

**An Exploration of the Respite Needs and Experiences of Parents
Caring for a Child with a Life-limiting Condition Requiring
Palliative Care.**

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of Doctor of Philosophy at the University of Dublin Trinity
College.**

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Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university and it is entirely my own work.

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Julie Ling

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Thesis Summary

Title: An exploration of the respite needs and experiences of parents caring for a child with a life-limiting condition requiring palliative care.

Background: Respite is a key component of children's palliative care. The majority of children who require palliative care are born with non-malignant life-limiting conditions and have an uncertain prognosis. Their condition is frequently marked by a fluctuating disease trajectory often resulting in a number of near death experiences. Mothers are most often the primary carers with the majority of care provided in the family home by parents with varying degrees of support from health care professionals. Respite either in-home or out-of-home offers parents a break from the routine of caring.

Aim: Underpinned by the family system theory, the aim of this research was to explore the concept and meaning of 'respite care' for parents caring for a child with a life-limiting condition requiring palliative care in a real world context. The objectives of the research were to describe and define respite service delivery from the perspective of parents, identify the elements of the respite experiences that are important to parents and to identify barriers and facilitators to the delivery of respite care.

Methodology: Utilising case study methodology enabled an in-depth exploration of the respite needs and experiences of parents caring for a child with a life-limiting condition from multiple perspectives. The main methods of data collection were semi-structured in-depth interviews. Parents were the primary participants and were recruited from the caseload of a hospital-based palliative care team. Participant observation, documentary evidence and research notes were also used to compile the 'case'. Utilising the family systems theory, parents were asked to identify those who assisted in the provision of respite for their child. In order to build the 'case' these participants were also interviewed. Individual case reports were compiled by utilising all data collected. Cross-case comparison was then undertaken.

Findings: Respite care is of importance to parents of children with life-limiting conditions but only when it is provided in a format and location that parents find acceptable. Past experience of healthcare institutions (hospitals and residential care settings) resulted in parental scepticism and mistrust regarding their ability to provide suitable care for their child and therefore frequently parents' preference was to care for their child at home with support. Caring for a child with a life-limiting condition in-home has an impact on every aspect of family life, resulting in changes, particularly for siblings. It also has implications for the staff providing care. Whilst consistency of staffing and maintenance of routine are important to

parents this is hampered by limited access to suitably qualified and experienced staff in the community.

Findings indicate that there is no one-size-fits-all approach to providing respite care. Indeed in this research there were distinct differences between children with different life-limiting conditions, providing evidence that the use of and need for respite services is linked to the child's diagnosis. The child's age is also an important consideration in the provision of respite where there is a need to develop a diverse range of respite services reflecting the differing needs of each age group. The specific needs of adolescents were highlighted in this research.

This study gives a uniquely Irish perspective. Within the family system, culturally, mothers fulfilled the primary caring role and relied on their husbands for support within the immediate family. There is a perception in healthcare that family, friends and neighbours are a ready and available source of support and respite however, this is not supported in the findings of this research. Those who were trusted and provided support shared several key features: all had provided care from soon after birth or diagnosis, many felt confident in their ability to provide care and all were female.

Evident in this research are the challenges faced by parents to access accurate information enabling them to maintain control over their situation and make informed decisions about the care their child required, including the role, suitability and utilisation of respite care. Information given to parents regarding key issues such as diagnosis and prognosis impacted on access to services and respite provision and utilisation.

Conclusion: This original and uniquely Irish research highlights that the respite needs of parents of children with life-limiting conditions are not static, changing over time and are often dictated by parent's understanding of their child's condition. The impact of caring for a child with a life-limiting condition ripples across the whole family system with the most evident impact on the immediate family unit. Frequency, location and type of respite vary according to the child's age, diagnosis, geographical location and the family's capacity to meet their child's care needs. Despite being identified as an essential and integral part of children's palliative care, findings of this research do not support the need for respite for all children with life-limiting conditions as a universal contention. However, for some families respite, regardless of type, location and provision, is recognised as an essential component of the care of their child.

CHAPTER 1: INTRODUCTION

1.1 Background

¹The effect of a child's death is far reaching and cannot be underestimated having a profound impact on the entire family system. In palliative care the child and family are viewed as one unit of care. Palliative care for children is a small and highly specialised field of healthcare providing an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancing the quality of life for the child and providing support for the family, and includes the management of distressing symptoms, provision of respite and care through death and bereavement (ACT 2009). A life-limiting condition is defined as any illness where there is no reasonable hope of cure and from which the child or young adult will die (DOHC/IHF 2005). Ideally support for children with palliative care needs starts at diagnosis, and for many children with life-limiting conditions this can be at birth. Palliative care support can be given alongside active treatments aimed at cure or prolonging life and should be provided at the child and family's location of choice (ACT 2009). Most children with palliative care needs will have these needs met by their family at home supported by locally provided services.

There are on average 500 childhood deaths per year in Ireland and of these approximately 350 are from life-limiting conditions (DOHC/IHF 2005). Currently, access to services for children with life-limiting conditions is dependent on diagnosis and geographical location (DOHC 2010). It is increasingly recognised that home is the place of choice for parents to care for their child with a life-limiting condition. While this may be the ideal it is highly dependent upon the availability of comprehensive respite and support services. It is estimated that 1400 children are currently living with a life-limiting condition in Ireland, whilst not all of these children will require specialist palliative care; the majority will require respite care (DOHC/IHF 2005). Parents of children with life-limiting conditions are often the primary carers of their child yet many have to continue to work and care for other children too. Some life-limiting conditions are hereditary and therefore a number of families care for more than one child with a life-limiting condition or may have already had to cope with the death of a child.

¹ Throughout this thesis, for ease of reading, unless otherwise stated, the term "life-limiting" refers to children with a life-limiting, life-threatening or life-shortening condition. The term "child" refers to neonate, child, adolescent or young person.

Palliative Care for Children in Ireland – A National Policy (DOHC 2010) identifies a dearth of information regarding where respite care is currently provided and what level of respite is available. Indeed, the need for more information on respite provision is identified as one of the key priorities of the policy.

Parents value respite care and see it as essential to enable the family to continue to cope with the inherent stresses of caring, often long-term for a sick child (Eaton 2008). Respite care has been identified as an essential part of enabling parents to care for their child at home allowing them to attend to their own needs, spend time with other children or to get a good night's sleep (Maguire 2000). In Ireland, as in many other countries, access to respite care is reported to be inequitable and insufficient and is dependent on geographical location and diagnosis (DOHC/IHF 2005). For children with cancer, liaison nurses are available to coordinate care and organize services in the home including: community services; respite admissions; and access to adult palliative homecare services if required. For children with non-malignant conditions this is more complicated and relies on serendipity rather than design.

Respite and palliative care support for children with a non-cancer diagnosis is challenging, many of these children have disabilities and complex care needs. Many children with life-limiting conditions rely on voluntary providers of care. These organisations often have specific referral criteria relating to certain age groups or specific diagnoses. Most of the providers of respite care for children with life-limiting conditions do not have the facilities to care for a child requiring palliative care who has complex medical and nursing needs. Currently, demand outstrips supply for respite services for children with disabilities and most services have waiting lists for new children or for children who are receiving services but who require additional assistance (DOHC 2010).

Respite care for children with life-limiting conditions has been identified as an essential component of children's palliative care (ACT 2009), however there is ambiguity surrounding definitions such as 'life-limiting' and 'respite' resulting in difficulty in provision and planning of services to meet the needs of children and their families (Ling 2012). The aim of this thesis is to explore the respite needs of parents caring for a child with a life-limiting condition requiring palliative care. The components of respite services are poorly understood.

1.2 Aim

The aim of this research is to explore the concept and meaning of ‘respite care’ for parents caring for a child with a life-limiting condition requiring palliative care in a real world context.

1.3 Objectives

The objectives are to:

- describe respite service delivery from the perspective of parents
- identify the elements of the respite experiences that are important to parents
- identify barriers and facilitators to the delivery of respite care

Gaps in knowledge

It has been suggested that respite care for children with life-limiting conditions has limited visibility within children’s palliative care literature and that it continues to lack a significant voice in research (Corkin *et al.* 2006). This research aims to address these gaps in knowledge and explores the experiences and specific respite needs of parents caring for a child with a life-limiting condition requiring palliative care.

Despite the acknowledgment of the importance that respite care plays in the provision of services to children with life-limiting conditions and their families, there is currently a dearth of information regarding where respite care is provided, the nature of services available and the effectiveness of services in meeting the needs and expectations of the child and their family. It is evident that parents’ views and experiences of respite care differ considerably (Olsen & Maslin-Prothero 2001). Even the use of the term respite has been reported to be unacceptable to some parents with the term “short break” the preferred term (Brown 2007). Ambiguity surrounding the terms used in children’s palliative care is problematic. Some parents are understandably reluctant to acknowledge that their child has a life-limiting condition and the euphemistic term ‘complex needs’ is gaining popularity in the literature. There is a dearth of research published to demonstrate best practice in the area of respite care for children with life-limiting conditions requiring palliative care (Eaton 2008). One way to establish what respite truly means to and for parents is to extrapolate their understanding and experiences of respite care across the continuum of their child’s illness. This research utilising a case study approach enabled parents to describe, explore and explain their respite experiences in a real world context.

Background to the study

Internationally there is a dearth of accurate and contemporaneous data relating to the number of children living with, and dying from, life-limiting conditions. It is increasingly recognised that this lack of information coupled with a lack of research-based evidence presents challenges for planning and provision of palliative care services for children. This is not however, exclusively an Irish problem, in the United Kingdom work is currently underway exploring the use of minimum data sets for life-limited children and an accompanying mapping process is also underway. Work on this project has been slow because of the ambiguity and confusion that remains around definitions used in children's palliative care including the identification of conditions that are considered to be life-limiting. Research and developments from other countries are helpful in the planning and delivery of services in Ireland and standardized data collection makes comparison possible. However, factors that make Ireland unique such as the health delivery system must also be considered and direct comparisons may not always be possible. It is therefore important that high quality Irish data on the specific respite and palliative care needs of children with life-limiting conditions and their families are available.

Research design and methods

Respite, where available, is frequently provided by a variety of statutory and voluntary agencies in differing care environments and geographical locations. Services have developed in an 'ad hoc' fashion often influenced by local, organisational, political and historical issues. By utilising a case study methodology, this research was able to capture and take account of these factors. Children's palliative care is multifaceted and often complex involving a myriad of different people and services. Parents' respite experiences have a similarly complex configuration that is often contextually defined and geographically diverse. Case study encourages the collection of data concurrently thus participants can often refer to a similar timeframe or the same incident of care (Payne *et al.* 2007), which is of importance in case study research where data are collected in a real-life context. Thus case study methodology is an appropriate strategy for exploring the respite needs of parents caring for a child with a life-limiting condition requiring palliative care.

1.4 Format of thesis

This thesis consists of 8 chapters. Following this introduction, Chapter 2 provides insight into the theoretical underpinnings of the research. Chapter 3 aims to contextualise the rationale for choosing to explore the respite needs and experiences of parents caring for a child with a life-limiting condition by presenting a review of literature. Chapter 4 describes

and discusses the methodology employed in this research and Chapter 5 details the method of this research by providing details of how case study research was undertaken. Chapter 6 describes the demographics of participants, the findings from multiple sources of data and cross-case comparison. In Chapter 7 the implications of this research are discussed by drawing on findings of this study and the literature. Chapter 8 concludes with a summary of key findings of this research, the strengths and limitations and their implications for policy and practice.

Impetus for undertaking this study

The lack of research-based evidence on the topic of respite for children with life-limiting conditions and their families was the catalyst for undertaking this research. This dearth of evidence impacts on the development of services and hampers the provision of responsive, flexible, patient-focused respite care. The lack of understanding of the concept and meaning of respite is recognised not only in the literature but also in the national children's palliative care policy and this research attempts to address these issues.

What will it add?

It is hoped that this research will identify the elements of respite experiences that are important to parents and identify the barriers and facilitators to the delivery of respite care by describing and defining respite service delivery from the perspective of parents. This information will enable service providers to be guided by the needs of children with life-limiting conditions and their families. It will also highlight the challenges of providing such services from the multiple perspectives of the parents and others in the family system involved in the provision of respite. By viewing this through the theoretical lens of the family systems theory it is hoped that issues across the system will be identified from the Microsystem of the immediate family through to the socio-political and economics in the Macrolevel, identifying the need for changes at all levels.

CHAPTER 2 - FAMILY SYSTEMS THEORY - DEVELOPING A THEORETICAL FRAMEWORK

Introduction

Theoretical frameworks can guide the development of a research question, underpin research, or develop either inductively or deductively during the research process or be an outcome of the research process (Simons 2009). So whilst the merits of theory in qualitative research have been highlighted (Gilgun 2006), there is no clear guidance on the utilisation of a theoretical framework in qualitative research indeed there are very different perspectives and opinions (Sandelowski 1993). This ambiguity is evident in the literature relating to the utilisation of theory where, depending on the literature accessed, theory is considered: essential at the outset (Wu & Volker 2009), can be an inductive or deductive part of the research process (Simons 2009) or an outcome of the findings (Cresswell, 2003). Thus there is not clear consensus on when or if qualitative researchers should employ a theoretical framework. This appendix critically evaluates relevant literature and presents details of the theoretical foundation that guided and underpinned this research and the thinking and rationale behind this decision-making process. The process was a challenging as there is no one established method for applying theory in qualitative research (Wu & Volker 2009) nor one particular theory that relates to the topic area of children's palliative care.

The place of theoretical frameworks in qualitative research

A compelling argument for qualitative research starting with prior structural, composed, conceptual theory is that it provides a foundation for observation and guides the development of the research proposal (Creswell, 2003). Others are more pedantic and state that qualitative research and theory are inseparable and therefore a theoretical framework should be employed from the outset of the research process (Wu & Volker 2009). Indeed Wu and Volker (2009) go on to insist that as part of selecting a qualitative methodological approach to research it is necessary to examine the underlying theoretical and philosophical foundations of the chosen method and assume the use of a theoretical framework selected to fit the phenomenon under study (Wu & Volker 2009). However, Sandelowski (1993b) presents a convincing counter argument and suggests that in qualitative research where theory development is one of the outcomes (for example grounded theory), having a theoretical framework at the outset can hamper emergent theory (Sandelowski 1993). The notion of theoretical frameworks being applied at various times throughout the research process has

also been presented (Wu & Volker 2009) the inference being that although often complicated and time-consuming, particularly in case study research, building a theory from the data has the advantage of being derived and grounded in the participant's real world experience (Simons 2009) and has the added benefit of avoiding the pitfall of forcing data to fit a pre-determined theoretical framework (Simons 2009). The use of theory and theoretical frameworks specifically in case study research are considered further.

Theoretical frameworks in case study research

The two main proponents of case study research (Yin and Stake) present differing perspectives on the use of theory or 'propositions' in case study research. Yin (2009) taking an empirical approach to case study suggests that theory is essential in order to produce good quality data and improve validity and reliability. He suggests that the use of theory (propositions) and emergent propositions are critical not only in providing direction to the research but also as the first step in analysis (Yin 2009) and provide the foundation from which information obtained in the case be analysed (internal validity) and from which it is possible to evaluate how useful the case findings are if transferred to other settings (external validity) (Yin 2009). Others agree that the advantages of developing propositions is the role they play in helping to define key areas within the study that are derived from theory (Chamberlain *et al.* 2004). This pragmatic approach almost insinuates rigidity however, Yin (2009) goes on to stress that compared to an experimental hypothesis, propositions are more tentative and flexible as they can be revised during data analysis and indeed that propositions and theory may emerge during the research process (Yin 2009). The unique and unpredictable nature of interviews with the parents of children with life-limiting conditions, inevitably propositions emerge and therefore this flexibility further confirms the suitability of the chosen methodology. Others utilising case study in palliative care warn against inventing propositions when there is no theory available (Lee 2002) whilst others suggest that ideally propositions should be equally measurable and limited in number (Wu & Volker 2009).

Stake (1995) suggests a more flexible naturalistic approach to the use of theory in case study. He suggests that researchers in developing research questions bring "etic" (of, relating to, or involving analysis of cultural phenomena from the perspective of one who does not

participate in the culture being studied) issues from outside of the research (Stake 1995). Stake (1995) suggests that “etic” issues are often the researcher's own or can be those of the larger research population, colleagues or authors, whereas “emic” issues emerge, these are the issues brought by those involved in the case from the inside rather than the outside (Stake 1995). In case study research, Stake (1995) refers to a researcher’s summary of interpretations (an assertion or claim) as a ‘propositional generalisation’ added to these is the researchers own personal experiences or ‘naturalistic generalisations’. Hammersley *et al* (2000) see this slightly differently and go so far as to see theory development as one possible end point of case study research, albeit for the individual case (Hammersley *et al.* 2000). Others warn of the dangers of theoretical frameworks misleading the researcher by forcing data to fit preventing the researcher from seeing the unexpected (Simons 2009). Whilst this adds to the debate regarding the use of theory in case study it also adds to the confusion regarding whether a theoretical framework should be applied and if so, when.

Selecting a theoretical framework

In seeking to source an appropriate theoretical framework numerous theories, concepts and models were considered and reviewed. There are several nursing theories or models focusing on family care (Casey 1988, 1995; Cummings 2002; Wright & Leahey 2005) and parent participation in care (Coyne 1995) however the multidisciplinary nature of children’s palliative care coupled with the extensive impact of caring for a child with a life-limiting conditions led me to look beyond nursing. Following an in-depth literature review of respite provision to parents of children with life-limiting conditions requiring palliative care, a number of key concepts and issues were identified including: respite; parents; child; life-limiting conditions (Widger *et al.* 2009); palliative nursing (Davies & Oberle 1990); short breaks; loss (Maciejewski *et al.* 2007); hope (Herth & Cutcliffe 2002); uncertainty (Mishel 1981, 1983): family involvement in palliative care (Andershed & Ternstedt 2001). In isolation, none of these concepts encompassed respite care and the impact on the family of caring for a child with a life-limiting condition. Family, and in particular the family interactions and situations associated with caring for a child with a life-limiting condition are considered to be the focus of care in nursing (Segaric & Hall 2005) and in palliative care (WHO 2002) but also specifically in children’s palliative care where the family are viewed as

an integral part of the unit of care (ACT 2009) where every family member is of equal importance to the sick child (Deeley *et al.* 1998).

Ecological model of human development (Bronfenbrenner 1992)

Set within the context of human developmental systems theories (Damon & Lerner 2006), the seminal work of Bronfenbrenner (1992) on an ecological model of human development emphasizes the importance of both interpersonal and social relationships in the child and is based on three theoretical propositions (Bronfenbrenner 1992):

That humans develop through processes of increasingly more complex interactions between evolving, active, bio-psychological human beings and the people, symbols and objects in their immediate environment. The content, form, power and direction of these ‘proximal processes’ effecting development vary according to:

- The characteristics of the developing person
- The environment
- The nature of the development outcomes under consideration
- Processes serve as a mechanism for achieving genetic potential

Bronfenbrenner’s theory (1992) relates to four structures:

Microsystems - “a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics” (Bronfenbrenner, 1979:26).

Mesosystems – “comprises the interrelation among two or more settings in which the developing person actively participates (such as, for a child, the relations among home, school, and neighbourhood peer group; for an adult, among family, work, and social life)” (Bronfenbrenner, 1979:25)

Exosystems - “one or more settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the

setting containing the developing person”. An example could be the parents work place (Rolls 2004).

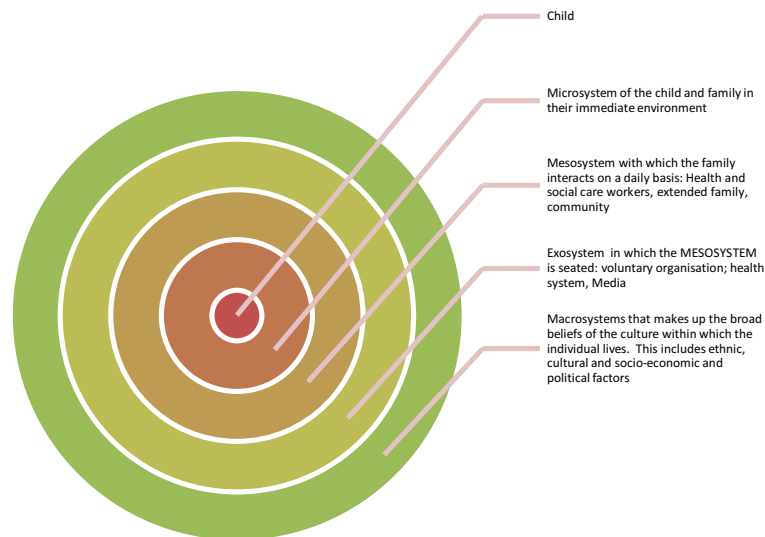
Macrosystems – “consistencies in the form and content of lower-order systems (Microsystem, Mesosystem, and Exosystem) that exist, or could exist, at the level of the subculture or the culture as a whole, along with any belief systems or ideology underlying such inconsistencies”.

Bronfenbrenner (1992) describes four cyclical interrelated nested systems each situated within the next and emphasizes the interrelated dynamic between the child and their environment, culture and context. Later work by Bronfenbrenner further developed the model to include a fifth structure, the Chronosystem, which reflected the cumulative experiences over the course of a person’s lifetime. This introduced the concept of the Process-Person-Context-Time model (Tudge *et al.* 2009) which included not only major life events but environmental events and major transitions such as marriage, divorce and the birth of a baby.

Family Systems Framework (FSF)

In this thesis, it is proposed that Bronfenbrenner’s ecological model of human development and the multi-system principles it offers is a valuable foundation upon which to study parental needs and experiences of respite care for children with life-limiting conditions by using a case study methodology. This model will be operationalised by the use of the Family Systems Framework (FSF) identified by Lewis and Prescott (2006) (Figure 25) (Lewis & Prescott 2006). This framework specifically developed for use in children’s palliative care, helps to ensure that experiences are not viewed in isolation but from multiple perspectives within and between immediate and larger environments and as part of the family system. The FSF builds on the work of Bronfenbrenner and adapts the four structures to encompass the FST as it specifically relates to the care of a child with a life-limiting condition (Lewis and Prescott, 2006). In this model the child at the centre of care presents significant challenges to the functioning of the whole family system. The family system theory provides the theoretical lens through which: this research been developed; the research method was been chosen; and through which data were collected and analysed.

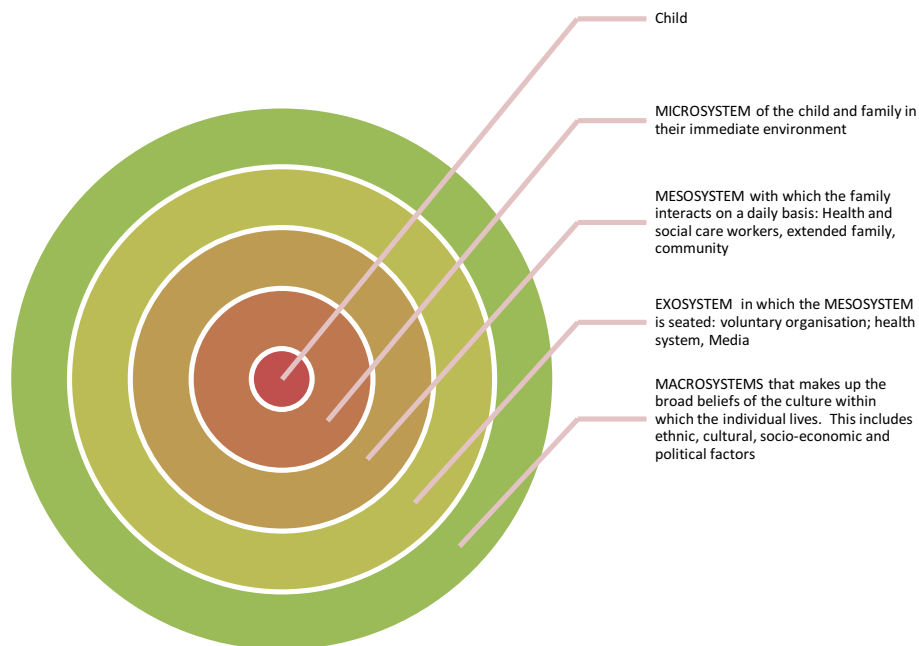
Figure Diagram: Four levels relating to the family systems framework (FSF) for children with life-limiting conditions (Lewis & Prescott 2006)P.156



Family systems theory

General systems theory, where the whole is considered to be the sum of its two or more parts (Anaf et al. 2007) is the foundation for the family systems theory. FST has its origins in the social sciences (Broderick 1993) and is based on the premise that a family is also more than the sum of its parts and that individuals cannot be understood in isolation but only as part of their family (Whyte 1997; Wright & Leahey 2005; Mehta et al. 2009) and of the wider system to which they belong (Lewis and Prescott, 2006) (Figure 2). A FST approach moves the focus from the individual, in this case the parents and child, to the wider social context of the family system where the family are viewed as a small group of interrelated and interdependent individual elements (Mehta *et al.* 2009). By adopting a FST approach, the respite needs of parents caring for a child with a life-limiting condition may be viewed not only at the individual, micro-level of the immediate family but can also take cognisance of the wider organisational, societal and cultural levels identified through the FST.

Figure 2 Family systems theory as it relates to children’s palliative care (Lewis & Prescott 2006)



2.3.1 The Family Systems Framework (FSF)

The FSF was specifically developed for use in children’s palliative care and helps to ensure that experiences are not viewed in isolation, but from multiple perspectives within and between immediate and larger environments and as part of the family system. The FSF builds on the work of Bronfenbrenner (Bronfenbrenner 1992) and adapts the four structures identified in his work and the work of others to encompass the FST as it specifically relates to the care of a child with a life-limiting condition (Lewis and Prescott, 2006). In this model the child at the centre of care presents significant challenges to the functioning of the whole family system. The FSF provides the theoretical lens through which this research has been developed, the research method was chosen, and data were collected and analysed.

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interdependent individual elements (Mehta *et al.* 2009). By adopting a FST approach, the respite needs of parents caring for a child with a life-limiting condition can be viewed not only at the individual, micro-level of the immediate family but can also take cognisance of the wider organisational, societal, organisational and cultural levels identified through the FST.

Various frameworks for the application of the FST into research or practice have been suggested (Wright & Leahey 2005) however for the purposes of this study a Family Systems Framework (FSF) suggested by Lewis and Prescott (2006) has been utilised. Based primarily on the work of on the work of Bronfenbrenner on the Ecological model of human development (Bronfenbrenner 1992) and utilising the work of others (Thompson & Gustafson 1996; Mitchell & Winslade 1997; Rolls 2004), Lewis and Prescott (2006) have developed a Family Systems Framework (FSF) specifically for children with life-limiting conditions.

Summary

No one theory captures all of the elements identified that are relevant to the task of explaining findings (Hammersley *et al.* 2000) and therefore throughout the research process emerging theory was explored and discussed. Due to the specific topic of this research, Lewis and Prescott's FSF (Lewis & Prescott 2006) based on the work of Bronfenbrenner (Bronfenbrenner 1992) has been identified as the most suitable theoretical framework for this research.

CHAPTER 3: LITERATURE REVIEW

2.1 Introduction

Children's palliative care is a small, highly specialised and rapidly developing area of healthcare that has become increasingly of interest to healthcare professionals (Liben *et al.* 2008). Respite care has been recognised as an essential component of care for children with life-limiting conditions and is frequently cited as beneficial to both the child at the centre of care and their parents (McConkey & Adams 2000; Neufeld *et al.* 2001; Horsburgh *et al.* 2002; MacDonald & Callery 2004; Eaton 2008; Nageswaran 2009). Care for children with complex healthcare needs impacts on family life at all levels including: emotionally, psychologically, physically, financially and socially. Respite seeks to decrease the burden on caregivers by providing them with a break from the routine of caring (Steele 2000; Horsburgh *et al.* 2002; Corkin *et al.* 2006; Nageswaran 2009); however, ambiguity surrounding the terminology used has resulted in respite in children's palliative care being poorly defined.

The aim of this thesis was to explore the concept and meaning of 'respite care' for parents caring for a child with a life-limiting condition requiring palliative care. In this chapter the background literature is presented with the aim of contextualising the rationale for choosing respite in children's palliative care as the focus of this research. The chapter commences with an explanation of the process undertaken in sourcing the literature under review. Children's palliative care is defined and described and the evolution of children's palliative care as a specialty is critically discussed through the lens of the family systems theory (FST). The challenges of defining and describing the concept of respite in children's palliative care will be explored through the review of relevant literature. The aim of this chapter is to provide a context and rationale for choosing respite in children's palliative care as the focus of this research. International and national policy on children's palliative care provides the foundation of service development and both are reviewed and discussed in the context of respite in children's palliative care.

2.2 Sourcing literature

Literature was sourced through a variety of methods including a search of the grey literature and an extensive search of computerised databases (Cumulative Index of Nursing and Allied

Health Literature (CINAHL), MEDLINE (PubMed) and PsychINFO). This search was undertaken in 2010.

Children's palliative care is a relatively new specialty; adult palliative medicine was first recognised as a medical specialty in the UK in 1987 and therefore this was chosen as the oldest parameter for my literature search. All articles published in the English language between 1987 and 2010 were included.

In order to focus on the chosen topic of respite needs in children with life-limiting conditions it was necessary to keep the search terms broad; for example many children with life-limiting conditions also have disabilities and complex care needs (Craft & Killen 2007). The following search terms were used and combined with the 'and' and 'or' Boolean operands: 'children' or 'pediatric' or 'paediatric' and/or 'palliative' or 'end of life' or 'terminal' or 'life-limiting' or 'complex care' and/or 'respite' or 'short break'. This combination of search terms yielded 137 articles; once limited to English language a total of 133 articles were identified. These were sourced and read in full. Secondary references were identified from these articles and from journals read during the course of this research. Any articles pertaining to respite in other areas of healthcare was also sourced especially if related to palliative care. Reflecting the multidisciplinary nature of children's palliative care, the majority of papers were published in interdisciplinary health and social care journals. Throughout the course of the research, new literature was published and accessed and this will be referred to in the later discussion chapter².

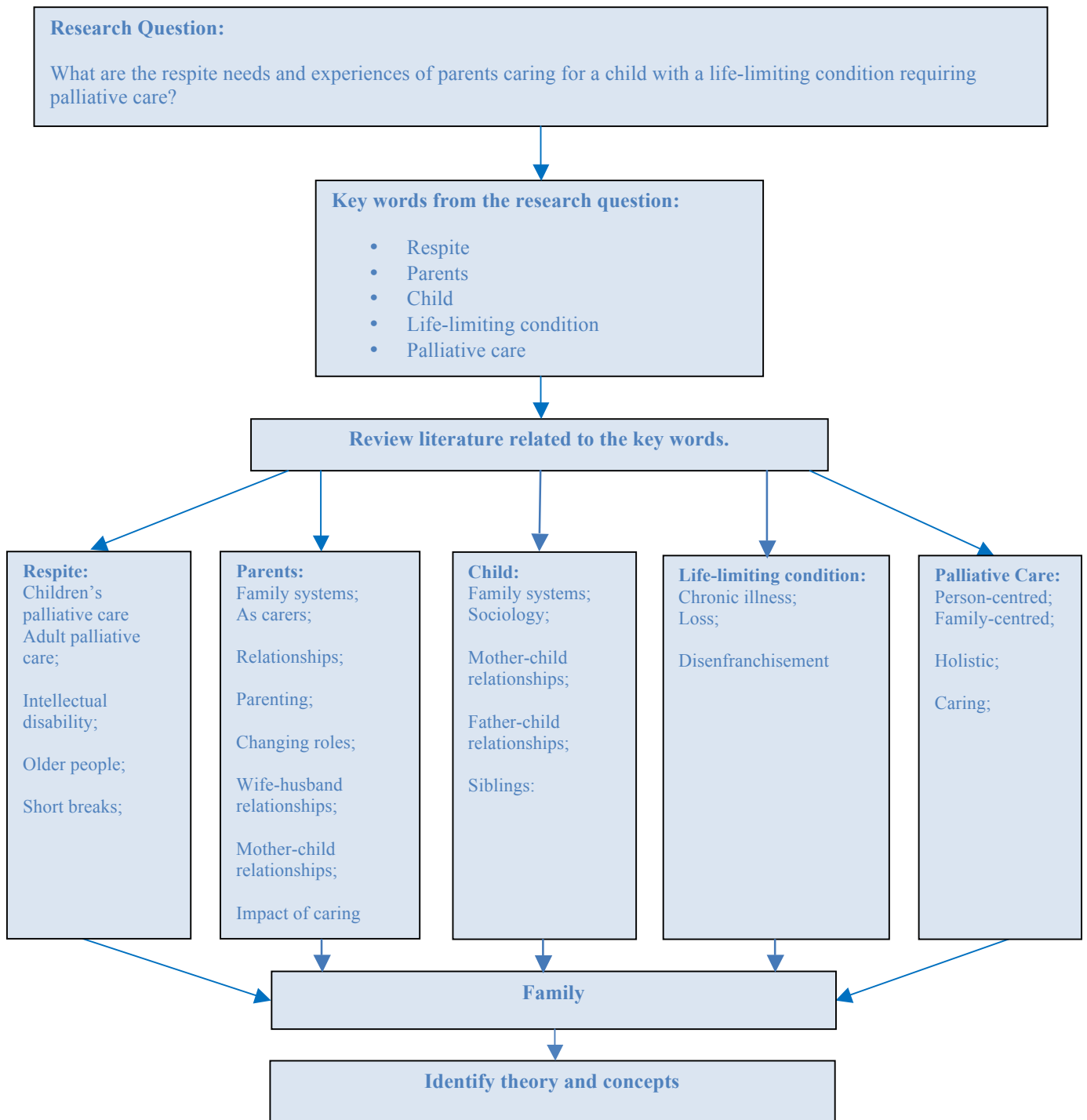
Textbooks³ and papers including reviews⁴, editorials and commentaries are referred to throughout this thesis however; 34 research-based articles published in peer-reviewed journals were selected as being of particular relevance to this study. Criteria for articles included were established using a process shown in Figure 1. Although it has been suggested that the presentation of findings in this format is too simplistic (Sandelowski 2007) a summary of the characteristics and key findings of each of these papers is contained in Appendix 1.

² A literature review was published on respite in children's palliative care
Ling J. (2012b) Respite support for children with a life-limiting condition and their parents: a literature review. *International Journal of Palliative Nursing* **18**(3), 129-134.

³ Where textbooks have been used it is noted that such is the dearth of research in children's palliative care that many authors refer to their own clinical experience, or research undertaken outside the specialty and in other related areas.

Policy documents pertaining to or impacting on the provision of children’s palliative care have also been sourced and reviewed. These include national and international policies but do not include local policies or guidelines.

Figure 1 Targeting relevant literature



⁴ Literature reviews and systematic reviews of related areas of interest were accessed

2.4 Child and family as the unit of care

For children with life-limiting conditions palliative care should be introduced early in some cases at the time of birth (Mack & Wolfe 2006) and should complement other therapies aimed at prolonging life (American Academy of Pediatrics & Committee on Bioethics and Committee on Hospital Care 2000).

In children's palliative care, the child and their family are viewed as one unit of care. Parents often take on the role of primary carer and the prognostic uncertainty that is a hallmark of children's palliative care can result in parents facing significant vagueness over the duration and type of often complex care they are committing themselves to providing (Steele 2000; Hynson 2009). Despite these uncertainties the majority of parents are committed to caring for their child (Steele 2002).

Caring for children in a healthcare setting inevitably involves working with their families where evidence supports the premise that children's physical and emotional outcomes in healthcare are strongly linked to the functioning of their families (Contro *et al.* 2004). The diagnosis of a life-limiting condition in a child impacts not just on the immediate family, but on the wider family altering interactions and communication between them, often resulting in on-going adaptation and reorganisation of family roles and responsibilities (Davies & Steele *et al.* 2004). Parents of children with complex care needs clearly state that they do not want their child viewed as separate but as an integral part of their family as a whole (McConkey *et al.* 2007). In order to provide holistic care to families it is essential to understand the relationships within and between the family members, particularly when a child has an uncertain future (Contro *et al.* 2002).

2.5 Living with uncertainty

Immediately that a diagnosis of a life-limiting illness has been made the relationship between the parents and their child becomes organised around the threatened or impending loss (Sourkes 2006). Chronic illness brings with it uncertainty and this is the aspect of caring for a child with a life-limiting condition with which most families have difficulty coping (Steele

2000). Whilst parents live with long-term uncertainty the intensity of this changes over time and depends on various factors including their child's condition (Steele & Davis 2006).

Kleinman (2006), an eminent anthropologist, suggests that uncertainty is an inescapable part of life and helps to define what it is to be human (Kleinman 2006). Uncertainty has been described as unpredictability and ambiguity surrounding symptoms; the absence of a diagnosis; lack of information or unclear explanations of healthcare issues (Mishel 1981)⁵. In his work Mishel (1981) identified four main sources of uncertainty and subsequent stress this uncertainty causes. All four causes have been clearly identified in the research-based literature concerning children's palliative care and are: Ambiguity (Syren *et al.* 2006; Monterosso *et al.* 2007b); Lack of clarity (O'Brien 2001); Lack of information (Monterosso *et al.* 2007b; Eaton 2008) and Unpredictability (Steele 2000; Redmond & Richardson 2003; Steele 2005).

In order to further develop his model of uncertainty Mishel (1983) subsequently tested the care of children and adolescents with cancer as a conceptual model thus combining hope with an unpredictable outcome (Stewart *et al.* 2010). His findings indicated a strong correlation between the child's own level of psychological distress and uncertainty but furthermore he identified the role of parental uncertainty and the subsequent effect on family life and how this also impacted on the child (Mishel 1983; Stewart *et al.* 2010). This once again demonstrates the importance of viewing the family as part of the family system rather than in isolation.

One of the main differences between adult and children's palliative care is the uncertain disease trajectory faced by many children (Appendix 3). Using grounded theory methodology Steele (2000) described parent's experiences of facing the inevitable death of their child at an uncertain time. All families were referred through a paediatric hospice-care programme or a children's hospital. All of the children in families recruited had neurodegenerative life-limiting conditions. Children were observed but not interviewed as part of the research process, it is not clear if they were to be considered research participants.

⁵ The work of Mishel exploring the role of uncertainty in illness and the subsequent development of 'The Mishel Uncertainty in Illness Scale' aimed to measure uncertainty in adults with chronic conditions Mishel M. (1981) The measurement of uncertainty in illness. *Nursing Research* 30(5), 258-263.. This work was the foundation for a further scale assessing the impact of uncertainty on parents of hospitalised children Mishel M. (1983) Parents' perception of uncertainty concerning their hospitalized child. *Nursing Research* 32(6), 324-330.

From eight families, 29 participant family members were interviewed both individually and as a group. The research report does not indicate or distinguish how many participants were parents or who the other family interviewees were. This information is important, as it would enable the reader to elicit whether those interviewed were involved in the care of the child. The main method of data collection was in-depth interviews with participant observation in the family home (the location of all interviews). Following initial analysis the researcher sought member checking and conducted primarily telephone interviews with participants seeking their comments. Steele’s (2000) findings portray the uncertainty that family’s caring for children with a life-limiting condition live with as “*navigating uncharted territory*” (Steele 2000) p61. The metaphor of living on ‘plateaus’ is utilised to describe the relative stability of family life prior to the next crisis. With the next crisis the family drop to another lower ‘plateau’. This uncertainty is compounded as families have no idea when a crisis may occur or how long they will live on the relative stability of each plateau and is this presented diagrammatically (Figure 3⁶) (Steele 2000).

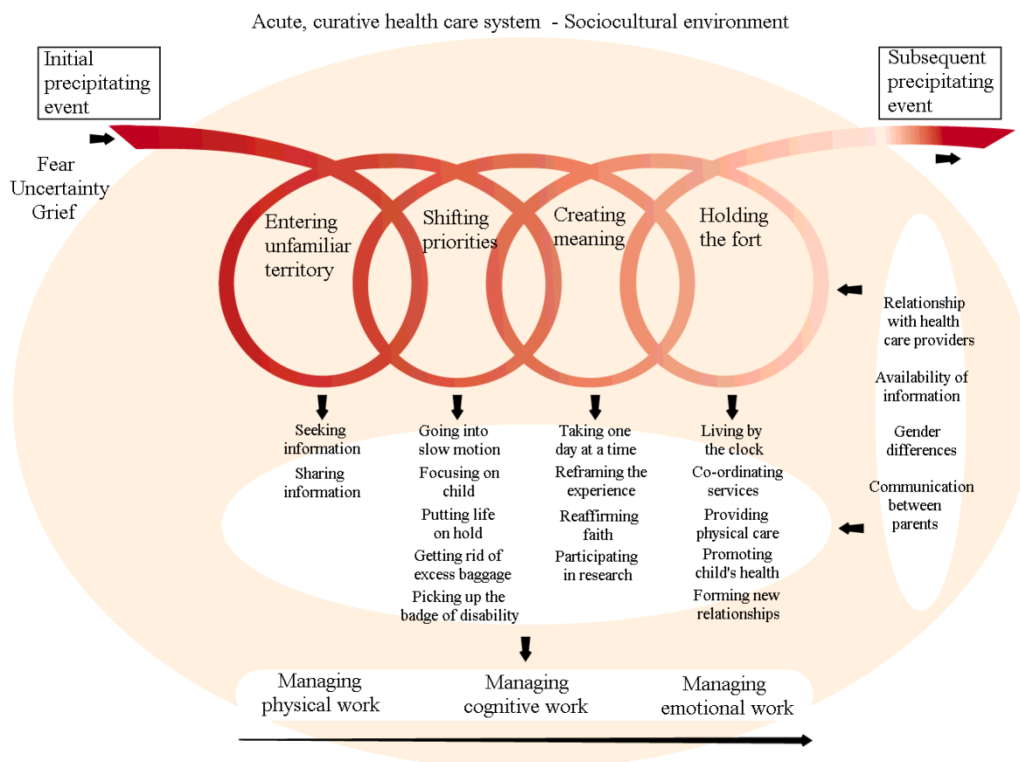


Figure 1. Navigating uncharted territory

⁶ Used with permission of author

Figure 3 Navigating uncharted territory (Steele 2000)

Steele's (2000) work builds on the seminal work of Glaser and Strauss (1968) who described four types of death expectation in using a combination of time and certainty:

1. Certain death at a known time
 2. Certain death at an unknown time
 3. Uncertain death but a known time when certainty will be established
 4. Uncertain death and an unknown time when the question would be resolved
- (Glaser & Strauss 1968)

The work of Glaser and Strauss (1968) describes the death expectations of adults where trajectories can be easier to predict than in children's palliative care⁷. Steele (2000) found that as a result of the uncertain trajectory of their child's illness parents lurched through emotion and stress with no idea how long they would be caring for their child. Physical, emotional and psychological stress all takes their toll. Families described the process of taking their child home to die on multiple occasions as "*a rollercoaster ride*" (Steele 2000). Subsequent papers relating to different aspects of this original research relating specifically to children with neurodegenerative conditions have also been published (Steele 2002; Steele 2005). Uncertainty is a key feature of many conditions seen in children's palliative care.

Confirming the findings of Steele's (2000) work, another study of children with neurodegenerative conditions in children aged 4 and under was undertaken in Ireland. Whilst this study reports employing predominantly a qualitative approach utilising semi-structured interviews, further methodological information is not available in the report which impacts on the reliability of the reported findings. However, the study explores the service needs of 17 mothers of children with severe intellectual disabilities (Redmond & Richardson 2003). Living with uncertainty was a key issue whereby mothers reported that the uncertain life expectancy of their child resulted in an inability to plan for the future. Many mother pragmatically reported making the most of each day (Redmond & Richardson 2003).

⁷ A more recent publication further highlights the differences between adult and children's palliative care. Together for Short Lives (2013) *Children and adult's palliative care: A comparison*, Bristol, UK.

For children diagnosed with cancer, uncertainty is also a feature of their disease trajectory. Families are frequently given little time to adjust to the life-threatening nature of their child's diagnosis. Although parents were not interviewed in this research, in-depth interviews with 40 healthcare professionals involved in the palliative care of children with cancer revealed that uncertainty in paediatric oncology is framed as living with a cycle of 'optimism' and sometimes 'disappointment' (Spencer & Battye 2001). Although advances in paediatric oncology treatment have statistically led to improved survival rates (Walsh *et al.* 2011) as with all parents of children with life-limiting conditions, parents of those with cancer and haematological malignancies have to endure uncertainty regarding their child and whether their treatment will be successful. In response to this parents develop and employ various coping strategies.

2.6 Parental coping - Making the most each day

Parenting is an overarching term that captures the activities of adults providing child-care giving and child rearing activities (Arendell 1997). Parenting is a dynamic, social relationship between a parent and child that is continuously renegotiated and changes over time as the child moves towards independence (Arendell 1997; Collins *et al.* 2000; Kirk *et al.* 2005). Parenting continues in families throughout adjustments and significant changes (Arendell 1997) such as caring for a child with a life-limiting condition where parents often struggled to provide care to their child whilst also trying to maintain the usual activities of parenting. Making the most of each day is a theme that pervades the literature on children with life-limiting conditions (Gibson 1995; Steele 2000; Redmond & Richardson 2003) and which is closely associated with the concept of hope. Steele (2000) found that parents search for any positive aspects of their experience (Steele 2000). Hope has been also been identified as being significant in assisting 'mothering in other-than-normal children' in a metasynthesis of their care-giving to children with complex care needs (Nelson 2002). Further evidence supports the need for hope but notes that it evolves over time (Reder & Serwint 2009).

Focus groups with bereaved parents and healthcare professionals involved in the care of the child revealed the changing face of hope over time. Researchers found that although both bereaved parents and healthcare professionals agreed on certain elements of hope they both

approached it very differently (Reder & Serwint 2009). Parents spoke of taking each day as it comes and living for the moment, whereas healthcare professionals expressed concern regarding the concept of hope in children with a serious illness suggesting that it was often misinterpreted as denial of the seriousness of their child's condition (Reder & Serwint 2009). Understandably parents wanted to protect their children and maintain hope even whilst accepting a poor prognosis (Reder & Serwint 2009). This highlights an area where there is a need for improvement in communication between those in the Microsystem and those in the Mesosystem.

2.7 Family as carers

Where families are facing the death of a member the entire balance of family life is threatened (Lewis & Prescott 2006). The resultant destabilisation of the family often requires a reorganisation in order to deal with the impending changes to the family structure (Mehta *et al.* 2009). In family systems theory, change in one family member, such as the diagnosis of a life-limiting condition will inevitably influence the entire family system (Wright & Leahey 2005). Whilst each family is unique and responds to the impact of illness in their own way (Cummings 2002) there are some common elements in how families manage such crises.

The whole family system is put under strain and has to adapt as family members strive not only to deal with the sadness of the dying person, their own sadness and the sadness of other family members whilst also undertaking necessary practical tasks (Andershed & Ternstedt 2001). Within the family unit, each individual family member reflects their role within their family. Revealed through their interactions and interplay family members have their strengths and weaknesses; vulnerabilities and resilience; and actions and behaviours (Syren *et al.* 2006). Through unspoken rules, each family develops its own individual family relationship agreements and develops and maintains predictable behaviour patterns with and between family members (Wright & Leahey 2005). Ultimately families are systems of independent but interconnected individuals, none of whom can be understood in isolation from the system within which they exist (Lewis and Prescott, 2006).

2.7.1 Defining family

In Ireland the legal definition of an Irish family stems from the Irish Constitution (1937) and includes married parents and their children. According to the Irish Child Care Act (1991) a

child is defined as a person under the age of 18 years. In the Irish version of the Constitution (1937) the terms ‘home’ and ‘family’ are both ‘An Teaghlach’ thus indicating the connection and meaning between the two terms in Irish culture (Kennedy 2001). In Ireland the essential and unique function of the family is to care for and nurture all of its members as it is in the family context that a person's basic emotional needs for support, security, belonging, and intimacy are satisfied (Commission on the Family 1998). Ireland is a patriarchal society where until recently women’s voices and concerns went unheard and where the woman’s position is clearly identified in the home and with the family (O'Connor 2000). However, in common with other countries, societal changes in Ireland, have resulted in different types of family units and the need for more inclusive definitions (Daly 2004).

Despite struggles to define the term ‘family’ (McClement & Woodgate 1998), multiple definitions of the term exist (Segaric & Hall 2005). Family has been broadly defined as including all individuals with whom the patient feels a connection through a legal, blood or emotional tie (King & Quill 2006). Others take a much broader view defining family as “*whoever the person says his or her family is*” (Canadian Hospice and Palliative Care Association 2003) or the family is “*who they say they are*” (Wright & Leahey 2005) and this can include, partners and friends. The United Nations (United Nations 1990) definition of the family is purposely broad and inclusive: “*any combination of two or more persons who are bound together by ties of mutual consent, birth and/or adoption or placement and who, together, assume responsibility for, inter alia, the care and maintenance of group members, the addition of new members through procreation or adoption, the socialisation of children and the social control of members.*” Whilst these multiple definitions do have commonalities it is not surprising that researchers struggle to define the term ‘family’ (Lewis and Prescott, 2006).

In children’s palliative care it is important to accept the families’ own definition of themselves as a family even if this does not fit with the conventional or traditional view as regardless of its composition it can encompass and value the strength of the traditional family groups (Lewis and Prescott, 2006). Non-traditional family groupings must be recognised as these are now a feature of contemporary society and include single parent families, same sex couples and co-habiting couples (Wright & Leahey 2005). Functioning of the family has been the focus of the work of a number of authors (Bronfenbrenner 1992; Whyte 1997; Cummings

2002; Wright & Leahey 2005). Bronfenbrenner's (1992) Ecological Model of Human Development emphasizes the importance of both interpersonal and social relationships in the developing child viewing them as part of a wider system (Bronfenbrenner 1992) This promotes the notion that regardless of the composition or location of the family, all are part of a larger network also known as a family system. In order to provide effective care to families caring for a child with life-limiting condition healthcare professionals must develop an understanding of the family boundaries defined by the family system in order to gauge whether they will be able to make an impact on the family unit (Mehta et al. 2009). It is within the context of the family that the majority of care for children with life-limiting conditions takes place and therefore in order to truly assess the respite needs and experiences of parents caring for a child with a life-limiting condition it is essential to view this within the context of the family system as a whole.

2.8 Describing and defining children's palliative care

Due to technological advances and developments in care, children born with or developing life-limiting conditions are living longer. Evident in the definition of a life-limiting condition in a child is the approach taken in identifying those who require palliative care "*...any illness for which there is not reasonable hope of cure and from which the child or young adult will die*" (DOHC 2010) p.52. Whilst this definition is purposefully broad in order to capture all those who may require palliative care, it may also encompass many children who will not require palliative care services. Further evidence of this is inherent in the definition of palliative care for children where all aspects of the child's personhood, including their family, are encompassed into one broad definition: "*...an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement*" (ACT, 2009:p.7). Whilst these attempts have been made to define children's palliative care ambiguity remains regarding the language used in the specialty⁸⁹ how services are developed and accessed, and around perceptions of which children should and need to be able to access services.

⁸ Ling J. (2012a) Definitions in children's palliative care: black and white or shades of grey? *International Journal of Palliative Nursing* **18**(9), 419.

⁹ Together for short lives have recently begun a discussion - Chambers L. (2013) *The language of children's palliative care*. Together for Short Lives, Bristol, UK.

Although there are some similarities between children's and adult palliative care, children's palliative care is a distinct specialty in its own right with significant differences identified between the adult and child specialty Table 1(ACT 2009a)¹⁰. Services in both adult and children's palliative care should ideally commence at diagnosis, however in children this can be from as early as birth. Children's palliative care is often provided in conjunction with active treatments aimed at cure and there is an increased emphasis on providing this care in the family's location of choice, most frequently the family home¹¹. As with adult palliative care, this involvement should last for the duration of the child's life and continue with the

Table 1: How palliative care for children is special (ACT 2009a)p.9

- *The number of children dying is small, compared with adults*
- *Many of the individual conditions are extremely rare with diagnoses specific to childhood although the child may survive into early adulthood*
- *The time scale of children's illness is generally different from adults; palliative care may last only a few days or months or extend over many years*
- *Many of the illnesses are familial. There may be more than one affected child in the family and genetic counselling should be offered*
- *Care embraces the whole family. Parents and siblings are especially vulnerable and parents bear a heavy responsibility for personal and nursing care*
- *A characteristic of childhood is the continuing physical, emotional and cognitive development which is reflected in their communication skills and ability to understand their disease and death*
- *Provision of education and play when a child is sick is essential and education is a legal entitlement. This introduces an additional professional intervention which adds to the complexity of care provision*

provision of bereavement care for the family (ACT 2009a).

¹⁰ These differences have been more clearly demarked in a later version of this document - Together for Short Lives (2013) *Children and adult's palliative care: A comparison*, Bristol, UK. Appendix 3

¹¹ Some argue that palliative care should be a human right for all children with life-limiting conditions. Foley K. (2012) Palliative care as children's right. *Minerva Pediatrica* 64(Suppl.1), 3.

2.8.1 Diagnosis of a life-limiting condition

Developing and accessing children's palliative care services is challenging. There is no definitive list of conditions that are considered to be life-limiting and therefore empirical data is not available on the numbers of children living with and dying from life-limiting conditions. Although four categories of life-limiting conditions in children (ACT 2009a) (Table 2) have been accepted and are used globally¹², these categories are not definitive and are only useful for planning children's palliative care services as they remain open to interpretation. Not all children with the conditions named in the four categories will die prematurely. As a result of this, accurate data are not available¹³. In the absence of a more robust method of providing data these four categories currently underpin all the national statistics and figures on children's palliative care in Ireland. Importantly, this has implications for the parents of children who are diagnosed with one of these conditions.

A challenge for both clinicians and researchers in children's palliative care is the reluctance of some parents, particularly those of children with complex chronic disabilities, to acknowledge that their child has a life-limiting condition. Other parents actively seek a diagnosis in the hope that it will result in the provision of services, such as respite, for their child. In the process of being given a diagnosis for their child, parents are reported to highly value a physician breaking bad news who knows them, allows them to speak, gives information that is accurate and who can clearly demonstrate a sensitive, caring attitude (Contro *et al.* 2002; Levetown 2008). Parents also value non-technical easy to understand information given in a simple and honest way and where possible, parents want to be left with hope even if this is for a miracle (Contro *et al.* 2002). Good communication is essential to providing families with the information that they need.

In some specialties the way in which information such as diagnosis has been delivered has been researched in particular the needs of adults with cancer (Leydon *et al.* 2000; Jenkins *et al.* 2001). The communication and information needs of parents caring for a child with a life-limiting condition have also been subjected to inquiry (Levetown 2008); studies relating to decision-making (Miller *et al.* 2011) and specific conditions such as cystic fibrosis (Hodgkinson & Lester 2002) and cancer (Wolfe *et al.* 2000) have all been reported. Some of

¹² E.G. International Children's Palliative Care Network (ICPCN), Together for Short Lives

¹³ Work is on-going to develop a definitive list of ICD conditions that are considered to be life-limiting.

Hain R., Heckford E. and McCulloch R. (2012) Paediatric palliative medicine in the UK: past, present, future. *Arch. Dis Child* **97**, 381-384.

the findings from these studies are applicable to all children with life-limiting conditions however the vast array of diagnoses and thus varying disease trajectories seen in children's palliative care requires clinicians to consider each case individually and to tailor information needs of parents to meet the individual needs of each family.

Table 2: Categories of life-limiting conditions in children (ACT 2009a)p.9

Category
<p>Group 1 Life-threatening conditions for which curative treatment may be feasible but can fail. Where access to palliative care services may be necessary when treatment fails. Children in long-term remission or following successful curative treatment are not included. (example: cancer; irreversible organ failure of heart or kidneys)</p>
<p>Group 2 Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. (example: cystic fibrosis)</p>
<p>Group 3 Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years (example: batters disease, mucopolysaccharidoses; muscular dystrophy)</p>
<p>Group 4 Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death (examples: severe cerebral palsy; multiple disabilities such as brain or spinal cord insult).</p>

2.8.2 Incidence of life-limiting conditions in childhood and childhood deaths in Ireland

In the absence of definitive data and in order to plan and develop services including respite care, several countries including Ireland have attempted to estimate the prevalence rate of children living with life-limiting conditions¹⁴. This lack of significant empirical data on incidence and mortality in children's palliative care is not exclusively an Irish problem¹⁵ and despite these challenges, end-of-life care and palliative care services in Ireland have been highly ranked both in Europe (European Parliament Committee on the Environment 2008) and internationally (Economist Intelligence Unit 2010).

¹⁴ England, Italy, Scotland, Northern Ireland

¹⁵ Work is underway in the UK on a standardized data collection system. ACT (2009b) *Making life-limited children count. National Palliative Care Minimum Data Set and Services Mapping Initiative for Children and Young People*. Association for Children with Life-threatening or Terminal Conditions and their families Children's Hospices UK, Bristol.

In Ireland each year it is estimated that there are an average of 563 deaths in children. Of these 370 children die from one of the life-limiting conditions identified in the ACT categories (DOHC/IHF 2005)¹⁶. The children's palliative care needs assessment undertaken in 2002 and published in 2005 used a prevalence rate of 12 children with life-limiting conditions per 10,000 children (aged 0-17 years), producing an often quoted figure of 1,369 children living with a life-limiting condition (DOHC/IHF 2005). This was based on 2002 United Kingdom (UK) prevalence rates and was considered, even at the time of publication of the Irish report (DOHC/IHF 2005), to be an underestimate. A proviso warned that for a number of reasons, including the assumption of similarity between UK and Irish prevalence rates, the figures may be higher¹⁷. In many cases advances in antenatal screening results in parents knowing about a child's potentially fatal congenital condition prior to birth and where abortion is available, some parents may elect to terminate the pregnancy. Others choose to continue with their pregnancy in the knowledge that their baby will die soon after birth. Unlike other countries, in Ireland termination of pregnancy is illegal unless the life of the mother is threatened (Government of Ireland, 1892). Although this may have an influence on the number of children born with congenital abnormalities, this has not been subjected to scrutiny.

2.8.3 Diagnosis in the pre-natal period

In developed countries congenital abnormalities are one of the main causes of childhood death. The majority of childhood deaths occur in the first days and months of life (Pierucci *et al.* 2001; DOHC/IHF 2005), thus neonatal palliative care is an emerging area of interest (Catlin & Carter 2002; Himelstein 2006). The introduction of palliative care in the perinatal period can provide families with the opportunity to plan for the limited amount of time they may have with their baby (Sumner *et al.* 2006) and has also been shown to enhance end-of-life care by reducing the number of invasive procedures undertaken and the amount of time spent in ICU for neonates (Pierucci *et al.* 2001). By identifying conditions that are thought to be incompatible with life the use of an end-of-life palliative care protocol specifically for neonates may assist both parents and healthcare professionals in providing optimum care (Catlin & Carter 2002) including the provision of respite care. The use of an end-of-life

¹⁶ More recent data indicates 322 as the average number of childhood deaths from life-limiting conditions - LauraLynn and Irish Hospice Foundation (2013) *Respite services for children with life-limiting conditions and their families in Ireland; a national needs assessment* Dublin, Ireland.

¹⁷ Recently prevalence rates in the UK are estimated to be over three times higher than original estimates at 32:10,000 - Fraser L.K., Miller M., Hain R., Norman P., Aldridge J., McKinney P.A. and Parslow R.C. (2012) Rising National Prevalence of Life-Limiting Conditions in Children in England. *Pediatrics* 129(4), e923-e929.

palliative care pathway may help carers identify the parents' wishes and these often include a desire to take their baby home to die thus creating a need for urgency, organisation and information. The majority of children born with life-limiting conditions also have physical or intellectual disabilities (Craft & Killen 2007).

2.8.4 The overlap between children's palliative care and disabilities

One of the major differences between adult and children's palliative care is that the majority of children have non-malignant life-limiting conditions often coupled with chronic and complex disabilities (Craft & Killen 2007). This overlap adds to ambiguity surrounding definitions, where some children who have life-limiting conditions are cared for through disability services. For completeness, in this literature review, publications pertaining to research undertaken in with children in the disability services were also scrutinised. Research of significance to this study has been published focusing on areas of interest such as children with intellectual or physical disabilities (Nelson 2002; Redmond & Richardson 2003; MacDonald & Callery 2004), children with complex care needs or special care needs (Jerrett 1994; Yantzi *et al.* 2006); and those who are technology dependent (Glendinning *et al.* 2001; Kirk 2001; O'Brien 2001; Kirk *et al.* 2005). Whilst considering the specific needs of children with differing life-limiting conditions it is also important to acknowledge specific age-related needs. As children's palliative care by definition encompasses the care of those aged up to 18 years the specific needs of adolescents warrant particular attention.

2.9 Respite as part of children's palliative care

There is an empirical body of evidence suggesting that caring for a child with a life-limiting condition places huge strain on the family system and impacts on all aspects of family functioning (Stein *et al.* 1989; Sherman 1995; Steele 2000; O'Brien 2001; Steele 2002; Heaton *et al.* 2005; Yantzi *et al.* 2006; Eaton 2008). Care demands on parents can be diagnosis dependent. A study in Australia of parents of children with cancer and parents of children with other life-limiting conditions found significant differences in the two groups. Whilst parents of children with non-malignant conditions experiencing a much longer requirement of care, parents of children with cancer experienced much higher levels of anxiety and depression (Monterosso *et al.* 2007b). These findings are supported by Steele (2000) who found that families of children with neurodegenerative life-threatening illnesses often provided care to their child for long periods of time with little support and that care

demands increased and evolved as the family moved through the illness trajectory requiring them to undertake new tasks (Steele 2000).

Respite care is one way of providing support to families caring for a child with a life-limiting condition. In the majority of definitions of respite it is not only the patient that benefits from respite but the carer is also a beneficiary (Ingleton *et al.* 2003). Definitions of respite vary; Horsburgh *et al's* (2009) definition is cited in the Irish children's palliative care policy (DOHC 2010) where respite is described as; *"The provision by appropriately trained individuals of care for children with life-limiting conditions for a specified period of time, thus providing temporary relief to the usual care-giver"* (Horsburgh *et al.* 2002). The policy further develops respite care by describing specialist respite care as: *"... a setting of care, a programme of care or a service that provides additional services. It may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility or hospice. Specialist respite care provides the support required to meet the child's holistic care needs and enables children and families to access short break services. Specialist respite care will often address some aspects of symptom management"* (Department of Health 2008; DOHC 2010 p.53).

From these two definitions it is evident that respite in children's palliative care encompasses several elements and, far from being simply defined as a break from caring, it is a complex and multi-faceted phenomenon. At a broader level respite has been subjected to research in other areas of healthcare including care of the older person and palliative care.

2.9.1 Respite - Specific considerations for adolescents with life-limiting conditions

Independence is viewed as a critical life experience (Freyer 2004) and yet for many adolescents in palliative care this is coupled with a need for care and support (Craig 2006). Independence appears in many guises and is affected by the rapid changes in emotional, physical, cognitive and social development of the adolescent which continues despite illness or progressive disease (Craig 2006).

Service providers offering adolescents the opportunity to utilise respite may find their efforts hampered by specific issues that are unique to adolescents for example adolescents may be

reluctant to use respite due to treatment, their illness or if their physical appearance is different to their peers. Chronic ill-health can delay the onset of puberty and maturity with many teenagers living with a life-limiting condition looking younger than their age (Craig 2006). Physical changes due to their condition or treatment can include: alopecia, obesity, swelling, altered mental status, disfigurements and weight loss (Freyer 2004).

In an effort to establish adult autonomy the young person may seek to identify a life outside of the family. As part of adolescence and the ensuing independence, some young people develop an understanding of the consequences of their condition enabling them to be involved in decision-making about their care (Freyer 2004) including decisions regarding treatment options (Craig 2006) and the choice to utilise respite services. This can be problematic for some families where parents have been involved in every aspect of their child's life and may have difficulty in relinquishing the role (Freyer 2004). Thus the family system has to adapt not only to the care of a child with a life-limiting condition but also has to accommodate the adolescent's quest for independence, challenging not only the family order but often leaving parents feeling disempowered.

The challenge in palliative care is to provide adolescents with age-appropriate respite whilst acknowledging their often unique and changing needs. Findings of research relating to respite in adolescents with psychiatric conditions (Burns *et al.* 1995) and those with severe intellectual disabilities (White & Hastings 2004) dating back several years have been reported, however the findings of these reports are not of significance to this study and to date the specific respite needs of adolescents in palliative care has not been subjected to inquiry. However, as children with long-term conditions are now living longer and into adolescence, families require more intensive services over a longer period of time including respite care (Neff 2009).

2.9.2 Respite care for older people

A focus for respite-based research is the specialty of care of the older person, however the respite needs of older adults and their carers differs significantly from those caring for a child with life-limiting condition. The physical, psychological and social aspects of providing respite care to the two groups are vastly different and this is demonstrated in the findings of

two systematic reviews of respite care for older people (McNally *et al.* 1999; Mason *et al.* 2007).

A review of respite care in older people (McNally *et al.* 1999) examined 29 studies on respite provision to establish its effect on carers. It is important firstly to acknowledge that this review was conducted 14 years ago and thus the articles reviewed pre-date this. The majority of the articles included were reported in social work and geriatric journals with the majority of articles focusing on the experiences of stress and burden on carers; many were methodologically poor/limited and for example had small samples, or no control over variables. This review concluded that respite care as an intervention is often hard to isolate and interpret but that a more ‘carer-centred’ approach was required in the provision and evaluation of respite care.

A later systematic review by Mason *et al.* (2007) also focussed on the care of older people and their carers and reviewed community-based respite care provision. This paper aimed to identify and evaluate different models of effective respite care for older people (Mason *et al.* 2007). Although undertaken in the UK, their systematic review revealed that the majority of evidence on respite was obtained from the USA. Types of respite services evaluated included day care, host family, in-home, institutional and video respite. They concluded that respite provided only modest benefits for certain subgroups, however no reliable evidence was found to support that respite adversely affects care recipients. They also found that carers were generally very satisfied with the respite care provided. The report concluded that respite neither benefits or adversely affects care recipients but there is a lack of UK-based relevant good quality controlled evaluations for all types of respite care. They suggested that measures used should recognise that both older people and their carers have joint and separate interests and aspirations, nonetheless studies should aim to target outcomes that are relevant to both thus reflecting the needs and experiences of both the recipient of respite and their families. Findings of this study whilst interesting may not be transferrable to Ireland where the health system differs significantly and different services are available to families.

The authors of both of these reviews took an empirical stance of their examination of the research pertaining to respite care in older people and recommended more quantitative,

methodologically sound studies. The very nature of systematic reviews, seeking an evaluation of services and financial evidence of efficacy, is fraught with difficulties. The concept of respite is poorly defined in both papers and refers essentially to respite services. Implicit in both reviews is that the carer is the beneficiary of ‘respite’ rather than the patient. Based on the findings of these two reviews the findings of research in older person care is not usefully transferrable to children’s palliative care in Ireland as not only does the physical care of an older person differ significantly from the care of a child, respite options explored in older person literature are not appropriate or available for children with life-limiting conditions. Furthermore, both of these papers emphasize the benefits for the carer whereas the view of the child and family and resultant family systems approach seen in children’s palliative care further distinguishes the care of older adults from the specific and unique respite needs of children with life-limiting conditions and their families.

2.9.3 Respite care in adult palliative care

Although many service-users in palliative care are older people there are still distinct differences between how respite care is perceived and provided to the two groups. Ingleton *et al* (2003) suggest that in palliative care the duration and quality of caring is often different and dictated by a shorter trajectory of care need (Ingleton *et al.* 2003).

In palliative care some work has been undertaken to define and describe respite care as it relates to the adult specialty (Harding & Higginson 2003; Skilbeck *et al.* 2005)¹⁸. According to Ingleton *et al* (2003) although often regarded as a valuable resource, the assumption is that respite is good for patients and their families; however, there is little evidence to support this. The authors suggest that in palliative care there is a blurring of the definitional boundaries between respite and symptom control as reasons for referral. As a result of this, referral for respite care to specialist palliative care services may reflect the healthcare team’s need for support rather than helping informal carers by providing respite care. Ingleton *et al.* (2003) further suggest that in order to evaluate the effectiveness of respite in palliative care there is a need for clear definitions of the content and model of services. At present respite care is delivered in a diverse range of settings with wide variations in the pattern and mix of voluntary and statutory services and specialist and non-specialist services. Ingleton *et al.*

¹⁸ A more recent publication seeks to map the meaning of respite in adult palliative care Wolkowski A., Carr S. and Clarke C. (2010) What does respite care mean for palliative care service users and carers? Messages from a conceptual mapping. *International Journal of Palliative Nursing* 16(8), 388-392.

(2003) conclude that “*despite the implicit assumption of its worth, the evidence for efficacy of most respite services in promoting carer’s well being is equivocal*” (Ingleton *et al.* 2003) p.569. This is significant as it concurs with the findings of the two systematic reviews undertaken in older person care reported above. The findings from this review also confirm that there are significant differences in the way in which respite care is provided and viewed in adult and children’s palliative care and that, whilst interesting, findings of research conducted within adult services are not transferrable to the specialty of children’s palliative care.

2.9.4 Respite in children’s palliative care

Although respite has been identified as an ‘essential’ component of children’s palliative care providing benefits for both the child and their family (Craig *et al.* 2008; ACT 2009a), there is currently little evidence to support this assertion. Indeed, ambiguity surrounding the meaning and definition of the term is a key feature of much of the literature on respite in children’s palliative care (ACT 2003; MacDonald & Callery 2004; Nageswaran 2009; Neff 2009).

2.9.5 The language of respite in children’s palliative care

In Ireland, the term respite is culturally acceptable and seems to be understood and accepted by parents (MacDonald *et al.* 2006) whereas in the UK the term has been found to have negative connotations as it implies a burden of care or an inability to cope (Murphy 2001; Brown 2007). According to Thurgate (2005) parents struggle and find all of the terms used to describe respite unacceptable (Thurgate 2005); however, a compromise seems to be the use of the term ‘short break’ which has been embraced by organisations such as ACT (ACT 2009a)¹⁹. Despite being raised as an issue there is currently no published evidence to support the use of one term over another.

ACT (2009) point out that the term ‘respite’ has been used widely to represent many different services from home help through to admission for inpatient care (ACT 2009a). This ambiguity is one of the major challenges of research in this area. The terms ‘respite’ and ‘respite care’ are often used interchangeably as Ingleton *et al.* (2003) point out, the terms often referring to both an outcome and a service (Ingleton *et al.* 2003). An example of this is

¹⁹ Further confirmed in ACT (2012) *Children’s Palliative Care: Descriptions and Definitions*. Association for Children with Life-threatening or Terminal Conditions and their families.

Merriman & Canavan (2007) who, in attempting to define respite, describe respite services such as informal help from friends and family; formal respite care in the service user's home; out of home respite facilities; recreation and holiday breaks (Merriman & Canavan 2007). Neufeld *et al.* (2001) discuss this and in order to distinguish between the two concepts describe respite as “*an individual's perception of having a break*” (Neufeld *et al.* 2001)p.234 whereas ‘respite care’ is a service (Neufeld *et al.* 2001). This distinction allows the two concepts of ‘respite’ and ‘respite care’ to be examined further.

2.9.6 Respite

It is evident from research already conducted that respite is perceived to be invaluable to, and essential for, families caring for a child with a life-limiting condition (Davies *et al.* 2004; Eaton 2008; ACT 2009a). Davies *et al.* (2004) noted that respite provided parents with a break from the physical and emotional toll of caring for their ill child along with the accumulating uncertainties and frustrations and offered a break from providing physical care. MacDonald and Callery (2004) support this by suggesting that as no one definition exists, healthcare professionals need to be aware of the different meanings of respite to different people.

Rather than defining respite, other authors describe how parents spend their time away from their child. In the Microsystem of the FSF, parents are reported to appreciate a defined period of respite that provides them with an opportunity to plan their time away from their child with the comfort of knowing that their child is safe and being well-cared for (MacDonald & Callery 2004). The purpose of respite is to provide parents with a break enabling them to rest and replenish, enabling them to continue to provide care and thus maintain the family unit. Parents reported using their time away from their sick child to sleep (Yantzi *et al.* 2006; Eaton 2008), spend time with their partners (Olsen & Maslin-Prothero 2001; Steele 2002) , shop (Olsen & Maslin-Prothero 2001; MacDonald & Callery 2004) spend time with their other children (MacDonald & Callery 2007) and to be a ‘normal’ family (Davies *et al.* 2004; MacDonald & Callery 2004). Healthcare providers may need to approach respite support for these families in different ways as many of those caring for a child with a life-limiting condition may not wish to be separated from their child when life is short and therefore there may be no benefit in offering traditional respite care to these families (MacDonald & Callery 2004).

2.9.7 Respite care as a service

A mix of statutory and voluntary providers of care provides the majority of respite services for children with life-limiting conditions in Ireland. In particular for children whose diagnosis is ACT category 4, respite where available is often provided through the disability services. Respite care for the child and family should be viewed as central to quality care provision and can take place at any stage of the illness trajectory (Corkin *et al.* 2006) and should be designed to meet the needs of the whole family. Despite this somewhat idealistic view, Neufeld *et al.* (2001) suggest several reasons why parents may be reluctant to use respite services. These include: guilt and concern about leaving its child with a stranger; loss of privacy; anxiety and fear of separation; and previous experience (Neufeld *et al.* 2001). Other work suggests that parents' views and experiences of respite care differ considerably (Olsen & Maslin-Prothero 2001) and change over time (MacDonald & Callery 2004) with the need for respite care increasing as the functional limitations of children with special healthcare needs increases (Nageswaran 2009).

Research aimed at examining the cultural aspects of the meaning of respite care to both parents (mothers n=19; fathers n=7) of children with complex conditions aged 6-18 and the providers of care (nurses n=13 and social workers n=4) was conducted using an ethnographic approach (MacDonald & Callery 2004). Parents described three distinct types of respite services: short breaks provided by the extended family or friends; short breaks (3-4 hours) provided by an agency (usually in the home) and overnight respite out of the home (MacDonald & Callery 2004). Parental views on respite were compared to those of nurses and social workers. Only social workers felt the best place to provide respite care was in the home. In this study all parents with the exception of one expressed a wish to have overnight out of the home respite available (MacDonald & Callery 2004). This research was conducted with families of children with complex care needs and not specifically those with life-limiting conditions. It is possible that parents may have felt differently if they had known that their child had a short time to live. MacDonald and Callery (2004) conclude by suggesting that healthcare professionals need to be aware of the different meanings of respite to different people. This paper reports only one aspect of one theme of a much larger research study and therefore it is difficult to assess fully the implications for practice. A subsequent paper relating to different aspects of this original research has also been published (MacDonald &

Callery 2007). In this later paper using the same dataset the authors describe mapping respite services over time to meet the needs of families (MacDonald & Callery 2007).

In a paper primarily dedicated to the features of hospice and home respite care as they relate to the funding of services Eaton (2008) undertook interviews with 11 families receiving respite care through a palliative care service in either location. This unspecified qualitative element of a larger research project assessed family's experiences of the services provided. The author found that the care of the sick child impacted on the whole family including siblings. Respite was an essential component of care which families valued regardless of location. Parents were responsible for the physical care of their child and the emotional stress and 'burden' of caring for their child impacted on all aspects of their family life and in particular disrupted their sleep. Parents preferred continuity in and flexibility of services and staff with whom they were familiar. Better communication was suggested as a possible improvement in service.

Steele (2000) found that the majority of families had received respite care in various locations and in general, were grateful for the care they received (Steele 2000); however, parents' needs for respite are not static, with McDonald and Callery (2007) demonstrating changes over time as uptake of respite services increase with age (MacDonald & Callery 2007). An Australian study comparing the parents of children with cancer and those with other non-malignant life-threatening conditions found significant differences in the respite needs of the two groups. Most of those with a child with cancer did not use respite services whereas 40% of those in the other group regularly used respite services (Monterosso *et al.* 2007b), which further confirms that there is not a 'one size fits all' approach to meeting the needs of children with life-limiting conditions. The respite needs of children with life-limiting conditions and their families need to be assessed and regularly reviewed in order to ensure that they are being met.

McConkey *et al.* (2007) interviewed 30 parents of children with disabilities with complex needs living in Northern Ireland. The methodology employed and the age range of the children is not clear from this paper. Data were collected through telephone interviews with parents (n=15) and face-to-face interviews (n=15). Parents reported undertaking a range of

technological tasks related to their children²⁰. It is not possible to assess the methodological rigour of this research as insufficient information is provided in the report; however, many findings are aligned to those in other papers reviewed here including the description of respite as a service. McConkey *et al* (2007) suggest that when planning respite care that the aspirations and opinion of parents and where possible that of the children or young person should be reflected in all decision-making which whilst laudable, is very difficult to achieve. ACT (2003) also recommend meeting family's wishes and furthermore suggest that health services need to identify and fund the most appropriate facilities in accordance with these (ACT 2003). The research concluded with several key messages parents wanted service providers and planners to hear. Among these was that they wished to care for their child at home and that they needed more locally-based respite services (McConkey *et al.* 2007).

Whilst it is clear that respite services are of value to the parents of children with life-limiting conditions, these need to be tailored to meet the needs of the child and family. The provision and utilisation of respite varies and is dependent on a number of factors including the child's diagnosis and the subsequent availability of services. The preferred location of the majority of parents for the provision of respite care is the family home.

2.9.8 Location of respite for children with life-limiting conditions

It has been suggested that there is a link between the location of respite care and the level of break that parents experience (Olsen & Maslin-Prothero 2001). The location for the provision of respite care can be broadly divided into two categories: home-based respite and out-of-home respite. Parents may use a variety of types and locations of respite care in order to meet their child's needs.

Out-of-home respite

Options for out-of-home respite for children with life-limiting conditions include respite in centres provided by voluntary organisations, disability services (Neufeld *et al.* 2001), where available and acceptable to parents, in a children's hospice (Davies *et al.* 2004) and in some cases in acute hospitals (Robinson *et al.* 2001). Although some families are reluctant to use

²⁰ Tasks included: PEG tube feeding; tracheostomy care; and suctioning

out-of-home respite, where parents have had access to such services they state a preference for more locally available facilities (DOHC/IHF 2005; McConkey *et al.* 2007).

Respite can be beneficial to both the parent and the child however and it has been reported that a lack of appropriate support for parents, such as respite, can result in increasing levels of social admissions to acute children's hospitals (Olsen & Maslin-Prothero 2001). The location of care can also have an impact on the level of break that parents experience.

Respite in a Children's Hospice

Eaton (2008) reported that whilst families found the word 'hospice' frightening their experience of using a children's hospice for respite was helpful (Eaton 2008). Similarly, a study by Davies *et al.* (2004) reported that children, siblings and parents all benefited from respite services provided in a children's hospice. They undertook an action research project initially using postal questionnaires (65:144 responses) followed by interviews with the families (n=18) utilising the services of a children's hospice service in Canada. Evaluation of parent's experience of using hospice-based respite services revealed that parents found benefits for their child such as a safe environment, enabling socialisation and promoting independence. They also noted benefits for siblings where hospice-based respite provided a break for parents and reduced resentment of the sick sibling. The main benefits noted by parents were a break from the usual routine, being able to sleep, freedom, time for themselves and their families and a sense of 'normalcy'. Parents also noted respite provided learning opportunities with other families finding comfort in the fact that others lived similar lives to them. Hospice-based respite was difficult for families who lived in remote rural locations. (Davies *et al.* 2004). One of the advantages of the participatory nature of this action research was that feedback to staff so that they were able to implement the necessary steps to address the issues raised by parents during the research process. Davies *et al.* (2004) also reported that parents had difficulty when a planned respite break was cancelled at short notice, even if this was to accommodate a family with a child with 'palliative care' needs. Similar issues have been reported elsewhere when parents are reliant on hospices to plan respite breaks (Burne *et al.* 1984).

In a study by Grinyer *et al* (2010) the views of 11 families (24 family members) using respite services at a children's hospice were elicited using mixed methods research. Parents reported being reliant on hospice staff for allocation of much needed respite and perceived staff as being powerful as it was they who decided on the frequency and type of in-patient respite available to families (Grinyer *et al.* 2010). This concurs with findings in an earlier study where parents sought clarity regarding how respite was allocated by a children's hospice (Eaton 2008). Others report that parents simply want more or longer respite breaks (McConkey *et al.* 2007) and would welcome respite that was available at short notice to help with any unexpected events (MacDonald & Callery 2004). Hospice care in Ireland is limited as there is only one children's hospice service which is relatively new and therefore the role of children's hospices in Ireland has yet to be evaluated.

The findings of these studies raise several key issues for children's hospice services to consider. In particular they indicate a need for clarity regarding access to services and the allocation of inpatient respite. Geographical inequities and how these can be addressed also need to be considered. Hospice-at-home services are one way to provide respite services to children in their own homes.

Home-based respite

There is strong evidence in the literature to support home as the parents' location of choice for care (Steele 2000; Heaton *et al.* 2005), respite (Sherman 1995; Eaton 2008), and ultimately death (DOHC/IHF 2005) of a child with a life-limiting condition. Some authors suggest that at the Macrosystem level there has been idealisation of the home as the location of care where both the public and policy makers have put parents in an invidious position as regardless of their circumstances they feel obliged to care for their child at home often with inadequate support (Carnevale *et al.* 2008). However there is a growing body of evidence to suggest that providing care at home can result in a change in the meaning of home for the family (Kirk 1998; Yantzi *et al.* 2006). This change of meaning of 'home' for the family has a lasting impact on all members of the family. The home environment is not simply a place in which a family lives but has many meanings to the family such as security, privacy and identity and varies according to socio-demographic variables such as family size, ethnicity

and social class (Williams 2002). Others suggest that ...“*home is a place of contested, complex and multiple meanings and experiences*” (Yantzi *et al.* 2006)p.46.

Social and demographic changes in recent years also make caring at home more challenging (Yantzi *et al.* 2006). Both homes and families are smaller as a result of this; the dynamic of the family system has changed. Those from other parts of the family system (such as health carers in the Mesosystem) step in to provide the sometimes complex care and support that historically would have been provided by family members. Houses are now smaller and therefore, where care is available, there may not be space for the necessary equipment (Kirk 2001; Kirk & Glendinning 2002; Kirk *et al.* 2005). In Ireland, many women, who traditionally would have provided support, are now working outside of the home and are required to do so in order to meet the increasing living costs (Kennedy 2001; Daly 2004). The migration of family members is more common thus impacting on the ability of the wider family system to provide support. Some work has been undertaken internationally exploring the economic impact of caring for a child long-term (Lowson *et al.* 2007) which suggests that the financial impact of caring for a sick child puts a strain on many families. These findings have been confirmed by others (Steele 2005; Knapp & Contro 2009).

Decisions made in the Macrosystem by politicians and policy-makers impact on the family system at all levels. The increasing emphasis on the provision of home-based care by policy-makers is based on the premise that it is more cost-effective for health services but is also validated by parents desire to care for their child at home. What is more difficult to measure is the impact of the strain that the provision of this care places principally on the parents as primary carers but also on the entire family system (Carnevale *et al.* 2008; McIntosh & Runciman 2008). MacDonald and Callery (2004) found that parents of children with complex healthcare needs who had short breaks in their home often spent time prior to the arrival of the carer conducting complex care in case the carer was not experienced and often equated these carers to ‘babysitters’ (MacDonald & Callery 2004). Other parents reported that in-home respite care was hampered by high staff turnover (Robinson *et al.* 2001) causing parents further stress.

Despite the challenges, short-term respite for children at home is often highly valued by parents caring for a child with prolonged illness (DOHC/IHF 2005; ACT 2009a) and is frequently cited as their parents' preferred location of care (Sherman 1995; DOHC/IHF 2005; Craig *et al.* 2008; Eaton 2008). Parent participants in a study of respite by McConkey *et al.* (2007) urged parents to remain in control by deciding who comes into the home and to stand by what they believe is in their child's best interests (McConkey *et al.* 2007). Parent preference and control over their home environment therefore need particular attention when providing care in the family home where caring for a sick child has an impact on all aspects of family life.

2.10 Impact of caring

Caring for a sick child for a prolonged period of time at home inevitably interrupts sleep, meals and family routines (Eaton 2008) and can adversely affect health and relationships impacting on every aspect of family life (Sherman 1995; Yantzi *et al.* 2006; McConkey *et al.* 2007). Families often become isolated from friends and relatives as they become consumed by the tasks of caring (Davies *et al.* 2004; Rodriguez & King. 2009). Everyday tasks can become complex, for example travelling with a sick child can be difficult and further hampered by the need for equipment preventing some families from leaving their homes (Kirk & Glendinning 2002; Heaton *et al.* 2005; Yantzi *et al.* 2006). A systematic review was undertaken (papers reviewed dated from 1976-2011 with 21 of the 32 papers pre-2000) (McCann *et al.* 2012) looking at the daily patterns of time use for parents of children with complex care needs. It estimated that 77% of parents spent an average of one hour a day (excluding appointment time) travelling and attending out patients appointments for children aged 2-6 with complex care needs (Crettenden 2007; McCann *et al.* 2012). Whilst interesting, this research was undertaken in Australia and may reflect the relative geographical isolation and greater distances to healthcare centres; however, it is of relevance in Ireland where some rural locations can be at least a four hour journey to the paediatric unit in a tertiary hospital.

There is also evidence that parents live with regular sleep disturbance and chronic sleep deprivation (Heaton *et al.* 2005; Eaton 2008; Rodriguez & King. 2009). It has been suggested that such is the impact of fatigue caused by sleep deprivation on the parents of children with life-limiting conditions that it affects every area of family life (Steele & Davis

2006). Grounded theory work undertaken in Canada with eight families of children with life-limiting conditions revealed that sleep deprivation and the ensuing fatigue impacted on the physical, mental and psychological well-being of parents who were the main carers for their child (Steele & Davis 2006). Whilst acknowledging a dearth of research in this particular area of children's palliative care, the authors suggest a range of initiatives that may help parents manage their fatigue. Where available they suggest night respite. Other interventions suggested are exercise for parents, short breaks in their own home and the introduction of diversional activities. The authors conclude by suggesting parental fatigue in children's palliative care needs further exploration (Steele & Davis 2006).

Studies have shown the unremitting care responsibilities of parents caring for a child with a life-limiting condition and the adverse impact that this can have on not only parents' physical health (Steele 2000; Steele 2005; Yantzi *et al.* 2006; Monterosso *et al.* 2007a; Eaton 2008) but on their mental health (Rodriguez & King. 2009). Other authors support this view and have reported stress and depression in mothers caring for children with life-threatening disability (Redmond & Richardson 2003). Another stress reported by parents is the challenge of having to fight for the services that their child requires (Gibson 1995; McConkey *et al.* 2007).

Stress on parental relationships is also reported by several authors (Stein *et al.* 1989; Steele 2005; Yantzi *et al.* 2006; McConkey *et al.* 2007; Rodriguez & King. 2009) and can be exacerbated by other factors related to the care of their sick child such as strained family finances and limited employment opportunities due to caring responsibilities (Stein *et al.* 1989; McConkey *et al.* 2007). Parents also report many hidden costs directly and indirectly associated with caring for their child (Steele & Davis 2006). Families who have children with long-term conditions are often faced with considerable economic stress and burden that often increases over time as the child's condition becomes more severe or complex (Redmond & Richardson 2003). This care is all set within the context of a family environment that is characterised by low support and high conflict (Deeley *et al.* 1998). Parents describe their inability to maintain a social life not only due to the care needs of their child (Steele 2005; Rodriguez & King. 2009) but also due to the associated costs (Steele & Davis 2006).

The combination of these factors is often referred to as the ‘burden’ of care, (Ingleton *et al.* 2003; DOHC/IHF 2005); however, particularly in children’s palliative care; parents have objected to this term as it implies an onerous task that they themselves do not perceive as such (Steele & Davis 2006; ACT 2009a). Despite this, the term continues to be used in the literature related to children’s palliative care; for example, Nageswaran (2009) suggests that respite care seeks to decrease the ‘burden’ on caregivers enabling them to have a break from caring for their child (Nageswaran 2009). In children’s palliative care there is an expectation that parents will provide care for their child (Truffey *et al.* 2007) despite some of the care being complex technological care that would have previously been undertaken only in a hospital setting (Kirk, 2005).

2.10.1 Technology-dependent children

With improvements in treatment and the development of technology, children with complex life-limiting conditions are living longer often being cared for in their own home²¹. Despite the demands of treatment the majority of children cope well although this is influenced by their family, society and culture (Thompson & Gustafson 1996). Their care primarily falls to their parents and in most cases the mother is the primary carer (Stein & Woolley 1990; O’Brien 2001; Redmond & Richardson 2003; Steele & Davis 2006). Bowlby’s attachment theory (1969) suggests that for mothers and their children there is a need for both the child to establish a sense of security and for mothers to provide this (Bowlby 1969). Parents are often expected to learn and take on sometimes technically complex nursing procedures and to develop nursing skills in order to provide care for their sick child (Kirk & Glendinning 2002; Heaton *et al.* 2005; Kirk *et al.* 2005; Rempel & Harrison 2007).

In a grounded theory study of the experiences of being the parent of a technology-dependent child, in-depth interviews were conducted with 23 mothers (nine jointly interviewed with fathers) and one father of 24 technology dependent children and 44 professionals involved in the child’s care (Kirk 2001). These children whilst technology-dependent did not all have life-limiting conditions. Findings report that parents failed to understand the realities of caring for a technology-dependent child at home but felt an obligation to care for their child viewing this as part of parenting. Once competent in meeting their child’s needs parents

²¹ Whilst not all children who are technology-dependent have life-limiting conditions, many children with life-limiting conditions are technology-dependent.

found their position to be ultimately powerful particularly when providing care in their own home (Kirk 2001). Staff reported the challenges of working with this group of parents who were 'experts' in this child's care. Parents gained skills and knowledge that resulted in them not only knowing their own child but were also knowledgeable from the training and experience of caring for their child. This combination of assets enabled parents to not only assess staff skills but to judge their level of expertise (Kirk 2001). Families in this study may not be representative as they were self-selected. Despite this research being undertaken in Manchester a city with a large ethnic minority population, only one family included in the study was from this background. Subsequent papers relating to different aspects of this original research have also been published (Kirk & Glendinning 2002; Kirk *et al.* 2005). These findings are not exclusive to this study. A US study reported parents of technology dependent children became more comfortable and confident with technology over time (O'Brien 2001). Similarly a study in Ireland (Redmond & Richardson 2003) also reported that mothers acquired sophisticated nursing and physiotherapy skills (Redmond & Richardson 2003). Another commonly reported stressor for parents of technology-dependent children was the challenge of timely access to (Redmond & Richardson 2003; Kirk *et al.* 2005; McConkey *et al.* 2007) and storage of (O'Brien 2001) appropriate equipment and supplies (Kirk 1998; O'Brien 2001).

Using a purposive sample of 36 families and undertaking semi-structured interviews Heaton *et al.* (2005) also explored the experiences of families caring for a technology-dependent child. Not all children in this study had a life-limiting condition indeed many were capable of self-care. Parents reported the time-consuming nature of the technical care that they administered and the impact that providing care had on their sleep, work, finances and relationships. They also reported providing care for their child if they were hospitalised (Heaton *et al.* 2005). The study aimed to examine the temporal organisation and time consequences of the care required by technology-dependent children on their families. The sampling strategy of this study ensured that ethnic minority groups were included. The authors report several methodological anomalies such as poor record keeping of those approached regarding participation and more significantly that not all interviews were recorded causing doubt over some of the data which presumably relied on notes and memory rather than accurate recording and transcription. Parents provided technical care which was found to be time consuming and also required certain skills. Twelve of the children received

technical care at school demonstrating that it is not only parents who are capable and competent to provide this level of care.

Findings from these papers indicate that within the Microsystem, over time parents become very skilled at providing technical care and grow in confidence once they have developed new and highly technical skills by either trial and error (Nelson 2002) or by being taught by or observing healthcare professionals (Gibson 1995; Steele 2000; O'Brien 2001; Steele & Davis 2006). Developing skills and carrying out this care is one way that parents are able to take control of their situation. Control and empowerment are closely aligned. Gibson (1995) assessed the process of empowerment in 12 mothers of children with chronic neurological conditions. Using a grounded theory approach, she found that mothers developed a strong maternal bond with their child. Over time mothers assumed responsibility for caring and developed maternal knowing which enabled them ultimately to take charge of their child's care, whilst developing mutual respect for the clinicians involved in their child's care. Four specific factors in the process of empowerment are identified: values (sense of family); beliefs (hope and optimism and belief in their own abilities); determination (strong will and motivation) and experience (past life experience, education and their experiential learning to care for their child) (Gibson 1995). Gibson (1995) also noted the level of isolation mothers felt. Providing this care is time-consuming and often impacts on the quantity and quality of time spent with their well children.

2.11 Siblings of children with life-limiting conditions

Living in a home with a brother or sister with a life-limiting condition impacts on many aspects of family life and for those living in the Microsystem of the family, confers a '*different type of childhood*' (Heaton *et al.* 2005) p.447. Sibling relationships are possibly the first, most intense and usually the longest peer relation that any individual has and are an integral part of childhood development (Nielsen *et al.* 2012). The impact of having a sibling with a chronic condition is dependent on gender and birth order with sisters and brothers reacting differently to having a sibling with a life-limiting condition (Dauz Williams 1997; Murray 1999).

Well siblings of children with life-limiting conditions may not only receive less attention from their parents but may also be involved in child-minding other siblings to allow their parents time with the sick child or may take on a role in the care of the sick child themselves (Heaton *et al.* 2005). In research by Steele (2000) siblings were generally sad that their brother or sister was dying, but also upset or angry that their parents and others had focused the majority of attention on the sick child; however, in general for their ages, siblings of children with life-limiting conditions were less demanding than other children (Steele 2000). Well siblings are reported to be very empathetic (Nielson *et al.* 2012); it is suggested that this is as a result of parents' reallocation of their attention and time to the sick child or because well siblings naturally take on more responsibilities having grown up caring for a sick sibling (Nielson *et al.* 2012).

A worrying feature of a study of 52 siblings of children with life-limiting conditions was that researchers found despite parents perceiving siblings to be coping well, that this was not the case (Stallard *et al.* 1997). Siblings reported constant worry and sadness yet the majority reported being unable to talk to their parents about their concerns. Some (14%) were able to speak to extended family (located in the Mesosystem) usually grandparents; however, 48% of well siblings reported not talking to anyone about their concerns (Stallard *et al.* 1997). In order to avoid misunderstanding, brothers and sisters of children with life-limiting conditions need adequate information about the nature of their siblings' condition and its treatment (Contro & Scofield 2012). Fear for their health, the health of others, anxiety and isolation may result from misunderstanding. These fears may be well-founded as some life-limiting conditions are genetic (such as cystic fibrosis) and well siblings may have genuine concerns about their own health (Cummings 2002). Healthcare professionals can provide support to healthy siblings by providing honest answers to questions and by encouraging parents to spend time with their other children (Murray 1999). In particular younger male siblings of children with life-limiting conditions have been found to have the greatest need for good communication (Stallard *et al.* 1997).

Often the care of a child with a life-limiting condition consumes parents leaving little time for the other children of the family. This can result in well siblings believing that their sick brother or sister has a more central role in the family and that they are less important (Knapp & Contro 2009); this can lead to resentment (Sloper 2000). In a study of children with

cancer, siblings reported feeling stressed and having periods of anxiety and depression (Murray 1999). Another researcher found that siblings reported a bad atmosphere at home between their parents, made worse by cramped living conditions caused by the need for the equipment associated with the care of the sick child (Heaton 2005). Coping strategies employed by the siblings included talking to others, wishful thinking and attention seeking behaviour (Murray 1999). Several studies report that respite for the child with a life-limiting condition can alleviate some of the stresses associated with parents' caring role, enabling them to spend time with well siblings (Neufeld *et al.* 2001; Olsen & Maslin-Prothero 2001; Davies *et al.* 2004; MacDonald & Callery 2004).

2.12 The role of extended family in respite

In FST the family unit is part of a wider societal system where the family are influenced by their surrounding culture (Lewis and Prescott, 2006). The extended family, the health and social care workers providing care and the local community are an integral part of the Mesosystem. In children's palliative care the role of the extended family in caring for the sick child has been explored (Contro *et al.* 2002; Redmond & Richardson 2003; Yantzi *et al.* 2006) including those with cancer (Klassen *et al.* 2010) and those who are technology dependent (O'Brien 2001).

Findings of research with the parents of children with complex care needs found that whilst prevalent in infancy, short breaks provided by family members and friends dwindled over time as the child grew older (MacDonald & Callery 2004). Parents compared this type of care to baby-sitting rather than care-giving and expressed reluctance to access this help for fear of imposing, coupled with a lack of confidence in others ability to cope with their sick child. Another consideration was that as their child got older and bigger, care became more difficult and grandparents in particular felt less able to manage the physical demands of care (MacDonald & Callery 2004).

The issue of grandparents caring for, and raising well children has been subjected to research (Grant 2000), other studies have assessed the role of grandparents in caring for children with special needs such as developmental disabilities (Katz & Kessel 2002) and research has also been undertaken assessing the impact of bereavement and grief on grandparents (Gilrane-

McGarry & O'Grady 2011). Despite being recognised as important (Monterosso *et al.* 2007b) there is a paucity of research specifically assessing the role of grandparents in the care of children with life-limiting conditions. This includes the need to include them in communication about the child's condition (Browning 2002).

Using a qualitative descriptive design, Israeli grandparents (n=16) were interviewed using a structured questionnaire as a guide. It was found that whilst some grandparents provide an important source of support to the parents of children with life-limiting conditions, this is not always the case, particularly when there are impaired intergenerational relationships or issues with geographical distance (Katz & Kessel 2002). In some cases the support provided is financial, in others babysitting. Maternal grandmothers were found to visit more frequently with many providing direct help. Katz and Kessel (2002) argue that indirect help is provided simply by their involvement and acceptance of the child. Interestingly they also found that whilst many grandparents accepted their grandchild with disabilities they displayed negative attitudes to others with disability. Furthermore the level of paternal grandparental involvement was found to be directly related to their relationship with their daughter-in-law. In general grandmothers were found to be more involved than grandfathers with all grandparents expressing frustration that they could not offer more emotional and practical support. Grandparents reported that it was their adult children who prevented them from being more involved (Katz & Kessel 2002). Cultural differences may mean that these findings are not directly transferable.

Interestingly, Steele (2000) found that many families in her study replaced extended family support by developing friendships with other families in a similar position who were able to provide support and information and empathy (Steele 2000). These findings were confirmed by others (O'Brien 2001).

2.13 Health and social care workers in respite care

Ultimately, regardless of location, respite care requires that parents handover their caring responsibilities to others. In order for them to feel comfortable with delegating this responsibility it is essential that they are certain that the care provided will be equal to their own standard and will follow their established pattern (Neufeld *et al.* 2001). Thompson et al

(2003) conducted research focusing on how trust develops and suggest that parents develop one of three outcomes: 'General trust' where their expectations of care were met, 'Global trust' where parental expectations were exceeded and 'Distrust' when parents' expectations of care were not met. These labels were found to be changeable depending on what parents observed, and parents continued to be vigilant (Thompson *et al.* 2003). The researchers identified that parents' expectations were based on several factors including their previous experiences of hospital and point out that parents not only assess technical competence but also sub-consciously evaluate every intervention between healthcare professionals and their child. This evaluation provides parents with the opportunity to develop trust. Parents also judged staff on whether they met parental needs and expectations such as being kept informed and respecting privacy. In particular, friendly, caring staff who saw the child behind the illness and provided continuity of care were important to parents. Inhibiting factors to parental trust included staff who exhibited negative behaviour towards either the parents or the child. This included not enabling parents to be with their child by not providing meals or sleeping facilities for them and expecting parents to perform procedures for their child which they did not feel comfortable providing (Thompson *et al.* 2003).

It has been suggested that building a trusted relationship with respite service personnel is the best form of support for families (McConkey *et al.* 2007). In research undertaken in Ireland looking at the respite needs of children with intellectual disabilities (MacDonald *et al.* 2006), families ranked confirmation from provider that services would maintain the dignity of the cared-for person as important prior to accepting a respite service. Families were reluctant to use facilities where they were unsure or unfamiliar with the support workers. They relied on reports of other parents to assure them that their child's personal care needs would be met with skill and dignity (MacDonald *et al.* 2006). Addressing these issues poses challenges for the providers of respite care. Reputation is important and families need the time and connections to enable them to make these judgements. As with all manpower issues the practicalities of ensuring familiar and trusted staff are rostered and available is particularly difficult. Some similar findings from respite in adult palliative care are reflected where caregivers are reported to consider rejecting services that do not meet their needs or that are not of a suitable quality. Key aspects of providing respite are services that are consistent yet flexible and responsive, address the needs of the person they care for, respect their individuality and promote good quality of life (Ingleton *et al.* 2003). For families there is

great importance in maintaining their child's routine regardless of who or where care is provided (Steele 2005; MacDonald *et al.* 2006; Eaton 2008). Providing care at home not only minimises disruption to the families' routine it has also been found to improve the families, and specifically siblings', adaptation after the death of the child (Williams 2002).

Providing care at home to children with life-limiting conditions can be challenging for healthcare professionals. In the UK, both community paediatric nurses providing care and parents of children with special healthcare needs were asked to identify key issues in care provision (McIntosh & Runciman 2008). They identified that the development of good parent-professional relationships needs insight into the experiences of parents caring for their sick child and respect for their routines. This helped parents to have confidence in the levels of care by developing a partnership model (McIntosh & Runciman 2008). This was also a finding of Heller and Solomon (2005) who found that parents particularly liked their child to be known to the healthcare professionals caring for their child. This familiarity resulted in parents feeling that their child was receiving high quality care (Heller & Solomon 2005).

In many cases, at least initially, the healthcare professional that families know best is their General Practitioner. As life-limiting conditions in children are rare, the majority of GPs have little or no experience of providing this care. A postal survey in the UK assessing the role of GPs in end of life care for children found that the majority of respondents wanted to be involved in the care of these children but perceived there were barriers to being involved including a lack of experience and insufficient training. They were also concerned about being isolated from secondary care and poor communication and co-ordination. General Practitioners found this area of healthcare challenging and they needed support. GPs have an important role in providing essential symptom control and family support to families caring for a child at the end of life and early referral and good communication would assist in their provision of this care (Shaw *et al.* 2010).

Another major consideration for healthcare professionals providing care in a child's home is the need to acknowledge parents' expertise and experience. Through close contact in the privacy of their home mothers were found to know their child intimately and had the ability to know when their child was unwell. This maternal judgement is not always respected by

healthcare professionals (Callery 1997). Steele (2006) found that by using subtle clues parents knew when their child needed attention and became expert at reading their child's body language. Her findings confirm the earlier work of Callery (1997) who found that parents were very skilled at assessing their own child's healthcare needs by reading subtle changes in their child's appearance and behaviour (Callery 1997).

2.14 Voluntary organisations, the health system and the media

In the FSF the Mesosystem (providers of healthcare, extended family) is seated within the Exosystem (Lewis and Prescott, 2006). In the context of this research the Exosystem incorporates the organisations in which care originates such as voluntary organisations providing support for children with life-limiting conditions and the healthcare system at an organisational level. The work of these organisations, and the decisions made within them have a direct impact on the parents of children with life-limiting conditions. An example of this is the assessment criteria for entry to services or for the allocation of nursing and respite hours by staff working within the organisations. Whilst often relying on this care parents are often unable to have any impact on the decisions made which ultimately impact on their whole family system.

In the Exosystem the impact of the media and the dissemination of information are also featured. The provision of information to parents by healthcare professionals has been found to be diagnosis dependent with parents of children with cancer being more likely to be satisfied with the information given (Spencer & Battye 2001; Monterosso *et al.* 2007a; Monterosso *et al.* 2009). Whilst parents are reported to have difficulty in accessing information about their child's condition from healthcare professionals, they have been found to access the information that they require from other parents (Redmond & Richardson 2003; Davies *et al.* 2004; Steele & Davis 2006). Steele (2006) also found that finding information on services such as nursing and respite was initially difficult for families but that as time went on parents gained confidence and were able to make contacts and search out information effectively. Redmond & Richardson (2003) found mothers sought out other parents who had similar experiences (Redmond & Richardson 2003). Steele (2000) also found that once families knew how and where to get information, that they wanted to share this information with other families in similar positions. They spoke to support groups and other parents

individually in order to pass on the benefit of their own knowledge and experience of their experience altruistically hoping others would not have to go through the same (Steele 2000).

2.15 Respite in children's palliative care in the Macrosystem

In FST, the family unit is part of a wider societal system where they are influenced by their surrounding culture (Lewis and Prescott, 2006). The Macrosystem is made up of the broad beliefs and cultural aspects within which the family live. This includes all aspects of the community such as the cultural, socioeconomic and political factors that impact upon the child with a life-limiting condition and their family (Lewis and Prescott, 2006). The social system in which the child and family are situated and the wider social context influences their experiences of caring for their child with a life-limiting condition e.g. decisions regarding cuts in health spending ultimately impacting on services such as respite care.

All societies have a culture that gives its members an identity and a sense of belonging however it should not be assumed that all members of society view this belonging in the same way. Both within and between family members differing views of their culture exist. Whilst within each unique family every member has specific communication patterns, roles, rules, expectations and patterns of behaviour, the role and influence of ethnicity and culture on family functioning cannot be underestimated (Lewis & Prescott 2006).

Communities share aspects of culture, especially around important characteristics of life such as behaviour, illness and death. Culture has been described as a shared system of meaning (values, perceptions, expectations and lifestyle) built on the foundation of a common language and history, enabling the members of the community to function together (Brown & Dominica 2012). This description of culture infers that all aspects of community benefit from working together that has been found to be beneficial. Social connections described by Putnam (1995a) as social capital work between and among networks, neighbourhoods and communities creating a sense of belonging (Putnam 1995a, 2001; Bunting 2007). Putnam (1995a) suggests that issues with society such as crime rates, public health, human happiness and life-expectancy are all affected by the connections we have with friends, family, neighbours, co-workers and the community as a whole. In 1995, Putnam surmised that over time opportunities to build social capital were fewer and there was less involvement in the community, which had led to less social connections and more mistrust. He linked these issues to key factors such as: changes in family structure (divorce, mothers working outside of the home); suburban sprawl (people living and working further apart and therefore less likely to know each other) and electronic entertainment (increased time spent watching

television and using technology) (Putnam 1995b). This fits well with the notion of the FST and its interconnecting systems impacting on all aspects of family life. For families caring for a child with a life-limiting condition this lack of social capital and the connections and support that this brings have inevitably led to parents feeling isolated.

Yantzi (2006) points out that there is a very poignant paradox that by providing long-term care in the home that enables individuals with disabilities and chronic illness to live in the community, carers can often become spatially and socially separated from their communities with parents in some studies feeling imprisoned (Steele 2005; Eaton 2008). It is not uncommon for families caring for a child with a life-limiting condition to become isolated from friends and families as they become consumed by the tasks of caring (Eaton 2008). Yantzi (2006) found that mothers talked about being stuck and disconnected from their communities and were unable to leave the house easily. This added to the mother's feelings of isolation and concurs with the findings of other research (O'Brien 2001); however, other authors suggest that isolation may be self-imposed (Fisher & Goodley 2007).

A qualitative study of the challenges faced by the mothers (n=11) of children with physical and developmental long-term care needs using in-depth interviews was undertaken in Canada (Yantzi *et al.* 2006). Field notes also formed part of the data analysis. Despite 40 families meeting entry criteria only 11 mothers participated, raising questions about whether the group were representative of the available sample. Findings revealed that mothers had to deal with three distinct types of challenges. Physical challenges: such as accessing equipment; getting their child in and out of the car; and exhaustion and lack of sleep. Social challenges such as: Family and friends' knowledge, skills and expertise; Misconception that family and friends can provide respite due to a lack of training and skills; Family and friends can provide financial assistance and help with other children; Employment opportunities were hampered by the mothers' caring responsibilities and Service challenges: There was often a gap between the respite services provided and the needs of the mothers; Mothers did not always have faith in the skills of the care provider; More flexibility was needed; Mothers need to have confidence in the carers; Mothers in urban areas had greater access to out-of-home respite. The author concludes that providing care in the home for children with complex care needs has created the social and spatial isolation for mother caring. The rigidity of routine in caring for children at home is also highlighted where every trip out of the home has to be

meticulously planned (Yantzi, et al. 2006). Of importance to parents is how others in the community view their sick child. Parents attach importance to others in the community seeing past their child's condition and to see them as a person (Yantzi *et al.* 2006). Parents also described other people not understanding their reality adding to the sense of isolation.

Ireland has until recently been a predominantly homogenous society with a very strong cultural identity where the majority of people are white, Celtic and Catholic (Tracey & Ling 2005). In Ireland and particularly in palliative care many healthcare services and facilities were founded by the religious orders and as such there is a strong tradition of catholic influence (O'Brien & Clark 2005). Putnam found that the only area where social capital was higher was where people had religious affiliations (Putnam 1995a; Bunting 2007). In society in general he found trust was lower, altruism and community cooperation rare and friends fewer.

Putnam also found that immigration and ethnic diversity reduced social solidarity and thus social capital (Putnam 2007). It can be challenging when caring for families from different cultures and of different religious beliefs. This aspect of culture needs to be carefully considered, as it cannot be assumed that the parents of children with life-limiting conditions respite needs are the same regardless of culture however there is huge variation in racial and ethnic, religious beliefs, and lifestyle (Firth 2007). Despite this there is a dearth of evidence to support the care of families from different religious or cultural backgrounds. The lack of participation by these groups in research is pointed out as a limitation in several of the research-based studies included in this literature review (Kirk 2001; Heaton *et al.* 2005; Yantzi *et al.* 2006) with findings therefore unable to take account of their specific needs. One American study, however, found a higher use of respite services from parents of children from ethnic minority backgrounds (Nageswaran, 2009)²².

There are other cultural factors that are likely to influence parent's use of respite care for their child. According to Nageswaran (2009) children with special healthcare needs whose mother was young or uneducated had a higher requirement for respite. This study also found that

²² More recent work from the UK shows that those of different ethnic origins are less likely to access children's palliative care services Fraser L.K., Miller M., Hain R., Norman P., Aldridge J., McKinney P.A. and Parslow R.C. (2012) Rising National Prevalence of Life-Limiting Conditions in Children in England. *Pediatrics* 129(4), e923-e929.

children with complex care needs from low-income households had higher requirements for respite care. However, whilst a higher requirement for respite has been identified in low-income households as Horsburgh et al. (2002) found, it is parents who were confident, articulate and wealthy enough to pay for additional support who were more likely to access support. This is likely to reflect their greater knowledge of the system and their ability to source the help they need.

The utilisation of respite by the parents of children with life-limiting conditions and the imbalance in access to services is an issue across all levels of the family system. However, ultimately the issues discussed in the literature regarding changes in society, culture and ethnicity are impacted upon by decisions made in the Macrosystem.

2.16 The impact of policy on the provision of respite care for children with life-limiting conditions

Both nationally and internationally, the development of children's palliative care is at varying stages often led by pioneering individuals such as parents, bereaved parents and healthcare professionals. As a speciality, palliative care for children has evolved from paediatrics rather than through palliative care, this supports the recommendations of the United Nations Convention on the Rights of the Child which suggests that children are cared for by those specifically trained and experienced in the care of children (United Nations 1990) whilst this is an idealistic and important recommendation the implications of this for practice are often untenable in resource poor (staff and finances) services.

Several countries have undertaken needs assessments aimed at identifying the requirements of children with life-limiting conditions and their families (Maguire 2000; DOHC/IHF 2005; Spizzichino *et al.* 2006). Regardless of country of origin, healthcare system or stage of development of palliative care services, the findings of these needs assessments are remarkably consistent. Consistent findings are that respite or "short breaks" are an essential component of providing care to a child with a life-limiting condition and their family and that 'home' is the location of choice for parents caring for their sick child (DOHC/IHF 2005; Craig *et al.* 2008; European Association for Palliative Care 2009). Although no international studies have been undertaken to assess these similarities in findings they are also evident in literature reviews focussing on children's palliative care originating in New Zealand

(Horsburgh *et al.* 2002) and Northern Ireland (Corkin *et al.* 2006). Research studies assessing various aspects of children's palliative care also report these core findings from countries such as Australia (Monterosso *et al.* 2007a) Canada (Steele 2002; Davies *et al.* 2004) and England (Heaton *et al.* 2005). The fact that parents wish to care for their child at home and need respite care to enable them to do so transcends culture and geographical boundaries and may indicate that these needs are related more to parenting and family rather than health service provision.

National children's palliative care policies have also been developed in several countries including England (Department of Health 2005; Craft & Killen 2007; Department of Health 2008), and Italy²³. Whilst in other countries such as New Zealand (Ministry of Health 2001) and Australia (Australian Government Department of Health and Ageing 2010) children's palliative care has been incorporated into a national generic palliative care policy. This amalgamation of adult and children's palliative care policy has been criticised as policy makers need to recognise the difference between child and adult palliative care and developing services accordingly (European Association for Palliative Care 2009). Whilst many elements of the policies are similar, such as reflecting the principles of children's palliative care, they are also specific to the country and health system in which they are developed. A national policy for children's palliative care has been developed in Ireland.

Irish Healthcare Policy

In healthcare in Ireland, as in many other countries, in recent years there has been a move away from institutionalised care towards the provision of care in the community or primary care (DOHC 2001a; Australian Government 2011; Department of Health 2012). Published in 2001, the Irish health strategy "*Quality and Fairness - A Health Strategy for You*" (DOHC 2001b) whilst placing limited importance on child health issues did place a strong emphasis on the development of services in the community. Based on health and social gain, the policy encouraged the development of integrated care emphasising that primary care should be the central focus of the health system. In order to provide this care there was a promise of new developments and additional funding for carers, for respite care and for home care supports. The accompanying publication "*Primary Care: A New Direction*" (DOHC 2001a) set out a

²³ A national children's palliative care policy has been developed and was published in 2012

plan for the development of interdisciplinary healthcare teams in the community throughout Ireland and emphasised the need for high quality care in the community (Murphy & O'Riordan 2011). Whilst these policies were laudable in principle many of the recommendations were not implemented in practice.

This shift away from institutionalised care is not only considered to be more cost-effective but is also reflective of healthcare consumer preference where home is frequently cited as the preferred place of care (DOHC 2001a). Furthermore research undertaken in Ireland indicates that for the majority of people, including the families of children with life-limiting conditions home is also the preferred location for death (IHF 2004; DOHC/IHF 2005). Despite the publication of the primary care strategy and its subsequent phased implementation plans, there are many obstacles to accessing community-based healthcare services including respite care. An exception to this is cancer services where there has been a policy onus on the provision of care in the community for some time and as a result of being included in *The Cancer Strategy* (Department of Health 1996) services for people (including children) have developed. A key recommendation of the Cancer Strategy was the development of palliative care services throughout Ireland. Subsequently a palliative care policy was developed.

Report of the National Advisory Committee on Palliative care (DOHC 2001c)

The *Report of the National Advisory Committee on Palliative care* (DOHC 2001c) is the national policy for palliative care in Ireland. It stresses the importance of access to respite for patients and families. For adults requiring palliative care, respite facilities are predominantly out-of-home services providing opportunities for rehabilitation, assessment of symptoms and a change of environment for the patient providing carers with a much needed rest (DOHC 2001c).

The National Advisory Committee Report (DOHC 2001c) suggests that respite care may be accessed by admission to a specialist palliative care inpatient unit, attendance at a palliative day care centre or admission to a community hospital. The provision of locally based respite care is considered to be particularly important allowing patients to be close to their families and friends. The policy recommends respite should be available to all patients with advanced progressive disease and should include the provision of help for carers such as trained care

assistant or companions which may postpone or even prevent admission to inpatient facilities (DOHC 2001c).

The report of the National Advisory Committee (DOHC, 2001c) is government policy and states that regardless of diagnosis, “*all palliative care patients should have adequate access to respite care in a setting of their choice*” (DOHC 2001c) p 94 which includes children with life-limiting conditions.

A palliative care needs assessment for children (DOHC and IHF, 2005)

A national needs assessment was undertaken in Ireland (Quin *et al.* 2005), a summary of which was published by the Department of Health and Children and the Irish Hospice Foundation (DOHC/IHF 2005).

The needs assessment attempted to estimate the number of children living with and dying from life-limiting conditions. Despite using several cross checks, the researchers concluded that their figures were likely to be underestimates. They also found that services to children and their families were dependent on the child’s diagnosis and their geographical location within Ireland. The report strongly indicated that home was the preferred location of care and death for both parents and healthcare professionals providing care. The needs assessment confirmed the importance of respite care for families providing care to a child with a life-limiting condition (DOHC/IHF 2005).

Palliative care for children with life-limiting conditions in Ireland – A national policy (DOHC 2010)

In response to and based upon the findings of the needs assessment (DOHC/IHF 2005), a national policy was developed by the Department of Health and Children (DOHC 2010) and was accepted as Government policy prioritising the development of services in the community. Whilst this is in response to parent’s wishes, caring for a child with a life-limiting condition at home also places significant demands on family carers (Corkin *et al.* 2006; Eaton 2008).

The policy described how caring for a child with a life-limiting condition in the community requires the support of various primary care services such as the General Practitioner, Public Health Nursing services, with the input of some other health care professionals and voluntary providers of care. The majority of care however is provided by the family, in most cases the parents and often without the support of the above community healthcare professionals (DOHC/IHF 2005). The nature of life-limiting conditions in children means that care may be required over months and sometimes years. Providing on-going care is challenging especially when there are other children in the family (O'Brien *et al.* 2009). As many life-limiting diseases are hereditary some parents may also have to face the challenge of caring for more than one child with a life-limiting condition (ACT 2009a).

2.17 Summary of Chapter 2:

In this chapter findings of a comprehensive literature review have been reported. A broad approach to reviewing literature has been taken as children's palliative care encompasses or overlaps with other related areas of healthcare. The literature has been reviewed using the FSF as a foundation. What is apparent from this review is that whilst there is some research-based literature, which encompasses some aspects of respite care for children with life-limiting conditions, there is need specifically for in-depth research in this area of children's palliative care. One way to establish what respite truly means to and for parents is to extrapolate their understanding and experiences of respite care across the continuum of their child's illness. Using the FSF as a theoretical lens, this research will utilise a case study approach that will enable parents to describe, explore and explain their respite experiences in a real world context. In the following chapter the theoretical underpinnings of this research are identified and discussed.

CHAPTER 4: METHODOLOGY

4.1 Introduction

The purpose of this chapter is to explore the methodological issues, challenges and processes that have formed the foundation of this research. After exploring the feasibility of using alternative methods of conducting this research, this chapter provides the rationale and process for selecting case study methodology to answer the research question and discusses the philosophical, ethical and methodological underpinnings of this methodology.

4.2 Consideration of research approaches

From the outset, all research should aim to answer a carefully derived and developed specific research question by the most appropriate method (Denzin & Lincoln 2003). Defining a research question is one of the most important steps in designing a research study (Yin 2009) and in order to provide a valid answer, questions must be carefully considered and should be scientific, ethical, focused and concise (Payne 2007). Research questions are also the foundation of fundamental debates about two terms that are often used interchangeably (Guba & Lincoln 2006), epistemology (how knowledge can be obtained) and ontology (what there is to be known and what reality is) (Yardley & Marks 2004b). Although closely aligned these two terms clearly have different meanings. At its most basic level research can be divided into two paradigms; qualitative and quantitative research. The on-going debate regarding the two competing research paradigms is as a result of differing philosophical positions with positivism at one end of the scale and constructivism at the other (Yardley & Marks 2004a).

4.2.1 The positivist paradigm

From an ontological position positivism assumes the existence of objective realities that can be tested using a scientific approach to investigate phenomena. Positivist approaches to research require the researcher to be independent with participants chosen through objective criteria aimed at providing ‘cause and effect’ relationships by isolating variables (Polit & Beck 2010). The most common example in healthcare is the randomised controlled trial which utilises the classic experiment as its foundation. The positivist philosophy embraces a formation of truth where verifiable statements agree with the ascertainable facts of reality and where truth is reliant on the belief that it is verifiable through both examination and observation of external reality (Crossan 2003). It has been argued that this positivist

approach is artificial and does not reflect the real world (Hammersley *et al.* 2000) with Playle (1995) going so far as to suggest that by promoting a quest for objective scientific knowledge, positivism dehumanises subjects of research and thus the findings (Playle 1995).

Therefore while quantitative research methodology typically answers where, what, who and when questions (Crabtree & Miller, 1999; Silverman, 2000) it does not address adequately why a phenomenon occurs or how it occurs (Denzin & Lincoln, 2000; Silverman, 2000).

Palliative care prides itself on providing holistic person-centred care and this humanistic philosophy does not always sit well with positivist approaches to research. Despite a willingness on the part of many patients to participate in research in palliative care (White & Hardy 2010), it is recognised that regardless of chosen methodology, research in the specialty is notoriously difficult from both an ethical and practical perspective and presents particular challenges (Addington-Hall *et al.* 2007). Walshe (2011) describes five challenges of conducting research in palliative care, which are equally applicable to the specialty of children's palliative care. These are:

1. Variable services from multiple providers are inconsistently used or provided.
2. Participant's condition deteriorates over the course of research leading to issues with participation and attrition.
3. Randomisation is challenging and there are ethical issues regarding withholding of care or services.
4. Qualitative approaches alone can give little information about cause.
5. Experimental approaches on the whole examine only certain aspects of issues but these are often complex issues in need of scrutiny from all angles.

In order to overcome these challenges in palliative care research, such as this, it is necessary to think innovatively and mindfully. Ingleton *et al.* (1997) stress the importance of utilising methodologies that respect the fundamental principles which underpin the specialty of palliative care (Ingleton *et al.* 1997). From an early stage it was possible for me to reject the notion of undertaking research using a quantitative approach as my research did not seek to control or measure variables. Investigating salient issues in children's palliative care such as respite where there is a dearth of research; no clear definitions; multiple variables; and scanty

theoretical underpinning it was important that the research method selected was able, in a contemporary context, to generate detailed insight into the phenomena of interest from multiple sources which led me to consider constructivist or naturalistic approaches.

4.2.2 The constructivist paradigm

Constructivists argue that knowledge can only be gained through the human mind and body and therefore all knowledge is socially constructed (Yardley & Marks 2004a). The constructivist perspective rejects the view that there is only one truth or that knowledge exists separately from consciousness and instead promotes the concept that there are multiple realities (Polit & Beck 2010). Construction is viewed as a social process that is shaped by our culture and interactions (Yardley & Marks 2004a) which helps people to make sense and explain their own unique experiences (Appleton & King 2002). In the constructivist domain, rather than seeking to isolate variables and remove bias, the aim is to investigate phenomena, from multiple perspectives (Yardley & Marks 2004a) thus enabling people to make sense of their experiences in their own individual way (Appleton & King 2002). In order to achieve this, a range of qualitative methods based on differing philosophical positions and epistemological standpoints are utilised.

Qualitative research seeks to build knowledge (Sandelowski 1986; Denzin & Lincoln 2003) and regardless of the chosen method is “...*quintessentially about understanding the particular in the all-together*” (Sandelowski 1996) p525. Regardless of methodology, all qualitative research is characterised by inductive, interpretive, processes that develop knowledge. This is achieved by exploring phenomena and building knowledge about the lives and experiences of participants (individuals, groups or communities) (Morse and Field 1996). Qualitative research is context dependent, requiring the researcher to provide rich descriptions of people and their experiences in their natural environment (Cresswell 2003), with the aim of understanding, explaining or describing behaviours, beliefs, and meaning in the context within which it normally occurs (Wu & Volker 2009).

Methodology dictates how participants are recruited, what data are collected, how data are analysed and what conclusions can be drawn from the findings of the research (Payne 2007a). In order to meet both the aim (to explore the concept and meaning of ‘respite’ for parents

caring for a child with a life-limiting condition requiring palliative care in a real world context) and the objectives (To describe respite service delivery from the perspective of parents caring for a child with a life-limiting condition requiring palliative care; to identify the elements of the respite experiences that are important to parents; to identify barriers and facilitators to the delivery of respite care) of this study, careful consideration was given to the choice of methodology to ensure that the research question could be comprehensively answered.

Qualitative research methods include: phenomenology (exploration of the lived experience of individuals); ethnography (the study of the culture of a group of people); grounded theory (developing theories grounded in real-world observations); action research (combining change with research) and qualitative case study research (in-depth analysis of an individual or group in real-life setting) (Polit & Beck 2010). Built on contrasting philosophical underpinnings, both phenomenology and grounded theory share common features and seek to explore individuals' experiences in the world in which they live. Phenomenology however, relies almost exclusively on the collection of interview data to describe the 'lived experiences' of participants whereas grounded theory through the collection of data from multiple sources seeks to develop theory (Bainbridge *et al.* 2011). Grounded theorists use 'constant comparison' to strengthen their findings by proving or disproving emerging evidence from their findings (Polit & Beck 2010) with the ultimate aim of producing theory. Ethnography takes place in the natural setting ('the field') and, through observation studies the culture of participants (Ballinger *et al.* 2004).

One of the main proponents of case study methodology, Stake (1995), considers constructivism to be based on a belief that knowledge is derived from a social interpretation of experiences which subsequently creates new realities of those phenomena (Stake 1995). So, whilst not explicitly and overtly adhering to a constructivist philosophy, Stake (1995) does portray a leaning towards construction rather than the discovery of knowledge suggesting a bias in this direction (Appleton 2002). This is important in case study methods because constructivists aim to conduct research within natural settings and argue that people give meaning to realities through social processes (Appleton & King 2002). This demonstrates that whilst case study incorporates many aspects of other research methods ultimately it is a unique and comprehensive research method in its own right. Constructivists

recognise the importance of the subjective human creation of meaning and by developing a relationship with participants; the researcher enables participants to tell their story. Story-telling is an essential component of case study research (Yin 2009) as it allows participants to describe their views of reality and enables the researcher to better understand the participants actions (Baxter & Jack 2008). Thus in constructivist philosophy, case studies are ideally placed to explore people's real world experiences and systems, thus constructivism is well suited as the philosophical basis for my research and fits well with my study aims and objectives.

4.3 Case study methodology

Case studies are different from other types of qualitative research, providing intensive descriptions and analyses of single units bounded by time and space (Hancock & Algozzine 2006). Although predominantly associated with the qualitative research paradigm, case study can be either qualitative or quantitative or may include elements of both within a single study but always with the express aim of gaining an understanding of one singular entity (Sandelowski 1996). Case study, draws on principles of naturalistic inquiry and has its origins in the social sciences (Yin 2009) and in particular social anthropology (Payne *et al.* 2007) and has been used extensively in education (Stake 1995; Hammersley *et al.* 2000; Simons 2009; Tight 2010) and a number of other areas including: management science, sociology and political science and disciplines including social work (Walshe *et al.* 2004) and nursing (Zucker 2001; Walshe *et al.* 2004; Baxter & Jack 2008).

There are two main proponents of case study methodology (Stake 1995; Yin 2009) and although they advocate very different approaches to case study (Appleton 2002) they share some common elements such as defining the case and the use of multiple methods of data collection. Yin in his early (1994) and subsequent work presents a somewhat positivist approach advocating the use of both qualitative and quantitative methods. Stake (1995) however, suggests a philosophical and focused study of the qualitative aspects of each case (Appleton 2002) indeed it has been suggested that much of Stake's work is not only of relevance to case study but to qualitative research in general (Tight 2010).

Case study has different meaning to different people and varies from and between disciplines. Several authors have pointed out the challenges of describing and defining case study (Appleton 2002; Luck *et al.* 2006; Baxter & Jack 2008). Some suggest that this may be due to the conflicting literature (Appleton 2002), whilst others suggest that case study can be confused with the clinical case studies often used in healthcare to describe the details of a patient and their care (Payne *et al.* 2007). Tight (2010) adds to the debate by pointing out many articles that profess to report on the methodology have often been conducted without reference to the research literature on case study. He suggests that it may be more practical to call the type of research conducted in the name of case study, '*small sample, in-depth study*' as this essentially describes case study (Tight 2010).

There are several definitions of case study available. Yin (2009) defines case study as "*An empirical inquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon are not clearly evident*" p.18. Stake (1995) presents a more ambiguous definition; suggesting case study is... "*The study of the particularity and complexity of a single case, coming to understand the activity within important circumstances*" p.xi. Whereas Simons (2009) simply states that case study "*...is the study of the singular, the particular, the unique*" p.3. Despite this existence of multiple definitions of case study, all agree that case study is a context dependent in-depth study of the singular, utilising multiple sources of data. Various approaches can be utilised when undertaking case study.

4.3.1 Approaches to case study research

Several approaches to case study research exist and utilisation is dependent on the research question, aims and objectives. Yin (2009) describes four distinct types of case study whereas Stake (1995) identifies three (Table 3). Whilst both agree that there are different approaches to case study design, Stake (1995) argues that clear boundaries can be identified. In this research the approach utilised was instrumental, collective case study research with the aim of providing insight and understanding not specifically about parents but about their respite needs and experiences of caring for a child with a life-limiting condition requiring palliative care from multiple perspectives and within the family systems theory. By selecting different cases the aim is to gain an understanding of the experiences and needs of parents from their differing perspectives and experiences enabling the research to look at the collective case.

Table 3 – Case study approaches - comparing Stake and Yin (Adapted) (Stake 1995; Appleton 2002; Yin 2009; Tight 2010)		
Yin (1994)		Stake (2000)
Single case Examines a critical case or a unique or extreme case	Exploratory Defining the questions and hypothesis and determining the feasibility of a research project	Instrumental case Aims to provide insight or understand something that goes beyond the case itself
Multiple cases Contains more or several different cases	Explanatory Attempts to demonstrate casual relationships	Intrinsic case Phenomena are studied to get a better understanding or learn about that particular entity for its own intrinsic worth
Holistic case Relates to a global phenomenon	Descriptive A full description of a phenomenon of interest within its context	Collective Case Two or more instrumental cases within a study, whereby a connection is made between the cases
Embedded case Contains a number of sub-units embedded within a case that need to be assessed separately before becoming part of the whole		

All case study approaches provide the researcher with the opportunity to follow relevant leads that emerge during data collection period (Payne *et al.* 2007). This is possible as in case study research the onus is not on statistical power calculations. This allows the researcher the flexibility to gather relevant data from a variety of sources however, in case study research one of the key challenges is the identification of the ‘case’.

4.3.2 Identifying the case

Despite appearances, case study research is a challenging methodology to utilise (Yin 2009) with one of the most challenging and fundamental issues being identification of the ‘case’, which should be clearly stated at the outset (Appleton 2002; Polit & Beck 2010; Tight 2010). In this research from a very early stage, the parents of children with life-limiting conditions were identified as the ‘case’. Ultimately one of the primary considerations in this choice of research method is the ability of case study research to view a phenomenon from differing

perspectives. In this research, the utilisation of case study enabled the researcher to identify respite needs and experiences not only of parents but also how this had an impact on all levels of the family system. By recognising interdependency of past and present (Anderson *et al.* 2005) this research gives a unique insight into the impact from a whole system perspective.

As it only uses a few selected cases, one of the main concerns regarding case study methodology is that of generalizability; however, the intention of case study is not to make empirical generalisations but to make theoretical observations (Payne *et al.* 2007). Case selection is therefore crucial, with purposive rather than convenience sampling employed (Payne *et al.* 2007). Despite pointing out the benefits of using case study Walshe *et al.* (2004) also raise the issue of generalizability as a challenge but go on to argue that rigorously conducted case studies present a different type of evidence if the approach chosen is appropriate to the research question posed. Respite care for children with life-limiting conditions meets these criteria.

4.3.3 Boundaries in case study research

A comparison has been made between the development of inclusion and exclusion criteria in quantitative research and boundaries in case study research (Baxter & Jack 2008). This refers to the process of placing boundaries to assist in narrowing the scope of the research. Many authors stress the importance of boundaries in case study (Stake 1995; Appleton 2002; Yin 2009), whilst others argue against binding the case, suggesting that this may prevent the researcher from gaining important insights in what occurs across boundaries (Anderson *et al.* 2005). Baxter and Jack (2008) suggest the importance of considering not only what your case is but also what it is not which can be achieved by ‘binding’ a case. According to Cresswell (2003) the case should be a specific single phenomenon, Stake (1995) adds that the case is a system bound by place and time. Furthermore he suggests that the case should be purposive with boundaries set to include a description of the environment and culture (Stake 1995). Yin (2009) pragmatically suggests that a literature review may assist in the provision of the boundaries of the case allowing for comparison with similar research (Yin 2009).

4.3.4 Case study in health care research

It is generally agreed that case study is a suitable methodology for healthcare research where it has gained popularity among those seeking to investigate phenomenon in their real world context (Appleton 2002). In nursing, case study research has become popular as an approach to constructivist inquiry where the credibility and sensitivity of case study may not only appeal to nurses (Payne *et al.* 2007) but also complements topics that are of relevance and interest in nursing (Zucker 2001; Anthony & Jack 2009). To date, case study has been principally utilised to evaluate and gain an understanding of complex social situations and systems (Payne *et al.* 2007). It has been posited that there are two reasons why case study is attractive to healthcare researchers, firstly healthcare provision is dynamic and case study is seen as a way to capture this (Payne *et al.* 2007). Secondly, case study in healthcare research provides the opportunity to gain detailed information about a case from multiple perspectives allowing data to be viewed and understood in its wider context (Ingleton & Davies 2007). It is also possible to collect data from multiple participants who all refer to the same event or incident from differing perspectives (Payne *et al.* 2007) and enables the researcher to understand systems and processes (Anderson *et al.* 2005). Case study research has also been identified as a potential way to overcome some of the inherent challenges of conducting research in palliative care where research is notoriously difficult (Walshe *et al.* 2004; Payne *et al.* 2007). Ultimately case study is “*valuable for health science research to develop theory, evaluate programs and develop interventions because of its flexibility and rigor*” (Baxter & Jack 2008) p.544 and thus is also a suitable method for use in palliative care.

4.3.5 Case study in palliative care

To date, various aspects of palliative care have been explored using case study methodology including: day hospice (Lee 2002); evaluation of services (Ingleton *et al.* 1997); bereavement services and community hospitals (Payne *et al.* 2007); care of the terminally ill in the community (Bergen 1992); community palliative care services (Walshe 2011); Family beliefs about end of life and death (James *et al.* 2007) and new palliative care services (Ingleton *et al.* 1997). The use of these examples from the palliative care literature demonstrate the versatility of case study research and show the range of issues that can be explored using case study and led me to believe that this approach to research is most likely to yield an accurate picture of the respite needs and experiences of parents caring for a child with a life-limiting condition. In particular the multiple sources of data allow the researcher to use all

information available to them to develop the case report and to tell the family's individual story.

Case study research stresses the importance of the particularity and complexity of a phenomenon and aims to analyse features of that phenomenon in order to gain an understanding of its activity within its context (Stake 1995). Walshe *et al.* (2004) present a compelling argument for case study in palliative care suggesting it is appropriate when: situations are complex; the “real-world” context of the service is central; multiple perspectives are needed; flexibility is desirable; research needs to be congruent with clinical practice; there is no obvious suitable theory and other methods present practical difficulties all of which apply to this research. Furthermore, they suggest that case study has the ability to deal with change and complexity in healthcare where other traditional methods have failed. As in this research, this ability to deal with multifaceted complexity is often a deciding factor in the choice of case study as a research method. Walshe *et al.* (2004) also stress the importance of using multiple perspectives to ensure the picture of the case is more complete and suggest that case study strategies have the ability to assess complex situations is frequently the key to the choice of this method. In order to capture the complexity of the phenomenon of respite in children's palliative care, this is reflected in the design of this study where, not only have multiple perspectives been incorporated into the study design, but also the utilisation of multiple sources of data are also a key component of this study.

Anderson *et al.* (2006) suggest that whilst many cases appear to have characteristics in common, frequently internal processes differ significantly between and within organisations (such as the family system) often with people within each unit interacting differently (Anderson *et al.* 2005). This research attempts to capture the unique complexities and issues around respite experienced by parents caring for a child with a life-limiting condition in a ‘real-life’ context from differing perspectives and multiple sources of data collection.

4.3.6 Case study – the case and the context in this research

Case study has a number of qualities that make this the ideal method for exploring the respite needs and experiences of parents caring for a child with a life-limiting condition. Firstly, according to Stake (1995), a case study is the in-depth study of the singular (a person, group or organisation). In this research the ‘case’ selected were the parents of a child with a life-

limiting condition requiring palliative care all with unique experiences to share. Secondly, case study allows this exploration to take place whilst considering the wider social, cultural and political aspects of care (Mehta *et al.* 2009) such as an exploration of respite care within the family systems theory. Thirdly, case study (and the FST through the Chronosystem²⁴) is flexible and data can be collected over time. Fourthly, case study methodology encompasses an understanding of the whole case from differing perspectives which fits well with the ethos of palliative care where the provision of holistic care is the aim. Finally, the use of multiple case studies such as this is also thought to strengthen findings (Yin 2009).

4.3.7 Multiple sources of data

In case study research, methods from across the traditional research paradigms can be utilised in order to explore the case of interest as long as there is an explanation for their inclusion (Luck *et al.* 2006). Yin (2009) suggests that data collection should be treated as a design issue that will enhance the construct and internal validity of the study, as well as the external validity and reliability (Yin 2009). Furthermore he suggests that the use of multiple methods not only provides a more in-depth data set but also allows the researcher to validate findings and thus increase the reliability of the findings (Yin, 2003). He identifies three principles of data collection for case study researchers: use multiple sources of data; create a case study database and maintain a chain of evidence. These principles underpinned the collection of data in this research and were adhered to during the data analysis phase.

²⁴ Described in detail in Appendix 2 – Theoretical framework



Figure 4 Six types of research evidence identified by Yin (2009)

4.3.8 Interviews as data collection

Several different interview designs exist, each with its own fundamental derivation and potential to gain different data from participants. Approaches to interviewing include structured, semi-structured, unstructured and informal designs. A structured approach asks each participant the same questions in the same order (Polit & Beck 2010). Positivist researchers favour these as they aim to obtain facts and objective information. Unstructured interviews offer total flexibility regarding the course of the interview and are most commonly used in grounded theory (Polit & Beck 2010). An interview has been defined as ... *“a meeting where a reporter obtains information from a person, as a meeting with another person to achieve a specific goal, and more generally, as a conversation with a purpose”* (Kvale, 2006: p.483). In this research where sensitive issues were being discussed it was important to have a conversation with participants but essentially the role of the researcher is to obtain information. Qualitative interviews were chosen as my primary source of data collection as they provide the opportunity to investigate human experiences, to seek an understanding of the participant’s points of view and to unfold the meaning of their experiences (DiCicco-Bloom and Crabtree 2006). The use of interviews in this study provides research participants with the tools to present their experiences using their own words and simultaneously allow a relationship to develop between the participant and the researcher (Kvale 2006). In order to gather in-depth data, there is an onus on the researcher to develop a rapport with the interviewee in order to create a context within which

participants feel comfortable enough to express the inner feelings and thoughts (Simons 2009).

4.3.9 Relationship between the researcher and the participant

In quantitative research reliability is often based on the assumption research findings can be objective and independent of the researcher; however, in all quantitative research one of the major issues is that of the influence of the researcher and of their participation in the research process (Stake 1995; Sheldon & Sargeant 2007). Kvale (2006) warns that in qualitative research interviews, the power dynamic between interviewer and interviewee cannot be disregarded and should be made transparent in the presentation of the methods of data collection in particular he feels that the potential biases of a consensual warm interview relationship impacts on the validity of the knowledge produced and fails to acknowledge the real power relations (Brinkmann & Kvale 2005). The researcher has reflected on this and has where possible referred explicitly to this in areas of the findings and discussion where such a relationship may have had an impact. Likewise, Hewitt (2007) warns that qualitative research may be vulnerable to bias through the qualities and attitudes of the researcher. The following factors have been identified as influencing the relationship between the researcher and the participant: age; social class, appearance, culture, inequalities in the level of power and knowledge, gender and environment (Yardley & Marks 2004b; Hewitt 2007) and through the process of reflexivity these have all been considered.

Different standpoints have been developed throughout the literature regarding the role of the researcher in qualitative research. Sandelowski (1993) points out that whilst both participants and researchers aim to produce work that fairly represents their experience these may differ in what they consider to be “a fair account” (Sandelowski 1993). Kvale (2006) comments on the power the researcher conducting interviews has by being in a dominant position that may lead to an invasion of the subject’s privacy. He also suggests that interviewers may use this power to masquerade as a friend in order to get the information and in order to get this disclosure of information; researchers create trust through the development of a personal relationship (Kvale 2006). Although relationships with all research participants were developed during the course of this research, care was taken ensure that the work produced as a direct result of this research fairly represents the views of the participants; that invasion of privacy was avoided; and that where possible professional rather than personal relationships or friendships were developed. Despite best efforts, DiCicco-Bloom and Crabtree (2006)

argue that whilst aiming to find out about people it is important to establish trust and this is best achieved by reducing the hierarchy between researchers and informants, they suggest that this can be achieved by sharing sometimes personal information in response to the informant's requests. For example in this research many parent participants asked if I was a mother; this seemed important to them and this was personal information that I shared.

Sheldon and Sargent, (2007) agree suggesting that in order to build and maintain the trust of participants in the role as researcher, it is necessary to engage in the everyday social conversations, as this produces a degree of reciprocity that can facilitate the research process. Furthermore they suggest that the researcher's practice background also has an impact on the researcher/participant relationship and give the example of nurse researchers being expected to behave in a certain way or to have the ability to give advice or assistance (Sheldon & Sargeant 2007). The relationship between the participant and the researcher fits with the notion of reflexivity.

In order to elicit information pertaining to respite in children's palliative care and to ensure all of the salient issues were discussed during the interview process, in this research the primary method of data collection was multiple semi-structured interviews. Krueger and Casey (2000) suggest the use of an interview schedule, prompting open-ended questions, (Appendix 19) this was incorporated into the design of this study and was used to generate initial discussion. The interview schedule was developed by the researcher based on the literature (MacDonald & Callery 2004; Eaton 2008) and was refined following the first interview. Although a guide was used, interviews remained flexible in order to reveal in-depth views and experiences and to ensure openness to new information from participants (Payne 2007a) space was left on the interview guide where notes were recorded during each of the interviews. Taking notes during interviews has been suggested as a backup for any potential equipment failure (Simons 2009).

By undertaking multiple interviews, Sandelowski (1993) warns that participants can change their stories from one interview to the next as telling their story can cause them to see the connection and nature of their life events differently. Notwithstanding, this by providing parent participants in this research with the opportunity to be interviewed on more than one

occasion provides the opportunity for clarification and checking of previous responses to ensure accuracy, thus adds to the trustworthiness of data and corroborates evidence obtained from other multiple sources (Yin 2009).

4.3.10 Observation as data collection

According to Simons (2009) observation has a long tradition in social research and is particularly useful in case study where it is necessary to observe closely a specific case and to interpret the findings from other methods or sources of data collection (Figure 5). Various forms of observation are available to the researcher and these include ‘structured’ methods such as pre-categorisation and classification where a structured observational schedule is utilised. In this study participant observation was incorporated throughout the research process. Participant observation is closely aligned with ethnography, is historically associated with qualitative research and entails watching people in their natural setting. Four types of observation have been classically identified by Gold (1958): *Complete participant* (takes an insider role often covertly); *the complete observer* (whose role is concealed and does not interact); *The observer as participant* (undertakes observation, has a minimal role and is known as the researcher) and *the participant as observer* (has negotiated access and is part of the events being observed). Observation not only enables researchers to capture process and context it also enables a view of the whole situation including the physical environment (Mulhall 2003) all of which sits well with case study research and the family system’s theory.

Observation enhances understanding of issues within case study and is an integral part of the research process from entering the field to the completion of data analysis (Stake 1995; Yin 2009). It has also been suggested that by incorporating participant observation into the research design the researcher is able to assess the dynamics of the informal organisation of the case (Anderson *et al.* 2005) and enables researchers to perceive situations from a number of different perspectives (Stake 1995; Yin 2009).

Figure 5 Observation as a companion method to interview in case study research (Simons 2009)

1. Through observation of surroundings and people one gains a comprehensive ‘picture’ of the whole situation.
2. Documenting observations about events and incidents gives ‘rich description’ which may be further explored, interpreted and analysed
3. Through observation norms and values can be discovered
4. Observation captures the experiences of those who cannot be interviewed
5. Observation can be used to cross-check data from interviews – sometimes seen as a way of strengthening validity.

4.4 Data Analysis and interpretation in case study

Data analysis in case study research can be complex and compounded by large amounts of data (Yin 2009). In this research, data have been collected from multiple sources in order to develop nine individual case studies. Whilst Yin (2009) is prescriptive in his five analytical techniques for case study research, these are not in keeping with my decision to utilise an instrumental case study approach. Stake (1985), gives little guidance to case study researchers when discussing approaches to data analysis, suggesting each researcher should adopt what they perceive to be the best approach (Appleton 2002). As with all qualitative data analysis there is a requirement on the part of the researcher to be fully immersed in the data (Elo & Kyngas 2008) in order to familiarise oneself with the diversity and range of data collected.

4.4.1 Data analysis in case study research

Yin (2009) speculates that case study research analysis is the least well described part of the methodology because of the challenges that it poses. Simons (2009) agrees and suggests three reasons for the dearth of information on case study analysis:

1. The interpretation of qualitative case study research data relies on the specific skills and experiences of the researcher, which can differ widely

2. Establishing guidelines on analysis that can be utilised or replicated in other situations is difficult because of the individual nature of each case
3. The dearth of specific tools for analysing case study data.

This section sets out to address these issues and to discuss the data analysis process as it relates to this research with reference to the contemporary literature.

There are two clear schools of thought on the analysis of case study research from the two main proponents of the method. Stake (1985) advocates an inductive approach to all aspects of case study and suggests that the research should be open to the data and should analyse their case study data without a previously defined hypothesis. Stake (1995) advocates that there is a requirement that the descriptive evidence depicted by the researcher as the ‘case’, would also have been presented by another researcher if they had access to the same case. Furthermore in multiple case study design Stake (1995) suggests that there should firstly be direct interpretation of an instance, this refers to singular occurrence and where multiple cases are used there should be an aggregation of instances that refers to recurring phenomena.

Yin (2009) goes as far as describing data analysis in case study research as the most difficult aspect and suggests that the analysis depends heavily on the individual style of the researcher and their “*rigorous empirical thinking*” coupled with their ability to present sufficient evidence. He contests that researchers also need to be able to offer alternative interpretations of the data. Yin’s (2009) approach to data analysis is both pragmatic and systematic suggesting it should include:

- Pattern matching – a comparison of findings with theory enabling the researcher to either strengthen their contentions or to offer an alternative (rival) explanation.
- Explanation building – using analysis to build an explanation about the case
- Time-series analysis - following events or episodes over time
- Logic models – use of complex chains of events observing cause and effect
- Cross-case synthesis – using a rigorous and systematic process to not only analyse cases individually but to then compare with other cases.

Both Stake (1985) and Yin (2009) advocate the use of multiple methods of data collection in order to increase confidence in findings this can result in researchers utilising more than one approach to data analysis.

4.4.2 Analysis in qualitative research

In qualitative research there is no one prescriptive and established approach to data analysis, despite the many approaches to the analysis of qualitative data all share some common features (Miles & Huberman 1994) (Table 4).

Table 4 - Common features of analytical methods (Miles & Huberman 1994) p.9

- | |
|---|
| <ul style="list-style-type: none">• Affixing codes to a set of field notes drawn from observation or interview• Noting reflections or other comments in the margins• Sorting and sifting through these materials to identify similar phrases, relationships between variables, patterns, themes, distinct differences between sub-groups, and common sequences• Isolating these patterns and processes, commonalities and differences and taking them out of the field in the next wave of data collection• Gradually elaborating a small set of generalisations that cover the consistencies discerning the database• Confronting those generalisations with a formalised body of knowledge in the form of constructs or theories |
|---|

Sandelowski (1996) argues that qualitative research is in some way always about an individual case and the ability to make sense of it. She goes on to argue that no matter what analytical technique is employed that those analysing qualitative research must first make sense of the individual case by focussing on the individuality and uniqueness of each case. She also warns qualitative researchers against being distracted by the more traditional quantitative approach (Sandelowski 1996).

4.5 Cross case comparison

Theories are not derived through simple perception but through the rigorous approach of cross-case comparisons (Hammersley *et al.* 2000). In case study where large amounts of data are gathered this process helps the researcher to identify and focus on relevant data and ignore data that is interesting but not directly related to the research question (Yin 2009).

4.6 Application of case study to the research question

Case study has a number of features that make it the ideal method for collecting data on the experiences of parents caring for a child with a life-limiting condition. First and foremost case study provides the medium to explore a contemporary phenomenon in its real-life context when boundaries between phenomena are not clearly evident (Yin 2009). This has been demonstrated in children's palliative care where ambiguity surrounds definitions; there is no clear indication of how services can be accessed or which conditions are considered to be life-limiting. Furthermore, case study research is especially suitable when the question posed requires a detailed investigation of a real-life intervention where the event maybe ill-defined and success or failure of the event is difficult to focus on (Payne *et al.* 2007). Respite is one such intervention where there is a dearth of published research-based literature pertaining to children's palliative care and the context of the provision of respite. Case study also enables the study of phenomena as a whole (Anderson *et al.* 2005) as demonstrated in this study where the impact of respite care for children with life-limiting conditions and their families are viewed from the perspective of their impact on the whole family system.

Respite care, where available, is frequently provided by a variety of statutory and voluntary agencies in differing care environments and geographical locations. Services have developed in an 'ad hoc' fashion often influenced by local, organisational, political and historical issues. By utilising case study methodology, this research has the ability to capture and take account of these factors. By viewing respite from a holistic perspective through the lens of the family systems theory, it is possible to gain an understanding of the each case in its entirety across all levels of the family system. Case study complements the actions and interactions between the four systems identified in the FSF and provide the opportunity for in-depth study, of and between, phenomena (Figure 6). The application of this to respite in children's palliative care may, for example, reveal that whilst parents have the same opportunities to access respite services in reality there may be factors that militate against their uptake of services such as social class, geographical location, or access to appropriate care.

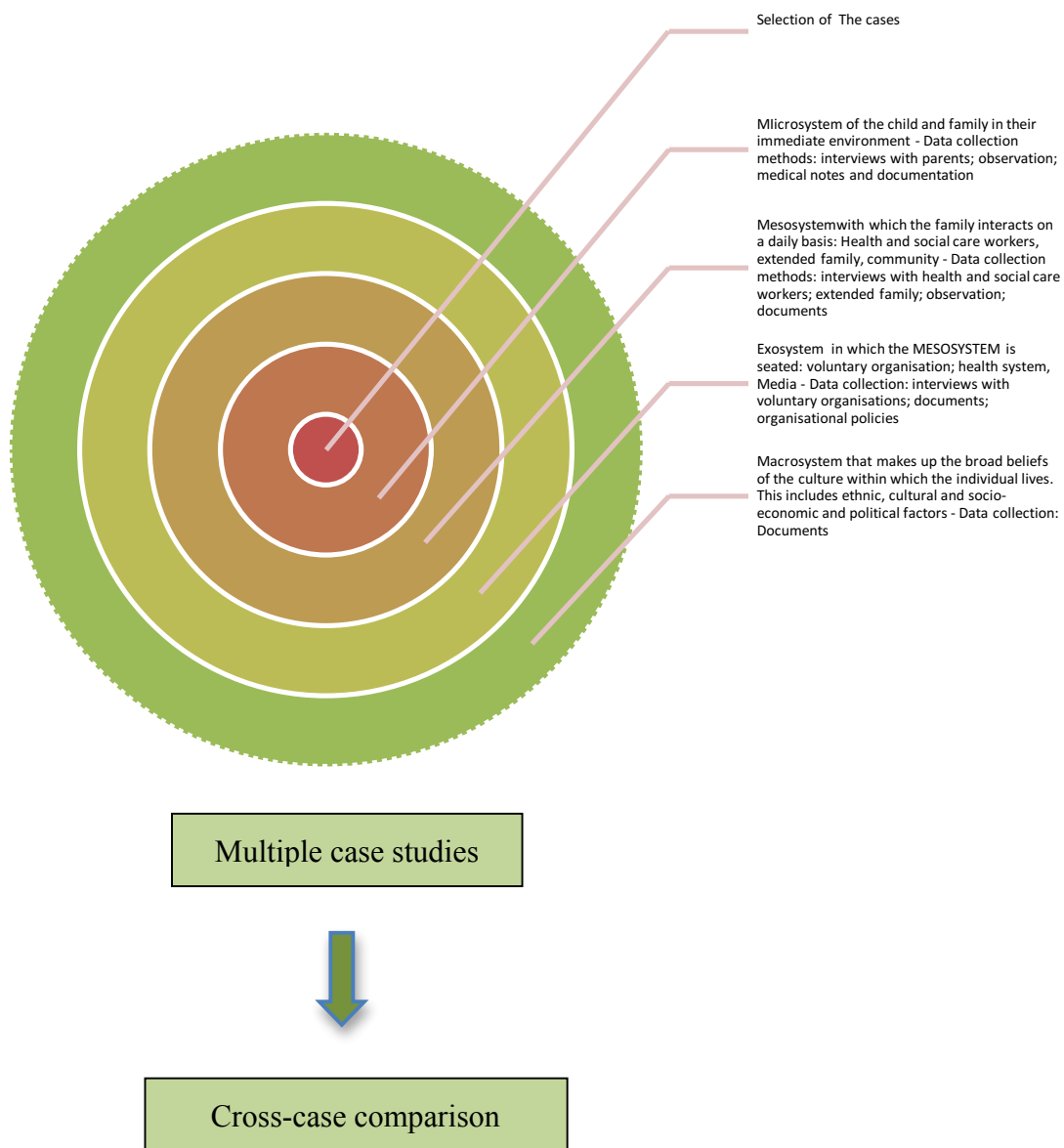


Figure 6. Case study in family systems theory

Anderson *et al.* (2005) suggest that in case study research, in order to describe actions independently of each other that researchers often isolate them however they stress the importance of understanding interdependence and the system as a whole (Anderson *et al.* 2005). This fits well with family systems theory where all parts of the system interact and are interdependent. Furthermore, they suggest that because the method facilitates the exploration

of the informal organisation, case study is well-matched to recognising dynamics. This is another integral part of the family systems theory.

4.7 Summary of Chapter 4

In the context of children's palliative care there is currently a lack of respite related research. To compound this there are no clear agreed outcomes or criteria for success or failure in children's palliative care and ambiguity remains regarding many of the definitions used. Children's palliative care is multifaceted and often complex involving a myriad of different people and services. Parents' respite experiences have a similarly complex configuration that is often contextually defined, geographically diverse and changes over time as family needs vary. Case study encourages the collection of data concurrently thus participants can often refer to a similar timeframe or the same incident of care (Payne et al. 2007), which is of importance in case study research where data are collected in a real-life context. Thus case study methodology is an appropriate strategy for exploring the respite needs of parents caring for a child with a life-limiting condition requiring palliative care. Recruitment to all palliative care studies is challenging (White & Hardy 2010) and children's palliative care research is no exception (Tomlinson *et al.* 2007). In circumstances such as this where little is known about a particular issue, utilising a case study strategy can be especially useful (Appleton 2002).

In this research, I have opted to work within a constructivist paradigm using case study methodology to explore the respite needs and experiences of parents caring for a child with a life-limiting condition because case study research facilitates detailed examination of a single "case" (the parents) within its real-life (everyday caring experience) and contemporary situation (reporting the caring process and reflecting the location of care) using multiple sources of data (interviews, observation, documents). The phenomenon under study can be an individual, a group or an organisation (parents) from differing viewpoints (others involved in the respite care provision) examined within the framework of the family systems theory. The results of a case study are specific to the case and context and should be examined and reported in their own right without regard for generalisation; however, cross case comparison was undertaken. The approach in which case study methodology was implemented in this research is documented in the following Methods chapter.

CHAPTER 5: RESEARCH METHODS

5.1 Introduction

This chapter describes the way in which the philosophical and methodological foundations of case study have been put into practice.

5.2 Research question

What are the respite needs and experiences of families caring for a child with a life-limiting condition requiring palliative care?

5.3 Aims and objectives

The primary aim of this study is to explore the concept and meaning of ‘respite care’ for parents caring for a child with a life-limiting condition requiring palliative care in a real world context.

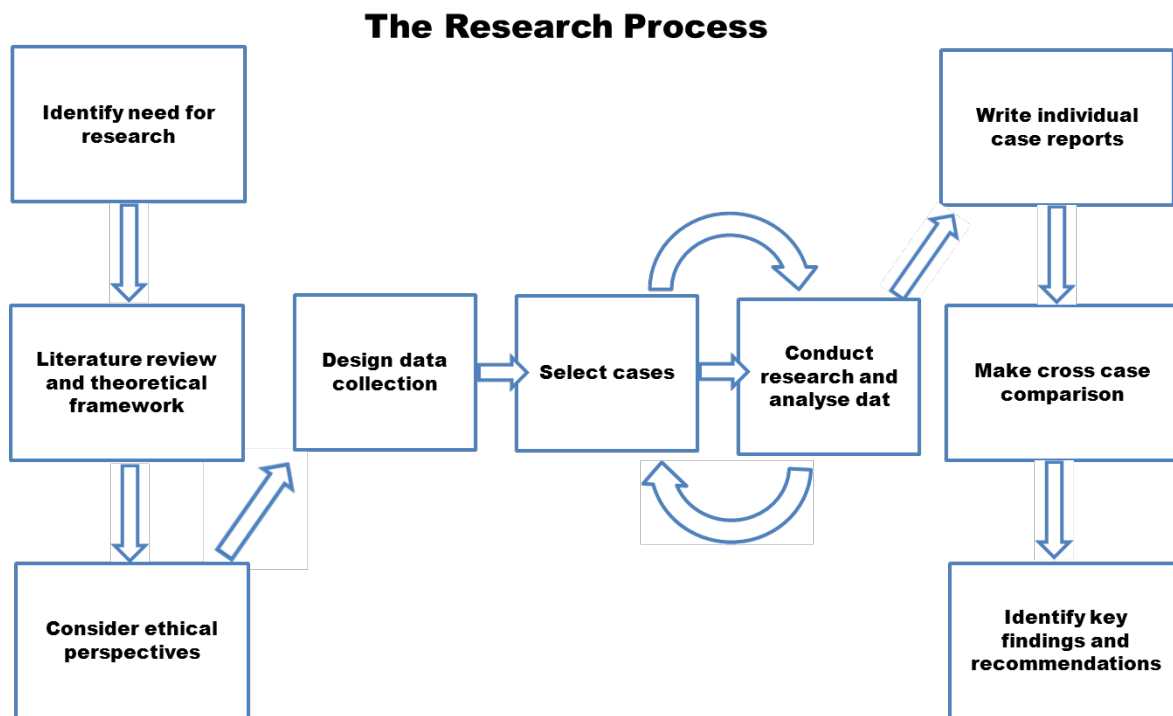
Objectives:

- To describe respite service delivery from the perspective of parents caring for a child with a life-limiting condition requiring palliative care
- To identify the elements of the respite experiences that are important to parents
- To identify barriers and facilitators to the delivery of respite care

5.4 Method and design

Case study is the in-depth study of the singular that is of interest for its particularity (Stake 1995). In this research the singular case is the parents of a child with a life-limiting condition requiring palliative care. By identifying parents as the ‘case’ and viewing them from a theoretical perspective through family systems theory, it was possible to identify the complex and interconnected phenomenon of respite from multiple perspectives over a period of time. Allowing parents to identify those who had a role in the provision of respite care enabled the research to view the concept of respite as whole and from differing perspectives. This research utilised a multiple case study design conducted over time. The process for this research is shown in Figure 7.

Figure 7 The Research Process



5.5 Selecting the sample

Several factors such as family size, functioning and location have been identified in the literature as having an impact on respite experiences of families of children with life-limiting conditions (DOHC/IHF 2005; Corkin *et al.* 2006). In order to take account of this, maximum variety sampling was employed which aimed to provide a variety of data within each case. The sample in this study was aimed at specifically recruiting parents from a mix of:

- Rural and urban areas;
- Small and large families;
- With a male or a female child;
- With malignant and non-malignant condition

If possible a child from each of the four ACT categories would also be recruited (ACT, 2009) (Table 2).

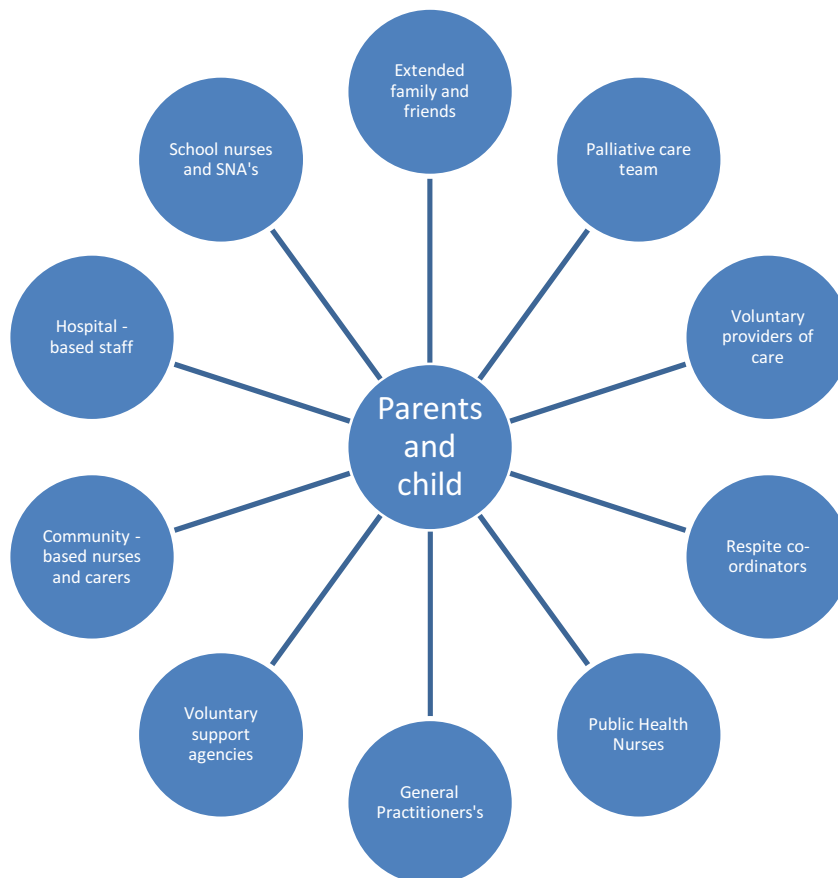
Case study provides the researcher with the opportunity to assess the complexity of a situation from a holistic perspective and to immerse themselves in the details of each case examining contextual issues as they relate to process and experience of participants

(Chamberlain *et al.* 2004). As each case is viewed as an individual entity within the research process it was not possible at the outset to predetermine the number of cases that would be undertaken, however it was estimated that a maximum of ten case studies would be undertaken in a two-year period. The exact number was determined following preliminary data collection; review of cases as they developed and analysis progressed; and discussion with my supervisors. With the ultimate aim of sampling being to capture a relevant range of contexts of phenomena that enable the researcher to make strategic and cross-contextual comparisons and helps build well-founded arguments (Mason 2002).

5.6 Identification of the case

This study was designed to focus on the parents of a child with a life-limiting condition requiring palliative care and therefore the ‘case’ was the parents. During interviews with the mother, father or both, parents were asked to identify the key people who they regarded as having a role in the provision of respite for their child (Figure 8). Those identified were all part of the wider family system.

Figure 8 – Potential participants with a key role in the provision of respite care



5.7 Binding the case

‘Binding’ the case, by placing boundaries that narrow the scope of the research when using case study, is the equivalent to developing inclusion and exclusion criteria (Baxter & Jack 2008). In this research the case boundaries or criteria for inclusion were:

- Parent (mother, father or both) of a child referred to the palliative care team at a large national Children’s Hospital during the study period
- Aged 18 years or over
- Able to communicate in English
- Willing and able to participate

Further participants were purposively recruited via the parent participants. These were identified and approached by parents who gave them information about the research and asked to contact the researcher if they were willing and able to participate.

5.8 Gaining access to the Research Setting

There is controversy regarding what constitutes a life-limiting condition in a child (Craft & Killen 2007) and in order to ensure that I was accessing the target population for this study (the parents of children with life-limiting conditions requiring palliative care), I sought access to the caseload of a hospital-based paediatric palliative care team. This team has approximately 60 referrals per annum. I contacted the consultant and team leader by phone to discuss the proposed research and met with her on several occasions, ultimately putting this request in writing. The consultant agreed to not only assist in recruitment to my study but also agreed to be a clinical co-supervisor²⁵.

5.9 Ethical considerations and obtaining ethical approval

In all healthcare research the protection of the participants and maintenance of ethical principles are paramount. Conducting research in palliative care is fraught with difficulties and raises some specific and unique issues. In palliative care, research frequently aims to address what may be regarded as sensitive issues with potentially vulnerable populations (Wolfe & Siden 2012). In this section the ethical issues as they relate to this research are discussed. There are three primary ethical principles (Polit & Beck 2010) which are: Beneficence; Respect for human dignity; and Justice. Each of these principles will be discussed as they were applied in this research.

²⁵ The letters have not been included as they may compromise confidentiality and anonymity of participants

5.9.1 Beneficence

Beneficence is one of the fundamental principles of research where studies should produce benefits for participants themselves or for society as a whole (Polit & Beck 2010). Beneficence ('to do good') and non-maleficence ('to do no harm') are core principles of the right not to be harmed. At the outset of this research as a registered nurse I am bound by a Professional Code of conduct which states that: *"In taking part in research, the principles of confidentiality and the provision of appropriate information to enable an informed judgment to be made by the patient must be safeguarded. The nurse has an obligation to ascertain that the research is sanctioned by the 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 practice"*(An Bord Altranais 2000 p.8). Although adhering to this code of conduct gives guidance, the perceived vulnerability of the population under study in this research required a more in-depth analysis of the ethical issues involved.

In considering beneficence in this population, researchers need to be mindful not only of the patient's ill-health and their potential inability to participate but also need to consider the impact on family members participating in research. In children's palliative care parents are most often the primary carer often resulting in fatigue and emotional exhaustion (Lee & Kristjanson 2003). In children's palliative care the potential burden on participants should always be considered and researchers should consider that in children's palliative care there is potential to burden participants, particularly at the later stage of the child's disease trajectory. The family may have previously participated in research and may not be willing or able to participate again. Particularly when their child's prognosis is short, parents may perceive time spent in interviews as time that could be spent more usefully with their child (Contro *et al.* 2002).

A further consideration for researchers is that in exploratory qualitative research such as this where part of data collection incorporates interviews, it is also not always possible to know where questioning will lead and whether this will cause distress to participants (Sheldon & Sargeant 2007). This issue was addressed in the design phase of the research where appropriate structures were put in place in order to provide support for participants should

they require it. In this research this was negotiated in advance with the social work department of the children's hospital²⁶.

In this research, parents of children with life-limiting conditions were interviewed on varying number of occasions. An awareness of the potential issues that would be raised during the interviews enabled the researcher to be prepared and was aware of some of the issues that could be raised during the interview process and of the potential discomfort or upset that some of these issues could cause. The researcher provided support to the participants by spending time with them enabling them to ask questions and answering all of their questions and allowing them the time and space to air any anxieties or issues. The participants comfort and safety were paramount. On occasions where the child with a life-limiting condition was present during the interview if necessary their care needs were always prioritised. For the purposes of this research children were not included as participants; many children with life-limiting conditions also have complex care needs and would not be able to participate in the research particularly those with conditions in ACT category 4 (ACT 2009). The interviews were conducted whilst scrupulously upholding ethical principles of confidentiality, privacy and rigour.

5.9.2 Respect for human dignity

The ethical principle of respect for human dignity includes the right to self-determination and a right to full disclosure and covers ethical issues such as informed consent. The principle of self-determination refers to the right of potential participants to decide voluntarily whether to take part in the research without concern for the consequences of their decision. This principle also affords potential participants the right to seek information, ask questions and to withdraw from the research at any stage.

5.9.2.1 The consent procedure

In qualitative palliative care research such as this, consent is based on trust (Sheldon & Sargeant 2007). The process of gaining informed consent was carried out in a manner that explicitly reflected the researchers' ethical responsibility to both the research process and the participants (Sheldon & Sargeant 2007). All participants were asked to acknowledge this

²⁶ ²⁶ The letters have not been included as they may compromise confidentiality and anonymity of participants

process by signing a consent form ([Appendix 4](#) and [Appendix 5](#)). Consent was not viewed as a one-off process and in order to ensure that participants were informed and understood their role throughout the research consent was viewed as an on-going process (Sheldon & Sargeant 2007). As a researcher 'process consent' not only enables renegotiation of consent at different stages of the research process between the participant and the researcher but also served as a reminder to me of my ethical obligations. Process consent is particularly suitable for longitudinal approaches to research, such as this, where participants were contacted on several occasions and where consent sometimes needed to be renegotiated (Beaver *et al.* 1999).

A further concern for both ethics committees (Hinds *et al.* 2007) and researchers in children's palliative care is that parents, when asked to participate by healthcare professionals, may feel obliged to do so especially when those asking appear to be kind and caring (Tomlinson *et al.* 2007). Hinds *et al.* (2007) refute the claim that the parents of children with life-limiting conditions feel obliged to participate in studies when asked to do so by their healthcare professionals and, on the contrary found that parents can and do refuse to participate on a number of grounds, including: methods were too involved; topic was too sensitive; they were worried about other issues; had concerns about issues of study design such as data collection times; or were simply not sure why they did not want to participate (Hinds *et al.* 2007). Guarding against coercion to participate in research is an important consideration. In this research processes were put in place in order to avoid this. The researcher had no direct access to potential participants and utilised the services of gatekeepers.

As the initial contact point for potential participants gatekeepers provided information to eligible families thus giving them the opportunity to decline to participate if they so wished. Whilst ethically the use of gatekeepers protected participants from the threat of coercion this also had an impact on the recruitment of potential participants and their opportunities to make an informed decision about their participation in the research. Gatekeepers regularly protected potential participants from what they perceive as the burden of participating, mentioning on several occasions families who were eligible but whom they felt were not able to participate due to the stage of their child's illness or their protective instincts for the parents (Tomlinson *et al.* 2007). Choosing whether to participate or not is part of the right to self-determination. Hinds *et al.* (2007) suggest that in order to overcome this, a flexible

approach to research methods for parents of children with life limiting conditions is needed, allowing choice but one that balances with rigour taking into account their extraordinary circumstances, a flexible approach was taken throughout the research process, for instance, parental choice was always considered for the location of interviews which was always decided by parents. They found that parents appreciated being able to participate in their location of choice notably their own home (Hinds *et al.* 2007).

5.9.2.2 Ensuring participants right to full disclosure

In line with parent's rights to full disclosure (Polit & Beck 2010) in this study particular attention was paid to individual participants and respect for their autonomy. Participants were provided with both verbal and written information about the study, which explained the purpose and process of the research, and emphasized informed choice, consent, and confidentiality. All potential participants were spoken to by telephone prior to the initial interview to ensure that they understood that their participation was entirely voluntary and confidential, whilst reiterating the purpose and process of the research. At all stages of the research process, potential and actual participants were given every opportunity to voice anxieties, ask questions and discuss their participation in the study. They were informed of their right to withdraw at any time and prior to signing the consent form the voluntary nature of participation and assurances of confidentiality were reiterated. In this study during the consent process it was emphasized to participants that, where possible, anonymity and confidentiality was assured, the only exception to this being if issues were raised during the research that had an impact on the child's safety or well-being (OMCYA 2004).

5.9.2.3 Justice

The final ethical principle is justice, which encompasses the right to fair treatment and the right to privacy. The principle of fair treatment aims to protect those who may be exploited through the research process and who are unable to protect their own interests (Polit & Beck 2010) and also aims to ensure that all participants are treated alike regardless of their social, financial or physical status. This principle also sets out to ensure that all participants are treated with respect and kindness throughout the research process.

In research such as this, from the outset, participants have the right to expect that all data collected will be kept confidential (DiCicco-Bloom & Crabtree 2006). Maintaining confidentiality in case study research can be challenging due to the intensive and unique investigation of individuals and the depth of detail obtained. However, it is an ethical imperative for participant's anonymity to be protected at all times and in this research measures were taken to ensure this. Case numbers were assigned to each case and all names and references to organisations and geographical locations were changed to protect the participant's identity. The researcher exclusively maintained a list of participant details. However, despite best efforts, the small potential pool of participants taken from the caseload of a palliative care team inevitably makes anonymity more challenging. The in-depth analysis of the nine cases under scrutiny also presents ethical issues regarding presentation of findings; however, every effort was made to maintain confidentiality and protect the identity of participants (Payne *et al.* 2007). The issue of anonymity was discussed with participants during the informed consent procedures however; many were unconcerned about their anonymity demonstrated by, for example, offers of photographs of their child.

5.9.3 Obtaining research ethics committee approval

Prior to any contact with the clinical staff at the children's hospital, application was made for ethical approval²⁷. Hinds *et al* (2007) point out some of the challenges posed by ethics committees when considering end-of life studies in children, such as concerns about the lack of benefit to participants and their perceived vulnerability (Hinds *et al.* 2007). These were taken into consideration in the completion of the ethics application forms and for the meetings with the committees. Ethical approval was sought from both the study site and also by the University of Dublin, Trinity College, Faculty of Health Sciences Ethics Committees. This required detailed submissions and attendance at both ethics committee meetings. Each made requests for minor alterations of written material. Ethical approval to conduct the study was granted by both institutions in June 2010 (Appendix 17 and Appendix 18).

The rights of children aimed at their protection as vulnerable people have received increasing acceptance (United Nations 1990) and this may enhance the perceived vulnerability of potential participants seeming to be at odds with their rights. This apparent vulnerability can

²⁷ Some aspects of application forms and letters received have been changed or omitted in order to maintain confidential identity of place and persons

lead to paternalism by ethics committees (Hinds *et al.* 2007; Tomlinson *et al.* 2007) who may consider the research to pose a threat to the child and family's ethical rights such as beneficence and non-maleficence (Tomlinson *et al.* 2007). There are, however, compelling counter arguments to these views indicating that participation in research can be a good thing in palliative care. For some people, talking through their experiences may evoke distressing or upsetting memories or feelings but equally there is evidence to suggest that some participants find interviews both painful and helpful in providing the opportunity to discuss and reflect on their experiences. The opportunity to tell their whole story was particularly valued (Payne *et al.* 2007). In children's palliative care Steele *et al.* (2005) found that parents often agreed to participate in research even if they found it challenging, with an altruistic wish that it would be of benefit to other people in similar situations. Contro *et al.* (2002) also found that families were grateful for the opportunity to tell their story and help improve palliative care services (Contro *et al.* 2002). Even when potential participants express initial reluctance, knowing that their story may help other families was important in their decision to participate (Davies *et al.* 2009). There is also a school of thought that participating in research may not only improve outcomes for future service users but can lead to benefits for the participants themselves and thus to deny them the opportunity to participate may deny them potential benefit (Tomlinson *et al.* 2007).

5.10 Initial entry into the Field: Preparing and Informing Health Care Professionals

In this study the palliative care nurses and consultant at the children's hospital agreed to act as 'gate keepers' to assist with recruitment of families to this study. It is important for researchers relying on 'gate keepers', in this case the palliative care team, to both build and maintain relationships throughout the research process (Sheldon & Sargeant 2007). An initial meeting was arranged at a suitable time and in a convenient location to allow the maximum number of team members to attend. In preparation for this meeting and in order to assist with recruitment, a study folder was developed containing: a study protocol ([Appendix 8](#)); a parents' consent form ([Appendix 4](#) and [Appendix 5](#)); a statement of interest ([Appendix 9](#) and [Appendix 10](#)); information sheets for participants ([Appendix 11](#) and [Appendix 12](#)); inclusion and exclusion criteria ([Appendix 13](#)); and a copy of ethical approval letters from both the hospital and the University ([Appendix 17](#) and [Appendix 18](#)). A meeting took place between two palliative care nurses, a medical registrar, the consultant and me where I gave an

overview of my research and welcomed any questions. Potential participants were discussed. The team was positive and supportive of my work.

One of the recruitment aims of my research was to recruit children from all four ACT categories (ACT 2009). In order to elicit the referral of potential participants with a malignant diagnosis I attended one of the oncology team's weekly psycho-social meetings and presented my research proposal at the oncology team meeting. They too were supportive of this research and at the meeting discussed potential participants. Contact details were provided to ensure that the team had access to the researcher should any issues arise regarding eligibility, progress of the study or in case there was a need for any support regarding recruitment issues.

A further pragmatic consideration for those undertaking qualitative research is the need for personal safety (Sheldon & Sargeant 2007). During this study Trinity College 'Lone researcher guidelines' were followed (Appendix 14).

5.11 Recruitment Procedure

As home is most frequently the location of choice for the care of a child with a life-limiting condition (DOHC/IHF 2005) the palliative care team is frequently involved in the organisation of complex discharges including the on-going provision of palliative and respite care. Initially, five study packs for potential participants were left with the team. This pack included a letter of introduction to the study ([Appendix 15](#)), an information sheet ([Appendix 11](#) and [Appendix 12](#)) that included the researcher's contact details, an statement expression of interest form ([Appendix 9](#) and [Appendix 10](#)) and a stamped addressed envelope. Potential participants were identified and approached by the palliative care team members and study packs were distributed.

Parents were able to indicate their interest in participation by returning an expression of interest letter directly to me at the School of Nursing and Midwifery, Trinity College, Dublin in a stamped and addressed envelope included in the study pack. This was taken as an indication of the parents' wish to be contacted in relation to the study. Once this letter was

received the researcher made contact with the parents directly and discussed what participation entailed, including the voluntary nature of participation and the right to withdraw or change one's mind at any stage. A meeting date and time was arranged at a time and location convenient to the participant with a promise by the researcher to make contact the day before by text to their mobile phone in order to ensure that they were still willing and able to participate.

5.12 Duration of the study

The duration of data collection was two years from the time of receipt of ethical approval (commencing 25th June 2010) Parents were contacted on several occasions during their participation. Due to the unpredictable nature of life-limiting conditions in children, it was envisaged that this study would follow parents of some children through to end-of-life care and that other children might survive beyond the planned duration of the study.

5.13 Data collection²⁸

Multiple sources of data are a hallmark of case study research (Stake 1995; Walshe *et al.* 2004; Yin 2009). Data were collected from a range of sources including: documents, medical records, observation and a research journal; however the main source of data collection was interviews with parents and other participants (Figure 9). Over the course of the research, as data and information of interest relating to each case were collected, this was filed in an individual case folder. In case study, data are examined and interpreted throughout the data collection period providing the opportunity to make some tentative conclusions throughout the research process (Hancock & Algozzine 2006) and also enabling leads to be followed and the further evidence to be gathered.

²⁸ This section reports on the specific data collection methods utilised in this study. Data analysis processes will be described and discussed in a later section



Figure 9 - Data collection methods utilised

5.13.1 Documents as data

In case study research the use of documents adds depth to case study research and also adds context (Simons 2009). The importance of reviewing documents as part of case study research has been highlighted by Yin (2009) who stresses the vital information that documents can provide in substantiating, corroborating and enhancing evidence from other sources. Simons (2009) suggests that by analysing documents prior to field data collection can assist in by highlighting what researchers should explore in observation and interviewing (Simons 2009). Whilst analysis of documents of interest prior to data collection was helpful in this research, I was also mindful to include any further documentation and literature accessed during the data collection process. Although the use of visual documentation such as photos or pictures can enhance findings in case study research (Hansen-Ketchum & Myrick 2008) and some participants readily agreed to provide photographs, due to ethical concerns regarding the protection of the participants' identity, these were excluded.

5.13.2 Medical records

Approval from the research ethics committee allowed access to the participants' children's medical records as part of the data collection process. Medical records of the child were scrutinised and detailed notes were made. In all cases information was routinely collected to verify dates, diagnosis and other information on the child's medical condition. Notes made

by clinicians were also examined and salient issues, such as conversations regarding help or respite and issues such as prognosis were recorded in note format. These formed part of the overall data collected.

5.13.3 Observation

Observation as a research method sits well in the naturalistic research setting (Ballinger *et al.* 2004) and in particular in case study research which describes phenomenon in their real-world context. In case study, the most frequently utilised method of observation is ‘unstructured’. This is naturalistic and direct with no preconceived check list. It describes events and settings as they naturally occur, and in these circumstances the observations are more descriptive and intuitive and acts as a companion method to the data collected during interviews (Simons 2009). This type of observation is also referred to as participant observation.

It is suggested that the recording of observations from the position of a researcher requires carefully documented field notes made as soon as possible after the interaction and should include the researcher’s own personal view (Ballinger *et al.* 2004). In this research notes were hand-written or recorded (using a voice recorder) after each interaction with participants these were then expanded, transcribed and edited on to a contact sheet ([Appendix 16](#)) within 48 hours. This included comments and observations about the location of the interview and what was seen and heard. Notes were also made regarding the location and environment in which the interview took place.

5.13.4 Research journal

Throughout the research process I kept a research journal. Sheldon and Sargent (2007), suggest that as a practitioner and a researcher it is possible to become more sensitive to the ‘*everydayness*’ of the world you take for granted and suggest that keeping a research journal can be of help in following feelings, thoughts and observations during fieldwork. In this study the researcher’s field notes also constitute a component of the research data. ([Appendix 16](#)). All data collected throughout the research process was used to build a comprehensive picture of each ‘case’ and was also part of the “chain of evidence” (Yin 2009), this included interview data.

All interviews were undertaken in a location of the participant's choice. With the participant's prior consent all were recorded using a portable voice recorder. In each case the first interviewee was the parent (or both parents) who had contacted me regarding participation and who, according to them, was deemed to be the primary carer. Further interviews with parents were arranged at a frequency depending on the individual family and their circumstances. This was assessed by regular phone and text contact with parents regarding their child's condition and was dictated by the parents and their availability and with respect for their other commitments. The interviews took place over an extended period of time. In each individual case parents were asked to identify other participants who they perceived had a role in the provision of respite for their child. These participants were all viewed by the researcher as part of the family system for example: the 'Microsystem' interviews with a parent or parents; the 'Mesosystem' extended family and health and social care professionals and in the 'Exosystem' voluntary providers of care were interviewed.

The decision to audio record interviews was made in order to ensure accurate recounting of the interview process. Simons (2009) warns that interviewers may not listen as thoroughly if they know they can listen to the recording which may lead to less in-depth interviewing and that potential equipment failure may result in the researcher having no data. A further challenge is that the transcription of audio recordings is time-consuming and needs to be carefully checked by the researcher for accuracy. However, according to Simons (2009) the biggest challenge of recording data is the time lag between taping, transcription and analysis which often leaves the researcher reliant on memory (Simons 2009). Hewitt (2007) suggests that accurate transcription of interviews is one way to ensure rigour in qualitative research.

5.14 Addressing the issue of rigour in this research

The quality of research and its findings are directly related to the commitment and rigour with which the researcher engages with the topic under study, coupled with the skill and competence with which the chosen method, in this instance qualitative case study methodology is applied (Yardley & Marks 2004). Every effort was made to ensure that this research was designed, conducted and analysed rigorously. Several authors have suggested ways in which rigour can be addressed in qualitative research such as this (Sandelowski

1993a; Hewitt 2007; Li & Seale 2007). Hewitt (2007) suggests that to ensure that rigour is addressed in qualitative research researchers need to address reflexivity, respondent validation, and accurate transcription.

5.14.1 Reflexivity

It has been suggested that in order to ensure rigour, researchers need to be both self-conscious and self-aware and able to critically examine their own beliefs and assumptions (Hewitt 2007). Reflexivity is the process of the researcher raising awareness of and reflecting on their own biases, interests, and values about the research process and topic; where the researcher-self and the personal-self are inseparable (Cresswell 2003). The process of reflexive analysis and reflection should ideally commence when research is conceived (Finlay 2002) and continue throughout the research (Sheldon & Sargeant 2007). In this research, reflexivity was considered from the inception and throughout the research process.

Case study research is inevitably influenced by the researcher's own ontological and epistemological beliefs as the research process initially draws on the researcher's own intuition, knowledge and experience about the research topic (Hancock & Algozzine 2006). As a qualitative researcher it is essential to keep the notion of reflexivity to the fore and in particular to be aware of issues such as for example the power differential between the researcher and the participant and the influence of this on the research process (DiCicco-Bloom & Crabtree 2006). Stake (1995) suggests that throughout the research process the constructions that are provided by both the participants and the researcher form a new reality (Stake 1995). He suggests that if the researcher's aim is robust research and the work is undertaken in a constructivist paradigm, such as this research, then the role of both the researcher and the participant in constructing and finding knowledge must be acknowledged. As the main data collector I was an inescapable part of the study; interacting with participants and influencing the research through my world-view (Simons 2009). It is therefore essential that I both acknowledge and declare these through the process of reflexivity, acknowledging for instance not only my role as a researcher but also for example as a woman, a nurse, a mother, and an English person living in Ireland. All of which have an impact on the research process and recognise that case study is influenced and shaped by social constructs around the unit of analysis, in this case the parents of children with life-limiting conditions and the researcher but through the wider family system.

In qualitative research, participant and researcher relationships are often viewed as necessary and are built on trust and a respect for the interviewee and the information that he or she shares (DiCicco-Bloom & Crabtree 2006). By sharing information the researcher is also susceptible to becoming involved with the participants at an emotional level (Morse 2007). It has been recommended that following interviews debriefing may be necessary (Kvale 1996). When required, in this research, debriefing took place in a variety of ways but primarily through support of colleagues and my supervisors. It has also been suggested that there is potential for harm to not only researchers but also to transcribers and supervisors when the research topic is of an emotional nature and this should be factored into the research project planning (Lalor *et al.* 2006; Morse 2007). In this research a professional transcription service was utilised, regular checks were made with the transcribers to see if external support was required.

5.14.2 Respondent validation

A further recommendation for ensuring rigour is that there should be sufficient quotes from transcripts used to accurately represent and present both responses and the processes used (Hewitt 2007). This is an integral part of reporting qualitative case study research findings and fits with Yin's suggested 'chain of evidence' (Yin 2009). Hewitt (2007) further suggests that this may be achieved through the use of respondent validation that may reduce misinterpretation of participants' experiences. This refers to participants being asked to read and verify the researcher's interpretation of their interview and its emergent themes in order to add to the credibility of the research as it relates to internal validity. Evidence that this process does not add rigour have resulted in this approach not being undertaken in this research. Kvale (2006) argues that "member checks" are only an attempt to equalise the role of the researcher and the participants and that the research subjects rarely have any say in the reported findings of research (Kvale 2006). Sandelowski (1993) also points out that whilst participants may agree to participate in a formal checking process this can be to please the researcher whereas in reality they may not wish to participate in this type of exercise and ultimately may find it difficult to disagree with researchers interpretations. Others argue that once data are analysed and study findings have been synthesized, decontextualized, and abstracted from (and across) individual participants, participants may not be able to recognise themselves or their particular experiences (Sandelowski 1993b; Morse & Field 1996).

Furthermore in this research as participants were interviewed on more than one occasion it was possible to clarify points of ambiguity directly with the participants in subsequent interviews.

5.14.3 Transcription of interviews

The accurate transcription of interviews is also suggested as a way to ensure rigour (Hewitt 2007). It has been suggested that whilst not always feasible, researchers should not only be the interviewer but should also transcribe (Eason *et al.* 2000) however due to time constraints this is not always possible. In this research by way of compromise the researcher undertook some transcriptions (Payne 2007a) prior to commissioning the services of a professional transcription service. Transcriptions were made as soon as possible after each interview (this ranged from a few days to in some cases, a few weeks).

There are inherent challenges when transcribing recorded interviews where the spoken word in text form at times does not reflect the interaction or context. DiCicco-Bloom and Crabtree (2006) point out that a simple error in punctuation can change the entire meaning of a sentence (DiCicco-Bloom & Crabtree 2006). Researchers should not therefore assume that an interview has been transcribed correctly and should ensure rigorous checking of each transcript. This was undertaken by simultaneously listening to the recording and checking the transcript. Any changes to punctuation and grammar and over simplification were rectified and in particular, any section marked 'inaudible' by the transcriber, was checked by the researcher. Each recording was listened to several times and notes made of any important points. This process commenced once interviews were transcribed as it is important that data analysis should occur concurrently with data collection. This is helpful in ensuring that the sequence of data collection and analysis are an iterative process (DiCicco-Bloom & Crabtree 2006).

Data analysis included: interview data; analysis of patient journeys; observational data; and analysis of documentation including policies. An audit trail has been created as it is an essential element of case study research, providing a chain of evidence that strengthens rigour and trustworthiness (Hsieh & Shannon 2005; Yin 2009). Care has been taken in this research to maintain records of all contacts, documents, observational and interview data.

5.15 Developing case stories

Story-telling is an integral part of case study research (Yin 2009) and therefore initial analysis in case study research should include the writing of a case report or case story (Hancock & Algozzine 2006). There is no accepted or standard approach to this, it is suggested that all reports should identify the event or situation under study and state if and how the research is bound by time and space (Hancock & Algozzine 2006). In this research case stories were developed utilising all available data including interview data, observation, field notes and the researcher's journal. Stories were developed bearing in the mind the research question, aims and objectives.

5.15.1 Documentary analysis

In this research documents were selected for inclusion by the researcher only if they were considered to be of relevance to the research question and added to the understanding of the individual case. Copies of all documents were collected in their original format where possible (Hancock & Algozzine 2006). Some documents developed in the Macrosystem such as national policies²⁹ and the literature and newsletters of national organisations providing support services to children with life-limiting conditions³⁰ had the potential to impact on respite care in all of the cases whereas other local policies developed in the Exosystem had an impact on individual cases and the provision and uptake of respite. Whilst documents such as policies from local organisations were included in the analysis, in order to protect each participant's identity the name of the organisation has not been included. All documentation included was appraised with a critical awareness and without the assumption that the content was accurate (Yin 2009). The contents of the documents were analysed and summarised in narrative form and presented in tabular format as suggested by Hancock and Algozzine (2006). Findings from documents provide a context for interpretation of observational and interview data (Simons 2009) and also can provide very helpful perspectives, accounts and additions to the data (Stake 1995). The documentary sources accessed in this research aim to

²⁹ DOHC/IHF (2005) A palliative care needs assessment for children. Stationery Office, Dublin, DOHC (2010) Palliative Care for Children with Life-limiting Conditions in Ireland - A National Policy. Stationary Office, Dublin, IHF and CSH (2011) *Respite Services for Children with Life-limiting Conditions and their Families. A needs assessment for the HSE Dublin Mid-Leinster and HSE Dublin North East area.* Irish Hospice Foundation/Children's Sunshine Home, Dublin.

³⁰ Names of these organisations are omitted to preserve anonymity

assist in constructing the context for my cases and in some instances to corroborate information given during interviews.

As part of my ethical approval, in order to substantiate information regarding diagnosis, prognosis and patient history, I sought access to the children's medical notes. These were accessed via the children's hospital medical records department. Notes of salient issues were made including information regarding diagnosis and prognosis and any record of conversations with parents or healthcare professionals regarding the provision of respite were noted and recorded in a research journal.

As part of the data analysis process documents were read and key points noted in a tabular format. The information was primarily descriptive but provided context for the provision of services. Care was taken to protect the anonymity of organisations referred to within the documents. Stake (1985) suggests that gathering data through the review of documents is the same as observation or interviews and should be coded and stored in the same way as other data.

5.15.2 Observational data analysis

Analysis of participant observation data aims to provide the most simple and accurate representation of the setting and the interactions that took place (Mulhall 2003). The majority of parent interviews were undertaken in the family home and therefore field notes were made about the layout of the house, and what I observed or experienced during my visit. This served as an aide memoire for me when considering other factors in this research such as the impact of caring for the child in the family home and the impact on the family system as a whole. Further observations were recorded in a research journal. As in all aspects of qualitative research there is a need to acknowledge the role of the researcher in the study through the process of reflexivity in the analysis of observational data.

Noting my observations during interactions with participants allowed me the opportunity to assess body language, non-verbal communication and emotions such as anxiety, all of which added to richness of the data collected (Simons 2009) and also allowed me to reflect on the environment, the family interactions and my role in the research process. I recorded my

personal impressions, observations and reflections on the interview process: who was in the house; where we conducted the interview; interruptions; equipment; how people reacted to me as an interviewer; and what we spoke about before and after recordings³¹. It has been posited written field notes such as these enhance data and are better than audio recorded interviews alone (Halcomb & Davidson 2006); however, it is my contention that a combination of multiple data sources provides a more comprehensive approach to each case study. The importance of utilising observation in case study research has been recognised as it not only assists in gaining a greater understanding of important issues identified within a case but provides a context for a situation (Stake 1995; Yin 2009).

5.15.3 Interview analysis

Interviews as the primary way of obtaining multiple realities (Stake 1995) were the main source of data in this case study research. Interview data can be analysed in several ways ranging from paper and pen to the employment of computer software (Payne 2007a). In case study research the use of computer software can be helpful, however interview data are only one component of the research data collected and other data can be more difficult to capture and record using computer software. In this research the utilisation of NVIVO® software was considered to support the organisation of interview data and I even undertook an introductory course; however, data management is a matter of personal preference and I chose to manage and analyse data manually and by using ‘Word’ software and a personal computer.

In this research thematic analysis was employed as the primary form of interview data analysis. This analysis of data involves systematically and rigorously identifying patterns of similarity in the text that are of relevance to the research question. Joffe and Yardley (2004) contextualise thematic analysis in relation to other analytical procedures such as constant comparison and narrative methods and highlight the differences between the approaches. Thematic analysis allows an explanation of the data, without the theoretical restrictions of interpretative phenomenology or grounded theory. Unlike content analysis, thematic analysis enables the researcher to capture and record similar responses even where specific phrases are not used. The flexibility of thematic analysis means that themes can be generated both by deduction where the themes are explored using previous theory and research, and inductively

³¹ It was my intention to include an excerpt from this journal but I am unable to maintain participant confidentiality in doing so.

from the data generated during the study (Joffe & Yardley 2004; Hsieh & Shannon 2005; Elo & Kyngas 2008; Yin 2009), in this research analysis was primarily inductive.

As a first step in interview data analysis, it has been suggested that researchers should read through the transcripts as many times as they need in order for them to gain insight into the data's essential features without feeling that they have to begin analysing (Elo & Kyngas 2008) while others suggest that reading through transcripts is in itself preliminary analysis (Sandelowski 1995). By reading and re-reading of the transcripts I became familiar with the content and emerging codes and categories were identified. Joffe and Yardley (2004) suggest that for thematic analysis there is a need to develop conceptual tools to understand and classify the phenomenon under study. They suggest that this can be achieved through coding. Coding is the process of breaking down the text into small units and organising them according to category (Simons *et al.* 2008).

My first step in analysing interview data was to manually commence a process of open coding³² examining interview transcripts, highlighting points of interest and significance and making notes. Codes are effectively category labels assigned to units of meaning to the inferential or descriptive information gathered during a study (Miles & Huberman 1994; Fereday & Muir-Cochrane 2006) they can refer to a section of text ranging from a single word to a paragraph and are used to retrieve and organise text. Coding enables the researcher to efficiently identify specific segments of text as they relate to the research question and the underpinning principles of the research (Joffe and Yardley, 2004).

Familiarity with the transcripts enabled me to identify text that was significant. A code was assigned to these words or statements by writing in the margin of the transcript (Joffe & Yardley 2004; Elo & Kyngas 2008) sometimes notes were made by hand and other times electronically ([Appendix 6](#)). Codes were derived inductively where segments of text from the participant's interview headed each theme (Fereday & Muir-Cochrane 2006). I then mapped out these codes on to A1 sheets of paper ([Appendix 7](#)) and populated each heading with direct quotes from the transcripts relating to each heading (Simons 2009). Once these codes

³² Open coding refers to a process where all content that was deemed by the researcher as important or relevant to the research question was highlighted. These decisions were based on the literature review and the researcher's experience.

were established they were organised into categories based on their relationship to each other and how they were linked (Hsieh & Shannon 2005). During this stage of data analysis each case had several A3 and A1 mapping sheets reflecting various categories and sub-categories. Analysis activity is marked by the complexity of dynamic movement back and forth between data (Graneheim & Lundman 2004) and at this early stage of analysis this process is required to ensure that the initial categories reflect the data collected.

Categories and sub-categories were used to group codes and organise them into significant clusters. Whilst categories were influenced by my research question and the background literature care was taken to ensure that the categories reflected the data rather than these factors (Elo & Kyngas 2008). This initial analysis was then further scrutinised for overlapping or similar categories, informed by the analytical and theoretical ideas developed during the research, these categories were then further refined and reduced in number by grouping them together (Miles & Huberman 1994). This process of data reduction through clustering enabled me to view each case clearly and to begin the process of drawing conclusions by categorizing data into themes (Simons 2009).

There is an onus on the researcher to ensure that the themes that are developed are directly grounded in participant's descriptions. This can be achieved by referring back to the transcripts and the original recordings of interviews (Smith & Firth 2011) and by utilising the process of constant comparison throughout the data analysis process. This involves the researcher reading and re-reading transcripts or listening to audio recordings of the interviews throughout the data analysis process in a constant search to understand data and to identify emerging themes (Elo & Kyngas 2008). Through this process of clustering, codes and categories, overarching themes were established and supported by sub-themes. In this research each theme was assigned a phrase that described the meaning underpinning it; for example 'Living with uncertainty'. These are diagrammatically illustrated in the findings chapter. It has been suggested that trustworthiness can be achieved by the researcher describing the analysis process in as much detail as possible to enable readers to understand the processes that have been followed. The use of visual displays such as graphs and tables may help to demonstrate links between the data and the results (Elo & Kyngas 2008) also the use of authentic citations increase the trustworthiness of the findings (Elo & Kyngas 2008).

These suggestions have been followed with detailed flow diagrams of how themes evolved and of how this relates back to the information gathered during the course of this research.

Throughout the research process care was taken to focus on answering the research question rather than being distracted by interesting topics that were outside the scope of the research question (Elo & Kyngas 2008). In the literature, one suggested way of accomplishing this is the use of an analytical framework that aims to maintain consistency in analysing data. This is an important consideration (Sandelowski 1995) several analytical frameworks exist (Colaizzi 1978; Burnard *et al.* 2008). More recently a specific ‘framework approach’ to qualitative data analysis has also been developed (Smith & Firth 2011)³³. In order to look collectively at the case studies in this research, following in-depth analysis and development of each individual case, cross case comparison was undertaken.

5.15.4 Cross-case comparison

The primary aim of this research was not to identify a sample that would provide generalisable findings instead it sought to initially present the unique needs and experiences of parents and others caring for children with life-limiting conditions within an individual case. Data were compiled into individual case stories or reports that allow each case to be viewed as a separate entity. Once analysed cases were compared for commonalities and differences through a process of cross-case comparison, to capture emerging conceptual issues and analytical themes. Key themes were identified in each case and these were compared and contrasted to other cases seeking shared or similar experiences. These were then presented in a tabular format.

5.16 Trustworthiness

Trustworthiness (Guba 1981; Lincoln & Guba 1985) was addressed in this research. It is a concept containing four aspects: credibility, transferability, dependability and confirmability as specific strategies to demonstrate qualitative research rigour. Morse et al (2002) suggest that in order to verify the reliability and validity of their data that researchers should: aim for *methodological coherence* by ensuring that the research question and the method are

³³ Utilisation of an analytical framework was considered and attempted in this research but this notion was rejected. Analytical frameworks aim to explicitly and systematically apply the principles of analysing qualitative data whilst guiding the researcher through interconnected stages of qualitative research. In this study it felt as though I was forcing my analysis to fit the framework rather than the framework assisting in the analysis.

matched; ensure that the *sample is appropriate*; *collect and analyse data concurrently* as this iterative interaction is the essence of attaining validity and reliability; *thinking theoretically* where ideas from the data are confirmed in new data; and *theory development*. Furthermore Hsieh and Shannon (2005) suggest achieving unbiased neutral results requires researchers to provide evidence through an audit process and trail to assist with neutrality and confirmability of trustworthiness. These issues were all comprehensively addressed in this research as demonstrated throughout this methods chapter.

5.17 Summary of Chapter 5

There are inherent challenges in undertaking case study research and some of these have been highlighted in this chapter that sets out the processes and practices of undertaking this case study research. The development of the research question, aims and objectives, through to the ultimate analysis of multiple methods of data collection have been discussed and described. The ethical issues, considerations and procedures both theoretical and practical have been highlighted. The data analysis process has been explained in detail where it has been suggested that the key to success is the repetitive and continual review of data collected (Chamberlain *et al.* 2004; Hancock & Algozzine 2006) and this has been clearly demonstrated in this research. In the following chapter findings from this research will be presented.

CHAPTER 6: FINDINGS

6.1 Introduction

In this section findings of this research will be presented. This chapter is divided into four sections. The first, details the characteristics of the families recruited to this study including the numbers of families approached and recruited and some demographic information. The second part presents the nine individual case stories. These are derived from multiple sources of data collected throughout the research process. The next section details a cross-case comparison. The final section presents the findings of in-depth interviews undertaken with both the families of children with life-limiting conditions and those involved in the provision of respite care.

6.2 Characteristics of families participating

A total of 17 families were approached regarding participation in this research. These families were identified by the palliative care team at the Children's Hospital and were given information packs. Of these 17 families, nine contacted me regarding participation and were duly recruited. The sampling strategy was selected by the researcher in order to achieve a sample of cases that met a number of different criteria and demographic characteristics. These are shown in table 5 below.

In total 39 semi-structured interviews were undertaken with the number of interviews relating to each case ranged from two to seven interviews (Table 6); interview time with parents ranged between 24 minutes and 171 minutes with one parent interview lasting nearly three hours. This particular interview was with a participant whose first language was not English and it was challenging for her to make herself understood without explanations and sometimes the use of a translation package on her computer. During the study recruitment and data collection period October 2010 - October 2012, two of the children featured in the nine cases presented here, died.

Table 5: Characteristics of the nine participating families

Table 5	
Characteristics of the nine participating families	
Characteristic	No.
Age range of child	
0-2 years	1
>2-5 years	
>5 – 10 years	3
>10-15 years	3
>15-18 years	2
Total	9
Position of child in family	
Youngest	2
Eldest	4
Only	1
Middle	1
Twin	1
Total	9
Geographical location of family	
South	0
West	2
North West	1
North East	1
Leinster	5
Total	9
Nationality	
Irish	7
Other	2
Total	9
Marital Status of parents	
Married	8
Single	0
Separated	1
Total	9
ACT Category of ill child	
1	2
2	1
3	0
4	5
Unknown	1
Total	9

TABLE 6 Case and interview details at a glance

VARIABLE	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7	Case 8	Case 9
Name	Molly	Aisling	Patrick	Magda	Emma	Ellen	Grainne	Harry	Max
Age	13	10	9	13	17	9	18	<1	8
Diagnosis	Global developmental delay	Global developmental delay	Global developmental delay	Brain tumour	Neurofibromatosis	Global developmental delay	Cardiac	Unknown	Cerebral palsy
ACT Category	4	4	4	1	2	4	1	?	4
Geographical location	West	East	West	East	North East	East	North West	East	East
Number of children in family	5	2	2	2	2	2	3	1	1
Single parent	no	no	no	no	no	no	no	no	yes
DATA COLLECTION									
Interview 1 Parents	19/11/2010	14/1/2011	31/1/2011	15/2/2011	28/2/2011	13/4/2011	14/4/2011	13/7/2011	22/11/2011
Interview 2 Parents	17/1/2011	10/6/2011	25/6/2011	13/10/2011	26/9/2011		29/5/2012	28/2/2012	4/09/2012
Interview 3 parents	18/5/2012	27/1/2012							
Number and type of other participants interviewed in each case	Respite nurse 17/1/11 Respite co-ordinator 17/1/2011 Palliative care nurse 17/1/2012	Respite nurse 24/11/2011 Respite co-ordinator 16/1/2012 Mother-in-law 27/1/2012 PHN 14/5/2012	Respite carer x 2 25/6/2011 Nurse 15/3/2011 Aunty 25/6/2011	Voluntary organisation 14/11/2011 Clinical nurse specialist 5/5/2011 Respite centre 26/5/2011	Palliative care nurse 30/5/2011 Voluntary organisation 8/10/2012	Respite carer 13/4/2011 School teacher/nurse 27/6/2011	Nurse 29/5/2012	Voluntary organisation 14/11/2011 Respite care co-ordinator 13/10/2011	
Total number of interviews - 39	6	7	5	5	4	3	3	4	2
Date of Death	October 2012					February 2012			

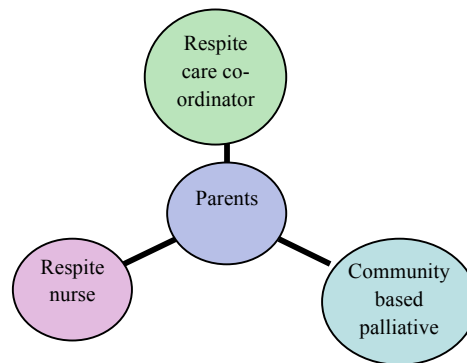
6.3 Case stories

6.3.1 Introduction

In case study research the focus is on telling the ‘story of the case’ (Stake 1995; Simons 2009; Yin 2009) aimed at giving the reader a sense of the interpretations and inferences of events and issues that make up the story as a whole. Nine individual case stories are presented viewed through the lens of the family systems theory. Each case is an individual story that has been carefully developed from evidence collected from multiple sources of data (observation, documentary evidence and a research journal) and from semi-structured interviews with parents and other participants involved in the provision of respite. All names have been changed and pseudonyms employed to protect the identity of all participants. Locations and providers of care have also been anonymised in order to further protect confidentiality. Each case story commences with a diagram of the case participants and will conclude with a matrix of where participants were situated within the family systems framework.

6.3.2 Case 1 – Molly’s Story

Figure 10 - Case 1 - Case participants



The first time I spoke to 13 year old Molly’s mother Anne, she told me that when her daughter was born *‘I was told she had a 99% chance of dying and a 1% chance of living’*. Molly is the second of five children. Located in rural Ireland, Molly has her own suite of rooms accessible through a door off the kitchen in her family home. Following placental abruption and the resultant lack of oxygen at birth Molly has lived for 13 years with profound disability. The doctors told Anne if Molly were to survive that this would be *“a dilemma that society would have to face”*. Words said 13 years ago clearly engrained in Anne’s mind.

Anne recalled the initial frustrations of caring for Molly as a baby and the lack of information and support available to her and her family during this initial phase. Once Molly, aged one, was diagnosed with cerebral palsy a limited number of services became available. In the early days Anne recounts the help and support provided by family and friends and how over time people drifted away. Molly’s initial poor prognosis and her subsequently fluctuating condition have resulted in Anne and Sean being told several times that she was unlikely to survive. Multiple near death experiences have left them expecting her to survive each episode.

Initially, guilt prevented Anne from availing of respite services that were offered for Molly: the use of such services insinuating that they were unable to cope. Anne recounted her first experience of respite describing the two hour journey with her husband for a three hour respite and how they sat in the car outside the respite centre until it was time to pick Molly up

and take her home again. Eventually Molly would be admitted for the weekend, however, Anne stressed that this was dependent on which staff were on duty, some calling them before they were home to go back and pick Molly up if she wasn't well. Anne was cautious of other children under the care of the respite centre where Molly's physical fragility meant she had to be isolated from some of the other respite attendees with conditions such as autism.

The provision of respite care enabled Anne to return to employment, describing work as "*a complete break*". Respite also allows her to socialise with her husband by getting out to the local pub; she describes this as "*respite in a different way*". Anne describes her decision that Molly should attend the local national school with her siblings rather than being picked up on a bus and sent to a special school. She has a Special Needs Assistant and attendance is dependent on her physical condition. When she is well enough to attend, school also provides a break for Anne.

Anne describes Molly being admitted to hospital as a nightmare impacting on the whole family. They would never leave her in hospital without one of the parents being present. This is based on past experiences and mistrust of the care standards hospitals are able to provide.

Anne's preference is that respite should be a continuation of home; maintaining routine. In order to access home respite a local charity gives Anne a cash grant thus technically making her an employer. She utilises this grant to fund primarily babysitting for Molly. Anne describes how ... "*we have had hundreds of people through our home*" she interviews carers, some who do not take the post. Living in a small rural area, when she sees them, she describes feeling hurt that they don't want to help care for her daughter.

In recent years out-of-home respite has been provided by a local charity in a nearby house where Molly has a room for her exclusive use. Despite this, Anne's preference is to have respite at home this is not without its challenges and Anne describes having a stranger in the home caring for Molly and the impact that this has on family life. Anne acknowledges that her extended family have been supportive over the years by providing babysitting for Molly's siblings but that most people who help with Molly are paid to do so.

Three months later I arrive at the respite centre where Molly avails of out-of-home respite to talk to the staff nurse who cares for Molly. The nurse, Fiona, has been caring for Molly for eight years. She is employed by a charitable organisation and cares for Molly both in the respite centre and more recently in Molly's home. She knows the family from caring for Molly but also from living locally. Fiona describes trying to provide flexible patient-centred care as a nurse working in both locations. She says being flexible has its down side "*Sometimes you are prepared to go and then cancelled and stuff like that*" stressing that whilst the needs of the family are important flexibility can impact on the nurse's own life.

I next meet Anne with her husband Sean 17 months later in the children's hospital. We meet in Molly's room where she has been admitted for assessment and review by the paediatrician. Since I last saw her she has become less well. Sean and Anne talk about Molly and her condition. They tell me that they are going on holiday with the rest of the family and that they are leaving Molly in the respite unit. Anne says "*you can't put your life on hold*".

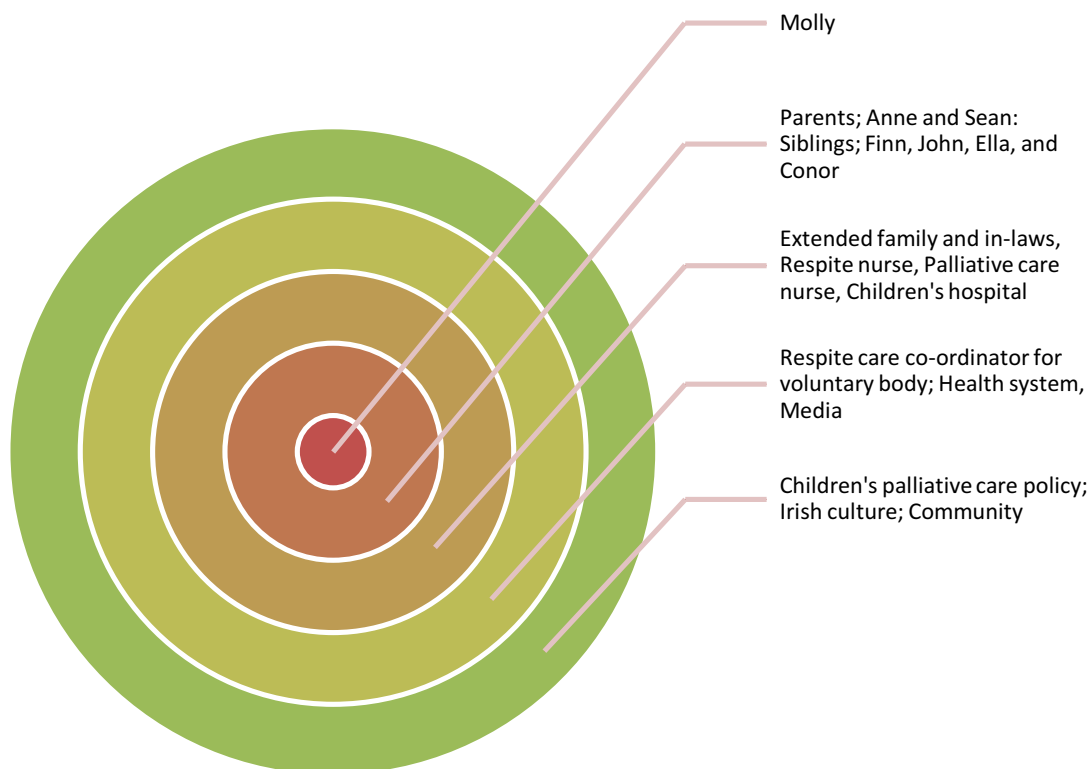
Five months later the palliative care team tell me that Molly has died, that Anne and Sean are devastated and really hadn't expected it. Molly's condition deteriorated as it had so many times before but this time she didn't recover. Four months after Molly's death and nearly two years after our initial meeting I receive a phone call from Anne. She tells me about the death of her daughter and about the huge void in her life.

6.3.2.1 Key aspects of this case:

- Born with multiple disabilities and told at birth that she was unlikely to survive
- Hospital experiences
- Multiple near death experiences
- Location of care
 - a. Home
 - b. Respite centre
- Small rural community

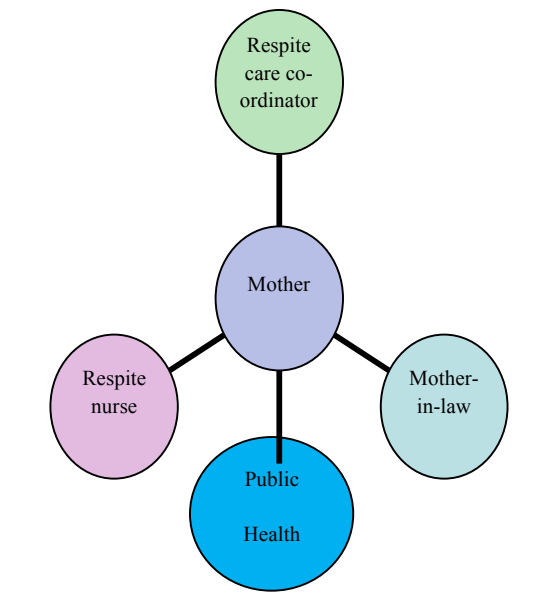
- Living with uncertainty
- Living with guilt
- Finding help
- Impact on siblings and family life
- Fluctuating disease trajectory
- Respite experiences
- Sadness
- Hope ► Being down – Fluctuating
- Information needs ‘nobody told us’
- Trust in carers
- Death

Case 1 - Family systems view of participants



6.3.3 Case 2 - Aisling's story

Figure 11 – Case 2 - Case participants



Lorraine has twin daughters born prematurely. Twin-to-twin transfusion resulted in Aisling being born with severe global developmental delay and spastic quadriplegia. She also has cortical blindness and crohn's disease. On many occasions her parents have been told that Aisling will not survive and yet she has defied expectation and is now 9 years old. When the twins were born one was perfect and healthy and Aisling '*got all the problems*'. Lorraine delivers complex nursing care on a daily basis but despite the offer of respite care outside of the home, Aisling has predominantly been cared for by her mother at home with some nursing support provided by the Health Service Executive (HSE).

Lorraine receives eight hours of nursing care in the home a week and trusts the nurse implicitly and says she doesn't know what she would do without her. The nurse is a paediatric nurse, competent, trustworthy and employs a flexible approach to the provision of respite; changing her hours to suit the family and even working weekends for them at times. She is not only a nurse but a mother and to Lorraine this is important.

Lorraine lives in the community where she grew up, close to her parents and siblings. Whilst her family offer to help with caring for Aisling, Lorraine has concerns about their ability to

provide the level of care required. Her in-laws live 200 miles away and yet the only family member in whom she has trust and confidence is her mother-in-law who comes up to stay at least once a month.

There is a local respite centre but Lorraine has never used this service. The centre is also a school for the intellectually disabled which Aisling attended for a short period of time. Lorraine acknowledges for some families out-of-home respite is valuable however, she is adamant that under no circumstances would she want Aisling to be cared for in the respite centre and she cites Aisling's inability to communicate as a key concern in her decision-making. Past experience healthcare institutions also influences Lorraine's choices. Hospital admissions for Aisling are particularly stressful for Lorraine as she would "*absolutely never leave her there*" alone. She cites incidents of poor care in the hospital which have led them to be mistrustful of all hospital services.

After our second interview when the voice recorder is switched off, Lorraine described being the mother of twins, two children exactly the same age but with such differing needs and with only one making all her developmental mile stones. She says it makes her sad but "*what can you do?*" She tells me that her other daughter is unhappy at school and "*hates it*", that she doesn't have many friends, that she is a "*drama queen*" We discuss this attention-seeking behaviour. Lorraine agrees and gives another example where Dervalda often asks to be picked up and when Lorraine says she is too heavy she says "*but you always carry Aisling*".

Nine months on from our initial meeting, Aisling is unwell her heart rate has dropped to 35 beats per minute. She has been in hospital for tests and now has a monitor that goes off all night when her pulse is low. The doctors have told her there is nothing else they can do. Lorraine is very sad and discusses the new nurse with me but misses her trusted nurse and is sad that she has gone.

A year after our initial meeting Lorraine tells me that Aisling has been an inpatient in the children's hospital and two consultants have told her that there is "*no more that the doctors can do*". She has low albumen and her breathing and pulse are both weak. Lorraine tells me "*we have been here before*" and that "*she could pull back up*".

When I arrive to interview Lorraine's mother-in-law, Aisling is lying on the sofa attached to an oxygen saturation machine and pulse monitor. Lorraine gets tearful telling me about her conversation with the paediatrician who has told her that Aisling is becoming more unwell.

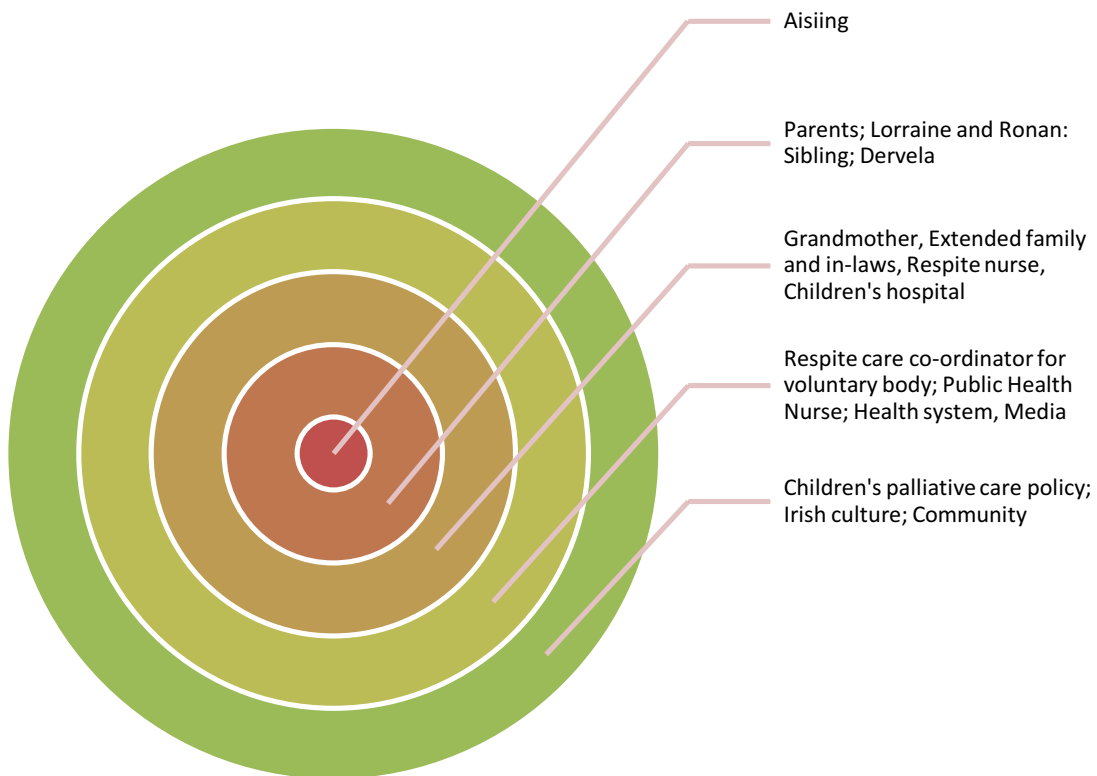
Interviewing Aisling's Public Health Nurse she tells me that Lorraine does not really want any more help than she gets and that this is her choice. She has concerns about Aisling's sister and the impact on her.

Eighteen months on from our initial meeting I speak to Lorraine. Aisling is unwell and has been very swollen due to her low albumen. Lorraine has been unable to leave the house lately. She finishes our conversation by telling me that Aisling smiled at her today and that this *"makes it all worth while...she is such a little fighter"* she says.

6.3.3.1 Key findings from this case:

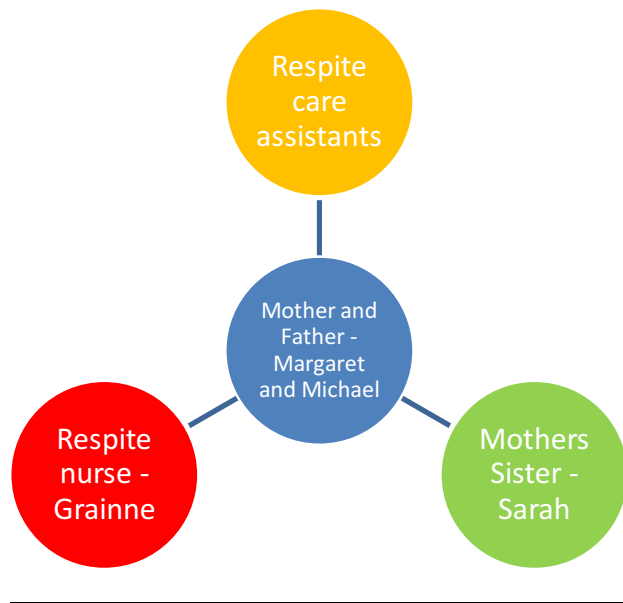
- Diagnosed at birth
- Location of care - Home
- Hospital experiences
- Fluctuating condition and multiple near-death experiences
- Finding help
- Trust
- Uncertainty
- Parents as carers
- Expert parent
- Family support
- Impact on sibling
- Outside in

Case 2 - Family system view of participants



6.3.4 Case 3 – Patrick’s story

Figure 12 – Case 3 - Case participants



Patrick is 11 years old and following a birth injury suffers from Cerebral Palsy. He is dependent on a bi-pap (nippy) ventilator and is fed via a PEG feeding tube. He lives at home with his mother, Margaret and father, Michael and his younger brother Niall who is severely autistic. They live in a small rural community. Due to legal proceedings following his birth injury, Patrick is a ward of court. The house has recently been extended to include facilities specifically for Patrick.

During our interview Margaret asks if I mind sitting at the Island in the kitchen so that she can observe the oxygen saturations monitor that is attached to Patrick. Of note when Michael and I were sitting at the kitchen table whilst she was out he didn't look at the monitor at all. Margaret runs a small family business from home this enables her flexibility to care for Patrick. She has nursing support every night which allows both parents to sleep and enables them to provide care for their sons during the day. They also employ two local women to provide respite care one afternoon per week. Both of these supports are considered to be respite by Margaret. She spends the respite time she has away from Patrick cleaning and cooking and working from home. She only goes out when her husband is at home. She has certain staff that she trusts implicitly.

I return to the house six months later to interview the two weekend respite carers, Patrick's dad Michael and his auntie. The two carers have known Patrick since he was born. They are sisters and their mother cared for Patrick when he was young and they "*know him so well*" considering the boys to be like "*little brothers*". They are happy to provide care for Patrick but they are unable to meet all of his care needs requiring one of his parents or a specific nurse also to be available. Patrick occasionally requires deep-suctioning as he becomes distressed when a plug of mucous becomes lodged. They consider their input to be babysitting rather than providing respite.

Margaret's sister Sarah is happy to help; she loves both boys. She visits most weekends and whilst she is able to provide support and care she too is afraid to suction which means that someone competent to deep suction needs to be available.

Patrick's father, Michael describes how his two sons' with special needs have changed his perspective on life. Respite for him is two or three hours outside the home going to the pub, for pizza or to the pictures, never too far from home so that they could get back if they were needed. Michael describes the technical care that he and his wife are able to give telling me that deep-suctioning can only be performed by someone who is trained. They were initially shown how to do this in the children's hospital by one of the consultant anaesthetists. To him this is the main issue with leaving his son in other people's care. He describes the level of responsibility that comes with being able to carry out this technical task and simply says that Patrick would die if they are unable to remove the plugs of mucous.

Having night nurses means that his wife is able to get a night's sleep enabling her to cope with her role as primary carer for both boys during the day. Michael says he sleeps really well but that Margaret always hears if an alarm goes off in the night. His ideal nurses to provide support are those who are knowledgeable, trustworthy, dependable and technically-competent but Patrick's parents expect more than these skills; to them it is really important that anyone caring for Patrick sees him as a person.

Michael would not use out-of-home respite. He gives a variety of reasons for this reluctance: the co-dependency of his wife and their son; the need for special care from them; doubts that others are capable of providing the same level of care and worries that his son is "*helpless*" and that he would be in bed all day with "*nobody talking to him*". Michael is also cynical about hospital stays and confirms what his wife has already told me that they would never leave Patrick alone in hospital "*when he is in hospital it's a killer*" ..."*you have to be with your child the whole time*" because "*we know better than they do a lot of the time*".

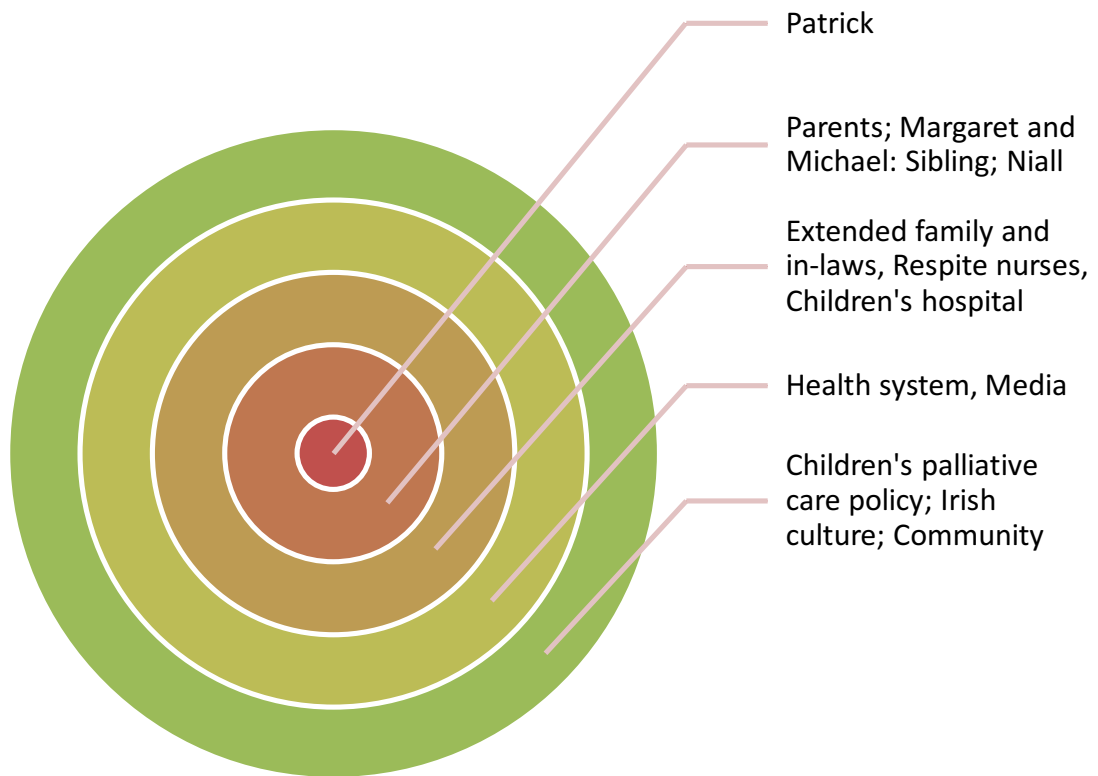
He talks about his son's prognosis and how life is taken one day at a time. Living with uncertainty is challenging for all of them and impacts on their lives and decisions. He says they still have hope that he will get better or that there may be some new treatment. Michael tells me that they are happy as a family and that "*we'll do anything for him (Patrick)*".

The respite nurse who cares for Patrick describes her role as senior nurse with responsibility for organising the rota of night staff for Margaret and also for recruiting and selecting the nurses who provide care for Patrick at home. The nurses are organised for night duty seven nights a week. Grainne is employed directly by the family and has never had a conversation with anyone from the medical profession regarding Patrick's care and all information is relayed through Margaret - including the issue of his resuscitation status. She says that she and the other nurses feel clinically unsupported and discusses the challenges of providing care in the home without the support of a medical team. In the past nurses have been employed and have been found asleep whilst caring for Patrick and this has led to a certain degree of mistrust on the part of the parents. Familiarity with Patrick's care needs is important to both the child and family.

6.3.4.1 Key findings of this case:

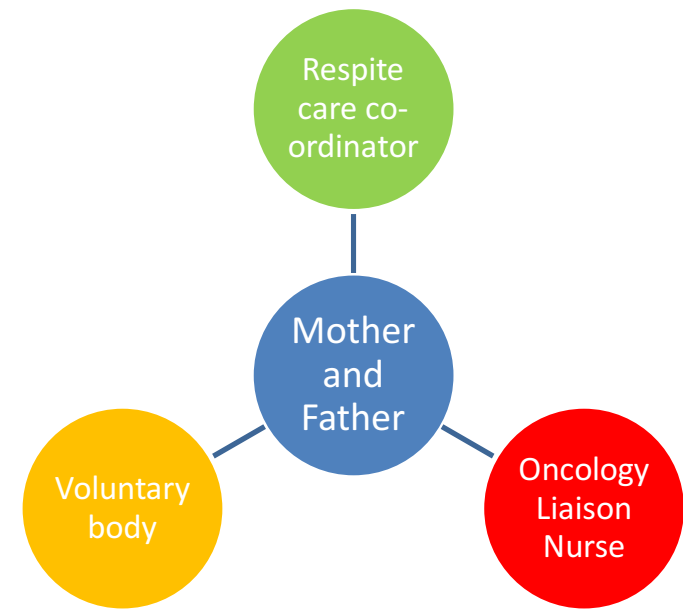
- Diagnosed at birth
- Multiple near-death experiences
- Home as the location of care
- Getting a night's sleep
- Living with uncertainty
- Finding help
- Trust and confidence in carers
- Information needs
- Fluctuating condition
- Equipment
- School as respite
- Hospital experiences
- Care of child and sibling
- Loss
- Parents as carers and technical competence
- Co-dependency
- Living in a small rural community

Case 3 - Family systems view of participants



6.3.5 Case 4 - Magda's Story

Figure 13 - Case 4 – Case participants



Magda is a fourteen year old girl originally from Eastern Europe who was diagnosed with a malignant brain tumour. She lives with her mother, father and her older brother. On arriving in Ireland, Agata and Pavel started a business with Pavel also working nights to make extra money. Although Agata and Pavel have no extended family in Ireland, friends have been very supportive. When Magda was diagnosed both were advised to give up work in order to be eligible for Magda to receive free health care. English is not Agata's first language; interviews are long and conversations slow and interspersed with the use of Google translate.

Magda had a normal childhood until the age of ten when a slow-growing malignant brain tumour was diagnosed. Pavel and Agata sent their children to Romania for two months during the summer holidays. Agata describes how not having seen her children for two months that she noticed upon her return that there was something wrong with Magda's eye "*she will have cross eye*". Due to on-going issues with her GP Agata took Magda to an Eastern European Medical in the city. The doctor noted raised pressure in her eye and referred her to a neurologist.

A diagnosis of Mid-brain Thalamic Pilocytic Astrocytoma was made. Magda commenced high-dose steroids causing changes not only in her behaviour but also in her appearance. Due to the position of the tumour in the brain, treatment options were limited. In order to get the

experimental surgery that Agata believed would help her daughter they travelled to the UK. The surgery was deemed a success but rendered Magda temporarily disabled with a severe hemiplegia.

On return to Ireland Magda was readmitted to the children's hospital from where she travelled daily to the radiotherapy centre. The impact of the radiotherapy and the side-effects of treatment on Magda's appearance were particularly challenging for Agata to accept describing her daughter as '*monster*'. On completion of the radiotherapy, Magda left the children's oncology ward and was transferred to a respite centre. Agata found this difficult as all other service-users had severe intellectual disabilities. Facilities such as call-bells were not routinely available as other service-users were unable to master them and in her view Magda did not receive the rehabilitation she had expected.

Agata felt that she made herself unpopular with healthcare professionals involved in Magda's care in all locations by fighting to secure the best care for her daughter. She felt that she and Pavel never gave up hope. After spending a short period of time at home, Magda was admitted to a hospital for rehabilitation where she made progress. Home was made ready for her return; a stair lift was installed and paid for by a local charity and Magda returned home.

Despite successful treatment Magda's tumour was only partially removed, leaving her with residual disabilities and unable to walk distances. Much to her mother's disappointment Magda is reliant on the use of an electric wheelchair.

Agata reported that the tumour was not fully removed but was unable to talk about prognosis even when prompted. Healthcare professionals involved in the case confirmed that the tumour type that Magda has is often dormant for a while but that if and when it recurs that it usually comes back with ferocity often resulting in death.

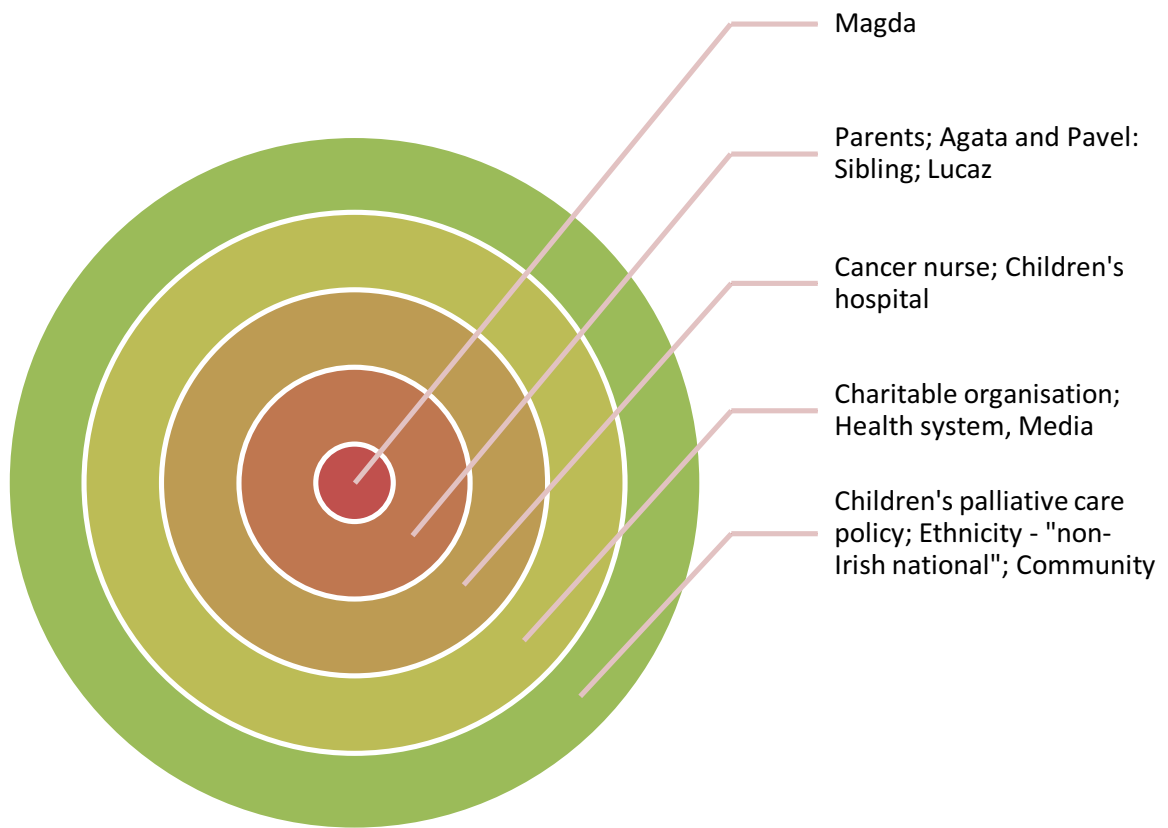
Once Magda returned home she was offered respite in various forms and locations. The respite centre where she had been an inpatient offered on-going support and the children's hospital organised a family break at a rural centre. The family are very close and do not like to be separated which has influenced their uptake of offers of respite services or breaks. Agata is insistent that she doesn't need a break from caring for her child. That she is happy to do whatever is needed and that she really doesn't need a break. Despite the disruptions to his life, months without his mother being available to him and where there was always one parent away from home, Lucaz is doing well at school.

I next met Agata, Pavel and Magda six months later, now at senior school, Magda has a Special Needs Assistant in class with her. Other children were curious about her condition asking why she uses a wheelchair and whether she has broken her leg. Their main support comes from Edith a co-ordinator in a voluntary organisation. She has coordinated Magda's care, helped them with allowances and benefits, organised practical care such as equipment provision and has offered them respite care. Agata and Pavel don't go out as a couple but do everything as a family. Agata told me that she hates eating out as when the bill comes she thinks to herself how many meals she could make at home for the same money. Finances are of concern as neither has worked since Magda has been diagnosed.

6.3.5.1 Main findings of this case study:

- Dealing with acute onset of life-threatening disease in an otherwise normal child
- Care of an adolescent
- Location of care
- Fighting for your child
- Denial
- Getting help
- Uncertainty
- Knowing your child
- Healthcare experiences
- Lack of family support
- Impact on sibling
- Day-to-day toll of care-giving
- Changes in appearance (normal to "*monster*")
- No respite

Case 4- Family system view of participants and influencing factors



6.3.6 Case 5 – Emma’s Story

Figure 14 - Case 5 – Case participants



Emma and her sister Siobhan live with their parents Breda and James. The family home is a semi-detached newly-built house in a close off a laneway, a short walk from the centre of the village. On the walls of the front room hang several large black and white portrait photographs of the two girls.

Emma has been sick since she was 8 years old. Her condition is progressive and has impacted hugely on her life. Aged seventeen, she is now almost completely blind, deaf in one ear and has facial disfigurement which has had a huge impact on her self-esteem and body image. She suffers from depression and is under the care of a psychiatrist. She has poor balance and walks with a cane. She used to have a large circle of friends but now sees them rarely and instead seeks the company of her younger sibling.

Emma left school after her junior certificate. Prior to this she had a Special Needs Assistant (SNA) for her last year. She found this very difficult as up to this point she was very independent. She found it very distressing that people spoke to the SNA instead of her and felt that the SNA was not sensitive to this.

She has been under the care of the local community adult palliative care team (PCT) for over two years and during this time has developed as a team member. Breda accepts the input of the team on “*her own terms*” and they only come to the house when she invites them. The family live in a small rural community and Breda is concerned that neighbours will notice who calls to the house and therefore Breda tries to control the number of visitors as this impacts on her privacy.

At the initial visit Breda is stressed and tells me that she has “*no support*” and “*no respite*” except if her husband takes time off work to care for Emma. On these occasions Breda gets to go out and for example visit the hairdressers. Her mother and her sister both live locally but she is reluctant to ask them for help as “*they have their own lives*” and also because she would feel indebted to them. She has been offered a family respite break at a national centre but feels that neither she nor Emma would want this and they would dread going.

Once I stopped recording Breda continues our conversation. Asking if I have ever seen a TV programme called “Beauty and the Beast” she tells me that the boy (the “Beast”) has the same condition as Emma. She invites me into the kitchen where rather than the large posed photos displayed in the living room, there are photos of how Emma is now. She talks to me about how sad it makes her feel that Emma’s friends don’t call for her anymore, even the ones who live locally. She tells me that a leaflet has been posted through the door about home nursing and how she has kept this, thinking that maybe they could help her- even for a couple of hours. Breda says she just has a thing that she would be happier to pay someone to help her than to ask family or friends.

The community palliative care nurse (PCN) reports that Breda was initially reluctant to accept the service but did so in the absence of other healthcare services in the area. Emma’s prognosis on referral was six months. Breda only sees the PCT when she wants to and building a relationship with her has been a very long, slow process. She describes Breda as a “*very private*” person. All other contact is by phone. She also reports that Emma has had a difficult experience with her SNA who did not respect Emma’s boundaries; for example, staying with her whilst she chatted to her friends at lunchtime.

The PCT suggested that the Public Health Nurse become involved in order to organise a carer to help Breda. She has refused help afraid she would not know who the carers would be and that any help Breda does accept is “*hand-picked*”. The PCN stresses that to Breda control is essential but that ultimately Emma “*knows what she wants*” and decides “*who comes in and who doesn’t come in... and Breda ...supports her in that*”.

Seven months later I return to meet with Breda who told me that there had been a lot of changes since my last visit. Measures have been introduced by a voluntary organisation to assist Emma with her balance and increase her independence. After speaking to me Breda organised a respite grant. This was back-paid for the last year enabling her to pay her mother to provide respite for Emma. She has also been offered home help which she is reluctant to take as she knows some people who work as home helps and says that it is “*too close for*

comfort, I would feel everyone would know your business". Breda uses her respite time to shop, visit the hairdressers and to spend time with Siobhan. Emma is also attending classes and Breda now has time and is able to "*do whatever I want to*".

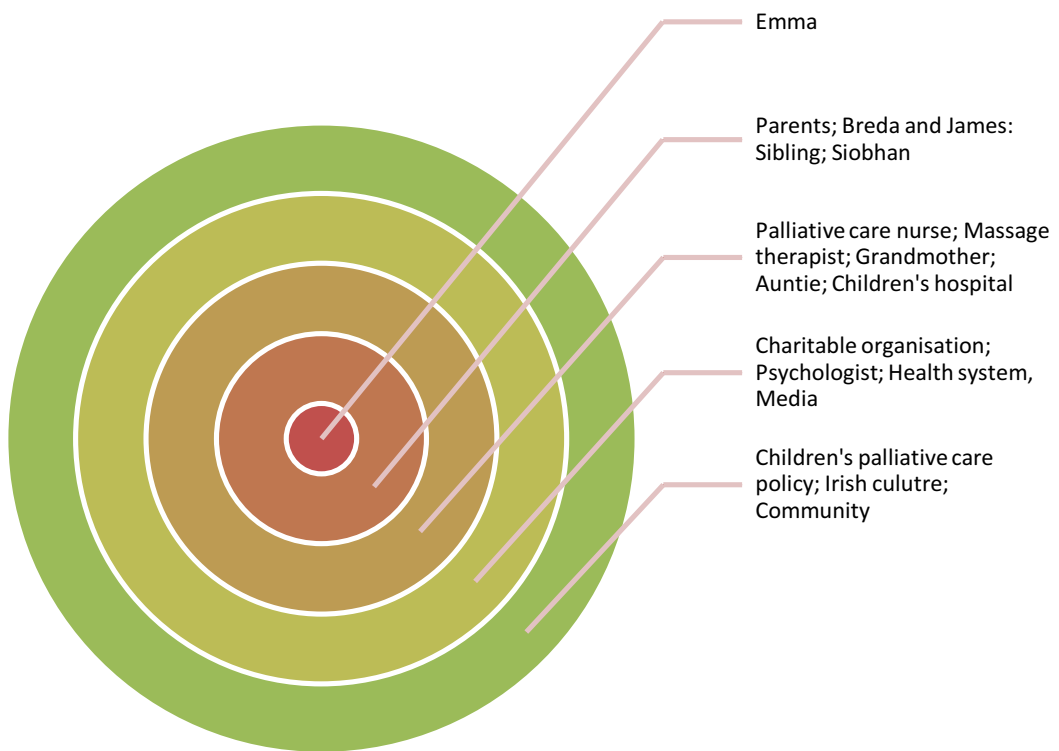
Ger, Breda's key contact in the voluntary organisation, has a close bond with Emma; she has a daughter the same age who went to the same school. She tells me about her work with the family. Visibly upset when talking about the palliative nature of Emma's condition she says she was shocked when a palliative care nurse phoned her to discuss Emma's case. She describes the isolation that Emma experiences due to her condition. A teenager who is interested in all the same things every teenage girl is interested in, boys, make-up, clothes and going out, but who is unable to do any of these things on her own.

6.3.6.1 Main findings from this case study:

- Acute onset in an otherwise well child
- Parents as care-givers
- Changes in appearance
- Living with uncertainty
- Public versus Private
- Finding help
- Information
- Adolescence
 - Depression
 - Independence
- Hawthorne effect³⁴
- Accepting help
- Respite grant
- Small rural community - Keeping others in the dark

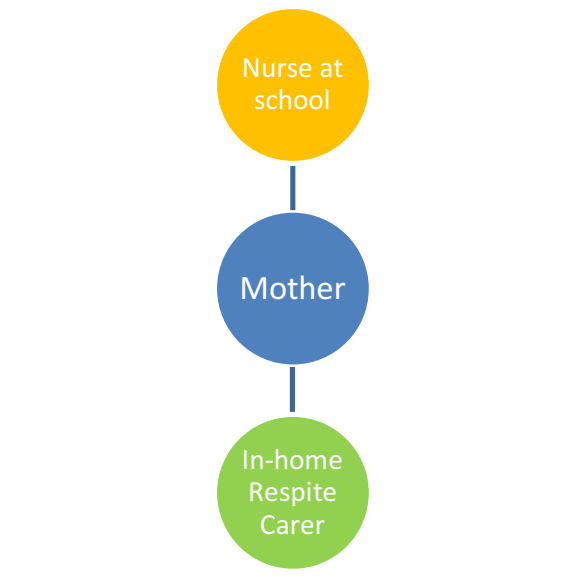
Case 5 - Family system view of participants and influencing factors

³⁴ The Hawthorne effect refers to ...



6.3.7 Case 6 - Ellen's Story

Figure 15 - Case 6 – Case participants



Ellen is a ten year-old girl born with Arthrogyriposis and multiple congenital abnormalities leading to global developmental delay and kyposcoliosis. She lives at home with her mother Michelle and her father Derek and her older brother David who is eleven years old. Ellen has required complex care since birth and is in receipt of a number of different services. Despite initial challenges accessing services and information, a disease-specific support group influenced and guided them to navigate the system in order to access services and equipment.

Michelle described the level of care Ellen requires. Her main break from caring is when Ellen is at school which she attends five days a week. The HSE also provide two nights of nursing care. When no night nurse is on duty Ellen sleeps in the bed with her parents. Claire the carer is funded through money provided by a national charitable organisation and Michelle also sometimes pays her extra to care for Ellen. Ellen also attends a respite centre once a month on a Saturday. Michelle considers all of these aspects of care as “respite”. Michelle’s preference is to have respite at home.

Michelle’s husband works full-time and at weekends he takes Ellen allowing Michelle to spend time with her son. Michelle’s extended family lives a short distance away. She is particularly close to her sister who babysits for David but who is afraid to care for Ellen.

This fear is well-founded as Ellen recently had a cardiac arrest when being lifted into the school bus.

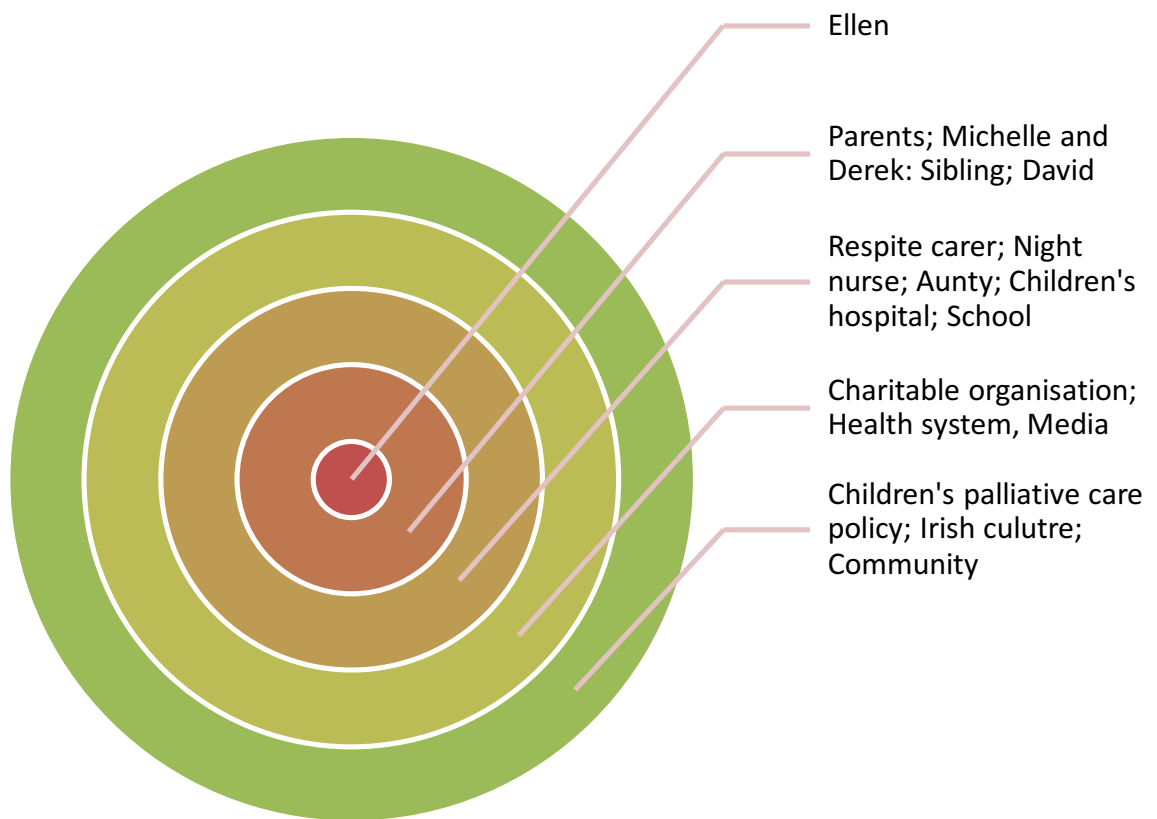
Interviewing the school nurse, she described the incident of Ellen's cardiac arrest in detail and reports helping Michelle in any way she can, this includes giving Michelle her personal phone number. She has taken calls from Michelle at weekends and during school holidays and Michelle has dropped Ellen off to the nurse's own home. The nurse says she helps because there is no support for families such as this.

When I speak to Michelle six months later Ellen has been unwell again and is now at home all of the time. She is too sick to attend school as the travel is too uncomfortable for her. She needs more help and they have nursing care for Ellen day and night. They are "*taking it all a day at a time*". Ten months after my initial visit Ellen died. She was admitted to the children's hospital on a Friday and died as an inpatient on the Monday.

6.3.7.1 Key findings of this case:

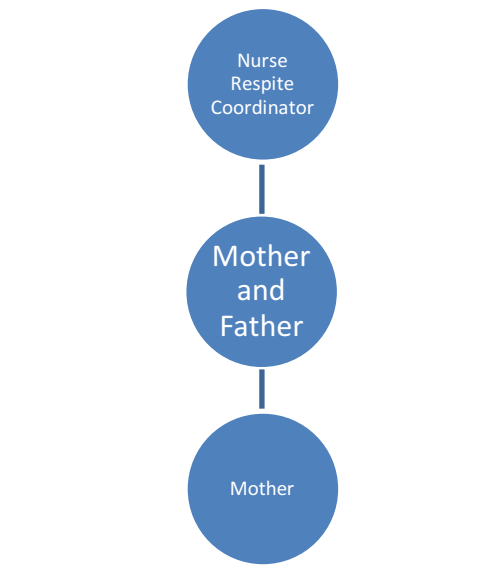
- Diagnosed at birth
- Getting information
- Living with uncertainty
- Getting help
- Living in the public eye
- Near death experiences
- Trust and confidence in carers
- Fluctuating condition
- Fear of caring
- Time to sleep
- School as respite
- Impact on sibling
- Small rural community
- Death

Case 6 - Family systems view of participants and influencing factors



6.3.8 Case 7 – Grainne’s Story

Figure 16 - Case 7 – Case participants



Grainne was diagnosed at birth with a congenital abnormality of the heart. Her parents, Maire and Tom were told to have her christened quickly as she would not survive beyond her first birthday. She is now 18 years old. My interview with Maire and Tom takes place in the children’s hospital whilst Grainne is having an appointment with the psychologist. They tell me about her depression and the impact that this has had on both her and the family. They are happy to drive four hours each way if the appointments help Grainne.

Grainne has lived with a chronic debilitating condition which has impacted on every aspect of her life. Physically she is small and frail; her mother describes her as having the same physique as a 12 year-old. She lives with chronic breathlessness which impedes her mobility and is susceptible to infections which can cause result in life-threatening episodes. The breathlessness that Grainne experiences means she cannot walk far and has a wheelchair; an electric one at home and portable one for trips out of the house.

Grainne’s parents know that Grainne has a limited prognosis and that Grainne herself also knows this. Maire tells me that her physical and psychological health are closely aligned and recalls that depression started to manifest when Grainne first had excessive palpitations at night and felt that she was going to die.

Grainne lives with her parents and her two adult siblings in a remote rural location. She has her own extension which was originally built for home-schooling but which she now uses for her art work. Her neighbours are all her mother's brothers and their families.

She had home tutoring to limit exposure to infection up to junior certificate level, as a result of not attending school she has few friends and limited social connections. The friends that she does have are contacts made through her older sister with whom she socialises frequently.

Grainne has just started work on a voluntary basis in an office when she is well enough to go. Any care that Grainne requires is provided by her mother. She tells me that Grainne rarely needs help with physical care although she sometimes seeks the reassurance of having her mother there. Several years ago her mother was offered home help which she refused. She never availed of any services for Grainne including respite. Now that Grainne is older she feels comfortable to leave her with her brother and sister as long as she is not going too far and could get back if Grainne needs her. She feels that Grainne's is now old enough to make decisions regarding her care.

When speaking about Grainne's prognosis Tom and Maire both become tearful. Once the interview is over Maire insists that I go with them to meet Grainne after her psychology appointment. Whilst waiting outside the consulting room, coincidentally Grainne's cardiologist passes and stops to talk and asks about Grainne. Maire takes the opportunity to ask if there are any new treatment options for Grainne to which he replies no. Maire tells me that now Grainne is 18 she no longer has the opportunity to talk to the doctors as she attends appointments alone, therefore chance meetings are opportunistic. She says she already knows there is nothing more that he can do but that she just has to hope.

Anna, a nurse, is identified by both parents as the person who has helped them the most with Grainne's care; both Grainne and her mother have a very close link with her. She has helped them with various grant applications, getting Grainne voluntary work and visits the family every 6-8 weeks at home. Anna tells me she knows the family well after being involved with them for the last six years. She has a special bond with Grainne and says that they communicate via text or email. She speaks about them as a close family with a strong connection. She tells me that Grainne's mum is her primary carer.

Over the last six years she has offered Grainne and her parents various respite options which to date they have not accepted. Anna instead concentrates her efforts on helping the family in

other ways such as securing a part-time job for Grainne providing her with the opportunity to experience work and giving Maire a break.

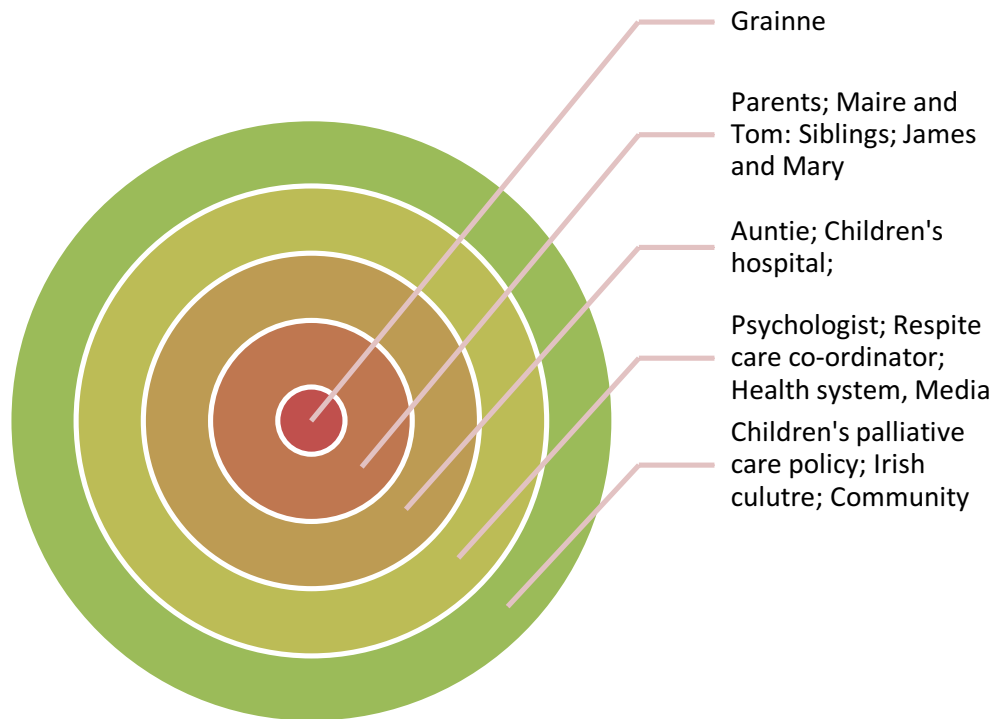
Anna tells me that Grainne did not attend school and talks about how this has impacted on her socialisation. Grainne is learning to drive as this will increase her independence. She loves art (Figure x) and Anna has arranged for an art teacher to go to Grainne at home. Anna tells me that Grainne knows how serious her condition is. We discuss Anna's role in the provision of respite and what is available locally. Anna has offered Grainne teen respite in an holiday home for her exclusive use where she can invite family and friends which she has declined.

I meet Grainne and Maire a year later. I drive to their home which is just as had been described in a very rural and remote location. There are no street names or numbers and I have to phone Maire from the nearest landmark which is a local supermarket. They live on the top of a hill close to two other houses. Maire explains to me that these belong to her family. She is an only girl with four brothers all of whom live locally. She is particularly close to her sister-in-law who lives next door. She is a self-confessed home-bird who is not interested in holidays or going out, she just loves being at home and tells me that Grainne is the same. Once I stop taping Maire talks more. She tells me that she doesn't leave Grainne as she is afraid that something will happen "*in case she dies – I would never forgive myself*".

6.3.8.1 Key findings from this case study:

- Living with uncertainty since birth
- Fluctuating condition
- Others worse off
- Rural location
- Travel
- Carer
- Teenage
 - Independence
 - Depression
 - Appearance
- Hope

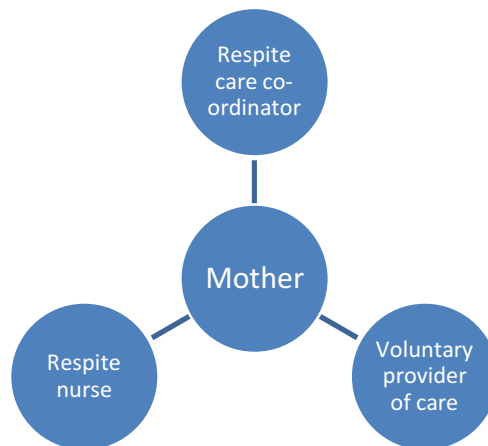
Case 7 – Family systems view of participants and influencing factors



Picture 1 – Example of Emma’s art work

6.3.9 Case 8 - Harry's Story

Figure 17 - Case 8 – Case participants



Jane is a 35 year old who lives with her husband Liam. They have one son Harry who when I first meet him is six months old. Initially her pregnancy was uneventful. A scan at 35 weeks revealed that the baby was small. After an induced-labour Harry was delivered and taken away by the medical team; Jane and Liam were told that the team needed more time with Harry and that they should come up to ICU in one hour. The staff caring for Jane mentioned that Harry had some “*worrying features*” including a high forehead, low ears and his toes were crossed which were sometimes associated with Edwards Syndrome. For Jane this was ‘*the start of that horrible feeling*’ going from the high of child-birth to the outlook being ‘*very bad*’ and the prognosis maybe only hours or days. Jane says it just seemed to be one thing after another so they tried to enjoy every minute.

Soon after birth Harry started to have apnoea attacks; in light of his poor prognosis, the medical staff discussed resuscitation with Jane and Liam and it was decided not to intervene in the event that he has a cardiac arrest. It was assumed that he would eventually have an apnoea attack from which he would not recover. The family were referred to the palliative care team and Jane and Liam’s wish to take Harry home became paramount.

In the meantime tests to ascertain a diagnosis were on-going. Harry’s parents found this to be very frustrating and upsetting as it often involved blood samples from their infant son. Genetic tests were undertaken and sent abroad for analysis and results were slow to return in some cases taking weeks.

Jane tells me that their one wish was that Harry would get home and not die in hospital, and his uncertain prognosis meant that speedy discharge was required. She described her

frustration at the process to get Harry home. The different teams having to sign off on the discharge, a post-mortem was arranged, Harry was baptised, and support was organising at home (night nursing, services and equipment).

Jane describes this time as a '*living wake*': arriving home with her infant son who was going to die. A voluntary provider of care to children with life-limiting conditions had organised a nurse to be there for the night. Throughout the night the nurse called Jane and Liam to come and be with Harry when he had an apnoea attack. Each one passed and he made it through the night and then several more nights.

Jane wanted Harry home so that they could spend time as a family in their own home. However, Jane described how multiple healthcare professionals visited them at home saying that at times she was unsure who they were or why they were there. She felt obliged to offer them tea and felt that she ended up looking after them instead of spending precious and very limited time with her son.

Jane describes Harry being sent home to die and then when he survived, living with uncertainty. Harry was visually impaired and profoundly deaf. His condition oscillates between stable to life-threatening. They have now experienced so many events that were potentially life-ending that Jane has become blasé and refers to these by saying that suddenly '*you're back from the edge*'. Jane also describes the challenges of being a first-time mum of a child with special needs and for example how Harry was upset and had a temperature and how this caused her concern only to find that Harry was teething, a part of normal childhood. An on-going source of frustration and upset for Jane is that despite multiple investigations, Harry has no diagnosis. It is important for her as she feels that without a definitive diagnosis treatment and service options for Harry are limited.

By the time I next meet with Jane, Harry is one. He continues to grow and thrive although during his short life he had many episodes of ill-health and life-threatening episodes. Jane travels to the children's hospital for appointments describing that in a typical week this can be four times. Her mother travels with her sitting in the back to care for Harry on the journeys. She describes the care Harry needs and how exhausted she is with this. Whilst Jane's family offer to help her however they are afraid, having witnessed his apnoea attacks and other acute events.

Despite the financial impact, Jane has decided not to go back to work as she is the best person to care for Harry; she still avails of respite care four nights a week. As Harry often sleeps

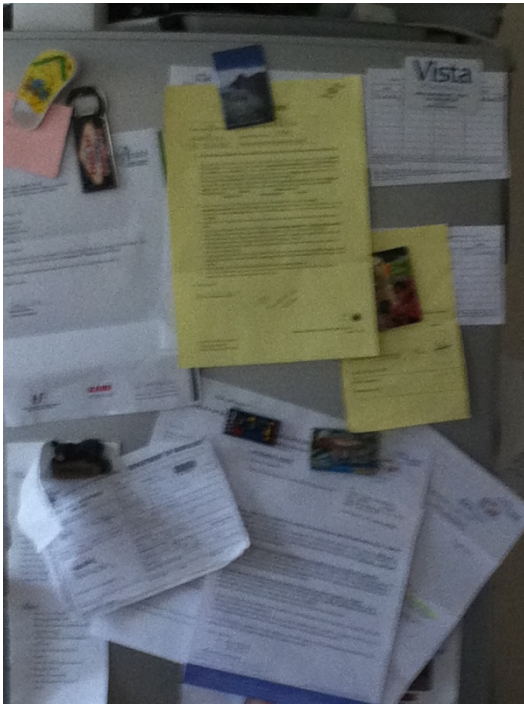
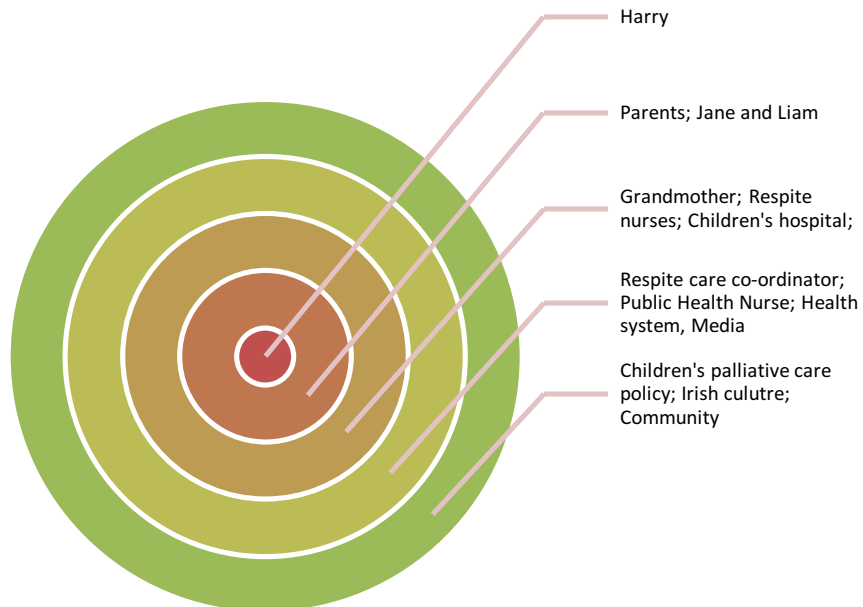
throughout the night she feels this is not the best utilisation of the nursing hours allocated to her and is moving some of these hours to day-time.

Jane has grown to know Harry well and sometimes feels that she knows better than the healthcare professionals who are caring for him. She says he is stronger than they think. She doesn't know what Harry's prognosis is and tries to make the most of every day. Most of her time is taken up with appointments in the hospital or visits by healthcare professionals (Picture 2). She says she has very little time for a social life and that she and her husband rarely go out. She describes waiting for her husband to come home so that he can take over the care but that he is often tired and that he often goes to bed early.

6.3.9.1 Main findings of this case:

- Born and prognosis of days
- Living with uncertainty
- A living wake
- Fluctuating condition
- Respite time to sleep
- Caring for the carers
- Home as the location of choice
- Professional and family support in the home
- First time mum – I didn't know any different
- Appointments
- Parents as care-givers
- Information needs

Case 8 – Family systems view of participants and influencing factors



Picture 2 – Harry's outpatient appointments

6.3.10 Case 9 – Max’s Story

Figure 18 - Case 9 – Case participants



Ingrid is a 32 year old lady of Eastern European origin. She has lived in Ireland with her son Max for the last four years. She is a slight woman who speaks with broken English but seems to have a good understanding and comprehension of the language and even has an Irish inflection in her spoken English.

They live in an apartment block on the first-floor in an inner-city location. The apartment is small and immaculately kept. I take off my shoes at the door. A large television is showing non-English cable channels. In the sitting room there is an empty wheelchair and a portable oxygen machine. She tells me from the kitchen that Max is at school. A bus comes to pick him up every day at 8am. She also tells me that he is often not well enough to go.

Ingrid is a single parent and has no contact with Max’s biological father. She met and married a man who was not Max’s father but she refers to him constantly as Max’s dad. They are now separated and in the process of getting divorced. She tells me that despite the fact that he is not Max’s biological father that he is very involved in his care and helps her with Max. She has a fractured relationship with her mother, her father is an alcoholic and her only sibling is a brother who lives in England. She is currently in a relationship with an Irish man who lives 60 miles away and they try and see each other at weekends. Many of her friends have moved to Ireland and some even live in the same apartment block. They provide her with support and help with Max. She has no job and she is worried about her finances.

As a result of toxoplasmosis in pregnancy, Max was born with multiple disabilities. She was told at the time of his birth that he would not survive, he is now 8 years old. She is his primary carer. Max is regularly a patient at the children's hospital and they have linked them him with a local intellectual disability centre that provide education through their school and support via their social worker. They have offered Ingrid respite overnight but to date she has not availed of this service as she does not like Max being away from her. She tells me that as he has grown older that it is much more difficult to care for him at home. He is heavy and she has no hoist. Bathing Max is very challenging as it hurts her back to lift him in and out. He has been on steroids and this has added to his weight problem.

She has friends who offer her help and support but does not have full confidence in their skills and ability to care for Max. The only person she feels she can trust completely to care for him is her soon to be ex-husband. Ingrid asks me about allowances and money. She says that she finds it hard to cope on her current income with all of Max's needs. Washing his clothes, feeding him and she tells me that she has to have a car in order to care for Max yet it is very expensive to run and maintain.

She gives me the names and contact details of two people who help her with respite. A social worker and a teacher who both work in the intellectual disability service where Max goes to school. She tells me that her friend also helps sometimes, although never for more than 2-3 hours. I contact both of the people she has mentioned but am told by both that they are unable to speak to me unless I have ethical approval from their organisation's ethics committee.

A second interview with Ingrid takes place almost a year after the first. I arrive at the apartment block. The shops at ground level are still empty but once inside the courtyard it is obvious that most of the apartments are now let. There are flags of eastern European countries draped over the balconies and Ingrid tells me that nearly everyone who lives in these flats is from Eastern Europe.

This visit Max is at home, he is in his wheelchair wearing his pyjamas. As Ingrid described he is very overweight but she explains that he has been started on growth hormone which has

caused his weight to increase more. She has kept him out of school to limit exposure to potential infection as they are going to her home country to finalise her divorce and to have a holiday. She has organised equipment (oxygen, suction) and has also sent supplies on ahead.

Max still attends school when he can and this is respite for her. Her estranged husband occasionally takes Max but otherwise he is with her all the time, still sleeping in bed with her. She compares her flat to a prison as she finds it hard to get out and tells me that she is waiting for a corporation house which could take 4 years. Ingrid still does not accept any respite care or help but says she is thinking about it. She says what stops her using respite is that the people caring for Max might be good but they just don't love him like she does.

6.3.10.1 Key findings from this case study:

- Diagnosis at birth
- Living with uncertainty
- Living away from home
- Regular sleep disturbance
- Lack of family support
- Physical burden of caring
- Respite services
- Information about benefits and entitlements
- Support
- School as respite

Case 9 – Family systems view of participants and influencing factors



6.4 Cross-case comparison

By conducting cross-case comparison it is possible to identify key themes across all nine cases and to highlight key commonalities and differences between the cases (Table 6). Seven children were diagnosed at birth with their life-limiting condition whilst two had experienced 'normal' childhoods up to the time of diagnosis. Parents of these two (now adolescent) children had not experienced the multiple near-death experiences described by the other participants but presented other challenges for both parents and their child such as issues with body image (appearance) and also notably these families received no respite services at all.

All families described their role as the primary care-givers for their child with a life-limiting condition. Many also described the challenges of living with their child's fluctuating condition where they had experienced multiple near death experiences of their child thus never knowing if or when their child would die. Living with uncertainty was described by all participants.

Past care experiences of using health care institutions appeared to impact on parents' decisions regarding the use of certain services. All described their past experiences of hospital care and all expressed resolutely that they did everything that they could to avoid their child being admitted to hospital. If and when their child was admitted all but two families stated that they would not leave their child alone in hospital. This was based on their perceptions of the staff, the level of care available, the environment, the impact hospital admission had on family life³⁵, infection risk but primarily mistrust of the staff and the hospital system based on past experience. This theme of lack of trust also pervaded parental responses to carers in the home where parents were very adept at caring for their child often becoming 'expert' carers, in five cases they had also developed technical nursing skills such as suctioning and feeding via gastrostomy tubes. Despite having funding available, five families had difficulty in accessing what they perceived as suitable carers for their child. Extended family had a role in the care of three children but other parents described the lack of support from their extended family. Whilst undertaking cross-case analysis emerging conceptual issues and analytical themes were identified. These were: Living with uncertainty; The care experience; and Navigating the system.

³⁵ Parents described leaving siblings with relatives or one parent having to stay at home whilst the other stayed with the sick child. The duration of admissions varied from days to months.

Table 7: Comparing key findings from case studies

Case	1	2	3	4	5	6	7	8	9	Emerging themes
Diagnosed at birth	x	x	x			x	x	x	x	Theme 1: Living with uncertainty
Multiple near death experiences	x	x	x			x		x	x	
Living with uncertainty	x	x	x	x	x	x	x	x	x	
Time to sleep			x			x	x	x	x	
Fluctuating condition	x	x	x			x	x	x	x	
Acute on-set of illness in an otherwise well child				x	x					
Sadness, loss, denial, hope	x		x				x	x		
Location of care				x						
Hospital experiences	x	x	x	x	x	x	x	x	x	
Parents as care - givers	x	x	x	x	x	x	x	x	x	
Caring for carers								x		
Family support	x	x	x	x				x		
Expert parent/technical competence	x	x	x			x		x		
Fear of caring						x				
Child's appearance				x	x		x		x	
Care of an adolescent				x	x		x			
Equipment	x		x						x	
Respite	Location									
	In-home	x	x	x			x		x	
	Out-of-home	x					x			
	School			x			x		x	
	Other									
	No respite				x	x		x		
Trust and confidence in carers	x	x	x	x		x				
Finding help	x	x	x	x	x	x			x	
Impact on siblings	x	x	x	x		x				
Small rural community	x		x		x	x	x			Theme 3: Navigating the system
Outside-in/public versus private	x	x			x	x				
Information needs	x		x		x	x		x	x	
Fighting for your child				x						
Accessing help from voluntary organisations	x	x	x	x	x	x	x	x	x	

6.5 Findings from interviews

In this section findings are presented using quotations from the data collected during semi-structured interviews with both parents and other participants identified by parents as having a role in the provision of respite care. Measures have been taken to protect anonymity of all participants and to maintain confidentiality. Every effort has been made to ensure that the families cannot be identified: all names have been changed and pseudonyms have been employed; and all reference to location of the family home has been removed; the names of organisations providing care and support to the families have been changed to the generic term “voluntary provider of care” or “voluntary organisation”.

Excerpts of interview data from all nine case studies are presented although quotations from some cases appear more frequently depending on the theme and the issues which arose during the interview process. There are common themes across all nine case studies that have been identified through the process of cross-case comparison and which form the headings in this section. However, some of the common elements that connect the nine cases also hide some of the unique aspects of each story and by presenting findings in this chapter using direct quotes from participants each story is developed and the unique experiences and needs of each case are highlighted.

Figure 19 - Theme one: Living with uncertainty

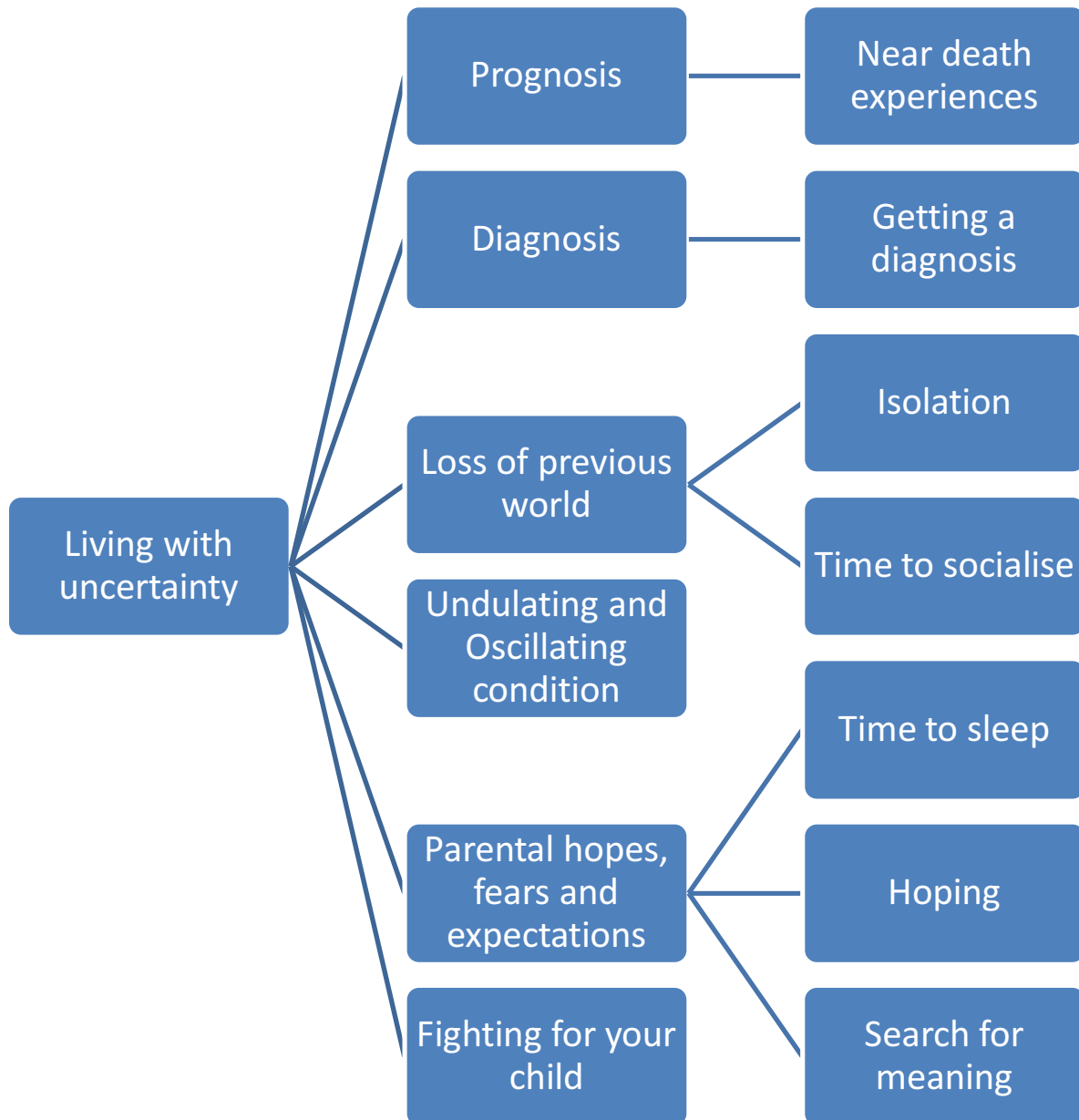


Figure 20 - Theme two: The Care Experience

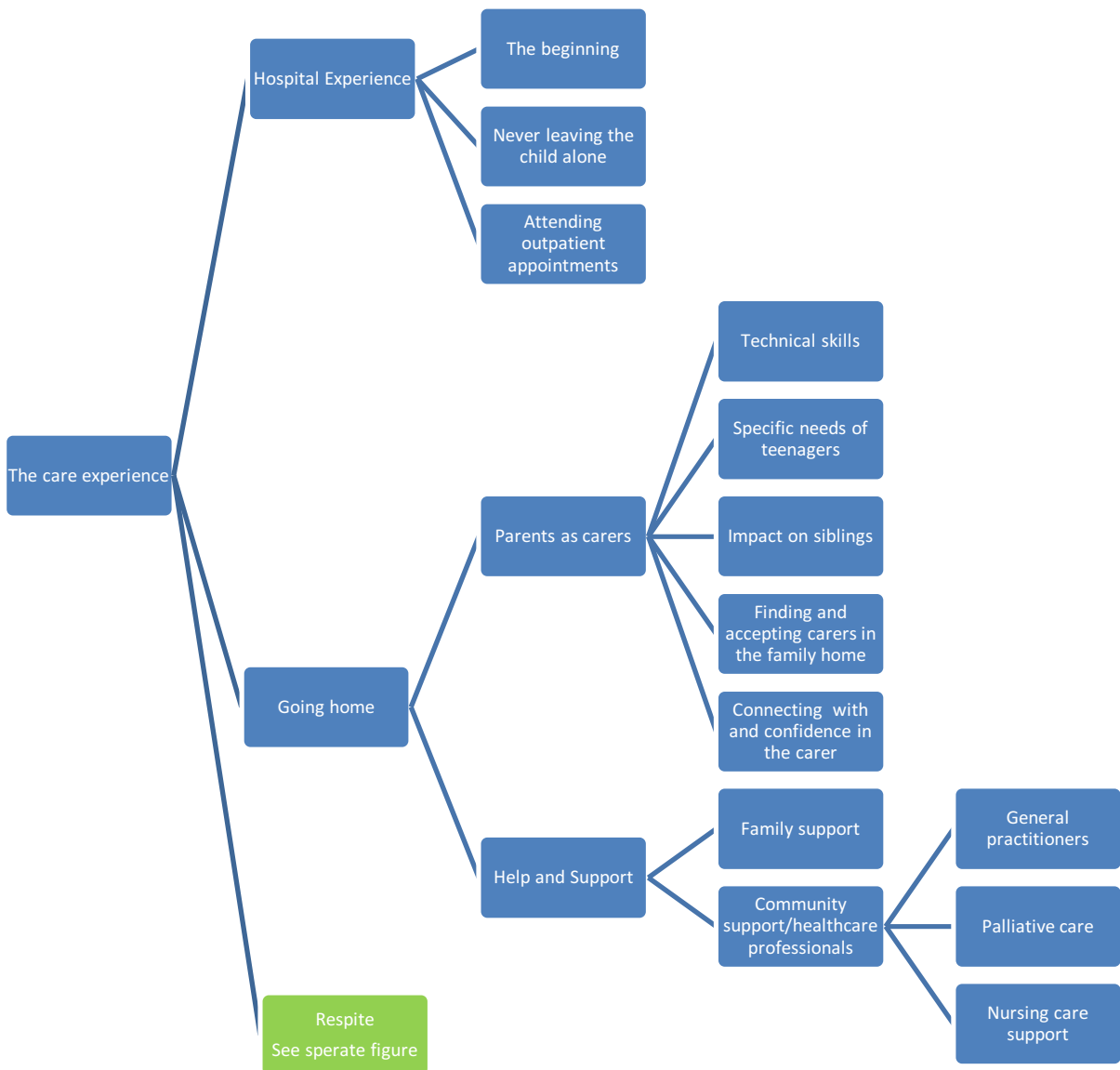


Figure 21 – Sub-theme - Respite

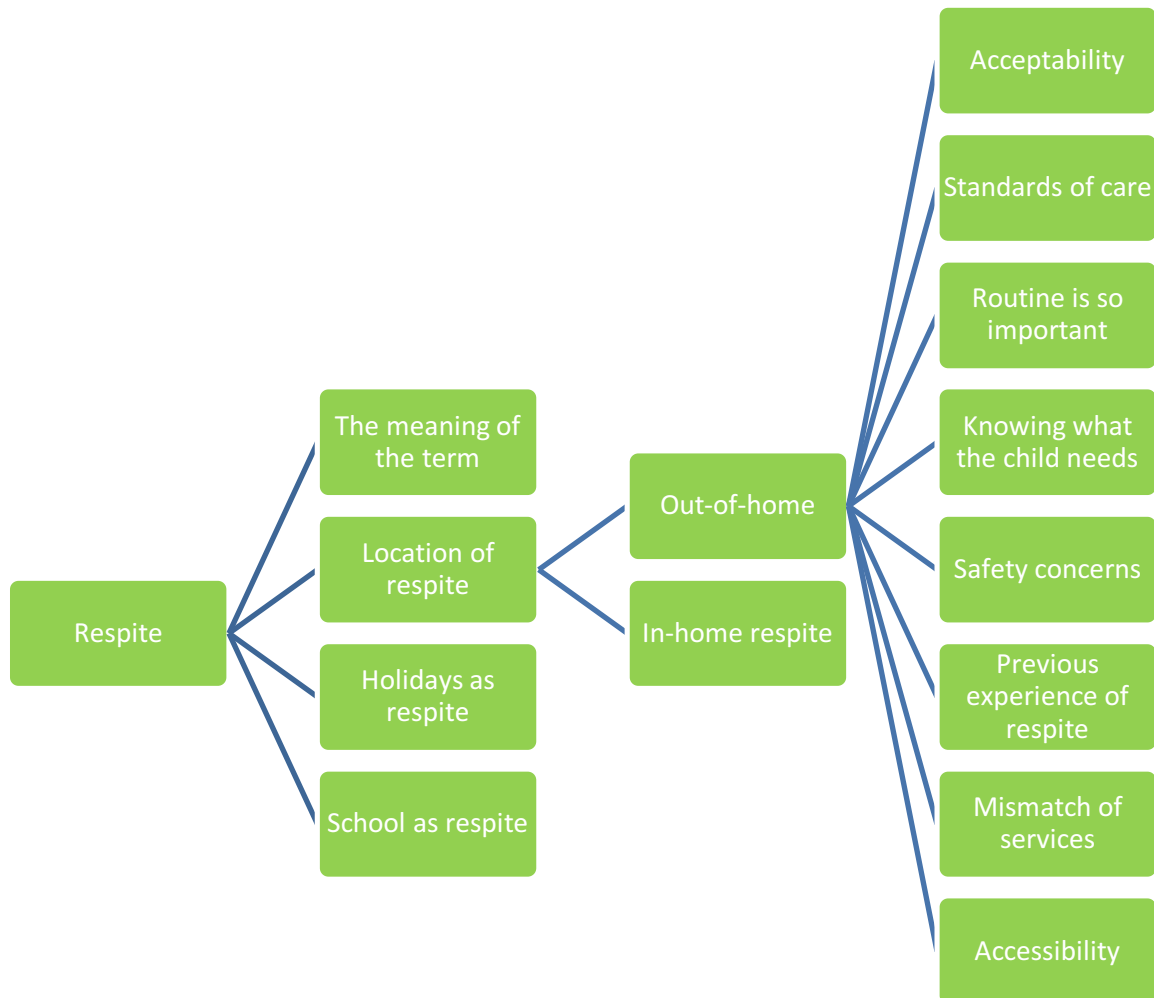
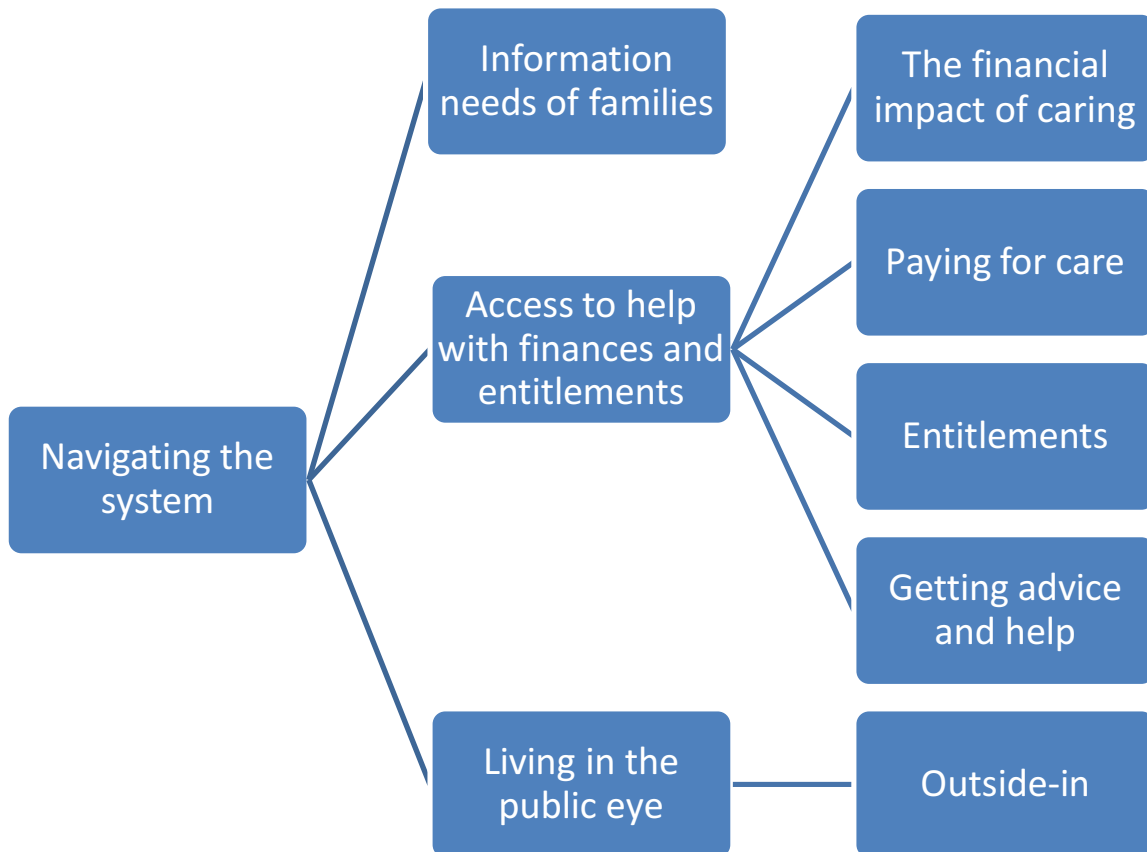


Figure 22 – Theme 3 - Navigating the system



6.5.1 Theme 1 – Living with uncertainty

6.5.1.1 Introduction

For the majority of parents of children with life-limiting conditions living with uncertainty is part of everyday life. Parents are required to live with the knowledge that their child is going to die but do not know when this is likely to occur. As a result of this the whole family system requires reorganisation in order for them to cope, not only with the child's prognosis, but also with the ups and downs of the illness trajectory. Children who are born with a life-limiting condition may have had several episodes of life-threatening ill health from which they were not expected to recover but ultimately from which they survived. This process of an undulating prognosis and fluctuating clinical condition is extremely challenging for parents who constantly live with uncertainty but who often feel the need to make the most of the time that they have left with their child.

Parents and other family members often struggle to come to terms with the loss of their previous world and of their previous expectations and hopes and are forced to accept their new reality of living with a child with a life-limiting condition. Some feel a sense of isolation from the wider family system of their family, friends and the community. Their new and often unimaginable life often leads them to search for meaning in their situation.

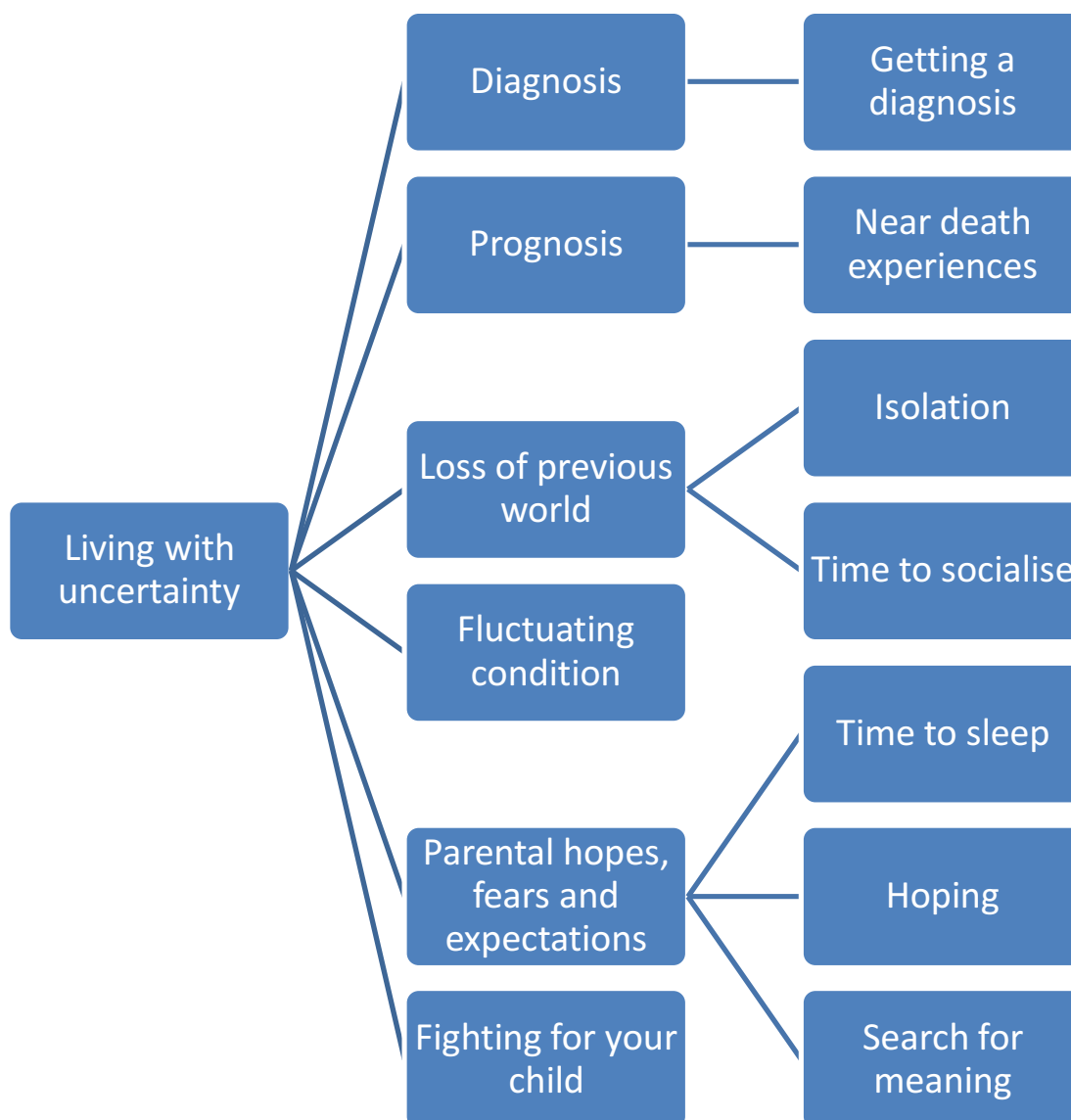


Figure 23 – Living with uncertainty

6.5.1.2 Sub-theme 1 – Diagnosis

One of the key moments in a parent’s journey with their child with a life-limiting condition is the point of diagnosis. Despite in some cases an initial reluctance to have their child labelled; services for children with life-limiting conditions are often diagnosis-dependent and parents often regard getting a diagnosis as key in accessing services for their child.

Getting a diagnosis

For seven of the nine families participating in this research, diagnosis of a life-limiting condition was made at birth. For parents whose child was born with a life-limiting condition the struggle to find a diagnosis was reported to come in the first years of life. Some parents reported that coming to terms with their child's condition was overshadowed by their infant child's immediate care needs:

Molly's mother tells of how she had a placenta abruption:

1MIV1 –“which meant she had no oxygen supply for a very short period but it did dreadful damage to her brain...initially they said 99% chance she would die and 1% chance she would survive” 91

Due to a birth injury Patrick was born with cerebral palsy he is now dependent on bi-pap ventilation. His mother Margaret recalls during his birth:

3MIV “...Patrick was born...40 hours since the waters had broken and he was born flat...I just looked down and saw this beautiful red-haired baby and I just said oh he's beautiful...the next thing he was whipped away...we were listening for the cry and the cry never came...the next morning the paediatrician came into the room... the first 24 hours was crucial ...we should have him baptised that day because he might not survive...we had him baptised that afternoon...so anyway he survived”66

In one case a mother of a child born with congenital heart disease recalled that in her daughter's case she received both a diagnosis and prognosis simultaneously, her parents being told that:

7MD “it's too high risk so they won't touch it... they said...she wouldn't survive operations.....so it was only medication” 124

In the other two cases, parents of apparently healthy children recalled being told that their child had a life-limiting condition. When Magda presented with a mid-brain/thalamic pilocytic astrocytoma, her mother describes being faced with treatment decisions.

4MIV “*always very sleepy in her life... her tumour is in special area of the brain it effect sleep hungry ... (neurologist) “he make on this day ...she had shunt done and 7 days later they take biopsy...when they make a dangerous surgery for the brain they can touch the behind...you can have coma all your life... they don’t know a lot about so nobody would like to make operation...that won’t be typical operation that will be like experiment so you have to agree can be happen everything – I said we don’t have other choice” 390*

Emma was diagnosed with neurofibromatosis type 2, de novo mutation her mother recalled:

5MIV1 “*she would have been 8 going on 9 and we noticed problems with her eyesight very quickly, almost overnight...she was diagnosed with a brain tumour...wasn’t operable...they noticed smaller tumours appearing...diagnosed with neurofibromatosis. She has pretty much hardly any eyesight...two years ago she was diagnosed with another tumour at the top of her spine...radiotherapy...held the tumour...it hasn’t grown” 36*

Harry was born with some features of various congenital abnormalities but no definitive diagnosis; his mother describes the experience of being told about the medical concerns regarding their infant son:

8MIV1 “*...they were concerned about a couple of features... about his syndrome...God that was kind of...the start of...the horrible feeling...low set ears...high forehead...one little toe overlapping on each foot...Little horseshoe kidney...a little ASD...typical Edwards...syndrome ...because of the cluster...of features...he’s a cleft palate as well...there was absolutely myriad of tests... and the next big blow was kind of I suppose only a few days”131*

By the time we met again seven months later Harry still had no diagnosis. This has had an impact on the services available to the family.

8MIV2 “*no diagnosis...still nothing, still no diagnosis...I kind of go through different feelings about it to be honest... it consumed us in the beginning...you need a diagnosis...when everything is going okay you are happy enough to go on and*

pretend...you're asking all these things, that they actually can't answer...maybe if you had a diagnosis you could have some answer" 717

The above quotes demonstrate the varying experiences of parents being given their child's diagnosis. This is stressful and impacts on the services available to them. At the time of diagnosis some parents were also given their child's prognosis.

6.5.1.3 Sub-theme 2 - Prognosis

Regardless of whether the child was born with a life-limiting condition or developed their condition during childhood, once a child is diagnosed as having a life-limiting condition part of the information many parents feel that they need to cope with this situation, is knowing how long they have left with their child. Being given a prognosis is part of this process. Whilst the initial prognosis given to parents seemed poor in all cases it emerged that in some cases the children "defied the odds" to live beyond their life expectancy.

Many parent participants of children born with neurological disabilities, report similar experiences of being told their child's prognosis. For instance one mother was told her daughter had...

1MIV1 "99% chance she'll die; 1% chance she'll live... if she survives... a dilemma for society..." 97

Another was told:

2MIV1 "I mean they didn't know whether she would survive so everything was just doom and gloom and they didn't know what she would do...how long she would live but they didn't expect her to live basically...but she defied all the odds and did" 55

Interestingly in some cases despite prompting, parents did not speak about prognosis however healthcare professionals, identified by parents as key informants recounted their understanding of the child's prognosis for instance in one case a nurse pointed out:

4VB "the tumour was still there...it's not gone away" 223

4OLN "her tumour could lay dormant for maybe...a couple of years...it may never come back, in my experience...this type of tumour...comes back...aggressively and its palliative and within weeks she would die" 61

Another nurse involved in Emma's care points out that:

5PCN "I went to see Emma 2½ years ago; at that stage we were told that she had a prognoses of about 6 months."21

Grainne is 18 years old and her mother recalls being told:

7MD "they thought (she) wouldn't last past her 1st birthday...then they thought 5 year" 141

The nurse involved in her care suggests that:

7CNS "they feel they are almost on borrowed time because the prognosis always so poor...because it was inoperable... she defied all the odds up to now" 206

Those caring for Harry feel that his prognosis has changed:

8RP "his apnoea had become quite severe...more frequent...more prolonged...he was not for active resuscitation...in everybody's mind a very short window of time for Harry when his parents took him home initially" 42

8RP "Yeah and I mean, I suppose, I mean like Harry is here 10 months, Harry wasn't supposed to be here 10 days" 574

8RP "miraculously Harry seems to have more or less grown out of his apnoea" 55

Whilst some parents sought information regarding prognosis, in all cases their children's life expectancy had far exceeded the prognostic information which they had been given.

Near-death experiences

In this research some parent participants had lived through multiple near-death experiences of their child. Some parents described emergency incidents where their child had an episode or event where they required resuscitation but survived.

6MIV1 “in January she aspirated coming out of school and stopped breathing all together...the nurse resuscitated her for me and got an ambulance....it’s the worst feeling in the world when you are not there”261

Whilst the parents of older children were able to recall many incidents of near-death experiences over the life-time of their child, the parents of baby Harry witnessed several emergency incidents including cardiac arrests in the first six months of his life. These quotes from his story clearly demonstrates how near-death experiences impact on parents.

8MIV2 “they were trying to get blood....he got stressed...I could see that his colour went off a little bit...next thing...he literally takes a turn...they were bagging (him)...they asked us to step outside...we were sitting outside and next...there’s a crowd in the room...we were like what the hell is going on...a few minutes later there’s people running the arrest call had gone out...he was in ICU for a week after... that it’s just reflective of how things end up being so acutely bad and then suddenly its you’re back from the edge ...oh the drama” 640

After several emergency incidents hospital staff expressed concerns regarding Harry surviving and discussed the issue of resuscitation with his parents.

8MIV1 “He’d had those apnoeas; you know where he stopped breathing...resus on him and at that stage they decided...you know with everything...the complex problems and you know...how much do you intervene basically...what’s next...do you intubate...I had been there all the time...one evening I asked my sister to sit with him...literally I’d got out of the shower...I got a phone call from (the hospital)...my sister was with him when he had...(apnoea attack) she was giving him his bottle when this happened, you know the way. So of course I sped up and that night he was in the ICU and that was the night we had the conversation with the consultant.”364

Harry’s mother described living with the uncertainty of knowing how unwell her infant son was, being told he would not survive but not knowing when he would die

8MIV1 ““...everything was so negative...one thing after another ...next morning...I was asleep on the chair beside Harry...the heart rate monitor went off...his colour had kind of changed....the sats monitor alarmed...he had a terrible convulsion...I thought that was very scary now, very, of all the things now that we've been through that was a real scary one ...it was by the day they were discovering something else was wrong...just seemed to be...every single thing...they felt that this thing was going to reoccur and he wasn't going to come back...like...he was going to stop breathing at some point and without resuscitation wasn't going to start again” 449

Near-death incidents became part of their caring experience and Harry's mother describes how she and her husband came to recognise these incidents.

8MIV1 “So it was nothing, we'd just hold him...he'd literally ...stop (breathing)...you'd see the colour run out, like he'd just kind of, you know lips...he'd just completely...like he'd nearly go...almost kind of a grey, kind of an ashen colour and then he'd, almost a waxy pallor by times...we'd be just holding him and you know and Liam...would be putting the finger down to feel his chest, you know the way...he's like oh God, he said there's the faintest little tick... it would just come back and next thing (intake of breath) be this gasp and then you know back he'd be the bionic boy” 560

8MIV2 “Like every time he gets bad in hospital you are nearly is this it... I know it's because he is obviously very complex and that but it is the not knowing” 731

These quotes, all from one case clearly demonstrate the process that Harry's parents had been through and the change in their coping and expectations. Parents in other cases described a more gradual deterioration in their child's condition where they were told their child was dying. In these cases parents had been given a short prognosis and yet all survived these episodes of a near-death experience for instance one mother recalled:

2MIV2 “it was before Christmas and they didn't think she'd last the night” 804

9MIV2 “With him it is very hard to talk about future, you know he is eight...and doctor told me he should not live”355

From the above quotes it is evident that healthcare professionals, using their professional judgment, endeavour to prepare parents for what they perceive as an inevitable outcome. However with each near-death experience, parents become more sceptical of the information they are given regarding their child's prognosis. Parents and other participants described living with uncertainty, expecting that their child will die but not knowing when this is likely to happen.

2G "They were told the last time it's kind of the beginning of the end for her you know, she (Lorraine) just doesn't want to leave her and that's what she is really basically, that's what Lorraine is afraid of that she'll come back some day and she'll be gone, she wants to be there, she wants to spend every last minute with her" 790

The grandmother went on to say:

2G "she had a very bad turn... then they didn't think she was going to last the night that time" 812

Several parents reported being told to ensure their child was christened, euphemistically confirming the serious and life-threatening nature of their child's condition.

7MD "she was christened that was an important thing...they said she'd have to go off to the Dublin children's hospital as soon as possible...we went with her in the ambulance" 93

Some parents were faced with taking their child home to die and described the practical issues of achieving this.

8MIV1 "We sat down with one of the consultants...went through it all...what would your wishes be...How much, how many times or how much support you would... (talking about resuscitation) you don't want him to be artificially kind of kept going either...we never did like...he said you know we would be concerned...I just said I'd like to be able to take him home... that was my greatest wish" 349

Although meeting the express wish of the parents, discharging a child from hospital to die required preparation and parents described the practical challenges of this.

8MIV1 “the hoops you’ve to go through...it took us so long to get out of there... you just wanted to get out of there because I was thinking I don’t want him to die here... it’s like a sense of relief when we got home... a living wake... All I wanted was just to get home...I was praying and praying and praying that no matter what happens that we’d just even get inside the door...”527

In a very practical sense and as a result of prognostic uncertainty some parents reported being unable to make plans. In some cases these plans were house alterations to accommodate the sick child and in others everyday decisions such as holiday plans were put on hold pending the health of their child.

1MIV1 “we should have built it years ago but we always thought... to be honest with you we thought Molly wouldn’t survive you know...” 1212

Ironically Molly died less than a year after the extension was completed. She was one of two children who both had typical fluctuating illness trajectories who died during the course of this research. After so many near death experiences parents described the shock and devastation caused by the unexpected nature of their child’s death for which they ironically felt ill-prepared. In this research it was evident that clinicians, using their professional judgment, endeavoured to prepare parents for what they perceived as an inevitable outcome.

6.5.1.4 Sub-theme - Loss of previous world

Parents reported the life-changing nature of caring for their child resulting in the loss of their previous world. Although willing, parents felt ill-prepared for this new role requiring them to commit to caring for an indeterminable period of time. Parents described feeling different and having the ability to just get on with the task in hand.

1MIV1 – “When you have a child like that sick you don’t really function normally like people are talking about things and you are not part of the real world you’re like off out there you don’t really connect with reality” 203

2MIV1 “you don’t realise how hard it is because you just have to keep going...you just have to get on” 358

One mother described the physical changes in her previously beautiful daughter who was diagnosed with a brain tumour and treated with high dose steroids and radiotherapy.

4MIV “everybody call (her) Julia Roberts... she was pretty, pretty, pretty... she will have cross eye like nobody in my home...had cross eye... she was monster ... depend on steroids...changing...her body...she starts to be really paranoid...” 365

A consequence of her brain tumour was the subsequent change in physical appearance; Magda’s parents described the impact of her appearance on the way their daughter was viewed at school and by their local community.

Isolation

Parents reported feeling isolated and that other people didn’t understand what they were going through. Viewed through the lens of the family systems theory, not only did parents find having a child with a life-limiting condition isolating, they also expressed difficulties in being part of the wider community. Many were unable to leave their homes due to care demands and practical issues such as transporting their child and the equipment they required.

9MIV2 “I’m like in prison here”468

2MIV2 “...you’re very hemmed in...like the thoughts of going out is just...by the time I get everything organised it’s hardly worth it” 247

Mothers as the primary carers were frequently at home for long periods of time without any contact with others.

5MIV1 “at times I do feel there is very little support and you feel isolated...I don’t know anybody else who’s in the same (situation)... I mean...most days he’s (husband) the only other adult I would see you know...I could be here for hours on end and wouldn’t see another single person” 724

For one mother the decision to keep her child at home and the subsequent isolation also served a purpose where it limited her daughter's exposure to potentially life-threatening infection.

2MIV1 "you are very housebound ...if you are bringing her in and out she is going to pick up stuff (infection)...it seems like we mollycoddle her but it is the best way for her because we are limiting her bugs...since we have taken Aisling out of school...trips in to hospital have gone down dramatically"456

From the above quotes it is evident that mothers as the primary carers feel isolated and lonely in caring for their sick child at home. Healthcare professionals involved in the care of the children also reported issues with parents becoming isolated where the majority of contact that mothers had with others was with those involved in the care of their child.

8RP "she is busy everyday doing something...or having someone in the house in relation to Harry and what he needs...I would love to see Mum getting out...I know it's so easy to lose your own identity in all of this because you're absorbed and learning a whole new chapter of life" 594

Extended family members also expressed concerns regarding the isolating impact of caring for a child at home. One grandmother reported having concerns for her daughter-in-law:

2G "I'd be very concerned for (her) wellbeing... Lorraine has been here the last ten years with that little girl morning noon and night... she has given the last ten years of her life to her and if anything happens to Aisling Lorraine will go to pieces...(her husband)...goes to work he has some outlet Lorraine has nothing...I'm more worried about what's going to happen to Lorraine I really am"875

These excerpts from interviews demonstrate the level of isolation particularly mothers as primary carers experience when caring for their sick child at home.

Time to socialise

In this research participants described their social activities and how these provided a break from caring. Many described rare but vital activities that brought them into contact with

friends and family and the wider community with one mother going as far as describing going to the pub as respite.

1MIV1 “we would relax when we are out...we’d stay because we are with friends or neighbours for the chat and the craic” every single weekend ...go out...it was fantastic...that was respite in a different way...the pub is beside the house...so we would go” 392

Other parents also described visiting the local pub when they were able.

3D“if people we knew and trusted were with him I might consider it but not for long periods ...we don’t go too far”41

6MIV1 “if we do it might be just down the local for an hour or two”321

Other parents did not feel comfortable leaving their child and instead socialized in their own homes.

3RN“they got a Mexican take-away, and had their Corona’s and put on a movie and that’s often what they do” 297

2MIV2 “we don’t have a big thing about going out... it’s easier for people to come to me...it’s an open house”252

In one case the father felt able to go out but knew that his wife was not happy to leave their daughter:

2D”(re going out) “I know Lorraine can’t, at the moment anyway...I would probably be a bit more, I could kind of put it to the back of my mind you know, Lorraine can’t I don’t think...I mean it is non-existent the times we go out, it’s hard”751

It is clear from these quotes that having a social life and finding time to spend with their partners was of importance to parents; however this was always tempered and dictated by their child’s condition.

6.5.1.5 Sub-theme - Fluctuating condition

The essence of living with uncertainty for the parents of a life-limited child is the fluctuating nature of their child's condition. Parents and others were able to identify frequent episodes of fluctuating ill-health describing how the child's condition could change without warning.

8RP "...the emotion and trauma that's been built around watching those apnoeas and thinking is he going to take that next breath and you know thinking in the background well we have to make funeral arrangements...then suddenly he hasn't been doing that...he's thriving" 69

The uncertainty of not knowing if and when their child's condition might change impacted heavily on parents who were reluctant to leave their child in case there was a sudden deterioration:

5MIV1 "I would find it very hard to even when she was at school say to go out or to go very far because I'd be waiting on a phone call"388

8MIV1 "Yeah uncertainty ...you're worried about everything...down to any kind of a temperature... You just don't know if that's going to be the one."884

Parents describe being told that their child's death is imminent on several occasions.

9MIV1 "I heard maybe ten or fifteen times that it's time for him...but he's seven now."41

3M"there were times...I didn't think he would make Christmas never mind be in the tub with the rest of us" 605

Parents and other participants describe coping with the child's fluctuating condition by and the constant effort that this takes:

1MIV2 "...it does play havoc with you...I don't know it is just you have to keep putting your feet to the floor every morning and taking one step forward... every time Molly hits a low because you think I have to keep going because she is probably going to

pull through and we have to keep going...it's constantly you know trying to keep...to push yourself each time ...We know it is just around the corner...it's always over your shoulder"25

Others report taking one day at a time:

3D"you're better off taking it a day at a time...you're better to try and enjoy the time you have with him now and try to make it as happy as we can and just take it day by day" 372

8MIV2 "at the beginning it was all very short term...you didn't have to think long term so therefore you were making the very most of every minute and every day" 766

6.5.1.6 Sub-theme - Parental hopes, fears and expectations

The hopes, fears and expectations of parents was a theme that ran through many of the interviews with parents and other participants. Caring for a child with a life-limiting condition can test parents' coping skills to the full. Many parents relish the opportunity that a respite break from caring provides and utilise this precious time to spend time with their partner or their family. A major issue for many of the parent participants in this research was the impact that sleep deprivation and the subsequent exhaustion had on every aspect of their lives. Many noted that sleep deprivation influenced their ability to cope with care needs of their sick child and caring for their well children.

Time to sleep

The majority of parents in this research identified sleep deprivation as a key issue. Many reported being disturbed several times each night.

2MIV1 "...if she is up in the night you do feel it the next day...sometimes you'd have to physically get up and bring her downstairs and sit with her for a while"752

9MIV1 "he sleeps maybe for all his life maybe all night he sleeps twenty times...Every two hours he wakes, every three hours, and I wake and change him nappy"319

Others reported being woken by equipment alarms or in order to provide physical care for their child.

6MIV1 *“she has to be turned during the night to prevent pressure sores so I have to turn her...every couple of hours... most nights she would wake up looking for a drink... I'd say since she was born I haven't had a night's sleep...am always alert...I get the nurse twice a week but even at that I would hear her and I would hear the monitor going off...”* 98

Although her adolescent daughter did not require physical care one mother reported the need for psychological support at night.

7MD *“there are times that she felt very weak...she might say mammy would you come in with me in case anything happens me, that would be very seldom now... she would have called me at night...just couldn't sleep...when the depression was bad there definitely it was nearly every night she couldn't sleep, you know and she would call me”* 487

Some parents reported sleeping with their child in their bed:

6MIV1 *“most nights anyway she's in the middle of the bed...so I can just reach out and turn (the monitor) off ...he thing about having her in the bed...it's a lot easier for me because if she wakes up or if I need to turn her, well I roll over and turn her”* 425

9MIV1 *“he sleeps with me.”*398

Some parents chose to have respite hours at night as this enabled them to cope with day time caring.

3M *“just fantastic, if you can't get to bed at night...it just wears you down...neither of us would be able for that”* 393

6MIV1 *“the night hours are good because I'm usually exhausted”*594

8MIV1 *“I'd say I probably sleep better the nights there's a nurse here...”*894

From these quotes it is evident that sleep disturbance and the ensuing exhaustion is an issue for many parents caring for a child with a life-limiting condition and indicates the benefits of access to respite nursing or care hours at night.

Hope

Despite their child being diagnosed with a life-limiting condition all families expressed hope that their child would defy medical expectation.

1MIV1 "6 weeks after she was born he said she won't see she won't eat she won't hear she won't know love, she won't know this and she won't know that and I said Good Jesus couldn't believe it like, but she does like she can see she can hear she knows her family she loves being here" 695

Parents explored all options in an effort to give their child their best chance:

3M "we wanted him to talk...we were always hoping...we brought him to Budapest for a month to the Pato Institute and we tried that... it really was too hard for him...but we weren't sorry we tried it" 184

Even when parents knew that their hope was ill-founded this did not deter them:

3D "you'd always hope Patrick would get better or they'd find something, you know" 449

4P "I am grateful we never cut hope...never, never, never" 87

Hope was perceived as very important to parents:

8MIV1 "like every so often...things...would give you a huge hope...bit of hope was just so important like it really gave you so much strength...helped you through everything" 446

Search for meaning

Parents in this research looked for meaning in their child's ill-health through various means. Some raised money for a charity closely linked to their child's condition,

1P "Sean did a big fundraiser for Voluntary Provider of Care...he raised €13,000...gave them a heffer" 495

Others underwent genetic testing;

3M “we went to a geneticist at the time to see was there any connection between (our son’s problem) and the miscarriage...I suppose you always feel kind of that you’re responsible in some way, there’s some kind of guilt there ...he said no....it’s just bad luck....just bad luck”438

Fighting for your child

Some parents suggested that there was a need to fight for your child to ensure that they got the best care possible regardless of making yourself unpopular.

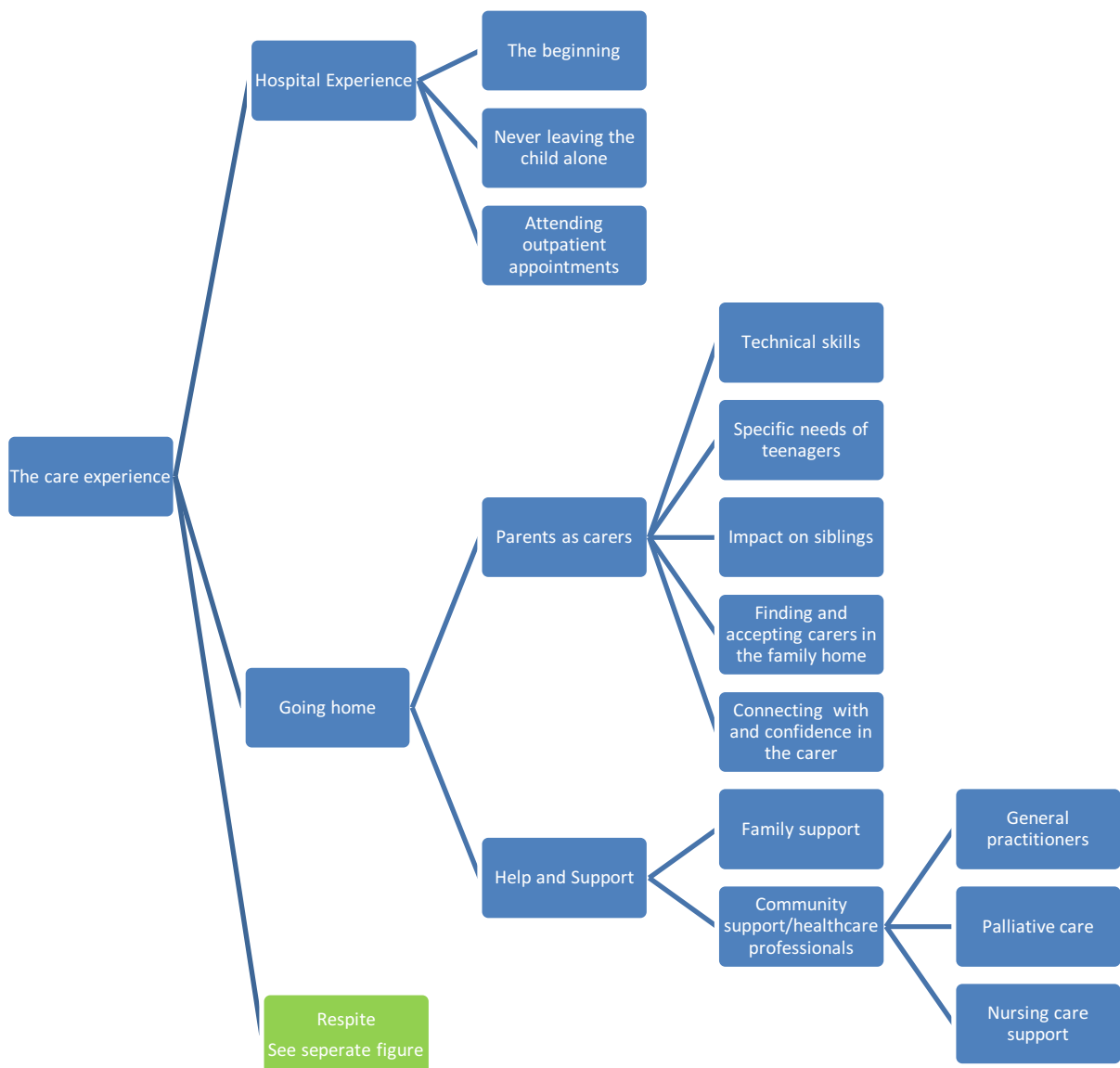
3M“a friend of mine...has a child with disability....she says you have to act the tinker...sometimes you just have to let fly”121

4MIV “I was fighting and fighting and argue and crying...I was like...fox...I make Second World War...everybody know me... they hate me because...I was very formal...every tablet you have to show me” 767

6.5.1.7 Summary of theme One – Living with uncertainty

Living with uncertainty is a part of the everyday reality of caring for a child with a life-limiting condition. This uncertainty impacts on all strata of the family system and on the family’s access to and utilisation of respite services which are often dependent on the child’s diagnosis. Parents of children with life-limiting conditions live with uncertainty regarding their child’s prognosis. Many of the children have defied medical expectation, experienced multiple near-death experiences and fluctuating life-threatening conditions. Parents find themselves in a new reality and the loss of their previous world is inevitable. They still express hopes and expectations for their child but these are often coupled with the uncertainty that pervades many aspects of their daily lives. Parents describe the impact of sleep deprivation on not only their ability to provide the care their child needs but on all aspects of family life. Parents describe having to fight for services for their child.

6.5.2 Theme Two: The care experience



6.5.2.1 Introduction

Becoming the parents of a child with a life-limiting condition brought families into contact with organisations and situations that were unfamiliar to them. Their family system widened to encompass healthcare professionals, voluntary organisations and care providers. In this section findings on the family care experience will be reported. The impact of the caring and the child's condition on the parents, family and siblings will also be highlighted.

6.5.2.2 Sub-theme 1: The hospital experience

Parents reported that their previous care experiences had an impact on their current uptake of services. These experiences included: children's hospitals; out-patient appointments; travel to and from hospital and respite care.

The beginning

Early experiences of hospital had an impact on many of the families involved in this research. For children born with a life-limiting condition lengthy hospital stays were initially inevitable. This was challenging for parents particularly when they had other children at home.

IMIV1 "I would have been in the children's hospital for months on end and left (my son) with my mother and different people and that is very tough... you want to be in both places but you can't" 1475

Never leaving their child alone

Negative experiences of hospital resulted in all nine sets of parents saying they would not leave their child alone in hospital. Parents revealed a variety of reasons for making this decision:

IMIV1 "she is never in hospital that's one thing as a family we say would destroy us when she goes to hospital because we have to stay there... is impossible to give the care she needs in a busy ward where children are going to theatre and there's infections and it is just the worst scenario for us is if (she) ends up in hospital" 772

Some parents raised issues regarding the standards of care, expressing the view that staff were unable to provide care to a standard that they would regard as suitable to meet their child's needs. It was suggested by some that there were inadequate staffing levels.

3D “when he’s in hospital it’s a killer... you have to be with your child all the time, you won’t get the care because they’re so busy... (mother) is so used to looking after him now, she’d be nearly left to her own devices...they know we know better than they do a lot of the time” 513

Parents also expressed doubts about the quality of care provided in hospital:

2MIV1 “myself or (my husband) would not leave Aisling in hospital for 5 minutes...because she doesn’t get looked after properly...she would be left in the bed all day basically ...I’ve experience of her...I could run and get a cup of coffee and come back and find that she’s lying in sick...I mean she can have a dirty nappy...the sheet mightn’t be changed and to me that is not acceptable ...that to me is just not the way that I think my child should be looked after...one of us has to be there to make sure”535

Their child’s inability to communicate was also a deciding factor:

3M “always we’d have either ourselves or someone in the family in the room...he can’t speak...you had to have somebody that knows Patrick...and was going to be a voice for him”

Other parents question the clinical skills of staff and describe anecdotes of where their skills as parents have been ignored by staff:

3M “I was begging people...I said make sure that nobody turns up the O2 while I’m gone...the nurse...called the reg...what’s the big deal...a stretcher came down for him...could have killed him” 287

Another participant commented:

9MIV2 “you know who looks after better, like me, who look after him better than me, who check you know every minute, every hour a nappy, who, you know who give him hug, you know they can’t do this”

Parents also talked about staying in hospital with their child and the inadequate facilities.

3M “I’d stay with Patrick on the floor in the hospital...one of us would always” 542

Attending outpatient appointments

Travelling with a sick child to outpatient appointments and clinics was reported to be very stressful due to practical issues such as transporting equipment and medical supplies:

9MIV1 “take his buggy and take from car to buggy and because his buggy is very heavy and put in buggy after to car and again and again and this is hard, very hard for me.”274

Other parents commented:

2MIV1 “going in the car and stuff like that it was pretty much a nightmare”1011

1MIV1 “you can’t just hop in the car, everything has to be planned” 742

Others referred to multiple long journeys to the tertiary children’s hospital and the practicalities and realities of trying to park their car in order to attend appointments.

5MIV1 “children’s hospital...meant a lot more travelling for us...it takes both of us because the car parking is terrible”62

One participant in the study described the travel arrangements for one of the children. No longer able to sit, her parents can no longer provide transport for her and the only way she can travel is either by ambulance or on the school bus where the driver allows her to travel lying down.

6SN “she travels lying on the bus” 170

6SN “she wouldn't be coming to school either at the moment only for the goodwill of the driver who lets her lie on the seat on the bus” 311

6.5.2.3 Sub-theme 2: Going home

Caring for a child with a life-limiting condition at home is challenging. In the Microsystem of the immediate family in all cases mothers were the child’s primary carer. The majority of care took place in the family home.

Parents as carers

In most cases both parents had a role in the provision of care to their sick child at home, however the role of the main carer fell to the mothers. Some mothers commented that for their husbands, work was a break from caring for their child.

5MIV1Re: father "he's kind of different too because he has his break, he gets to work..." 715

Ultimately mothers were the primary carer of their child.

6MIV1 "I'm her carer 24/7"78

3D (about his wife)" ...her primary function now is to mind Patrick" 318

The level of care required by the children ranged from needing total care to the child being able to carry out all self-care. Where needed care was usually carried out by the child's mother including assistance with hygiene needs, mobility pressure area care, dealing with incontinence and feeding. One mother described the level of care her child required:

6MIV1 "she can't stand, walk, talk, do anything, she can't feed herself, turn over, so she needs full 24hr care... she has gone from where you could bring her for walks, she'd sit in her pushchair and be on O² ...now she....has to be lying down all the time. 49"

Technical skills

Participants spoke about the technical care that the child required. One father described suctioning his son.

3D "we were shown a couple of times and we were supervised and that was it, you had to do it...I hate doing it... he won't let anybody else...down deep, he'll get panicky and he'll resist...there's only myself, Margaret...if Patrick is in distress...that was the worry there last week like if we didn't manage that he'd die so that's you know it's an awful responsibility" 214

Another mother describes routinely changing her daughter's Percutaneous Endoscopic Gastrostomy Tube:

2MIV1– “it has always been fine – we change it ourselves...”

Many parents despite no formal medical training were able to use medical terminology and abbreviations.

‘Knowing’ your child well was a feature of many of the interview’s with parents in this research and in many cases feeling that they knew more about their child than the healthcare professionals:

2MIV2 “They can do whatever tests they want, at the end of the day I actually think I know more myself than they do” 741

Another commented:

4MIV “she is not well I know her very well” 228

Two mothers simply said:

6MIV1 “parents...know more than anyone”810

8MIV2 “I know it’s hard to imagine but you really feel that you know him better than they do...he is stronger than they think he is”743

In one case a teenage girl required very little physical care from her parents.

7MD “Grainne would be able to say more when she feels herself unwell, she would phone you, she would tell you but say when she was younger I wouldn’t have left her with anybody other than say half a day to go to city for a bit of shopping” 429

Many parents felt that they were able to provide the best care for their child and this was also acknowledged by some of those involved in the care of their child.

2PHN “she doesn’t like other people looking after Aisling when she is there because she feels she can do it better” 127

Ultimately one mother pointed out:

6MIV1 "I'd always be wondering is she okay? Are they checking her...because I'm her mother and you always assume that no one is going to look after her like you" 185

In many cases parents were left to make clinical decisions regarding their child's care.

1MIV2 "There are so many situations that arise with her that I make quick decisions about...they could be right or wrong but I make them and that's it they're made, whereas in there (respite) they would have to seek medical advice and then the GP would certainly refer to the hospital...then she would end up in hospital" 296

In all nine case studies the children had mobility issues of varying degrees. Several were unable to move independently. Some parents used lifting equipment, whilst others had no equipment at home to assist with moving their child.

9MIV1 "Max is not really big...but my back, I feel sore every day my back....It's very hard for me to bath him...he's heavy and I need to lift him and this is problem for me." 184

Parents caring for a baby with a life-limiting condition can sometimes also require pragmatic advice regarding normal development issues, one healthcare professional spoke about a mother's need for basic information.

8RP "telling her all about normal teething...when to start weaning...I think everybody forgot the basics" 552

The specific needs of teenagers

Depending on the child's age their care needs differed. In this study four of the children were in this age range (13 to 18) and thus classified as adolescents. Molly was both severely intellectually and physically disabled and even during the interview process was cradled on her mother's lap. The children in the other cases were all female and struggling with the challenges of living with a life-limiting condition as an adolescent.

Despite not finishing school Grainne was determined to work even though this work was unpaid. It had been organised by the CNS involved in her care.

7MD "she goes to the (office) Monday and Friday to do a bit of computer...on Tuesday...the ECDL course...she has Wednesday off" 526

Having recently reached the age of 18 Grainne's mother no longer attends GP and hospital appointments with her. As part of her drive for independence Grainne who is wheelchair dependent outside of the home is learning to drive. The CNS tells me that:

7CNS "Grainne...holds a diary with all her appointments and her visits and the schedule for those" 101

Grainne's mother no longer has access to the information from the doctors.

7M "Grainne is 18 now and she's fit to go into the doctor herself now, right...to ask whatever she wants to ask. When she was younger...I would say to him (doctor)...tell me if there are any changes....anything getting worse...I wouldn't ask that now" 450

She wonders if there was anything wrong who would be told:

7M "Do you know if there was anything going wrong... would (he) come out with it to Grainne?" 478

According to their parents and others involved in their care both Emma and Grainne struggle with their appearance, the isolation that looking different brings and the impact this has on their peer relationships.

5PCN "She stopped going to the school she felt that people were looking at her... ostracising her."151

5VB "she was something about relationships and boys...Emma has the same wants and needs as any other 17 year old"771

Emma's condition means that she has very little sight and is reliant on her guide dog or needs to take someone's arm to guide her. This has severely impacted on her independence and prevents her from socialising with friends independently. Although she is in contact they no longer visit her at home.

5MIV1 "she has a couple of really, really good friends who have always stuck by her...they don't really come around no... she's in touch with them on email and text"
439

Another participant commented on Emma's debs evening:

*5VB "the night of her debs...the girls would get up and move...and dance...Emma...wouldn't be able to keep track of them."*797

And the difficulties she encountered with her vision going to the cinema:

*5VB "she went to the cinema and it was...the girls mightn't have...appreciated that ...Emma...in a dark area...her vision would be wiped out... would have been very traumatic"*792

In this research both girls were being treated for their depression. In order to receive this treatment both were travelling long distances to attend appointments at a tertiary children's hospital as services were not available locally. In both cases depression was a key issue for parents.

5MIV1 "...really, really, really take hold of her...wouldn't engage with you, talk with you, she was just down in the dumps" 372

Another parent experienced similar with her daughter:

7MD "she really got depressed then...I think she needed somebody else to talk to"
760

Her mother has made the link between her congenital heart defect and her depression:

7M *“the heart would be the bigger problem, the two are linked, the heart has the depression there”* 73

Living in a remote rural community one adolescent had few friends of her own; making friends vicariously through her older sister.

7CNS *“her whole circle of friendship would be around her family and neighbours...she would have a very good support there and her sister’s friends would also become her friends... where they live, very isolated...the speckled houses along...the hillside...one of her neighbours would be of similar age”* 337

Her mother explains:

7MD *“You know friends wouldn't be a big thing but I suppose the way I would look at it she has her friends through somebody else. When I look back on it now, where if she had went to school, more than likely she would have picked up with a friend of her own”* 586

Impact on siblings

Of the nine cases included in this research seven of the children had siblings. Living with a sibling who has a life-limiting condition has an impact at every level of the family system, but nowhere more so than in the nuclear family. Parents reported spending time with their other children and if they are not able to, extended family members such as grandparents took on this role.

2G *“(Sibling to Granny)Nan she said is (she) going to die and I said no Derval, I said (she) is not going to die...the doctors are going to make her better but she is very ill this time...she said if Aisling died who would change her nappy and who would give her food and look after her... I said if Aisling had to go up, I said holy God there’s be somebody there, I said special angels to look after her and to do all that kind of thing for her. Oh she said that’s alright so ...she hasn’t spoken about it since and that was back 3 or 4 years... I spend an awful lot of time with Derval...”*1026

This was demonstrated in this research by one participant whose daughter had been diagnosed with a brain tumour. Speaking to her son she felt she had to reiterate that whilst his sister required more of her attention this did not mean that he was less important.

4MIV1 “my pain is in heart because of course we was talking with him... still remember we are with you as well it’s only more care for Magda, not more love””
978

Respondents in this research gave many examples of how caring for their child with a life-limiting condition impacted on the lives of their healthy siblings. One mother reported how plans sometimes had to be changed without warning to accommodate the needs of the child with a life-limiting condition:

1MIV1 “(siblings) they can give out because everything can be changed at a moment’s notice”508

Ultimately the family made structural changes to their house building new rooms in their home to accommodate their daughter and her carers.

1MIV1 “this room is Molly’s now and the bathroom...this room is ideal for carer’s because they had a huge problem in our home with the busy, busy dinner, homework, football boots and they were trying to get Molly’s drugs ready and it was very difficult for them...it’s not Molly that’s the problem it is all that comes with her the fact that she needs staff with her ... the fact that it is somebody in your home even though they are out here you can’t really let go with the children and discipline them or you know you’re very conscious that you are actually in your own home but yet you can’t relax you couldn’t come down in your pyjamas ...it’s just different...(brother) would come out of the bedroom and ask if there is anybody here? Fifteen because he can’t like slouch around ...like he has to be kind of on edge in your own home when there is a carer here...but the kids know we need carers ...we know we need carers we wouldn’t be able to have Molly at home without carers”735

In this research several families reported attention seeking behaviour by siblings of their sick child.

1MIV1- “(brother) his behaviour for the first years of life was dreadful...he would just turn everything upside down and behave really badly...he was seeking attention...everyone was coming to see (his sister)” 348

Another mother spoke about her well daughter:

2MIV2 (sister) "she's a drama child...she could make something bigger than what it is ...she always was dramatic...if (she) got a nick in her finger it would be like oh my God and what she goes through, she gets a nick it's like the whole world is falling apart...the minute Ronan comes in she'll say to him lift me up, he'd say Dervela you're getting too big, I can't lift you like, you can lift Aisling so there's a big issue there, it's huge, the minute you sit down she is nearly sat on top of you so it's definitely there's definitely an issue there" 612

The same mother described her dilemma about telling the well-sibling about her sister's predicted imminent death.

2MIV3 " I can't either because we don't know ourselves so what way am I meant to approach the situation, do you know what I mean, like it's not fair to worry her because we've been here so many times...and then Aisling has come back up again... it's hard to know what to do for the best, you know that kind of way, you're kind of doomed if you do and doomed if you don't, that kind of way" 537

In this study parents who had other children reported that one of the main stresses caused when their sick child was hospitalised was caring for the siblings. One participant described the positive impact of giving birth to her next baby who was fit and healthy and brought 'normality' back to their home.

1MIV1 "we went to Lourdes and I came back pregnant...it was brilliant because we had a healthy little boy who I believed had everything wrong with him for the first month...he was absolutely fine and that made us just realise that there was a normality brought back to the home and it was brilliant" 474

Incidents of this were demonstrated by two participant families in this study.

2MIV2 "If kids come in they'll stare at Aisling and they'll be like oh my god...but to Dervela it is just normal" 649

Following treatment for a brain tumour Magda's mother describes the impact that her cancer treatment has had on her daughter's appearance:

4MIV "I'm mother for me she will be pretty for her life but she was like monster really...she was huge with rash everywhere, was really bad time" 530

One family has a son with a life-limiting condition and another son with severe autism. Their mother describes the relationship between her two sons:

3M "he'd never touch his equipment, even though he's autistic and he'd be touching everything" 47

This was played out in this research where parents reported well siblings helping them meet the care needs of their sibling.

6MIV1 'he's brilliant...he knows exactly what to do as regards her equipment and her machines, he knows it all you know he's great"624

2MIV2 "if I say ...go upstairs and get me something for Aisling clothes nappy whatever, she'll go like...never really a question asked...but if I say to her get up and get your runners, why do I have to go up and get my runners, can you not go get them"629

Finding and accepting carers in the family home

One of the key issues for parents caring for a child with a life-limiting condition is the issues of connecting and having confidence in those who provide care for their child regardless of the location of care. However this alone does not explain parent's reluctance to leave their child which is exacerbated by the knowledge that their child is going to die but not knowing when this will happen.

3M "I don't know how much time we're going to have with Patrick but that's part of the reason....I'd hate to be gone if something happened, you'd want to be here" 141

Connecting with and confidence in carer

Most often the carers that parents had confidence in were those who they also liked and respected. In one case the respite provider said of the mother:

8RP "it's like calling to see a friend now that's how much the relationship has evolved...I will go and do a bit of hands on with Harry...it also gets me the opportunity to get to know Harry and what his needs are and what I can do to support them" 220

Despite having trust in her daughter's carer one mother made this point

1MIV2 "... I would trust them but I suppose they are not going to love her like we love her...you know it's a job like and they treat it as a job"276

Participants spoke about how parents chose who provided care for their child:

1RN "some people are better at it than others....she chooses herself...she may prefer one person over another" 284

One participant commented on the level of control a parent needed:

5PCN "It would have to be the people she (mother) hand-picked, control is huge and it keeps (her) safe."301

Another perspective on this was given by a mother who describes the lack of trust she had in others ability to provide care:

9MIV1 "I don't trust different people like my friends, I know nobody wants to hurt my son but maybe I should try but I'm afraid about it."381

Parents also explained how they assessed the competence of the carers and who you can trust:

1P "(assessing competence)"you'd have to see them in action a few times before you'd know"176

Another mother agreed:

2MIV2 "I just hung around...I wouldn't be great...to confront someone...if you are going to leave someone looking after your child, you're going to make sure that they're going to look after them right...she need to learn that you know what she looks like when she's uncomfortable...she is still learning...she's not able to come in and just learn overnight"355

A father also needed to assess the carer's skills prior to leaving his son:

3D "...we want to see them for a while in action" 743

Another parent described the traits of her ideal carer and the challenge of finding another suitable nurse to care for her daughter once her trusted nurse had left:

2MIV2''(the nurse) that is a big thing when someone walks in with confidence and they're well able to do things, whereas someone coming in and they're a bit oh show me that now, I'm not sure of that ...but (nurse) knew bang, bang, bang straight away...I was so close to (nurse), so it was hard for (the new nurse) to walk in here after (nurse) being here you know...I think no matter who walked through the door it was going to be hard''383

Past experiences of carers also influenced confidence in carers:

3D''there's been a couple of nurses alright that didn't work out, just didn't care enough... you don't want to get to the stage where you'd have to put a camera up in the room... you want people you trust'' 342

Help and support

The family systems theory identifies the various support structures available to families caring for a child with a life-limiting condition in each of the four systems, however all families function in their own unique way and as the balance of family life changes to meet the needs of a child with a life-limiting condition, the systems that are in place around the family adapt in order to try and support the family and meet the needs of the child.

Family support

Extended family support for the parents of a child with a life-limiting condition was discussed by all participants. Families described the support that they received in the initial phase immediately following diagnosis, which in some cases was at the time of the birth of their child. Other participants including grandparents and aunties were also interviewed and asked about their role in providing care and support.

Gender differences were noted in those offering their care and support with female relatives offering to help more frequently than male family members. In particular sisters were cited as providing support.

1MIV1 “one sister is fantastic...everybody is busy she has her own four children and she is working ...we don't ask, we didn't really ask them when she was small now we certainly don't...you know people have their own lives... everyone who comes in to her we have to pay... helps us mind Molly is paid... there is nobody who really comes in here like just to sit with Molly like...to give us a dig out there is no one... people are busy...they would have taken Finn anywhere they certainly wouldn't be taking Molly anywhere you know” 1065

Other mothers commented of their sisters:

3M “I don't think she sees the value (in herself)”

8MIV1 “there's times like my sister would be here and I'd say will you sit with him...that's no problem” 800

One participant commented on the differences between male and female family members and the help she received from her sister and mother:

6MIV1 “I think brothers are different, I certainly don't think they would offer to take her because...they wouldn't know what to do before we had any help...my sister and my mum were the only ones we could leave her with...” 654

The same mother commented that although her sister was a big support that concerns related to the care of the child would prevent her from keeping her overnight:

6MIV1 (sister) “I don't think she would take her overnight...I wouldn't ask her...I think she would be nervous and I would hate for her to do it and for something to go wrong” 619

One mother noted that whilst her sister, who works with children and was keen to help, that she would not trust her.

2MIV2 “(she) works with kids...she wouldn't feel comfortable...the meds that type of thing...she wouldn't see the warning signs...her lips going a different shade” 801

Many grandmothers played an important role in supporting their daughters as carers:

8MIV1 "my mother comes over every day, every morning like and she'd be like doing housework basically...she's great like" 743

However, whilst able to provide support by helping around the house she was unable to provide care to the child:

8MIV1 "I suppose my mother...she's actually quite nervous because she was with me a few times when he had little turns...I'd say now to be honest she's just a little bit nervous...naturally enough...she hasn't kind of offered... she'd do anything for you, do you know that kind of way... I wouldn't blame her, likewise my sister... she's down every day...she's nervous even handling...they don't actually offer to be honest...they're just I suppose afraid" 770

One mother commented that whilst her family was supportive that:

1MIV2 "...when (the child) is really bad they just could all be here at the same time and then they are all gone" 115

Grandparents also played a part in providing support in several cases and were noted for their absence in others. One grandmother provided regular support to her daughter-in-law by caring for her child:

2MIV1 "she will be 70 next year...Aisling is getting bigger...from a lifting point of view it's kind of hard...my dad would come up and put Aisling to bed if we are not here because there is no way that Breda would be able to lift her up or down stairs...I wouldn't expect her to you know it's very dangerous" 913

Despite accessing the help of her mother-in-law the same mother did not ask her own mother for help:

2MIV2 "unfortunately mam wouldn't be as confident as (other grandmother), like she'd be afraid of the meds....she just wouldn't be as comfortable...I'd leave Mam...with Aisling during the day but not for long...dad would be great" 286

In other cases the help of grandparents was utilised not for care but for babysitting:

5MIV1 “they are really good, they’d be our main fall-back for babysitting” 308

As the children in the study moved further through their disease trajectory some families described a change in family attitude and the level of support offered.

1MIV1 – “family support was fantastic...gradually they fell back to their own lives so you know you are left on your own with your child like to try and muddle along” 165

Changes in their child’s condition often required more support and help with everyday care or with the care of siblings.

1MIV1 “they definitely don’t get involved but at the same time if I was to ring and say I am really stuck would you mind collecting Colin or would mind bringing Colin to football Molly is really sick they would say ohh when...what time...through gritted teeth...(mother in law)...like even if she sits here it’s like she has something burning her bum to get back over to her own house” 1120

Some extended family members are unable to face the realities of caring and were unwilling or afraid that were not able to meet the child’s care needs,

1MIV1 “They’d visit, they wouldn’t be of any practical help...people were afraid” 378

Some mothers describe how afraid people are to care for their child:

8RP “they’re afraid of him...very afraid of him” 371

9MIV2 “everybody afraid Max” 179

1MIV2 “keep their distance... terrified of the tubes” 108

Another participant spoke of her sister-in-law and the support she offered:

7MD “I have Brenda across, just like...a sister-in-law of mine and Brenda would be like a sister to me, they’d be very, very kind you know and very helpful anytime” 391

Support from outside of the family was also mentioned by participants. In particular those who originated from other countries and who had limited support:

4MIV “we have a lot of friends here they always help us” 451

Community support/healthcare professionals

Support for the parents and the child with a life-limiting condition varied within and between cases. Varying parts of the wider family system at both the Mesosystem and Exosystem level were involved including healthcare professionals and in all cases at least one voluntary organisation was involved.

As the entry point to the healthcare system, in all cases GPs (General Practitioners) were involved with families. This involvement varied considerably. Dealing with a child with a life-limiting condition is a rare occurrence for GP and whilst it can be very challenging, their knowledge of the child, if involved, can provide stability. In particular GPs seemed to recognise the parent’s knowledge and expertise in the care of their child where some parents provided clinical guidance to them. One parent commented about this and noted that the GP got upset when she took her daughter for consultation:

1MIV1 “He would give (the child) anything...he will do anything he is very good but really I rarely bring her in, if she is very sick now I bring her in he gets upset because he thinks oh I didn’t know she was this unwell, why didn’t you tell me...I would have come to the house and he’s very nice and he’s very good...yeah could not say a thing about him” 891

1MIV1GP – “is guided by us whatever we want he will try his very best” 1372

Another mother referred to her GP in the following terms:

2MIV3 “he’s a saint” 347

She added:

2MIV1GP – “very lucky that we have such a good GP...he is such a nice man and he adores Aisling and he is just really good so from that point of view we are lucky to have a good GP” 928

The community nurse interviewed pointed out:

2PHN "He's possibly the only stable person she's had from the medical perspective...everyone else has moved away. 306

Another mother drove long distances to avail of the services of her GP:

6MIV1GP – "he's very good...knows her inside out...he's excellent, it's quite a bit away, would take 40mins"514

Other parents had an opposing view:

4MIV "I would like to be diplomatic...but GP is disaster" 199

One mother avoided taking her son to the GP instead opting to go straight to the children's hospital accident and emergency department:

9MIV1 "Doctor is doctor...we don't go very often to GP...if Max cry and I know that something is really, really wrong with him...we go in straight to Children's Hospital"425

Parents were asked about their involvement with palliative care either in the hospital or in the community. One mother described her interaction with the community palliative care team:

1MIV1 "they are like Nanny McPhee to me they arrive when she is sick and they disappear when she is like now...they are good...they give great practical help"806

By the time I interviewed her again she had a different perspective:

1P (palliative care team)"we gave them their P45...they gave us conflicting information and advice...there's too many people involved here...too many people...nobody was really listening"360

Another mother described her relationship with the local palliative care team:

5MIV1 “they introduced us to the palliative care team...which is local...if we need to change anything they can do it rather than having to travel to Dublin...it saves time for us” 44

She went on to describe how her relationship with the team worked:

5MIV1 “Palliative care nurses...links in with us...she doesn’t call because I don’t want her to call...because I don’t like people interfering...I want to keep things as normal as possible...she (PCN) know what I want and she respects that” 593

5MIV2 “we have an understanding; they only call if something is wrong.”237

The palliative care nurse acknowledged the challenges of forming a working relationship with this mother:

5PCN “the family were extremely private... very ... on every level...it was hard to establish a relationship... it’s been a very, very long, slow process...She did reluctantly accept us as time went on.”66

Another participant commented:

6SN “she’s more comfortable since the palliative care team took over” 143

A worker from a voluntary organisation who has adopted the role as key worker for one family, described how she felt when she realised that the palliative care team was involved with the child:

5VB “I remember even when the palliative care nurse phoned here, I was a bit taken aback...I just couldn’t connect this to Emma”535

The mother of one infant boy recalls her interaction with the palliative care team:

8MIV1 “that evening and that night 5 to 6 incidents like that of stopping and palliative care team came, they were brilliant like...just fantastic...they just took control” 458

And of how well the team communicated with her and her husband:

8RP (palliative care consultant) "such a good communicator" 110

Participants found accessing appropriate nursing support at home to be challenging. In particular nurses were difficult to find in isolated rural locations with sparse populations. One mother commented on training staff to look after her thirteen year old daughter:

1MIV1 "it is very tiring training in staff and after they don't stay...you're not sure if they are going to actually take it on and it is very hard to make a judgment... (number of carers had) 20, maybe more...it's a lot of people through your home" 488

Another mother had experienced difficulty in accessing nursing care due to the isolated and rural location of her home:

6MIV1 "the agency can't seem to get anyone that would cover due to geography" 368

A nurse involved in the care of another family from a similar rural area also commented:

7CNS "...family would have very little contact with services other than myself...I'm the jack of all" 407

In one case a school nurse provided a source of support for the mother of one of the children. This support was provided out of work hours in the nurse's home.

6SN "I have...given mam my phone number so I think probably 4/5 times on a Saturday she rang because she was worried ... I just say mammy, you know if you're in trouble ring us, we'll see what we can do" 25

The mother dropped her daughter to the nurse's home at the weekend:

6SN "you know just bring her in, she just lies on the sofa watching telly or whatever and you sit there for a few hours with her and you don't think twice about it and you wouldn't look for hours or you wouldn't look for money"458

The nurse wants to help as she knows how isolated the family is:

6SN "that's why I give her my phone number because it's such a distance from home to the children's hospital"243... "There's a lot of good will around in situations like this" 316

And feels she is able to as there are so few families in the same situation:

6SN "you wouldn't have...15 parents ringing you...we'd only have herself and maybe one other...ring us the odd time...it's not as if you're inundated ... we just get so fond of all the kids and it just becomes part of life you know...you'll do that for parents you know because the services are not there"404

The provision of care in the home by people other than the immediate or extended family was generally perceived as a positive contribution although it did present challenges in terms of acceptability and training of staff in order for them to meet the care needs of the child and the standards acceptable to the parents.

A parent said of one nurse providing respite to her daughter:

2MIV3 "she's alright...there's points where she has been good but then there's point when she's not so good you know, like I'm not 100% about going out...but then I'm not 100% about going out anyway"398

Another mother said of a voluntary organisation that had provided support to the family:

5MIV1 "I can't stress enough how much help she's given they are really, really excellent"607

Care in the home also has an impact on practical issues such as not only nursing practice and working terms and conditions but also about how nurses felt about working autonomously in a patient's home.

One nurse pointed out that transferring respite care to the home:

1RN "threw up a lot of difficulties as well as personalities and contrasts and how nurses felt about it" 57

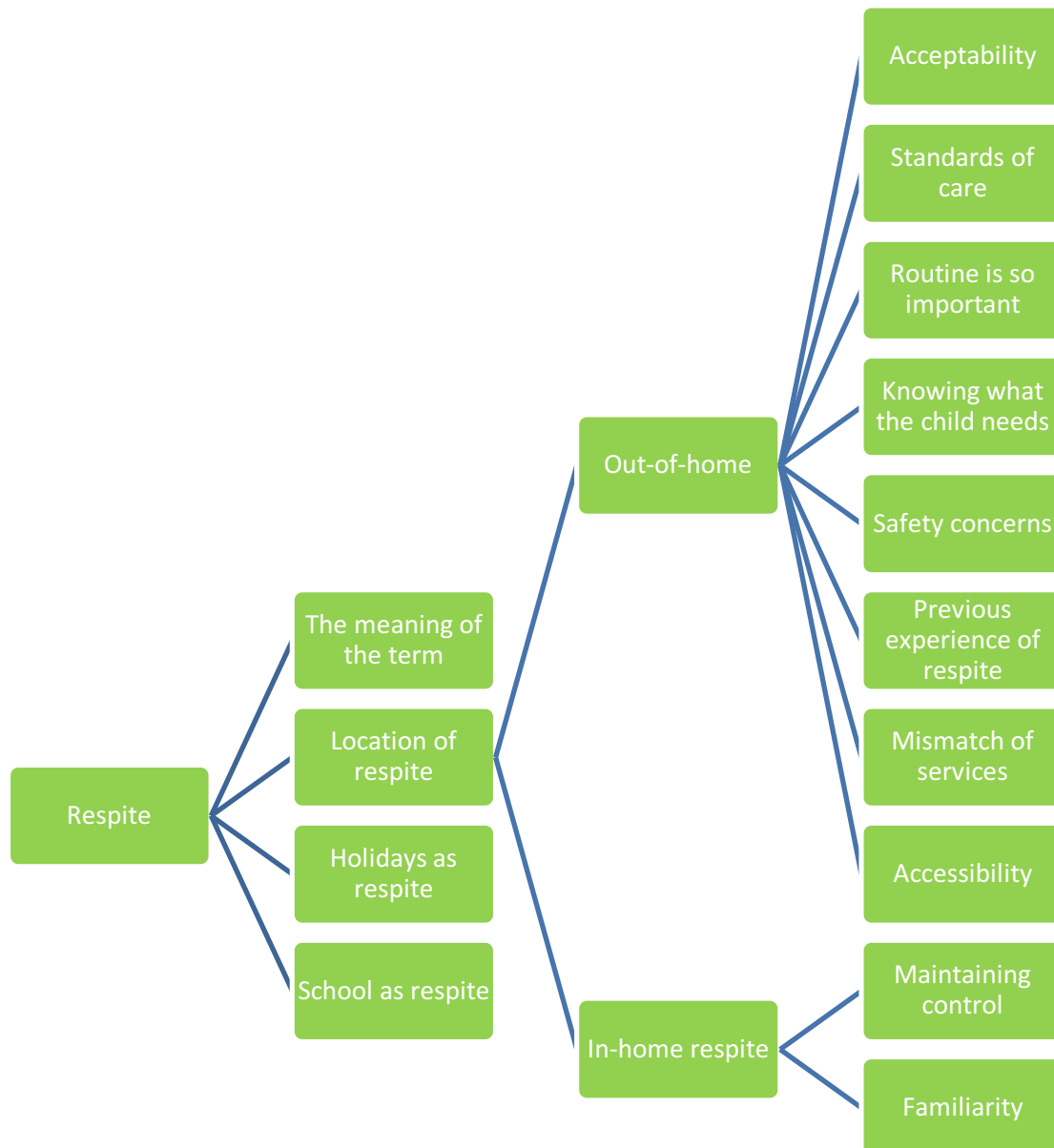
In many cases the task of finding suitable staff to care for their child was left to parents. The contentious issue of paying staff was also raised and revealed that parents are frequently given cash grants that they can pay directly to carers who were expected to deal with tax and insurance issues themselves. Some parents were not comfortable discussing issues related to payment.

Another issue for nursing staff working in the home of the child was that they were often isolated and received clinical instruction from parents rather than from their medical and nursing colleagues.

3RN "I'm not in contact with any of the medical team... (mother) tells me what happens and I take it from there" 145

3RN "I would prefer more support...you are on your own...you've no back-up, no nothing" 245

6.5.3 Sub-theme 3: Respite



The essence of this research is the exploration of the meaning of respite to the parents of children with life-limiting conditions. Parents described what respite meant to them and depicted their involvement in initiating and accepting services for their child. All parents expressed a preference for in-respite yet recognised the importance of having a variety of options available. By describing their role in decision-making, parents identified the level of control this gave them regarding the utilisation and quality of the services provided. Parents were concerned regarding the quality of care and regarded maintenance of routine as a key issue. Previous experience of care outside of the home strongly influenced their opinion and utilisation of services including respite care. Parents reported wanting accessible services

that were matched to their child's specific care needs. The location of respite was important to parents.

6.5.3.3.1 The meaning of the term respite

Respite was explored from a family systems perspective, in detail with participants. This exploration encompasses the role of family and the wider community in meeting the respite needs of parents caring for a child with a life-limiting condition. Participants were explicitly asked about respite, what it meant to them; what type of respite they had been offered or used and also how often respite was available to them. Respite options including the location of respite care was also explored.

Parents of children in ACT category 4 in particular had unusually experienced respite care through the disability services. Whilst recognising the important and valuable role of respite for some parents one mother commented:

2MIV1 "I assume they would keep her over night like – but that is just not something that either of us want I mean it is for some people and it is just not for others... umm and I just feel that it is not for us "486

Other mothers describe their understanding of the term respite:

6MIV "Respite to me is getting a couple of hours to myself or whether it's on my own or whether it's myself and (my husband) or even (my son), it's just to be able to ...to sit down for an hour and know that someone is looking after her and that she's fine and that she's taken care of and that if she wants something that there's someone there minding her, that to me is, you know, even if it's only getting out for a walk, that to me is respite, you know and I know someone is there"982.

8MIV1 "I suppose respite would be, like that kind of where you can maybe go off out for a while, you know like for him to be minded like so you can go to, you know let's say for a few hours out to, even if it is to, you know meet somebody for a while or you know to go you know get your hair done"698.

9MIV1 "Respite is when I leave Max with somebody here or away"258

Parents of children other than ACT category 4 reported that they had never used respite services. Their mothers described respite in the following ways:

5MIV1 "Well respite I would always think of applying to somebody who is very, very physically disabled, who maybe would be in a wheelchair and wouldn't have the use of their arms or legs. And maybe every once a month or once every two months they go into a home for a weekend that's my, what I would think of as respite"540

The other mother commented:

7PIV" Well that's what I'm going to ask you, do you mean respite is put Grainne in somewhere for say 2 weeks to give me a rest, do you mean respite would be Grainne go away to some, like Local town for a week and stay there in that amusement place or whatever and everything paid for or the family goes with her say, what do you mean by respite?"405

Reflecting their own needs rather than their child's, other parents described how their 'break' as a result of respite was spent. This time away from their sick child inevitably involves some tasks related to caring such as shopping or trips to the pharmacy but also parents were able to identify activities that they undertook for themselves such as meeting friends or going to the hairdressers. All parents described spending their respite break as getting out of the home.

2MIV2 "my main thing is the gym, take that away from me and you might as well just take everything because that it my sanity..."141

As well as using the gym this mother also takes the opportunity to spend time with her other child:

2MIV1 "I would bring (her sister) somewhere maybe the park or just do stuff with her or maybe get some shopping in" 305

Other mothers described taking the opportunity of their child being cared for to do something for themselves:

3MIV "Respite is like the Saturday that I can get off to town with my sister or into town or whatever or we'd go for a pizza to town every couple of weeks for a couple of hours if he's well" 727

7M "Now...I would go and do my shopping in town. She has a mobile and if she feels unwell she'll ring me...I'd be away there maybe 3 hours at a time...if (she) felt unwell she would ring me... I would never be too far away from her" 187

Others describe it as the opportunity to be ‘normal’:

6MIV1 “we might go out for a meal...something normal” 582

Parents also reported spending respite time carrying out tasks associated with aspects of caring for their child:

9MIV1 “What I’m doing clean the house, go to shopping, go to collect some medicine for Max, go to doctor for new prescription, busy.”201

Seeking out what is available one mother commented:

5MIV1 “somebody who could come for a couple of hours once a week...that would be nice... it’s just really to have somebody who could sit in the house whilst you’re gone for a couple of hours” 773

Demonstrating the ‘Hawthorne Effect’, following my initial interview with this mother she thanked me for influencing her decision to apply for respite help:

5MIV2 “We applied for the respite care grant...and got it... it means... I can pay; my mother comes in now ...I didn’t like asking...she does 4 hours a week... it means... I’m going to the hairdressers ... meeting a friend for lunch...so mammy will be here ... it means I’m not worrying, rushing back.”103

Some mothers felt that they were not in need of respite at all:

4MIV “I don’t need break from my children...we always going together everywhere, so I don’t need exactly respite” 1513

Another commented:

9MIV2 “Last time we were in doctor in Children’s Hospital and they ask me, what about respite, still no, no, no.”112

Parents described the specific issues relating to the respite needs of adolescents with life-limiting conditions. Whilst parents are grateful for the opportunity for their child to avail of

respite the mothers of two teenagers in this research also acknowledged the need for their daughters' developing independence and allow them to decide for themselves. Two mothers described their experience of being offered respite:

7PIV "...we were offered ... to go for a week, the family there in the summer time when she was younger but I put it to Grainne and Grainne didn't want it, so there was no use in me taking Grainne somewhere where she didn't want, she didn't want to go, maybe again she wasn't feeling just herself to go to it so we just said no (to nurse), we'll let it be, you know she gave you a week to think on it, you phoned her up and no she didn't want to go. Grainne would rather just go out say for the day and back again in the wheelchair with us or whatever, that's the only way I would find Grainne being happy... her own bed at night 422

Undeterred the nurse offered again:

7M "lately (nurse) did say....there's a place...she can go for a week...bring me or friends...Grainne wasn't interested...no way, she didn't want it...she...just loves being around home that's the way Grainne is" 242

Another mother commented:

5MIV1 (offer of a family break in a respite centre) "...we haven't ever been down there...Emma wouldn't go...she doesn't want to be seen as different...you see sick kids everywhere...I don't want to be surrounded by that" 658

5MIV2 "it just seems too happy-clappy to me ... I just wouldn't feel comfortable and I would be dreading going."313

These quotes demonstrate the need to consider the unique respite needs of adolescents.

6.5.3.3.2 Location of respite

Broadly respite care is provided in one of two locations, either out-of-home or in-home. Within each of these locations there are a number of factors which influence parent's utilisation of services.

Out of home respite

All participants had been offered some form of out-of-home respite, some had experienced such services and yet only one child regularly attended a residential respite centre on a regular basis.

Acceptability

In this study parents and other participants described the rationale for the utilisation of out-of-home respite. The acceptability of the respite services provided was a key factor in their decision-making. Despite limited if any experience of using out-of-home respite the majority of parents expressed the view that they would not utilise such services:

3M "it would have been down through the years, it would have been offered to us...I just wouldn't feel happy" 734

Similar sentiments were expressed by a mother caring for her infant son:

8MIV1 "no, no I don't think so, no, no...not to go anywhere...I'd hate it now" 789

Another mother felt accepting overnight respite reflected negatively on her parenting:

9MIV1 "I think that if I leave Max to ID hospital overnight or to someone I'm not good mother." 387

It is interesting to note that for one mother, utilising respite out of the home was unthinkable:

2MIV1 "the way I look at things there is people out there who use respite and that's up to them and that's their way for their family but the way I see my family is here I don't see my child in a respite place but that's not saying that I don't think it is right

for other people but you know ... I wouldn't judge someone else for using respite that's the way they are ...they mightened have as much support maybe with their family as I do..."1167

This quote powerfully demonstrates this mother's need for control over the care of her child – limiting conditions confirms that to her she is best placed to provide care for her child in the family home and as part of her family.

Standards of care

Parents voiced concerns regarding the standard of care that out-of-home respite centres were able to provide and whether this would match the level of care that they provided at home.

2MIV1 "I just really feel that when she goes somewhere else that she won't get the same care" 504

Other parents were concerned that their child may die whilst in the respite unit away from them.

1MIV1 "we didn't want to leave her because I thought what if she dies now in those 3 hours" 141

Routine is so important

Some participants in my research cited the need for familiarity as a reason for not using out-of-home respite and stressed that the child was most comfortable and happy at home with their family.

2MIV2 "I honestly believe Aisling would go downhill in a huge way....not through negligence...just she loves being at home...she just likes calm, in her own house and that's it" 269

Others commented:

3RC "Patrick loves his home, he likes his own surroundings" 86

Familiarity was viewed as an important factor by parents both in terms of surroundings and carers.

3RN “for simple reason that they wouldn't know anything about him, they wouldn't know him and what if he took these turns during the night” 189

The disruption and disregard for routine was an issue for parents who stressed how important it was for their child:

1MIV1 “feeding times were not important...we wanted respite to be continuation of the home ... We still have a huge problem with handing her over because we know that routine is so important for Molly that is you don't give her everything on time then she will suffer” 312

Not all of the reasons for choosing not to use respite were related to the care of the child. Often the child was the focus of family life and parents expressed a wish to keep their child at home as this made them happier.

1P (when daughter in respite) “we were lost without her, we had nothing to do”66

Another participant commented of one mother:

3RN “(his mother) is happier when she can see him” 192

One mother clearly stated her preference for home even if this meant having carers in the house:

2MIV1 “I don't mind someone coming in to my home and minding Aisling but once ...she is somewhere else I don't like it”500

Interestingly one mother simply had difficulty in handing care over to others:

1MIV1 “we have a huge problem handing her over” 311

From the above quotes it is clear that parental preference is care for their child at home in familiar surroundings. Limiting disruption to the child and family routine is important to parents and is a way for them to maintain control of their situation. Parents demonstrate that it is difficult for them to relinquish the responsibility of caring to others as many feel that they have a unique understanding of their child and their care needs.

Knowing what the child needs

A major factor influencing the parent's uptake of respite out-of-the-home related to the quality of care provided by the respite centre. Parents were concerned about the standards of care provided and sought reassurance that the staff possessed the skills and ability to provide high quality care for their child. Parents also wanted to know the staff and for them to be familiar with the specific needs of their child. Parents raised concerns related to staff changes and continuity of care and the impact that this had on their child. These factors influenced their decisions regarding the suitability of the respite provided.

One child's aunt describes the importance of staff getting to know her nephew:

3A "it takes a while for all of them to get to know him and Patrick to get to like them too and know them so I'd say building up trust with some people, you know if he'd go in somewhere for a night it would be a big thing" 250

Another mother went as far as saying that unless the staff knew her child she would not use respite:

1MIV1 "(husband) and I would not send Molly into respite if the staff don't know her" 1143

Her rationale for this was that:

1MIV1 "regular staff...better for continuity" 872

Safety concerns

In this research parents expressed concerns for their children's safety including issues with other children resident in the respite unit.

2MIV1 "When she is not here...you can't relax, you're constantly wondering is she okay... if she was out of home I would constantly wonder is she okay" 702

An issue specifically mentioned by two participants was the importance of matching the children attending for respite with each other in order to ensure their safety and comfort:

1MIV1 “(in respite they would)... keep the room with (our child) locked to keep autistic children out from harming her...important that children going in are matched with (my child)l...see respite is very delicate because if there was a hair on her head harmed when she was there we would say oh were not sending her in next time” 305

6SN “you can’t put her in where there’s a group with challenging behaviour, active...throwing things...she can’t cope with loud noises and she gets upset” 391

Previous experience of respite

Where parents had previous experience, either positive or negative, of using out-of-home respite this seemed to impact on their views on whether they would consider using it again. When parents had a negative experience of a respite unit they were adamant that they would never use the service again and also wanted to tell others. Some families had out-of-home respite care tailored specifically to meet their child’s express needs. When parents had no previous experience of out-of-home care and could think about it hypothetically they were more accepting of its value.

7M “I suppose...if (our child) was in a state if she didn’t really know maybe who was with her...and you needed the break, surely you’d be glad of it” (respite)

Even when parents had experience of using a respite centre for day care they were still reluctant to accept overnight care there.

6MIV1 “we do get respite outside the house which would be one day a month in a respite house...one Saturday per month... I just arrange overnight here, I wouldn't do it outside the home” 179

One family had a room exclusively for the use of their daughter in a local respite centre which they used only once in a year. They were grateful for this person-centered approach but also critical of the organisation feeling that they could better utilise this valuable and expensive resource.

1MIV1 “They have a room that only for (our child)...she is the only child in that room...painted pink...all her clothes are there...all her supplies...it is her siblings second home” 642

1MIV2 "I don't understand why they don't offer it to more families...I just feel there are other children that would benefit from using it as well" 79

Mismatch of services

In one specific case only, a teenage girl with cancer was discharged to a respite centre where the majority of other children had severe intellectual and physical disabilities. This mismatch of services was stressful for both the family and the healthcare staff providing her care. Both the parents and their child found the other residents behaviour upsetting:

4MIV "for children without mind this is very good place ...wrong place for children who understand...everything is perfect...food everything is great...not for child who understands" 833

Accessibility

Respite that was accessible and local to families was an important issue. Parents were unlikely to use services that required them to travel far from home. In one case parents described their use of a service two hours from their home:

1MIV1 "there was no respite in the area... we would sit in the car and wait 3 hours to pick her up... we didn't know what we were supposed to do...we just went through the motions of doing this because someone told us to do it ... many times we wouldn't leave for home and they would ring...we turned around and go back it depended on the staff" 216

In-home respite

In all nine cases the majority of the child's care was carried out by the family in their home. Parents all stated a clear preference for home as the location of choice to care for their child and also as their preferred location for respite. Having their child at home allowed parents to maintain higher levels of control, for the child there was a familiarity of being cared for at home and this also enhances the strong bond between home, the family and the child as part of both.

Maintaining control

For parents of children with life-limiting conditions maintaining a sense of control is important. Having respite services in the home allows parents to maintain a level of control

whilst essentially handing caring responsibility to others. Parents regularly reported their child not leaving home for example to go to school or respite if they were unwell, inferring that only they could provide care for their child in these circumstances.

As one mother commented:

1MIV1 "moving the service practically to home...that for us is a better break than going in. Over the last 6 months Molly has got much sicker and we have cancelled respite over and over again so we never get the break" 705

Another mother agreed:

6MIV1 "I prefer here (home), I always wanted her here and I think I'd rather have her here and have the nurse help here...it would always be home" 914

Another commented on the impact of moving her child to avail of respite:

2MIV1 "She doesn't like being disturbed she like her life to be easy to you know lie on her sofa or her bean bag...listen to a few stories she doesn't like you dragging her around the place...she hates it"709

2MIV1 "She loves being at home she likes her own surroundings and she likes her own things and I just really feel that when she goes somewhere else that she won't get the same care"506

Another mother commented on her rationale for preferring care at home:

6MIV1 "if they need me (night nurses) when she is here and the nurse is here it's different, you know if they need me, which one night she called me...it would be a different story...if she was in respite centre" 188

One parent who was a healthcare worker felt that although respite in the home was best for her child she found that the carers sought her advice and approval regarding care.

1P "...they would bump everything off us if she was sick...what will I give her you know, you don't really get a break like"113

1P "we get a break but there is someone in your home all the time"75

Familiarity

The familiarity with their home surroundings was reported by parents as being important to their child.

1MIV1 “(the child)is 100% better in her own home” 1293

One parent simply referred to home as her son’s sanctuary:

3M“he would always think that our home is Patrick’s sanctuary, you know that nothing bad can happen to him here and everybody is for his good” 30

6.5.3.3.3 Holidays as respite?

Participants were asked about holidays and whether they took their sick child with them or travelled without their child and whether this provided them with a break from the usual routine of caring:

Family holidays

Some families reported taking their sick child on holiday with them. Although it was not without stress, others felt a holiday was good for their sick child and went to huge efforts to get away.

2MIV1 “Aisling is well travelled she’s been to America...Turkey, Portugal where we go she goes... we are a family we like to go places together, it’s important that we have a holiday” 620

Others were reluctant to leave their child or felt that taking them on holiday would be too stressful:

3D“we tried a couple of times going places...but you'd need someone awake all night looking after Patrick” 53

Holidays without their child

Some families chose to have their child cared for and take a holiday without them. One family reported only taking holidays in Ireland

1MIV2 “we have always felt bad about her like...we always feel bad on family holidays if she is not with us and the kids feel...they’d say wouldn’t it be lovely if Molly was down here as well even though it would be totally impractical to have her” 254

When I interviewed the parents eighteen months later they said:

1P “I’m not being flippant I’d be serious like, I’d hope nothing will happen to her when we are gone (on holiday)...if it did I think I wouldn’t want her to stay another day because each day she suffers like. You know what I mean, it’s not that I want her to linger is she is very sick for the sake of me being with her like” 315

1P “(going to France) I just hope she is ok when we come back...it’s a chance you have to take...I’d hate anything to happen to her when we are gone but we have to live our lives...we have to live, we have to go on holiday and we have to live” 282

Other parents felt unable to leave their child to go on a holiday:

6MIV1 “I don’t have holidays....I wouldn’t put her in for a week anywhere...my idea is she’s part of the family and if we were going anywhere she’s coming” 201

Another mother simply commented:

7MD “we wouldn’t be the holiday type” 554

For one family a trip back to their country of origin with their daughter was a holiday but was interrupted by the father having to return to Ireland to make his social welfare claim:

4VB “last year they all went over there (Romania) for 6 weeks...that was such a welcome break for the whole family...Pavel had to sign on for his social welfare claim, fly back to sign on every week” 396

6.5.3.3.4 School as respite?

Although not always directly associated with respite, in some cases school was a source of a break to the parents. One mother described sending her eleven year old son to the local national school with a Bi-pap ventilator.

3M “don’t think the school fully realised that it’s a ventilator...the same school as Niall (his brother)...he loves the stimulation of other children” 462

And describes his first day at school, in preparation the teacher spoke to the other children in the class telling them that a special boy was coming.

3M “there’s a special boy coming...they all came over...I think they expected he could fly...can he walk? I said no, he can’t, can he talk? No, can he read? No, can he write? No, they were all losing interest in him quickly...Patrick can...laugh and he can smile and he can sleep and he can eat...he was just part of the group” 478

Molly also attended the local national school as her parents felt there was a stigma attached to her being collected on a special bus:

1MIV1 “didn’t want special bus...we wanted her not to be seen as the little child going off on the special bus and the people in the community not knowing who she was as a person” 516

For some children in this research school was seen as an integral part of their lives. In one case the child attended a school for children with severe and profound disability and there were nurses on site. The school nurses were very familiar with one child who attends school most days.

6RC “she loves school, you’d know by her, she loves it, she’s so well looked after” 110

One mother reported being on-call when her child is in school. When he is well enough Max also attends a special school on the site of a hospital for people with intellectual disabilities.

9MIV1 “Yes I have little rest now. When he’s in school but he’s very often sick and he can’t go to school...Sometimes he is grumpy and crying and I need to collect him from school ... on a bad day”385

Other parents did not have such positive experiences of school for their child.

2MIV1 “I used to drop her and collect her now there is a bus service that they come and collect the kids and bring them to school but I preferred dropping (her) to school and picking her up cause the day would have been too long and they could be on a bus a fair bit by the time they got to school so to make things easier on her I dropped and picked her up ...plus I would normally pick her up earlier...the day would be too long...they could be on the bus a fair bit...I would never leave her in school all day because she just wasn't able... it's a special needs school and there's a respite part”413

The same mother also reported not sending her child to school in order to prevent her exposure to infection:

2MIV1 “you are very housebound when it comes to (her) because if you are bringing her in and out she is going to pick up stuff...it seems like we mollycoddle her but it is the best way for her because we are limiting her bugs...we are limiting her time in hospital – since we have taken Aisling out of school...trips in to hospital have gone down dramatically”456

In this research three children had an Special Needs Assistant (SNA) and reported differing experiences. In one case the help that his SNA provided was valued by his mother.

3M “All the SNAs all love him...I bring him in at about 2 for ½ an hour...for his own sake that he is not stuck with mammy all the time” 497

Two of the children receiving the assistance of an SNA were adolescents. In one the experience of having a SNA was isolating and upsetting. She found that people spoke through the SNA to her instead of directly speaking to her. Coupled with her poor stability and increasingly poor sight she felt socially segregated. Eventually due to her deteriorating condition coupled with depression Emma opted for home tuition. Her mother commented that it was a big problem:

5MIV2 “it was just getting too much for her (school) it was making her miserable... if I had my choice of SNA's it wouldn't have been her...Emma didn't want an SNA... She was too bossy... the other problem was people speaking through the SNA to her...it was getting to the stage where the girls were asking her...questions to Emma...which really hurt her” 167

Causing social isolation:

5MIV1 “she felt...very segregated when she got her (SNA)...socially she felt she didn't belong”359

5VB “you don't want this person trailing around after you having to walk her from class to class, when your mates are all chatting”263

Magda's experience of her SNA is that she is 'great' and allows her the time and space that she needs to be with her friends.

4P “SNA is great...she don't use that wheelchair at all...on break, she can go on the crutch....other children they can see her walking, they understand she's not only sitting on a wheelchair...they didn't know about Magda's brain tumour...they didn't know reason why she's in wheelchair” 128

Although the rural and isolated location of one teenager's home resulted in her availing of home schooling this was also considered a better option by her parents. Her frail medical condition meant that Grainne was susceptible to infection and home schooling was seen as minimizing the risk. The converse to this is the impact that not attending school has on the ability of the child to socialize and meet peers.

7MD “we did home schooling...we thought if we sent her into school...she's going to pick up all infections... she was dead happy at that because she felt she wouldn't be able to cope with nothing else... we thought we were doing the right thing but sometimes I would think back...maybe I done the wrong thing... maybe she would have had more friends... you were doing whatever you thought was right for her”228

6.5.3.4 Summary of theme 2: The care experience

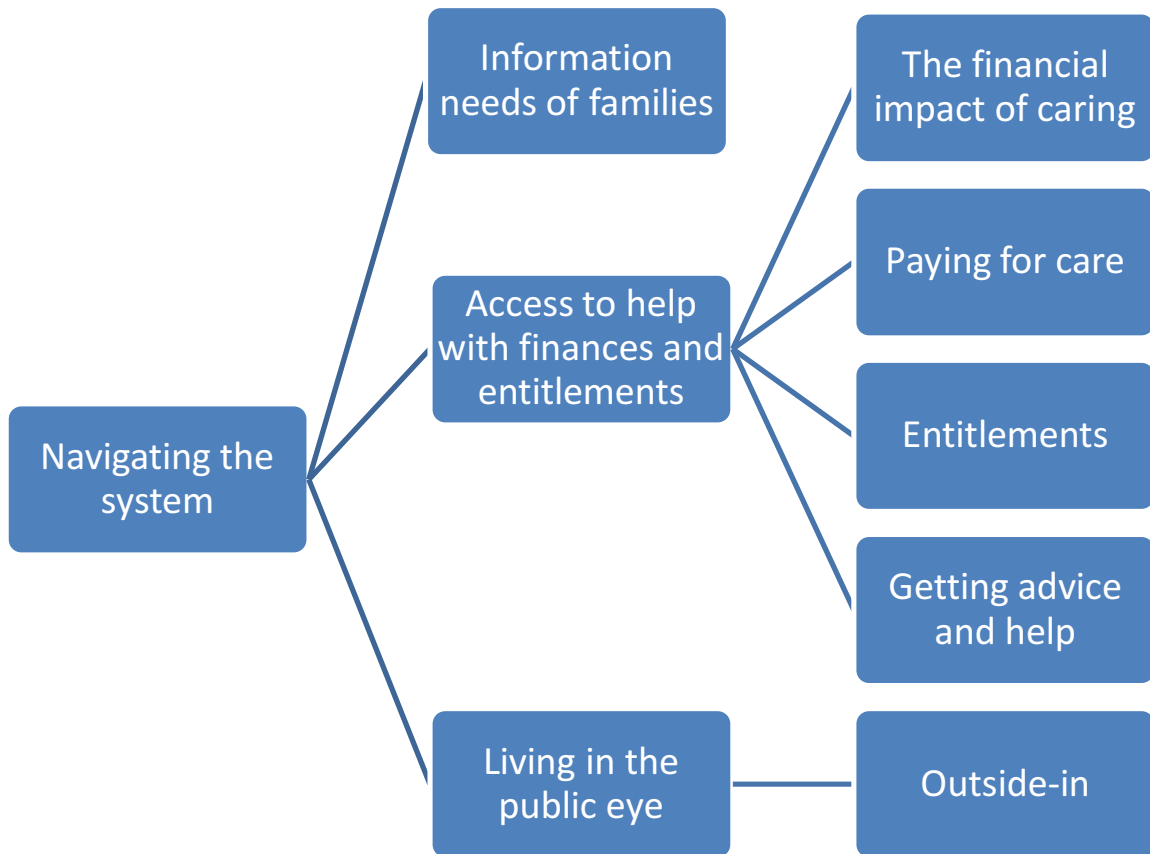
It is clear that parent's previous experiences of care for their child have an impact on their utilisation of services for their child with a life-limiting condition such as respite. Experiences of care in maternity and acute hospitals early in their child's illness trajectory undoubtedly have an impact on their view of care outside of the home environment. Such is their anxiety over the standards of care available, parents report not leaving their child alone in hospital requiring usually a parent to stay with the child. This impacts across the family system where reorganisation is required in order to provide care for well siblings and spouses.

Home is the location of choice for all parents for the care of their child. Parents take on the role of carer for their child and acquire and develop the necessary skills to care for their child. Over time as their confidence increases parents often become 'expert' in meeting their child's care needs. Providing high quality care for their child increases expectations of others and a lack of trust in their ability to provide this care resulted in parents demonstrating a need to maintain control of their child's care. Family composition varied between respondents. Those with teenage children had differing needs to others. The immediate family was always impacted upon by the care of the sick child in the family and siblings were reported to require special attention from their parents. Extended family played a part in meeting the needs of the parents and child.

All families had been offered respite over the course of their child's illness. Children in ACT category 4 were more likely to receive respite than those with other conditions. The respite needs of teenagers require special consideration. Respite at home was always considered to be preferable by parents. Respite out of the home was hampered by poor parental perception of services. Factors influencing parents' decisions to utilise respite included the maintenance of their child's routine, the standards of care, careful matching of services to the child's needs, safety concerns and primarily acceptability to parents.

6.5.4 Theme 3: Navigating the system

Figure: Theme Three: Navigating the system



6.5.4.1 Introduction

Navigating the system refers to the process that the parents of children with life-limiting conditions are required to undertake in order to access services and support in caring for their child. For the majority of children diagnosed with a life-limiting condition these are present at birth. Parents are often ill-prepared for the task of care-giving to a child with complex care needs and the huge challenges that this brings. At this time, as caring for a child with a life-limiting condition impacts on the family system at all levels, families are required to look outside of their immediate family structure for support in the often unfamiliar wider family system.

The new reality with which the family is faced when their child is diagnosed with a life-limiting condition often includes increased attention on them as a unit; their coping and caring are brought under scrutiny and without choice they can find themselves living in the public eye. This Theme is divided into two further sub-themes:

- Sub-theme 1 - Information needs of families
- Sub- theme 2 - Living in the public eye

One of these challenges is knowing how to ensure their child receives the care and services that they need through learning how the healthcare system works. These challenges include: information regarding diagnosis and prognosis; accessing the information they need; finding a way to communicate with various healthcare professionals; evaluating the practical aspects of life such as the family's financial situation and parent's source of income (work) and facing their reality as life as a carer.

6.5.4.2 Sub theme 3: Information needs of families

Some participants described where and how they got information: Parent participants highlighted some of the issues that they experienced with trying to get information about their child's condition. Information was not always easily obtained and parents reported using various elements of the wider family system to access this information from extended family members, healthcare professionals and voluntary bodies.

As one parent commented:

1MIV1 – “in hospital ...the information doesn’t get passed on to the person who needs it” 119

Another concurred:

6MIV1 “no one...they don’t tell you anything, absolutely nothing ...you start off in total limbo, you know no one tells you absolutely nothing” 830

The mother of a girl with a brain tumour felt that she did not receive adequate information:

4MIV “if you are rich if you have information, without money, without everything...without information... if you have lucky you heard somewhere – this is wrong” 610

As non-Irish nationals the family also relied on a voluntary organisation to help them:

4VB “everything had been literally turned on its head...there was nobody there that was able to actually guide them through the Irish system...” 47

One father displayed his mistrust of information given to him:

3D “yeah, we wouldn’t take it as gospel anything they’d tell us anyway” 554

6.5.4.3 Sub theme 3: Access to help with finances and entitlements

For parents accessing help with their finances and finding out about entitlements and benefits for their child with a life-limiting condition, was not always straightforward. Financial issues were of considerable concern to some participants. Families often reported that both parents had worked prior to the diagnosis of a life-limiting condition in their child and therefore not only did they have to cope with the stress and trauma of becoming a full-time carer, they also reported concerns regarding the impact on their finances.

Financial issues which arose broadly fit into four areas:

1. Financial impact of caring

2. Paying for care
3. Entitlements
4. Getting advice and help

1. Financial impact of caring

The financial impact of caring for a child with a life-limiting condition was reported by all participants in this research.

4P “children were never...worry them...hope they never feel...we can't buy for them...they don't want a lot” 701

Others recalled how their financial situation had changed with time.

1MIV1 “Good Jesus it was dreadful, we hardly had curtains on the windows like we were just starting out and we thought we were never going to get out of this one...if you have money worries on top of a sick child it is really difficult like we have come a long way” 1449

Another mother told how her GP had encouraged her to seek financial recompense through the legal system for the birth injury her son had suffered:

3M “my own GP...saying...you should bring a case because this should not have happened...Catholic idea that you're dealt your cards and you accept that it's God's will...he said if someone crashed...and your child was brain damaged would you not bring a case?...he said that's why doctors take insurance” 687

In all nine cases mothers had assumed the role of primary carer. Five had given up work in order to fulfil this role. Frequent hospitalization of their children and attendance at out-patient appointments meant that being able to commit to work was challenging.

2MIV1 “when (the child) would be in hospital so you couldn't commit yourself to a job because you wouldn't know when you could have to leave...you couldn't really give yourself to a job properly” 864

Another mother gave up work after the birth of her second son who also had special needs and when both children were frequently required to attend hospital appointments:

3M "I gave up work when (son) was diagnosed with autism... there was always appointments and stuff..." 588

Another mother also cited hospital appointments as a reason for no longer being able to work.

5MIV1 "she's going to have more hospital appointments now so the best thing was just to give up work"332

In the seven cases where fathers were working outside of the home they were all available should their child's condition require it.

2D " I just made them aware of our situation...they're fine...never any problem with hospital visits or appointments, I can get time off or if I need to come down I can ...the job...it's a lot tougher...sometimes it's a break, you would consider it a break but other times not"736

One father reported his change in attitude to work once his child was diagnosed with a life-limiting condition:

3D "I was a fierce worrier about work...it gives you a different view on what's important"366

He also commented on the compassion shown by his employer:

3D "They're great at work....I do feel embarrassed at times that I have to take time off but it can't be helped" 396

Work took on special meaning to one parent participant. She did not work initially after the birth of her child with profound disability but gradually over the 13 years of her daughter's life she resumed her career. Using the services of a respite carer to provide care for her daughter whilst she worked, she considered her job as providing her with a break from the routine of caring and as such was a type of respite:

1MIV1 "I didn't work for a long time...I tried to work ...but it was just so stressful... I said...I absolutely can't commit to a permanent job...because maybe (my child) that day would have been dying you know she could have been critical...Work was a complete break for me...you put on your uniform and you became the person you used

to be...you could have been up all the night before but I just found it didn't matter you just went in there and just put on the face...it was just brilliant" 448

Her husband also opted to change career and during my research took a post in healthcare, influenced by his role in caring for his daughter with a life-limiting condition.

1P "I would look at things an awful lot differently than other people...when you have Molly you understand, you have more experience" 252

In two cases the families were immigrants to Ireland from Eastern Europe. One mother was an unemployed single parent and was a full-time carer for her eight year old son. Heaton (2005) found that time spent caring resulted in limited opportunities for lone parents to socialise and that in particular mothers from ethnic minority groups experienced social isolation with no employment and little social life (Heaton *et al.* 2005).

The other family initially set up and ran a business in Ireland but when their daughter was diagnosed with a brain tumour they were both advised to give up work in order for their daughter to receive the free care she needed for her brain tumour.

4MIV "they say (to the child's father) you have to be without job because you need medical card... (he) was security man of the nights...he was driverhe had 2 jobs" 500

Once both parents had given up work they found the costs associated with her treatment still had a huge impact on the family finances. Some benefits and allowances were not payable when their child was hospitalized and an extra cost at this time was fuel and parking the car at the hospital.

4VB "parking in the hospital alone was €80 every week petrol going up and down...to the city...it's a big car...guzzles" 424

Assistance from a coordinator from a voluntary organisation helped this family and they were re-housed and financial assistance from the voluntary organisation paid for adaptations to their home such as a stair lift.

4VB "I came as an extra person in the family....to coordinate...they have had to run, the social welfare...filling in forms...carers allowance, domiciliary care allowance...there was months of a wait" 211

2. Paying for care

Some organisations providing care for children with life-limiting conditions provide support in the form of a grant which parents can use to pay staff for caring for their child. This in effect makes the parents an employer. As one parent commented:

1MIV1 payments are “off the record... very grey area... parents as employers” 543

Despite having money to pay for staff, the same mother went on to describe the challenges of trying to find help:

1MIV1 “neighbours ringing up...I didn’t know that was the job, I’m not interested and then when you are meeting them locally ...they can’t look you in the eye like it’s very awkward... we have opened our house to so many people and our children and it’s very difficult” 1179

Another found the system simple to use commenting that:

8MIV1 “you...basically organise it yourself...put the money into your accounts and then you pay them”725

Another parent suggested that there may be other motives for this method of finding help:

6MIV1 “when (the respite carer) is off...I don’t have anybody...they prefer you to pick someone so I suppose if anything goes wrong it’s your own fault...I don’t know if I’d like to go looking for someone else”717

Another commented on how she had found a nurse herself to provide care:

2MIV1 “we found (her) ourselves through a nursing agency”983

3. Entitlements

An area of concern for many parents was the lack of information available to them regarding their entitlements and financial assistance for caring for their child.

One parent described struggling to pay for care related items for her daughter:

1MIV1 “we weren’t informed of entitlements like even we were paying for all of her drugs and we only had one income...one day I arrived into a different pharmacy and

they said like why are you paying £60 for a bottle of tagmet and I said because I have to the child needs it and she said you don't have to – your child would get a medical card but this information seems to take forever to get to the person who needs it” 150

The same parent also laments not being told about a service providing care for children with life-limiting conditions:

1MIV1 “...weren't told to us all Molly's entitlements like her medical card that I could have got, carers benefit – instead we struggled here financially...for years...we thought Jesus there is no end to this...nobody told us about domiciliary care allowance...I just wished there was someone to sort ...like sit down with the family who go home and with a sick child and say these are the things we need to look at”824

Another mother stresses the importance of having information in order to care for your child;

4MIV “if you are rich if you have information, without money, without everything...without information... when your child in hospital you are not able to take carer allowance ... I am without work; we don't have money for life ...you are without money completely” 665

A single mother from Eastern Europe had been unable to access the financial help she required:

9MIV1 “I have problem with my claims...we don't have money”

9MIV1 “I am still waiting for one parent allowance, I apply last year”

4. Getting advice and help

Parents describe the challenges of getting advice and help they need in order for them to navigate the healthcare system and how difficult it is to access this information.

6MIV1 “HSE ringing them...are you entitled to this, that and the other and its always well it's not this department...it's not me...so and so is on holidays....so and so is on a day off and that's all you get...my cousin gave me a book about entitlements for people with disabilities ... extremely annoying within the HSE...too many people...should be done by one person... (hospital) had a lot of leaflets...I would have picked up a lot out there... if that was...given to the parents...what they need....who to ring...where to go for information...make things a lot easier”851

In many cases parents identified a person outside of their family that was able to help them with the task of navigating the system. It was often reported by parents that this key person helped them with many issues including financial issues and entitlements. Some were HSE employees such as Public Health Nurses.

2PHN “she knows exactly where to get things from and if she has a problem she rings me” 197

Others were clinical nurse specialists:

7CNS “sometimes you have to jump through hoops to get what you are entitled to – so just trying to ease that burden” 305

However the majority worked for voluntary organisations and voluntary service providers. In most cases they were not associated with the provision of palliative care for children and yet they played a vital role in supporting these families:

IRC “I use that as a grant...giving the family money for a babysitter ... it’s all about innovation and creative....there is not structure” 129

4VB “I helped them around letters...banks...I can support and guide them ... advocate for the family” 38

In this case the key person was from an organisation unfamiliar with palliative care but was able to help the family navigate the system:

4VB “everything had been literally turned on its head...there was nobody there that was able to actually guide them through the Irish system...total despair when I met them on that day and ever since...coordinating and linking people into services that are relevant to them...working around housing issues...big issue...private rented house...wasn’t accessible...I sent off letters of support” 83

One key person linking services and providing support has no palliative care experience but helped with financial and social issues

5VB “(the mother) will contact me if there’s...issues...benefits, entitlements”482

6.5.4.4 Sub-theme 3: Living in the public eye

Caring for a child with a life-limiting condition brings with it attention from extended family, friends and the wider community. In this research as the family system adjusted to meet the needs of the sick child, the attention this brought with it was not always welcome.

One parent described why she was reluctant to send her daughter to the special school and instead opted for the local national school:

1MIV1 “didn’t want special bus...we wanted her not to be seen as the little child going off on the special bus and the people in the community not knowing who she was as a person” 516

The respite nurse caring for this same child describes living in a small rural community that:

1RN “sometimes people say too much...people forget what they need to know when they are working in such a small community...we don’t need to know everything” 233

Patrick’s family also describes the challenges of living in a small rural community:

3M “An awful lot of people who would know Patrick...I don’t bring him to mass now very often...I bring him into Tesco...for walks and that so people would see him...the mask puts people off... I suppose you don’t see the child, you see the mask...some people wouldn’t even know the extent I’d say of his problems...one day...I had Patrick with me in the bank, in his chair...a man said to me...you did well (ward of court settlement)...you’d think we were after winning a prize in a raffle” 280

And how their private life and financial affairs became public which was stressful for them:

3M “We got this letter and was so upset about it...it said we have learned from media reports that Patrick has received a substantial sum of money... the Court case was settled the day of his 7th birthday” 315

Whilst it is often mooted that a small close-knit community can provide support, participants in my research also pointed out some of the disadvantages to living in a small and familiar community. One mother felt unable to avail of the home help services:

5MIV2 “There are some home help, I think is what you call it. I know a couple of people that do it and I wouldn’t be interested in having them coming in...Too close for comfort, I feel everyone would know your business...it’s a small village.”415

A worker from a voluntary organisation involved in her daughter’s care supported this view:

5VB “it is a small village and I know the mentality is small, everybody likes to know everybody else’s business.”628

Participants were also concerned about what other members of their community would think and this influenced some of the care decisions that they made regarding their child.

1MIV2 “immediate reaction (to respite) – no...What would other people think...did what I was told that was what I should do but didn’t want to do it” 183

In one case, concern regarding what others might think deterred a family from utilising the services of a wish granting organisation in case people thought that they were benefiting from their daughter’s brain tumour:

4P “feeling was like I don’t want them thinking I use (her daughter’s) illness...sick for happy” (re: Make-a-wish)

Outside-in

Parents described those from outside of their immediate family in the Exosystem and Mesosystem levels as not understanding their reality; viewing them from the outside in. Some parents felt that others were not able to understand their everyday reality of caring for a sick child at home. One mother described how she:

1MIV1 “always appear to be coping very well from the outside” 378

Another mother caring for her teenage daughter commented:

5MIV1 “I just feel nobody has a clue, not even my mother what it like to be here every day...to actually live the life of someone who has a sick child...people don’t know what

it's like...they can pity you and give you sympathy...at the end of the day they don't know until it happens to them"681

6.5.4.5 Summary of theme three – Navigating the system

For parents caring for a child with a life-limiting condition the ability to navigate the healthcare system is a prerequisite to accessing many services. A dearth of readily available information about their child's condition resulted in many parents accessing information by circuitous routes such as through friends, family members, voluntary organisations and the media. Parents were keen to share their experiences with others and some joined support groups.

Parents reported financial struggles directly related to the care of their child and noted the challenges of accessing information regarding allowances and entitlements. Several parents had received the assistance of voluntary organisations. Some had provided grants whilst others provided assistance to parents and gave help and advice regarding their rights and entitlements.

By having a child with a life-limiting condition parents felt that they were thrust into the public eye. Parents reported their previously private life was exposed through carers in the home and through curiosity from the local community.

6.6 Summary of Chapter 6

In this chapter findings of this research have been presented in four distinct yet interconnecting sections. Firstly demographic information regarding the participants was presented. Section two focused on the nine participant families and presented each individual case story. The case stories were constructed using multiple sources of data and are presented to demonstrate the interlinking and interconnecting parts of the family system as they function to meet the respite needs of children with life-limiting conditions and their families. The third section provided a cross-case comparison the themes identified provide the framework for the presentation of interview findings in the fourth section. Comprehensive findings from interview data are presented under three themes: Living with uncertainty, The care experience with respite as a sub-theme and Navigating the system. These findings will be discussed in the following chapter.

CHAPTER 7: DISCUSSION

7.1 Introduction

The primary aim of this research study was to explore the factors identified by parents of children with life-limiting conditions which influenced their respite needs and experiences. Using the theoretical lens of the family systems theory and relevant literature this research provides a uniquely Irish perspective of respite service delivery from the perspective of parents. In fulfilling the aims of this research both the elements of the respite experiences that are important to parents and the barriers and facilitators to the delivery of respite care are identified and explored.

The confluence of perspectives provided by the utilisation of case study methodology provided an in-depth understanding of the complex and interconnected factors that influence parents' respite needs and experiences for their child with a life-limiting condition requiring palliative care. Viewed from differing perspectives, each original, individual case study provided insight into aspects of respite. Cross-case comparison confirms that the preference of the majority of parents is to care for their child at home with support, and identifies many commonalities in parent's experiences.

Viewed through the theoretical lens of the family systems theory (Lewis & Prescott 2006), findings of this case study research provides unique insight into the real world context of caring for a child with a life-limiting condition from both the perspective of parents and those involved in the provision of respite. This study unravels the complex and diverse ways in which parents are able to access and utilise respite in order to meet their specific needs. A chronological format of the findings is presented as they relate to each part of the family system.

7.2 Respite care at the Microsystem of the family system

7.2.1 Introduction

In this study the impact on the family of caring for a child with a life-limiting condition was life-changing for all members of the immediate family unit who often struggled to rebalance in light of their new reality. The challenges faced by the family in the Microsystem ranged from changed family routines to the turmoil of dealing with near-death experiences of a family member. Where the trajectory of the child's condition and the demands for care were often unknown, family functioning was tested as they struggled to rebalance and establish a new 'normal'. This following section will discuss the findings of this study in relation to

parent's decisions and choices regarding the respite needs and experiences and how they navigate their way through the turmoil that caring for a child with a life-limiting condition can create in the Microsystem.

7.2.2 The beginning – getting a diagnosis

A key moment in each family's experience of caring for a child with a life-limiting condition is the time of their child's diagnosis. The range of conditions in children that are potentially life-limiting is vast (ACT 2009b; Hain *et al.* 2012) and therefore a definitive diagnosis is often difficult. Parents reported a range of emotions such as shock, numbness, and ultimately relief when their child survived. The lack of a definitive diagnosis often exacerbated their stress and anxiety particularly when complex tests and investigation were required. Such uncertainty about diagnosis has been found to be a burdensome and lengthy process in previous research with delays for some neurodegenerative conditions taking years (Steele 2000; Redmond & Richardson 2003; Monterosso *et al.* 2007b). Diagnosis can also be stressful and guilt-laden for parents particularly if the child's condition is genetic (Hodgkinson & Lester 2002).

A dichotomy was seen between children born with a life-limiting condition and otherwise healthy children who developed life-limiting conditions during the course of childhood. Parental stress and anxiety around the diagnosis of a life-limiting condition in their otherwise healthy child was common and often preceded by periods of ill-health misdiagnosis and misunderstanding. Similar findings are reported in previous research reporting on bereaved parents experiences of care for their child with an incurable condition (While *et al.* 1996; Knapp & Contro 2009) and this was found to impact negatively on parents' trust in the healthcare system's ability to care for their child.

For parents, the way in which their child's diagnosis was delivered left a lasting impact with parents able to recall how and by whom information was provided. Insensitivities at this time were commonly reported and in particular hurtful comments had a lasting impact; such findings confirm those of earlier research regarding breaking bad news in paediatrics (Farrell *et al.* 2001). The legacy of such interactions has also been demonstrated to lead to profound emotional distress and ultimately complicated grief (Contro *et al.* 2002). Dissatisfaction with communication by healthcare professionals in general is not uncommon (Farrell *et al.* 2001; Lewis & Prescott 2006) and recommendations have been made in order to improve the way that clinicians provide information such as diagnosis (Levetown 2008).

In this research, parents identified that they valued clear and honest communication with empathic healthcare professionals. Similar findings have been demonstrated elsewhere where parents valued bad news being broken by a person known to them, who allowed them to speak, gave them accurate information, demonstrated a sensitive, caring attitude and essentially left them with hope even if this was not realistic (Contro *et al.* 2002; Steele 2002; Levetown 2008; Knapp & Contro 2009) and this applied even when the issues under discussion were painful and upsetting (Contro *et al.* 2002; Levetown 2008).

7.2.3 Prognosis – defying the odds

Arguably one of the most difficult conversations for clinicians to have is telling parents their child has a life-limiting condition and a limited prognosis. Yet clearly illuminated in the findings of this research is the prominence of such information from a parental perspective. Decision-making often hinges on prognosis and yet the accuracy of this information is often called into question as the child experiences multiple episodes of sometimes life-threatening ill-health and yet survives. Prognosis refers to duration of life whilst also encompassing discussions regarding cure and longevity (Mack & Liben 2012) and if done well can lead to acceptance, understanding and adjustment (Fallowfield & Jenkins 2004). This research demonstrates that following an initial drive to secure a prognosis from often-reluctant clinicians, inaccurate prognostication frequently resulted in parental cynicism, disbelief and mistrust. The act of seeking a prognosis reflects parents' need to foresee what the future holds for their child (Fisher & Goodley 2007); however, it was clearly evident in this research that it was often not possible to predict prognosis with any accuracy and yet parents often based important decisions and care choices on the information that they were given.

One of the distinguishing features of children's palliative care is an uncertain disease trajectory (Steele 2000; Wolfe *et al.* 2000). This was clearly demonstrated in this research where the majority of children had outlived initial and subsequent prognoses by not only months but, in most cases, years. This was significant finding in this research where parents considering utilisation of respite services often declined services in the belief that their child's prognosis was short and their time with their child limited.

In this research not all parents were told directly that their child had a life-limiting condition. Although Paedobaptism is common practice in the Catholic Church in Ireland there is a

cultural understanding of the importance of a child being baptised if they are not expected to live. The Catholic doctrine advocates that ‘*if the infant is in danger of death, it is to be baptised without delay*’ (Catholic Church 1983). Whilst the use of euphemisms is not always clear and can prevent hope (Hagerty *et al.* 2005) this research confirmed that when told by healthcare professionals to have their child baptised, culturally Irish Catholic parents euphemistically understood this to indicate their child’s limited prognosis. This clearly demonstrated the interplay between culture in the Macrosystem and the impact on family functioning in the Microsystem.

7.2.4 Cycle of uncertainty

Demonstrated in this research, despite best efforts of clinicians to provide accurate information, prognosis was frequently outlived. Parents reported a cyclical process of receiving a prognosis, followed by an episode of life-threatening ill –health, followed by survival but frequently partial rather than full recovery, leading them to further hope. Findings are illustrated in the ‘Cycle of uncertainty’ (Figure 27). This cycle occurred at any stage of illness and with varying lengths of time between cycles. Typically as a child’s condition fluctuates, the cycle may be seen several times in each acute episode before a period of stability returns. Not knowing when or how their child would die and the issuant uncertainty this brought for parents led to a degree of scepticism of clinician’s prognostications.

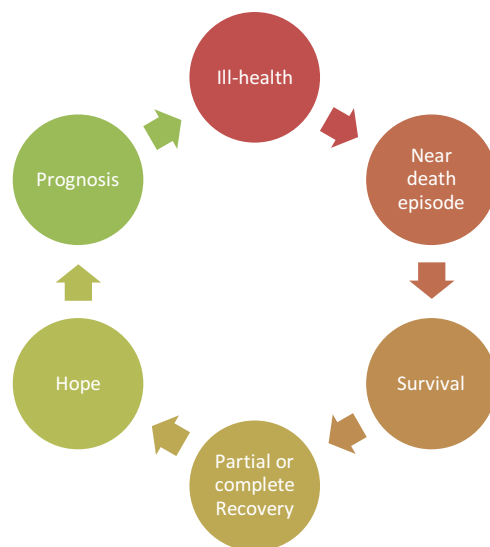


Figure 25 - Cycle of prognostic uncertainty

Death expectations are rooted in the seminal work of Glaser and Strauss (1968) and have been adapted for children's palliative care by Steele (2000) who use the phrase '*certain death at an unknown time*' to describe the phenomenon of children's fluctuating condition in palliative care. Findings of this research lend support to this contention where there is clear evidence that these episodes of ill-health and the uncertainty that they bring impact on parents' decisions and choices regarding care including respite. The uncertainty of not knowing when or how and the speed at which episodes occurred took its toll on parent's physical, emotional and psychological health. However, parents still maintained hope that whilst their child may not fully recover from their episode that they would survive.

7.2.5 Living with hope

Evidence from this research strongly indicated that parents wanted to maintain hope even when they knew it was not realistic. As part of their coping mechanism parents felt justified in maintaining hope based on their child's previous near—death experiences. Previous research has found hope to be significant in helping mothers in their care-giving (Nelson 2002) and despite an uncertain future for their child, hope helps parents to transcend normality or abnormality (Fisher & Goodley 2007). Pragmatically, in order to prevent parents receiving mixed messages and holding on to the most hopeful prognosis it has been suggested that there should be consistency and consensus between clinicians (Levetown 2008).

Hope was evident in all cases in this research but was always tempered by the reality of parents' experiences of caring for their child. Hope is a complex and individualistic phenomenon (Mack *et al.* 2007) fostered by honesty (Hagerty *et al.* 2005) yet closely aligned with denial and optimism (Spencer & Battye 2001; Reder & Serwint 2009). Whilst evidence suggests that denial can impact on the provision of palliative care by preventing necessary communication with patients, evidence also suggests that denial is a healthy part of the dying process (Zimmermann 2007). Others confirm that hope can be fostered even when the inevitable outcome is death by providing assurance that everything that can be done will be done (Harris & DeAngelis 2008). Hope is exemplified in this research where despite multiple near-death experiences of their child and evidence that suggests improved efficacy in end-of-life care and less regrets around decision-making (Dussel *et al.* 2009), the majority of parents had not made an end-of-life plan for their child. This provides further

confirmation of parents' doubts regarding prognostication whilst also demonstrating their underlying hope.

7.2.6 Parents as care-givers

As demonstrated in this research, parenting a child with a life-limiting condition requires parents not only to maintain the usual activities commensurate with parenting, but also requires adaptation and adjustments to all aspects of family life in order to meet their child's needs. Rooted in the seminal work of Bowlby (1969) it is well-documented that a child's need for comfort and protection is fulfilled by the presence of a mother figure³⁶. Demonstrating the interplay between the Mesosystem and the Microsystem of the family, mothers willingly adopted the culturally accepted Irish norm of fulfilling the role of primary carer for their child, a role which often consumed their life and energy. Despite their own shock, disbelief and sense of loss at their child's diagnosis, the developing maternal bond and ensuing love and sense of loyalty and obligation ensured that mother assumed the role of caring and carried this out to the best of their ability regardless of the child's diagnosis or care needs. Confirmed by the findings of others caring for children with: cystic fibrosis (Quittner *et al.* 1992); technology dependence (Kirk 200; Heaton *et al.* 2005; O'Brien 2001); complex care needs (Steele & Davis 2006; Eaton 2008; Nichol and Begley 2012), this combination of maternal love coupled with expertise in the care of their child has been highlighted elsewhere (Gibson 1995; Catlin & Carter 2002; Himmelstein *et al.* 2004; Kirk *et al.* 2005) and is strongly rooted in accepted gender and societal roles.

7.2.6.1 Developing caring skills

Prior to their child's diagnosis, the majority of parents had no previous experience of providing complex nursing care; however, over time and through necessity, parents acquired and developed the skills that enabled them to provide the care that their child required. Such skills were often taught by healthcare professionals or learnt through experience, and reinforce findings of previous research (Glendinning *et al.* 2001; O'Brien 2001; Kirk & Glendinning 2002; Kirk *et al.* 2005) where parents became adept often conducting complex and diverse procedures that in other circumstances would be the work of skilled clinicians.

³⁶ Whilst Bowlby's (1969) work relates to attachment between mothers and their children, it is noteworthy that he recognised the limitations in identifying individuals in isolation. His later work was expanded to encompass the family. Walker S. (2012) Systems theory. In *Effective social work with children, young people and families. Putting systems theory into practice* (Walker S., ed), SAGE publications, London..

Through this process parents gained competence and confidence and this, coupled with parental knowing was a powerful combination. These study findings support those of others (Kirk & Glendinning 2002; Steele 2002), where over time parents became empowered and, in their world, where so much uncertainty existed, exhibited attempts to maintain control of their child's situation.

Despite the diverse circumstances of each case and the differing characteristics of each family, gaining and maintaining control over their child's care was evident in each family and was reflected in their choices and decisions about all aspects of their child's care. Findings from this study support the contention that empowerment is a prerequisite to high quality children's palliative care (Davies & Oberle 1990; Gibson 1995; Widger *et al.* 2009) and is reliant on several factors including parental values, beliefs, determination and experience (Gibson 1995) and refute the notion that parents prefer to abdicate decision-making to healthcare professionals (Contro *et al.* 2002).

Parents readily made or influenced decisions regarding many aspects of their child's care including the utilisation of respite. These decisions were often guided by clinician's estimations of prognosis and influenced by the belief that their child's death was imminent. Once patterns of caring were established findings of this research demonstrate the difficulty parents had in relinquishing their control over the care of their child. Policy ideals suggesting that all parental decisions should be in the best interests of the child (United Nations 1990) were evident in this research where parents placed their child's welfare before other considerations. Despite being stressful, parental involvement in decision-making was welcomed by the majority of parents even when decisions potentially had long-term or sometimes life-changing consequences. Despite some evidence to the contrary (Miller *et al.* 2011) most research findings indicated that the essential role of parents in decision-making for their child where involvement in informed decisions is supported by others (Mack *et al.* 2007).

7.2.6.2 Parental knowing

Clearly demonstrated in this research was the concept of parental knowing also found in the work of others, this phenomenon indicates that over time by noting subtle clues and body

language parents, and in particular mothers, become expert at knowing their child's needs (Gibson 1995; Callery 1997; Steele 2002; Kirk *et al.* 2005; Eaton 2008; Nicholl & Begley 2012). Findings from Steele (2002) illustrate that when parents are treated with mutual respect as partners in care they feel more in control and are less angry. However, it has been reported that maternal judgment is not always respected by healthcare professionals (Gibson 1995; Callery 1997). Findings from this research refute this where parents were frequently regarded as the expert in caring for their child exemplified and subtly reinforced by carers regularly referring clinical decisions back to parents. Findings from interviews with clinicians and other participants in this study who were involved in the care of the child strengthened this contention where parent's skills and depth of knowledge were acknowledged and generally respected.

The findings of this research provide evidence to support how over time, mothers of children with life-limiting conditions through a powerful combination of maternal bonding, parental knowing, empowerment and acquired expertise take control of the care of their child.

7.2.7 Impact of caring

Without knowing the duration or intensity of care required, parents reported the unremitting nature of caring for their child. Such issues as the care of well-sibling, social isolation, and physical and emotional exhaustion were commonplace among parents and have been found in previous research in children with complex care needs (Steele 2000); those who are technology dependent (Heaton *et al.* 2005); and those with life-limiting conditions (Carnevale *et al.* 2008a; Carnevale *et al.* 2008b; Hynson 2012). Demonstrated in this study was the added physical strain of caring for the child over time as they grew older, bigger and heavier concurring with earlier findings in children with complex care needs reported by MacDonald & Callery (2004) and others who have noted musculoskeletal problems in parents from lifting and moving their child or performing physiotherapy (Rowse 2006; Monterosso *et al.* 2007b; Carnevale *et al.* 2008b).

All parents in this research altruistically expressed their commitment and obligation to provide care for their child at home however many reported physical, psychological, emotional and financial consequences of doing so. Whilst previous research has

demonstrated the burden of long-term care giving and the subsequent strain on the families (Dauz Williams 1997; Steele 2000; Carnevale *et al.* 2008b) this is refuted here where parents rejected the notion of caring as a burden. Key issues identified in the context of this research and confirmed by the findings of others including regular sleep disruption and loss of privacy in the family home (Eaton 2008) and social isolation (Yantzi 2006; Heaton *et al.* 2005).

Exacerbated by stress and worry about their child, the majority of parents reported regular sleep disturbance as a consequence of their child's care needs. In order to meet their child's routine nocturnal care some parents reported sleeping with their child in their bed. The issuant fatigue parents experienced inevitably impacted all aspects of their lives. A link between chronic sleep deprivation on cognitive functioning and physical strength has been identified (Van Dongen *et al.* 2003) and between the manifestation of physical and psychological issues experienced by the parents of children with life-limiting conditions (Emond & Eaton 2004; Heaton *et al.* 2005; Rowse 2006; Steele & Davis 2006; Rodriguez & King. 2009). The provision of night time respite is presented as one solution to this issue allowing parents the opportunity to rest and thus fulfil their caring responsibilities during the day.

For parents, accessing night respite services was serendipitous with no needs-based assessment system in place; access had often evolved over time. The provision of such services reportedly relied heavily on voluntary organisation funding, which highlights a significant issue (IHF & CSH 2011). Parents identified a dearth of suitably trained and qualified carers particularly in remote and rural locations. Interestingly, similar findings were reported in both Wales (Heaton *et al.* 2005) and Canada (Steele & Davis 2006) where similar isolated rural communities exist.

7.2.7.1 Loss of privacy in the family home

In this research the evolution of home into a place of care for the child involved changes of varying magnitude from structural adaptations to hospital-style furniture and equipment. This change in living environment had a profound impact resulting in changes for the whole family. Space within the home was an issue for some families, particularly when their child required large equipment such as a wheelchair or a hoist. It has been suggested that caring for

a child in the family home can change the meaning of home for the family (Kirk 1998; Steele 2002; MacDonald & Callery 2004; Yantzi *et al.* 2006; Eaton 2008) with equipment serving as a constant reminder of the child's illness (Kirk & Glendinning 2002). As seen in this research using home as a place of care can conflict with the concept of home as a place of privacy (Williams 2002) and confirms the requirement of families to make considerable adjustments (Steele 2000).

Whilst reinforcing the necessity of having carers in the family home parents contended that this impacted on family dynamics. The issuant exposure of Microsystem family functioning was exemplified by one mother describing the parenting of her well children in the privacy of her own home. Being conscious of carers' presence resulted in an inability to freely discipline her other children or for her teenage son to walk around at home in his underwear confirming findings of an earlier study (Eaton 2008).

7.2.7.2 Social isolation

Whilst some parents in this research reported feeling socially isolated, findings of this research refute the suggestion by Fisher & Goodley (2007) that this isolation may be self-imposed (Fisher & Goodley 2007). Several factors prevented parents from maintaining normal social relationships; for instance, the challenges of transporting their child or the number of time-consuming care-related appointments they attended. Taken for granted by most, mothers frequently mentioned shopping or going to the hairdressers as the everyday pastimes in which they most wished to participate in if they had time. A combination of factors impacted on the social isolation that parents reported including parental reluctance to utilise certain types of respite. It is not uncommon for families caring for a child with a life-limiting condition to become isolated from friends and family as they become consumed by the tasks of caring (Eaton 2008; Rodriguez & King. 2009) resulting in disconnection from their community (Yantzi *et al.* 2006). Hynson (2012) suggests that parents of children with life-limiting conditions experience multiple losses and for parents in this research this represented loss and further removal from their previous life.

Parents lamented the loss of their old life and found establishing a new 'normal' challenging; stressing the importance of maintaining social contact. Connections within the Mesosystem

were an important support for parents and in particular for participants living in rural Ireland who placed great importance on socialising, for instance, going to the local pub. Serving several functions for parents such as socialising opportunities provided a break from caring, allowed parents to spend adult time together and importantly for parents provided the link and subsequent sense of belonging between them and their community, again reaffirming the 'normal' in their life. This was in direct contrast not all parents valued maintaining a social life which concurs with findings of other research (Steele 2002; Heaton *et al.* 2005; Steele & Davis 2006) with some parents equating the care of their child with the end of any social life (Rodriguez & King 2009).

This study also found that parents identified the benefits of surrounding themselves with positive people and spoke of others who they perceived to be worse off than them thus reinforcing the findings of Steele (2000). In common with the findings of other research, the search by parents for meaning in their experience was frequently reported (Steele 2002; Steele & Davis 2006; Syren *et al.* 2006). Despite their generally overtly negative attitude to the hospitalisation of their child some parents in this research reported meeting other parents in hospital as a positive experience. This has been described as '*reframing their happiness*' which through the reinforcement of positive perceptions of their own essential role as their child's primary carer, enables mothers to gain a sense of self-fulfilment as reported in previous Irish research involving children under four with neurodegenerative conditions (Redmond & Richardson 2003).

Findings of previous research indicate that invariably parents are unable to continue with most aspects of their previous life-style and the time demands of care, exhaustion and stress impact on family routines and marital relations (Stein & Woolley 1990; Steele 2000; O'Brien 2001; Heaton *et al.* 2005). Findings from this research support this contention and add that this stress can be exacerbated by, for instance, their sick child sleeping in the bed with them. Whilst marital strain and break down has been reported as a finding of some studies of children with complex care needs and life-limiting conditions (Steele 2000; Rowse 2006; Rodriguez & King. 2009), this was not confirmed in this research. One mother was a single parent, all others were married and purveyed the strength of their marriages describing how caring for their child had made their relationship stronger. In many cases a strong triadic relationship was demonstrated between the parents and their sick child. Concerns regarding

the impact on the well siblings of living with a child with life-limiting conditions were raised with parents expressing guilt at the time-consuming nature of providing care for their child.

7.2.8 Impact on family life

Participants in this study raised concerns regarding the siblings of the child with a life-limiting condition. As most chronically ill children live at home inevitably impacts on siblings (Dauz Williams 1997; Nielson *et al.* 2012). In this research siblings were reported to respond in different ways to having a child with a life-limiting condition in their family.

Research has reported that the siblings of children with cancer experienced stress and periods of anxiety and depression about their sick siblings condition (Stallard *et al.* 1997). Concurring with the findings of others, findings from this research indicate that siblings often seek support from extended family members such as grandparents (Stallard *et al.* 1997), need reassurance that they are unlikely to contract the condition that their sibling has (Cummings 2002) need information about their sibling (Contro & Scofield 2012) and essentially require respite for their sick sibling in order that parents can spend time with them (Neufeld *et al.* 2001; Olsen & Maslin-Prothero 2001; Davies *et al.* 2004; MacDonald & Callery 2004). Findings of this study confirm the importance parents placed on spending time with their well children; demonstrated by the emphasis that the majority placed on setting time aside for them and often using the opportunity respite provided to do so.

7.2.9 Guilt and divided loyalties

Hospitalisation of their sick child had in many cases resulted in parents spending, sometimes prolonged, periods of time away from their well children where they were often forced to make alternative arrangements for them. Concurring with the findings of others, hospitalisation put a strain on the whole family system (O'Brien *et al.* 2009). Parents reported feeling guilty and having divided loyalties and described talking to their well children and rationalising their absence. The impact of living with a sibling with a life-limiting condition has been addressed in previous studies where similar findings are reported (Heaton *et al.* 2005) and where finding indicate that well siblings may believe that they are less important than their brother or sister (Crawford 2002; Knapp & Contro 2009).

7.2.10 The impact on well siblings

There is evidence to suggest the use of avoidant behaviour can be displayed toward the child with a chronic condition by older siblings who may feel different or even embarrassed as a result of their sibling's condition (Nielson *et al.* 2012). Reports of some participants in this research confirmed this as demonstrated by one well sibling wishing she had a 'normal' sister. Reporting coping strategies employed by siblings it has been suggested that talking to others, wishful thinking and attention seeking behaviour are all utilised (Murray 1999). Behavioural issues with well siblings were also evident in this research in particular attention seeking was described by many parents for example one sibling, despite being too big, insisted on sitting on her father's knee like her sister with complex needs.

7.2.11 The particular needs of teenagers

This research uniquely highlights that the specific respite needs of adolescents are demonstrably different to those of younger children. Within the age ranges identified by ACT (2001), four of the participants in this research were adolescents (ACT 2001). In considering the respite needs of these teenagers other issues complicated their access to and utilisation of respite care. Three of the teenagers in this research struggled with the specific challenges of living with a life-limiting condition as a teenager. Previous research has indicated that respite needs change over the lifetime of a child (MacDonald & Callery 2007) and that the respite needs of adolescents differ from those of younger children (Craig 2006) confirmed in the findings of this research.

A major concern for all three girls reported by their parents was the impact that their underlying condition had on their physical appearance and the ultimate isolation that looking different brought. These differences in physical appearance are noted elsewhere (Freyer 2004; Craig 2006). Parents also reported how their child's condition impacted on their development of peer relationships and acceptance. Missed school through ill-health or hospitalisation often resulted in social isolation further exacerbated by many participants living in remote rural locations. This in turn also impacted on their teenager's quest for independence demonstrated for instance by their desire to drive, work and meet boys. Parents reported, whilst welcoming this normal part of their child's development, they also found it difficult to, for example, be excluded from conversations that doctors had with their child. Parents were very introspective and whilst they expressed a wish to let go after years of

caring they also felt that they needed to maintain an element of control. Freyer (2004) investigating the needs of dying adolescents lends support to these findings suggesting parents of teenagers who have life-limiting conditions have difficulty in relinquishing their role as decision-maker.

In two cases, invariably, parents' concerns centred on their child's medical condition; however, a diagnosis of clinical depression in the adolescents resulted in both requiring the services of a psychologist at a national centre. This required travel for several hours for each appointment impacting on parents pragmatically but more importantly emotionally. Parents' describing their own sadness and helplessness at their child's fear and sense of isolation recognised the connection between the child's depression and their life-limiting condition. Rates of depression are notably higher in adolescents with life-limiting conditions (Hynson 2012); however, there is paucity of contemporary research literature to support this contention. There was reluctance from both families described here to utilise any respite service, regardless of the location and type. Whilst it is likely that these decisions were multifactorial it is unclear whether their child's depression played a part in these decisions.

The issues raised by the parents of adolescent's present challenges when aiming to meet their respite needs. In this study parents reported none of the adolescents had availed of the various respite services that had been offered to them. This included specific respite opportunities that were aimed at teenagers. The overwhelming message that parents presented was that despite ill-health their teenager craved normality and acceptance of peers. This research highlights a dearth of suitable respite for adolescents indicating that the respite care currently being offered to teenagers does not meet their needs or those of their parents. The importance and lack of respite facilities specifically for teenagers has been identified (ACT 2001) and in the UK respite facilities specifically for adolescents have been developed (Helen and Douglas House 2013). It is clear from these findings that there is no 'one-fits-all' approach to respite in children's palliative care and that the needs of adolescents require a considered response.

7.2.12 The meaning of respite

Despite literature to support the contention that the term ‘respite’ is not acceptable to parents of children with life-limiting conditions (Murphy 2001; Brown 2007) findings of this research do not support this contention. There was no indication from parents that they found the term offensive and all were clearly able to articulate their understanding of the term ‘respite’. Culturally the term respite is accepted and used in Ireland particularly in the context of disability services and as a result of the overlap between children’s palliative care and disabilities many parents had experience or knowledge of respite in this context. Conversely, parents of children with conditions other than those in ACT category 4 (Table 2 – page 31) recognised the term respite but perceived it to be for children with disabilities and not their own child. The majority of parents described respite as a ‘*break*’ with many elucidating this further by describing the activities that respite enabled them to undertake for instance: shopping; going to the hairdressers; and cleaning the house.

Ultimately, regardless of type and location, respite care requires that parent’s handover their caring responsibilities to others. In this research there was ambiguity surrounding what parents regarded as a respite service. For parents there was some confusion regarding in-home respite and whether care provided in the family home constituted ‘care’ or ‘respite’. Generally, parents referred to respite as the hours of nursing care that had been allocated to them by various voluntary and statutory agencies.

7.2.13 Respite as a service

An important finding of this study is that although previous research and government policy (DOHC, 2010; Craig *et al.* 2008; ACT, 2009) emphasised the importance of respite in children’s palliative care evidence from this research does not support this as a universal contention. A clear dichotomy was seen between the needs of children with neurodegenerative conditions and those with other conditions. This is an important finding of this research and demonstrates the need for differing approaches to the provision of respite services for children with life-limiting conditions. A clear example of this is the significantly diverse respite needs of teenagers without cognitive impairment and younger children with neurological disabilities. All are children with life-limiting conditions but there is an unambiguous demarcation between the needs of the two groups thus demonstrating the importance of age and diagnosis appropriate respite services. This further supports the notion

that planners of respite need to develop services to meet the diverse needs of parents (Olsen & Maslin-Prothero 2001) but also more specifically of children.

Of the parents requiring respite for their child many reported the struggles that they had endured and the tenacity they had to display in order to access services. It has been posited that the need for respite evolves over time (MacDonald & Callery 2007) and this is demonstrated in this research however increased utilisation of services as the child ages may also reflect parent's greater depth of knowledge and understanding of the system and their increased ability to access services. Importantly, MacDonald and Callery (2007) when considering children with complex care needs also suggest possible inequity in the allocation of services as a result of parental articulateness. Whilst findings of this research support this contention this raises an interesting issue. Despite describing themselves as initially non-confrontational, mothers in this research reported that through necessity they had developed the ability to fight for their child and the services they required. In order to achieve equity and fairness in the allocation of respite clarity is required around the process of accessing services, which should not be reliant on parental articulateness.

Reliant on factors such as the geographical location, age, and diagnosis of the child, evidence from this research indicates variation in the provision of respite care within and between cases. Whilst supporting findings of previous national overviews of respite in children's palliative care (DOHC/IHF, 2005; LauraLynn & IHF, 2013) evidence from this research adds significantly to the scant data currently available by providing in-depth of knowledge of where and how parents accessed respite care.

7.2.13.1 Accessing respite services

Standardised procedures and assessments for the allocation of respite were not evident in this research. Allocation of respite services or funding for respite services was serendipitous and reliant on a combination of statutory and voluntary funding. Between and within cases the number of hours allocated to families differed significantly and changed over time. It was evident from this research that respite services need to be tailored to meet the individual needs of the child and parents, reinforcing the findings of MacDonald and Callery (2004).

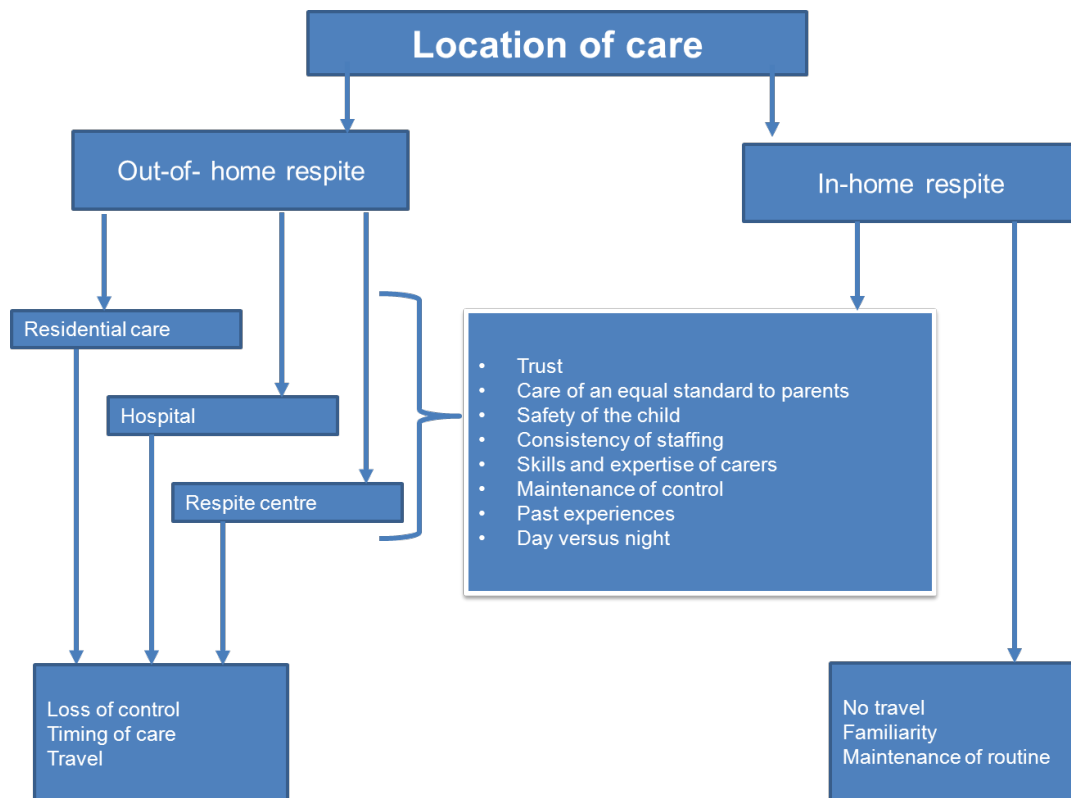
However, the complexity of each child makes this difficult and therefore developing a standard respite assessment for all children with life-limiting conditions may not be possible.

Parents were very specific about the type of respite they wished to receive and the location of such care. For some, in particular, those whose child had a neurodegenerative life-limiting condition out-of-home respite services were frequently offered through the disability services. Interestingly whilst parents were theoretically supportive of such services and acknowledged their importance they did not regularly access such services for their own child instead specifying a preference for respite at home. A number of factors influenced parent's decisions regarding the utilisation of respite services such as past experiences but ultimately parents stressed that they did not wish to be parted from their child particularly if their child was unwell or they perceived that they had limited time left making home respite a more appealing option.

7.2.13.2 Location of respite care

ACT (2003) suggests that a range of regular respite should be offered to all families caring for a child with a life-limiting condition. This should include respite over varying periods of time, away from the family home and in the home and should include symptom management and nursing care. In this research some families received all of these elements of respite and others none. Parents described a number of locations where respite was offered or provided which were broadly divided into two categories; out-of-home respite and in-home respite these are shown in Figure 24 and discussed in the following section.

Figure 26 Location of Care



7.2.13.3. Out-of-home respite

The term out-of-home respite incorporates any location that is outside of the family home for instance hospital, respite centre or residential care centre. The majority of parents had been offered respite out-of-the home and yet few had availed of such services. Further exploration of this issue revealed that parental decision-making regarding the utilisation of out-of home respite care is based on a number of interconnecting factors.

A primary concern for parents in accepting out-of-home respite is that the care provided has to be of an equal standard to that provided by them at home. This concurs with findings in earlier research where parents only felt comfortable delegating their caring responsibilities once reassured that standards and routines were maintained (Neufeld *et al.* 2001). A major issue for, particularly, parents of children who were medically and physically frail was the safety of their child. One mother described leaving her daughter in a unit where she had to be locked into a room to keep the other children with severe behavioural issues from harming her. Others expressed major concerns regarding their child's exposure to infection through contact with other children. Steele (2000) confirms these findings in her research with

children with neurological conditions reporting that parents made great efforts to ensure their child stayed well and worked hard at keeping them safe (Steele 2000).

A key finding of this research centres on parental concerns raised regarding care staff in out-of-home respite services. These issues related not only to the competency and experience of staff but also to workforce planning issues such as staff turnover and continuity of care. Parents stressed the importance of consistency in staffing and valued the stability this brought for their child. Their primary concern was that the staff would know their child and be familiar with their needs thus enabling them to maintain the child's routine. Consistency of staffing was found to be directly related to maintenance of routine in previous research (Heller & Solomon 2005). The importance of routine in caring for a child with a life-limiting condition has been reinforced by the findings of others (Neufeld *et al.* 2001; Steele 2005; MacDonald *et al.* 2006; Yantzi *et al.* 2006; Eaton 2008) where one author contends that parents 'caring-giving' is 'the routine' suggesting that the terms are interchangeable to parents of chronically ill children (Jerrett 1994). This evidence would suggest that these two interconnected factors, familiarity with staff and routine, are essential in enabling parents to relinquish some control over their child's care and allow others care for their child. It has been suggested that out-of-home respite could also be viewed by parents as giving up on their child (Nageswaran 2009) thus exacerbating any associated guilt.

7.2.13.4 Previous experience and trust

Findings in this research suggest that when parents had no previous experience of out-of-home respite care and could think about it hypothetically they were more accepting of its value. However, over the lifetime of the child the majority of parents had availed of various out-of-home services. These previous experiences impacted upon their views and influenced their choices and expectations of services. When parents had experienced problems with any aspect of care in a respite unit, they reported not utilising the service again concurring with findings of Steele & Davies (2006). These problems ranged from staff changing their child's clothes to institutional ones on admission (thus in parents eyes impacting on their child's identity) to serious clinical errors of judgement (not recognising signs of a sudden deterioration in the child's condition). Even when parents had good experiences of the respite services this did not always convert to trust in the organisation, for instance one parent

reported being satisfied with the day care her daughter received at a respite centre but was adamant that she would not accept overnight respite care there.

A unique finding of this study was the clear demarcation between parents' acceptance of people's help with their child during the day and the distinction made regarding their ability to help at night. Interestingly parents reported that depending on a few prerequisites (for example stable condition of their child and no complex care due) they were happy for certain people to care for their child for lengthy periods of time during the day only. For instance one parent reported leaving her mother with her daughter during the day but clearly stated that she would never leave her to care for the child at night. In seeking a rationale for this decision-making, parents were unable to explain. There is a dearth of literature pertaining to this particular important issue that warrants further investigation.

7.2.13.5 Proximity of respite

A key factor influencing parent's decision-making regarding respite was the proximity of the location of the care setting providing out-of home respite to their home. Parents were reluctant to send their child into a respite unit if they perceived it as too far from their home even if the unit would suit the needs of their child. Transport to and from the unit was an issue as trips outside of the home were difficult for parents to make, exacerbated by factors such as the care of well siblings and transporting equipment. Many children in this research were medically frail making travel difficult and parents pragmatically noted that even if the respite centre organised transport this could result in their child being in transit for long periods of time. Previous work in Ireland has identified the need for locally based services (DOHC/IHF 2005; IHF & CSH 2011).

Evident in the finding of this research is that all out-of-home respite is dependent on the child's condition. Parents reported that respite was cancelled (sometimes at short notice) if their child was unwell confirming the findings of earlier an study (Olsen & Maslin-Prothero 2001).

7.2.13.6 In-home respite

In this research, in all cases, parents specified home as their location of choice for respite care. Using the family home as the location of providing respite is often seen as the ideal model of care, providing benefits for both the parents and the child by maintaining the child's routine and avoiding the disruption of travel to a respite centre. Home as the location of choice for parents of children with life-limiting conditions has been confirmed by others (Steele 2000; Kirk *et al.* 2005; Quin *et al.* 2005) and the notion has also been idealised and supported by government policy (DOHC, 2001b). However this is often motivated by perceived savings to healthcare budgets rather than facilitating the wishes of the child and parents (Kirk 2001; Olsen & Maslin-Prothero 2001). Providing respite care at home is not without its challenges; it can be expensive and this coupled with difficulties in recruiting and retaining qualified carers can place undue stress on the family (Monterosso *et al.* 2007b; Knapp & Contro 2009).

7.2.13.7 Accessing appropriate care

Workforce issues impacted on parent's access to respite services, even where funding was available a dearth of locally-based suitably qualified and experienced staff often prevented parents from accessing suitable respite services. Parents described the challenge of being given responsibility for accessing appropriate carers for their child at home, grant schemes rendered them at least technically as the carer's employer.

In this research, it was clearly demonstrated that families were much more accepting of carers in their home who they felt they could trust reinforcing findings of Steele (2002) and Nichol and Begley (2012). Parents generally rejected the notion that others could select and allocate carers for their child and reported that if and when they found somebody who gained their implicit trust, they did everything they could to maintain their working relationship which often developed into a personal friendship.

7.2.13.8 Gaining parental trust

Findings of this study highlight that in order to enable parents to get a break from caring, regardless of the child's diagnosis, prognosis, geographical area, provider of services or duration of illness all parents need to have trust and confidence in those providing care for their child. The process of parents developing trust is similar to that described in adults with

chronic illness where initial naïve trust in carers is replaced by relationships of convenience (Thorne 1993). In children's palliative care uninformed parental trust is reported to evolve overtime into parent's taking control (Steele 2002) and this is clearly demonstrated in this research where parents demonstrated over time and through experience that they moved from naïve belief and faith in clinicians to taking control of their child and their care needs.

The provision of high quality care of an equal standard to that provided by parents is a key factor in the development of parental trust in carers. Similar findings are reported in the parents of hospitalised children (Thompson *et al.* 2003). In this research, in order to gain the trust of parents; carers were required to pragmatically demonstrate that they were able to meet parental care expectations and standards over time with parents judging their clinical skills and manner. Gaining parental trust was a process; findings confirm that not all experiences of carers were positive ones for instance parents hearing an alarm and finding their child's night time carer asleep. This continuous process has been described by others (Thompson *et al.* 2003; Monterosso *et al.* 2007a).

This study demonstrates that parents and carers in this research valued mutual respect and shared previously identified by others (Nelson 2002; Heller & Solomon 2005). Parents especially valued carers who were friendly, treated both them and their child with respect, who did not patronise them and who respected their family privacy. In particular they had negative feelings towards carers who portrayed pity or who did not address the child directly, findings also found in other research (Contro *et al.* 2002). Trust was not dependent on the age, gender, professional qualifications or past experience of the carer but was judged by the parents during their interactions over time. Previous research has indicated that all those caring for children with a life-limiting condition should have specific paediatric experience and skills (Monterosso *et al.* 2007b), however this research suggests that parents considered the other factors to be of greater importance than qualifications. Parent's resented the process of repeatedly training new staff to care for their child. Similar findings are reported by parents of children with disabilities (Robinson *et al.* 2001b) and those whose children received hospice care (Eaton 2008).

Demonstrating the interconnecting Micro-Meso-Exo-levels of the family system, as with all health service manpower issues the practicalities of ensuring familiar and trusted staff are rostered and available is especially difficult. Particularly parents from isolated rural locations reported the challenges of not only accessing funding for respite care but reported even when funding were available a bigger challenge was to find available, acceptable, suitably qualified and experienced carers. In some cases, parents recruited by a 'snow-ball' process where a trusted carer recommended or assessed others.

Whilst some parents spoke of the relentlessness of caring for their child and the role of respite in relieving this, paradoxically they also reported that when this care was provided in-home it was hard for them to get a break. As experts in their own child's care, many reported being consulted regularly by those who had been employed to provide care thus negating the notion of respite providing a break from caring. Others conversely felt unable to fully relax and entrust the care of their child to others, for instance one mother reported having an experienced nurse on duty, yet if she heard the child's equipment alarming at night it would wake her and she would investigate the cause herself. This leads to the question of whether parents can ever truly get a break from caring for their child, particularly when this care is provided in such close proximity to them.

7.2.13.9 Family holidays as respite?

For most people holidays are considered to be a break from normal routine. For some parents of children with life-limiting conditions holidays take on a different meaning. Sometimes holidays are offered by charitable organisations at the end-of-life (Vickers & Chrastek 2012). For others holidays represent a window on their past life and are a goal that families aim to meet (Bluebond-Langner *et al.* 2012). In UK many parents use hospice services for their child whilst they go away on holiday themselves (Eaton 2008), whilst this was supported in one case, in general findings from this research do not support this contention. In this research parents expressed differing views on the notion of holidays as a break and reported varying experiences of taking their child with them on holiday. Some reported the challenges for instance of their child being hospitalised in a different country. Pragmatic considerations are suggested for taking a child abroad and include the provision of adequate health insurance and detailed documentation of their child's condition (Vickers & Chrastek 2012). In this

research parents reported the increased stress associated with taking their child on holiday for example travelling was complicated by transportation of equipment, feeds and drugs, which often negated the potential benefit of a holiday. As a result of this several families reported that they simply found the prospect of going on holiday with their child too stressful and thus did not perceive holidays as respite. Equally the majority of parents did not wish to take holidays without their child. Whilst play day schemes as a form of respite for parents of children with intellectual disabilities have been reported (McGill 1996), the concept of holidays as respite is not referred to in the research literature.

7.3 The impact of the Mesosystem on respite

7.3.1 Introduction

Research has shown that one of the most important issues for parents is their ability to trust those providing care for their child with a life-limiting condition regardless of whether this is a family member, nurse or carer (Heller & Solomon 2005). The Mesosystem encompasses the extended family and the health and social care workers that the family interact with on a daily basis. The community within which the family live is also part of the Mesosystem. In this section the impact of caring for a child with a life-limiting condition as it interfaces with the structures within the Mesosystem are discussed.

7.3.2 School as respite?

In this research some parents referred to the time that their child spent at school as respite, this has been recognised by others (ACT 2003), where it provides a natural break from caring (Johnson & Steinhorn 2012). However not all children attended school and parents had mixed views on the value of school for their child. In some cases children attended a ‘special’ school for children with disabilities whilst others attended their local school. Various factors affected parent’s decisions regarding their child’s schooling and if school is to be considered as a type of respite these factors require further explorations.

Education is an essential component of life and development for all children including those with life-limiting conditions (ACT 2009a) with school being a part of normal everyday life. In adolescents with life-limiting conditions, attending school has been identified as a key factor in maintaining normality (ACT 2001). Some children with life-limiting conditions

have few opportunities to experience the normal activities associated with childhood however several parents in this study displayed determination that attending school would be one such activity. In children's palliative care school can offer children the opportunity to develop friendships and peer groupings which cannot be filled by their family (Brown, 2012) and in children with profound and complex learning needs school may provide the opportunity for children to communicate with others (Brown 2012).

In this research all children who were of school age, either had, or continued to attend school. For parents, even their child's need for complex care did not deter them. For instance one child attended the local school with a ventilator. The symbolism of their child doing something normal such as attending school and being part of the wider community was often a motivating factor for parents. As an example one parent concerned about what the neighbours thought, sent her daughter to the local school rather than sending her on the "special bus" to a "special school". Research by the National Disability Authority (2007) indicates that attitudes to disability in Ireland have changed and that there is more acceptance of people with disability in society (NDA 2007), but despite this those who lived in small rural communities found this challenging.

7.3.2.1 Special needs assistants

Several children in this research had or still availed of the services of a Special Needs Assistant (SNA) at school with varying success. The role of the SNA in caring for a child with a life-limiting condition is to provide care whilst the child is at school without being obtrusive. The role incorporates many activities including physical assistance or technical care that should be undertaken whilst recognising a need for independence (Brown, 2012). Special needs assistants have an indirect role in the provision of respite where parents consider the time their child spends at school as respite, in some cases SNA's facilitated this break.

In cases where SNA were involved, they had a primary role in caring for the child during school hours and parents reported varying experiences. In this research one teenage girl in particular found that the SNA assigned to her did not respect her boundaries, for instance not leaving her to talk to her peers alone. Brown (2012) suggests that part of the SNA role is to

recognise the need for independence and uninterrupted socialisation without adult intervention. In this particular case, during adolescence the struggle to gain peer acceptance and the quest for independence were challenged by the need for an SNA, which in this instance ultimately resulted in the teenager leaving school. This decision was influenced by a number of other factors however, ultimately school as respite was no longer an option for this parent. It is reported that increasing isolation from healthy peers is not uncommon in adolescents with life-limiting conditions; however, school is not only a place of learning but a place of socialisation (Craig 2006).

In this research ill-health was reported to often prevent children from attending school. Some parents also reported reducing exposure to infection by not sending their child to school, a strategy also described in other research (Steele 2000; Craig 2006) which aimed to ‘*safeguard precarious survival*’ (Rempel & Harrison 2007). This keeping their child at home was viewed as limiting exposure to infection. There is a dearth of research based evidence relating to the role of school in the provision of respite for parents caring for a child with a life-limiting condition and related areas. Whilst school may offer a break from the routine of caring for some parents and this may be viewed as respite, not all parents want their child to attend school and have various reasons for making this decision (Brown 2012).

7.3.2.2 Extended family support

There is a perception in healthcare that family, friends and neighbours are a ready and available source of support and respite. Whilst taking account of factors such as possible impaired intergenerational relationships and constraints posed by geographical distance between family members (Katz & Kessel 2002), findings of this research suggest that the role of extended family in the care of children with life-limiting conditions is limited. Parents reported that initially, soon after birth or at the time of diagnosis, extended family members were very supportive however, over time offers of such support dwindled.

Reflected in the findings of this study, the respite and care needs of children change over time. In infancy the child’s special needs are often masked by the normal needs of babies (MacDonald & Callery 2007) making them easier to care for physically and psychologically. In this research as care needs became more complex parents reported that the majority of

extended family no longer provided care for their sick child. As their child grew older and heavier not only did parents struggle to meet their child's physical needs, grandparents also reported this to be a key factor in whether they were able to provide support and thus respite for parents with similar findings reported elsewhere (Yantzi *et al.* 2006; MacDonald & Callery 2007). In order for extended family to have a role in supporting the child and family many resorted to helping in other ways rather than direct care for instance providing financial assistance or babysitting for well siblings confirming the findings of referring to children with disabilities (Katz 2002; Katz & Kessel 2002; MacDonald & Callery 2004; Yantzi *et al.* 2006). Ultimately parents reported a reluctance to seek the help of extended family members doubting their ability to provide care but also the imposition such requests placed upon them.

Parent's doubts regarding extended family member's ability to meet the care needs of their child were evident in this research. Despite willingness to help, extended family members' underlying apprehension and fear of caring for the sick child often prevented parents from taking up their offers by subconsciously reinforcing parent's fears about their ability to cope. Despite their obvious need for support parents described being unable to handover control to well-meaning family unless they were confident in their ability to provide care. Other research supports this contention (Steele 2000; Yantzi *et al.* 2006; Nichol and Begley, 2012). Interestingly, despite the fact that they had frequently mastered their caring skill-base for their child through informal teaching and experiential learning, many parents were reluctant to pass these on to extended family members through the same method. Parents stressed family members' fear and expressed doubt about their capacity to learn and undertake such skilled and complex care. This is a complex issue where factors such as parental trust and control coupled with the fear and insecurities of others appear to interplay. In another example of parental control in this and other research, parents reported conducting all care prior to the arrival of the family member (Yantzi, 2006).

This research highlighted when extended family members were involved in the care of the child they reported that they were flattered and honoured by the trust bestowed on them by parents recognising that they had been specifically selected. Further investigation of this revealed that several key features of these family members: all had provided care from soon after birth or diagnosis; many felt confident in their ability to provide care and all were female.

A significant finding in this research is the gender differences noted in those offering to assist parents in caring for their child. This research undertaken in Ireland reflects the role of women in Irish society (O'Connor 2000) and in all cases the extended family members both offering and providing care to the children were female and included mothers; grandmothers and sisters and female in-laws. It was evident that these female members of the extended family were not randomly selected but were chosen by the child's mother based on their relationship and their judged competence at caring for the child.

Interestingly, findings of this study do not support those found in previous research where it was identified that families of children with neurodegenerative life-limiting conditions replaced extended family support by developing friendships with other families in a similar position who were able to provide support and information and empathy (Steele 2000).

7.3.2.3 The role of healthcare professionals

Due to the small number of children living with or dying from life-limiting conditions³⁷, the majority of healthcare professionals have limited experience or exposure to providing care to the child and family. The benefits of the parents of a child with a life-limiting condition having access to a key worker have been recognised (DOHC/IHF 2005). In this research parents were not allocated a key worker but self-selected a key person who they credited with providing them with the most support. This was generally done without regard for the person's qualifications or experiences for instance an information officer employed by a voluntary provider of care was involved in sometimes complex organisation of respite care and support for a child with a life-limiting condition. She reported that this was a role that she gladly assumed but for which she felt ill-equipped requiring support and advice from a local palliative care team.

Viewed from the perspective of the healthcare professionals providing respite care, most acknowledged that the parents were the experts and as such they felt justified where necessary in deferring decisions to parents. Often working in isolation, those providing

³⁷ In Ireland there are an estimated 322 childhood deaths per year from life-limiting conditions (LauraLynn & IHF, 2013)

respite in the home specified a lack of medical support as an issue and often found they were reliant on parents to relay information to them regarding the child's clinical needs. This was a source of frustration to the carers who felt disempowered and whilst playing to parents desire to maintain control this paradoxically also prevented parents from truly getting a break as decisions and care choices are constantly deferred to them.

This research adds weight to the argument that it is the parents who remain the primary carer and decision-maker regardless of the location of care and adds to the debate concerning the issue of conflict of who holds the power when care is provided in the family home (Eaton 2008). Providing the flexibility in caring for children in-home that parents desired was challenging for staff, as for instance one participant pointed out the impact on her own family life was affected by sudden changes to schedules when families cancelled at short notice. Whilst the primary concern and focus of many healthcare professionals is meeting the needs of the child and family, there are many pragmatic factors to consider from the perspective of those providing respite in the family home.

No GPs were interviewed as part of this research as parent participants clearly felt that GPs did not have a role in the provision of respite care. Parents had differing experiences of their GP services with some less than satisfied with the service than others. One study reported that GPs had little experience and insufficient training to care for a child with a life-limiting condition (Shaw *et al.* 2010). GPs are in a powerful position to assist families in accessing the help that they need including respite care and thus it was surprising that parents did not acknowledge this.

The respite needs and experiences of parents caring for a child with a life-limiting condition are influenced by and have an impact on the wider family system. Providers of care do not fit into discreetly labelled roles and evidence from this research indicates that families select those who they deem to be the most appropriate person to help them find the help and support (including respite) that they need. Ultimately, competence is a prerequisite for trustworthiness (Steele 2002), and the selection is based on past experiences, the development of a familiar trusting relationship and on the parents' ability to entrust the care of their child to others.

7.4 The impact of the Exosystem on respite

7.4.1 Introduction

The Exosystem in the family systems theory reflects the wider context of the healthcare system. It encompasses the integrated systems of care and the themes within current health and social inter-professional working (Lewis and Prescott, 2006). In effect it houses the services, both direct and indirect, provided by voluntary organisations and health systems providing care and the media and its impact on the child and family as part of the Mesosystem. The discussion will focus on various aspects of the Exosystem as they relate to the provision and use of respite by parents of children with life-limiting conditions.

7.4.2 Hospital experiences

Maternity hospitals and acute children's hospitals were familiar settings for all parents in this research and their experiences of using these services often had a lasting impact. During their child's illness trajectory, all parents had, at some time, experienced prolonged periods of hospitalisation. Findings of this research indicate that these experiences of hospitalisation influenced parents' decisions regarding their choice of location of care including respite.

Parents reported that the physical environment in hospitals was not conducive to providing the quality of care that they aspired to for their child; for instance, parents recounted their child being left in a soiled bed or described circumstances where a clinical decision had not been dealt with appropriately. One parent compared staying with her child in the children's hospital with no facilities for accompanying parents, to time she had spent as a volunteer in India. Similar findings were found in a study of parents in a general hospital who noted that despite being encouraged to stay with their child there was a lack of sleeping amenities and catering facilities for parents (Lam *et al.* 2006) and in the parents of children with neurodegenerative conditions (Steele and Davies, 2006). A lack of facilities did not deter parents from staying with their child; on the contrary, all parents explicitly stated that regardless of the length of admission they would not leave their child alone in hospital without a parent or proxy in attendance, including overnight stays. Thus parents did not equate hospitalisation of their child with a break, on the contrary parents reported finding this even more stressful than providing care themselves at home.

There are multitudes of influencing factors that provide plausible explanations as to why the parents of children with life-limiting conditions are reluctant to leave their child alone in hospital. For instance their role as primary carer, their level of knowledge about their child's need and even their own need to maintain control and protect their child; however, research with other groups of parents indicates that regardless of age, culture, the severity of their child's condition or levels of trust, parents are reluctant to leave their child alone in hospital (Sheilds & King 2001; Thompson *et al.* 2003; Lam *et al.* 2006). Others simply contend that stays in hospital should be kept to a minimum (McConkey *et al.* 2007).

When their child was unavoidably admitted to hospital, parents took the view that they were best placed to provide a sense of security for their child during their admission and reported reorganising their lives to accommodate their child's hospitalisation. For those who had other children to consider, this disruption to family routine was a primary concern. In some instances their spouse stayed at home with siblings but in others well siblings were placed with extended family. Similar findings are reported elsewhere (Lam *et al.* 2006; Forbat *et al.* 2010); however, one exception to this was found in a study where parents left their children in hospital unaccompanied but only if they had confidence that their child was known to staff (Heller & Solomon 2005).

Having learnt to 'navigate the system', in this study most parents reported having a key contact in the children's hospital. Interestingly several named this person as the palliative care nurse who they valued for her role in coordinating care and appointments and providing them with information, for instance test results. Previous research identified that in order to meet the needs of children with life-limiting conditions in hospital, staff required training in symptom management and communication (Contro *et al.* 2004). In this research clinicians who were interviewed also identified the need for more educational support with several feeling ill-prepared to deal with a child with a life-limiting condition. Some education programmes have been subsequently implemented by one children's hospital in Ireland (Phelan *et al.* 2006)³⁸.

³⁸ This research was undertaken with families prior to the implantation of an education programme on children's palliative care at the hospital

The role of acute children's hospitals in the provision of respite for children with life-limiting conditions is ambiguous. It is suggested in the literature that despite being more difficult to book or plan (Olsen & Maslin-Prothero 2001), hospital admissions have a role in the provision of respite support for children with life-limiting conditions (Robinson *et al.* 2001b). Several reports have intimated that respite is covertly provided to children with life-limiting conditions (IHF & CSH 2011) and this is confirmed in interviews with clinicians. It is reported that in order to fulfil hospital admission criteria such respite admissions are organisationally labelled to reflect more acute needs of the child rather than respite. This was not supported by the findings of this research where no participant reported accessing respite in an acute hospital.

7.4.3 The development and recognition of children's palliative care

Through the Exosystem and Macrosystem the public view of children's palliative care is developed and reinforced. Stereotypical images of portraying children are used often and many parents in this research felt these did not relate to their situation or in meeting their respite needs. Many parents are reluctant to describe their child as life-limited and also in rural Ireland where close-knit communities are the norm, parents are reluctant to publicise their personal information and details of their child's condition

All parent participants in this research recognised the important past and present role that voluntary organisation provided for them and their family. In recognition of this work several reported undertaking fundraising activities for such organisations. Parents reported that accessing help such as respite from voluntary organisations was not always easy that in some situations this was as a result of a lack of information and in others it was as a lack of ineligibility due to diagnosis or geographical location.

7.5 The impact of the Macrosystem on respite

7.5.1 Introduction

As part of the family system the Macrosystem makes up the broad beliefs of the culture within which the families live and is the foundation for the beliefs and values of the whole family system. This includes the cultural, socio-economic and political factors that impact on

the family system as a whole. The family may have very little direct input into these systems and beliefs but all are influenced and impacted upon by these.

7.5.2 Culture and community

Ireland has a strong cultural identity and sense of community. The majority of parent participants in this research lived in rural Ireland, most were still living in the community where they had grown-up and had extended family and friends living nearby. Living in a small rural community can be viewed as being beneficial to the family with strong local links and a well-developed network of support. Community is at the heart of rural Ireland (Brennan *et al.* 2009) with shared values and culture which both have a major impact on the behaviour and world view of its members (Brown & Dominica 2012).

The new reality with which the family were faced when their child was diagnosed with a life-limiting condition often resulted in increased attention on them as a unit; their coping and caring skills were brought under scrutiny and without choice they found themselves living in the public eye. This manifested in several ways. Parents reported consciously making an effort to ensure that their child with a life-limiting condition was viewed as part of the community, for example one parent spoke of taking her son to the supermarket to ensure that he met local people.

Some families participating in this research found the attention of the local community paradoxical. The notion of being part of community and the social capital this brought (Putnam, 1995) was often viewed as beneficial; living close to extended family members, friends and the wider community which provided support for both their child and for their family and allowed them the opportunity to maintain a sense of belonging. Yet families also found being part of a small community impacted not only on them but also on the choices they made regarding the care of their child. Parents were concerned about their standing in the community, other's perceptions of them and their situation. They reported the impact of carers being part of their daily life and the impact this necessary intrusion had on their family functioning by exposing their private world. Participation in this research allowed some parents the opportunity to reflect on their decisions regarding the use of respite. Demonstrating the Hawthorne effect, in one case as a direct consequence of participating in

this research, a mother previously reluctant to accept respite, reported regular utilisation of such services.

The implications for the wider family system are clearly demonstrated in this research where having a child in the immediate family with a life-limiting condition at a Microlevel is seen to ripple through the whole family system as it has an impact at each level. Irish culturally-specific issues were highlighted in this research where the sense of belonging to the community was clearly demonstrated particularly in those living in small rural communities. In a sociological case study of a rural Irish community the ability of local residents to influence social change through organised activity was highlighted (Brennan *et al.* 2009) and demonstrated in this research, where one father described a fundraising initiative that he had organised for a voluntary body providing respite care for children with life-limiting conditions. This confirms the findings of Knapp and Contro (2009) assessing family support services in palliative care they suggest that altruism is one way in which parents can find meaning in their child's condition (Knapp & Contro 2009).

7.5.3 Lack of information

A dearth of information for parents was a theme that pervaded this research. Many described the initial challenge of obtaining the information they required about their child such as their condition, diagnosis, treatment options and the services that were available to them thus suggesting that little has changed since research was undertaken in Ireland by Redmond & Richardson (2003). Over time parents developed the skills to locate the information they required concurring with findings of Steele (2000). Information was often received through circuitous routes for instance family and friends rather than healthcare professionals. Concurring with the findings of others, once parents had the information they needed it helped parents to reduce uncertainty and fear (Steele 2002). Parents recognised the value of using the internet to access information about their child's condition however, many conditions in children's palliative care are extremely rare and there is little evidence regarding the best treatments and approaches to care. Much of the information available on the internet regarding these conditions is from academic journals rather than being written in a format that is suitable for parents and other family members. However, ultimately, whatever the format, access to contemporary and accurate information helped parents not

only maintain control over their situation it also enabled them to make informed-decisions about the care their child needed, including the role and suitability of respite care.

Some parents found support groups to be a major source of help. Once parents had information they wished to pass this on in order to help others thus supporting the findings of Steele (2000) who found parents altruistically shared their knowledge and experience in the hope of helping others (Steele 2000). Parents particularly valued practical information including issues pertaining to finances and benefits.

7.5.4 Socio-economic impact of caring

Caring for a child with a life-limiting condition inevitably had an impact on the family finances. Overt costs such as purchasing medication and supplies and hidden costs such as additional heating and lighting at home were all met by parents. Increased utility bills have previously identified as a cost associated with caring for a child with a life-limiting condition at home (Stein *et al.* 1989; O'Brien 2001; Heaton *et al.* 2005). Earlier research suggests such care has a significant impact on family financial circumstances (Heaton *et al.* 2005; Carnevale *et al.* 2008b) where there are many hidden costs attached to caring (Redmond & Richardson 2003; Steele & Davis 2006). Whether voluntary or statutory, the majority of services, including respite, provided to families in this research were free at the point of delivery, however, regardless of location of these services parents reported that there were associated costs that they were expected to meet.

Information about financial assistance was challenging for parents to access usually entailing a protracted process. Several participants had made structural changes to their home (hoist tracking; stair lifts or extensions) in some cases this partially or fully funded by parents³⁹ and in others through grant processes. Regardless of the size of these projects a key factor in meeting the cost was gaining access to the appropriate information regarding grants and entitlements. Previous research in Ireland has identified such information to be difficult to access and time consuming (Redmond & Richardson 2003). Family, friends and voluntary organisations frequently supplied information about financial assistance.

³⁹ In some cases where the child's condition was found to be as a result of birth injury or negligence during the birth parents had received financial compensation and were able to fund renovations and other care related costs from these funds

Similar to Nichol and Begley (2012) parents in this research reported the challenges of travelling with their child. The stress and financial impact associated with travel not only limited the number of journeys they undertook but impacted on their decisions regarding the location of care such as respite. The majority of families lived in isolated rural locations requiring a car for even the shortest journeys. Travelling to hospital for appointments or admission or to a respite centre was a lengthy process. Parents reported the costs associated with buying a large vehicle in order to transport their child and their equipment such as wheelchairs and feeding devices and the need to consider further costs such as fuel and parking at the hospital with one family reportedly paying €80 a week to park whilst their daughter was an in-patient.

Whilst many services to the children in this study were provided to parents free of charge, some parents reported paying for extra services such as care or respite in the home; other research lends support to this practice (Redmond & Richardson 2003; Monterosso *et al.* 2007a). Some reported being the recipients of a grant from one of several voluntary organisations that effectively rendered them the employer of carers. This is as a result of an anomaly of the Irish healthcare system where the health service provides funding through various voluntary bodies who in turn give cash grants to families who then effectively become the carer or nurses' employer. The process and governance issues surrounding this practice are not clearly evident and despite requests, no respite provider furnished policies or written information related to this practice. There was no evidence from the perspective of those providing care of the onus on them to work within a clinical governance framework ensuring the provision of a commitment and culture of reaching agreed quality and levels of care (Quality and Patient Safety Directorate 2012).

7.5.4.1 Being able to work

Findings of this research indicate that for mothers, caring for a child with a life-limiting condition and working outside of the home was extremely challenging. The majority of mothers reported giving up their paid employment in order to become their child's primary carer. Similar findings are reported elsewhere (Heaton *et al.* 2005). Attendance at hospital appointments, outpatient clinics and prolonged periods of hospitalisation coupled with their

child's fluctuating condition were reported to render the role of carer incompatible with a working life outside of the home; findings are supported by others (Steele 2000; Heaton *et al.* 2005). Significantly mothers also lamented that their exit from the workforce also exacerbated social isolation. Loss of social contact in the work environment as a result of caring for a child with a life-limiting condition was noted in previous research (Redmond & Richardson 2003). For those mothers in this research who worked, this was much more than a job. The normality and social contact that a working life brought was significant and were not motivated by financial gain. In some cases work was referred to as respite. Similar findings are reported in research with children with complex care needs (Redmond & Richardson 2003; Yantzi *et al.* 2006).

7.5.5 Accessing help from voluntary organisations

The important role of the voluntary organisations involved in the care of children with life-limiting conditions was confirmed in this research where a diverse range of organisations were represented. Although few had written policies and guidelines, when asked about accessing services most had admission criteria or acceptance policies with the majority being diagnosis-dependent.

Several authors have pointed out the value of a link person or coordinator of care to help parents of children with life-limiting conditions access the information and services they require in order to care for their child (DOHC/IHF 2005; Craig *et al.* 2008) and this is further endorsed in the national children's palliative care policy (DOHC, 2010). This recommends that the role of children's outreach nurse be developed in order to fulfil the role of key worker for families of children with life-limiting conditions. However the findings in this research indicate that the parents selected this key person themselves and they in turn assisted families by providing information, access to finances, equipment, carers, respite and other essential services and remained involved with the family for considerable periods of time. Such support has been reported in other specialities such as cancer in adults (Spencer & Battye 2001). In this study the people assuming this role for families were from diverse organisations with often little experience or expertise in the area of children's palliative care. This is a particularly significant finding, which warrants further investigation.

At the Macrosystem it is noteworthy that many parents in this study were disappointed in the level of state support for their child but were in receipt of a respite or care grant from one of several voluntary bodies paid directly to them. Ironically many of the voluntary bodies named by participants in this research were in receipt of at least partial Government funding through the Health Service Executive and thus unbeknown to parents they were receiving state support for their child. The lack of a coordinated approach to providing services to children with life-limiting conditions is well-documented (Redmond & Richardson 2003; DOHC/IHF 2005). Yet from this research it would seem that children with life-limiting conditions received often comprehensive packages of care that frequently included some respite services, however the process that parents had undergone in order to access these services relied on serendipity and lacked clarity.

Whilst legislation and changes in education and health policy all impact on the care of the child with a life-limiting condition in the Mesosystem (Lewis and Prescott, 2006), in Ireland there are clear policy guidelines on the development of respite care for children with life-limiting conditions (Department of Health 2010). Whilst parents in this research were not aware of or involved in the development of these policies ultimately the services their child received were impacted upon by the decisions made at this political level. In order to fully implement the recommendations clarity is required regarding where respite services are currently provided and the entry criteria for different services (IHF & CSH 2011; LauraLynn & Irish Hospice Foundation 2013). The diverse range of life-limiting conditions and the manifestation of these conditions mean that there is no one-fits-all approach to respite service delivery requiring service providers to think innovatively in order to meet the needs of parents and their child.

7.6 Summary of Chapter 7

In this chapter findings from this research have been discussed as they relate and impact upon the four interconnecting systems of the family. In attempting to interpret and explain findings this chapter has highlighted how the respite needs and experiences of parents have been shaped and has provided an in-depth exploration of the key factors as they relate to parental experience of respite in children's palliative care.

Caring for a child with a life-limiting condition impacts most acutely and deeply affects the functioning in the Microsystem of the immediate family. In describing their respite needs and experiences parents highlighted the changing needs of their child over time. Utilisation of services was dependent on many interconnecting factors. Parent's understanding of their child's condition, diagnosis and prognosis all impacted upon their decision-making in regard to the utilisation of respite. Past experiences of healthcare provision was also an influential factor, and negative experiences of in-patient care of their child left a legacy of doubt for parents regarding the ability of others to provide care.

Parents, and in particular mothers, were the primary carer for their child and over time they developed skills and expertise in caring. Parents once empowered did not easily relinquish their control over their child's care and in order to do so, regardless of qualifications or experience, parents required evidence that the carer was competent and capable of providing an equal standard of care to that which they provided. Developing this trust was a process and once established parents valued carers and felt comfortable leaving their child and this was respite for them. Finding such staff was difficult and dependent on not only the required skill set but funding and essentially the geographical location of the family home.

The majority of families utilising respite services were caring for a child with intellectual and physical disabilities. Those with other life-limiting conditions were less likely to avail of respite services. In particular the respite needs of adolescents were more difficult to assess and meet. Findings indicate that this group experience social isolation as a result of their condition and traditional respite supports offered to them are not acceptable to them.

The interplay and interconnections across all areas of the family system were seen in the findings of this research exploring respite needs and experiences; the cultural, religious, socio-economic factors that influenced the everyday lives of the parents of children with life-limiting conditions. The impact of living with a child with a life limiting condition on the immediate and extended family and the wider society can all be seen.

In light of the findings of this research the following chapter draws together the evidence from this research relating to respite in children's palliative care and presents

recommendations for the future development of respite services for children with life-limiting conditions and their families arising out of this research.

CHAPTER 8 – CONCLUSION AND RECOMMENDATIONS

8.1 Introduction

In this chapter recommendations arising from the findings of this research are presented. The strengths and limitations are highlighted and possible gaps in the findings are identified. Areas where further research is required are also suggested.

8.2 Key conclusions and recommendations

Children's palliative care is a relatively new specialty which has developed and evolved in Ireland over the last decade. This thesis has explored the respite needs and experiences of parents caring for a child with a life-limiting condition, from multiple perspectives viewed through the lens of the family systems theory. It is suggested that the outcome of data analysis is to create or discover something new (Sandelowski 1995). This is the first in-depth study of this phenomenon in Ireland and this research using multiple case study methodology has resulted in some important and unique findings.

This thesis highlights that parent's need for and use of respite services varies over time and is dictated by their child's condition and their understanding of their child's illness. Evidence is presented here that not all children with life-limiting conditions require respite. Parents all specified a preference to care for their child at home and indicated that a number of key factors influenced decision-making regarding respite.

This thesis proposes that there is no one-size-fits-all approach to providing respite care to children with life-limiting conditions. Indeed in this research there were distinct differences between children with life-limiting conditions, providing evidence that the use of respite services is linked to the child's diagnosis and underlying condition. Age of the child is an important consideration in the provision of respite where there is a need to develop a diverse range of respite services reflecting the differing needs of each age group. In this research the needs of adolescents were clearly identified as being unique and warranting further investigation.

This thesis highlights the challenges of access to accurate information for parents enabling them to not only maintain control over their situation but to make informed decisions about the care their child needed, including the role, suitability and utilisation of respite care. Information given to parents regarding key issues such as diagnosis and prognosis also impacted on access to services and respite provision and utilisation.

This thesis confirmed the development of expert skills by parents. Parental knowing and the level of control displayed in caring for their child were usually respected by the healthcare professionals providing care. Parents sought consistency in staffing and the development of a familiar, trusting relationship before they were able hand over their caring responsibilities to others. Finding suitable and experienced staff to provide care presented a major challenge. Despite the diverse circumstances of each case and the differing characteristics of each family, gaining and maintaining control over their child's care was evident in each family.

For parents the impact of caring for their child was all-consuming and impacted on all aspects of family life. There is a perception in healthcare that family, friends and neighbours are a ready and available source of support and respite for parents caring for a child with a life-limiting condition at home however, this is not supported in the findings of this research. Those who were trusted and provided support shared several key features: all had provided care from soon after birth or diagnosis, many felt confident in their ability to provide care and all were female.

Respite offers a break from the routine of caring and was preferred in the family home even though it often resulted in a loss of privacy for other family members. The specific needs of well siblings were of concern to parents and this was demonstrated by the emphasis that they placed on setting time aside for their well children often using the opportunity respite provided to do so.

There appeared to be no systematic process for accessing respite services. Adding to parents' mistrust of the system, over time they learnt where and how best to access services or funding for care and often resorted to organising and sometimes paying for this care themselves. In order to achieve equity and fairness in the allocation of respite clarity is required around the

process of accessing services. In seeking to access help for their child parents were able to identify a key person who had provided assistance. In this study the people assuming this role for families were from diverse organisations with often little experience or expertise in the area of children's palliative care.

Home was the location of choice and parents stressed that they did not wish to be parted from their child particularly if their child was unwell or they perceived that time was limited. This made respite at home more appealing. During inevitable hospitalisation a lack of suitable facilities for relatives did not deter parents from staying with their child; on the contrary, all parents explicitly stated that regardless of the length of admission they would not leave their child alone without a parent or proxy in attendance, including overnight stays. So whilst appearing to give parents a break from caring, on the contrary, parents found hospital admissions more stressful than providing care themselves at home.

The issues raised by the parents of adolescents' present challenges when aiming to meet their respite needs. In this study parents reported none of the adolescents had availed of the various respite services that had been offered to them. This included specific respite opportunities that were aimed at teenagers. The overwhelming message that parents presented was that despite ill-health their teenager craved normality and acceptance of peers. It is clear from these findings that not all children with life-limiting conditions require respite and that there is no one-fits-all approach to providing respite in children's palliative care.

This thesis indicates the need to distinguish the significantly different respite need of children with life-limiting conditions. These are dependent on diagnosis and the age of the child for instance the vastly differing needs of teenagers without cognitive impairment and younger children with neurological disabilities. There is an unambiguous demarcation between the needs of the two groups thus demonstrating the importance of age and diagnosis appropriate respite services.

This thesis highlights a clear demarcation between parents' acceptance of people's help with their child during the day and the distinction made regarding their ability to help at night. Interestingly parents reported that depending on a few prerequisites (for example stable

condition of their child and no complex care due) they were happy for certain people to care for their child for lengthy periods of time during the day only. There is a dearth of literature pertaining to this particular important issue that warrants further investigation.

8.3 Strengths and limitations

8.3.1 Limitations

As a novice researcher this thesis reflects the principal investigator's limited experience in conducting qualitative research and more explicitly a lack of previous experience utilising case study methodology. However, the case study approach was fully embraced and the method carefully utilised in order to meet the study aim and objectives.

This research is limited to the experiences of nine specific families and as such findings cannot be generalised. However, whilst generalisation is not possible as findings were specific to each case, cross case comparison does reveal commonalities in findings within and between cases.

There is a dearth of contemporaneous literature pertaining specifically to children's palliative care. In its absence, literature from related areas has been utilised and therefore where findings have been confirmed by supporting literature this is often not specific to children's palliative care. This is further complicated by the ambiguous terminology in children's palliative care.

Participants in this research were selected by gatekeepers who chose parents based on their perceived ability to fulfil study inclusion criteria and to fully participate in the research process. There is a need to determine if the needs of those parents who were not referred differ from findings presented here. Similarly, parents themselves then became gatekeepers when asked to identify other research participants from within the family system. This resulted in some clear omissions of important and interesting potential participants from across the family system.

8.3.2 Strengths

This research is the first of its kind in Ireland, specifically looking at respite in children's palliative care and therefore provides a unique view of this phenomenon. Through the lens of the family systems theory this research also provides a unique view of the impact of Irish

culture on the respite needs and experiences of parents of children with life-limiting conditions.

A strength of this study is that the researcher was not known to any of the participants and was not associated with organisations providing respite care to children with life-limiting conditions. Therefore parents were able to share their experiences and opinions without judgement or recrimination and, by ensuring confidentiality, parents were able to openly and honestly discuss the issues that impacted on their respite needs and experiences.

By utilising case study methodology it was possible to view respite in-depth from multiple stakeholder perspectives.

8.4 Accomplished aims and objectives

The aim of this study was to explore the concept and meaning of ‘respite care’ for parents caring for a child with a life-limiting condition requiring palliative care in a real world context.

Objectives:

- To describe respite service delivery from the perspective of parents caring for a child with a life-limiting condition requiring palliative care
- To identify the elements of the respite experiences that are important to parents
- To identify barriers and facilitators to the delivery of respite care

This thesis clearly identified and described the delivery of respite services to the parents of children with a life-limiting condition from multiple perspectives providing clear evidence of the range and diversity of experiences within and between cases. Respite in children’s palliative care is a multifaceted phenomenon and untangling the interlinking factors that impacted on parents’ experiences of respite was challenging. Several key factors have been identified and explored throughout this thesis. Barriers and facilitators to the provision of respite care to children with life-limiting conditions and their families have been also identified and discussed.

8.5 Implications for policy and practice

Based on the findings of this research this section proposes a number of recommendations for practice and policy⁴⁰:

8.5.1 Implications for policy

Whilst a national policy for children's palliative care exists (DOHC 2010) and a national needs assessment has been undertaken (IHF & CSH 2011; LauraLynn & Irish Hospice Foundation 2013) specifically aimed at assessing respite services for children with life-limiting conditions. However despite the publication of these documents there remains a dearth of accurate and contemporaneous data relating to the provision of respite for children with life-limiting conditions and their families. This thesis adds to the data available and gives insight into some of the factors that need to be considered in order to meet the range of respite needs.

Based on the findings of this research it is recommended that policy makers:

- Identify where and how respite care is currently provided to neonates, children and adolescents with life-limiting conditions regardless of their diagnosis
- Ensure equity in the provision of respite to children regardless of diagnosis, age and geographical location
- Commission research specifically aimed at identifying the respite needs of neonates, children and adolescents with life-limiting conditions as distinct groups
- Oversee the development and implementation of an assessment process aimed at identifying the specific respite needs of neonates, children and adolescents with life-limiting conditions
- Ensure the assessment process is repeated at intervals appropriate to the child's condition bearing in mind the changing needs for respite over time
- Review the process for allocation of funding for respite care including cash payments to families and the practice of allocating funding through voluntary bodies

⁴⁰ The findings of this study will be disseminated widely. The dissemination strategy for this research includes the development of an e-booklet of key findings and recommendations available in two versions: one for families and one for healthcare professionals. A number of presentations have already taken place at national and international conferences and several more such presentations are planned.

- Develop and implement policies that ensure high quality care is provided and that clinical governance measures are in place to enable services to meet the respite needs of parents caring for a child with a life-limiting condition

8.5.2 Implications for practice

This thesis is original and provides insight into the respite needs and experiences of parents caring for a child with a life-limiting condition from multiple perspectives. This thesis highlights the factors that impact on parents' use of respite services.

Some findings of this research are similar to other studies (Steele 2000; MacDonald & Callery 2004; Heaton *et al.* 2005; Eaton 2008); however, these studies relate to children with specific conditions or needs and not all have been diagnosed with a life-limiting condition. This research adds to the body of evidence on respite as it specifically relates to children who have a life-limiting condition regardless of diagnosis and age.

Findings of this research suggest that current respite service provision does not meet the needs of parents caring for a child with a life-limiting condition. Using a family systems approach to understanding the physical, psychological, social and cultural context of parents caring for a child with a life-limiting condition enables healthcare professionals to provide the practical support that parents require in order for them to get a break from caring for their sick child. This study provides unequivocal evidence to suggest that in order to enhance the experience of each individual family there is a requirement to understand the factors that are important to families. These include:

- The provision of honest and open communication about important issues such as diagnosis and prognosis whilst maintaining hope
- Considering ways in which parents' experiences of maternity and children's hospitals can be improved
- The importance of maintaining the child's routine when providing care such as respite
- The acknowledgement that respite and care needs change over time and this should be managed by those involved in the care of the child and family
- The need for carers to respect the child, their family, their home and parents' knowledge as expert carers

- The need for parents to be involved in choosing who cares for their child
- The specific respite needs of adolescents need to be considered
- The need for clinical governance issues to be addressed to ensure that families are receiving the best quality respite care

8.6 Gaps and further research

There is very little empirical evidence to support many aspects of children's palliative care practice including the provision of respite. This is partly due to the fact that it is a relatively new and emerging specialty but also as there is ambiguity surrounding many of the terms used resulting in a lack of clear research focus. Whilst this thesis offers unique and original insight into aspects of the respite needs and experiences of parents caring for a child with a life-limiting condition, through the research process and findings it is possible to identify areas where further research is needed.

- An exploration of healthcare professionals' role in giving information to parents of children with life-limiting conditions including diagnosis and prognosis in an Irish context
- The pragmatic aspects of the provision of respite care to children with life-limiting conditions regarding issues such as:
 - Parents as the direct employer of care staff in the family home
 - Clinical governance of staff working with families in their home
 - Equity in and access to the provision of respite services
 - Age-specific respite opportunities
- To assess the specific respite needs of teenagers with a range of diagnoses
- The views of children and adolescents with life-limiting conditions on their respite needs and experiences
- Why parents were more likely to accept offers of respite during the day time than at night
- Various factors affect parents' decisions regarding their child's schooling and if school is to be considered as a type of respite, these factors require further explorations.

8.7 Conclusion

This thesis is original in its contribution by explicating multiple perspectives on the scant body of knowledge regarding respite in children's palliative care. It attempts to bring together the various elements of respite and explores and explains parental perspectives on their need and experiences of accessing respite for their child with a life-limiting condition.

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APPENDICES

Appendix 1 - Table 1 – Papers included in this literature review

Table 1 – Papers included in this literature review								
Title of paper	Authors	Location of research	Target disorder	Participants	Year	Geographic Location	Key findings:	Study design
Life threatening illness and hospice care. <i>Archives of Disease in Childhood</i> 64; 697-702	Stein, A., Forrest, G., Woolley, H., Baum, J.	Children's Hospice	Children's Palliative Care	25 Families (In 5 the child had died) of 26 children	1989	Oxford, England	<p>Families reassured by experience of staff</p> <p>Five families had previously experienced the death of a previously ill child</p> <p>Not only were parents concerned about their child's physical condition and symptom management it was also found to be impacting on parents:</p> <ul style="list-style-type: none"> Marital relations Psychosocial functioning Finances/Employment Siblings <p>Conclusions:</p> <p>Need for flexible care and support for the whole family</p> <p>Bereavement support</p> <p>Symptom management</p> <p>Relief and help with everyday caring</p>	Mixed methods Semi-structured Interviews; Questionnaires
Impact of Home-based Respite Care on Families of Children With Chronic Illnesses. <i>Children's Health Care</i> 24(1);33-45	Sherman, B	Home-based pediatric respite	Chronic illness	73 families	1995	Albany, New York, USA	<p>Assessed:</p> <p>Demand for the service and the number of respite sessions utilised</p> <p>Nursing skills of home care nurses and their capacity to provide care including technical care such as the administration of medicines</p> <p>Effectiveness of services evaluated during interviews with families</p> <p>Parents described the stresses of caring for</p>	Mixed methods Pre and Post evaluation design Questionnaires Interviews

							<p>their child with a chronic illness and assessed their patterns of respite utilisation.</p> <p>Higher use of respite was shown to correlate with lower sibling stress</p> <p>Small sample resulted in inability to conclusively prove the benefits of respite</p> <p>There were issues with accessing appropriate staff to provide care at home</p>	
Study of care management arrangements for dying children	While, A., Cornish, J., Citrone, C.	Four different health authority regions	Life-limiting incurable disorders	72 interviews with: Social workers; Paediatricians; Nurses; Service managers; Respite workers	1996	UK	<p>Focussed on the organisation and provision of services</p> <p>The need for more respite was a key finding</p> <p>The need to meet child and family preference</p> <p>That services varied according to geographical location</p>	<p>Case study:</p> <p>Postal survey</p> <p>Semi-structured interviews</p>
The process of empowerment in mothers of chronically ill children	Gibson, C.	Neurological unit of a large children's hospital	Children with Neurological disabilities	12 families	1997	USA	<p>Empowerment was conceptualised as it related to parents caring for a chronically ill child</p> <p>Overtime as parents confidence grew they were able to challenge and take charge in the care of their child</p> <p>Maternal knowledge and intuition were key in this process</p> <p>Parents wished to help others in similar situations</p>	<p>Grounded theory</p> <p>Participant observation</p>
Matching short break	McConkey R.	Rural and	Intellectual/	476 families	2000	Northern	Census completed by family social worker	Census

services for children with learning disabilities to family needs and preferences. <i>Child Care Health Dev.</i> 26(5), 429-444.	and Adams L.	urban health board area	Physical Disabilities aged 19 and under	76 parents of children who had received a short break service		Ireland	106:476 had residential breaks 106:476 used hospital breaks 69% were deemed to need more breaks 77% had received short breaks in the last year There are insufficient respite places to meet demand Hospital breaks are not a favoured option Family income impacts of the breaks received Local services were preferred	Interviews
Trajectory of certain death at an unknown time: children with neurodegenerative life-threatening illnesses. . <i>Cancer Journal of Nursing Research</i> 32, 49-67.	Steele R.	Pediatric hospice-care programme and a children's hospice	Neuro-degenerative Conditions	8 families (29 family members) with a child with neuro-degenerative life-threatening illness	2000	Ontario, Canada	Parents reported that the child's illness trajectory was marked by settled periods followed by a decline in physical health "dropping off the plateau". Once on the plateau families waited for the next fall. Parents described feeling isolated and scared and reported increased fear, uncertainty and grief Parents valued relationships with healthcare professionals and other key individuals. Having a connection in a tertiary hospital was viewed as important to parents Ongoing contact with professionals providing information and co-ordination helps alleviate anxiety and isolation	Grounded theory In-depth interviews
Negotiating lay and professional roles in the care of children with complex health care needs. <i>Journal of Advanced Nursing</i> 34(5), 593-602	Kirk S.	Home	Complex Needs	Purposive sample of parents of 24 technology-dependent children and;	2001	Manchester, UK	Parents decision to care for their child at home was influenced by feelings of obligation and absence of alternative options in the provision of community care. Ultimately parents, as carers and decision-makers felt a sense of control	Qualitative: Grounded theory - In-depth interviews

				Purposive sample of 38 health care professionals caring for them			Professionals raised concerns regarding whether the parents had a choice.	
Respite care users who have children with chronic conditions: are they getting a break? <i>J Pediatr Nurs</i> 16(4), 234-244	Neufeld S.M., Query B. and Drummond J.E.	Home	Children with chronic conditions	54:299 (21% response) primary care givers using a respite service for persons with chronic conditions	2001	Alberta, Canada	<p>All respondents were women</p> <p>Children had a wide range of diagnoses</p> <p>Respondents identified a range of respite services</p> <p>The majority used in-home respite</p> <p>A quarter of respondents rarely used respite</p> <p>There was a lack of people or agencies to provide respite</p> <p>Availability of qualified staff was the most cited concern for parents requiring a break</p> <p>Many parents using respite services did not perceive themselves as getting a break</p> <p>Funding needs to be provided in different ways</p> <p>There is a need to educate respite providers</p>	Postal survey
Living in a house of cards: Family experiences with long-term childhood technology dependence. <i>Journal of Pediatric Nursing</i> 16(1), 13-22.	O'Brien M.E.	Home	Technology-dependent children	Purposive sample of 15 families (11 mothers and 4 parent couples)	2001	Milwaukee, USA	<p>Families described managing life with a technology dependent child; maintaining a functioning family and making sense of life</p> <p>Frequent and unexpected change was inherent part of family life</p> <p>Parents expressed concern about the future</p>	Interviews

							<p>Parents developed the skills and knowledge required to manage the technology needed by their child</p> <p>The home environment was impacted upon by the equipment and care of the child</p> <p>Parents also described the impact of caring for their child on their: their marriage; finances; and relationships with extended family and friends</p>	
<p>Dilemmas in the provision of own-home respite support for parents of young children with complex health care needs: evidence from an evaluation. <i>Journal of Advanced Nursing</i> 34(5), 603-610.</p>	<p>Olsen R. and Maslin-Prothero P.</p>	<p>Home-based respite service</p>	<p>Complex Needs</p>	<p>18 families referred to an outreach service and in receipt of respite services</p>	<p>2001</p>	<p>Leicester, UK</p>	<p>Following a topic guide parents identified the factors influencing family well-being</p> <p>Parents wanted diversity and flexibility in the provision of respite services</p> <p>Respite gave parents time to sleep and spend time with siblings</p> <p>Parents require respite to be provided in diverse ways</p> <p>Pre-booked respite does not always meet the needs of parents</p>	<p>Qualitative: In-depth interviews</p>
<p>Short breaks for families caring for a disabled child with complex health needs. <i>Child & Family Social Work</i> 6(1), 67-75.</p>	<p>Robinson C., Jackson P. and Townsley R.</p>	<p>Children's Hospice</p>	<p>Disabled children with complex needs</p>	<p>4 children's Hospices – 38 families 39 families</p>	<p>2001</p>	<p>UK</p>	<p>Some families experienced difficulties accessing short-term care to suit their child's needs</p> <p>Age limits often applied</p> <p>Parents had real concerns regarding the quality of care provided in out-of-home locations</p>	<p>Semi-structured interviews with self-selected parents and healthcare professionals</p>

							Trust in carers was a deciding factor Care in the family home impacted on the home environment Parents' were generally happy with the care provided by hospices Hospital stays were being used in place of respite breaks	
Palliative care in the community for children with cancer in South East England. <i>European Journal of Oncology Nursing</i> 5(3), 190-197	Spencer, L., Batty, L.	Community	Palliative care for children with cancer	40 Health care professionals	2001	South East England	Explored palliative care service provision from the perspective of healthcare professionals. Multi-agency collaboration is needed Key areas for improvement: Communication between services 24 hour specialist advice Continuity of nursing and respite care Services should not be diagnosis specific	Qualitative: In-depth interviews
Hospital staff and family perspectives regarding quality of pediatric palliative care. <i>Pediatrics</i> ;114;1248-1252	Contro N., Larson J., Scofield S. and Sourkes B.	Children's Hospital	Children's Palliative care	446 Healthcare professionals 68 family members of 44 deceased children	2002	California, United States of America	Staff felt ill-prepared and unsupported to deal with palliative and end of life issues. Families reported distress regarding their child's care and communication with them regarding their child Staff and parents had shared concerns from differing perspectives	Mixed methods Written survey to health professionals Interviews with families of deceased children
Do children with non-malignant life-threatening	Horrocks, S., Somerset, M.	Community	Children's Palliative Care	29 Families – 16 families received pre and	2002	Bristol, UK	Assessed: Child's healthcare needs (physical, emotional and dependency related needs	Quantitative: Questionnaires

conditions receive effective palliative care? A pragmatic evaluation of a local service. <i>Palliative Medicine</i> 16:410-416				post questionnaires, 13 families follow up only questionnaires			<p>Need for services</p> <p>Quality of life of families</p> <p>The need for follow-up by healthcare professionals</p> <p>Families were excluded if their child was too close to the end of life and therefore sample may not be representative</p> <p>Findings included the need for better communication, the provision of a 24 hour a day service and improvements in respite care</p>	
Family perspectives on the quality of pediatric palliative care <i>Arch. Pediatr. Adolescence Medicine</i> 156, 1419.	Contro N., Larson J., Scofield S. and Sourkes B.	Children's Hospital	Children's Palliative care	68 family members of 44 deceased children	2002	California, United States of America	<p>Families reported: Confusing, inadequate or uncaring communication regarding treatment or prognosis;</p> <p>The profound impact of certain isolated incidents;</p> <p>Unmet needs of siblings;</p> <p>Inconsistent bereavement follow-up</p>	Interviews with families of deceased children
Experiences of families in which a child has a prolonged terminal illness: modifying factors. <i>International Journal of Palliative Nursing</i> 8(9);418-434	Steel, R.	Pediatric hospice – care programme and a children's hospice	Neuro-degenerative Conditions	8 families (29 family members) with a child with neuro-degenerative life-threatening illness	2002	Ontario, Canada	<p>Families sought to find a way to manage the physical, cognitive and emotional work associated with caring for their child</p> <p>Physicians were most often the pivotal figure in families interactions with the healthcare system</p> <p>Parents' are highly selective in allocating</p>	<p>Grounded theory</p> <p>Observation</p> <p>In-depth interviews</p>

							<p>their trust</p> <p>Parents needed to be assured of carers competence and technical skills</p> <p>Good communication from the outset was seen as desirable and a prerequisite to good relationship between parents and healthcare professionals</p> <p>Respite was very important as if provided time for parents to talk</p>	
<p>Supporting 'expert' parents - professional support and families caring for a child with complex healthcare needs in the community. <i>International Journal of Nursing Studies</i> 39, 625-635.</p>	Kirk S. and Glendinning C.	Home	Complex Needs	<p>Purposive sample of parents of 24 technology-dependent children and;</p> <p>Purposive sample of 38 health care professionals caring for them</p>	2002	Manchester, UK	<p>Parents knowledge was derived from both training and experience</p> <p>Parents valued having their knowledge acknowledged by professionals</p> <p>Continuity in parent-professional relationships was valued</p> <p>Parents valued support including: being there; listening; building confidence; practical support; organising equipment and advocacy</p> <p>Relationships between parents and professionals are dynamic</p>	<p>Qualitative: Grounded theory - In-depth interviews</p>
<p>Just Getting on with it: Exploring the Service Needs of Mothers Who Care for Young Children with Severe/Profound and Life-Threatening Intellectual</p>	Redmond B. and Richardson V.	Home	Intellectual Disabilities	<p>17 mothers of children aged under 4 years of age in receipt of assistance from a voluntary organisation</p>	2003	Republic of Ireland	<p>Focused on: the usefulness of the financial, practical and emotional supports offered to parents</p> <p>Mothers were found to be under considerable emotional and psychological distress relating to the care of their child</p> <p>Mothers noted a lack of information</p>	<p>Narrative descriptions</p> <p>Semi-structured interviews</p> <p>General Health Questionnaire</p>

Disability. <i>Journal of Applied Research in Intellectual Disabilities</i> 16(3), 205-218.							available to them Mothers spoke of: Living with uncertainty The financial strain Geographical inequities Accessing equipment Co-ordination of services	
Different meanings of respite: a study of parents, nurses and social workers caring for children with complex needs. <i>Child: Care, Health and Development</i> 30(3), 279-288.	MacDonald H. and Callery P.	Respite centres, schools and data base of 'special needs children'	Children with complex care needs	Interviews with 19 mothers and 7 fathers of children aged 6-18 AND 13 nurses 4 Social workers	2004	North West England	Reporting on one aspect of a larger study. The meaning of respite from two perspectives parents and providers and the features most valued. Parents identified 3 types of respite: Short breaks provided by the extended family or friends Short breaks (3-4 hours) provided by an agency (usually in the home) Overnight respite out of the home. Parents need for respite grew as their child got older. Their main concern was that regardless of location of care their child was safe and well-cared for. Parents and Nurses valued overnight respite out of the home. Social workers felt it was better for the child to be cared for in the family home. Uptake of respite increases as the child grows older. Careful examination of the meaning of respite to parents is required	Qualitative: In-depth interviews

<p>The impact on families of respite care in a childrens hospice. <i>Journal of Palliative Care</i> 20(4), 277-286.</p>	<p>Davies B., Steele R., Collins J., Cook, K., Smith, S.</p>	<p>Children's Hospice</p>	<p>Children's Palliative Care</p>	<p>Questionnaire responses from 65 parents of children using hospice services</p> <p>Interviews with 18 families</p>	<p>2004</p>	<p>Vancouver, Canada.</p> <p>Rural and urban caseload mix</p>	<p>Evaluation of parents experience of using hospice-based respite services:</p> <p>Parents reported beneficial for:</p> <p>Child – providing a safe environment, enabling socialisation and promoting independence</p> <p>Siblings – providing a break for parents and reducing resentment of sick sibling</p> <p>Parents – providing a break from caring and time for themselves and providing the opportunity to meet other parents in a similar situation</p> <p>Hospice-based respite was difficult for families who lived in remote rural locations</p> <p>There is a need for studies on respite in children's palliative care in order to meet the needs of families</p>	<p>Action research</p> <p>Postal survey;</p> <p>Interviews</p>
<p>Families experiences of caring for technology-dependent children: A temporal perspective. <i>Health and Social Care in the Community</i> 13(5), 441-450.</p>	<p>Heaton J., Noyes J., Sloper T. and Shah R.</p>	<p>Hospital, hospice or voluntary organisation</p>	<p>Technology-dependent children</p>	<p>Purposive sample of 36 families of technology-dependent children</p>	<p>2005</p>	<p>North of England</p>	<p>Technology dependent children are not all life-limited</p> <p>Some children were capable of self-care</p> <p>Sleep disturbance in parents was a regular occurrence</p> <p>Technical care was time consuming and required certain skills</p> <p>20 families received no out-of-home respite</p> <p>12 children received technical care at school</p>	<p>Qualitative:</p> <p>Face-to-face semi-structured interviews with parents; childre and siblings</p> <p>Pre-interview questionnaire</p>

							<p>When children were hospitalised parents provided care for their child</p> <p>The impact on parents including work, finances and relationships are highlighted</p> <p>The impact on siblings and the home environment are discussed</p>	
<p>Strategies Used by Families to Navigate Uncharted Territory When a Child Is Dying. <i>Journal of Palliative Care</i> 21(2), 103-110.</p>	Steele R.	Pediatric hospice – care programme and a children’s hospice	Neuro-degenerative Conditions	8 families (29 family members) with a child with neuro-degenerative life-threatening illness	2005	Toronto, Canada	<p>Information was key in providing strategies for parents to cope with their child’s condition. Sharing information was essential.</p> <p>Families reported changing their priorities, slowing down their pace of life in an attempt to savour every moment</p> <p>Families altruistically focused on the care of their sick child</p> <p>Parents felt as though they were constantly on call and provided the majority of the care</p> <p>Parents were unable to maintain their relationships outside of the family home</p> <p>Parents reported “taking one day at a time” and that the threat of death never left them</p> <p>Parents’ reframed their experience looking at the positive side. No matter how bad things were for them – there was always someone worse off</p> <p>Parents underwent a spiritual and moral struggle to find meaning in their child’s illness.</p>	<p>Grounded theory</p> <p>In-depth interviews</p>

							<p>Parents' reported the importance of routine</p> <p>Caring was a full-time job but most received some respite in the home. Having people in the home was challenging –preferring people they trusted and knew</p>	
<p>Parent or nurse? The experience of being the parent of a technology-dependent child. <i>Journal of Advanced Nursing</i> 51(5), 456-464.</p>	<p>Kirk S., Glendinning C. and Callery P.</p>	Home	Technology-Dependent Children	<p>Purposive sample of parents of 24 technology-dependent children</p>	2005	Manchester, UK	<p>Parents described: Their dual role as both carer and parent</p> <p>Undertaking technical tasks</p> <p>The transformation of the family 'home' to a place of care with the equipment and personnel required to care for their child</p>	<p>Qualitative: Grounded theory - In-depth interviews</p>
<p>Impact on parents when a child has a progressive, life-threatening illness. <i>International Journal of Palliative Nursing</i> 12(12), 576-585.</p>	<p>Steele R. Davis B</p>	Unknown	Children with life-limiting conditions	<p>8 families 29 family members</p>	2006	Western Canada	<p>Sleep deprivation and the issuant chronic fatigue exacerbates many of the caring issues for parents</p> <p>Parents do not perceive caring for their child as a burden</p> <p>Parents were able to identify positives to their experiences of caring for their child</p> <p>The financial impact of caring for their child was far reaching and there were many 'hidden costs' associated with this</p> <p>Help was not always available or useful</p>	<p>Grounded theory</p> <p>Observation Multiple interviews</p>
<p>Getting out of the house: the challenges mothers face when their children have long-term care needs.</p>	<p>Yantzi N., Rosenberg M. and McKeever P.</p>	Family home	Children with long term care needs	<p>11 Mothers of children with physical and/or developmental long-term care</p>	2006	Ontario, Canada	<p>Mothers revealed physical, social and service challenges</p> <p>Physical challenges: Managing equipment</p>	<p>Semi-structurec interviews</p> <p>Field notes</p>

<i>Health and Social Care in the Community</i> 15(1), 45-55.				needs			Getting in and out of the car with a wheelchair bound child Exhaustion and lack of sleep Social challenges Family and friends knowledge, skills and expertise Misconception that family and friends can provide respite due to a lack of training and skills Family and friends can provide financial assistance and help with other children Employment opportunities were hampered by the mothers caring responsibilities Service challenges There was often a gap between the respite services provided and the needs of the mothers Mothers did not always have faith in the skills of the care provider More flexibility was needed Mothers need to have confidence in the carers Mothers in urban areas had greater access to out- of- home respite	
Use of respite care and coping strategies among Irish families of children with intellectual disabilities. <i>British Journal of Learning Disabilities</i> 35, 62-68.	MacDonald E., Fitzsimons E. and Noonan Walsh P.	Out-of-home respite	Intellectual Disabilities (range of disability mild to profound)	46 children with intellectual disability who were eligible to use respite services of a voluntary service provider 71 carers	2006	Republic of Ireland	Some children included in this study had mild disabilities and were able to self-care Most family carers were female Family size did not impact on the decision to use respite The importance of routine was reported by parents	21-item Demographic checklist 38-item carer's assessment instrument (CAMI)
Complex Needs. The nursing response to children and	McConkey R., Barr O. and Baxter R.	National study	Complex physical healthcare	30 parents of children with complex	2007	Northern Ireland	Families wanted their child to be part of the family with minimal hospital stays	Unspecified: Interviews with parents

young people with complex physical Intellectual Disabilities healthcare needs. <i>Department of Health, Social Services and Public Safety, Belfast.</i>			needs	physical needs 52 healthcare professionals Round table meetings with managers and commissioners			The impact of caring on parents lives included marital separation; giving up careers; financial difficulties; illness and stress Parents valued trusted relationships with carers More respite was needed in particular locally-based residential facilities Getting equipment was challenging	Focus groups and questionnaire with practitioners
Parenting children requiring complex care: a journey through time. <i>Child Care Health Dev.</i> 34(2), 207-213	MacDonald H. and Callery P.	Respite centres, schools and data base of 'special needs children'	Children with complex care needs	19 mothers and 7 fathers of children aged 6-18 4 grandmothers 3 grandfathers AND 13 nurses 4 Social workers	2007	North West England	The need for respite changes over time Respite is more important the older the child gets but there is inequity in the provision of services The input of family carers reduces as the child gets older The use of respite closely follows the development of the child	Qualitative: Ethnographic approach – In-depth interviews; Participant observation; Eco-maps; Documents
Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: Evidence to guide the development of a palliative care service. <i>Palliative Medicine</i> ; 21;689	Monterosso, L., Kristjanson, L., Aoun, S., Phillips, M.	Children's Hospital and Home	Children's Palliative Care	134 parents 20 service providers	2007	Western Australia	Parents identified the following issues Duration of care Access to services Financial and practical assistance Marital issues Information needs Skills of carers	Mixed methods Phase 1: Questionnaires (face-to-face or phone) Six questionnaires were used to assess: 1.Children's

							<p>Access and availability of services</p> <p>There were significant differences in care provision between children with malignant and non-malignant diagnoses.</p> <p>Parents of children with cancer were more adequately cared for in a co-ordinated way.</p> <p>Families of children with a non-malignant diagnosis often experienced more fragmented care over a longer duration.</p> <p>Parents of children with cancer were bereaved at the time of participating. Other parents were still caring for their child</p>	<p>abilities</p> <p>2.Resource utilisation</p> <p>3.Carer's needs</p> <p>4.Anxiety and Depression</p> <p>5.Family needs</p> <p>6. Home caregiver needs</p> <p>Phase 2: 38 face-to-face or telephone semi-structured interviews</p>
Safeguarding precarious survival: Parenting children who have life-threatening heart disease	Rempel, G. Harrison, M.	Tertiary referral centre, Children's Hospital	Hypoplastic left heart syndrome	16 parents of nine children	2007	Canada	<p>Parents wished to care for their child at home even when this required changes to the home environment to prevent life-threatening infection thus 'safeguarding precious survival'.</p> <p>Parents supported each other in caring and also elicited the help of extended family</p> <p>Parents reported undertaking complex care of their child using technology</p>	Grounded theory
'I don't know how we coped before': a	Eaton, N.	Children's Hospice and	Complex Healthcare	11 families (sub-group of	2008	South West of England	Eliciting views on hospice and home services.	Part of larger study

study of respite care for children in the home and hospice. <i>J Clin Nurs</i> 17(23), 3196-3204.		Home	Needs	larger sample) receiving care in either the hospice or at home			Part of a larger study – Parents reported: Care impacted on family including siblings The physical and emotional stress and ‘burden’ of caring for their child including its impact on their sleep Hospice respite was helpful, although the word ‘hospice’ was frightening Fighting for their child Findings – Parents wanted: Continuity and flexibility of services Familiarity with the staff Better communication Access to equipment at home.	Qualitative: Semi-Structure Interviews
Respite care for children with special health care needs. <i>Arch. Pediatr. Adolescence Medicine</i> 163(1), 49-54.	Nageswaran S.	Out-of-home respite	Special Health Care Needs	3178:38831 respondents to a question regarding respite	2009	United States of America	24% of parents reported unmet respite needs Transport to and from respite was an issue In-depth analysis of issues around respite provision were not assessed	Part of a larger survey Random cross-sectional study of a national survey
The lived experience of parenting a child with a life-limiting condition: A focus on the mental health realm	Rodriguez, A. King, N.	Not specified	Children with life-limiting conditions	2 children with cancer; 8 children with a non-malignant diagnosis	2009	Northern England	Parents reported feeling a huge responsibility for the care of their child Many parents reported withdrawing from social life and resultant social isolation The psychological impact of caring for their child impacted on every aspect of their life.	Phenomenology

							Parents reported feeling 'trapped' in caring for their child	
Issues of power, control and choice in children's hospice respite care services: a qualitative study. International Journal of Palliative Nursing, 16(10);505-510	Grinyer, A., Payne, S., Barbarachild, Z.	Children's Hospice	Children's Palliative Care	24 children's hospice service users	2010	North East England	<p>Only studys inpatient and day care services of a children's hospice</p> <p>Parents reported feeling isolated with little support from extended family</p> <p>Parents reported being reliant on hospice staff for respite</p> <p>Staff were reported as being powerful as it was they who decided on the frequency and type of respite available to families</p>	<p>Mixed- method</p> <p>Questionnaires</p> <p>Interviews</p>

Systematic reviews and literature reviews included in this literature review	Country or Jurisdiction	Year of Publication
Horsburgh M., Trenholme A. and Huckle T. (2002) Paediatric respite care: a literature review from New Zealand. <i>Palliative Medicine</i> 16, 99-105.	New Zealand	2002
Ingleton C., Payne S., Nolan M. and Carey I. (2003) Respite in palliative care: a review and discussion of the literature. <i>Palliative Medicine</i> 17, 567-575.	United Kingdom	2003
Mason A., Weatherly H., Spilsbury K., Arksey H., Golder S., Adamson J., Drummond M. and Glendinning C. (2007) <i>A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers</i> . HTA, York	United Kingdom	2007
McNally S., Ben-Shlomo Y. and Newman S. (1999) The effects of respite care on informal carers' well-being: a systematic review. <i>Disability and Rehabilitation</i> 21(1), 1-14.	United Kingdom	1999
Corkin D.A., Price J. and Gillespie E. (2006) Respite care for children, young people and families-are their needs addressed? <i>Int J Palliat Nurs</i> 12(9), 422-427.	Northern Ireland	2006
Strunk, J. (2010) Respite care for families of special needs children: A systematic review. <i>Journal of Dev Phys. Disability</i> . 22:615-630	Virginia, USA	2010

If you have any questions about the information in this document, or would like to know more about the differences between children's and adult palliative care, please get in touch by calling 0117 916 6422, or emailing info@act.org.uk.

Appendix 2 – The differences between adult and children's palliative care (ACT 2009)



Although it is acknowledged that there are similarities in the principles of palliative care for adults and children, it is crucial to emphasise underlying differences. Often service users, providers and commissioners make assumptions about the two sectors.

This document aims to help to clarify the similarities and differences, tabulating children's and adults' definitions side by side for easy comparison and understanding.

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	Children's Palliative Care	Adult Palliative Care
Palliative care	<p>Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.</p> <p><i>ACT (2008).</i></p>	<p>Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.</p> <p><i>World Health Organisation, 2002.</i></p>
Hospice care	<p>Children's hospice services provide specialist respite, emergency, palliative and end of life care for children with life-limiting conditions, either in the setting of a purpose built hospice or within the child's own home.</p> <p>Children's hospice care teams bring together a range of professional skills and services under one roof and offer care and support to all family members. Children's hospice services offer a rich array of specialist children's palliative care delivered through day care, hospice at home, specialist respite, telephone/advice, bereavement support, terminal care, emergency care and contact/key worker visits. Bereavement support is provided to the immediate family, extended family and schools and delivered both pre and post bereavement via a number of different models. These include activity weekends, workshops and one-to-one work.</p> <p><i>Children's Hospices UK, Children's Hospice Services, 2006.</i></p>	<p>Adult hospices care for the whole person, aiming to meet all needs – physical, emotional, social and spiritual. At home, in day care and in the hospice, they care for the person who is facing the end of life and for those who love them.</p> <p>Nearly half of all people admitted to a hospice return home again. The average length of stay is just 13 days. All care is free of charge. Within hospices you find a range of services – pain control, symptom relief, skilled nursing care, counselling, complementary therapies, spiritual care, art, music, physiotherapy, reminiscence, beauty treatments and bereavement support.</p> <p><i>Help the Hospices, 2007.</i></p>

	Children's Palliative Care	Adult Palliative Care
	All hospice care is free of charge.	
Hospice service provision	Care is provided over a longer period of time with regular short breaks and support for whole family. The service is often involved with the child and their carers from diagnosis to end-of-life.	Less respite and more focus on end of life care and symptom management. The hospice service usually only becomes involved as the disease/condition progresses.
Prevalence of Hospices	Over 40 services across UK. As there are few services across the UK, families often have to travel considerable distances to their geographically closest hospice.	Generally adult hospices are available locally across the UK.
Conditions	<p>Those children and young people accessing children's palliative care services will have a wide range of conditions including some cancer conditions. Leukaemia is the most common cancer in children.</p> <p>A variety of childhood conditions are rare, and length of illness can vary greatly from days to years. The child may survive into early adulthood, extending palliative care over many years.</p>	<p>The large majority of deaths at the start of the 21st century follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia.</p> <p><i>End of Life Strategy, DH 2008.</i></p>
New technologies	New technology has led to improved survival rates e.g. more premature babies are surviving and new techniques enable children to live for longer e.g. assisted ventilation for young men with Duchenne Muscular Dystrophy.	New technology and techniques lead to increased survival rates e.g. new cancer drugs. As more children with life-limiting conditions survive into adulthood, they will need adult palliative care services.
Links to other sectors	Strong links to disability and specialist chronic illness groups.	Strong links to agencies working with older people.
Transition	The population of young people with life-threatening and life-limiting conditions is growing as many chronic progressive conditions now reach a crisis during late adolescence and young adulthood. Many young people have	There is an increased demand on adult services from young people who are moving from children's services. There are few dedicated services for young people.

	Children's Palliative Care	Adult Palliative Care
	conditions which were formerly limited to childhood, and there are therefore limited relevant services that have been developed in the adult sector.	
Family issues	<p>Palliative care affects the whole family, with the burden of care falling upon parents and siblings or grandparents.</p> <p>Some illnesses are 'familiar' and more than one child may be affected. In most cases the direct family are the primary carers for the child/children. Siblings will also have support needs.</p>	Adults may not have family carers. Adults may also be carers for children in the family.
Developmental issues	Children continue to develop physically, emotionally and cognitively throughout their illness; this affects both their medical and social needs and their understanding of disease and death.	Generally deterioration (physical/psychological) is associated with the aging process.
Community support	Children's community nursing service provision covers 85% of the UK (<i>Royal College of Nursing, 2005</i>) and does not always provide seven-day care. CLIC Sargent, Macmillan and other voluntary organisations also provide supportive care.	District nursing services are widely available across UK and often available throughout the week. Macmillan and Marie Curie provide additional supportive care within the community.
Medical care	GPs are often unfamiliar with children's care and medical care is usually consultant led, often from tertiary centres, as many of the wide range of conditions are rare.	GPs are often involved in care and medical care is usually co-ordinated at local level.
Education & Employment	<p>Access to education is a legal entitlement for children.</p> <p>Often parents are unable to maintain full-time employment, as they are the key carers for their child.</p> <p>Many young people are unable to enter the employment market as they are unable to find employers who are willing to invest in their employment or support their specialist medical leave.</p>	<p>By the time adults are referred to palliative care services, many will no longer be in employment because of their deteriorating health.</p> <p>The age group receiving palliative care services is predominantly older and many will already be retired from employment.</p>
Commissioning	There is often a lack of understanding of	Commissioners may use a range of

	Children's Palliative Care	Adult Palliative Care
of services	services needed and the multi-agency provision adds to the complexity of commissioning services. The numbers of children affected are relatively small which means that commissioners may need to use a variety of processes to ensure the range of services are available for children and young people at local and regional level.	commissioning arrangements: PCTs in partnership with other local commissioning agencies; Local Specialised Commissioning Groups (LSCGs) at a population of 1-2 million; Specialised Commissioning Groups (SCGs) at a population of 3-5 million; and The National Specialised Commissioning Advisory Group (NSCAG) with top sliced funding from PCTs.
Funding	Unable to identify NHS spend. Children's palliative care services heavily rely on a large contribution from the voluntary sector.	Easier to identify NHS spend. Large contribution from voluntary sector.
Diversity issues	Challenge of providing appropriate care to diverse range of cultures.	Challenge of providing appropriate care to diverse range of cultures.
Care pathways	ACT has developed pathways for children's palliative care and transitional care and is currently developing a neonatal care pathway. The Department of Health is developing a continuing healthcare pathway. The Liverpool Care Pathway for the Dying Child is being developed and work on the Gold Standards framework for children is underway. The Preferred Place of Care tool can be adapted for use in children's services.	There are a number of national pathways e.g. the Liverpool Care Pathway and the Gold Standards Framework. The Preferred Place of Care is a nationally recognised tool for all palliative care patients used to record patients and carer's wishes in relation to their care and ultimate place of death.
Place of death	Children and young people are often unable to be supported to die in their preferred place of care e.g. home, because of lack of community support.	Most deaths (58%) occur in NHS hospitals, with around 18% occurring at home, 17% in care homes, 4% in hospices and 3% elsewhere. <i>End of Life Strategy, DH 2008.</i>

ACT for children **ACT** for families **ACT** together **ACT** now! **Appendix 3- Parent consent form**

PROJECT TITLE: An exploration of the respite needs and experiences of family's caring for a child with complex healthcare needs.

PRINCIPAL INVESTIGATORS: Julie Ling and Professor Mary McCarron

BACKGROUND

The purpose of this research is to find out the respite needs and experiences of parents caring for a child with complex healthcare needs. To do this the researcher would like to interview you on a number of occasions over the coming weeks and months. With your permission interviews will be voice recorded. If during interview you mention someone else who has been involved in respite care for your child (either a healthcare professional or a member of your family), with your permission the researcher may seek to interview them too. Should you agree to participate any information collected during the study will remain confidential. The only rare exception to this is if there is any risk to your child's safety.

DECLARATION:

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

PARTICIPANT'S NAME:

CONTACT DETAILS:

PARTICIPANT'S SIGNATURE:

Date:.....

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE:.....

Date:.....

(Keep the original of this form in the investigator's file, give one copy to the participant, and send one copy to the sponsor (if there is a sponsor).

Appendix 4 - Other participant consent form

PROJECT TITLE: An exploration of the respite needs and experiences of family's caring for a child with complex healthcare needs.

PRINCIPAL INVESTIGATORS: Julie Ling and Professor Mary McCarron

BACKGROUND

The purpose of this research is to find out the respite needs and experiences of parents caring for a child with complex healthcare needs. You have been identified as someone involved in the respite care of a child with complex healthcare needs. The researcher would like to interview you and with your permission interviews will be voice recorded. Should you agree to participate any information collected during the study will remain confidential.

DECLARATION:

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

PARTICIPANT'S NAME:

CONTACT DETAILS:

PARTICIPANT'S SIGNATURE:

Date:.....

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE:.....

Date:.....

(Keep the original of this form in the investigator's file, give one copy to the participant, and send one copy to the sponsor (if there is a sponsor).

Appendix 5 – Coding Sample

956 think like I nearly physically feel I want to get sick going in even after all these years

957 like. Like even the ...said like would you not arrange to meet the obstetrician and

958 speak with them I said I feel like this I said ahhhh I just couldn't

959

960 JL: and you never spoke to him about it

961

962 MOTHER: No never only after 6 weeks she was born he said she won't see she wont

963 eat she wont hear she wont know love, she wont know this she wont know that and I

964 said good Jesus couldn't believe it like, but she does like she can see she can see she

965 can hear she knows her family she loves being here like

966

967 JL: you can see as soon as you picked her up ...

968

969 MOTHER: Ahh yes she is a good little girl like she is very good and she has brought

970 love to ...the amount of people like who pass our home and their kids would

971 remember Molly and they be now in their teens and they are not coming in to see us

972 they are coming in to see Molly. She sitting in the chair quiet but she just seems to

973 draw people to her because she is non-complicated in a way you know what I mean.

974 (To Molly) is that right Molly?

975

976

977 JL: and Molly's is getting ready for a weekend away this evening?

978

43

Comment [JL150]: Memories of b

Comment [JL151]: Health profesio
communication

Comment [JL152]: Living with a child
with a LLI

Appendix 7 - What are the respite needs and experiences of families caring for a child with a life-limiting condition requiring palliative care?

A key aspect of providing palliative care to children with life-limiting conditions and their families is the provision of respite care. Access to respite services is often inequitable and insufficient to meet the needs of the parent and child⁴.

Aim: To explore and describe the respite needs of parents caring for a child with a life-limiting condition requiring palliative care.

Objectives: To:

- describe respite service delivery from the perspective of parents
- identify the elements of the respite experiences that are important to parents
- identify barriers and facilitators to the delivery of respite care
- assist in the development of theory on respite care

Design:

A multiple case study design will be utilised which is an ideal method to enable parents to describe, explore and explain their respite experiences in a real world context.

Methodology:

Children's palliative care views the unit of care as the child and family. Parents with a child under the care of the palliative care team at a children's hospital will be asked to participate in this research. Case study utilises multiple sources of data collection both qualitative and quantitative. In this study methods used will include interviews, documentation, diaries and policies. Multiple interviews with parents will be conducted over time. Using family systems theory⁸ other key informants will be identified and may also be interviewed. Each individual case consists of a "whole" study, where facts gathered from various sources help to build the 'case'. Within each individual case various analysis techniques are needed according to the data collection method utilized¹⁹. Data will be analysed using a mixed methods approach. Once data from each case has been individually analysed, cross-case comparisons can be made to highlight and explore commonalities and differences²⁰ in parents experiences of respite care and theory can be developed.

Background

Palliative care

Palliative care for children is a small and highly specialised field of healthcare providing an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancing the quality of life for the child and providing support for the family, and includes the management of distressing symptoms, provision of respite and care through death and bereavement¹. A life-limiting condition is defined as any illness where there is no reasonable hope of cure and from which the child or young adult will die. Four categories of life-limiting conditions have been identified (Table 1)². Children's palliative care differs significantly from adult palliative care².

Ideally support for children with palliative care needs starts at diagnosis, for many children with life-limiting conditions this can be at birth. Palliative care support can be given alongside active treatments aimed at cure or prolonging life and should be provided at the child and family's location of choice². Most children with palliative care needs will have these needs met by their family supported by locally provided services. In Ireland there are on average 490 childhood deaths per year. Of these approximately 350 are due to life-limiting conditions with the majority occurring in the first year of life³. It is estimated that there are 1400 children living with a life-limiting condition in Ireland⁴, whilst not all of these children will require specialist palliative care, the majority will require respite care.

Children's palliative care is family-focused with the child and family viewed as the unit of care. The 'systems theory' is the foundation for this approach and is based on several interlinking theories that all centre on the multiple factors and circumstances that influence the functioning of the family unit. Four levels of family systems, as they relate to the care of a child with a life-limiting condition, have been identified (Diagram 1^{5,6,7}) where the child at the centre of care presents significant challenges to the functioning of the family system⁸. The family system theory provides the theoretical lens through which: this proposal has been developed; the research method has been chosen; and through which data will be collected and analysed.

Respite care

Several countries have developed children's palliative care policies^{9,10} and others, including Ireland, have undertaken needs assessments aimed at identifying the requirements of children with life-limiting conditions and their families^{4,11,12}. Regardless of country of origin, healthcare system or stage of development of palliative care services, the findings of the needs assessments already performed have been remarkably consistent¹³. All stress that home is the location of choice for both children and their families through illness and ultimately death. Respite care has been identified as an essential part of enabling parents to care for their child at home allowing parents to attend to their own needs, spend time with other children or to get a good night's sleep¹¹. However the components of respite services are poorly understood. When respite care is provided, its effectiveness in meeting the needs of the child and family has not been evaluated. For the purpose of this study respite care is defined as "The provision by appropriately trained individual(s) of care for children with life-limiting conditions, for a specified period of time, thus providing temporary relief to the usual

care-giver”¹⁴. Respite should ideally be tailored to meet the individual needs of the child and their family and can be provided either at home or outside of the home.

Respite care - Ireland

Parents value respite care and see it as essential to enable the family to continue to cope with the inherent stresses of caring, often long-term for a sick child,¹⁵ yet in Ireland, as in many other countries, access to respite care is reported to be inequitable and insufficient^{4,15,16} and is dependent on geographical location and diagnosis. Liaison Nurses are available to children with cancer to coordinate care and organize services in the home including: community services; respite admissions; and access to adult palliative homecare services if required.

Respite and palliative care support for children with a non-cancer diagnosis is challenging, many of these children have disabilities and complex care needs. Respite care for children with disabilities is provided through the Health Service Executive in residential and non-residential settings and is generally only available for children aged over 5 years. Many children with life-limiting conditions under 5 years of age rely on voluntary providers of care. These organisations often have specific referral criteria relating to certain age groups or specific diagnoses. Most of the providers of respite care for children with life-limiting conditions do not have the facilities to care for a child requiring palliative care who has complex medical and nursing needs. Currently, demand outstrips supply for respite services for children with disabilities and most services have waiting lists for new children or for children who are receiving services but who require additional help¹⁷.

Development of respite

In order to assist families and carers to provide care and support for a child with a life-limiting condition at home a range of flexible respite options needs to be developed. Including flexible locally-based respite both in-and out of the home¹⁷ Despite acknowledging the importance respite care plays in the provision of services to children with life-limiting conditions and their families, there is currently a dearth of information regarding where respite care is provided, the nature of services available and the effectiveness of services in meeting the needs and expectations of the child and their family⁴. It is known that child-friendly and accessible respite for children with life-limiting conditions in Ireland is limited⁴.

It is evident from research already conducted that respite care is invaluable to and essential for families caring for a child with a life-limiting condition^{4,12}. It is evident that parent’s views and experiences of respite care differ considerably. Even the use of the term respite has been reported to be unacceptable to some parents with the term “short break” the preferred term²⁴. Ambiguity surrounding the terms used in children’s palliative care is problematic. Some parents are understandably reluctant to acknowledge that their child has a life-limiting condition and the euphemistic term ‘complex needs’ is gaining popularity in the literature¹⁵. There is a dearth of research published to demonstrate best practice in the area of respite care for children with life-limiting conditions requiring palliative care¹⁵. One way to establish what respite truly means to and for parents is to extrapolate their understanding and experiences of respite care across the continuum of their child’s illness. This proposed research will utilize a case study approach which will enable parents to describe, explore and explain their respite experiences in a real world context.

Research question:

What are the respite needs and experiences of families caring for a child with a life-limiting condition requiring palliative care?

Aims and objectives:

The primary aim of this study is to explore the concept and meaning of ‘respite care’ for parents caring for a child with a life-limiting condition requiring palliative care in a real world context

Objectives:

- To describe respite service delivery from the perspective of parents caring for a child with a life-limiting condition requiring palliative care
- To identify the elements of the respite experiences that are important to parents
- To identify barriers and facilitators to the delivery of respite care

Method and design:

A longitudinal case study methodology will be utilised to explore the needs and experiences of parents caring for a child with a life-limiting condition.

Rationale for selecting method

Case study is defined as “an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon are not clearly evident” (p.13)¹⁸. There are two main proponents of case study research Yin¹⁸ and Stake¹⁹. Recent literature supports the use of case study research as a suitable method of studying palliative care phenomenon^{20,21}. This suitability stems from the ability of case study research to deal with context-dependent, complex situations, where multiple perspectives need to be addressed and where other research methods are difficult to use²¹. Furthermore, case study research is especially suitable when the question posed requires a detailed investigation of a real-life intervention where the event maybe ill-defined and success or failure of the event is difficult to focus on²⁰. Respite care for children with life-limiting conditions meets these criteria. Respite care where available, is frequently provided by a variety of statutory and voluntary agencies in differing care environments and geographical locations. Services have developed in an ‘ad hoc’ fashion often influenced by local, organisational, political and historical issues. By utilising a case study methodology, this research has the ability to capture and take account of these factors.

Children’s palliative care is multifaceted and often complex involving a myriad of different people and services. Parents’ respite experiences have a similarly complex configuration that is often contextually defined and geographically diverse. Case study encourages the collection of data concurrently thus participants can often refer to a similar timeframe or the same incident of care²⁰, which is of importance in case study research where data is collected in a real-life context. Thus case study methodology is an appropriate strategy for exploring

the respite needs of parents caring for a child with a life-limiting condition requiring palliative care.

Study design

This research will utilise a case study design. Replication is reported to strengthen the results of case study research¹⁸ and therefore a multiple case study approach will be used. The proposed process for this research is shown in Figure 1.

In the context of children's palliative care there is a lack of respite-related research and therefore no clear theoretical framework to underpin this study. To compound this there are no clear agreed outcomes or criteria for success in children's palliative care and ambiguity remains regarding definitions. Yin suggests case studies benefit from the prior development of theoretical propositions which guide both data collection and its analysis¹⁸. Others argue that theory and thus theoretical propositions can be developed during the case study process¹⁹. Theory as an explanation of situations or phenomena may range from formal academic theories to speculations made by research participants²⁰. Therefore whilst Yin recommends that 'propositions' are developed about the research reflecting important theoretical issues¹⁸, it is also accepted that where the topic is the subject of an exploration such as this research, propositions are not needed at the outset.

The duration of this study will be two years from the time of receipt of ethical approval. Due to the unpredictable nature of life-limiting conditions in children, it is envisaged that this study will follow parents of some children through to end of life care and other children may survive beyond the planned duration of the study.

Selection criteria

This research will be conducted [REDACTED] a national referral centre. It is the location of the only children's palliative care team. The team receives approximately sixty referrals from within the hospital per annum. Home is most frequently the location of choice^{15,16}, therefore the palliative care team are frequently involved in the organization of complex discharges including the ongoing provision of palliative and respite care. Potential research participants will be identified from this caseload and will be approached regarding participation. A leaflet explaining the inclusion and exclusion criteria, the purpose, design and dissemination strategy of the research and the researcher's contact details will be developed and given to potential participants.

Inclusion Criteria

- Parent (mother, father or both) of a child referred [REDACTED] during the study period
- Aged 18 years or over
- Able to communicate in English
- Willing and able to participate

Sample

In case study research cases must be selected in order to maximize what can be learned from the study in the time available¹⁸. Case study research requires that cases that are selected should be easy and willing subjects^{18,19}. Due to the nature of this research method it is not possible to predetermine the number of cases that will be undertaken however based on case study research reports an estimated maximum of twelve case studies will be undertaken in a two year period.

It has been suggested that where multiple cases study design is chosen it should follow replication rather than sampling logic¹⁸. Maximum variety sampling will be employed²⁰ and will aim to sample parents: from rural and urban areas; with small families and large; with a male or a female child; with malignant and non-malignant diagnosis. Some of these factors have been identified in the literature as having an impact on respite experiences^{2,4,16}. Whilst the findings of case studies do not seek to generalize, the literature confirms that the use of multiple case studies does increase the confidence that readers have in the findings¹⁹. The sample described above will provide a rich variety of data within each case study that will add to the body of knowledge regarding parent's experiences of respite care.

Data collection:

According to Yin, data collection should be treated as a design issue that will enhance the construct and internal validity of the study, as well as the external validity and reliability¹⁸. He suggests three principles of data collection for case studies research: use multiple sources of data; create a case study database and maintain a chain of evidence. These principles will underpin the collection of data in this research.

Case study research is marked by its use of multiple sources of data collection and can use either qualitative or quantitative methods to collect data including questionnaires, surveys and statistical data analysis²⁰. It can have either an inductive or deductive approach to theory²¹.

Six sources of evidence in case studies have been identified^{18,19}:

- Documents
- Archival records
- Interviews
- Direct observation
- Participant-observation
- Physical artefacts

Whilst all of these methods are available for use in case study methodology, only those that are pertinent to the study should be used, each bringing their own strengths to the research²¹. In this research multiple sources of data collection will be utilised including: documents, archival records and physical artefacts such as diaries. Observation may also be utilised,

however interviews will be the major component of data collection. Case study research also requires that the researcher move back and forth between the literature and the findings of their research during data collection²².

Interviews:

Interviews are particularly useful in case study not only for the rich data produced but also as a way to verify information and corroborate evidence obtained from other multiple sources. All interviews will take place in a location of the participant's choice and be recorded with the participants consent. The first interviewee will be the parent deemed to be the primary carer. The literature indicates that this is usually the mother²³. Further interviews with parents will be arranged at a frequency that will depend on the individual family and their circumstances and will depend on the pace, depth and content of each case²⁴. These interviews may take place over an extended period of time. By utilising the family system theory (see Diagram 1) the researcher will identify other key informants. In the 'microsystem' interviews with different family members are likely. In the 'mesosystem' extended family and health and social care professionals may be approached and in the 'exosystem' voluntary providers of care may be interviewed. The minimum number of interviews for each case is estimated to be three with a possible maximum of twenty interviews. Staggered entry to this study is important to allow the researcher to collect data thoroughly to help build the 'case'. The literature suggest interviews may take between 30 minutes and two hours each^{15,24}.

Interviews will be semi-structured using an interview guide developed by the researcher based on the literature^{15,25} and will tested and piloted prior to use. Interviews will be flexible in order to reveal in-depth views and experiences and open to new information from participants²⁰.

The researcher's field notes will constitute a component of the research data. All data collected throughout the research process will be used to build a comprehensive picture of each 'case'.

Data Analysis

Case studies frequently produce large amounts of diverse data requiring a pragmatic approach to management; therefore a general analytical strategy will be developed¹⁸. Data will be collected from various sources and therefore a mixed-method approach to data analysis will be utilized. Each individual case consists of a "whole" study, where facts have been gathered from various sources and conclusions made based on those facts. Within each individual case various analysis techniques are needed according to the data collection method utilized²¹. Analysis in this study will include thematic analysis of interview data²⁶, longitudinal analysis of patient journeys and analysis of documentation including policies. Interview transcripts will be coded using thematic categories drawn from the research aims. Organisation of interview data will be supported by NVIVO software. Data will be compiled into individual reports allowing each case to be viewed as a separate entity. Emerging conceptual issues and analytical themes will be identified. Triangulation is a mixed methods approach to data analysis and will be employed in the analysis of data in this study.

Triangulation is most appropriate where multiple sources of data (some qualitative and some quantitative) need to be analysed such as case study methodology²⁷.

Once data from each case has been analysed, cross-case comparisons may be made to highlight and explore commonalities and differences. It is also possible to use cross-case comparisons to make evaluative judgments about less and more successful activities and the factors associated within cases²¹. This analysis is based on a search for patterns across a number of cases¹⁹

Justification of steps to ensure rigour

In order to ensure that construct validity is not effected by investigator subjectivity Yin suggests the use of multiple sources of evidence, establishing a chain of evidence and allowing key informants to review a draft case study report¹⁸. In case study research a chain of evidence should also be maintained to increase the reliability of the study¹⁸. In this instance an external observer should be able to follow evidence from the initial research questions to the case study conclusions. These suggestions will be followed in this research.

External validity deals with knowing whether the results are generalizable beyond the immediate case. The use of multiple case study methodology strengthens results by replicating the pattern-matching between findings and theory, thus increasing confidence in the robustness of the theory¹⁸.

Access to and use of datasets how they will be managed

Access to medical and nursing notes at [REDACTED] will be required as part of the data collection process for this study. Confidentiality will be maintained throughout the study and use of coded numbers and pseudonyms will be employed. All data collected will be protected within the regulations set out in the Data Protection Act²⁸.

All data collected throughout the study from different sources including interviews, relevant documents, narratives, tabular materials, and other notes will be organized and included in a database.

Ethical considerations:

There are particular ethical considerations pertaining to this study and these are highlighted in palliative and research literature. These relate to the vulnerability of ill patients, in this case children, and their families, the researcher as insider/outsider and protecting anonymity. In accordance with the principles of consent all participants will be provided with written and verbal information on the study prior to interview. The principles of process consent are particularly pertinent and will be applied throughout the study period. Participants will be free to withdraw consent at any time. Continual checks will be made to establish that the participant wishes to continue prior to and during each interview. The principles of non-maleficence will be initiated by ensuring that psychological support will be available to the participants if required and this will be negotiated in advance with the support agency. Confidentiality will be maintained and use of coded numbers and pseudonyms will be employed.

Reflexivity

Reflexivity is a reflection on the research process coupled with an active critical engagement in an on-going process of self-exploration and awareness including your values and biases. The researcher making their values, biases and prior knowledge explicit, leads to greater transparency to the research process including data collection and interpretation²⁹.

As a palliative care nurse, my ontological and epistemological position has been influenced by my practical experience and professional philosophy, which asserts a holistic, patient-centered approach. My practical experience has been in the context discussed previously and my experiences in Ireland have been influenced by my work in other contexts of palliative care in addition to my experience in policy formation.

Involvement of stakeholders and service users

Access to the parents of children with life-limiting conditions in this research will be through [REDACTED] where the Consultant [REDACTED] [REDACTED] has offered support with accessing the sample and assisting in the research process by acting as my clinical supervisor. There is growing evidence to support the participation of family members in palliative care research suggesting that many value the opportunity to tell their story as a whole²⁰.

Case study research encompasses the views and experiences of stakeholders and services users by using multiple methods of data collection from various sources. In this study the views of parents, extended family members and service providers (both statutory and voluntary) will all contribute to the data. Stakeholders and service users will also be included in the dissemination of the research findings.

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Appendix 8 - Statement of interest

Julie Ling
School of Nursing and Midwifery
Trinity College Dublin
D'Olier Street
Dublin 2

Telephone - [REDACTED]

Name (block capitals): _____

Parent of _____

I wish to be contacted to discuss participation in the study entitled: An exploration of the respite needs and experiences of family's caring for a child with complex healthcare needs.

I can be contacted at the following telephone number_____. I understand that by agreeing to discuss the study with the researcher, I am not consenting to participate in the research.

Signature: _____

Appendix 9 - Participant statement of interest

Julie Ling
School of Nursing and Midwifery
Trinity College Dublin
D'Olier Street
Dublin 2

Mobile - [REDACTED]

Name (block capitals): _____

Caring for: _____

I wish to be contacted to discuss participation in the study entitled: An exploration of the respite needs and experiences of family's caring for a child with complex healthcare needs.

I can be contacted at the following telephone number_____. I understand that by agreeing to discuss the study with the researcher, I am not consenting to participate in the research.

Signature: _____

Appendix 10 - Parent Information Sheet

Title of study: An exploration of the respite needs and experiences of family's caring for a child with complex healthcare needs.

1. Introduction

You are invited to take part in a study looking at your need for and experiences of respite services for you and your child. Before you decide whether or not to participate it is important that you understand why the study is being done and what it will involve. Please take time to read the following information. If you have any questions that are not answered in this information sheet please contact the researcher (contact details are given at the end of this sheet).

2. Purpose of this study

This study aims to explore your need for and experiences of respite services for your child. By talking to you and other parents about their experiences the researcher hopes to identify ways that services can be improved to meet the needs of parents and their children.

The researcher, Julie Ling is an experienced nurse. This study is part of her thesis for the degree of PhD in Nursing.

3. Procedures: What will the study involve?

The researcher wants to find out more about the respite experiences and needs of parents caring for a child with complex healthcare needs. She would like to meet you and talk to you about respite care. In order to find out about your respite experiences it is likely that the researcher will have to interview you more than one occasion (for example once a month for three months). Each meeting should take about one hour and with your permission this conversation will be audio taped. This is so that the researcher can make an accurate record of the discussion for her research. After the interview the tape will be analysed. Your name will not be used in the recording and will not be included in the interview transcripts. An identity number will be used instead. The tape will be kept in a secure place. If you wish to have a transcript of the interview, the researcher will be happy to provide you with this upon request. All meetings will take place at a time and location of your choice (either home or in hospital, depending on which you prefer). As well as interviews the researcher will also look at policies, documents and your child's medical records. This is so that the researcher will be able to build up a detailed account of your experiences.

The findings of this research may be submitted for publication or presented at conferences. You will not be identified in any publication or conference paper from this research. The research may help others to have a better understanding of the respite needs of parents caring for a child with complex healthcare needs.

4. Who can take part in this study?

You are invited to participate in this study if:

- You are the parent of a child who has been referred [REDACTED] who is likely to require respite care
- You understand the purpose of the research
- You wish to take part in this research

5. Who cannot take part in this study?

You cannot participate in this study if:

- You are unable to participate in the interview process
- You do not understand the purpose and process of the research
- You are unwilling or unable to participate in the study

6. Benefits:

There is no promise or guarantee of any benefit from this research. It is hoped that hearing people's respite experiences of caring for a child with complex healthcare needs may help to improve the experiences of others in a similar situation.

7. Risks

There are no known risks to those taking part in this study. However some people may become upset whilst being interviewed. If this happens, you may end the interview at any time. If you wish you may resume the interview at another time of your choosing. You can withdraw from the study if you wish at any point.

8. Confidentiality:

Your identity will remain confidential and an identity number will be used instead. Your name will not appear in any report, paper or publication. Your identity will not be given to anyone outside the research group. All information will be kept anonymous and confidential. The only exception to this is if an issue is raised during the research that has an impact on your child's safety or well-being.

9. Compensation:

This study is covered by standard indemnity insurance. Nothing in this document restricts or curtails the rights of those who take part in the study. There is no payment for taking part in this study.

10. Voluntary Participation:

You do not have to take part in this study but may volunteer to do so. If you agree to take part you may change your mind at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not be giving up any benefits that you had before this offer to take part in the study.

11. Who is supporting this study:

The researcher is a student at the School of Nursing and Midwifery at Trinity College Dublin. [REDACTED] also supports this study.

12. Permission:

Application for ethical approval has been made to the Research Ethics Committees' of your hospital and the Faculty of Health Sciences. Trinity College Dublin. The research will not be undertaken until both committees have given their approval.

13. Further information:

You can get more information or answers to your question about the study, your participation in the study and your rights, from **Julie Ling** who can be telephoned at [REDACTED] or **emailed at** [REDACTED]. Alternatively you can contact **Professor Mary McCarron**, Study Supervisor at the School of Nursing and Midwifery on [REDACTED] or by email: mccarrm@tcd.ie

If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once.

Appendix 11 - Information leaflet for other participants

Title of study: An exploration of the respite needs and experiences of family's caring for a child with complex healthcare needs.

1. Introduction

You are invited to take part in a study looking at the need for and experiences of respite services for parents caring for a child with complex healthcare needs. Before you decide whether or not to participate it is important that you understand why the study is being done and what it will involve. Please take time to read the following information. If you have any questions that are not answered in this information sheet please contact the researcher (contact details are given at the end of this sheet).

2. Purpose of this study

This study aims to explore parents need for and experiences of respite services for their child with complex healthcare needs. The researcher wants to look at the experience of respite parent's perspective but also from different angles and view points. It has been suggested that you may be able to help by talking to me about respite care. The researcher hopes to identify ways that services can be improved to meet the needs of parents and their children.

The researcher, Julie Ling is an experienced nurse. This study is part of her thesis for the degree of PhD in Nursing.

3. Procedures: What will the study involve?

The researcher wants to find out more about the respite experiences and needs of parents caring for a child with complex healthcare needs. She would like to meet you and talk to you about respite care. The meeting should take about one hour and with your permission this conversation will be taped. This is so that the researcher can make an accurate record of the discussion for her research. After the interview the tape will be analysed. Your name will not be used in the recording and will not be included in the interview transcripts. An identity number will be used instead. The tape will be kept in a secure place. If you wish to have a transcript of the interview, the researcher will be happy to provide you with this upon request. All meetings will take place at a time and location of your choice (either home or in hospital, depending on which you prefer).

The findings of this research may be submitted for publication or presented at conferences. You will not be identified in any publication or conference paper from this research. The research may help others to have a better understanding of the respite needs of parents caring for a child with complex healthcare needs.

4. Who can take part in this study?

You are invited to participate in this study if:

- a. You have been identified as part of the research process as a key informant on the respite experiences of a family caring for a child with complex healthcare needs.
- b. You understand the purpose of the research
- c. You wish to take part in this research

5. Who cannot take part in this study?

You cannot participate in this study if:

- a. You are unable to participate in the interview process
- b. You do not understand the purpose and process of the research
- c. You are unwilling or unable to participate in the study

6. Benefits:

There is no promise or guarantee of any benefit from this research. It is hoped that hearing people's respite experiences of caring for a child with complex healthcare needs may help to improve the experiences of others in a similar situation.

7. Risks

There are no known risks to those taking part in this study. However some people may become upset whilst being interviewed. If this happens, you may end the interview at any time. If you wish you may resume the interview at another time of your choosing. You can withdraw from the study if you wish at any point.

8. Confidentiality:

Your identity will remain confidential and an identity number will be used instead. Your name will not appear in any report, paper or publication. Your identity will not be given to anyone outside the research group. All information will be kept anonymous and confidential

9. Compensation:

This study is covered by standard indemnity insurance. Nothing in this document restricts or curtails the rights of those who take part in the study. There is no payment for taking part in this study.

10. Voluntary Participation:

You do not have to take part in this study but may volunteer to do so. If you agree to take part you may change your mind at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not be giving up any benefits that you had before this offer to take part in the study.

11. Who is supporting this study:

The researcher is a student at the School of Nursing and Midwifery at Trinity College Dublin. The Palliative Care Team at Our Lady's Children's Hospital also supports this study.

12. Permission:

Application for ethical approval has been made to the Research Ethics Committees' of your hospital and the Faculty of Health Sciences. Trinity College Dublin. The research will not be undertaken until both committees have given their approval.

13. Further information:

You can get more information or answers to your question about the study, your participation in the study and your rights, from **Julie Ling** who can be telephoned at [REDACTED]. Alternatively you can contact **Professor Mary McCarron**, Study Supervisor at the School of Nursing and Midwifery on [REDACTED] or by email: mccarrm@tcd.ie

If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once.

Appendix 12 - Inclusion Criteria

- Parent (mother, father or both) of a child referred [REDACTED] during the study period
- Aged 18 years or over
- Able to communicate in English
- Willing and able to participate

Appendix 13 - Safety Policy for Lone Researchers

This safety Policy relates to the safety of social researchers, particularly those conducting research in the field on their own. The policy focuses on safety in interviewing or observation in private settings but is of relevance to working in unfamiliar environments in general.

There are a number of dimensions to the risk that social researchers may face when involved in close social interaction:

- risk of physical threat or abuse
- risk of psychological trauma, as a result of actual or threatened violence or the nature of what is disclosed during the interaction
- risk of being in a compromising situation, in which there might be accusations of improper behaviour
- increased exposure to risks of everyday life and social interaction, such as road accidents and infectious illness
- Risk of causing psychological or physical harm to others.

In order to ensure researcher safety and protect participant anonymity this policy will be adopted by the research team.

1. Participants will be offered the choice of interview setting (e.g. home or neutral/public venue)
2. The researcher's status as a guest in the participant's home will be respected.
3. The researcher will carry a mobile phone when visiting participants' homes.
4. A member of the research team will act as the researcher buddy.
5. The researcher's buddy will be made aware of the date, time and general location of the impending interview.
6. A contract will be agreed between the researcher and her buddy before the visit to the participants' homes
7. The researcher will telephone her buddy before entering the participant's home informing the research supervisor of how long the interview should last and agreeing to phone the buddy when the interview is complete.
8. If the researcher's buddy does not receive a phone call from the researcher after the agreed time the researcher's buddy will phone the researcher.
9. If there is no response from the researcher, the researcher's buddy will go to the location of the interview to assist the researcher.



Appendix 14 – Letter to Participants

1 April 2011

Dear Parent

Re: *An exploration of the respite needs and experiences of family's caring for a child with complex healthcare needs.*

I am writing to ask you to consider participating in this study which aims to gain a better understanding of how respite services are experienced by you and other parents of children with complex healthcare needs. I would like to speak to you about your experiences of respite care. This research aims to see whether the respite services currently provided meet the needs of your family.

I am an experienced nurse and this research is part of my PhD thesis. I am undertaking this study because there is currently very little research on respite care for children and especially in the care of those with complex needs. I hope the results from this research will highlight areas of respite care where services need to develop further in order that they can better meet the needs of families.

I would like to speak to a number of families regarding their experiences of respite care. If you are interested please read the enclosed information which describes the nature and purpose of the study and what participation will involve. You will also find a consent form. This is for your information. If you decide that you wish to participate in this study, I will ask you to sign the consent form when we meet. Before you sign this, I will discuss the research with you and answer any questions you may have.

Should you wish to discuss involvement in this study, please complete the enclosed statement of interest and return it to me as soon as possible using the stamped addressed envelope provided. This form is an indication to me of your willingness to participate. I will then contact you to discuss participation and answer any questions you may have. Should you decide not to participate in this study, you will not be contacted further regarding this matter.

Yours sincerely

Julie Ling

HRB Research Fellow

Appendix 15 – Observations and reflections

Observation / Reflection Date:

Written by:

Today's Date:

- 1. What are the main issues or themes that struck me in this contact?**
- 2. Summarize the information you got (or failed to get) in this contact.**
- 3. Anything that struck you as salient, interesting, illuminating or important in this contact?**
- 4. What new (or remaining target questions / observations) do you have in considering the next contact with this site?**
- 5. Any other comments you might like to make?**

Appendix 16 – Ethics Committee Approval

ETHICS (MEDICAL RESEARCH) COMMITTEE OFFICE
Tel: (01) 409 6307/6243

Ms Julie Ling RGN MSc BSc (Hons)
HRB Research Fellow
School of Nursing and Midwifery
Trinity College
Dublin 2

23rd June 2010

REC Reference: GEN/153/10

Re: An exploration of the respite needs and experiences of family's caring for a child with a life-limiting condition requiring palliative care.

Chief Investigator: Ms. Julie Ling

Dear Ms Ling

At a meeting which took place on 22nd June 2010, the Ethics (Medical Research) Committee approved the above project.

The Committee would like to thank you for being present at the meeting and wish you every success in the future.

Yours sincerely

Appendix 17 – Ethics Committee Approval



THE UNIVERSITY OF DUBLIN
TRINITY COLLEGE

SCHOOL OF MEDICINE
FACULTY OF HEALTH SCIENCES

Professor Dermot Kelleher, MD, FRCPI, FRCP, F Med Sci
Head of School of Medicine
Vice Provost for Medical Affairs

Ms Fedelma McNamara
School Administrator

Ms Julie Ling



Trinity College, Dublin 2, Ireland
Tel: +353 1 896 1476
Fax: +353 1 671 3956
email: medicine@tcd.ie
email: medschadmin@tcd.ie

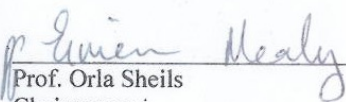
Friday, 25 June 2010

Study: An exploration of the respite needs and experiences of family's caring for a child with a life-limiting condition requiring palliative care

Dear Applicant (s),

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in March 2010, we are pleased to inform you that the above project has been approved without further audit.

Yours sincerely



Prof. Orla Sheils
Chairperson
Faculty of Health Sciences Ethics Committee

Cc
Prof Mary McCarron,
School of Nursing & Midwifery,
24 D'Olier Street,
Trinity College,
Dublin 2

Appendix 18 – Interview Guide

Interview Guide

Family.

- Family composition / role in respite
- Who is the main carer for...?
- Caring role

Respite

- Sources / Meaning / type of respite
- Knowing the service / quality of service
- Benefits / Potential improvements of service
- Suggestions for changes to service

Conclusion to the interview:

- Explain how/when/where interview data will be stored and disposed of
- Answer any questions the participant raises
- Remind the participant of the researcher contract details and that they can have a copy of the interview transcript if they wish
- Check participant well-being
- Thank the participants for their involvement