic fibrosis, who reported that it was expected that their role was to care for the children’s health needs and that they did what needed to be done in the situation. Redmond and Richardson’s (2003) study similarly reports this response. Guerriere and McKeever (1997:110), in a study of children who survived major brain injuries reported that mothers “had ‘no choice’ but to move on with their situation and ‘move on’ with their lives” and they also “redefined their priorities and changed the tempos of their lives”. This is similar to my study where negotiation in, and preparation for, this demanding care-giving role was lacking and mothers had little choice but to take their child home and to manage as best they could. This is similar to the perspective reported in partnership in care in children’s nursing literature where the responsibility and negotiation of care-giving between parents and nurses is problematic (Lee, 1999; Lewis and Noyes, 2007). Wilson, Morse and Penrod’s (2007) finding of a refusal to give up in mothers of ventilator-dependent children and their continuing uncertainty is similar.

10.8 Knowingness

The complexity of the care given by mothers in technical care-giving and pre-emptive caring, and the delivery of high level technical skills are evident from this study (Section 7.8). Price and Thomas (2007) recommend the need for a comprehensive and robust training programme prior to discharge for parents of children with continuing care needs and assessment by a competent practitioner, yet there is no comment on the need for adaptation of training to the home situation. In this study mothers did identify specifically how they knew to do what they had to do and did not report being taught any of the skills. They did not report on negotiation in their role, or training for it, as is commonly advised in discharge planning (Price and Thomas, 2007). The advice given was frequently incorrect and often lacking in its applicability in home care situations. Mothers provided highly technical care-giving knowingly and did not have the anxiety in performing technical tasks that parents of sick children in hospital do. Coyne and Crowley’s (2006) work in hospital indicates that technical nursing care for sick children was generally viewed by parents as the nurse’s responsibility because of their training and expertise. Mothers accepted their care-giving role and all that it entailed and that learning the skills happened experientially in a trial and error situation at home without negotiation in their

role. Kirk, Glendinning and Callery (2005) similarly suggest that parents in these situations construct parenting as having both a parenting and nursing dimension. Mothers delivered highly technical skills in medications and equipment management that others, including carers and health professionals would not, or could not, do (Sections 7.8 and 9.4). Jackson and Robinson (2003) identified similar issues in technology-dependent children where there are few non-parent carers who are trained, or insured, to provide this type of care at home. If carers are unable to undertake this care then mothers cannot learn from them. Benner, Tanner and Chelsea (1996) suggest that expecting parents to function similarly in a relatively short timeframe, and during a time of significant emotional stress, underscores the enormity of the challenge that mothers face. Sometimes, however, the mothers' technical care-giving was different to that which would be delivered in hospital and how they knew how to do this was unclear. Mothers were left to provide care on their own and to make decisions in care-giving without external advice or negotiation of the care-giving activities needed by the child at home. The focus of teaching that was provided offered a hospital perspective, for example NG tube changing, with little understanding of how this could be adapted to the home setting. Emond and Eton (2004) have similarly suggested that clinical care in children's homes is often based around good hospital practice and the evidence base for many areas of clinical activity in the community is lacking. This would account for the lack of specific information, and appropriate advice for mothers, as evidenced in this study. Mothers did not explicitly report how they learned to adapt these skills, or the stress caused, but trial and error learning was evident in medication management and feeding the children (Section 7.8). Planned interventions to reduce the child's symptoms were often absent with little evidence of teaching or providing information to support mothers. Developing knowingness and having knowingness of their child's needs, and how to manage them, may have been a coping mechanism. This is similar to stress and coping theory in which control is viewed as a mediator of stress and control in these mothers was developed by them seeking information and from their own learned experiences. The lack of support, training or advice available to help was part of the mothers' experience and is linked to the mother's 'no choice' situation. If the mothers wanted their child at home they had no choice but to "get on with it", whatever "it" entailed and with whatever consequences followed. Lewis and Noyes (2007) have suggested that in discharge planning for children with complex needs the role of the parents is generally assumed. This view would be supported in my study where mothers had no choice but to provide whatever care their children needed.

Mothers' knowingness impacted on service provision and health care relationships. This is similar to the work on expert parents. In this study conflict in what mothers knew needed to be done for their child resulted in them not being believed at times in health care situations (Section 9.4). Mothers knew the totality of their child's needs, including individualised needs, child characteristics and symptom management that were not recognised by others. This is linked to others' unknowingness.

10.9 Unknowingness

The unknowingness of others, and its impact on mothers, and how mothers respond to others' unknowingness was evident. Mothers reported on their experiences and relationships with staff during hospital visits, and in the home situation, where others' knowledge and understanding of their situation was limited. Mothers' knowingness was in conflict with the others' unknowingness at times (Section 9.4). Patterson et al (1994) reported that staff competence and skill were important to parents working with professionals and when a chronically ill child is hospitalised parents find themselves in an adversarial position with health professionals. Parents find it problematic when they, as experts in their child's care, have to hand over that care to those whom they view as less skilled than themselves (Section 9.4). Kirk and Glendinning (2004) have emphasised the need for further research into relationships between parents and nurses and findings from this study would support this in that there was a conflict between mothers and others involved with the child's care. Often appropriate information and services were not available to mothers. Lewis and Noyes (2007) suggest that teaching technical skills to parents is insufficient and that emotional support mechanisms need to be put in place to provide ongoing support following discharge. These mechanisms were not in place for mothers in this study at home or during many hospital experiences. Within the literature, the care and support provided for families in hospital is problematic. Studies identify concerns in many aspects of hospital delivered paediatric nursing including relationships with staff, lack of information, conflicting advice, a lack of information, non-negotiation of roles, feelings of loneliness and a lack of clear delineation of tasks undertaken (Darbyshire, 1993; Canam, 1993; Coyne, 1995). In their hospital experiences mothers in this study did not always get the support they needed during these contacts (Section 9.4) and may have been viewed as experts. The consequences of this were not being believed, isolation and avoidance.

Seligman and Darling in their work on disability suggest that stigmatising attitudes may be an issue in professional's responses to parents and that "other professionals, such as

paediatricians...may not enjoy working with children with disabilities at all” (1997:203). They also suggest that some professionals may “actually fear parents because of the threat they pose to professional dominance” (208). Wilson, Kendall and Brooks (2006) have reported that nurses’ responses to expert patients include anxiety which reduced their role and increased their vulnerability. Within palliative care nursing the emotional demands of caring for children, and the avoidance of emotional involvement with mothers as a method of professional distancing, is identified (Maunder, 2006). Nurses distance themselves from unfamiliar or threatening situations, by concentrating on nursing tasks in order to avoid being overwhelmed by emotions when working with patients and families. This may be the cause of some of the reactions of health professionals perceived by mothers in this study who often avoided providing emotional support for mothers (Section 9.4).

The uncertainty about the nature of the child’s illness impacted on service provision and the uncertainty about whether the child meets the criteria for admission to services is caused by, what Maunder (2006) suggests is a the “grey area”, where the prognosis is unpredictable, and increased survival rates into adulthood can occur. It may be that mothers’ expert knowledge additionally threatened others’ knowingness, which leads to parents and professionals having different expectations of the child’s ongoing needs, causing potential conflict. Glendinning and Kirk (2000) report that few professionals felt that they distanced themselves from expert parents of technologically-dependent children but some parents felt nurses avoided them for this reason. Nuutila and Salanterä (2006) report that parents of children with long-term illness found that health professionals’ attitudes to them, as knowledgeable and competent parents, revealed a lack of appreciation for the parent’s skills, knowledge and experience. In this study mothers reported explicitly on not being believed when they reported their concerns about deterioration to others (Section 9.4), which is an issue for all practitioners working with mothers of children with such complex needs as those in this study. Nuutila and Salanterä (2006) also support the findings in this study when they indicate that a lack of trust was shown by some professionals in the parent’s expertise in caring for the child and the parents too did not always trust that the professionals involved in care-giving were sufficiently informed about the child’s treatment and condition.

In this study mothers reported on not being believed, a lack of planning in their child’s care and a lack of understanding of their situation (Section 9.4). The professionals’ unknowingness and inability to cure may play a part in these responses. Starke and Möller (2002;250), in a Swedish study of parents of children with Turner’s syndrome, found that they perceived that doctors had little or no knowledge of the syndrome and as “a

consequence were incapable of explaining the condition” while other parents found that the doctor was incapable of explaining the syndrome in a comprehensible way. Gill (2006, 184) similarly reports on disabled peoples’ distrust of the health care system and how they “have an avoidance of hospital and have resolved to protect their lives by bunkering themselves in a familiar surroundings, until the end. The medical system is...a dangerous place for them.” The mothers in this study did not have the same choices but had to manage care-giving in situations in the three worlds where support and understanding was limited (Section 9.4). Within the literature it is recognised that families caring for children have multiple and complex needs, that require effective support from care-givers and that the child’s physical care must be supplemented and interventions that reduce parents worry and stress (Read, 2003). In relation to providing support for mothers McIntosh and Runciman (2006) have reported on the importance of the nurse’s role with parents of children with special health care needs, when they are confronted with a crisis or deterioration in their child’s condition. In this study unknowingness in others added to the mothers’ difficulties in caring. It reduced mothers’ trust in others in delivering care to the child and in those who made decisions about the child’s medical care.

The establishment of trust has been found to be a key therapeutic intervention for the nurse and factors that inhibit the development of trust are reported by Thompson, Hupcey and Clark (2003). They suggest that trust is demonstrated by allowing the nurse to care for their family member and that vigilance is part of the parental role, and not necessarily an indicator of mistrust (p145). Thompson et al (2003) indicate too that the giving of timely and accurate information is absolutely essential to the formation of a trusting relationship with parents of hospitalized children. This may be the cause of the apparent mistrust that mothers in this study appeared to have of professionals and all those involved in her child’s care (Section 9.4). Within the literature, sharing of information between parents and professionals is viewed as critical to the empowerment of parents (Tonks et al, 2005).

The health care systems’ focus is on a disease-orientated model and it is clear that not clearly fitting in to this approach added to others’ unknowingness. In this study the way the diagnosis, and child’s deterioration, was managed influenced mother’s reactions and relationships with doctors and medical staff (Section 9.4). Within the literature on chronic illness the initial reactions of shock and anger are reported (Warner, 2006). The findings from this study are similar but the lack of a clear diagnosis for some mothers added to others’ unknowingness. During this study, for one mother, getting a diagnosis was accompanied by relief that the child’s diagnosis was now known, but this knowingness immediately added to the mother’s concern because of the genetic implications for her

older child, who, until a diagnosis was made was an “older sibling,” and after the diagnosis may have been a “potential disease carrier.”

In the study others’ unknowingness and the public perceptions of the child and family were evident (Section 9.4). In the literature on epilepsy Morrell (2002) notes that public misperceptions can contribute to social disability and stigma. She suggests that until the community has an understanding of epilepsy, stigma will continue to be a challenge. This is similar in the individualised behaviours of the children reported that were little understood by others, including family relatives. Gray’s Australian work (2002) outlined the felt and enacted stigma in parents of children with autism, and found that felt stigma was commonly experienced in public situations, and also that avoidance by others was a common reaction to the child. In this study, like Gray’s (Gray, 2002) mothers responded by isolating themselves from others (Section 8.5).

Unknowingness in family and friends has been explicated from this study (Section 9.4). Literature on the impact of stigma in epilepsy has shown, for example, the negative impact of this on family support (Mu, Mu and Chang, 2005), as well as the cultural stigma attached to this (Mu, 2008). The findings are significant given the importance of family support in families with children with complex needs in reducing social isolation, which is a recognised in caring for children with long term needs (Yantzi, Rosenberg and McKeever, 2006). In mothers of children with disabilities, social isolation, loneliness and reduced contact with friends and family have been reported (Noonan Walsh, Conliffe and Birbeck, 1994), yet family support has been found to help mothers of children with spina bifida feel competent and satisfied with their parental role (Fagan and Schor, 1993). Within this study the experiences of caring for mothers were ones in which she was isolated both by her actions, and by the actions, and responses, of others in all worlds. Support was lacking and misperceptions that all was ‘grand’ reduced contact and caused avoidance of the child and family. One reason for this apparent lack of support may be that stress and anxiety in others causes them to draw back from the situation in which they feel unable to carry out the child’s care, or manage the situation. Avoidance of the situation by friends and family, further add to the mothers’ isolation and reduces support for her in all three worlds (Section 9.4). Tonks et al (2005) report similar findings in parents of children with chronic illness who are isolated as friends and family do not know how to deal with the child’s condition, yet family support is a mediator of stress.

For the mothers in this study, however, other family members were busy with their own lives at times and could offer little, if any, help with the child. When they did offer help to the family this was very limited, and conditional, and focussed on the siblings, or

household tasks, rather than the child with complex needs. Distancing by family members resulted. Some reasons for this are evident but others may be more complex and related to the view that “Western society does not prepare itself well that some children will die young” (Maunder, 2006: 27). It may also be due to the fact that illness can often force an extreme emotional vulnerability on patients and families (Dowling, 2004) and this emotional challenge may be difficult to deal with for close family members, and others involved with the child. Denial and rejection may play a part (Darling and Seligman, 1997) but others’ unknowingness had a direct impact on mothers, the child and family in all three worlds (Section 9.4). Caring for children with a chronic illness and the resulting family stress is “chronic, serious and invisible” (Mu, 2005: 369). This invisibility may have been the cause of many of the findings from this study, and the unknowingness of the situation by others, of the mothers’ real experiences.

10.10 Constant communication

Within the study, findings indicate that there are issues raised for the mothers when working with others in caring for their child related to constant communication (Section 9.5). The use of the mobile phone makes constant communication an essential dimension of mother’s experiences. Communication plays a necessary part in ensuring the child’s physical and practical needs for care are met and services provided. However, constant communication for mothers of children with complex needs has additional functions. It reinforces mothers’ knowingness, and the unknowingness of others, if she is separated from the child (Sections 9.3 and 9.5). It provided an information mechanism which is linked to the development of control and empowerment. The constant communication may be linked to the development of trust that is needed in the mother-carer relationship and constant communication may be a requirement in the development of trust between mothers and carers.

Within the literature on communication little is written on the impact of constant communication but its importance in information giving and support is evident. Telephone support services for parents are reported (For example, Parentline, Dublin) and in the literature communication studies include those focussed on peer support and Dale et al (2008) suggest that there is an increasing interest in providing support by telephone which may have better accessibility and availability than face-to face meetings. Other communication studies are focussed on parents’ information needs (Kai, 1996) but little is reported on the use of the telephone in communication with families of children with complex needs. Wilson, Morse and Penrod (2007) advocate the use of a telephone hot line

as a valuable support system for mothers who are newly discharged but the findings from this study suggest that in itself constant communication can impact negatively on mothers. In this study the mobile phone added to the constancy of communication that is used when the mother is separated from the child for whatever reason, be this respite, or for a break, or to communicate with the services needed by the child (Sections 7.9 and 9.5). It is a two way communication mechanism that is used in all worlds to connect mothers with their children and carers. It provided a mechanism by which carers can ensure that the mother was kept advised of their child's condition and can get information from mothers about the child's needs. Within the literature on respite Neufield, Query and Drummond (2001) report a reluctance to leave the child with strangers, and the complexity of the child's care, as reasons for not using respite services. This is similar to the mothers in this study and, where children were left, the mobile phone was used as a mechanism to continue contact with the child and carer. This may add to what Neufield, Query and Drummond reports, in that mothers who did use respite did not always perceive it as a break from care-giving as they were in constant communication with the carer (Section 9.5). Given that respite care is often viewed as a solution by health professionals to meeting the mothers' needs, constant communication warrants attention given its impact physically, financially and emotionally on mothers.

The findings related to constant communication explicate in detail the consequences of constant caring. Baldwin and Carlisle (1999) revealed that mothers faced with the daily routines of care can become isolated, with considerably restricted social lives. Isolation may also be caused by mothers avoiding telephone calls as they manage the constancy of caring within the inside world. This isolation may be added to because of the difficulties of finding and trusting another person capable enough to take over caring from them, which is reinforced by the use of the mobile phone for contact during the mother's absence. This may further limit the mother in time out from caring and isolation from friends and family is identified within this study.

10.11 Summary – caring in three worlds

Within the study over-arching findings emerged in that caring for children with complex needs is provided in three worlds and not solely within the home. Within the findings a going-between world of caring emerged (Section 8.). The mother's ability to come and go between the inside and outside worlds was limited as the experiences of car journeys were often difficult and involved significant planning (Section 8.3.2). The journeys described by mothers indicate that constancy of observation pervades all aspects of the mothers'

experiences and the child's unpredictable needs added to the difficulties. Many of the mundane, seemingly routine, activities that are part of the daily life of many mothers, for the mothers in this study had to be altered and renegotiated (Section 7.8). Brinchmann (1999) has reported that parents often feel imprisoned in their own home, but the mothers in this study were in a 'no choice' situation of having to travel at times. The accounts that the mothers provide identify the difficulties that they face in the chores of daily life such as journeys to go to the shops, the chemist and appointments (Section 8.3.5). They reported on limitations that their child's complex care placed on getting into the outside world and the impact of this on siblings, whose needs often had to be accommodated, as well as those of the child with complex needs (Section 8.3.9). Little is reported explicitly within the literature on this going-between world, though Orloff et al, (2004: 151) reports that "the everyday tasks of chauffeuring a sibling to soccer practice, walking the dog...or going on a family vacation, can be challenging, if not impossible." Kirk (1999) reports on the need to take equipment when taking the children out and Yantzi, Rosenberg and McKeever, (2006) have identified the social isolation this causes for mothers, but actual accounts of the journeys are not reported. Providing care for children was socially, and spatially, isolating for the mothers because of the difficulties, and work entailed, in moving the child and their equipment (Section 8.2). The need to maintain care routines, which impacts on the mother's freedom to come and go, is similar to the work of Teeland (1998) who raises the issue of spatial restriction when caring for an individual at home who is sick for a short time. However, unlike those family members in Teeland's study, these mothers experienced this restriction over long periods and the restriction in moving was reported as getting more difficult as the child grew up. The isolation that occurs, and its causes and consequences, are evident. The mechanism of turn-taking between mothers and their partner that emerged in this study (Section 7.8), as an alternative to travel, may have consequences for the family relationships and add to the "wide ranging, unrelenting and sometimes overwhelming emotional, social and financial stressors on the family" (Thurgate, 2005: 14).

In the study, care of the child in the outside world emerged, which included care of the child by others in hospital and respite. Stalker and Robinson (1993) have found that, for a small number of families, the psychological benefits associated with respite care were negligible, with deterioration in behaviour on the child's return from respite care cited as impacting on any psychological benefits derived whilst the child was away. They found that a small number of parents admitted to feelings of guilt in using respite. The emotional conflict, and consequences, for the child on their return home after using respite services is

evident in my study (Section 9.9.3). The conflicts and dilemmas that respite caused for the mothers, alongside the pragmatic organisational difficulties in travelling to respite services is evident. Respite out of home caused conflict for the mothers between their guilt and the need for rest, as well as conflicts in the care that the child would get away from the mother, compared to that which the child would receive from them at home. The unknowingness in others and the psychological impact of separation on them and the child causes mothers concerns (Section 9.3.4). There is also no reason to suggest that these children would suffer less separation anxiety than that which has been reported elsewhere that occurs when children go into hospital (Shields, 2001), yet little is written about this in children's nursing literature on respite.

Mothers of children with complex needs experience isolation and exhaustion (Carnevale et al, 2006) and a strain on family life (ISPCC, 2006). Once outside the home mothers experience difficulties, similar to those reported in autism by Gray (2002). These challenges include physical, social and service challenges and challenges to the resilience of the family system (ISPCC, 2006). The outside world is one that is impacted upon by the reactions to the mother and child from those outside the immediate family. These reactions are frequently negative and impact significantly on the mothers who appeared to have little support at times. The unknowingness of outsiders isolates mothers further. The negative reactions impact on the other siblings in the family (Section 8.3.9), including bullying, that may result in furthering the heightened demands being placed on the family systems (ISPCC, 2006). The reactions in the outside world reported in this study may be the stigma that is associated with disability, or the 'differentness' of the child. Supportive reactions were not always provided and add an additional aspect to the mothers' experiences. Gill (2006) suggested that the general public equate disability with suffering which may impact on their reactions to the mothers in the study, and even loved ones often pity and misunderstand disability. In this study the fact that some of children with conditions that "are terminal...may increase the vulnerability of the mothers and may, in fact, add to discriminatory treatment" (Gill, 2006:188).

10.12 Conclusion

This study advances knowledge on the needs of mothers who care for children with complex needs at home. Mothers in this study identified a range of experiences in the complex nature of their caring activities. They outlined the constancy of caring in the inside, going-between and outside worlds. Within the literature the experiences of caring for children with special needs is usually defined as a tragedy, and measured by levels of

care-giver stress, and there is much written about the negative effects of caring for a child rather than examining aspects of caring (Baker, Yardley and McCaul, 1995), which this study has done. However, given the increasing number of children with chronic illness and increasing levels of complexity, with a developing focus on community care, there is a danger that community parental participation in care will be an essential prerequisite and mothers may be coerced to comply (Coyne and Cowley, 2006). Placing such expectations on mothers' impacts on them, as well as overall family functioning, and evidence of the potential causes of this were explicated in this study. The ongoing shift from hospital to community care has significant implications for mothers, similar to those in this study, who were required to plan, and deliver, highly complex technical care with few supportive interventions from others. Simultaneously they had to meet the other demands of family life, care for the siblings and husband or partner with minimal support in a 'no choice' situation in their homes, that were not purpose built for care-giving, and with inadequate resources (Coyte and McKeever, 2001).

The physical, emotional, financial and social impacts on the mother become evident in this study, but the mothers' experiences in caring for children with complex needs are greater than this. It is these added dimensions that this phenomenological study identifies.

10.13 Post-script

Throughout the study despite the complexity of their experiences mothers identified clearly that their children were dearly loved. A sense of joy and love, similar to that described in families of disabled children (ISPCC, 2006) was clearly evident and the positive impact that the child had on the family was also apparent during the interviews. The positive attributes of the children were clear and positive perceptions of parenting related to the children were evident (Section 7.8.1 and Appendix 14). The children offered much to their family and mothers reported positive, as well as adverse, experiences in caring for their child. These are important points to note in conjunction with acceptance of the main study findings.

Within this chapter the findings from the study have been discussed. The final chapter of the study follows in which the limitations and recommendations are reported.

CHAPTER 11 - CONCLUSION TO THE STUDY

11.1 Introduction

The focus in this concluding chapter is on the limitations and recommendations from the study.

11.2 Limitations in methodological approach

In selecting my methodological approach the current and ongoing tensions in the literature on phenomenological approaches and interpretations from original texts are a limitation. Differences in individual phenomenological approaches exist within different cultural perspectives. I used translated sources of Heidegger and Gadamer as my sources of information, and others' interpretations of these. This removed me from the original understanding of the work as it had been already interpreted.

I adopted an American type approach which does not “insist on an objective scrutiny of the phenomenon under investigation” (Caelli, 2000:370). My focus was on the mothers' experiences as they were presented and I attempted to make sense of them but recognised that these experiences had already been interpreted by mothers. The interpretation of the findings is based on hermeneutic phenomenological principles where multiple realities and interpretations are possible. The findings can therefore differ depending on the interpretation of the reader and their view of hermeneutic phenomenology. Geneallos (1998) suggests that in the hermeneutic tradition interpretations of data are always an approximation and are never complete or final. The findings consequently cannot be generalised and remain my interpretations of these particular mothers' experiences. Findings have, however, been verified by professional colleagues, experts caring for children with complex needs and mothers who have read a summary of them. They have been found to represent mothers' experiences.

11.3 Limitations in sampling

In sampling there was no attempt to form a homogenous group of mothers. It is recognised that there are homogenous groups within life-limited children, but equally there are children with no diagnosis, or whose illness trajectory does not fall neatly into medical or palliative care models. I was interested in children with complex needs and their mothers. I followed Ironside et al's (2003:172) view that “studying only particular chronic illnesses

overlooks (albeit inadvertently) the common experience and shared meaning that emerge across chronic illness and inadvertently overlooks...the totality of the experience”.

Using gate-keepers to select mothers is a limitation as they may be influenced in who they select to recruit. Two mothers worked in health care and three mothers had more than one child affected which could have influenced the gate-keepers who may have felt these mothers were more able to contribute. The genetic nature of some disorders means that families may have more than one child with complex needs so these mothers’ experiences add quality and depth to the study. The mothers who did contribute provide a realistic mix of experiences that includes a fairly representative range of children across the spectrum of complex needs.

The nature of the complex needs was not initially defined, except to the gate-keepers. Consequently, children are included whose mothers determined them as having complex needs. This is both a limitation and an advantage but the children had a range of disorders, which offers a perspective on experiences of care needs, rather than a medical focus on the impact of particular diseases.

The mothers were from all parts of Ireland, North and South, and it is recognised that services provided may differ in the two jurisdictions. However, I was not investigating service provision *per se*, but rather the mothers’ experience of caring, which could include these experiences, if they chose to discuss them.

These mothers’ experiences may differ from those who did not agree to participate and may not be representative of all mothers of similar groups of children. The study population was limited to mothers in Ireland so the findings are not generalisable to mothers living in other countries where health care delivery, and services, may differ. However, the findings are partially supported by evidence from other research studies throughout the world.

The final limitation is the focus on a single family member rather than adopting a family perspective, which was outside the scope, and feasibility, of this work. However, the literature does suggest that mothers are the main carer so it is relevant that their experiences were captured to provide a background for subsequent studies in children with complex needs and to identify areas for further research. It is my contention that the mothers’ perspectives in Ireland adds a valuable source of information pertaining to the care of children and that mothers also expressed their feelings and experiences in a more open way that they would have in the presence of others.

11.4 Limitations in data collection methods

Phenomenological method depends on the accuracy of the descriptions given by the participants at the point of data collection (Polkinghorne, 1988). This can be criticised in that interviewing elicits a retrospective viewpoint, which may not be the same as getting a description from someone when the event is actually occurring. However, I would support Hycner's view that "the best we can do through the medium of language is one step removed from the original experience" (1999: 157). A retrospective viewpoint has some of the same shortcomings as other methods of data collection method as even a concurrent description of any experience is already different from the experience itself, given the nature of language.

Retrospective reporting of events may be influenced by recall bias as mothers reported their experiences over time. However, what they reported was viewed by the mothers as part of their experiences and was as they recalled it happening. Polkinghorne (1989) suggests that any time delay may facilitate a more comprehensive description because the opportunity to reflect back over the experience has been provided. The use of repeated interviews, as advised by Van Manen (1997), enabled mothers to have a number of opportunities to contribute information over, at least, a three month period and to add comments to the data by continued contact with me over this period. This provided opportunities for reflection, reconsideration and discussion of interpretations.

The interview and diary data may not fully reflect the totality of the mothers' experiences but only those that they chose to discuss, and the meaning that the experiences held for these mothers. The interview process, however, did provide an opportunity for an in-depth exploration of the mothers' experiences that quantitative methods would not have captured. The diaries add to the realities of the data collection, though it is recognised that the headings used for guidance; 'good day', 'bad day' and 'normal day'; were framed from my perspective and not the mothers'.

11.5 Limitations – a single researcher

The analysis was affected by my intuitive and analytical abilities and the findings are influenced by my values, attitudes, beliefs and assumptions as I was the major instrument of data collection. Mays and Pope (1995) suggest that research that relies exclusively on observation by a single researcher is limited by the presence of the researcher that "may, in some way that is hard to characterise, have influenced the behaviour and speech that was witnessed" (109). In the interview situation my non-verbal cues and behaviour could have

impacted on the mothers' reactions and responses but I consider this to be positive, rather than negative. This limitation applies to all research where data are collected by face-to-face interview.

For data analysis I used a software programme to enable others to follow my decision trail, and alternative views and interpretations were sought. Data excerpts are included throughout in sufficient length for the reader to understand the context and my interpretation in the findings. Bias is hard to control but its potential impact is a limitation. However, I have reported my background and the factors that may have influenced my interpretation are made known, and recorded (Appendix 15). I have adopted a systematic and self-conscious approach in my account of the research processes used and how the findings emerged. This has been reported in a way that would enable another trained researcher to analyse the data and arrive at essentially the same conclusions (Mays and Pope, 1995: b).

11.6 Limitations – the 'I'- a reflection

I began the study wishing to explore the mothers' experiences of caring. I now think it would have been better to focus on a very specific aspect in the experience of caring for a child with complex needs, for example, seizure management. Given the volume and breadth of data a narrower focus would have been an advantage throughout the study. However, the data do offer the 'real sense' of the mothers' experiences, rather than any particular aspect. There were difficulties with the methodological approach and the interpretations of the work of Heidegger and Gadamer. I initially found the terminology confusing, abstract and conceptual and the original untranslated terms in the literature were difficult at times. The array of methods and approaches to phenomenology, and how they have been adopted differently across studies, was problematic (Caelli, 2001; Dowling, 2007). The lack of a clear and consistent method required me to develop methodology and design to manage emerging and unexpected events in data collection and analysis. This is similar to the experiences described by others where there is a tension between the philosophical interpretations of phenomenology and the research method, processes and reflective awareness and phenomenological approaches adopted in nursing (Van Manen, 1990; Lawler, 1998; Dowling, 2007).

There were also tensions in data analysis. Using a model suggests that the analysis is a step that "finishes the process," while in fact analysis is ongoing in this work even to the end point as writing and rewriting continues. These processes are not apparent in the model used. The themes emerging from this study, and the text, may therefore be different for

each reader but, critically, though the reader may not share my interpretation, they should be able to follow the pathway that led to the interpretation I have provided (Benner, 1994). Selecting from the volume of data collected to provide exemplars to support the findings remains a dilemma and an ethical tension, but I intend in post-doctoral work to develop the data further. I felt a tension at times in developing the content to fit that which was already in the literature, where the financial, physical, emotional and social aspects of caring are reported. Themes could have been developed around these ‘knowns’, or a theory of caring experiences developed, to link with those in the literature. To me it was evident, for example, that the mothers’ experiences had emotional, physical, financial and practical impacts on every aspect of their ‘being’ that may not be fully captured in the data reported here. The specific excerpts included, however, are intended to broaden the understanding between the mothers’ experiences and the reader, and my interpretation of the eight dimensions and three worlds I have identified. Given the volume of data, I have had to remove some of it which is of equal importance in the mothers’ experiences. Many other aspects of physical care reported are, for example, excluded, which has resulted in data being “culled”. Further analysis would not have added anything to my current interpretation of three worlds and the eight dimensions but not to use all the data collected remains a tension given that it was part of the totality of the mothers’ experience under investigation. Confirmation of the findings is included in excerpts from my research diary and mothers’ diaries (Appendices 11 and 14).

11.7 Implications and recommendations - introduction

The study illuminates the experiences of the mother of a child with complex needs caring for a child at home. The findings have implications for those involved with these families, including strategic planners, service providers, practitioners, educationalists and researchers.

11.8 Implications for strategic planners

1. The needs of children who require complex care at home need are not clearly recognised or identified within community services (Sections 7.9 and 9.4).
2. Mothers of children with complex needs are not fully supported within community services (Section 9.4).
3. Community services for children are not coordinated, planned or delivered in a way that meets mothers’ needs and the individualised needs of their children (Section 7.8.2).

4. Long term service planning and funding is currently absent from service provision for children being cared for within the home (Section 7.9).
5. The demands that care-giving in the home makes on the family, particularly mothers, is not clearly recognised in current service provision (Section 7.8).
6. There is no coherent or multi-professional approach in the delivery of services to families of children with complex needs (Sections 7.9).

11.8.1 It is recommended that strategic planners

- a. Develop a coherent national strategy to identify, plan and implement services to meet the current and ongoing needs of children with complex needs and their families at home.
- b. Build a coherent and funded infrastructure that is regularly reviewed to support families, particularly mothers, fully in all aspects of their care-giving roles.
- c. Investigate and implement appropriate models of community support for mothers that are flexible, responsive and needs focussed.
- d. Introduce multi professional education, particularly across nursing and social care disciplines to ensure a coherent approach to service delivery and needs assessments is developed for families caring at home.
- e. Ensure that community care experience and education on caring within the home and working with expert parents is a core component in all social and health care curricula.

11.9 Implications for service providers

1. Specialised and needs focussed community services are not well developed for children with complex needs (Sections 7.9 and 9.4).
2. The demands placed on families, particularly mothers, are not currently clearly identified or given priority in hospital and community services (Sections 7.8 and 9.4).
3. Mothers lack information, resources and information about the demands placed on them when care at home is delivered (Sections 7.8 and 8.5).
4. Service providers lack a consistent, coordinated, flexible and needs based approach to service delivery (Section 7.9)
5. The difficulties in travelling with, and transporting, children with complex needs are unrecognised by service agencies and providers (Sections 8.3 and 8.4).
6. Family support, over the long term, is currently assumed in planning and implementing home care services (Section 9.4).

7. Technical care-giving requires expert skills that differ when they have to be delivered in the home setting, and this is unrecognised by service providers (Section 7.8.3)
8. Mothers' knowingness and expert knowledge of their child and the complexity of their needs is not commonly accepted or recognised by service providers (Section 7.8.5).
9. Mothers' use of services is influenced by others' competence and unknowingness of their situation and a lack of trust in providers (Section 9.4).

11.9.1 Recommendations for service providers

- a. Provide the full range of care and support services from the point of diagnosis for all families caring for children with complex needs at home.
- b. Implement discharge planning and community care packages for all children with complex needs that are tailored to the individualised child and family situation.
- c. Provide a collaborative approach in discharge planning between hospital and community services to ensure home care is fully supported and resourced.
- d. Implement discharge planning that should include contingency planning for restocking, resupply and replacement of all equipment and long term planning for changing needs.
- e. Provide a flexible, coordinated and supportive infrastructure for families in which the physical, social, emotional and financial needs of care-giving are identified and met.
- f. Explore models of appropriate community nursing support to develop a coordinated response to meeting the child and family needs over the twenty four hour period, in cases of emergency and crisis intervention and, particularly, if the child's or family situation changes.
- g. Provide accurate information and physical, emotional and social support mechanisms as an automatic part of the child's care package.
- h. Negotiate the full range of home care services for children with mothers, and their children, and deliver these in a skilled, appropriate, coordinated, timely, reliable, responsive and proactive manner, without inducing a need for payback.
- i. Provided skilled, appropriate and relevant support with all components of care-giving.
- j. Ensure that appropriate help is available and the prerequisite training, indemnity and policy issues are addressed to ensure carers can effectively assist mothers in care-giving.

- k. Provide for all aspects of the child's care needs, including individualised needs, and the emotional needs of the mother, child and siblings which should be supported by appropriate interventions.
- l. Fully support all aspects of care-giving within the home, particularly if caring is long term or when the complexity of the child's needs increases. The technical and psychosocial skills of care-givers should be such that they are trusted by mothers as alternative care-givers.
- m. Accommodate the care needs of the children flexibly, for example by developing a 'one stop multi-professional shop' where children's needs could be met at a single visit to hospital.
- n. Plan care and assessments so that the need for multiple visits and travel is avoided where possible and at home visits facilitated as possible. Appointments outside the home should be arranged to accommodate mothers' and children's individual situations.

11.10 Implications for practitioners working directly with families of children with complex needs

1. Mothers lack support in all aspects of their role in care-giving at home (Section 7.8).
2. The eight dimensions outlined and their impact on the child, mother and family need consideration when working with families of children with complex needs (Section 7.8).
3. Mothers needs require flexible, dynamic, appropriate services that do not entail unnecessary paperwork, administration and planning (Section 7.9).
4. Care and management of the child within the home needs to be recognised as different from that provided in hospital and appropriate adaptations are required in care delivery (Section 7.8.5).
5. Mothers are expert carers and their contribution to the child's care needs to be acknowledged and form part of the plan of care (Section 9.3)
6. Alternative carers and care services must be competent to deliver appropriate care in the absence of the mother (Section 9.4).
7. The importance of trust between mothers and care-givers needs to be recognised in home and out of home services (Section 9.4).
8. Paperwork and administration and constant communication and their impact on mothers need to be considered in care planning (Section 7.9).

11.10.1 Recommended for practitioners

- a. Ensure that specific and focussed discharge planning occurs to ensure that appropriate training, adequate services, funding and human and practical resources are in place before discharge occurs.
- b. Identify the individual implications for each mother and family and develop and implement appropriate discharge plans based on individual situations.
- c. Have adequate knowledge, skills and training to teach and assist expert mothers in their care-giving role.
- d. Consider support mechanisms, home location, equipment and service provision when planning care within the home and recognise that this may require long term planning.
- e. Pay particular attention to technical care-giving skills that need to be adapted to the home situation and how mothers may need help to manage skills particularly tasks that require two people.
- f. Demonstrate a greater understanding of the challenges that occur in families of children with complex needs and respond by, proactively, implementing strategies to assist mothers, fathers and siblings to cope effectively.
- g. Be proactive in ensuring that the child's needs for equipment and resources that change over time are met. Systems for resupplies should be fully implemented and not contribute additionally to the mothers' responsibilities.
- h. Offer practical help in providing resources, information, support and advocating for services.
- i. Should understand the short and long term impacts on the care-giving mother and family.
- j. Understand of the challenges faced by mothers who leave their child in the care of others. The practical implications of care-giving by others, and the issues of trust and competency in care-giving, need to be considered in care planning.
- k. Recognise mothers' expertise in care-giving and use this as a basis for planning. Mothers' knowingness needs to be recognised and accepted in assessment of needs and care-giving.
- l. Consider the impact of constant communication on the mother and the impact of this mechanism on the mother in care management.
- m. Recognise the difficulties in travel and avoid unnecessary journeys for health issues. The need for multiple appointments should be assessed and a coordinated approach adopted. Mothers should be assisted in travel as needed.

- n. Use information technology for resupplies as appropriate.
- o. Recognise the issues mother face in the outside world, including stigma and the impact on siblings, and provide support and advice to help with these emotional challenges.
- p. Advise and educate others of mothers' experiences of caring by undertaking research, publishing and advocating for greater understanding of the challenges of caring for a child with complex needs at home.
- q. Implement treatments particularly that consider the practical realities faced by mothers at home. Education and advice in management of treatments must be realistic, and based on care provided in the home by mothers, and are not those provided by a professional in a hospital setting.
- r. Discuss the consequences of care-giving at home with families and the intervention strategies implemented to reduce these including information, communication and skills.
- s. Develop sibling and support for family members that should form part of discharge planning.

11.11 Implications for education

1. The needs of mothers who undertake a care-giving role at home are not fully recognised by health professionals (Section 7.8).
2. Current philosophies of care, including partnership and negotiation, are not always part of the mothers' experiences (Section 9.4).
3. Boundaries in mothers' roles as mothers and care-givers are blurred, which results in increased anxiety and concerns for mothers (Section 9.3).
4. Care-giving skills in those who help families with children with complex needs are limited (Section 9.4).

11.11.1 Recommendations for educational providers

- a. Focus on care-giving by parents at home in all nurse education and child and social care programmes.
- b. Include relevant technical care-giving skills, teaching skills, adaptation, trust, decision making and advocacy skills in children's nursing education programmes.
- c. Apply and further develop key philosophies in children's nursing in the context of care within the home.
- d. Include discharge planning and assessment tools for discharge planning in all nursing programmes.

- e. Develop and implement training programmes for other care-givers to ensure they are appropriately trained and skilled, to help support mothers effectively in their caring responsibilities.
- f. Develop multi professional education programmes to enhance an interprofessional approach to care-giving for children with complex needs.

11.12 Implications for future research

1. Service delivery for families of children with complex needs is uncoordinated, and at times, inappropriate to meet the needs of families at home (Section 7.9 and 9.4).
2. Research on the impact on family members caring within the family home, including one parent families, is lacking in this cultural context (Section 9.4).
3. The experiences of mothers and families of children with complex needs, including their siblings, fathers and extended family and friends, are under-researched (Section 9.4).
4. The responses of others in the outside world to children with complex needs, and their families, are under-researched (Section 9.4).
5. The relationships between professionals and mothers of children with complex needs, and their development, are under-investigated (Section 9.3).
6. The philosophies, practices and models of care for children with complex needs at home need to be further investigated (Section 8.5).
7. Care-giving skills in mothers, and practitioners, and how they are developed in families of children with complex needs, warrant attention (Section 7.8).

11.12.1 Recommendations for future research

- a. Investigate the fathers' perspective on caring for a child with complex needs.
- b. Explore the experiences of siblings of children with complex needs in an Irish context.
- c. Investigate the needs of mothers of children with complex needs from a multicultural and cross cultural perspective.
- d. Devise, implement and evaluate effective interventions to meet mothers' needs in care giving at home.
- e. Investigate models of service delivery for families of children with complex needs to ensure that technical, individualised and holistic care is provided for the child, the family and siblings.

- f. Investigate communication and communication mechanisms between health professionals and ‘expert’ parents and parent-professional relationships in children with complex needs.
- g. Investigate strategies that identify and promote trust in relationships between expert carers and health professionals.
- h. Investigate the technical and psychosocial skills needed to work in partnership with expert parents in care-giving in the home setting.
- i. Investigate how parents learn expert care-giving, and knowingness, in the home setting.
- j. Investigate concepts including family centred care, negotiation in care and partnership models, in terms of their suitability for use with this group of children.
- k. Investigate further individualised behaviours in children with complex needs, pre-emptive and technical care-giving in the home and how these are managed by mothers.
- l. Investigate models of discharge planning, and service support, for children with long term and changing needs, and unknown disease trajectories.
- m. Confirm and extend the findings from this study in other groups of children using a larger sample and quantitative approach to develop an assessment tool to measure the impacts, and consequences of caring, and to provide documentation for, and evidence of, the care of children with complex needs at home.

11.13 Conclusion

The findings provide valuable in-depth insights from the lives of mothers of children with complex needs in Ireland. They offer a unique in-depth insight into the world lived by mothers of children and challenges faced on an everyday basis in three worlds of care. Caring at home for a child with complex needs is more than caring within the home and the study identifies a new context of care-giving for these children and their mothers. Eight specific dimensions in care-giving in children with complex needs have been identified.

To conclude the mothers made some recommendations for health professionals in relation to what would help them care for their children within the three worlds of care-giving.

Orla:

I’m not asking you to turn around and tell me what it is; I want you to make life comfortable and pleasing for her and us as a family.

And finally;

Paula:

So you need to listen to us, you know...You know, sometimes when I'm saying 'things are alright and I can take my child home from hospital and cope and everything will be fine'. Actually no, it's not.

REFERENCES

- Adams, R., Gordon, C. and Spangler, A. A. (1999). "Maternal stress in caring for children with feeding difficulties: implications for health care providers." Journal of the American Dietetic Association 99(8): 962-966.
- Addington-Hall, J. (2002) Research sensitivities to palliative care patients. European Journal of Palliative Care 11 (3): 220-224.
- Ahmann, E. (1994) Family-Centered care. Pediatric Nursing 20 (2): 113-117.
- Alvesson, M. and Sköldböck, K. (2000) Reflexive Methodology New Vistas for Qualitative Research. London: Sage Publications.
- An Bord Altranais (2000) The Code of Professional Conduct for each Nurse and Midwife. Dublin: An Bord Altranais.
- Annels, M. (1996) Hermeneutic phenomenology: Philosophical perspectives and current use in nursing research. Journal of Advanced Nursing 23: 705-713.
- Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) and Royal College of Paediatrics and Child Health (RCP&CH) (1997) A Guide to the Development of Children's Palliative Care Services. Report of a Joint Working Party. Bristol: ACT. London: RCP&CH.
- Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) and Royal College of Paediatrics and Child Health (2003) A Guide to the Development of Paediatric Palliative Care Services. 2nd Edition. London: ACT and RCP&CH.
- Association for Children with Life-threatening or Terminal Conditions and their Families, (2003) Voices for Change. London: ACT.
- Association of Children's Hospices (2005) Annual Review 2005/6 (online). Available: www.childhospice.org.uk. Accessed 17 May 2007.
- Atkin, K. and Ahmad, W. (2000). "Family care-giving and chronic illness: how parents cope with a child with sickle cell disorder or thalassaemia." Health and Social Care in the Community 8 (1): 57-69.
- Atkinson, B., Heath, A and Chenail, R.(1991) Qualitative research and the legitimization of knowledge. Journal of Marital and Family Therapy 17:175-180.
- Audit Commission (1993) Children First: a Study of Hospital Services. London: HMSO.
- Audit Commission (2003) Services for disabled children. A review of services for disabled children and their families. London: HMSO.

- Baker, C., Wuest, J. and Stern, P. (1992) Method slurring: the grounded theory phenomenological example. Journal of Advanced Nursing 17: 1355-1360.
- Baker, J., Yardley, J. and McCaul, K. (1995) Characteristics of responding issues related to parental consent in school-based survey research. Evaluation Research 19: 663-674.
- Baldwin, S. and Carlisle, J. (Eds) (1999) Living with a disability-the experience of parents and children. Oxford: Blackwell Publishing.
- Barrera, M., Fleming, C. and Khan, F. (2004) The role of emotional social support in the psychological adjustment of siblings of children with cancer. Child: Care, Health and Development 30 (2): 103-111.
- Benner, P. (1994) Interpretative phenomenology. Embodiment, Caring and Ethics in Health and Illness. London: Sage.
- Benner, P., Tanner, C. and Chelsea, C. (1996) Expertise in Nursing Practice: caring, clinical judgement and ethics. New York: Springer.
- Beresford, B. (1995) Expert Opinions: A National Survey of Parents Caring for a Severely Disabled Child. Bristol: The Policy Press.
- Berg, B. (2004) Qualitative Health Research Methods for the Social Sciences. Boston: Allyn & Bacon.
- Bernehall Claesson, I. and Brodin, J. (2002) What families with brittle bones want to tell. Child: Care, Health and Development 28 (4): 309-315.
- Betz, C. (2004). "Transition of Adolescents with Special Health Care Needs: Review and analysis of the literature." Issues in Comprehensive Pediatric Nursing 27: 179-241.
- Brinchmann, B. (1999) When the home becomes a prison: living with a severely disabled child. Nursing Ethics 6: 137-143.
- Brown, B., Crawford, P. and Carter, R. (2006) Evidence-based Health Communication. McGraw Hill/Open University Press:
- Broster, K. and Warner, H. (Eds) (2006) Getting it right-the initial diagnosis. London: Routledge.
- Bryman, A. and Burgess, R. (Eds) (1999) Qualitative Research Volume III. London: Sage.
- Burke, R. and Greenglass, E. (1995) A longitudinal examination of the Cherniss model of psychological burnout. Social Science and Medicine 40: 1357-1363.
- Burns, N. and Grove, S.K. (2005) The Practice of Nursing Research Conduct, Critique and Utilization. St Louis, Missouri: Elsevier Saunders.
- Burns, S. and Bulman, C. (2000) Reflective Practice in Nursing The Growth of the Professional Practitioner. Oxford: Blackwell Science.
- Burton, L. (1974) Care of the Child Facing Death. Routledge and Keegan Paul: London.

- Butz, A. (2004) Use of Health Diaries in Pediatric Research. Journal of Pediatric Health Care 18: 262-263.
- Caelli, K. (2000) The Changing Face of Phenomenological Research: Traditional and American Phenomenology in Nursing. Qualitative Health Research 10 (3): 366-377.
- Caelli, K. (2001) Engaging with Phenomenology: Is it more of a Challenge that it Needs to be? Qualitative Health Research 11 (2): 273-281.
- Canam, C. (1993) Common adaptive tasks facing parents of children with chronic conditions. Journal of Advanced Nursing 18: 46-53.
- Carnevale, F. Alexander, E., Davis, M., Rennick, J. and Trioni, R. (2006) Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. Pediatrics 117 (1): 48-60.
- Carter, B. and Levetown, M. (Eds) (2004) Palliative Care for Infants, Children, and Adolescents. Baltimore: The John Hopkins University Press.
- Casey, A. (1995) Partnership Nursing: Influences on Involvement of Informal Carers. Journal of Advanced Nursing 22 :1058-62.
- Cass, H., Price, K., Wisbeach, A. and Mcconachie, H. (1999) A model for the assessment and management of children with multiple disabilities. Child: Care, Health and Development 25 (3): 191-211.
- Cavet, J. and Sloper, P. (2004) Participation of disabled children in individual decisions about their lives and in public decisions about their involvement. Children and Society 18: 27-290
- Chambers, E. and Oakhill, A. (1995) Models of Care for Children Dying of Cancer. Palliative Medicine 9: 181-185.
- Chestnut, M. (1998). Pediatric Home Care Manual. Philadelphia, PA: Lippincott.
- Chisolm, J. (2000) The context, content and consequences of mothering a child with disabilities. AXON 22 (2): 22-28.
- Chuang, P. and Liu C. (1997). "AIDS: The stigma of HIV/AIDS means to the client and the public." Nursing Research 5: 52-64.
- Coffey, A. and Atkinson, P. (1996) Making Sense of Qualitative Data Complementary Research Strategies. Thousand Oaks: Sage.
- Cohen, M. (1987) An historical overview of phenomenologic movement. Image: Journal of Nursing Scholarship 19: 31-34.
- Cohen, M. (1995a) The stages of the pre-diagnostic period in chronic, life-threatening childhood illness: A process analysis. Research in Nursing and Health 18 (1): 39-48.

- Cohen, M. (1995b) The triggers of heightened uncertainty in chronic life-threatening childhood illness. Qualitative Health Research 5: 63-77.
- Colazzi, P. (Ed) (1978) Psychological research as the phenomenologist views it. New York: Oxford University Press.
- Connors, C. and Stalker, K. (2003) The Views and Experiences of Disabled Children and their Siblings: A Positive Outlook. London: Jessica Kingsley.
- Contact a Family (2007) Home page. <http://cafamily.org.uk/index.html>. Accessed on 15 May 2007.
- Cooper, C. (1999) Continuing Care of Sick Children: Examining the Impact of Chronic Illness. Dinton: Quay Books.
- Cormack, D. (1991) The Research Process in Nursing. 2nd Edition. Oxford: Blackwell Science.
- Corti, L. (1993) Using diaries in social research, Social Research update Issue 2. Guildford: Department of Sociology, University of Surrey.
- Coyne, I. (1995) Parental participation in care: a critical review of the literature. Journal of Advanced Nursing 21: 716-722.
- Coyne, I. (1997) Chronic illness: the importance of social support for families caring for a child with cystic fibrosis. Journal of Clinical Nursing 6: 124-129.
- Coyne, I. and Crowley, S. (2006) Challenging the philosophy of partnership with parents: A grounded theory study. International Journal of Nursing Sciences. doi/ijurnstu. 2006.03.002 On Line Accessed 1 May 2007.
- Coyte, P. and McKeever, P. (2001) Home Care in Canada: "Passing the buck". Canadian Journal of Nursing Research 33 (2): 11-25.
- Craig, G. and G. Scrambler (2006). "Negotiating mothering against the odds: gastrostomy tube feeding, stigma, governmentality and disabled children." Social Science Medicine 62 (5): 1115-1125.
- Creswell, J. (1998) Qualitative Inquiry and Research Design: Choosing Among Five Traditions. Thousand Oaks: Sage Publications.
- Creswell, D. (2003) Research Design: Qualitative, Quantitative and Mixed Methods Application. 2nd Edition. Thousand Oaks, California: Sage.
- Crotty, M. (1995) The Foundations of Social Research. London: Sage.
- Dale, J., Caramlau, I., Lindenmeyer, A. and Williams S.M. (2008). "Peer support telephone call interventions for improving health (Protocol)" Cochrane Database of Systematic Reviews (1): Article number CD006903.

- Dalheim Englund, A., Rydstrom, I. and Norberg, A. (2001) Being a parent of a child with asthma. Pediatric Nursing 27 (4): 365-373.
- Darbyshire, P. (1993) Parents, nurses and paediatric settings. Journal of Advanced Nursing 18: 1670-1680.
- Davies, L.K. (1993) Comparison of dependent-care activities for well siblings of children with Cystic Fibrosis and well siblings in families without children with chronic illness. Issues in Comprehensive Pediatric Nursing 16: 91-98.
- Deatrick, J. and Knaffl, K. (1990) Management behaviours: Day to day adjustments to childhood chronic conditions. Journal of Pediatric Nursing 5(1): 15-22.
- Denzin, N. (1978) The comparative life history method In: Denzin, N.K. (Ed) The Research Act. New York: McGraw Hill.
- Denzin, N. and Lincoln, Y. (Eds) (2003) The Landscape of Qualitative Research Theories and Issues. Thousand Oaks: Sage
- Department of An Taoiseach (2000) Programme for Prosperity and Fairness. Dublin: Stationery Office.
- Department of Health (1998) More Details Announced on Diana, Princess of Wales Children's Nursing Teams. London: DoH.
- Department of Health (2002) Partnership Working: The National Service Framework A Practical aid to implementation in Primary Care. London: HMSO.
- Department of Health (2004 a) Every Child Matters. London: DoH.
- Department of Health (2004b) National Service Framework for children, young people and maternity services: Primary care version. London: DoH.
- Department of Health (2005) NSF for Children, Young People and Maternity Services, Commissioning Children's and Young Peoples Palliative Care Services. London: HMSO.
- Department of Health and Children (2001) Report of the National Advisory Committee on Palliative Care. Dublin: The Stationery Office.
- Department of Health and Children (2005) A Palliative Care Needs Assessment for Children. Dublin: DOH&C.
- Derogatis, L. (1992) SCL-90 R Minneapolis MN:Minneapolis.
- Di Censo, J. (1990) Hermeneutics and the disclosure of truth: a study of the work of Heidegger, Gadamer and Ricoeur. Charlottesville, VA: University of Virginia.
- Diehl, S., Moffitt, K. and Wade, S. (1991) Focus group interview with parents of children with medically complex needs: An intimate look at perceptions and feelings. Children's Health Care 20 (3): 170-178.

- Disability Federation of Ireland (2006) Submission to the Department of Health and Children Sectoral Plan under the Disability Act. Dublin: DFI.
- Dowling, M. (2004) Pain assessment in children with neurological impairment. Paediatric Nursing 6 (3): 37-38.
- Dowling, M, (2007) From Husserl to Van Manen. A review of different phenomenological approaches. International Journal of Nursing Studies 44: 131-142.
- Dowling, M. and Dolan, L. (2003) Families of children with disabilities-inequalities and the social model. Disability and Society 16 (1): 21-35.
- Draper, G. (Ed) (1995) The Health of Our Children: Dicennial Supplement. London: Office for Population Censuses and Surveys.
- Duffy, B. (1995) PPRU Surveys of Disability Report 5 Disabled Children in N.Ireland. Services, transport and education. Belfast: Policy Planning Research Unit.
- Dupy, H. (1997) The General Well- Being Schedule. Washington DC: US Dept of Health Resources Administration.
- Easterby-Smith, M., Thorpe, R. and Lowe, A. (1991) Management Research An Introduction. London: Sage.
- Eatough, V. and Smith, J. (2006) 'I was like a wild, wild person': Understanding feelings of anger using interpretative phenomenological analysis. British Journal of Psychology 47: 483-498.
- Eker, L., and Tüzün, E.H. (2004) An evaluation of quality of life of mothers of children with cerebral palsy. Disability and Rehabilitation 26, (23): 1354-1359.
- Elliot, H. (1997) The use of diaries in Sociological Research on Human Experience. Sociological Research 2 (2): 20-27.
- Emond, A. and Eaton, N. (2004) Supporting children with complex health care needs and their families: an overview of the research agenda. Child: Care, Health and Development 30 (3):195-199.
- Fagan, J. and Schor, D. (1993). "Mothers of children with spina bifida: Factors related to maternal psychosocial functioning." American Journal of Orthopsychiatry 63(1): 146-152.
- Faulkner, M. (1996) Family responses to children with diabetes and their influence on self-care. Journal of Pediatric Nursing 11: 82-93.
- Finlay, L. and Gough, B. (Eds) (2003) Reflexivity A Practical Guide for Researchers in Health and Social Sciences. Oxford: Blackwell Science.
- Fisher, H. (2001) The needs of parents with chronically sick children: a literature review. Journal of Advanced Nursing 36 (4): 600-607.

- Fleming, V., Gaidys, U. and Robb, Y. (2003) Hermeneutic research in nursing -developing a Gadamerian based research approach. Nursing Inquiry 10 (2): 113-120.
- Fontana, A. and Frey, J. (2003) The interview: From Structured Questions to Negotiated Text. In: Denzin, N.K. and Lincoln, Y.S. (Eds) Collecting and Interpreting Research Materials. 2nd Ed. Thousand Oaks California: Sage.
- Foster, C., Byron, M. and Eiser, C.(1998) Correlates of well-being in mothers of children and adolescents with cystic fibrosis. Child Care: Health and Development 24 (1):41-56.
- Fradd, E. (1994) Whose responsibility? Nursing Times 90 (6):34-36
- Gadamer, H. (1975) Truth and Method. New York: Seabury.
- Gadamer, H. (1976) Philosophic Hermeneutics. Berkley, California: University of California.
- Gadamer, H. (1977) Theory, technology, practice: The task of science of man. Social Research 44: 529-561.
- Gadamer, H. (1979) The problem of historical consciousness. In Gadamer, H.G. (Ed) Interpretative Social Science: a reader. Berkley California: University of California Press.
- Gadamer, H.G. (1989) Truth and Method. New York: Continuum.
- Gadamer, H. (1992) On Education, Poetry and History. Applied hermeneutics. New York: State of New York Press.
- Gadamer, H. (1996) Truth and Method. 2nd Revised Edition. New York: Continuum Publishing Company.
- Gallo, A. (1990) Family management style in juvenile diabetes: a case illustration. Journal of Pediatric Nursing 5 (23-32).
- Gatford, A. (2004). "Time to go home; putting together a package of care." Child: Care, Health and Development 30 (3): 243-246.
- Gambetta, D. (1998) Trust: Making and Breaking Cooperative Relations. Oxford: Basil Blackwood.
- Ganong, L., Doty, M. and Gayer, D. (2003) Mothers in post-divorce families caring for a child with cystic fibrosis Journal of Pediatric Nursing 18 (5): 332-343.
- Gavin, L. and Wysocki, T. (2006). "Associations of Paternal Involvement in Disease Management with Maternal and Family Outcomes in Children with Chronic Illness." Journal of Pediatric Psychology 31 (5): 481-489.
- Gelman, V.S. and King, N.J. (2001) Wellbeing of mothers with children exhibiting sleep disturbance. Australian Journal of Psychology 53 (1): 18-22.

- Geneallos, R. (1998) Hermeneutic philosophy. Part 2. A nursing research example of the hermeneutic imperative to address forestructures /preunderstandings. Nursing Inquiry 5 (4): 238-247.
- Gerrish, K. and Lacey, A. (2006) (Eds)The Research Process in Nursing. Oxford: Blackwell Publishing.
- Gibbs, G. (2002) Qualitative Data Analysis Explorations with NVivo. Buckingham: Open University Press.
- Gill, C. (2006) Palliative Care 2006: Disability, constructed vulnerability and socially conscious palliative care. Journal of Palliative Care 22 (3): 183-189.
- Glendinning, C., Kirk, S., Guiffrida, A. and Lawton, D. (1999) The community based care of technology dependent children in the UK: Definitions, numbers and costs. Manchester: National Primary Care Research and Development Centre, University of Manchester.
- Glendinning, C. and Kirk, S. (2000) High-Tech care: Highly-skilled parents. Paediatric Nursing. 12 (6): 25-28.
- Glendinning, C., Kirk, S., Guiffrida, A. and Lawton, D. (2001) Technology dependent children in the community: definitions, numbers and costs. Child: Care, Health and Development 27 (4): 321-334.
- Government of Ireland (2000) The National Children's Strategy. Dublin: The Stationery Office.
- Gray, D. (2002). "Everybody just freezes; everybody is just embarrassed": felt and enacted stigma among parents of children with high functioning autism." Sociology of Health and Illness 24 (6): 734-749.
- Greer, F.A., Grey, I.M., and McClean, B. (2006) Coping and positive perceptions in Irish mothers of children with intellectual disabilities. Journal of Intellectual Disabilities 10 (3): 231-248
- Green, J. and Thorogood, N. (2004) Qualitative Methods for Health Research. London: Sage.
- Green, S. (2007). ""We're tired, not sad": Benefits and burdens of mothering a child with a disability." Social Sciences and Medicine 64 (1): 150-163.
- Grinyer, A. (2006) Caring for a young adult with cancer: the impact on mothers' health. Health and Social Care in the Community 14 (4): 311-318.
- Gubrium, J.F. and Holstein, J.A. (Eds) (2002) Handbook of Interview Research: Context and Methods. Thousand Oaks: Sage.

- Gupta, S., Mitchell, I., Guiffre, R.M. and Crawford, S. (2001) Covert fears and anxiety in asthma and congenital heart disease. Child: Care, Health and Development 27(4):335-348.
- Guerriere, D. and McKeever P. (1997) "Mothering Children who Survive Brain Injuries: Playing the Hand you're Dealt." Journal for Specialists in Pediatric Nursing 2(3): 105-115.
- Hammersley, M. (1992) What's wrong with ethnography? Methodological exploration. London: Routledge.
- Han, H-R. (2003) Korean mothers' psychosocial adjustment to their children's cancer. Journal of Advanced Nursing 44 (5): 499-506.
- Hartrey, L. and Wells, J. (2003) The meaning of respite care to mothers of children with learning disabilities: two Irish case studies. Journal of Psychiatric and Mental Health Nursing 10: 335-342.
- Hassiotis, A. (1997) Parents of young persons with learning disability: An application of the family adaptability and cohesion rate (FACES 11) British Journal of Developmental Disabilities 43 (1): 42-47.
- Hatton, D., Canam C., Thorne, S. and Hughes, A-M. (1995) Parent's perceptions of caring for an infant or toddler with diabetes. Journal of Advanced Nursing 22: 569-577.
- Health Research Board (2004) National Disability Database. Dublin: HRB.
- Heaton, J. Noyes, J., Sloper, P. and Shah, R. (2005a) Families' experiences of caring for technology-dependent children: a temporal perspective. Health and Social Care in the Community 13 (5): 441-450.
- Heaton, J., Noyes, J., Sloper, P., and Shah, R. (2005b). "The Experiences of Sleep Disruption in Families of Technology-Dependent Children Living at Home." Children and Society 20: 196-208.
- Heggarty, H. (1994) Good beginnings In: Hill, L. (Ed) Caring for Dying Children and their Families. London: Chapman and Hall.
- Heidegger, M. (1962) Being and Time (Trans J .McQuarrie and E. Robinson.) New York: Harper and Row.
- Heller, T., Hsieh, K. and Rowitz, L. (1997) Maternal and paternal care-giving of persons with mental retardation across the life-span. Family Relations 46 (4): 407-415.
- Hewitt-Taylor, J. (2005a) Caring for children with complex and continuing care needs. Nursing Standard 19(42): 41-47.
- Hewitt-Taylor, J. (2005b) Children with complex needs: educating staff. Primary Health Care 15(3): 36-41.

- Himmelstein, B., Orloff, S., Evans, D. and Wheeler, J. (2004) Palliative Care in the Home, School and Community In: Carter, B.S., and Leverton, L.M. (Eds), Palliative Care for Infants, Children and Adolescents. Baltimore: The John Hopkins University.
- Himmelstein, B. (2006) Palliative Care for Infants, Adolescents, and Their Families. Journal of Palliative Medicine 9 (1): 163-181.
- Hoare, P., Harris, M., Jackson, P. and Kerley, S. (1998) A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care. Journal of Intellectual Disability Research 42 (3): 218-227.
- Hodgkinson, R. and Lester, H. (2002) Stress and coping strategies of mothers living with a child with cystic fibrosis: implications for nursing professionals. Journal of Advanced Nursing 39 (4): 377-383.
- Holloway, I. (1997) Basic concepts for Qualitative Research. Oxford: Blackwell Publishing.
- Holmbeck, G., Coakley, R., Hummeyer, H.S., Shapera, W.E. and Westhoven, V.C. (2002) Observed and perceived dyadic and systemic function in families of preadolescents with spina bifida. Journal of Pediatric Psychology 27: 177-189.
- Holstein, J. and Gubrium, J. (1995) The Active Interview. Thousand Oaks: Sage.
- Hope, K. and Waterman H. (2003) Praiseworthy pragmatism: Validity and action research. Journal of Advanced Nursing 44 (2): 120-127.
- House of Commons Health Committee (1997) Health Services for Children and Young People in the Community-home and school 3rd Report. London: The Stationery Office.
- Horner, S. (1997). Uncertainty in mothers' care of their ill children. Journal of Advanced Nursing 26 (4): 658-663.
- Hughes, J. and Callery, P. (2004) Parent's experiences of caring for their child following day case surgery: a diary study. Journal of Child Health Care 8 (1): 47-58.
- Hunt, F. (2007). "Changing from oral feeding to enteral feeding: impact on families with disabilities." Paediatric Nursing 19 (7): 30-32.
- Husserl, E. (1965) Phenomenology and the crisis of philosophy. New York: Harper and Row.
- Hycner, R.H. (1999) Some Guidelines for the Phenomenological Analysis of Interview Data In: Bryman, A. and Burgess, R.G. (Ed) Qualitative Research Volume 111. Thousand Oaks, CA: Sage.
- Ingersoll, G. and Golden, G. (1995). The diabetic child in context: 'the family'. In Kelnar, C.J.H. Childhood and Adolescent Diabetes. London: Chapman and Hall Medical, 449-456.

- Ironside, P.M., Scheckel, M., Bailey ME., Power, S., and Seeley, D.K., (2003) Experiencing Chronic Illness: Co creating New Understandings. Qualitative Health Research 13 (2): 171-183.
- Irish Society for the Prevention of Cruelty to Children. (2006) An exploratory study of the impact of disability on individual family members, relationships, family life and dynamics. Dublin: ISPCC.
- Jack and Jill Children's Foundation Homepage Available on <http://www.jackandjill.ie> Accessed on 15 May 2007.
- Jackson, P. and C. Robinson (2003). "Children's hospices; where do they fit?" Critical Social Policy 23 (1): 103-112.
- Jardine, D. (1990) Awakening from Descartes' nightmare: on the love of ambiguity in phenomenological approaches to education. Studies in Philosophy and Education 10: 211-232.
- Jardine, E., O'Toole M., Paton, J.Y. and Wallis, C. (1999) 'Current Status of Long-term Ventilation of Children in the United Kingdom: A Questionnaire Survey. British Medical Journal 318 (7179): 295-299.
- Jerrett, M.D. (1994) Parent's experiences of coming to know the care of a chronically ill child. Journal of Advanced Nursing 19: 1050-1056.
- Jerrett, M.D. and Costello, E.A. (1996) Gaining Control. Clinical Nursing Research 5 (3): 294-308.
- Johnson, M.E. (2000) Heidegger as meaning: Implications for phenomenological research. Nursing Philosophy 1: 134-146.
- Jordan, A.L., Eccleston, C., and Osborn, M. (2006) Being a parent of the adolescent with complex pain: An interpretative phenomenological analysis. European Journal of Pain 11: 49-56.
- Kai, J. (1996). "Parents difficulties and information needs in coping with acute illness in pre-school children: a qualitative study." British Medical Journal 313 (19 October): 987-990.
- Katz, S. (2002) When the Child's Illness Is Life-Threatening: Impact on the Parents. Pediatric Nursing 28 (5): 453-463.
- Kearney, P. and Griffin, T. (2001) Between joy and sorrow: being a parent of a child with a developmental disability. Journal of Advanced Nursing 34 (5): 582-592.
- Keen, E. (1975) A primer in phenomenological psychology. New York: Holt, Reinhart and Winston Inc.
- Kiernan, J. (1997) Who cares about respite? Dublin: Disability Federation Ireland.

- Kirk, S. (1998) Families' experiences of caring at home for a technology-dependent child: a review of the Literature. Child: Care, Health and Development 24: 101-114.
- Kirk, S. (1999) Caring for technology-dependent children at home British Journal of Community Nursing 4 (8): 390-394.
- Kirk, S. (2001) Negotiating lay and professional roles in the care of children with complex health care needs. Journal of Advanced Nursing 34 (5): 593-602.
- Kirk, S. and Glendinning, C. (2004) Developing services to support parents caring for a technology-dependent child at home. Child: Care, Health and Development 30 (3): 209-218.
- Kirk, S., Glendinning, C. and Callery, P. (2005) Parent or nurse? The experience of being a parent of a technology-dependent child. Journal of Advanced Nursing 51 (5): 456-464.
- Koch, T. (1993) Towards Fourth Generation Evaluation: Listening to the Voices of Older Patients. A Hermeneutic Enquiry. Unpublished PhD Thesis: University of Manchester.
- Koch, T. (1995) Interpretive approaches in nursing research: the influence of Husserl and Heidegger. Journal of Advanced Nursing 21:827-836.
- Koch, T. (1996) Implementation of a hermeneutic enquiry in nursing: Philosophy, rigor and representation. Journal of Advanced Nursing 24: 174-184.
- Kohlen, C., Beier, J. and Danzer, C.T. (2000). "They don't leave you on your own": A qualitative study of the home care of chronically ill children." Pediatric Nursing 26: 366-371.
- Kuster, P., Badr, L.K., Chang, B.L., Wuerker A.K. and Benjamin, A.E. (2004). "Factors influencing Health Promoting Activities of Mothers Caring for Ventilator-Assisted Children." Journal of Pediatric Nursing 4 (4): 276-287.
- Kvale, S. (1996) Interviews. An Introduction to Qualitative Research Interviewing. Thousand Oaks, California: Sage
- Laverty, S. (2003) Hermeneutic phenomenology and phenomenology. A comparison of historical and methodological considerations. International Journal of Qualitative Methods 2 (3): 1-29.
- Lavigne, J.V. and Faier-Routman, J. (1993) Correlates of psychological adjustment to pediatric physical disorders: a meta-analytic review and comparison of existing models. Journal of Developmental and Behavioural Pediatrics 14: 117-123.
- Lawler, J. (1998) Phenomenologies as research methodologies for nursing: From philosophy to researching practice. Nursing Inquiry 5 (2): 104-111.
- Lee, P. (1999) Review: Partnership: What does it mean today? Journal of Child Health Care 3 (28): 28-32.

- Lee, P. (2004) Family involvement: are we asking too much? Paediatric Nursing 16 (10): 37-41.
- Lenton, S., Stallard, P., Lewis, M. and Mastroyannopoulou, K. (2001) Prevalence and morbidity associated with non-malignant, life-threatening conditions in childhood. Child: Care, Health and Development 27 (5): 389-398.
- Lenton, S., Franck, L. and Salt, A. (2004) Children with complex needs: supporting the family in the community Editorial. Child: Care, Health and Development 30 (3): 191-192.
- Leonard, B.J., Brust, J.D. and Nelson, R.P. (1993) Parental distress: Caring for medically fragile children at home. Journal of Pediatric Nursing 8 (1): 22-30.
- Lewis, G. (2000) Introduction: Expanding the social policy imaginary. In Lewis, G., Gerwitz, S. and Clarke, J. (2000) Rethinking Social Policy. London: Open University Press: Sage.
- Lewis, M. and Noyes, J. (2007). "Discharge management for children with complex needs." Paediatric Nursing 19 (4): 26-30.
- Lincoln, Y. and Guba, E. (1985) Naturalistic enquiry. Beverley Hills CA: Sage.
- Lincoln, Y. and Guba, E. (2000) Paradigmatic controversies, contradictions and emerging confluences. In: Lincoln, Y. and Guba, E. (Eds) Handbook of Qualitative Research. Thousand Oaks: Sage.
- Lobo, M. (1992) Parent-infant interaction during feeding when the infant has congenital heart disease. Journal of Pediatric Nursing 7: 97-105.
- Lowes, L. and Lyne, P. (1999) A normal lifestyle: parental stress and coping in childhood diabetes. British Journal of Nursing 8: 133-139.
- Lowoko, S. and Soares, J. (2002) Distress and hopelessness among parents of children with congenital heart disease, parents of other children with other diseases and parents of healthy children. Journal of Psychosomatic Research 52: 193-208.
- Mackie, P.C., Jessen, E.C., and Jarvis, S.N. (1998) The lifestyle assessment questionnaire: an instrument to measure the impact of disability on the lives of children with cerebral palsy and their families. Child: Care, Health and Development 24 (6): 473-486.
- Maguire, H. (2000) Assessment of need of life- limited children in N. Ireland. Belfast: Northern Ireland Hospice Children's Service.
- Maguire, H. (2001) Developing a hospice service in Northern Ireland. Paediatric Nursing 13 (8): 19-21.
- Manuel, J., Naughton, M., Balkrishnan, R., Paterson Smith, B and Koman, L.A. (2003). "Stress and adaptation in mothers of children with cerebral palsy." Journal of Pediatric Psychology 28 (3): 197-201.

- Marino, P. and Lipshitz, M. (1991) Temperament in infants and toddlers with cardiac disease. Pediatric Nursing 17 (5): 445-448.
- Mason, J. (2002) Qualitative Researching. 2nd Edition. London: Sage Publications.
- Massarick, F. (Ed) (1981) The interviewing process re-examined. In Reason, P. and Rowan, J. (Eds) Human Inquiry: a case book of new paradigm research. Chichester: Wiley.
- Maunder, E. (2006) Palliative care for children and young people: a community paediatric nursing perspective. International Journal of Palliative Nursing 12 (7): 329-333.
- Maykut, M. and Morehouse, R. (1994) Beginning Qualitative Research A Philosophic and Practical Guide. London: The Falmer Press.
- Mays, N. and Pope, C. (1995a) Qualitative research in health care. 1st Edition. London: BMJ Books.
- Mays, P. and Pope, C. (1995b) Qualitative Research: rigour and qualitative research. British Medical Journal 311: 109-112.
- McCracken, G. (1988) The Long Interview. Qualitative Research Methods Series 13 London: Sage Publications.
- McCubbin, H. and Patterson, J. (Eds) (1983) Family transitions: adaptation to stress. 1. New York: Brunner/ Mazel.
- McCubbin, H.I and McCubbin, M.A. (1988) Typologies of resilient families: Emerging roles of social class and ethnicity. Family Relations 37: 247-254.
- McCubbin, M. and Svavarsdottir, E. (1996) The care of my child with asthma. Madison WI: University of Wisconsin Press.
- McCubbin, H. and Svavarsdottir, E. (1999) The care of my child with cancer questionnaire. Reykjavik: Faculty of Nursing, University of Iceland.
- McDonald, E., Fitzsimons E, and Noonan Walsh, P. (2007). "Use of respite care and coping strategies among Irish families of children with intellectual disabilities." British Journal of Learning Disabilities 35 (1): 62-68.
- McDonald, H. (1995). Chronic renal disease-the mothers' experience. Pediatric Nursing 21: 503-505,574.
- McGrath, P. (2001) Identifying support issues of parents of children with leukaemia. Cancer Practice 9: 198-205.
- McGrath, P. (2001) Findings of the impact of treatment for childhood acute lymphoblastic leukaemia in family relationships Child Family Social Work 6: 229-237.
- McIntosh, J. and Runciman, P. (2006) Exploring the role in partnership in the home care of children with special health needs: Qualitative findings from two service evaluations.

- International Journal of Nursing Studies. On line accessed 1May 2007.doi 101016/ijnurstu 2006.12.012.
- McIntyre, R. (2001) Interpretive Analysis: The Method In: Munhall, P. (Ed) Nursing Research A Qualitative Perspective. Boston: Jones and Bartlett.
- McKay, S. and Atkinson, A. (2007) Disability and caring among families of children Family employment and poverty characteristics Research Paper 460. Department for Work and Pensions. HMSO.
- McKeever, P. and Miller, K. (2004) Mothering children with disabilities. A Bourdieusian interpretation of maternal practices. Social Science and Medicine 59 (6): 1177-1191.
- Meltzer, L. and J. Mindell (2005). "Impact of a child's chronic illness on maternal sleep and daytime functioning." Archives of Internal Medicine 166 (16): 1749-1755.
- Middleton, C. and Sidey, A. (2000) A short journey down a long road; the emergence of professional bodies In: Muir, J. and Sidey, A.E. (Eds) Textbook for community children's nursing. Edinburgh: Balliere Tindall.
- Miles, M. and Huberman, A. (1994) Qualitative data analysis: an expanded sourcebook. 2nd Edition. Thousand Oaks: Sage.
- Miller, S. (1952) The Participant Observer and Over Rappost American. Sociology Review 17: 97-99.
- Milo, E.M. (1997) Maternal responses to the life and death of a child with a developmental disability. Death Studies 21: 443-476.
- Mishel, M. (1988) Uncertainty in illness. Image: The Journal of Nursing Scholarship 20: 225-232.
- Mitchell, W. and Sloper, P. (2001) Quality in services for disabled children and their families: what can theory, policy and research in children's and parent's views tell us? Children and Society 5: 237-252.
- Morelius, E., Lundh, U and Nelson, E.F. (2002) Parental stress in relation to the severity of congenital heart disease in their children. Pediatric Nursing 21 (1): 28-34.
- Morrell, M. (2002). Stigma and epilepsy. Epilepsy and Behaviour 3(6) Supplement 2 Dec: 21-25.
- Morris, R.R, Krawiecki, N.S., Wright, J.A. and Walter, L.W. (1993) Neuropsychological, academic and adaptive functioning in children who survive cardiac arrest and resuscitation. Journal of Learning Disability. 26: 46-51.
- Morse, J. (1991) Negotiating commitment and involvement in the nurse-patient relationship. Journal of Advanced Nursing 16: 455-468.

- Morse, J. (1994) The significance of saturation. Qualitative Health Research 5 (2): 147-149.
- Moules, N. (2002) Nursing on paper: therapeutic letters in nursing practice. Nursing Inquiry 9 (2): 104-113.
- Mu, P-F. (2005) Paternal reactions to a child with epilepsy: uncertainty, coping strategies and depression. Journal of Advanced Nursing 49 (4): 367-376.
- Mu, P., Mu, H. and Chang K.. (2005). "Boundary ambiguity, coping patterns and depression in mothers caring for children with epilepsy in Taiwan." International Journal of Nursing Studies 42: 273-282.
- Mu, P.-F. (2008). "Transition experience of parents caring of children with epilepsy. A phenomenological study." International Journal of Nursing Studies 24 (4): 543-551.
- Mullins, L., Olson, R.A., Reyes, S., Bernady, H., Hustzi, H.C., and Volk, R.L. (1991) Risk and resistance factors in the adaptation of mothers of children with cystic fibrosis. Journal of Pediatric Psychology 16: 701-705.
- Mulvany, F. (2000) Annual Report of the National Disability Database Committee 1998/1999. Dublin: Health Research Board.
- Munhall, P. (2001) Nursing Research A Qualitative Perspective. 3rd Edition. London: Jones and Bartlett.
- Nelson-Jones, R. (2002) Are there universal human being skills? Counselling Psychology Quarterly 15 (2): 115-119.
- Neufield, S., Query, B. and Drummond, J. (2001) Respite Care Users Who have Children With Chronic Conditions: Are they Getting a Break? Journal of Pediatric Nursing 16 (4): 234-244.
- Newacheck, P. and Taylor, W. (1992) Childhood Chronic Illness. Prevalence, Severity and Impact. American Journal of Public Health 82 (3): 364-371.
- N.I. Hospice (2004) NI Hospice Care 'Pay as you earn' and help the Hospice Care leaflet. Belfast: N.I. Hospice.
- Nicholl, H. (2006) Nursing children with life-limiting conditions: terminology used. An Bord Altranais News 18 (3): 11.
- Nicholl, H. (2007) Involving mothers in research studies: practical considerations. Paediatric Nursing 19 (1): 28-30.
- Nickel, R. and Desch, L. (2000) The physician's guide to caring for children with disabilities and chronic conditions. Baltimore: Paul H. Brookes.
- Noonan Walsh, P., Conliffe, C. and Birbeck, G. (1994) Assessing the needs of family carers. Lancaster: Lisieux Hall.

- Noyes, J., Hartman, H., Samuels, M., and Southall, D. (1999) The experiences and views of parents who care for ventilator-dependent children. Journal of Clinical Nursing 8: 431-439.
- Noyes, J. (2000). "'Ventilator dependent' children who spend long periods of time in intensive care units when they no longer have a medical need or want to be there." Journal of Clinical Nursing 9: 774-783.
- Nuutila, L. and Salanterä, S. (2006) International pediatric column. Children with a long-term illness: parents' experiences of care. Journal of Pediatric Nursing: Nursing Care of Children and Families 21 (2): 153-160.
- Oberle, K. (2002) Ethics in qualitative health research. Annals RCPSC 35 (8): 563-566.
- O'Brien, M.E. (2000) Living in a house of cards; family experiences with Long-term childhood technological dependence. Journal of Pediatric Nursing 16 (1): 13-22.
- Odenrats, S., Ehnfors, M. and Grobe, S. (2005) Living with Chronic Obstructive Airways disease Part 1. Struggling with meal- related situations: experiences among persons with COPD. Scandinavian Journal Caring Sciences 19: 230-239.
- Oliver, M. (1990) The Politics of Disablement London MacMillan
- Oliver, P. (2003) The Student's Guide to Research Ethics. Maidenhead: Open University Press.
- Olsen, R. and Maslin-Prothero, S. (2001) Dilemmas in the provision of own-home respite support for parents of young children with complex health care need: evidence from an evaluation. Journal of Advanced Nursing 34 (5): 603-610.
- Olsson, M. and Hwang, C. (2001) Depression of mothers and fathers of children with intellectual disability. Journal of Intellectual Disability Research 45 (6): 535-543.
- Olsson, M. and Whang, P. (2003) Influence of macrostructure of society on the life situation of families with a child with intellectual disabilities: Sweden as an example. Journal of Intellectual Disability Research 47: 328-341.
- Omery, A. (1983) Phenomenology: A method for nursing research. Advances in Nursing Science 61 (1): 49-62.
- Oostrom, K.J., Schouten, A., Kruitwagen, C.L., Peters, A.C.B. and Jennekens-Schinkel, A., (2001). Parent's Perceptions of Adversity Introduced by Upheaval and Uncertainty at the Onset of Childhood Epilepsy. Epilepsia 42(11): 1452-1460.
- Oppenheim, A. (1992) Questionnaire design, Interviewing and Attitude Measurement. (New Edition). London: Cassell.
- Orloff, S., Quance, K., Perszyk, S., Flowers, W.J. and Veale E., (Eds) (2004) Psychosocial and Spiritual Needs of the Child and Family. Baltimore: John Hopkins University Press.

- Pain, H. (1999) Coping with a child with disabilities from the parents' perspective: the function of information. Child: Care, Health and Development 25 (4): 299-312.
- Palmer, E. (2001) Family caregiver experiences with asthma in school age children. Pediatric Nursing 27: 75-81.
- Parahoo, K. (2006) Nursing Research Principles, Process and Issues. 2nd Edition. Hampshire: Palgrave MacMillan.
- Patterson, J., Jernell, J., Leonard, B. and Titus, J.C. (1994) Caring for medically fragile children at home: the parent professional relationship. Journal of Pediatric Nursing 9: 98-106.
- Patton, M. (1990) Qualitative Evaluation and Research Methods. Newbury Park, California: Sage.
- Payne, S., Sheldon, F. and Jarrett, N. (2002) Differences in understandings of specialist palliative care amongst service providers and commissioners in South London. Palliative Medicine 16: 395-402.
- Pederson, S.D., Parsons, H.G. and Dewey, D. (2004) Stress levels experienced by the parents of enterally fed children Child Care: Health and Development 30 (5): 507-513.
- Pelchat, D., Lefebvre, H and Perreault, M. (2003). "Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability." Journal of Child Health Care 7 (4): 231-247.
- Peri, G., Molinari, E. and Taverna, A. (1991) Parental perceptions of childhood illness. Journal of Asthma 28 (2): 91-101.
- Perry, K. and Burgess, M. (2002) Communication in Cancer Care. Oxford: BPS Blackwell
- Peter, E., Spalding, K., Kenny, N., Conrad, P., McKeever, P and McFarlane, A. (2006) Neither seen nor heard: Children and homecare policy in Canada. Social Science and Medicine 64: 1624-1635.
- Petr, C., Murdock, M. and Chapin, R. (1995) Home care for children dependent on medical technology: the family perspective. Social Work in Pediatrics 21 (1): 5-22.
- Phillips, D. (1987) Validity in Qualitative Research Why worry about warrant will not wane. Education and Urban Society 20: 9-24.
- Phillips, M. (1991) Chronic sorrow in mothers of chronically ill and disabled children. Comprehensive Pediatric Nursing 14: 111-120.
- Phillips, B. (2007) Nursing care and understanding the experiences of others Gadamerian perspective. Nursing Inquiry 14 (1): 89-94.

- Pit-Ten Cate, I.M., Kennedy, C. and Stevenson, J. (2002). Disability and quality of life in spina bifida and hydrocephalus. Developmental Medicine and Child Neurology 44 (5): 317-322.
- Polit, D. and Hungler, B. (1999) Nursing Research: Principles and Methods. Philadelphia: Lippincott.
- Polkinghorne, D. (1988) Narrative Knowing and The Human Science. Albany, New York: State University of New York Press.
- Polkinghorne, D. (Ed) (1989) Phenomenological research methods. New York: Plenum
- Porter, L. and McKenzie (2000) Professional Collaboration with Parents of Children with Disabilities. London: Whurr Publications.
- Prall, D. (2000) Who are we here for? (Editorial) Palliative Medicine 14: 91-92.
- Price, J. and McFarlane M. (2006) Care of the child requiring palliative care In: Glasper, E.A., and Richardson, J. (Eds) A Textbook of Children's and Young People's Nursing. Edinburgh: Churchill Livingstone Elsevier.
- Price, M. and Thomas, S. (2007) Continuing Care Needs In Valentine F Lowes L Nursing Care of Children and Young People with Chronic Illness Blackwell Publishing: Oxford.CH 7: 157-182.
- Punch, K. (2005) Introduction to Social research Quantitative and Qualitative Approaches. London: Sage Publications.
- Qualitative Solutions and Research QSR NVivo version 7*: Qualitative Solutions and Research, Melbourne, Australia.
- Quint, R, Chesterman, E., Crain, L., Winkleby, M. and Boyce, T. (1990) Home care for ventilator dependent children. American Journal of Diseases in Children 144: 1238-1241.
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walker, S.D., Russell, D., Swinton, M., Zhu, B and Wood, E. (2005) The Health and Well-being of Caregivers of Children with Cerebral Palsy. Paediatrics Volume, e626-e636 DOI: doi:10.1542/ peds.2004.1689.
- Rapport F. (2004) New Qualitative Methodologies in Health and Social Care Research. London: Routledge.
- Ray, L. and J. Ritchie (1993). "Caring for chronically sick children at home: factors that influence parents' coping." Journal of Pediatric Nursing 8 (4): 217-232.
- Read, J. (2000) Disability, the Family and Society: listening to Mothers. Buckingham: Open University Press.
- Read, C.Y. (2003) The demands of Biochemical Genetic Disorders: A survey of Mothers of children With Mitochondrial Disease or Phenylketonuria. Journal of Pediatric Nursing 18 (3): 181-186.

- Redmond, B. and Richardson, V. (2003) Just getting on with it: Exploring the Service Needs of Mothers Who Care for Young Children with Severe/Profound and Life-Threatening Intellectual Disability. Journal of Applied Research in Intellectual Disabilities 16: 205-218.
- Reeder, F. (1987) The phenomenological movement. Image-Journal of Nursing Scholarship 19 (3): 150-152.
- Reeves, E., Timmons, S. and Dampier, S. (2006). "Parents' experiences of negotiating care for their technology-dependent child." Journal of Child Health Care 13 (3): 228-239.
- Richards, L. (2005) Handling qualitative data. A Practical Guide. London: Sage.
- Ricoeur, P. (1981) Hermeneutics and the Human Sciences. Cambridge: Cambridge University Press.
- Ritchie, J. and Lewis, J. (2003) Qualitative Research Practice A guide for Social Science Students and Researchers. London: Sage Publications
- Roberts, K. and Lawton, D. (2001) Acknowledging the extra care parents give to their disabled children Child: Care, Health and Development 27 (4): 307-319.
- Rolfe, G. (2006) Validity, trustworthiness and rigour: quality and the idea of qualitative research. Journal of Advanced Nursing 53 (3): 304-310.
- Rosenberg, S.A. and Robinson C.C. (2004) Out-of home placement for young children's with developmental and medical conditions Children and Youth Services Review 26:711-723.
- Ryan, S. (2005). "'Busy Behaviour' in the ' Land of the Golden M'; Going out with Learning disabled Children in Public Places." Journal of Applied Research in Intellectual Disabilities 18: 65-74.
- Sandelowski, M. (1986) The problem of rigor in qualitative research. Advances in Nursing Science 8 (3): 125-130.
- Sandelowski, M. (1993) Theory unmasked: the uses and guises of theory in qualitative research. Research in Nursing and Health 16 (3): 213-218.
- Sandelowski, M. (1995a) Focus on qualitative methods: Sample size in qualitative research. Research in Nursing and Health 18: 479-482.
- Sandelowski, M. (1995b) Sample size in Qualitative Research. Research in Nursing and Health 18: 179-183.
- Schoenfelder, D.P., Swanson, E.A., Pringle Sprecht, J., Maas, M. and Johnson, M. (2000) Outcome indicators for direct and indirect care-giving. Clinical Nursing Research 9: 47-69.
- Schwandt, T. (2001). A post-script on thinking about dialogue. Evaluation 7: 264-276.

- Schwandt, T. (2003) Three Epistemological Stances for Qualitative Enquiry In: Denzin, N. and Lincoln, Y. (Eds) The Landscape of Qualitative Research. Thousand Oaks CA: Sage.
- Seligman, M. and Darling, R. (1997) Ordinary Families; Special Children: A Systems approach to Childhood Disability. 2nd Edition. New York: Guildford.
- Shields, L. (2001) A review of the literature developed and developing countries relating to the effects of hospitalization on children and parents. International Nursing Review 48:29-37.
- Shih, F. (1998) Triangulation in nursing research: issues of conceptual clarity and purpose. Journal of Advanced Nursing 28: 631-641.
- Shu, B-C. and Lung, F.-W. (2005) The effect of support group on the mental health and quality of life for mothers with autistic children Journal of Intellectual Disability 49,1, 47-53.
- Sidey, A. (1995) Competence for community health care nursing. In: Sines, D. (Ed) Community health care nursing. Oxford: Blackwell Science.
- Silverman, D. (2000) Doing Qualitative Research. London: Sage.
- Sloper, P. (1999) Models of service support for parents of disabled children. What do we need to know? Child: Care, Health and Development 25: 85-99.
- Smith, J. (1993) After the demise of empiricism: the problem of judging social and educational inquiry. Norwood NJ: Ablex.
- Smith, J. (1997) Developing theory from case studies Self-reconstruction and the transition to motherhood In: Hayes, N. (Ed) Doing qualitative analysis in psychology. Hove: Psychology Press.
- Smith, J., Jarman, M. and Osborn, N. (1999) Doing interpretive phenomenological analysis In: M. M. Murray and Chamberlain K. (Eds) Qualitative health psychology: theories and methods. London: Sage.
- Smith, J. (2003) Interpretative phenomenological analysis In: Smith, J.E. (Ed) Qualitative Psychology. London: Sage
- Smith, J. (2004) Reflecting in the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. Qualitative Research Psychology 1: 39-54.
- Smith, L., Coleman, V. and Bradshaw, M. (2002) Family-centred Care: Concept, Theory and Practice. Basingstoke: Palgrave.
- Spalding, K. and P. McKeever (1998). "Mothers experiences of caring for children with disabilities who require a gastrostomy tube." Journal of Pediatric Nursing 13(4): 234-243.

- Sparacino, P., Tong, P.S., Foote Chlesa, C.A. and Gillis, C.L. (1997) The dilemmas of parents of adolescents and young adults with congenital heart disease. Heart Lung 26 (3): 187-195.
- Speziale, H. and Carpenter, D. (2007) Qualitative Research in Nursing 4th Edition. Philadelphia: Lippincott Williams and Wilkins.
- Spiegelberg, H. (1975) Doing Phenomenology: Essays on and in phenomenology. The Hague: Martinus Niihoff.
- Stalker, K. and Robinson, C. (1993) Patterns of provision in respite care and the Children's Act. British Journal of Social Work 23: 45-63.
- Starke, M. and Möller, A. (2002). "Parents' needs for knowledge concerning the medical diagnosis of their children." Journal of Child Health Care 6 (4): 245-257.
- Stebbins, R. (1972) The unstructured research interview as incipient interpersonal relationship. Sociology and Social Research 56 (2): 164-177.
- Stutts, A. (1994). "Selected outcomes of technology dependent children receiving home-care and prescribed childcare services." Pediatric Nursing 20 (5): 501-7.
- Sudia-Robinson, T. (1998). "A question of ethics. Neonatal intensive care in the home." Home Care Provider 3: 290-292.
- Sullivan-Bolyai, S., Deatrick, J., Gruppuso, P., Tamborlane, W and Grey, M. (2003) Constant Vigilance: Mothers' Work Parenting Young Children With Type 1 Diabetes. Journal of Pediatric Nursing 18 (1): 21-29.
- Sullivan-Bolyai, S., Sadler, L.S., Knafl, K.A. and Gillis, C.L. (2002) Great expectations: A Position Description for Parents as Caregivers: Part 1. Pediatric Nursing 29 (6): 457-461.
- Sully, P. and Dallas, J. (2005) Essential Communication Skills for Nursing. Edinburgh: Elsevier Mosby.
- Sutherland, R., Hearn, J., Baum, D., and Elson, S. (1994). Definitions of paediatric palliative care. Health Trends 25 (4): 149-150.
- Svavarsdottir, E. and McCubbin, M. (1996) Parenthood transition for parents of an infant diagnosed with congenital heart disease. Journal of Pediatric Nursing 11 (4): 207-216.
- Svavarsdottir, E.K., McCubbin, M.A. and Kane, J.H. (2000) Well-Being of Parents of Young Children with Asthma. Research in Nursing and Health 23: 346-358.
- Tatman, M., Woodroffe, C., Kelly, P.J. and Harris R.J. (1992) Paediatric home care in Tower Hamlets: a working partnership with parents. Quality in Health Care 1: 98-103.
- Tatman, M. and Woodroffe, C. (1993) Paediatric home care in the United Kingdom. Archives of Disease and Childhood 69: 677-680.

- Taylor, S. and Bogdan, R. (1988) Introduction to qualitative research methods: A guidebook and resource. 3rd Ed. New York: John Wiley.
- Teeland, L. (1998) Home sick: implications of health care delivery in the home. Scandinavian Housing and Planning Research 15: 271-282.
- Thompson, V., Hupcey, J. and Clark, M. (2003) The development of trust in Parents of Hospitalized Children. Journal for Specialists in Pediatric Nursing 8 (4): 137-147.
- Thorne, S., Kirkham, S. and McDonald-Emes (1997) Interpretive description: a non-categorical alternative for developing nursing knowledge. Research, Nursing and Health 20 (2): 169-177.
- Thorne, S. (2000) Data analysis in qualitative research. Evidence Based Nursing 3: 68-70.
- Thorne, S., Kirkham, S. and McDonald-Emes, J. (1997) Interpretive description: a noncategorical alternative for developing nursing knowledge. Research Nursing and Health 20 (2): 169-177.
- Thurgate, C. (2005) Respite for children with complex health needs: issues from the literature. Paediatric Nursing 17 (3): 14-19.
- Todres, L. and Holloway, I. (2006) The Research Process in Nursing In: Gerrish, K.L., A (Ed) The Research Process in Nursing. Oxford: Blackwell Publishing.
- Tomlinson, E. (2002) The lived experience of families of children who are failing to thrive. Journal of Advanced Nursing 39 (6): 537-545.
- Tonks, N., Fawcett, J.N., Baggaley C.N., Whyte, D. and Martinson, M.(2005). "Parental responses to health care services for children with chronic conditions and their families: a comparison between Hong Kong and Scotland." Journal of Child Health Care 9 (8): 8-19.
- Townsley, R., Abbott, D. and Watson, D. (2004) Making a difference? Exploring the impact of multi-agency working on disabled children with complex health care needs, their families and the professionals who support them. Bristol: Policy Press.
- Tritter, J. and Calnan, M. (2002) Cancer as a chronic illness? Reconsidering categorization and exploring experience. European Journal of Cancer Care 11: 161-165.
- Twigg, J. (2000) Bathing-The Body and Community Care. New York: Routledge.
- Van der Zalm, J.E .and Bergum, V. (2000) Hermeneutic phenomenology; providing knowledge for nursing practice. Journal of Advanced Nursing 31 (1): 211-218.
- Van Horn, M., DeMaso, D.R., Gonzalez-Heydrich, J., Dahlmeirer, F. and Erikson, J. (2001) Illness-related concerns of mothers of children born with congenital heart disease. Journal of The Academy of Adolescent Psychology 40: 847-854.
- Van Manen, M. (1977) Linking ways of knowing with ways of being practical. Curriculum Inquiry 6: 205-228.

- Van Manen, M. (1990) Researching lived experience: Human science for an action sensitive pedagogy. Albany NY: State University of New York Press.
- Van Manen, M. (1997a) From meaning to method. Qualitative Health Research 7: 345-369.
- Van Manen, M. (1997b) Researching Lived Experience: Human Science for an Action Sensitive Pedagogy. 2nd Edition London Ontario: Althouse.
- Van Manen, M. (2002). Writing in the dark: Phenomenological studies in Interpretive inquiry. Ontario, University of Western Ontario.
- Van Riper, M. (1999) Maternal perceptions of family-provider relationships and well-being in families of children with Down syndrome. Research in Nursing and Health 22: 357-68.
- Van Riper, M. (2007) Families of Children with Down Syndrome: Responding to "A Change in Plans" with Resilience. Journal of Pediatric Nursing 22 (2): 116-128.
- Vick, S. (1996) Caring for ventilated patients in the community; a pilot study examining costs, quality of life and preferences. Health and Social Care in the Community 4: 330-337.
- Voysey, M. (1975) A Constant Burden. London: Routledge and Keegan Paul.
- Wallander, J., Varni, J.W., Babani, I., De Hann, C.B., Wilcox, K.T. and Banis, M.T. (1989) The social environment and the adaptation of mothers of physically handicapped children. Journal of Pediatric Psychology 14: 371-387.
- Ware, J. and Raval, H.(2007) A Qualitative Investigation of Fathers' Experiences of Looking After a Child With a Life-limiting Illness, In Process and in Retrospect. Clinical Child Psychology and Psychiatry 12 (4): 549-565.
- Wang, K.-W.K and Barnard, A. (2004) Technology-dependent children and their families: a review. Journal of Advanced Nursing 45 (1): 36-46.
- Warner, H. (Ed) (2006) Meeting the Needs of Children with Disabilities Families and professionals facing the challenge together. Abingdon, Oxon: Routledge.
- Waterworth, S. and Luker, K. (1990) Reluctant collaborators: Do parents want to be involved in decisions regarding care? Journal of Advanced Nursing 15: 971-976.
- Watson, D., Townsley, R. and Abbott, D. (2002) Exploring multi-agency working in services to disabled children with complex health care needs and their families. Journal of Clinical Nursing 11 (3): 367-375.
- Weintraub, P. and Wamboldt, M. (1995) Pediatric asthma and comorbid psychopathology: is it due to nature and nurture? Current Opinion in Psychiatry 8 (4): 222-226.
- Wengraf, T. (2001) Qualitative Research Interviewing. London: Sage.

- While, A.E. (1991) An evaluation of a paediatric home care scheme. Journal of Advanced Nursing 16: 1413-1421.
- While, A., Citrone, C. and Corish, J. (1996) A study of needs and provisions for families caring for children with life-limiting incurable diseases. London: Department of Nursing Studies, King's College, London.
- Whittemore, R., Chase, S. and Mandle, C. (2001) Validity in Qualitative Research. Qualitative Health Research 11 (4): 522-537.
- Whyte, D. (1994). Family Nursing: the Case of Cystic Fibrosis. Aldershot, Ashgate Publishing.
- Williams, E., Barrien, V. and Trubey, P. (1992). The family with AIDS: multiple challenges. Journal of Hospice and Palliative Care 14: 293-299.
- Willig, C. (2001) Introducing qualitative research in psychology. Adventures in theory and method. Buckingham: Open University Press.
- Wilson, S., Morse, J.M. and Penrod, J. (2001) Absolute involvement: the experience of mothes of ventilator-dependent children Health and Social Care in the Community 6 (4): 224-233.
- Wilson, P., Kendall, S. and Brooks, F. (2006) Nurses responses to expert patients: the rhetoric and reality of self- management in long-tem conditions: a grounded theory study. International Journal of Nursing Studies 43 (7): 803-818.
- Wolcott, H. (2001). Writing up qualitative research. London, Sage.
- Woodroffe, C., Glickman, M, Barker, M, Power, C, (1993) Children, Teenagers and Health The Key Data. Buckingham: Open University Press.
- Yantzi, N., Rosenberg, M. and McKeever, P. (2006) Getting out of the house: the challenges mothers face when their children have long-term care needs. Health and Social Care in the Community 15 (1): 45-55.
- Yeh, C. (2002) Gender differences in parental distress in children with cancer. Journal of Advanced Nursing 38: 598-606.
- Zipitis, C. and Paschalides, C. (2003). "Caring for a child with spina bifida: Understanding the Child and Carer." Journal of Child Health Care 7 (2): 101-112.

APPENDICES

APPENDIX 1 - LETTER TO PROFESSIONALS

The School of Nursing and Midwifery Studies,
Trinity College
24 D'Olier Street
Dublin 2.
3 June 2004.

Dear X,

Thank you for taking the time to meet me recently to discuss the issues and concerns I have about the research study I am undertaking. Your advice, particularly about the methodological issues was appreciated.

I also appreciated advice about the practical issues I have about my study and the advice you gave from your research experiences was appreciated.

I hope to be able to talk again soon as the process of data collection begins.

In the meantime, and once again, thank you. Your help has been much appreciated.

With best wishes,

Honor Nicholl

BSc, MEd, RSCN, RGN, RCNT, RNT.

APPENDIX 2 - SCHOOL ETHICS COMMITTEE APPROVAL

HEADED PAPER

Ms. Honor Nicholl
School of Nursing and Midwifery Studies
Trinity Centre for Health Sciences
James Street
Dublin 8.
14th October 2002.

Re: Application for Research Ethics Committee approval

Dear Honor,

Further to your recent application to the School of Nursing and Midwifery Studies Research Ethics Committee, I am writing to inform you that the committee considered your application at their meeting on the 03rd October 2002.

The committee were impressed with your study and have approved your application subject to the following changes:

1. Applicant needs to identify if this study is part of a PhD.
2. Clarification is required in relation to how the sample will be sourced.
3. Further information is required on the information leaflet to be used.
4. The response to Question 21a is inappropriate as there is a possibility that a mother under the age of 18 or somebody who is depressed will wish to take part in your study.
5. The letter to parents needs to be reviewed.
6. The committee would like to see clarification on the outside agencies to be involved. Children's hospices are not in operation in the republic. How would ethical approval be sought?
7. In relation to Question 24 (a) and (b) researcher needs to have support service in place prior to interview.
8. Please clarify your comment regarding your employment as a children's hospice at home nurse (Page 2 of Project Outline Document).

It is the applicant's responsibility to make the required changes and consequently there is no need to forward any further documentation to the committee. In addition, the committee have approved your application subject to the above changes on a research ethical basis and have not commented on methodology unless aspects of methodology contain ethical issues.

On behalf of the committee, I wish you the best of luck in what is a very interesting and valuable study.

Yours sincerely,

Signed personally

[NAME]

Chairperson Research Ethics Committee

APPENDIX 3 – RECRUITMENT: INITIAL LETTER TO POTENTIAL PARTICIPANTS

Dear

I am a children's nurse and researcher who has recently been in contact with (Organisation) because of some research I am presently undertaking. I am currently undertaking a PhD in the School of Nursing and Midwifery Studies in Trinity College where I work as a lecturer.

As a children's nurse I have always had an interest in mother's experiences in caring for their sick child. The study that I am doing is developing this interest and I am currently really interested in mothers' experiences in caring for their children at home and especially in mothers whose children have complex needs.

It is because of this interest that you have received this letter from me via (Organisation#) as your child may have complex needs.

In the research study I am hoping to interview mothers of these children to better understand from a nursing perspective what this experience is like. Little is known about what providing this care is like for mothers especially in an Irish context.

With this letter of introduction I am enclosing some information about the study for you to read and I hope you will then consider taking part in this important nursing study.

If you do wish to be involved in the study then please complete the enclosed form and I will contact you again with further information about the study.

If you do not wish to then thank you for taking the time to read this letter.

Thank you once again for taking the time to read this and for considering this request. I look forward to hearing from you.

With best wishes

Honor Nicholl

APPENDIX 4 - RECRUITMENT – INFORMATION PROVIDED FOR POTENTIAL PARTICIPANTS

Who am I?

I am Honor Nicholl, a lecturer in nursing in The School of Nursing and Midwifery Studies, Trinity College. I am also a practising Children's nurse and work with sick children in their homes. I am completing a doctoral degree and to do so I am required to undertake a study in nursing.

Why this letter?

I am inviting mothers of children who are using X or Y services to contribute to a nursing research study that I am currently undertaking as part of a PhD study in The School of Nursing and Midwifery Studies. Professor C. Begley from the School is supervising the study.

What is the study about?

Little is known about mother's experiences in Ireland of caring for their child at home and the aim of this study is to explore the experience of mothers. I am interested in finding out about these experiences.

Some questions you may have about the study.

What do I have to do to be included in the study?

Firstly, you will have to give me some information about your child to let me know if you can proceed in the study. This is important as I am interested in talking with mothers of children with complex care needs.

What do I have to do in the study?

The study involves interviewing mothers for approximately one hour and tape recording the sessions. I will also be gathering information by using diaries and you will be asked to write about your experiences on three occasions. This should take no more than 30 minutes of your time and if you want you can talk into a Dictaphone instead of writing to do this.

What else will it involve?

As well as being interviewed and writing down your experiences you may be asked to help check my interpretation of your experiences. This will involve reading a document and confirming that what I have written is what you meant for me to understand of your experience. There is a possibility as I interview other mothers that I may need to come back and talk with you again. Reading the document should take no more than two hours or so of your time and this will be after the interviews are completed.

What are the benefits of the study?

There will be no specific benefits for you or your child directly in helping with this study. However, it is hoped that information from the study will help nurses and other professionals to an improved understanding of the needs of mothers. This information may also help others to deliver services that are more focussed on the needs of mothers.

Do I have to participate?

If you agree to contribute to the study, obviously I would like you to contribute fully in the interviews and diary keeping. However, if for any reason you wish to withdraw at any stage you can do so by telling me personally, by phone or by letter. I will not question your decision, nor try to persuade you to reconsider. If you do withdraw all information about you will be removed from the study and the tape recordings returned to you.

Is the information confidential?

All steps will be taken to ensure that the information that you tell me is held in confidence before, during and after the study.

Are there any other issues about the study that I need to consider?

Time will need to be given to the interviews, the diaries and reading the document. I would hope that this would not take more than a few hours of your time.

No fees will be paid to you for helping with the study.

The interview would be carried out in your own home, or another suitable venue at your convenience.

Thank you for taking the time to read this and considering this request for help with this study. I fully understand if you do not want to be involved but I do hope you will consider helping me understand you experience and help with this study.

Honor Nicholl RSCN, RNT.

Lecturer

APPENDIX 5 - RECRUITMENT – INITIAL AGREEMENT TO PARTICIPATE

Please let me know about contributing to the study by completing the slip below and returning it to me using in the envelope enclosed.

NO I am not interested in any involvement in the study.

Signed _____

Dated _____

YES I am interested in involvement in this study and would like to have more information about it.

Name _____

Address _____

Tel Number _____

Best time to phone _____

Email _____

OR

You can phone me at (R. Ireland) 01 608XXX or (N. Ireland) 048XXX and leave a message

OR email XXX

I will contact you to discuss further details of the study when I receive replies.

APPENDIX 6 - FOLLOW UP RECRUITMENT LETTER

Dear

Thank you for sending me a reply to my recent letter about the research project that I am currently undertaking in Trinity College.

I really do appreciate the fact that you are interested in helping me with this nursing study. As outlined in our recent telephone call the next stage is for you to read the enclosed information about the study and the consent form.

If, after reading the information you wish to sign the consent form then please feel free to do and return it to me in the enclosed envelope. However you may prefer to discuss some issues before you agree to consent and I will be happy to answer your queries when we first meet.

The next step after this is to arrange the first interview whenever and wherever is convenient for you. At this meeting I will outline the “diaries” and the other aspects of the study and again, answer your questions.

I am sorry if this all appears complicated, but at this stage I would like you to be clear about as much of the study as possible.

Thank you once again for taking the time to read this and for considering this request.

I look forward to hearing from you.

In appreciation and with best wishes,

Honor Nicholl

APPENDIX 7 - INFORMATION AND CONSENT

The aim of this leaflet is to answer some of the questions you may have about the study before you consent to be involved in it.

I have written the answers to questions that I have been commonly asked about consent at this stage. I would be very willing to answer any other questions that you have now, later or at any time during the study.

What is this study about?

The aim of the study is to explore mothers' experiences in caring for their child with complex needs at home.

What do I have to do to be included in the study?

To be included in the study the next stage is for you to consider giving written consent.

What does consent mean?

By giving your consent to become involved in the study you are consenting to:-

- being interviewed on three occasions to explore your experiences of caring for your child
- writing into a diary three different experiences of caring for your child.

Some other important issues to consider in giving consent.

Choices

- You can withdraw from the study at any time without needing to give me any reason.
- You can withhold any information you prefer not to discuss and can refuse to talk about any subject as you wish by telling me so.

Confidentiality of information

I have attempted to ensure that your rights of privacy and confidentiality are protected during and after the study by taking the following steps:-

- I have no access to your child's medical records.
- The secretary who typing the transcripts will sign a confidentiality agreement.
- My study supervisor will sign a confidentiality agreement.
- In the data analysis and reporting every step will be taken during to protect the privacy of participants and all data that may identify participants will be removed.

- In the unlikely event that something emerges during our meetings that I may need to divulge to others because of my role as a nurse, I will only do this to the extent required by my profession or law. Should this happen I will discuss this with you at the time.

Benefits

In this type of study the benefits from participating in the research are hard to clearly identify for you but:-

- generally people benefit from talking freely about their child in a confidential way.
- you and your family, will have participated in a study that will assist other families in similar situations, by contributing to the development of nursing knowledge.

However to be involved:-

- You will need to free up some time to be interviewed and to write the diaries, which may be a little inconvenient for you.
- There is also some possibility that you may feel uncomfortable or get upset while talking about your experience. Should this happen supports are in place.

I hope this information answers any questions you have about consent, but if not I will be able to answer any further queries when we meet or if you want to call me.

If you wish you could now return the signed consent form to me in the enclosed envelope, or if you would rather discuss the consent then I will do this when we first meet.

My contact phone number is 01-608XXX. This is a voice mail number. Please leave a message and contact number and I will return your call.

Thank you

Honor Nicholl

APPENDIX 8 - CONSENT FORM FOR RESEARCH PARTICIPATION

Title of the study –Mothers’ experiences of caring for their child with complex needs at home.

Principal Researcher:

Honor Nicholl RN, RSCN, RNT, BSc., MEd.

Lecturer,

School of Nursing and Midwifery Studies, Trinity College, Dublin

Tel 01XXXX : Email XXX@tcd.ie

This research is undertaken under the supervision of:-

Prof. C. Begley RGN, RM, RNT, FFNRSCI, MSc, PhD.

Director of the School of Nursing and Midwifery Studies, Trinity College, Dublin.

Tel 01-608XXXX.

Declaration of consent

- This study and this consent form have been explained to me.
- I have read, or have had read to me this consent form and its associated information leaflets.
- I have had the opportunity to ask questions and all my questions have been answered to my satisfaction by the researcher.
- I believe I understand what will happen to me if I agree to take part in this study.
- I hereby freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.
- I have received a copy of this agreement.

Participant’s name (Block Capitals): _____

Participant’s signature: _____ Date: _____

Statement of investigator’s responsibility

- I have fully and to the best of my ability explained the nature, purpose, procedures, benefits and risks of this research study to the participant.

- I have offered to answer any questions and fully answered such questions.
- I believe that the participant understands my explanations and has freely given informed consent.

Principal researcher's signature _____

Date: _____

APPENDIX 9 - INFORMATION ON DIARIES

Dear [participant by name],

As you are aware one of the methods of collecting information about your experiences of caring in this study is getting you to record your experiences on three separate occasions.

The aim of the diary recording is for you to report on your experiences on three separate occasions and your thoughts and feelings about these experiences.

The purpose of this leaflet is to give you guidance about how to do this.

General advice

- The diary should take no more than 30 minutes to write.
- There is no right or wrong amount to write.
- Within the record you can write whatever you feel is relevant but it would be helpful if you would report on thoughts, feelings and actions that made it as it was -good, bad or normal.
- You can include any thoughts, or visual record, for example pictures, photos, that you want.
- You can record the diaries in any order.

Confidentiality

- I will be the only person who will know whose diary it is.
- The information obtained from the diaries will be transcribed and from it I will identify the issues, and events that shaped your day. As discussed the information from the diary will be kept confidential.
- When reporting on the diaries no names or specific circumstances will be mentioned.
- The final report and publications arising from it may contain direct quotations from the diaries submitted but you will be consulted about what is to be quoted.

Diary 1

In diary 1 you are asked to record your experiences of caring on a good day. This could be any day that you felt that things went well and the day would be what you might refer to friends as “normal for you”.

This could include why it was good, who made it good, what made it good and when did it become good?

Diary 2

In diary 2 record your experience in caring on a bad day.

This could include why it was bad, who made it bad, what made it bad and when did it become bad?

Diary 3

In diary 3 record your experience in caring on a normal day. This could include why it was normal, who made it normal, what made it normal and when did it become normal?

I have provided you with three diaries (marked 1, 2, &3), envelopes and guidelines. Please return each diary to me when it is completed.

If you have any questions about this please ask.

Thank you for your continued cooperation with the study.

Honor Nicholl

APPENDIX 10 - DIARY FORMAT

All three diaries [good day, bad day and normal day] followed the same format

DIARY 1- Exploration of a Good day

Name _____

Date completed _____

CONFIDENTIAL

Have you used real names in this diary? Please tick

Yes

No

For researcher use only: Code: Diary code: _____

Important notes

- All material from this diary will remain confidential.
- You can use real names within the diary, as these will be changed or if you prefer you can use false names or initials in the diary.
- In the analysis of information I will make sure that all references to named people in the diary are removed.
- If you want to include any extra materials in the diary please add them at the back.

I think this is a great idea as sometimes these can help “describe” feelings-feel free to add these if you want.

- If you are including photographs or anything that you want returned please label them clearly. I will copy them and return them to you as soon as possible.
- When you have completed the diary please forward it to me in the envelope provided.

The diary should be completed by _____ If you have completed it before than please just send it in.

I will contact you _____weeks from now to see how you are getting on with filling in the diaries.

If you have any queries about writing the diaries please ask. Thank you for your continued help with this study. Your contribution is very much appreciated.

Three blank pages were supplied in each diary.

Final Advice: If you have any queries about the diaries, the study, your contributions to it or anything else about the study please feel free to contact me. I hope you find contributing to this study interesting and thank you for it.

APPENDIX 11 - AN EXAMPLE OF EXPLICATION OF THE FINDINGS

The eight dimensions are explicated from diary excerpts
Dimensions that I have identified are indicated in italics.
[Punctuation is as presented.]

Diary One [Emer] A Good Day Recorded 26/09/05

...Child* in recent weeks has been diagnosed as having (disease) and due to blood results and a bad rash on her face trunk, legs and arms, we are being told that there is nothing they (doctors) can do *Unknowingness*

“The start of the breakdown of the body.” Being told she hasn’t long to live and may be in severe pain with itching has opened a whole new view of the past years, almost five years since her stroke. *Constant instability*

She is now on palliative care on morphine, I watch, wait and wonder what’s next.

Knowingness

How much can this little girl take why, why, why I ask over and over again.

So you see each day is good especially those where she manages still to smile.

More work is involved now, still no extra help offered. I have to keep wet wraps on her four limbs to try and counteract the itch. *Technical care-giving/individualised care*

But now I know soon I’ll have so much time, time I’ll be wishing I had child* to hold and care for. This essay has been short. Child*’s life will be short. *Constant instability*

Diary 2 - “A Bad day”

As the alarm rings once again the day begins again. *Inside world*

Immediately I think ‘oh no she is going to respite tonight poor little pet’.

Going-between world/outside world/ ‘no choice’ situation

I get up to take over from the nurse to hear she is up since 2pm and by now she is quite upset and tired and her colour is quite dusky *Constant instability/Knowingness*

I get the others off to school, while feeding Child* in her buggy she retches a few times demanding my full attention. *Constant observation*

Unfortunately this morning I can’t try and get Child* back to sleep as the Occupational Therapist and Disability Liaison Nurse are visiting regarding some of her equipment

Paperwork and administration

I quickly clean around the sitting room and light the fire while singing to child* to keep her amused in her tumbleform chair *Constant observation*

Child* exhausted by now, I nurse in my arms as dictated by herself I get her to doze in and out of little cat naps in my arms. I look at her she is so peaceful in her own little nest cuddled into me and feel guilty about what lies ahead for her in the coming few days. Does she feel abandoned, scared, alone, no one knows *Outside world*

The O.T. and liaison nurse arrive and do their assessment of her bath seat and buggy. Child* now awake struggles even to smile as she is in and out of her seats not amused at all. The dietician from respite home* rings and I have to explain I have visitors and ask if she could ring back later *Constant communication*

Everything seems to happen at once usually I could sit for weeks without hearing from anyone *Inside world*

Feeds continue throughout the morning *Technical care-giving*
and before long the other (children) arrive home from school at 2 o'clock, early as it is mid-term break. *Normal mothering*

Within minutes Child's* home tutor arrives, she gets 7 hours weekly during school terms funded by the Department of Education. Now Child* sits with her tutor listening to music while I feed (the other children*), and now face the fact that I better pack unable to delay the process any longer *Going-between world*

I have a feeling in my stomach like I'm about to sit a driving test or a major exam or interview, nerves, guilt, the whole cocktail bring a tear to my eyes but I must disguise my feeling and continue. Enough clothes, pyjamas, creams, nappies, wipes, etc etc packed I now have to check all the medicine label for the night dose, date name all in order only feeds to do now I'm finished *Pre-emptive care-giving*

I should have time to relax, Child* content with the tutor?? feeds done. Siblings* start they don't want to go to Dublin "it's too long" "it makes me feel sick", I hear them all.

Going-between world

Eventually sibling* gives in with the bribe of stopping at the shop; other sibling* opts to go to Granny's

The tutor leaves and I resume full care of Child* holding her until husband* arrives home at 5.10. He eats his dinner, quickly changes and packs the car and we're ready for the off.

Child* sleeps most of the journey which is most unusual *Going-between world*

Arriving at our destination we are aware in a couple of minutes we leave our daughter in the care of a wonderful capable team of professionals but we also know we won't be truly at ease until we collect her again *Outside world/ knowingness/ unknowingness*

I kiss Child* goodbye, leave the building and shed a tear or two. It is the hardest thing I expect anyone could be asked to do because in a way I feel it's my choice to do so except if I don't I could lose more than I lost the day Child* took her (illness). *'No choice'*

Diary three – A "normal day"

...A quick report of the previous night, how she tolerated feeds, how long she has been awake... *Paperwork and administration*

This morning she has been awake since 2.30 having had only 5 hours sleep. The nurse heads home, husband* off to work.

I take Child* to the kitchen to get the children's breakfast, pack their lunch which husband* prepared. Off to school they go about 8.45 to get the bus. 8 o'clock feed now finished.

Child* and I go down to my bed for me to try to get her back to sleep. *Normal mothering*
Sometimes in vain but success after about 45 minutes of retching. I get up to the phone ringing and luckily Child* never stirred *Constant communication*

Almost 10 o'clock time for another 55 mls feed. I bring her pump down to the room, where I feed her while she remains asleep *Technical care-giving*

She looks so small in the big bed but quite cozy. Our home help arrives and does her jobs, usually light house work.

I now get a chance to catch up on a basket of ironing while listening attentively to any noise from my room. *Inside world/Constant observation/Constant instability*

Ironing all done, Child* wakes, I go down to the room to be welcomed once again by a smile. I carry her up to the sitting room, to realize she has a dirty nappy, I change and dress her no problem until I try and do her hair this she objects to big time I manage to get two half decent plaits in and cuddle and sing to her to settle her telling her I'm all finished and how beautiful she looks. *Individualised care/Normal mothering*

The nappy is now dirty again another quick change. The feeds the nappies continue throughout the morning, feeds 2 hourly the nappies it's just one of those days that happen every now and again, as she was straining for some days previous I was glad to feel she was being relieved *Inside world/Knowingness*

I watched some telly with Child* on my knee quite content. She would smile up at me every now and then. *Normal mothering*

She has the most beautiful smile; a smile I once thought I would never see again, a smile that took some years to return after her (illness). It's hard to contemplate what should have been now what is. This is very much in my mind today as it was four years yesterday since

she took her (illness). “The big one”, the one that took my child’s sight, ability to stand, feed or sit. I feel selfish when I say I miss her saying ma-ma, reaching out for me to lift her up after all its her that lost all.

Normal mothering

I still have my child just in a different state, unable to have a (organ) transplant, with cerebral palsy and epilepsy, two hourly feeds, numerous chest infections the list goes on and on.

Individualised care-giving/technical care-giving

Anyway a tear comes to my eyes but Child* gives a big smile, this came back and it helps me to cope. A smile from Child* with her eyes as well as her mouth and big dimples would melt even the hardest of hearts.

‘Wish you were here was on telly’ and was offering a “soothing and relaxing” break, just what I need I thought to myself but instead I got another dirty nappy and realize it’s time to get dinner ready for the kids after school.

Normal mothering

I lift Child*, now 20 kg to the kitchen put Child* in her buggy and start the dinner. At this stage I’m feeling sick with the hunger only getting breakfast early this morning. I manage a quick bowl of soup while pushing and entertaining Child* in her buggy

Constant observation

3 o clock medication now filled and given via the peg.

Technical care-giving

Siblings* now arrive home, telling me all about their school day. Feed them both, get them to change. Child* in good form sitting in her buggy with baby (special toy) whom she loves, he plays music which she seems to recognise. Often during the day he’s my baby sitter leaving him playing music while I spend a penny. I don’t like leaving her on her own

Constant observation

and she doesn’t like being on her own

Knowingness

Dinner gone we now try our best to get the homework done before the 4 o clock feed, otherwise it could go on all evening. I know the time I allocate the others is hugely compromised but I’m only human and do my best under the circumstances.

‘No choice’ situation

A successful evening homework done by 4 o clock, feeds start again in the sitting room. The other two entertain themselves. After the feed I begin to watch for husband* coming home. The others come in and talk to Child* and I play little games such as round and round the garden which she quite enjoys

Normal mothering

Husband* arrives home, we have a chat he gives Child*, a big kiss and he gets a big smile and she stretches trying to get into his arms. He has his dinner which he warms in the microwave.

Husband* now takes over child’s* care while I go to Weight Watchers.

Turn-taking

I was snacking on bars, crisps, the usual rubbish, finding it difficult to prepare a healthy lunch but things had to change.

Around 7.30 I return home full of joys, another 2.5lbs off. Husband* told me how Child* has been and that she has had her 7 o'clock medications but not the sleeping ones Triclofos and Melatonin. We now give these as she seems tired. *Knowingness*

This is the time of the day I dread most. Watching the soaps I try rocking Child* to sleep. Husband* turns on the oil which has to be left on all night for Child* and the nurse. No sign of her sleeping. Just retching after awhile she begins a severe cry, quite difficult to get her settled *Knowingness*

You would feel quite sorry for her at this stage asking "What is it all about?" why an innocent child? Husband* heads off to swimming lessons, another of our new year's resolutions. I ask the others to try to be quiet and get ready for bed. We almost have to lip read the telly now while we try for as little distraction as possible to get her asleep.

The others kiss me now I can't get down to tuck them in. Eventually at 9.40 I get Child* asleep in my arms. I transfer her into her bed in a room off the sitting room

Constant observation

Tip toeing out hoping for both our sakes she won't wake again *Pre-emptive care*

She doesn't, thank God, and I get 10 minutes to myself before the nurse comes at ten o'clock.

Arriving at ten o'clock I fill her in on Child's* day and let her know that she has just started a feed *Unknowingness in others*

Husband* arrives home and we head to bed leaving the nurse filling her 11 o'clock medication. Today I give her about 100 kisses and she gave me as many smiles in return

Normal mothering.

What is it all about? Well it's about having a child with a difference, trying to live a normal life with an abnormal child whom we all love very much.

Karen Diary Three- "A Normal Day"

Today we had a routine visit to ENT

Outside world.

After having waited for ages and being asked dozens of times- 'when am I going in?' Child* finally got to sit in the shiny silver spinning chair she loves so much. All this having been preceded by a constant yammering on and on that Child* thought she was going to be "going up soon", and that he was definitely going to call her soon!! God that is. And all the time me trying to re-assure her that he probably won't call her until she's an old lady. Anyway the doctor/consultant looked into her ears and immediately asked me

was I taking a holiday at all. Nothing planned I said as we don't really do planned in our house- fear of disappointment I suppose *Constant instability*

He told me she would definitely need to come into hospital and have the little grommets put in; there was poor hearing today and there is a big amount of fluid – he made me look inside the ear-first time for everything I suppose! I might as well have been looking at the surface of the moon I thought. Child* remains oblivious to all as he whipped out the consent form and asked me to sign it there and then. And could he please have my telephone and mobile no to contact! *Constant communication*

....Anyway when the doctor told me he was very unhappy with Child's* hearing today it was not at all up to scratch, he asked me what I thought and I said I felt it was good at the moment. He dismissed this and told me that "you only think it's good because that's what its usually like"! *Unknowingness*

So, we left shocked (me) and chatted to someone we knew at the clinic, she realised I was shocked- and on we went. On the way back to the car, child* having stopped to talk to almost every member of staff in the entire hospital, as they all know her so well. I said to her "there is something I need to talk to you about" and she very calmly said its ok "I think I know what it is!! I'm deaf!!" "No" I said, "you're not". *Individualised care-giving*

But I explained to her about the hospital and we decided to name it a procedure instead of an operation to take the drama out of it *Knowingness*

APPENDIX 12 - CONFIDENTIALITY OF DATA

22 November 2004.

Dear Transcriber [**Name**]

Thanks for taking the time to talk with me about my proposed research study and about transcribing the data for me. The study, as outlined, will involve interview data collection from a group of mothers with potentially three interviews per respondent. The topic is on the mothers' experiences of caring for their "life-limited child" which may evoke sensitive information, as you understand.

I really appreciate your help with transcription and am reassured by your comments, and assurances, about confidentiality during the transcription of data, and data handling, that you will be involved in. As discussed it appears that you have experience of this type of work already and are well aware of the issues that surround this type of research.

I have enclosed for your attention an information sheet and two consent forms. These should be signed by yourself and if necessary by the second person who may assist you. If you have any comments or questions about these please ask.

Once these are returned I will be in touch when data collection starts when I can discuss the practicalities of getting the information to you and its return to me.

In the meantime I look forward to receiving the signed consent form/s and look forward to meeting with you.

I hope to be able to talk again soon as the process of data collection begins.

In the meantime thanks once again in anticipation of your help.

With best wishes,

Honor Nicholl

BSc, MEd, RSCN, RGN, RCNT, RNT.

APPENDIX 13 - CONFIDENTIALITY AGREEMENT

Principal Researcher

Honor Nicholl RN, RSCN, RNT, BSc., MEd.

Lecturer,

School of Nursing and Midwifery Studies,

Trinity College, Dublin

Tel 016XXXX: **Email XXXX@tcd.ie**

Declaration of consent - TRANSCRIBER/RESEARCH SUPERVISOR

- I understand the importance of maintaining confidentiality during all the stages of data transcription that I will be involved in.
- I will maintain all of the data related to this study before, during, and after the study in a confidential manner at all times in accordance with good practice.
- The anonymity of the mothers, children, sites and any other identifying data in study will be maintained during all stages of the processes of data transcription.
- I will return all data related to this study to the researcher at the end of the study.
- I have received a copy of this agreement.

Name (Block Capitals)_____

Signature_____

Date_____

Principal researcher's signature_____Date_____

APPENDIX 14 - RESEARCH DIARY EXEMPLARS

This appendix contains five journal extracts from notes and diary recordings.

1 Pre interview notes Interview 2 with Gretta 11th July 2006

I haven't been in touch with Mother * since October last year except for letters. I wrote to her in May saying I would be in touch with her in a number of weeks to try and capture data for Interview 2 and Interview 3. I have contacted her by phone twice since then and have been unable to meet her but eventually on the 6th July I was able to talk to mum and she discussed the study with me and was quite keen and agreeable to go ahead with the interview tomorrow on the 11th. However she did note that she doesn't want to be interviewed using a tape recorder, but is quite happy to go ahead with the interview. This is not a new phenomena,...

She indicates suitable times for interviews when Child* is at school in the morning and he is home about two and Sibling* is in nursery four days a week. She is currently making decisions about school and what is best for Child*. She has two schools in mind and has to make a choice. One is further away but is a better and nicer school, except for travel and pick-up, but he'll be picked up and dropped off. But the psychologist is making the decision. Mum will be free between 10 and 11.30 tomorrow.... She reported that she knows that I know, that she doesn't like interviews and all those things and she doesn't like doing diaries. This raises ethical questions for me.

I need to remember aspects from last interview to use in introduction; I need to confirm findings with this mother- going-between world, unknowingness and knowingness.

Issues emerging in doing research include:-

Ethical issues in interviewing already busy mothers

I wonder how mothers have time to be included in this study.

Paperwork and administration is an issue. Research adds to this.

Constant observation, instability, mothering, technical role in care-giving are all emerging and are confirmed in this interview

2 Post interview notes Interview 2 Gretta 11th July 2006

Gretta, like other mothers, talked about the "bed hopping" experience and not getting a night's sleep. She talked about the importance of respite and without respite she would not be able to manage. She talked about the experience she has when child* is away.

Concerns about separation emerge and a 'no choice' situation is apparent. What issues are there in the data re out of home care- care by others? Need to look for these- set up a query in NVivo?

Gretta talked about the respite home# and how she leaves Child* in there# rather than with her family and the importance of the respite home# for providing respite for both family celebrations and for mum and dad to get a nights sleep, and also for quality time with their other child. – Is this a 'no choice' situation? She has been asked about her neighbours and do neighbours understand and she said she has friends living in the vicinity but they have their own children and she seems to think that their 'busyness' with their own family detracts from their support from her. She indicates that she's got nobody to help. A 'no choice' situation? Others unknowingness is evident- a negative reinforcement mechanism is present. Family support is absent, similar to other mothers.

She indicates that when she gets help there's a 'payback' on getting help and she reports in interview one that, for the first time recently, she was able to reciprocate the help that she got from her friend. Payback is emerging similar to others. Gretta talks about the time pressure in relation to caring for Child*, in terms of having to do things for him* at specific times and she seems very focused on the regime of care that Child* requires. Individualised nature of caring is evident. In relation to going out, she reports that her mother calls her the 'bag lady'. This is interesting because there is another mother who talks about the amount of equipment she has to take. Gretta similarly refers to this and the amount of equipment that is required and there's nothing planned. Going-between world and planning are needed

She talks at length about her lack of sleep and how she loved her sleep before 'child' was born and how she doesn't have sleep now. She talks about splitting the care and turn-taking is a response. Mum was quite tearful during the interview, in interview one and before this interview in her discussion on the telephone has reported to me always that she is never able to talk about Child* without crying. In relation to care by others it seems that Mum is very concerned that people know Child's* routine and she will only trust people who know of this. The dilemma is to leave him with others or to stay with him herself.

3 Notes on emerging findings July 2006

Instability is an issue for mothers in the home. Care-giving at home involves more than I thought initially. Travel in a going-between world is involved. Care-giving includes the outside world. I wonder how mothers know how to do what they do. How do they manage without help? What about father's roles and siblings? Should I report these issues in the

study? What is an essence and what is essential? What is the difference? Is this a theory or phenomenology - there is a tension between these approaches.

4 Post-interview notes for Interview 2 with Gretta

.....The third thing was mum's tearfulness. She seemed and has always said that she's quite tearful when she talks about Child* and can't talk about him. On the way out she showed me Child's* room and she was quite proud of what she'd done in moving and renovating it. Constant observation impacts on the structure of the home. She talked about going to outpatients and going to hospital appointments etc and she said 'there's not a week goes by but she doesn't have something'. Travel is an issue. Issues in the data are being confirmed- the lack of forward planning, administrative role, individualised needs.

5 Notes from data analysis January 2007

From the interviews it seems that there are negative reinforcement mechanisms in play at times, between the mothers, friends and families. There is a tension between mothers knowingness and others unknowingness which causes mothers concerns. There is a tension in phenomenology – am I looking for commonality or essences? I need to keep looking at the data to see what else is emerging- I have concerns about the volume of data and when to stop data collection. Check it out- I have a sense that the same findings are emerging. There is a tension between stopping and continuing with data collection. I am sure that I have got the main issues. Talk with others - to see if these are recognised in their experiences.

APPENDIX 15 – REFLECTIONS –THE ‘I’

In this study it is recognised throughout that I, ‘the self’, my fore-structures, pre-existing beliefs and preunderstandings and my subjectivity have pervaded all aspects of it. In order to contextualise the ‘self’, and to recognise my involvement throughout, I have included further aspects of this in this Appendix. This ensures my involvement in the co-creation of data is documented. I have selected two aspects to include; my personal and professional self which have influenced me throughout.

At the outset

The personal self

I am Honor, a person, a daughter to two parents, a carer, a significant other, an aunt and a God mother who loves life. I enjoy life and living, food, good company and good craic. I am unmarried and have no children of my own.

The professional self

I am a Children’s nurse and work in nurse education. I practise as a children’s nurse in a community children’s service working with ‘life-limited’ children at home.

2004-2006

The personal self

I am constantly catching glimpses of the emerging findings in all I do. I read the paper and frequently see articles about children with complex needs; on television there are similar documentaries. Life that is invaded by complex needs; my sleep is disturbed by emerging themes and questions about the data. I am constantly thinking about the emerging issues. One Friday night I go for a pizza with a friend, we sit down and hear a child cry beside us. My friend asks to move. The child has complex needs. Is this verification of the data and an example of what mothers face everyday? Reactions to and from others, and going out, are emerging in the data. I tell my colleagues “I am grand” when they ask about the study ...is this what mothers do—a defensive, protective response?

The professional self

I now understand the mother’s experiences better. I am concerned that I have not supported mothers as much as I could have. My practice has changed as I better understand the totality of mothers’ experiences. Key themes in the study are pervading my life—they are so obvious when I see families of children with complex needs-why did I not see this before? I now understand mothers’ experiences better than I ever have. I now view constant

observation, instability and the going-between world as part of the mothers' experiences. The mobile phone is a constant.

At the end of the study - new understandings emerge

The professional self

My understanding of mothers' experiences has changed as new insights have developed. I know mothers' experiences are more than caring in home. I see the dimensions inside the home. I know of the difficulties of travel. I see the obstacles, human and practical, in the outside world. My horizons differ. The findings are confirmed by observation, participation and discussion with others.

In practice I clearly observed mothers' experiences of children with no specific diagnoses whose needs required maximum at home respite care. I saw, heard and read about the impact on the family, and family members, and the tensions created by caring for a child with complex needs. I saw care being delivered by numerous carers in homes that looked like intensive care units and was aware of the consequences of this, and the medicalisation it caused. Mother's lives revolved around technical care-giving including feeding, suction and medication management. Mothers described care-giving as a constant uphill struggle. I recognised the paperwork and administration that mothers had to complete and became conscious of the volumes of paper that surround children's care at home. Care plans, policy folders, procedure manuals and equipment instruction booklets were all stacked up on shelves. I watched a mother listening for that moment when her child would need suctioning and saw constant observation and mothers' knowingness. I became conscious of how many times mothers had to recount their story to those who helped in care delivery. The individualised care required is not fully identified or evidenced in care plans, for example, the way the child turns or responds or their response to suction or to story telling. Mothers know this, others do not. Mothers' technical care-giving became obvious as I saw mothers give care when others could not do so, for example medication management – they demonstrated more knowingness and highly technical care-giving. I noticed how much administration went into getting equipment and resupply-order forms were part of the paperwork and it seemed to be mothers' responsibilities to coordinate restocking of equipment. Lists of supplies were everywhere.

Pre-emptive caring appeared as mothers watched for their child's every move and knew when help was needed and when and what steps she could take. "This is the way it is done" or "how I do it" is part of their experience.

The lack of privacy and the intrusion of having multiple carers, in a family home became obvious. However, I now see the impact of this on family relationships, the extended family and siblings, as well as the marital relationship. I see the house extensions and large cars and wonder how outsiders view these. Do they consider that the mothers are being well supported? Do they understand the mother's response when she says "Things are grand"? I think not. Do others in the family, as they look on at the delivery of complex treatments to the children find this so upsetting that they 'back away' and reduce their social support because of this? Yes.

I see turn-taking as mothers try to get a break and fathers attempt to help. I wonder what happens in single parent families, or when mothers feel ill and want a break. Care-giving is not a choice activity. I see trust being investigated in relationships and mothers checking out carers' credibility and skill level. I see watchfulness as new carers enter the family home for the first time. I see mothers of children struggle with having children who have no diagnosis, or who do not fit neatly into a medical model of diagnosis and treatment. Language is important and influences thinking, planning and service provision for children. I have seen the fragile, unstable nature of the world, the family responses, the constant caring, constant observation, constant communication, mothers doing it their own way and the impact on the mother in her "inside world" now with a different way of looking. I have a greater understanding of the going-between world and how difficult journeys can be when are travelling with a child with complex needs. I see obstructions in disabled parking spaces and know the implication of this. I am aware of the views and reactions of others to mothers of children with complex needs in the outside world. I see avoidance and staring. I see children point.

The personal self

My view of mothers' experiences is different as my understandings have been developed over time.