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'We are here for a good time not a long time:

Being and caring for a child with a life-limiting condition'

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A thesis submitted to the University of Huddersfield in partial fulfillment of

the requirements for the degree of Doctor of Philosophy

The University of Huddersfield

January 2009

Acknowledgements

Life is what happens to you while you're busy making other plans

John Lennon

Abstract

This research project sets out to explore the lived experience of Being and caring for a child with a Life Limiting Condition. This research uses van Manen's (1990) conceptualisation of hermeneutic phenomenology that is both a research methodology and a method. The first empirical work is a preliminary study using focus groups with professionals. The findings of this work acts as a backdrop to the further two studies that involve interviewing, in-depth, twenty eight parents and five children. The second study details the parents' lived experiences and the final study looks at five parent-child dyads and their combined lifeworlds. In keeping with the phenomenological methodology, data was analysed using Template Analysis (King, 2004).

It is a rare opportunity to observe and speak with children with Life Limiting Conditions and so gain insight into their lives. Their vulnerability is often characterised by rare and difficult-to-diagnose conditions, significantly shortened life spans with compromised quality of life. For the participants, the experience of Life Limiting illness was not only personal, but was also transactional, communicative and profoundly social. The challenge is one of Being thrown into an abnormal unready world which compels one to consider the paradoxical temporality of the here and now. This brings recognition of being the same as others in a lived space, but also being different in a fundamental way that has a significant impact. The challenge is met by adapting to the environment to find new ways of Being.

This research encourages readers to thoughtfully reflect on what is it like for these families and those involved in their care, and to consider practice improvements that address the triadic experience (of child, parent and professional). The full significance of such reflection will ideally promote further questioning and inquiry, in keeping with the always provisional nature of phenomenological inquiry.

Disseminated findings

Papers

1. Rodriguez, A. & King, N. (2008) The lived experience of parenting a child with a life-limiting condition: a focus on the mental health realm. Palliative & Supportive Care. (In press).

Oral Presentations

1. Rodriguez, A. June (2007) A Phenomenological investigation of the lived experiences of children with life-limiting conditions. Postgraduate Research Conference. School of Human & Health Sciences. University of Huddersfield.

2. Rodriguez, A. & King, N. June (2007) The lived experience of children with life-limiting conditions. The 10th Congress of the European Association for Palliative Care. Budapest. Hungary

Poster Presentations

1. Rodriguez, A. & King, N. September (2008) Conducting interviews with children with life-limiting conditions: The methodological needs and nuances. The BPS Qualitative Methods Conference. The University of Leeds.

2. Rodriguez, A. & King, N. June (2008) Conducting interviews with children with life-limiting conditions: The methodological needs and nuances. The European Association for Palliative Care Research Conference. Trondheim. Norway.

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Chapter 1: Introduction

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I have Duchene Muscular Dystrophy, a progressive and life-limiting condition for which there is currently no treatment. Having been diagnosed when I was only a year old, this knowledge has always been part of my life and inevitably, it has affected every aspect of my life. Young children are not known for their selfless actions and perhaps this explains why they would never tell me where their den was or help me to get to it in my wheelchair; they seemed to be protecting it as if it was Bletchley Park. Being excluded from normal things that my peers took for granted began to be part of my life - a pattern that got stronger as I got older. For a time, older siblings of my contemporaries filled the gap and helped me to enjoy activities such as fishing. People have often been willing to talk to me and help and I feel that the kindness of strangers is often underestimated. I have never been afraid to talk to people and ask questions, although on occasion, I have felt that there was surprise that a child in a wheelchair could ask intelligent questions. Perhaps there are still too many preconceptions about wheelchair users. Sometimes, though, I feel that mine is an existence, not a life. There are so many things I would like to be able to do that others take for granted - from the most mundane activity, such as walking to the shop, to discovering the vineyards of France. This does not mean that I am unhappy all the time and there are moments when I forget my physical situation and enjoy life - when I am making people laugh (especially my dad), when I read a good book (although someone has to turn the pages for me, a source of great frustration), or when I am in my garden making sure that my pumpkins are being watered. Life expectancy for this strain of muscular dystrophy is commonly 20s to 30s, but this is something I prefer not to think about, although it does have an impact on everything I do. As I have become more disabled the big things in

life are increasingly beyond my reach and small events assume greater importance: watching a flock of birds preparing to migrate, seeing seeds grow in the garden and experiencing the sun on my face. The progressive nature of my condition has meant that just when I should be gaining independence and control of my life - I am now 22 - I have become more dependent and reliant on other people, mainly my parents, to do everything for me except think, and sometimes they even try to do that for me! (Nick Wallis, 'My Life Long Desires' Guardian Newspaper, January 15th, 2007).

The introductory excerpt illustrates how a life limiting condition (LLC) can affect every part of the patient's life. Wallis (2007) illustrates lived experiences of exclusion, of others ill placed perceptions, of dependence and reliance. But interestingly he also talks of being happy, enjoying life and of appreciating the small things. This short but rich description of Being enticed me into wondering how LLCs are lived in their entirety by children and parents. There is little published qualitative research into the lived experience of life-limiting illness and of parenting a child with a LLC. Therefore, there is also a paucity of material in the literature to which health or social care professionals can turn to, to begin to develop an understanding of the experience. Equally, there is also little for a parent or child to compare their own experience with.

This chapter will detail my interest in the phenomena under study and will set the scene for the thesis. Issues of definition, policy and practice will be discussed, before the structure of the thesis is outlined.

1.1 My interest in the phenomena under study

My interest in the experience of living with life-limiting illness and of parenting a child with a LLC first developed when I met a parent through conducting a local service evaluation study. It is difficult to explain the initial feeling I had for her. To say that I felt sorry for her would be inadequate. I saw a woman struggling to make ends meet in caring

for her sick child, financially, physically and emotionally. Yet I also saw a woman who displayed incredible strength in a multitude of ways and a child who appeared 'happy' irrespective of his condition. Angered at my own ignorance and uncertain what to say, I found myself asking her to tell me what it was like to live with a child who has a LLC. Her words gave me a poignant sense of what it was like: her words framed the impetus for this study.

> Well they just say that his care is palliative, its all palliative, I mean they can't tell me can they, they can't answer me, I mean nearly every other week they were telling me that he wouldn't survive another day.

It is argued that we have often failed to recognise the special care that these families need:

> Due to the fact that my son's physical condition started to deteriorate when he was four years old, almost his entire life was a visible expression of that frailty and impermanence. As we lived our different sides of the experience within the family, it was obvious that his physical and cognitive impairments, his final illness and his death were, although unusual, simply one expression of our common human experience…Reflecting Frank's (1995) description of an ill body as one of essential chaos, my son's life was rendered completely chaotic and unpredictable as the result of impairment…Living alongside my son as he visibly journeyed from life to death in fifteen years, took me to the centre of life within death and death within life, a paradox we all live with, but spend most of our time in denial of (Murray 2003:523-524).

Health services have for many years concentrated on curative medicine or the promotion of health, and those who have long term disability, especially where death was expected, have taken a back seat (Craft 2004). There are enormous burdens for families, both physically and emotionally, and without adequate support, they will almost inevitably

face social isolation, burnout, mental and physical exhaustion and marriage break-up (Lindesay, 1999).

This thesis provides an exploration of the experience of living with a LLC within the framework of a phenomenological approach. The main aims of this work are as follows:

1. To elucidate the lived experiences of children with life-limiting conditions (LLCs) and their parents.
2. To consider the implications of these lived experiences for health and social care professionals.

1.2 Issues of definition

This area of research has been confounded by problems of definition and the semantics of whether conditions are life-threatening or life-limiting. The latest contribution proposed is that a life-threatening illness is one where there is a possibility that a medical intervention might prove successful (even if the treatment poses a threat to life). LLCs are those for which there is currently no available cure and the condition is likely to lead to the child dying prematurely. In practice, the distinction is often arbitrary since an individual child may oscillate between the two definitions especially during acute exacerbations of the illness, for example in children with cystic fibrosis.

For the purpose of this thesis a LLC is defined as:

> Any illness or condition developed in childhood whereby the child is likely to die before adulthood or with a limited expectation of life thereafter. Alternatively, any condition developed in childhood that, without intervention, will cause a child to die prematurely (NHS Executive 1998:5).

Children with LLCs have a wide range of diseases and disorders. Some are genetic and obvious from a very young age. Others, such as cancer, are contracted in childhood or

adolescence. The needs of children with LLCs and their families are complex and a large proportion have long term needs. Many of the conditions are associated with progressive deterioration, rendering the child increasingly dependent on parents and carers.

LLCs have been classified into four broad disease related groups by The Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) and The Royal College of Paediatrics and Child Health (RCPCH) (1997) and are detailed in Table 1.2.

Table 1.2 Classification of LLCs in Children (ACT and RCPCH 1997)

Group 1	Conditions for which curative treatment may be feasible but can fail e.g. cancer, irreversible organ failures of heart, liver, kidney.
Group 2	Conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death is still possible e.g. cystic fibrosis, muscular dystrophy.
Group 3	Progressive disorders without curative treatment options where treatment is exclusively palliative and may commonly extend over many years e.g. Batten's disease.
Group 4	Conditions with severe neurological disability, which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not usually considered progressive e.g. severe cerebral palsy.

In summary the classifications include possibly curable (Group 1), periods of good health but limited life (Group 2), progressive disorders with no treatment (Group 3), non-progressive but severe (Group 4). Accurate mortality and prevalence data for children with life-limiting conditions is not readily available, although it is estimated that 1 per 10,000 children die each year from a LLC and 10 per 10,000 children are likely to have a

LLC (ACT and RCPCH 1997). Estimates for mortality are based upon a study by While, Citrone and Cornish (1996) who listed LLCs leading to premature death and identified the number of deaths for the period 1989 to 1991 from OPCS data for England and Wales. They reported that approximately 1,100 children die each year from LLCs of which 40% are from cancers, 20% from heart disease and 40% from other conditions. The limitations associated with the reporting and coding of cause of death and differences in the practice of recording the primary cause of death are clearly recognised. Lenton, Stallard, Lewis and Mastroyamopoulou (2001) produced estimates that could be extrapolated to the UK population, but not applicable to many parts of the world where both LLCs and expectations are significantly different.

Children with LLCs are said to have palliative care needs. Palliative care is the holistic care of patients whose disease is not responsive to curative treatments (National Council for Hospice and Specialist Palliative Care Services, 1996). Palliative care was originally synonymous with end-of-life care – typically the adult with cancer reached a point in their disease when active treatment was no longer effective and life expectancy was measured in weeks or months. This approach also worked well for children with malignant diseases. However, there is a far larger group of children with non-malignant diseases whose condition is diagnosed early in life for example, congenital malformations, for which there is no active treatment and death is expected in childhood. It seems entirely appropriate to call the care they require, palliative care, even though it may span a longer period of time. Palliative care for children, centres on the quality of life for the child and provides support for the family, manages distressing symptoms and provides respite and care through death and bereavement (ACT and RCPCH 1997).

As in adults with LLCs, children with LLCs require packages of palliative care. Palliative care in children is a comprehensive multidisciplinary approach to care that seeks to enhance the life of children and families living with life limiting conditions. It involves a holistic approach embracing symptom management, psychosocial/spiritual care, and bereavement support. The need for palliative care begins as soon as it is clear that a child has a LLC. Whether community-led, disease-specific or specialist, active individually

designed palliative care approaches support children and families to lead as normal lives as possible.

1.3 Policy

According to the recent Department of Health document: Commissioning Children's and Young People's Palliative Care Services (2005); every child with a LLC and their family should be able to access services that:

- Promote their quality of life by managing pain, adverse symptoms and specialist palliative care needs.
- Integrate multi-agency assessment of the child's needs, involving them and their families as much as they want, in decisions about how their needs could be met in a choice of settings including home, hospital or hospice.
- Are coordinated at the point of delivery across health, social services and education.
- Respond to their changing needs as they move from children's services to adult services.
- Are delivered by competent staff.
- Are planned in partnership and provided by a network of agencies, including the statutory and voluntary sector.
- Provide information in appropriate formats and language about services and the child's condition and treatment.

Improving the quality of palliative care for children, young people and their families is an important aspect of the Children, Young People and Maternity Services National Service Framework (DoH 2004). The Children's NSF sets the health and social care developmental standards for services to children and young people by 2014. However, the child protection element of Safeguarding Children is core, under 'Standards for Better Health' (2004). In effect, the 2005 manifesto commitment to double funding for end of life care means that more people, including children, can have the choice to die at home. A number of other related policies also impact on delivering this commitment. These

include the public service agreement targets for long term conditions, access to services, and patient and user experience as set out in 'Improvement, Expansion and Reform: The Next Three Years' Priorities and Planning Framework, 2003-2006 (2004)', the 'NSF for Long Term Conditions' (DoH 2004), and the forthcoming White Paper on 'Out of Hospital Care'. Building on the five key outcomes that are set out in 'Every Child Matters: Change for Children' (2004) and 'The Children Act' (2004), Standard 8 of the Children's NSF expects high quality palliative care to be available for all children who need it.

Partnership working is considered to be crucial and is a core principle in the following key policies:

- Every Child Matters: Change for Children agenda (DoH 2004)
- The NSF for Children, Young People and Maternity Services (DoH 2004)
- Making it Better for Children and Young People (DoH 2007)
- Aiming High for Disabled Children (HM Treasury/Dept of Education and Skills 2007)
- The Children's Plan (Dept for Children, Schools and Families 2007)

In addition, 'Better Care: Better lives' (DoH 2008) published in February of 2008, builds on the 'Palliative Care Services for Children and Young People in England' report that was published in May 2007. The report was the result of an independent review of children's palliative care services which involved wide ranging consultation. The 2008 document is considered to be the next step in encouraging change. There are three aims:

1. To highlight key aspects of the independent review
2. To challenge and inspire local commissioners to prioritise the needs of this patient group
3. To act as a framework for future service design and delivery.

To try and ensure children's palliative care services are given priority and planned well, the following eight goals are put forward by 'Better Care: Better Lives':

1. Improved data
2. Equality of access to universal services
3. Responsible and accountable leadership
4. Choice in preferred place of care and widening of community services
5. Better end of life care
6. Stronger commissioning and value for money
7. Successful transition between children's and adult's services
8. Planning and developing an effective and responsive workforce

Phase two has been planned and will take the title of 'The Children's Palliative Care Project', whereby support materials will be developed and road show events organised throughout the country. This will be to publicise the strategy and to help localities to develop their own strategies for delivery.

Interestingly, in July 2008 we saw the publication of the 'End of Life Care Strategy' (DoH 2008). This strategy is focused on promoting high quality care for all adults at the end of life. ACT however, have published a briefing (also in July 2008) to highlight the implications and opportunities this document has for children's palliative care. This briefing is summarised in table 1.3.

Table 1.3 Implications/opportunities of the End of Life Care Strategy for children's palliative care (adapted from ACT briefing for members, July 18th 2008).

Strategy point	Meaning for children's services?	Linkage to 'Better Care: Better Lives' (BCBL)	Way forward
Differences are highlighted re: place of death between age groups • Those dying in young adult life (15 – 44) or in the middle years (45-64) are more likely to die at home. • Children and people aged 75-84 have the highest in-patient death rates.	This point identifies discrepancies across the age ranges. Is it the case that more young adults are able to die at home because district nurses are more accessible for support in the home, alongside specialist nurses for example Macmillan and Marie Curie nurses? Is it the case that more children die in hospital because community services are inadequate to provide support? Or is it because it has been the family's choice for the child to die in hospital?	BCBL suggests that community services are developed to support children and young people away from the hospital setting e.g. home or children's hospice.	Survey what services are available that provide home/community care to children and young people with palliative care needs. Determine if workforce development plans are aiming to look at the staffing numbers needed to provide 24 hour support and care to children and young people with palliative care needs. Do these plans also look at the needs of the non-statutory sector? Are there any education and training plans a foot to ensure staff are appropriately skilled?

Strategy point	Meaning for children's services?	Linkage to 'Better Care: Better Lives' (BCBL)	Way forward
Because medical care has advanced many of children and young people with LLCs who need palliative care are living for longer periods and can achieve a good quality of life if they and their families are well supported by services. However, the support they require is complex and as such a lot of careful planning is required by commissioners when considering transition to adult services and in planning end of life care services.	It is expected that children's, young people's and adult services will consider the needs of young people.	BCBL outlines a key objective – that transition from children's to adult services is planned and purposeful for young people with LLCs.	Determine who leads on children's palliative care in the local Primary Care Trust (PCT). Determine who leads on end of life care in the local PCT. Determine how transition is being viewed by commissioners and if young people with palliative care needs are being considered in any work on transition and end of life care.

Strategy point	Meaning for children's services?	Linkage to 'Better Care: Better Lives' (BCBL)	Way forward
The bereavement needs of children and adolescents should be acknowledged and information and support provided that is aligned with their development and level of understanding. Staff need to know that adolescents may wish to be totally aware of all the processes surrounding death and their parent(s) or guardian(s) will require support to understand this need. In addition, where a child or young person has been a caregiver in the home, this role should be acknowledged and respected at the time of death and in planning post death arrangements.	Is it possible for children's services to share their bereavement expertise with adult services to develop local response to need?	Not really considered by BCBL. However, there is recognition of the needs of siblings when looking at overall need for bereavement support.	Determine what services are provided in the area. Look at forging links with other providers to maximise local bereavement services that can be offered. Look at the support offered to staff.

In addition, the UK government has introduced a number of policies directed at improving support given to carers. The Carers (Recognition and Services) Act (Department of Health 1995) acknowledged carers' rights to have their needs assessed. The National Carers' Strategy (1998) set forth a process of consultation intended to determine strategies for addressing carers' needs, leading to the strategy document *Caring about Carers* (Department of Health 1999) and the *Carers and Disabled Children Act* (Department of Health 2000). Both the Health Act *Partnership in Action* (Department of Health 1998) and the White Paper *Valuing People* (Department of Health 2001) highlighted pooling of budgets and integration of services in order to facilitate better services for carers (Walker & Dewar 2001; Read 2002). The importance of effective, joined-up multiagency provision of services has long been recognised as important for disabled children and their families. The many issues identified in the literature have been recently reiterated in the report of the external working group for disabled children, as part of the Children's National Service Framework (Department of Health 2003). One specific group of these children has recently become the focus of interest – namely those children with LLCs, with a recent investment of £48 million from the New Opportunities Fund to develop children's palliative care services (Lenton, Franck & Salt 2004).

1.4 Practice

In the UK there are several different models of delivering palliative care to children, which have developed separately but are now increasingly working together (Hain 2002):

- The outreach model – a disease based approach, comprising paediatric outreach nurses liaising with a specialist paediatric consultant. This model is typified by paediatric oncology services, and increasingly emulated (for example by neonatal and respiratory teams).

- The children's hospice movement – Most are funded by charity, and run by nurses, with medical support from general practitioners. Unlike adult hospices, most focus on providing high quality specialist respite, rather than terminal care.

- The community nursing teams – these liaise where necessary with paediatric consultants. These teams can have a particular role in the care of many children with non-cancer LLCs.

Indeed, care for children with LLCs is delivered in many forms in all areas of the UK. The growth of services has traditionally been based on local interest and the availability of charitable funds. The heterogeneity of the patient population makes flexibility a key feature of any service and care for children with LLCs. Similarly, the complex needs of each family are unlikely to be met by a single service, which makes co-ordination of a number of different services and professionals an important element of care (Hynson and Sawyer 2001).

ACT and RCPCH (1997) made comprehensive recommendations for service development in relation to the care of children with LLCs. In addition to general legislation and government policy, their guidelines identified baseline principles to underpin service development. These included:

1. Joint planning and commissioning between health, social and education providers
2. Flexibility and choice for children, parents and families
3. Child/ family centred care
4. Continuity of care
5. Staff with training and expertise
6. Transition to adult services.

Sick children and those with ongoing health needs are spending less time in hospital than in previous years (Whiting 1997). Despite the increasing numbers of children admitted every year, there can be little doubt that children are being discharged from hospital 'quicker and sicker' (Audit Commision 1993).Whilst our capacity to manage at home children dependant on technology steadily increases (such as children requiring long-term ventilation or those dependant on parenteral nutrition), the evidence base on which to plan care packages is patchy, and often paediatricians and children's nurses have to

devise care plans based on limited experience and evidence. Good quality community care for children with complex healthcare needs should not only meet the medical and technological aspects of care, but also focus on enhancing the quality of life (QoL) for the child and providing support for the family (Abu-Saad 2001).

Few robust clinical studies have been conducted in this area because of the complexity and rarity of many conditions, the many variables involved with these vulnerable children, the difficulty of assessing children with communication problems, and the many ethical dilemmas around researching the patient group. The research agenda is broad and covers many different areas (Edmond and Eaton 2004), and despite the increasing number of studies and policies related to improving supports for parents who are carers, the acquisition of accessible and appropriate respite services remains problematic (Sloper 1999). This in turn raises further questions about the nature and type of provision required by children and families who have a long term condition and the interface between disabled children's services and palliative care services.

1.5 The structure of the thesis

To elucidate the lived experiences of children with LLCs and their parents, this research uses van Manen's (1990) conceptualisation of hermeneutic phenomenology that is both a research methodology and a method. In the context of research methodology, hermeneutic phenomenology refers to a certain theoretical philosophical framework in *'pursuit of knowledge'* (van Manen 1990:28). The methodological premise of van Manen advocates the philosophical belief that human knowledge and understanding can be gained from analysing the prereflective descriptions of people who have lived the experience in question. In other words, the essence of the phenomenon is uncovered by gathering text from those living it and then interpreting this text.

Although it may seem that the research question rather than the research methodology formed the important starting point of this study, this is only true to a certain extent. The reality is that the research conducted was very much guided by the methodology chosen. My interest in turning to the nature of the lived experience developed from a deep interest

in investigating how different people, in the context of particular individual and societal life circumstances, set out to make sense of certain aspects of human existence and the interpretations that are made of those existences (Heidegger 1962). Far reaching travels, lengthy home visits, in-depth conversations, extensive note taking and reflective practice were other central elements of the research method and my development as a qualitative researcher. It is a phenomenological study in which lived experiences of the world of everyday life are the central focus, and an idea that will be discussed extensively in the methodology chapters (Chapters 3 and 4).

Life-limiting illness will be explored by examining the views of professionals via three focus groups and then by interviewing in-depth twenty eight parents and five children. The children and parent participants will be questioned with regard to their understanding of their world through expression of their thoughts and perceptions. In doing so, I follow van Manen's methodological research approach in which human situatedness is placed centrally, based on the belief that human beings and the meanings they assign to their experiences can be best understood from the experiential reality of their life worlds (van Manen 1990). This means that the voices of participants are incorporated in the research to provide a description of life-limiting illness as it frames their lives.

Chapter two details the literature review. Here, the background issues to the phenomena under study are addressed. The literature review draws on research within chronic illness, disability and life-limiting illness and the possible impact on families is highlighted. The chapter culminates with a summary outlining any presuppositions' gained from the literature, detailing current gaps in knowledge, the main research aim and questions of the current study.

In chapter three, I describe in detail how hermeneutic phenomenology fits this study when seeking the meaning of life-limiting illness. I outline the theory behind the method by discussing the philosophical framework and the fundamental assumptions. I discuss how the central point of this thesis is the 'everyday lived experience' of human beings, as they find themselves in the world and as they give active shape to their world. It will be

demonstrated that through phenomenological thinking, it is possible to understand such experiences and therefore, subsequently, to act effectively in our dealings with people. I will detail the way in which the methodology, positioned within the interpretivist approach, was developed to draw out the intricacies and intimacies of the lived experience.

Chapter four outlines the research design and the methods conducted in this study, by detailing theoretical and practical procedures. It describes the data collection techniques – focus groups and interviews and outlines van Manen's (1990) phenomenological approach as combined with King's (2004) Template Analysis – used to organise the findings. This chapter also details the ethical issues of the study and how they were dealt with.

Due to the scale and complexity of the research findings, three chapters are dedicated to their description and discussion:

- Chapter five details the professional focus groups study – three focus groups were conducted with a number of professionals from health and social care backgrounds. These findings provide a backdrop to the lived experiences of children with LLCs and their parents.
- Chapter six details the parent study - here the focus is on a number of interviews conducted with parents whose children were not interviewed.
- Chapter seven details the parent-child dyads study – here I look at data gleaned from parents and their own children.

Chapter five details a qualitative analysis, however, as this data was originally from a service evaluation study, the material is often related to opinion rather than concrete examples of experience and thus limits phenomenological exploration. However, chapter six and seven detail a more in-depth phenomenological analysis as the interview schedules requested illustrative examples of lived experiences.

Chapter eight goes on to summarise the main findings of the research and details the essential themes. Discussion is focused upon these essential themes with reference to original data and some of the earlier reviewed literature. The chapter ends by drawing conclusions and indicating the limitations and implications of the findings for practice, research and education.

Chapter 2: Literature Review

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> When a child dies in a children's ward…. There is a whispering and a
> scuffling behind the scenes, a furtive moving of white covered trolleys
> in and out of the ward, usually during the night. Nurses and doctors are
> pre-occupied and do not answer questions and are unduly irritable.
> Above all, there is a stupid pretence that nothing unusual is
> happening… but do we really think that the 'secret' is not known to
> every child on the ward? (Yudkin 1967, cited in Judd 1996:40).

Have things changed? Over forty years on and with the introduction of palliative paediatric care, one would expect that there now is a greater professional awareness of the impact of a LLC on children and their families. Hopefully, the day to day lives and experiences of those facing premature death are more supported by systems of care, and are less taboo subjects for all.

This literature review will evaluate the research to date which holds resonance with the lived experience of LLCs for 'the professional', 'the parent' and 'the child' and will build a rationale that advocates the phenomenological study of professionals, parents and children to elucidate the richness and complexities of their lived experience of LLCs.

2.1 Perspectives on grief

Death means the loss of many things – the loss of this life, of self as a person, of tomorrow, of those we love, and of all we know. In families with a dying child, losses are felt by every member of the family. Not only must the parents prepare themselves for their child's death, but the ill child must also deal with this reality. Therefore, it is important to understand the experiences of death and dying that affect both families and those who provide care for them. It is also important to consider how dominant theories may shape how professionals and lay people understand and respond to grief.

In early conceptions, clinicians and theorists viewed grief as linear and time-bound. Terms such as grief, grieving, and mourning were used synonymously. Uncomplicated grief was seen as a progression through stages of shock and disbelief; developing awareness of loss; and prolonged recovery. The work of uncomplicated grief was expected to take four to six weeks to complete (Teel 1991). If mourning was delayed, chronic, exaggerated, or masked, then the grief response was said to be abnormal. Consequently, the extended grieving typical of families of a dead child was seen as pathological and requiring psychiatric assistance or counselling. Since Freud, grieving and mourning have been conceived as the processes whereby the bereaved person adjusts to the realities of their loss, enabling them to disengage from the deceased and reinvest in new relationships. John Bowlby's attachment theory (1969-1980) and Colin Murray Parkes' psycho-social elaborations (1972) offer psychological models of bereavement, allowing predictions regarding the outcome of an individual's bereavement process (Parkes 1993). Bowlby believed that our emotional bonds *arise out of deep seated innate mechanisms which have evolved in order to ensure survival* (p246). Bowlby argued that infants of many species have physical features and behaviours, which call forth care and protection from older group members. Infants also possess a motivational *attachment system designed by natural selection to regulate and maintain proximity between infants and their caregivers* (Fraley and Shaver 1999:736). The theory implies a cause-effect relationship between early attachment patterns and later reactions to bereavement, arguing that *whether an individual exhibits a healthy or problematic pattern of grief following separation depends on the way his or her attachment system has become organised over the course of development* (p740). Although there had been a number of theories proposed by social scientists about grief (e.g. Glaser & Strauss, 1965 – 'Awareness of Dying' and Glaser & Strauss, 1968 'Time for Dying'), in general little focus was paid to death and dying by social scientists until Elizabeth Kubler-Ross published 'On Death and Dying' in 1969 (Kubler-Ross 1969). This book was instrumental in bringing the staged model of grief into the public forum. According to Kubler-Ross, people go through five different stages when they are faced with dying: denial and isolation; anger; bargaining; depression; and acceptance. Consequently, this model argues that patients move through these stages until they finally accept their death.

Interestingly, many professionals and the general public continue to understand grief and bereavement as linear and time bound. For example, recently I accessed a number of cancer and bereavement related charity websites to find advice that was attuned to Kubler-Ross' (1969) model of grief.

However, the linear models of grief and their related concepts have been questioned by some clinicians and theorists (Cowan & Murphy, 1985, Worthington, 1989, 1994). Questions have been raised particularly in relation to the length of time considered to be 'normal' to continue grieving, and there have been queries centred on the assumption that failure to achieve resolution of grief is abnormal. Indeed, the five-stage model attributed to Kubler-Ross that was actually evolved from individuals facing their own death, not grief from bereavement - is not fully supported by research and has been labelled superficial, inadequate and misleading my some authors (Corr, 1993). During the 1970s the model of dying was morphed into a model or stages of grief. This may have been a result of its prominence in undergraduate sociology and psychology courses and Kubler-Ross' use of non academic language which made the model easily accessible to the media and general public (Friedman & James, 2008). Accordingly, there have been no real world examples of the existence of stages, or any evidence that suggests people actually move from stage one through to stage five. Instead, it is argued that humans cope in many ways, not just these 'five' and there also appears to be no prescribed or necessary ways in which people should cope with death and dying. Just as there is no 'right' or 'wrong' way to die. Instead, coping with dying is a richer and more complex process than merely progressing through certain ill-defined stages. Indeed, Kubler-Ross herself in her opening paragraph of 'On Grief and Grieving' (Kubler-Ross & Kessler, 2004:1) states:

> The stages have evolved since their introduction, and they have been very misunderstood over the past three decades. They were never meant to help tuck messy emotions into packages. They are responses to loss that many people have, but there is not a typical response to loss, as there is no typical loss. Our grief is as individual as our lives. Not everyone goes through all of them or goes in a predescribed order.

There is however, some empirical research to support a dynamic conceptualisation of grief. If anything is conceptualised as dynamic, this means that interactions are multiple and multiply connected. Furthermore, it is the multiplicity of the interactions through time which produces effects. In other words, grief cannot be meaningfully reduced to single or limited numbers of factors or variables (Bogg & Geyer, 2007). In a study by Cowles (1996), focus group participants from a variety of cultural backgrounds in the United States were asked to draw on their own personal experiences of grief. Their definitions of grief were similar to those in the professional literature. Irrespective of their culture, they viewed grief as a dynamic, all encompassing and highly individualised process. Participants agreed that culture or cultural background is a key component of the ways in which people respond to actual or potential health problems. They also believed that, though mourning rituals or traditions may be culturally defined and prescribed, each person experiences grief in his or her own way. In addition, grief happens to everyone and in different ways and across all age groups. The participants discussed their own grieving and experiences of how others have responded to death differently within their own culture. As a result, they were not judgemental about others' experiences of grief. Others' experiences were viewed as just different, not as wrong or pathological in any way. Most participants stated that the progression of grief is unpredictable and that changes over time vary. In addition, it was argued that grief does not necessarily have a particular end point. Indeed, the bereaved may continue to grieve for many years.

The extended period of illness experienced by children with LLCs may provide families with time to prepare for the death of their child. In accordance, Kubler-Ross (1983) proposed that when families have time to mourn losses as they occur, then the seriousness and frequency of psychological difficulties following the child's death will be less intense. Anticipatory mourning is the term given to the time spent preparing for the moment of death. Originally discussed as anticipatory grief, the phenomenon involves a number of tasks: grief and mourning, coping, interaction, psychosocial reorganisation, planning, balancing of conflicting demands, and facilitation of a good death. In general, the anticipatory mourning literature concentrates this process in adults who are going through experiencing the loss of another adult. There is very little research that has

addressed this phenomenon for parents and children. Although, where parents have been satisfied with end of life care after they have lost their child, their grief response is in fact less severe than those who were not satisfied with end of life care (Seecharin, Andresen, Norris & Toce, 2004). As a result, Carter & Levetown (2004) advocate that bereavement interventions commence prior to a death of a child. However, one difficulty with the concept of anticipatory mourning is that it leads to the assumption that an expected death is easier to deal with than an unexpected death. Many clinicians have observed that, despite education around anticipatory mourning, families are rarely prepared for the reality of their child's death. Davies (1993) noted that parents and siblings, who have accepted the inevitable outcome of the child's illness, often talk about the death in less logical terms such as, *'But I didn't think he would die until he graduated'* or *'I thought he would wait until I got home from school'* (p.141).

In summary, at the most obvious level, scientific studies have failed to support any real world sequence of emotional phases of adaptation to loss or to identify any clear endpoint to grieving that would designate a state of 'recovery'. Neither is it clear that a universal or normative pattern of grieving exists that would justify the confident diagnosis of symptomatic deviance from a healthy grieving template as grief that could be labelled 'disordered' or 'pathological'. More interestingly, some critics of linear or stage models have started to focus on the ways in which such indirectly disempower the bereaved and care givers by their indication that grieving people must pass through a sequence of psychological transitions that are a result of external events. They have queried the inference that emotional states should be of most relevance in theories of grieving, and as such they appear to marginalise both meanings and actions of individuals (Friedman & James, 2008). Finally, some theorists have begun to question the individualistic nature of traditional theories, which construe grief as an entirely private process, inconsiderate of the context of human relatedness (Neimeyer, 1998).

Encouraged by these criticisms, and supported by a contextualist, constructivist, and interpretive shift in psychology (Neimeyer & Mahoney, 1995), a new stream of grief theories is slowly emerging. These are thought to reflect a changing 'zeitgeist' about the

meaning of loss in human experience. These theories share key elements. They are sceptical about the universality of an expected emotional trajectory that ensues from psychological imbalance and leads on to readjustment. These theories have a greater appreciation of more complex patterns of adaptation. They are moving away from the ideology that 'successful grieving' happens once the bereaved removes their mental attention from the person who has died, and instead focuses on the potential mental well being that can evolve from having potentially continued symbolic bonds with the deceased person. This is a very important shift as it counters the dominant ideology since Freud.

Contemporary psychoanalysts, especially those who work from object relations theory, self psychology and relational psychoanalysis have moved on from Freud's psychological model of instinctual energy and isolated mental functioning. Mitchell (1993) highlights the move to accepting life as being fundamentally embedded in relationships and interpersonally oriented meaning. Psychological life is no longer viewed as private or predicatable and as such many long held beliefs are being reconstructed (Stolorow & Atwood, 1996). As a result, many theorists are questioning the standard Freudian model of mourning and its key characteristics (Gaines 1997, Hagman 1993, Kaplan 1995, Shane & Shane 1990, Shapiro 199, Shelby 1994). In his work 'Detachment and continuity: The two tasks of mourning', Robert Gaines (1997) stated:

> Emphasis on the need to detach from the lost object has obscured another aspect of the work of mourning, which is to repair the disruption to the inner self-other relationship caused by the actual loss… this is the task I call "creating continuity" (p.549).

A number of the contemporary mourning theories have supported Gaines's (1997) critique (Hagman, 1995, Kaplan, 1995, Shapiro, 1994). They talk about how too much focus has been centred on relinquishment and as a consequence the normal processes of preservation and continuity have been neglected and maybe even pathologised. Shapiro (1994) has even commented that:

Grief is resolved through the creation of a loving, growing relationship with the dead that recognises the new psychological or spiritual (rather than corporeal) dimensions of the relationship (p.552).

A fundamental argument of these new psychoanalytic and constructivist models (Neimeyer, 1998) of mourning is the need to maintain the attachment to the deceased, and the importance of maintaining a sense of the meaningfulness of the relationship that survives the loss. Kaplan (1995) commented on the importance of keeping the dialogue going with the deceased and has stressed the role of 'creating continuity'. In addition Shapiro (1994) has discussed the social factors that can maintain the connection and Hagman (1995) has discussed the transformation and internal restructuralisation of the attachment to the deceased person.

These models appear to be more attentive to broad cognitive processes that are entailed in mourning, thus supplementing the traditional focus on the emotional consequences of loss. They de-emphasise universal syndromes of grieving and instead focus on 'local' practices or cultural variations in accommodating loss. They argue for a greater awareness of the outcomes of major loss, in terms of the individual's identity, and for an understanding of how the bereaved may come to re-define themselves and they also have an increased appreciation of the possibility of learning and developing through loss. These approaches also have a broadened focus. They are not just interested in individual survivors but also how grief is negotiated within families and wider social forums. A further prominent theme in these newer theories is their insistence that meaning reconstruction in response to a loss is the central process in grieving (Neimeyer, 1998).

Indeed, grieving is something we do as the complicated whole persons we are. We respond in all dimensions of our being at once. Victor Frankl's (1992) seminal work, 'Man's search for meaning', conveyed that people have a psychological need to seek meaning and purpose in their lives, and this drive alone can help them to face and get through really difficult life events and experiences. Folkman (2001) has stressed the importance of trying to find benefit in a negative experience, arguing that successful

coping and positive affect are a result of 'positive reappraisal', a so called cognitive reframing of an experience to be able to view it in a more positive way. In her revised model, she talks of this reframing as a characteristic of meaning based coping, but stresses that further research is needed to explore the content and specific meanings attributed to experiences and how these occur over time.

In line with this new understanding there are a number of changes in clinical practice:

1. Each person's response to bereavement is unique, and what is normal and what is pathological must be considered in the context of the patient's specific personality, relationship to the deceased person, and his or her familial and cultural background. Openness to psychological individuality and a willingness to explore the unique bereavement response of the patient is crucial.

2. What therapists call 'pathological responses' may be unsuccessful strategies to maintain meaning and preserve the attachment to the lost object. Treatment requires not relinquishment but an exploration of the continuing value of the attachment to the survivor, with a consequent reconstruction of the meaning of that person in the context of the survivor's ongoing life.

3. Bereavement results in a crisis in the meanings by which a persons life is given structure and substance. Therefore, pathological grief is meaningful, however disturbed and painful it appears.

4. Grief affects are not the external manifestations of private processes but are efforts to communicate. Given this, pathologic mourning, traditionally viewed as regressive and asocial, must be assessed for its often-hidden communicative motive. No matter how withdrawn into grief a person appears to be, he or she is struggling to maintain relatedness, whether to the internal representation of the dead person or to the social surround.

5. Mourning is fundamentally an intersubjective process, and many problems arising from bereavement are due to the failure of other survivors to engage with the bereaved person in mourning together. (Hagman, 2001:25).

2.2 The lived experience of LLCs

Children with LLCs face an untimely death, but as highlighted in the introduction to this thesis, children are now living longer with their LLCs than ever before, due to medical and technical advances in care. However, these positive outcomes related to increased lifespan create other issues that impact on lived experiences and care, for example:

- How does the child perceive their LLC?
- Do they realise their condition is palliative?
- Does their stage of development impact upon their understanding of death?
- How do parents and professionals recognise different developmental needs and the concerns an individual child may have?
- To what extent should the child have a say in any treatment/palliative care decisions?
- What happens when a child may wish to know more or less than what the parent desires them to know?
- How do parents cope with the uncertainty of the LLC?

These issues alone make it apparent that the palliative care of paediatric patients can be far more complex psycho-socially than for adults. It is now forty years since physicians, lead by Dame Cicely Saunders, recognised the particular needs of the adult patient and their families with incurable disease, but it seems to have taken much longer for these needs to have been recognised by paediatricians and policy makers - regarding children.

Few studies have focused on the process and meaning of experiences for all involved. Researchers need to explore the voices of families where a child has a LLC in order to

achieve a better understanding of the reality of their life worlds. Here, we can draw on existential psychology which is grounded in a rich philosophical history. The tradition argues that human beings have a unique capacity that allows them to choose to become aware of and responsible for their own existence or Being in the world. Key existential themes include human freedom (Sartre, 1956), agency and responsibility (Heidegger, 1962, Levinas, 1969), self-transcendence (Frankl, 1992), and the quest for meaning (Frankl, 1961, 1988, 1992), and they each have significance when a person has to come to terms with life while confronting imminent death.

There is no greater existential crisis than that of facing one's own death or the death of your child. Existentialism is based on the fundamental premise that human beings have the capacity to question and reflect upon their own existence, that is, 'to be or not to be' (Heidegger, 1962). As such, we are cognitively aware of our existence, as well as of our potential for nonexistence. The ways in which individuals live their lives in the face of such uncontrollability, creates the basis for existential psychology. Issues of interest within existential psychology include patient anxiety (for example, Heidegger's (1962) notion of 'existential angst' as 'being-toward-death'), guilt (for example Heidegger's (1962) notion of 'indebtedness to being') and denial (for example Sartre's (1956) notion of 'bad faith'). Indeed, trying to find meaning (Frankl, 1992) and reasons to be alive become pivotal existential resources for helping patients come to terms with their past and their present, and to accept an uncertain future.

Although these existential themes may seem to be rather morbid, they are argued to hold significant potential for promoting meaningful reflection and transformation at the end of life. Frankl (1988) states that *'meaning can be found in life literally up to the last moment, up to the last breath, in the face of death'* (p.76). Taking meaningful ownership of one's life, feelings, choices, and beliefs is said to promote authentic relatedness with oneself, the world, and others (Heidegger, 1962, May 1979, 1983).

2.2.1 Children's understandings of death

Patterns of understanding in children are fluid; children's individual experiences, environment, including family environment, their intellectual capacities, their emotional profiles, ethnic, cultural and religious backgrounds – all contribute to how and when they come to fully understand the meanings of their illness and untimely death. What developmental theories have in common is the recognition that a child learns first that death occurs and then that it is both irreversible and inevitable, the child finally becoming concerned with details, such as physical changes. What the theories fail to acknowledge however, is the impact of life events on development, including life-limiting illness itself. It is argued that, a cognitively aware child with a LLC will typically acquire a precocious understanding of illness and death. However, to reject the contribution of psychology would mean explanations of childhood were completely social (Faulkner, 1993).

Those within the new social studies of childhood (for example Woodhead, 2009 & Jenks 2009) would argue that a social account is sufficient but such scholars do not recognise the fact that developmental psychology is more diverse than they realise and is not totally focused on developmental stages. Indeed stage theory has been criticised from within developmental psychology itself and thus Piaget's work is not construed as the whole truth (Goswami 2002). There are branches of developmental psychology that have an overt social realm and the work of Vygotsky (a contemporary of Piaget) (1978) challenges the research that argues that cognitive development is a universal process. Vygotsky's work was focused on the individual, like Piaget but in contrast he realised that to acquire an understanding of child development one needs to understand how and in what ways mental processes stem from and develop via social interactions and different contexts, and how mediating socio-cultural factors, particularly language, can affect development (Rowe & Westch 2002). Also, within Psychology we have the social constructivist movement which has moved forward a wider psychological debate, critiquing developmental psychology (for example see Burman 1994). The basic underlying arguments of social constructivist approaches hold resonance with contemporary sociological concepts. Social constructivists propose that development results from the interaction children have in their social environments. In addition, they

view children as reflexive – they can be critical and creative, actively monitor situations and people and as a consequence of their experiences and accrued knowledge, they go on to modify or reject norms. Thus, we may find that children with LLCs do not adhere to pre-defined stages of cognitive development (Piaget 1960) and that their understandings of their illness and death and dying may not be aligned to the biological age or assumed level of cognitive development (Morss 2002).

Stallion and Papadatou (2002) detail a progressive understanding of death in relation to the child's cognitive developmental stages, with a focus on children with LLCs. They argue that children irrespective of social factors determined by their illness still adhere to their developmental psychological milestones. They state that under the age of three, children do experience grief for themselves and others. With few developed verbal skills, they may express their emotions through crying and through manifest anxiety about separation. Thus they need comfort and reassurance and close and continuous physical contact (Armstrong-Dailey & Zarbock 1993). Pre-school children, roughly the age range of three to five years, can understand that they are very sick and not going to get better. Their concept of death appears to focus on departure without fully understanding what that means. They do not usually sense that death is an event that happens to children, including themselves. They may understand death as something that can be reversed almost by magic; going to sleep or going on a trip are also ways of trying to understand death (Armstrong-Dailey & Zarbock 1993). From the age of six onwards, children begin to understand that death is a permanent rather than a reversible state and gradually come to realize that everybody dies. They begin to develop a complex understanding of what death means. By the age of ten, they can begin to accept the full impact of what death is – the cessation of all bodily functions. Children at these ages with LLCs are highly observant of adult behaviour and so are able to pick up clues about their situation. They see that their peers may find outward symptoms and signs of their illness or treatment, such as baldness, difficult to cope with, which can also increase their isolation exactly when their peer group would normally be most important (Stillion & Papadatou 2002). They can understand that their death is imminent and can comment on their peers in hospital and how close they might also be to death. From now onwards into early

adolescence, children are thought to be fearful and troubled about death, which they often see as cruelly unpredictable. However, they can also be logical and consistent; they can spend time thinking about the meanings and impact of death and how they think death will affect those around them. We are also aware that through adolescence, young people can develop a careless attitude towards their well-being and take on risky behaviours, as if to defy the reality of death. At this age, they can be openly angry and express that anger through refusal to adhere to their treatment regimes. They may also struggle with major issues of their identity in the face of their sudden shortened future (Stillion & Papadatou 2002).

In accordance, Michelson & Steinhorne (2007) argue that to address the psychosocial needs of children with LLCs, we must still consider the child's developmental level. Infants and children with limited verbal ability and no concept of death depend upon sensations and a physical relationship to their surroundings. Being held, comforted, and soothed provides much of their support. In the preschool years, children may benefit from clear, unambiguous explanations about what is happening to them. In the primary school years, important interventions could include supporting a child's efforts to understand the situation, letting the child have control where possible, and allowing the child to participate in medical decisions when appropriate. For adolescent patients, reinforcing self esteem, respecting privacy, and again allowing participation in medical decisions are important aspects of care (Michelson & Steinhorne 2007).

2.1.2 Communication with children

Based on the views that were prevalent early in the development of knowledge about children and death, professionals advocated a closed approach in communicating with children, in order to protect them (Stevens 1993, Waechter 1971, 1985). Parents were told to maintain a sense of normality, to shield the child from knowing how seriously ill they were, and to remain cheerful and pretend that everything would be alright. However, some clinicians began to challenge this protective view (Bluebond-Langner 1978, Spinetta 1974, Waechter 1985). They noted that ill children were anxious and knew about their disease. These clinicians observed that children who had the opportunity to discuss

their illness, prognosis, and concerns seemed less anxious than children who were deprived of this opportunity.

Interestingly, Richard Lansdown, a doctor at the great Ormond street hospital for sick children in London was interviewed by Dorothy Judd (1996) about his views on children's attitudes to death. At this time he had worked with dying children for over twenty years. With this wealth of experience, I find his comments insightful and they appear to be more in line with the social constructivist's take on psychological development:

> I think it's quite important to get some idea of children's understanding of illness, so that their understanding of death is in context. The example I give is of a boy I saw many years ago. I first talked to him when he was five years. He had stage IV neuroblastoma and I asked him when he was going to die. He said he was going to die in an airplane crash. On a little more probing I learned he was going to join the RAF when he was grown up, and he thought that he would be killed in battle. He knew that he had a serious illness, but he was not equating his illness with death. It didn't then seem appropriate to encourage his parents to talk to him or to foster a discussion with him about death, because he wasn't seeing 'one equals one'. A year later I saw him, and he talked about having a second and third tumour. He produced a marvellous phrase, 'one tumour enough, two tumours too many', which was about right. He had radiation to get rid of the tumours, and I asked what would happen if he hadn't had the radiation. He said, 'if I hadn't had the radiation, I might have died'. That was a very different story from the one the year before. It seemed much more appropriate then to get him in some sort of communication pattern (about death and illness). This is something I think is often misunderstood in the literature and by the public. People either say you shouldn't talk about dying to anybody, or you should always talk about dying to children

with cancer, because there's such a taboo about the subject. Well, I think you've got to be much more sophisticated than either of those views, and take your cue from the children's understanding. What really counts is when the child sees another child dying. It is crucial when a child knows of another child who has died of the same condition… children may be told that they may die. Their parents may say to children, 'if you don't take your medicine, you will die', but children also hear mum saying, 'if you don't tidy your bedroom, I'll kill you', and she doesn't really mean that. And granny talks about 'I'm dying for a cup of tea', but she doesn't really mean that either. But when Elizabeth in the next bed dies of leukaemia, and she's got leukaemia like I have, then that really does hit me in the guts. That is a crucial time, a turning point in children's development and understanding of mortality (p.41-42).

Judd continued to ask Lansdown if he thought all children have the same sense of the seriousness of their illness. He stated that he did not feel they did. He admittedly contradicted the literature and in particular the work of Bluebond-Langer (1978), in referring to a number of children he had cared for. He argued that many children have an unconscious fear of dying, which they would deny if you talked about it to them. What he thought was key to a child's awareness of their terminal illness, was whether they had been an inpatient or not, and if they had experienced the loss of other children. As a result, Lansdown said that he was very wary of adopting a generalised practice suggestive of 'all children know this, all children believe that'.

And so, in practice at least it appears that information about a particular child's understanding of death and the appropriateness of the level of information disclosure can only be obtained by approaching the issue with that individual child - only introducing the issue of death if it seems appropriate in consideration of the child's current level of understanding about their condition. Accordingly, there are cues to action sensitive

discussion but these are maybe better recognised by the more experienced practitioners (Faulkner 1993).

Clarke, Davies, Jenney & Eiser (2004) investigated the issue of how and what to communicate to children with Cancer about their condition. The professionals in this study found that many parents find decisions about what to tell their child with cancer difficult. Although there is evidence in practice of the complex nature of this issue and how perhaps an approach to fit all is not appropriate, in this study it was found that open communication was generally considered the best policy and most health care professionals actively encouraged parents to talk openly and honestly about the illness with the child. But one then questions to what extent there are formal support mechanisms in place for parents and if not to what extent professionals have the time to support parents through this process. Interestingly, however, parents in this study differed in their perceptions in terms of what they thought they should convey to their child. In this study fifty five parents of children (thirty six boys and nineteen girls, mean age was seven years) newly diagnosed with acute lymphoblastic leukaemia (ALL) were interviewed about:

1. How the child reacted following diagnosis
2. Their views about what to tell their child
3. Factors influencing communication with their child.

Interviews were analysed using thematic analysis. Most children were reported to show behavioural and mood difficulties after diagnosis, in general it was just the older children who were given information about their condition. In addition, it was also found that parents' perceptions of childhood cancer affected the way in which they communicated with their child. Thus, a mitigating factor implicated in the broad brush approach to open communication with children could be the parents' readiness to firstly accept the condition and its allied prognosis themselves.

In other studies, the pivotal role played by health professionals in promoting partnership and negotiation in communication is critical to families in coming to terms with their child's diagnosis, prognosis and associated health needs (Callery & Smith 1991, Casey 1995, Coyne 1997). Coupled with this, there is a developing interest by doctors in the bio-psychosocial model of health (Ong, DeHaer, Hoos & Lammes 1995) which predicates a shift from an authoritarian and paternalistic relationship between doctors and parents to one which, more like nursing, values and promotes partnership and negotiation in healthcare. Thus, there is very much the scope now for professionals to tailor the care to the needs of families and for families to lead decision processes (Sharp & Strauss 1992, Eiser 1993, Eiser, Havermans & Eiser 1995, Fairhurst & May 1995). In addition, health policy makers are being urged to ascribe a higher status to children and parents and to incorporate their views into the formulation of strategies (Aynsley-Green, Barker, Burr, Macfarlane, Morgan, Sibert, Turner, Viner, Materson & Hall 2000).

For many dying children it is argued that their primary concern is to have their parents near but to also be able to communicate their thoughts and fears with others (Liben & Goldman, 1998). These two needs can place contradictory pressures on children. At home they are assured of the presence of their parents which helps to reduce a sense of abandonment. At the same time, care at home may give children fewer opportunities to explore the very issues they may sense are 'off-limits' for their parents. To maintain open communication is then very challenging. With children dying from cancer, it has been found that there is a kind of 'mutual pretence' where, in order to protect their parents, children allow them to decide and set limits on open discussion about illness and death. Another aspect that may limit communication is chronic and severe pain for a child, making it extremely difficult to actually articulate their feelings (Savins 2002).

In addition, although children who are dying have levels of awareness about their status, they may find it hard to ask direct questions. This again may be in response to parental pretence or desire to avoid mentioning death (Pizzo & Popplack 1993). Children can feel more lonely and isolated by not being able to talk about their feelings in such circumstances (Dangel 1998). Moreover, the level of communication dysfunction can

impact on the grieving process, by leaving a sense of unfinished buisiness. However, communication is more than just speech. Non-verbal forms of communication can also be highly relevant such as tone of voice, posture, mood, touches, hugs, lap sitting, as they all offer an enriching and vital context for a child. Recognizing a child's non-verbal cues can be vitally important. Expressive therapies such as drawing, art, music, puppetry, story-telling and drama can help children to explore issues around their deaths, to express their thoughts and feelings, anger, fear, loss of hope and so on as well as their unmet needs. There is also a strong case for using drawing with both dying and grieving children (Wellings 2001). Younger children with fewer verbal skills can express themselves through drawings and these can help family and carers to understand the child's world view. For older children, the internet and e-mail are resources whereby they can share their experiences with others in a similar situation. There is also the growing reality that children with LLCs are living longer into adolescence and young adulthood and need current support to help them in their realistic assessment of all their premature death means to them (Clatworthy, Simon, & Tiederman 1999).

Psychosocial support for children extends beyond addressing concepts of death and medical decisions. By focusing attention on age-and developmentally-appropriate personal goals, children can maximise the quality of their time with family and friends. For younger children, family activities such as taking a trip to Disneyland or getting a new Play Station may provide a sense of fulfilment. For older children, accomplishing long-held ambitions such as going to the end of school ball may help improve their quality of life and provide a sense of completion. One of the most critical aspects of children's needs is to enable them to deal with two worlds at the same time – their reality of serious illness and impending death and their reality of the world of home, school and community that is the world of normal children (Stillion and Papadatou 2002). It is advocated that children need to be given the opportunity to make meaningful use of their remaining time. This may include education and play, but also holidays and special final wishes or projects. In addition, Bouffet, Zucchinelly, Blanchard, Costanzo, Frappaz, Roussin, Mangavel and Brunat-Mentigny (1996) argue that education for these children is both possible and desirable. According to Liben and Goldman (1998), this can too

easily be neglected and its value dismissed because the child has no long term future, a decision that may be especially prevalent in social care systems that are financially deeply constrained. This would be to ignore the extent to which education and play give children a sense of normality and continuity. It can also give them a sense of purpose and permit them to develop short term goals. There is a large body of evidence suggesting children have high resilience, that they are able to draw strength from their experiences and successfully integrate themselves into society (Zani 1995).

In addition, children value choices but they need to make choices within safe boundaries. Attig (1996) argues that including children in decision-making about treatment options, symptom control, and so on helps them to shape their daily lives and can substantially reduce reactions of helplessness and powerlessness. It is important for them to be given full opportunities to try and understand all that is happening to them: they need to be encouraged to express their feelings appropriate to their levels of development. Children also need honest communication: answers to their questions and someone to listen to their fears. Children are perceptive and often understand verbal and non-verbal cues better than professionals and families realise (Goldman 1996).

There is surprisingly little literature on how children cope with hospitalisation and how they are affected by it. Experiencing hospitalisation may weaken children's coping capabilities (Spirito, Stark & Gill 1995), but this could be influenced by the nature of the experiences. Having accurate information about what hospitalisation entails is associated with less distress (Siegel & Weinstein 1983). However, how far children experience problems during and after hospitalisation may be explained by prior functioning (Siegel & Weinstein 1983).

Based on clinical experience and available research, Stevens (1993) provided communication guidelines for caregivers of seriously ill and dying children. He advocates, that questions should be answered truthfully, especially since it is claimed that the child often knows the answer and is just seeking confirmation. Discussing fears and promoting family togetherness is believed to be important for children aged two to seven

years. Expressive play with art and music may be helpful in encouraging children to share their fears and feelings (Gray 1998). Children seven to twelve years of age may fear abandonment, destruction, and body mutilation. It is suggested (Stevens 1993) that they need people to be truthful with them and to foster their sense of control over their deteriorating body. Friends are also important to children of this age and it is argued they should be encouraged to visit. One of the tasks of adolescence includes separation from parental control. Adolescents often struggle with the paradox of wanting support and yet wanting to meet challenges by themselves. They may prefer to talk to and confide in a peer group, especially with others in a similar situation. As with younger children, adolescents may be more concerned about their family and friends than about themselves. They tend not to be afraid of death so much as afraid of dying. Professionals are therefore encouraged to listen carefully to understand the adolescent's perceptions of their own illness and prognosis, as advocated by Lansdown (1996) previously. Privacy and a sense of independence are also important to an adolescent, as is peer contact and support. Offering choices may also give adolescents a sense of being in control, and may reduce anger, frustration, depression and anxiety. Creative tasks such as writing poems, letters or a journal or drawing have been shown to release pent-up emotions. In addition, many adolescents want to know that they will be remembered. Creating a permanent record to leave behind, such as a video, tape or photograph, may be valuable (Stevens 1993).

While these guidelines are helpful, further research is needed to evaluate the efficacy of these approaches, and the appropriateness for those approaches with all paediatric patients. From the available literature, it appears that there needs to be more consideration of individual and subjective differences and less attention on broad assumptions. This is especially pertinent in consideration of there being a dearth of research that has addressed children's needs from the perspective of the child rather than by proxy.

2.2.3 Working with dying children and their families

In her book 'Give sorrow words: working with dying children' (1996), Dorothy Judd includes diary excerpts of her work as a psychotherapist (spanning three months) with a seven year old boy. The excerpts are an illustration of how emotionally involved professionals working with children with LLCs can be. Dorothy details how she tried to keep her emotions under control and highlights the difficulties in knowing what to say to both child and family when one knows that the child is dying, despite her expertise. Leading up to the given excerpt, she details the child patient 'Robert' undergoing a bone marrow transplant, using his father's marrow. Afterwards barrier nursing is employed and continued even in times where there appears to be little hope. 'Robert' then goes through very dramatic bodily changes, and his parents struggle to cope with this. In addition, Judd observes how Robert appears to cope with his anxieties, his pain and frustrations. The three months cited are three months of this child slowly dying; for a person outside of this life world, the account is difficult to read as it is written with such illuminating prose. To illustrate:

p.121 (23rd October):

> I ask Robert if it is difficult to breath. He nods. There is a long silence. He is struggling, giving little moans, his eyes closed. I say, 'I wonder if there's anything you want to try and talk about… any worries you might have? There is a silence. I go on '… about where this is going to lead?' he does not respond. I do not know what he is hearing. He makes little twitches and occasional grimaces. I find myself having to summon courage to put thoughts into words beyond the point of comfort. I continue, '… whether there may be things you can't talk to mum or dad about, because you don't want to worry them or upset them'. He nods. Further silence. Then I say, you must sometimes wonder how long this will go on for, and if you are going to get better'. He gives another little nod. I feel immensely sad. I stroke his forehead for the first time. Its so soft and silky and warm. He seems to like it. I feel relieved that we no longer have to wear gloves. Dispensing with this rubber barrier parallels

with what feels like the more important removal of an emotional barrier between us. I stay a little while quietly by him. He has hardly opened his eyes since his mother left. I feel he reserves that way of actively 'holding on' with his eyes for when she is in the room. I say goodbye and mention to him that we can carry on with the story book next time… later in talking to one of the sisters she expresses her upset at 'the grotesque appearance' of Robert. 'Bloated, absolutely awful, absolutely horrendous'. She says 'and he is conscious of what is happening to him, and so aware that his body is not functioning properly'… I feel relieved that this sister, with her many years of experience of this work… is also in touch with what we agree is 'torture'.

Robert died on 17th December, having been able to communicate up until that very day.

p.158-160 (17 December):

Mrs Campbell (Roberts mum) tells me that this morning he had been breathing with difficulty since about 5am, so they provided oxygen. At about 10am Robert asked for the bedpan, but was too weak to lift himself up, and soiled the undersheet. Mrs Campbell tells me how he held out his little arm, which mother took, 'and it felt strange. He just looked at me with those great big eyes. I rang the bell. Mike (charge nurse) came, and then I went to get my husband. I think he was 'gone' by the time we came back…' After a long delay, we all go down to see Robert in a strange underground – or should I say underworld – part of the hospital, through various locked doors, escorted by a young man. Robert's body is in a little room, lit only by a candle-bulb. An iron cross stands next to it. He is covered up to the neck in a royal blue shroud. His bald head rests peacefully at last. His eyes are closed, behind pinkish lids. The rest of the face is pale, except for dark red lips. Are they painted, or is it purplish bruising? He wears the smart striped

pyjama top he wore before he became desperately ill… Outside the hospital, the darkness of the night is regaled by the Christmas lights. I curse the Christmas trees and the Christmas lights… Later, at home, I feel the need to care physically for my healthy seven year old. I look at him, stretched out in the bath, and gain succour from his health, while feeling a shiver of shock at the coffin-like surround of the bath. I have to begin my own process of mourning Robert.

p.160-161 (18th December)

I go up to the children's ward to add my last notes to Robert's medical files. I read the medical notes for yesterday. These are some extracts:

7:15am Very weak

7:30am Fairly rapid deterioration. Pneumonia.

9:30am Very unwell. Morphine prescribed.

10:10am No spontaneous respiration. No pulse. Certified dead (by the Senior House Officer).

I wander into Roberts empty room, feeling if I postpone this step it will become more fearful… At a staff meeting the next week, one of the staff nurses who knew Robert brightly tells me that she and the other nurses were 'really pleased' when Robert died. At first I think I have misheard her, and ask her to repeat herself. I then realise that she does mean what she says, and that she is referring to the understandable relief the nurses felt that the long and painful struggle was over. Nevertheless, it leads me to wonder about some of the nurses' difficulties in really feeling loss at Robert's death. Their training and work, with its emphasis on nursing people to health, does not seem to have sufficient place for thinking about, and staying with, the pain of terminal illness. But then, can anyone repeatedly experience this in an exposed way? I realise I have to spare myself too frequent encounters

with death through my work… to really share the process with the
dying and their families, I have to find a balance: somewhere between
the raw pain they are feeling, and the defended state of some of the
medical team, in order to be most useful to them. Weeks later, I go back
to Robert's medical file, and see that someone has written in the date of
his death under the 'date of discharge' column, and then inscribed, in
big letters, 'RIP'.

To witness suffering is both difficult and complex; it could be argued that it would not be
a human effort if the professional failed to be drawn into the world of the patient. Often,
it is claimed that doctors, nurses and allied health care workers become hardened to
patients dying, as a form of self protection. However, it is most probable that
professionals always to some degree are affected in some way by the pain and suffering
of their patients. Lingis (2000) discussed the experience of seeing suffering and said

We do not simply see the pallid surfaces, the contorted hands and
fingers; we feel a depth of pain… there is a contagion of misery. For
one does not view the pain behind the surfaces of his skin; one feels it
troubling one's look; one feels it up against oneself. The sense of
sharing the pain of another, the sense of the barriers of identity,
individuality, and solitude breaking down hold us. There is anonymity
but also communion in suffering. One suffers as anyone suffers, as all
that lives suffers (as cited in Komesaroff 2001:323).

A good death

The concept of a 'good death' has a diversity of meanings, centred on the ideal of dying
with dignity, peacefulness, preparedness, awareness, adjustment and acceptance (Hart,
Sainsbury & Short 1998). The achievement of a good death has become central to the
philosophy of the hospice movement (Hart *et al* 1998). Aggressive treatment of
signs/symptoms of discomfort, exploring the impact of illness on quality of life of
persons and family to improve coping, being present through all the patient's and

family's experience at the end of life, and assisting with living as well as possible until death without fear of loss of dignity, dying alone, or being in pain are all considered to be factors of a 'good death' (Gazelle 2003). However, writers from different disciplines have challenged the existence of a good death and suggest that cultural ideals of a good death could impose behavioural expectations on the dying (Ellison & Fuller 1998; Walters 2004).

In accordance, it is recognised that there are problems in the use of 'a good death' as an intervention outcome. In part, this is because historically (Steinhauser, Christakis, Clipp, McNelly, McIntyre & Tulsky 2000), the concept has largely been professionally conceived. As a result it may not be high priority or totally understood by patients (McNamara, Waddell & Colvin 1994, Low & Payne 1996, Hart *et al* 1998). Secondly, its focus is on the experience of death, which does not incorporate the full experience of dying and the concerns of dying patients. Thirdly, it is assumed that there is shared understanding between professionals regarding what constitutes a good death. This does not acknowledge there being aspects of individual understanding that are different. Finally, because it assumes a shared understanding of what is an acceptable death, it may unjustifiably reinforce negative or positive feelings that health professionals hold about the quality of care they have provided. Professionals may be uncomfortable in following set guidelines or procedures that are not in line with their own presumptions and how they feel their patients would like to die.

There is often uncertainty as to what is in a dying patient's best interests and conflicts arise when the dying child's family and practitioners hold different perspectives (Breen, Abernathy, Abbott & Tulsky 2001). Ethical dilemmas regarding the child's interests or goals of care can precipitate moral distress, caregiver suffering and grief (Hamric 2000; Kaplan 2000; Meltzer & Huckabay 2004; Papadatou 2000). In paediatric palliative care, practitioners are educated to provide peace, pain control, support and decision making/control for dying children and their families. Yet, it is expected that in this arena few practitioners call what they do 'promoting a good death'. For years, the focus of caregivers and researchers with regard to the notion of 'a good death' has been on adults

(see Nyatanga 2005). However, the situation is slowly changing. As Dr Jay Milstein has commented *'It may be painful to accompany a child or sibling on his or her final journey, but the experience has the power to transform lives'* (as cited in Bush Welch 2008:124).

Interactions with families

Over the last thirty years there has been a growth in literature that details personal experience of illness. These documents, authored by the patients themselves or their relatives are sometimes very critical of professionals. Hawkins (1993, cited in McWhinney 2001) has commented that this body of literature could be viewed as a reaction to a medicine *'so dominated by a biophysical understanding of illness that its experiential aspects are virtually ignored'* (p.340). Furthermore, he adds that two themes transcend these texts:

> The tendency in contemporary medical practice to focus primarily not on the needs of the individual who is sick but on the nomothetic condition we call the disease, and the sense that our medical technology has advanced beyond our capacity to use it wisely (p.340).

Toombs (1992), a phenomenologist who has multiple sclerosis has written about how the physician's attention is focused on the bodies of their patients, instead of their difficulties in living. She goes on to say that the patient is

> Reduced to a malfunctioning biological organism… no physician has ever inquired of me what it is like to live with multiple sclerosis or to experience one of the disabilities that have accrued… no neurologist has ever asked me if I am afraid, or… even whether I am concerned about the future (Toombs, 1992, cited in McWhinney, 2001:340).

This is something that is repeated in patient's accounts generally - that their experience is not considered and that diagnosis is a mechanical process of classification and abstraction.

Davies, Davis and Sibert (2002) interviewed thirty parents to look at their lived experiences of being told their child has a LLC. The majority of diagnoses given were Cerebral Palsy. For these parents they were aware of difficulties from the time of birth. However, where the diagnosis was that of a genetic disorder, parent's experience of things not 'being right' was of a more gradual nature. Receiving a diagnosis meant that they could reason their worries and at least begin to plan for their child's remaining future:

> The first time we were told his condition he was 14 years… you can't say it was a relief but in a way it was because we wondered what would become of him in the years to come. Who would look after him? In a way we were thinking well at least we can look after him for as long as he's got. It was nice to have a name (Mother of a son with Hallervarden Spatz disease, Davies, Davis & Sibert 2002:78).

In a further qualitative study of twelve parents whose children had died from cancer, it was reported that parents felt cared for when professionals spoke with them and treated them with respect, compassion, and sensitivity (James & Johnson 1997). Conversely, a professional's failure to listen to parental concerns had caused frustrations for parents. Moreover, parents felt abandoned by caregivers who had physically and emotionally withdrawn from them. They also reported feeling frustration, anger, and hopelessness when health care professionals refused to take parents' concerns seriously. However, other researchers have determined that it may not be easy for families to communicate with health professionals and as such issues are never aired (Clarke-Steffen 1997, Diehl, Moffitt & Wade 1991).

2.2.4 The family's lifeworld

In the case of a child with a LLC, the whole family has the difficult task of trying to adjust to a situation which is dominated by the stresses of long lasting uncertainty and uncontrollability (Patenaude & Last 2001). As a result of a LLC diagnosis, families face multiple burdens due to frequent hospitalisation, financial strain, time-consuming medical regimens, and other related stressors. The emotional impact on parents caring for a child with a LLC, is beginning to be documented. Because some of the LLCs are genetic, some parents may feel responsible for causing the child's illness. The guilt and anguish that may arise from this sense of responsibility has been noted in families where a child has a neurological condition (Hunt & Byrne 1995) or cystic fibrosis (Bluebond-Langer 1996, Whyte 1992), and in HIV infected parents who infected their child (Wiene, Theut, Steinberg, Riekert & Pizzo 1994). Perhaps this is something experienced by all parents, no matter how illogical this may be. Some parents may construe potential causes of their child's condition that lays some blame on themselves.

It is also realised that parents may focus on the ill child to the exclusion of virtually everything else, including their relationships with each other, extended family, and friends (Gravelle 1997). During their research at Helen House (the first children's hospice in the UK), Stein and Woolley (1990) discovered that families of children with a LLC had no time for social and leisure activities. Parents were unable to do anything as a couple or as a family because all their focus was on the ill child. Difficulties such as marital discord, sibling rivalry, inattention to other children, and loss of relationships with extended family and friends was reported to often result. Interestingly, marital difficulties have been reported by other researchers (Thoma, Hockenberry-Eaton & Kemp, 1993, Whyte, 1992). Indeed, some parents in these studies worried about the effect their child's illness would have on their marriages. They had heard about higher divorce rates in families with ill children. Martinson, McClowry, Davies & Kualeramp (1994) however, suggested that while illness can push parents apart, it can also strengthen their love and commitment in some couples.

Although limited, there is some evidence that families may be able to reduce the impact of their child's illness by reinforcing the family structure (Patterson, Leonard & Titus 1994, Ray & Ritchie 1993). Patterson, Leonard and Titus (1994) in their study of 48 medically fragile children and their families, found that parents who emphasise doing things together as a family strengthen family relationships and successfully cope with the impact of illness by facilitating family cohesiveness. Family cohesion, family organisation, and support from the community reduced the amount of strain parents reported having with home care providers. Whyte (1992) also reported that caring for a child with cystic fibrosis affected the interaction patterns and the coping responses of families. Where there was synchrony between the partners, family functioning remained strong. Whyte (1992) concluded that families perhaps need to move through the transition of seeing themselves as a 'normal' family to accepting that they are a family with a child with a significant health problem. Otherwise, relationships can become very strained.

Support

Although open and effective communication may be important for families as they care for their ill child (Clarke-Steffen 1997), other problems have been identified among family members (Clarke-Steffen 1997, Whyte, Baggaley & Rutter 1997), and between families and health care professionals (James & Johnson 1997). Proctor, Nagy, Stevens, Lord & O'Riordan (2008) explored the lives of life-limited children: their illness journey, their hopes, concerns, and health care related experiences. This was a large Australian qualitative study exploring families' experiences of caring for children diagnosed with LLCs. Ninety-one family members (parents, ill children, well siblings and extended family members) from twenty nine families with one or more ill children participated in home based, in-depth unstructured, audio-taped interviews. Participants spoke about how conditions such as muscular dystrophy, cystic fibrosis, cancer, leukemia, neuro-degenerative and genetic disorders impact upon family life, at the level of the individual, the nuclear and extended family units. Through this study, health care professionals are afforded a unique opportunity to learn directly from living and recently deceased seriously ill children and adolescents' experiences, as they reflect upon their lives and the

uncertainty of their future. At the time of writing, however this study has not been formally published and so we cannot debate its minute content. To date, this is the only study I have found that has aimed to elucidate the complexity of the lived experiences of being and caring for child with a LLC from the perspectives of all family members.

Previous research has mainly focused on identifying issues related to parents' uncertainty about health outcomes, for example the child's physical health and psychological adjustment. The construct of uncertainty has been discussed over the course of the past two decades by Mishel (1981, 1988), Koocher (Koocher & O'Malley 1981, Koocher 1984) and others (Cohen & Martinson 1988, Cohen 1995, van Dongen-Melman Pruyn, DeGroot, Koot & Verhulst 1995). Broadly defined, uncertainty pertains to both acute and pervasive fear of possible illness consequences, for example death, recurrence, and treatment-related sequelae (Stewart & Mishel 2000). A review of the literature on parental uncertainty by Stewart and Mishel (2000) included thirty four studies covering a wide variety of chronic illnesses. Most of the cited studies were qualitative or descriptive and highlighted a relationship between uncertainty and psychological distress (characterised by anxiety, depression, cognitive disturbances, and feelings of helplessness). Other research has investigated the emotional distress and affects of strict treatment regimens and protocols of care (Coffey 2006, Farmer, Marien, Clark, Sherman & Selva 2004). Some studies have also elucidated parental concern regarding obtaining the appropriate care for their children (King, Cathers, King & Rosenbaum 2001).

Parents' need for honest and appropriate information so that they can manage their situation has been well documented. These studies have been with families who have children with cancer (Clarke Steffen 1997, James & Johnson 1997), cystic fibrosis (Bluebond-Langner 1996) and neurological conditions (Davies 1996) and other chronic or life-threatening illnesses (Diehl, Moffitt & Wade 1991, Gravelle 1997, Walker, Epstein, Taylor, Crocher & Tuttle 1989). Information may be empowering (Clarke-Steffen 1997), and allow families some control in a situation where they have little control. It may also help to reduce uncertainty (Cohen 1995, Galloway & Graydon 1996). Yet, some researchers have shown that information needs are not always met. In a mailed

survey with a convenience sample of parents whose children had various chronic illnesses (n=910, 38% return), communication and information needs were ranked as important, though frequently not met. Many parents wanted more communication with health professionals. They needed to obtain information about programmes and services, financial planning for the future, the child's particular health problem, financial aide and insurance plans, and the treatment prescribed (Walker *et al* 1989).

Barriers faced by families when looking for information may include complex medical language, reluctance of some professionals to disclose information, and negative attitudes of those providing the information. Moreover, in situations where there is little information about the disease entity, as is the case with many genetic/neurological conditions, the task of providing the information parents need becomes more difficult. Thus, even when professionals are willing to share what they know, there may be no written information available to disseminate. In such cases, the scarcity of information has been seen to contribute to increased uncertainty and frustration in these families (Davies 1996).

Problems in communication have also been attributed to discrepancies that arise when parents need to talk about their feelings related to the child's death and dying and family members and friends are unwilling to discuss these issues (Diehl *et al* 1991). Our understanding of the complexities underlying communication problems for families has been extended by Jefidoff & Gasner (1993), in their study of Israeli parents of dying children. They found that even when families can discuss their fears and talk about the child's imminent death, they may be unable to articulate their more complex needs, such as those related to understanding changes in family dynamics that may occur in the final stages of the disease or describing feelings about the funeral and burial, unless they have the assistance of skilled paediatric palliative care staff. The investigators suggest that families' ability to recognise and deal with these potential stressors puts them at higher risk for further problems.

Care

The routine tasks of caring for a child with a LLC can cover all aspects of daily living including washing, dressing, feeding, lifting as well as general housework and other family commitments (Twigg & Atkin 1994). In addition to such everyday tasks, parents may also have to undertake a quasi-nursing role because of their child's specific medical needs, such as the administration of complex medication and the maintenance of technically sophisticated equipment and procedures. Baldwin & Carlisle (1994) revealed that mothers faced with such daily routines of care can become isolated, with considerably restricted social lives. Twigg and Atkin (1994) also suggested that primary carers may experience difficulty in finding and trusting another person to be capable enough to take over from them on a short term basis, thus further limiting their time away from their child. Family trips away from the home that can include the child with the disability can be viewed as more stressful than enjoyable because of practical access difficulties and the complexities of their child's medical condition or behavioural problems (Baldwin & Carlisle 1994, Beresford 1994). In addition, a few authors have remarked, almost in passing, that parents of children with LLCs are exhausted (Gravelle 1997, Stein & Woolley 1990).

Caring for any child has been found to have an impact on a family's financial situation relating to both expenditure and income (Carney, Fitzgerald, Kiely & Quinn 1994). However, in families where children have complex practical needs, this impact may be accentuated. There is a large body of research which suggests that caring for a child with severe disability places families under financial strain as a direct result of the increased amount of care, particularly if that child also has additional medical needs (Bradshaw 1980, Baldwin 1985, Baldwin & Carlisle 1994). In the past, studies have primarily looked at financial strain reported by families caring for a child with a disability as being related to extra costs associated with that caring, such as the provision of special clothing, equipment, transport or dietary needs (Baldwin 1985). However, more recent work has focused on the reduced ability of the primary carer, predominantly the mother, to participate fully in the labour market (Shearn 1998). It has been noted that many mothers feel obliged to cease labour market participation on the birth of a child with a disability or

at least reduce this participation (Shearn & Todd 1997, 2000). This diminution of the mother's ability to undertake paid work has the effect of reducing the family's income at a time when additional resources are required to cover the increased spending related to their child. Luke-Meyer, Meyers and Smith (2000) revealed that the effect of the caregiver's loss of earnings has particular impact on low-income families, increasing their chances of sliding into deeper poverty.

Children's hospices are a resource for families throughout the duration of a child's illness (sometimes before birth if a LLC is diagnosed prior to birth) and there are usually bereavement services in place and offered to families once the child has died (ACT/RCPCH 1997). Over recent years there has been a rapid growth in the number of children's hospices and a few of these also provide palliative care in the child's own home. Despite the growth of this movement there are still many children with LLCs who do not have access to Hospice care and amongst those who do access services, very few of these actually die within a hospice setting (While, Citrone & Cornish 1996). As stated by Andrews and Hood (2003) most people believe that home is the most appropriate place for a child with a LLC to die. This preference has also been put forward by many parents and children themselves (Davies 2005). However, for many children with LLCs their last days and untimely death will be in a hospital ward (Steele 2002). This is unfortunate because it has been noted that end of life care within the hospital setting is inadequate due to a lack of palliative care skills and knowledge (House of Commons Health Committee 2004:21). Within the hospital environment the focus is on curative treatment, privacy is not always accessible and there is often not enough room for the family to be with the dying child and be comfortable (Steele 2002). Also, if the child dies in hospital it is just a few hours after death that the child will be taken away from their parents by the funeral directors or transferred to the mortuary. In these circumstances, parents are not always aware that in the UK they have 'possession and control of the body' when a child has an expected death (Kennedy Report 2001: 49). This means parents are actually free to take their child home after death but as identified by Whittle and Cutts (2002) very few National Health Service hospitals convey this to parents. Conversely, in the hospice setting parents are encouraged to maintain their caring duties

until death and the environment means there is enough accommodation for all the family. The child's body can remain in the hospice with the family until the funeral (Gold 1997).

Interestingly, Moulton (1997) interviewed eight mothers of children who had died from a developmental disability. She found that where mothers had maintained their primary care role they were left to feel in control and these parents said they were more at peace in looking back on the time of their child's last few days and death. Where mothers felt as though they were not in control prior to their child's death, they reported to have feelings of guilt and spoke of how they would have liked to have done things differently. Davies (2005) supports the notion that a parent's memory of their child's end of life care has a continued affect in their bereavement. According to Goldman (1996) each child has specific needs, differing according to age and level of understanding. Goldman argues that for a child to be at home in a familiar environment among family and friends, and being able to maintain as much of normal life for as long as possible, is of primary importance. It is also argued that families prefer to have heir children at home with them throughout the full illness trajectory (Goldman, 1996).

2.3 Summary and rationale for the current research

Advances in the provision of care for children with LLCs are said by policy directives to allow children to grow and thrive. Despite this, the paediatric literature is replete with commentaries and articles advocating better care for the dying child and their families (e.g. Bush Welch, 2008, Feudtner, 2004, Hutton, 2002, Rushton & Caitlin 2002, Stephenson 2000). Of interest is the fact that most of the available qualitative research to date on LLCs has been from the perspective of professionals or parents. There have been few attempts to capture the views of the ill child. Yet, relying on adults to identify impacts on children may neglect the children's hopes, fears and anxieties and may also fail to capture their experiences.

Accordingly, it is a rare opportunity to observe and speak with children and adolescents with LLCs and so gain insight into their lives. Their vulnerability is often characterized by rare and difficult-to-diagnose conditions, significantly shortened life spans with

compromised quality of life. Their childhoods are scattered with periods of hospitalisation, missed developmental milestones and a loss of innocence as they address the reality of life with life-limiting illness. When a child has a LLC, a family experiences loss over months or years as the child's condition worsens. Their experiences of grief associated with these losses are not well understood. Moreover, parental feelings of recurrent grief may resurface during situational or developmental crises experienced by their children.

This review details a variety of studies that have identified gaps in the literature. Further research is needed for us to reach an understanding of the lived experience of Being and caring for a child with a LLC. In the paediatric literature in general, there are not many studies that have been interpretive in nature, viewing the child as an active user rather than a passive recipient of health and social care services. As stated by Eiser (1990) all children with illnesses are different and so it would therefore be inappropriate to perceive all children with LLCs to have the same experiences and perceptions of such. Indeed, the meaning of living with a LLC is not easily accessed from the available literature. Max van Manen (2001) argues that

> The clinical path of an illness for any particular person is often different from medical assessment. The experience of disease is never experienced in exactly the same manner from person to person. The individual human being always falls to a certain extent 'outside' of the dossier, the diagnosis, the description, and the prognosis (p.457).

Therefore, the challenge for contemporary research on children with LLCs is to study them and their carers (both parents and professionals) as their illnesses present themselves and as they are living the experience. This way we can stay genuine to the phenomenon. The research question that has emerged from a critique of the available literature asks what it is like being and caring for a child with a LLC. This broad question encompasses a number of research objectives for the current study:

1. To investigate the roles and care experiences of professionals working within palliative paediatric care

2. To explore the lived experiences of parents of children with LLCs

3. To explore the lived experiences of children with LLCs

4. To highlight the synthesis of the perspectives of children with LLCs, their parents and professionals.

A qualitative research design is the most suitable for exploring the given research question. Phenomenology is the method of choice and will be outlined in full in the following chapters. The phenomenological method is an inductive, descriptive research method, the goal of which is to describe the nature of lived experience, including the meanings that these experiences have for the individuals themselves. The study involves a number of focus group discussions with professionals and in-depth semi-structured interviews with parents and children. Five of these interviews will be framed as parent – child dyads.

Chapter 3: Philosophical Influences

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The philosophical underpinnings of a study embody the researcher's understanding of what it means to be in the world and how one knows what they know. These ontological and epistemological issues are closely linked and together they are fundamental to any social scientific inquiry.

3.1 Constructionism

The theoretical assumption that has formed the epistemological basis of the present study is constructionism – the construction of meaning. Plato was one of the earliest philosophers to describe the construction of meaning in his well known cave analogy (Bauman 1978). In the analogy, slaves were tied together in a cave faced towards a wall on which danced the shadows reflected from a fire. These slaves constructed a process of meaning that came from naming the shadows. The slaves in the analogy were unable to see the items that cast the shadows so they built a whole new system of meaning. The role of naming in the construction of meaning has been widely discussed since this time. As stated by Gadamer men are condemned to meaning making: *'To exist, humanly, is to name the world, to change it'* (Friere 1972:61). The slaves in this story earned respect and status by their ability to make sense of the shadows within the new system of meaning. One day a slave broke free and was able to turn to see what cast the shadows. When returned to the tethered position, he tried to tell his fellow slaves of the origins of the shadows, however the other slaves had no reason to believe this slave's description, or new construction of reality over their own. What is more he/she lost the ability to see the shadows through the other slave's construction of meaning and thus lost status in the group. Reality for the slaves was arrived at through the shared construction of meaning. This construction occurred within their community, and served them in their context. In contrast, Plato advocated that universal truths do exist. These truths exist in forms that every-day objects copy; they exist outside of time and space and are only available to humans in the disembodied state between life and death. New knowledge he claimed, is a

remembrance from a time in Anamnesis, the multiple cycles of life and death, when the person is disembodied and has access to original form (Lemay & Pitts 1994).

Immanuel Kant however, claimed that the human mind filters all sensory experience to make sense of it in a particularly human way. He argued that each person filters sensory stimuli or information through the attribution of meaning. Also, he believed that all humans have the same filters, or ways to construct meaning, and thus universal human knowledge or truths can be generated (Winfree 1999). Friedrich Nietzsche went on to articulate the belief that underpins the notion of constructionism when he stated that there is no universal truth waiting 'out there' to be discovered. He questioned the whole nature of truth and came to the conclusion that no such entity exists. There is he claimed, no complete truth, as whatever is revealed as truth conceals a great deal and not only this it conceals the concealment (Winfree 1999). A shift from truth to meanings is a shift from positivism.[1] Individuals construct meaning in the context in which they are situated in the world and so meaning is negotiated through interaction (Crotty 1996). The meanings or realities that people construct are social realities that are negotiated amongst people and distributed or shared in the evolving nature of culture. Heidegger constructed the term 'thrown-ness' to describe how people are placed into a situated context without an element of choice or consent (Lemay & Pitts 1994). Once situated in this context into which they are thrown, they are prone to construct meaning through the cultural lens that comes with this context. The culture is thought by Heidegger to shape an individual through circumstance and the construction of meanings.

3.2 Introducing Phenomenology

Phenomenology is a relatively new philosophy for which the finer points have remained open to debate up until this day. Anyone entering a dialogue with it is confronted with the conundrum of whose phenomenology to follow. Many people are attracted to this

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[1] In its broadest sense, positivism is a rejection of metaphysics. It is a position that holds that the goal of knowledge is simply to measure the phenomena that we observe. The purpose of science is simply to research what we can observe and measure. Knowledge of anything beyond that, a positivist would hold, is impossible (Trochim 2000). As such, positivists separate themselves from the world they study, while researchers within other paradigms acknowledge that they have to participate in real world life to some extent so as to better understand and express its emergent properties and features (Healy & Perry, 2000).

philosophy by the power of interpretation provided through the adaptations of some of phenomenology's later exponents. However, the works of Edmund Husserl (1859-1938), the man attributed with the honour of being the founding father of phenomenology in its modern sense provides a matrix from which the works of other exponents emanate. These works have significant differences in terms of emphasis and interpretation; however all still bear a relation to the work of Husserl (Langdridge 2007).

Phenomenology as originally envisaged by Husserl, was to be the study of universal eidetic structures or essences of phenomena. This reflected a theoretical perspective in which a phenomenon was seen as able to be reached in a prereflective or prepredictive state: that it was possible to separate the subjective experience (the noesis) from the objective phenomena (the noema), through the process of phenomenology (Husserl, 1980). From a constructionist perspective an obvious problem is that the only access we have to other's experience of phenomenon is through conscious interpretation, and the only way one has to access a phenomenon is through the construction of meaning. Husserl had an awareness of this and attempted to control for this through a rigorous process of bracketing aimed at the separation of the subjective from the objective.

Heidegger like Husserl recognised that human consciousness is temporal and perspectival and that there is potentially not just one universal eidos or essential nature of a phenomenon that can be accessed but that a variety of interpretations are possible and each may be valid (Heidegger 1962). However for Heidegger phenomenology, although not searching for a universal essence, was still more than the process of gathering the subjective. Phenomenology is a critical process in which normal everyday experiences are problematised with the aim to allow a fresh look, to get to that place where the phenomenon can be viewed in a new way (Crotty 1996). Phenomenology is about the development of a conversational relation with the phenomenon that is the focus of the study. The aim of the conversational relation is to break through or suspend the preunderstandings and structures of meaning that already exist and which influence the current construction of meaning about the phenomenon, to explore the phenomenon and allow the emergence of a new or renewed construction of meaning (Van Manen 1990).

At times this happens spontaneously in our lives. After an intense experience we sometimes find we can see the world anew. We feel dislocated from our previous construction of meaning or ways of seeing the world and feel free to take a new direction or the appropriateness of our current direction is reaffirmed (Crotty 1996). Phenomenology aims to achieve the same effect through a systematic and critical process. This is getting 'back to the things themselves' championed by Husserl and carried forward by Heidegger (Crotty 1996). Phenomena exist in the lifeworld (Van Manen 1990) and are reached through lived experience (Sandelowski 1997). Phenomena do not exist as separate or discrete entities waiting to be studied. What is available to our conscious being is a flow of experiences with no clear boundaries (Schutz 1932/1967). It is only through the process of turning towards, or focusing on the particular experience that we attach the meaning and understand it as a discrete phenomenon. The process of turning toward, or focusing attention upon, has been termed intentionality (Husserl 1988).

3.2.1 Intentionality

Husserl's discussion of intentionality encapsulates the notion that all consciousness is consciousness of something (Husserl 1929/1988). The act of directing consciousness or turning attention toward an experience lifts that experience out from the flow of experiences that seem to have no defined boundaries - or 'duree' (Schutz 1932/1967). This process is of attributing meaning to a situation which involves both reflection and recognition (Schutz 1932/1967). The recognition relies on drawing upon one's current construction of meaning of the world to make sense of a particular experience. Heidegger described phenomena as something which we can bring to light (Annells 1996).

Heidegger in his move from the epistemological basis of Husserl's work in which intentional acts were individual, to the ontological basis of hermeneutics further refined the notion of intentionality. Heidegger took intentionality out of the context of theory of meaning to a theory of being. Heidegger came to view intentionality as the constitution of consciousness itself (Kockelmans 1993). Consciousness to Heidegger was not an interior thing but a projection from oneself. A Being or 'Dasein' cannot be conscious of all things at once as it is limited by human facticity (the unrecognized and unthematised

everydayness and the fallenness, throwness and uncanniness of life) and finitude (factical nothingness). Thus, consciousness is an opening of oneself to an issue, but not all things at once (Kockelmans 1993). In addition, a Being can only project out from a limited horizon. This horizon is where the Being is situated in the world. Interpretation is not the acquisition of knowledge or information but rather a working out of the possibilities, which are projected in understanding (Heidegger 1927/1985). Therefore, Hermeneutics offers a horizon or place to project from.

3.2.2 Hermeneutics

Hermeneutics is a word of Greek origin, the usage of which in the Greek language refers to an explanation or translation (Crotty 1996). It is derived from the Greek verb, hermeneuin, to interpret (Van Manen 1990). The word was also influenced by the noun, hermeneia, or interpretation. Both Greek words were derived from Hermes, who in Greek mythology was the wing footed messenger god responsible for the discovery of language and writing through which he changed the unknowable into a form that humans could grasp and understand (Thompson 1990). The recorded hermeneutic tradition began with interpretation of biblical texts and has been dated to the seventeenth century (Van Manen 1990). When used in the context of hermeneutic phenomenology, hermeneutic retains the meaning of the interpretation of meaning acquired through text. Interpretation is the process through which a new or renewed and plausible meaning is constructed. It is the process of moving beyond mere description of a phenomenon or the cataloguing of currently accepted subjective interpretations. The hermeneutic process of interpretation is circular. It involves a movement between the specific and the whole, between projection of meanings and anticipation of understanding. The aim of this process is to uncover and explicate an understanding of the phenomenon.

The metaphor of the circle in hermeneutic interpretation has been revised by many scholars but represents the dynamic movement between the part and the whole of texts to seek understanding. This understanding is not as a way of knowing, but is experienced as a way of being (Annells 1996). Accordingly, the circle consists of two arcs and both are equally important in hermeneutics. The forward arc is considered to be one of projection

- this is what makes understanding possible. The arc projects from what Heidegger conceptualises as a fore understanding. Gadamer referred to this understanding as prejudice (Gadamer 1985). The word prejudice (pre-judgement) usually has negative connotations attached to it but Gadamer reinterprets it in a positive light as an inevitable aspect of understanding. For Gadamer, prejudice is something one brings into understanding but it does not restrict our understanding; instead by our prejudice, the world opens up to us. It is from this stance that the field is opened for interpretation. Therefore, the forward arc renders understanding possible and the return arc provides the space for evaluation of an interpretive account (Packer & Addison 1991).

Gadamer (1985) wrote of the interpretive account as the outcome of a fusion of horizons. These are the horizon of the text and that of the interpreter. For Gadamer, understanding does not happen independently; essentially it means coming to an understanding with others. In the process of understanding, our prejudices are brought into question and so understanding occurs in negotiation between oneself and one's partner in the hermeneutical dialogue. The aim of hermeneutical dialogues is to come to an agreement about the matter at issue and coming to such an agreement, for Gadamer, is establishing a 'horizon'. The fusion of horizons is situated historically as the horizon of the interpreter is formed within the traditions (horizons) and beliefs (horizons) of the time. Each time a dialogue is entered into with the phenomenon there is room for a reflective evaluation of pre-understanding and a refinement of interpretation or understanding. The acquired understanding becomes the interpretive account. Hence, all understanding is trapped in the 'hermeneutic circle' where everything is interpretation, contextual and circular.

In hermeneutical philosophy it is recognised that at any starting point of research one projects into the study. This context will affect the lens through which the study is viewed. The life world or lived experience is the ground from which all people come from and it can never be fully eliminated even if the ground is interpreted in a radically different manner (Bruzina 2000). There is no way to adopt a stance from which to view human life that is outside experience; the appearance of a phenomenon is embedded within attributed meaning. The researcher is called to be aware of, as far as is possible,

their current construction of meaning to allow the results of their interaction with the phenomenon to surprise them: to allow the shining through referred by Heidegger or be open to the fusion of horizons described by Gadamer. In hermeneutics this is not a formal process of bracketing as originally advocated in phenomenology by Husserl, but more a process of surrendering. This surrendering is an openness to incorporate and assimilate insight from the reverse arc of the hermeneutic circle (Wolf 1984 as cited in Wolf 2008).

The interpretation uncovered will be a true one in Heidegger's view if it provides an answer to the practical problem that motivated the enquiry. For Heidegger truth was uncovering or self-showing (Heidegger 1943/1993). For Gadamer truth comes from effective-historical consciousness. Understanding is possible only in the context of our prior involvement (prejudice). Understanding/interpretation occurs always from within a particular horizon that is defined by our 'historically determined situatedness'. Each interpreter brings to a text, a unique horizon, with the fusion of multiple horizons there is the possibility of more than one true interpretation.

3.3 The Foundations of phenomenology as applied to research

Applied to research, phenomenology is the study of phenomena: their nature and meanings. The purpose of such is to understand individual experience and the phenomenological researcher, through their analysis, aims to provide rich descriptions of the lived experience of a given phenomenon. The phenomenological researcher's mission is to 'return to the things themselves'. These 'things' refer to the elements of the world of experience as lived.

The lifeworld is a key theoretical concept and dominant focus of investigation for phenomenology. The life-world involves everything concrete and of meaning to us, as we perceive and experience it. This includes our experiences and understandings of our self, body and relationships. It is often defined as the being that is lived and experienced. This lived world is considered to be pre-reflective; it exists prior to any thoughts about it. The notion of the life world is that we live in a day-to-day world, rich with complex

meanings which we use to guide our everyday actions and interactions. The term life-world is used to direct thought towards the individual's lived situation and social world instead of towards a world of introspection. Merleau-Ponty (1962) famously explained that man is in the world, and it is only because he is in the world that he knows himself.

In addition, some phenomenological theorists (the Sheffield school – see Ashworth, 2003 & 2006) state that there are a number of essential structures of the life world; these are outlined in table 3.3.

Table 3.3 The essential structures of the lifeworld

Essential Structure	Description/Meaning
Selfhood	How does a given situation impact upon identity; the individual's sense of agency, their own feelings regarding their voice and presence in the situation?
Embodiment	How does a given situation impact upon feelings about the individual's body, their gender, emotions and disabilities?
Sociality	How does a given situation impact upon relations with others?
Spatiality	How does a given situation impact upon the individual's vision of their geography – the places they need to go to and act within?
Temporality	How is one's conception of time, duration and biography affected?
Project	How does a given situation impact upon the individual's ability to conduct activities that are considered central to their life?
Discourse	What language (e.g. educational, social, commercial or ethical terms) is used to elucidate the lived experience, the situation?

These inter-related 'fractions' (Ashworth 2003) are used to guide the analysis of phenomenological data. Here, it is not claimed that these fractions are relevant to all accounts of all phenomena. Instead, our knowledge of the 'lifeworld' suggests that we can at least take the potential presence of these fractions as given. The task for the researcher is to highlight these features and to describe the structural whole that is both a

socially shared and individual experience. Dahlberg, Waern and Runeson (2008:37) state, *'The overall aim of lifeworld research is to describe and elucidate the lived world in a way that expands our understanding of human being and human experience'*.

In studies, the researcher aims to display what participants are experiencing and how. Therefore, the focus is on the intentional relationship between the individual and the meanings of the things that individual is focusing on and experiencing. A good illustrative example can be found in a study conducted by Finlay (2003). In researching one woman's lived experience of having multiple sclerosis; Finlay determined that the participant was extremely concerned about the impact of her illness on the mothering of her children. This participant was specifically affected by the numbness in her hands which she said meant that she could no longer do the "mummy thing" and feel the softness of her children's skin. Here, the intentional, embodied relationship between a mother and her children was highlighted.

Phenomenological research asks, "What is this kind of experience like?", "What does the experience mean", "How does the lived world present itself to me (or to my participant)?" There is a double challenge here for the researcher: firstly, how to go about encouraging participants to talk about their world as vividly as possible; and secondly how to discuss and highlight the expressed dimensions so that the lived world – the life world – is adequately revealed. Meanings uncovered by the researcher evolve also as a result of the researcher's position; their attitude to the phenomena and the data. The way the researcher has investigated the phenomena and framed the questions they have asked is also of influence. In accordance, the researcher tries to 'bracket' or put aside previous assumptions or understandings so that they can be open to the phenomenon as it unravels. This bracketing process is often misunderstood and misrepresented as being an effort to be objective and unbiased. This is not the case, the researcher engages in this process to be open to and to see the world differently. The purpose is to move away from seeing how things supposedly are, moving towards an engagement in how they are actually experienced, recognizing our own Being in interpretation.

Given the broad philosophical underpinnings of phenomenological research, researchers have a number of empirical approaches they can choose from. The competing arguments for how best to do phenomenological research evolve from the different philosophical stances, theoretical preferences and methodological procedures. Indeed, different approaches are needed and determined by the type of phenomenon under study and the type of knowledge the researcher aims to achieve. Rather than being a fixed entity, the various phenomenological approaches are dynamic, constantly developing as the field of qualitative research also evolves. As argued by Garza, (2007:338): *'The flexibility of phenomenological research and the adaptability of its methods to ever widening arcs of inquiry is one of its greatest strengths'*. See Table 3.3b for an overview of the differences between Husserlian and Heideggerain phenomenology, in terms of research orientation.

Table 3.3.b. The key practical differences between Husserlian and Heideggerain Phenomenological research (adapted from Laverty, 2003).

Husserlian Phenomenology	Heideggerain Phenomenology
Otherwise termed Transcendental phenomenology.	Otherwise termed Hermeneutic Phenomenology.
Epistemological basis.	Existential – ontological basis.
Questions pertaining to knowing.	Questions pertaining to experiencing and understanding.
Concerned with how we know what we know.	Concerned with what it means to be a person.
Not concerned with historical perspective or context.	Historicality is implicit.
The subject of analysis is the meaning giving data.	The subject of analysis is the transaction between situation and person.
The essence of the conscious mind is shared.	Culture, history, practice and language is shared.
Meaning is not affected by the interpreters' own belief systems or experiences.	Interpreters impact upon the derived data.
Participant's meanings can be reconstituted via interpretation as it is believed that the data speaks for itself.	Considerate of the fore-structure of understanding – interpretation makes explicit what is already understood.
Bracketing supports the validity of the interpretation – as being objective.	The hermeneutic circle (including background, co-constitution, pre-understanding and evaluation) is acknowledged.

The emergence of phenomenological research in psychology was initiated by Giorgi and the Duquesne school in the 1970's (Wertz, 2005). Influenced by the work of Husserl, Giorgi worked to develop a rigorous descriptive empirical phenomenology to study

'essential structures' or 'essences of phenomena as they appear in consciousness' (Giorgi, 1985; Giorgi, 1994; Giorgi and Giorgi, 2003). In Husserlian words, the intuition of essence descriptively highlights the separate characteristics of a phenomenon and their meanings. Here, the phenomenologist from the outset has a concrete example of the phenomenon under study and *imaginatively varies* it in a number of ways so that its essential features can be seen as separate from those perceived to be particular, accidental or incidental.

Phenomenological methods have since proliferated from the work of Giorgi. Hermeneutic variants identify the researcher's role and the parameters of interpretation and heuristic approaches focus strongly on the researcher's role in self-reflection and how such is creative and highly influential when providing detailed descriptions of the lived experience. In addition, relational research approaches draw their attention to the researcher's journey, the research process and how findings evolve through dialogue that occurs between researchers. In considering the focus of the current study it is important to look at the different ways one could investigate it phenomenologically. In table 3.3c I have summarised a number of approaches. The next chapter provides a rationale for my choice of method.

Table 3.3c Phenomenological approaches.

Approach & main theoretical influences	Methods	Scholars
Descriptive empirical phenomenology: this is the most classically Husserlian method, being focused on identifying the essence of the phenomenon through epoche` and the psychological phenomenological reduction.	Researcher would compare written descriptions given by participants of an important event associated with their LLC. The researcher would then try to identify the essential or general structures underlying the phenomenon of living with a LLC.	The approach was first conducted by Giorgi and the Duquesne school. There are now other scholars who are prominent in this field including Les Todres.
The Sheffield School: this approach attempts to build on the work of Giorgi but has a more detailed focus on existential aspects of the lifeworld. This is achieved by including the thoughts of existentialists into an additional phase of data analysis. This is done by the researcher subjecting the phenomenological descriptions to the given existentials of the lifeworld (see table 3.3)	The researcher would conduct interviews and on their analysis focus on existential themes, for example the individual's sense of self and their relationships with others through their day to day experience of life-limiting illness.	Peter Ashworth and colleagues at Sheffield Hallam University.
Heuristic: Husserlian foundations. However, what is explicitly the focus of the approach is the transformative effect of the inquiry on the researcher's own experience. This is often achieved by a process called *discernment*.	The researcher would look at a number of types of data, for example from stories, poems, artwork, literature, and journals – all concerning experiences of LLCs. They would also look at themselves, turning the phenomenon of interest on to themselves. In doing so, the researcher would consider their own feelings/experiences of LLCs, possibly aided by a reflective diary. The aim would be to develop both a detailed description and creative synthesis of the experience of LLCs.	Heuristic inquiry was developed by Clark Moustakas and bares resemblance to *lived inquiry* developed by John Heron (1998), and *mindful inquiry* developed by Bentz & Shapiro (1998).
Relational approaches Heideggarian foundations. The findings are viewed to have been co-created in the dialogue of the research encounter.	The researcher might just interview one individual and choose to concentrate on the co-researchers' perception of identity and adjustment (their sense of self, their being-in-the-world and the ways in which they have learned to cope with their illness). Reflexivity would address the relational dynamics between researcher and co-researchers.	Linda Finlay. One variant is the dialogal research approach (Halling and Leifer, 1991 and Rowe *et al* 1989). This is where a few phenomenologists investigate the same phenomenon, discuss their findings and negotiate meanings.

Approach & main theoretical influences	Methods	Scholars
Max van Manen: considered to be a form of Hermeneutic phenomenology. Van Manen's four existentials of temporality (lived time), spatiality (lived space), corporeality (lived body) and sociality (lived relationship to others) illustrate a fusion of the objectivist hermeneutic circle (part-whole) and the alethic hermeneutic circle (pre-understanding). Like Heidegger, van Manen does not embrace Husserl's view of bracketing and asks: *'If we simply try to forget or ignore what we already know, we might find that the presupposition persistently creep back into our reflections'* (van Manen 1990:47).	van Manen gives the researcher the freedom to choose the mode of data collection and analysis most suitable for their sample and phenomenon of interest. Here, I chose to conduct a number of interviews and focus group discussions. Thematic analysis is conducted on the data and involves some acknowledged interpretation. The findings are viewed to be influenced by the researcher's interpretations. This method aims to bring to light the lived experience of life-limiting illness through utilising appropriate data collection methods and considering different perspectives in analysis (see the four existentials).	Max van Manen
Interpretative Phenomenological Analysis (IPA): a hermeneutic approach. With this approach there is less focus on description and more focus on interpretation and engagement with cognitive and social psychological literature.	Interviews would be conducted and individual experiences illustrated through thematic analysis. The findings would concentrate on the lived experience of LLCs and be viewed to be influenced by the researcher and co-researchers interpretations. IPA is inductive and grounded in the data, focusing on emergent themes and acknowledging dominant literature.	Developed by Jonathan Smith in the early 1990's.
Critical Narrative A hermeneutic approach. This approach draws mainly on the philosophy of Gadamer and Ricoeur.	Narrative analysis would be performed on interview data. There is an attempt to identify narratives and to analyse them for function and tone as well as thematic content. There is also a point in analysis where the researcher employs imaginative hermeneutics of suspicion to turn the analysis onto the researcher to decipher how and in what ways they are viewing the narratives.	Darren Langdridge at the Open University.

Despite their differences, all these forms of phenomenology share a similar purpose - to describe the lived experience and acknowledge the significance of our embodied, intersubjective lifeworld. Giorgi (1989) states that there are core characteristics that

remain constant across phenomenology, for instance that the research is *descriptive*, explores the *intentional relationship* between persons and situations, uses *phenomenological reductions* (the epoche and the phenomenological psychological reduction (processes of bracketing) and the eidetic reduction[2]) and provides knowledge of psychological *essences* or structures of meanings in human experience through imaginative variation (cited in Wertz 2005). However, there are other phenomenologists who argue that aiming to identify essences and use phenomenological reductions are not core to all methods. Indeed, some methodologies, for example the hermeneutic and idiographic approach of IPA, downplay or do not even acknowledge such elements in their research processes.

Whatever phenomenological path is chosen, the methods need to be in line with the aims of that form of phenomenology – and there can be overlap as can be seen from the discussion of the various approaches. However, the scientific worth of qualitative methods leads from the ability of the researcher to communicate to others the appropriate systematic approach of the study (Kvale 1994).

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- The *epoche* is where the researcher avoids reliance on theories, explanations, scientific conceptualisations and knowledge. By doing this, the researcher is aiming to return to the natural attitude of the prescientific lifeworld (i.e. a return to the unreflective understanding of the lived, everyday world).
- The *phenomenological psychological reduction* is where belief in the existence of what is observable in the lifeworld is suspended. Instead attention is given towards the subjective appearances and meanings.
- The *Eidetic or transcendental phenomenological reduction* is a more radical take on the epoche where a 'God's eye view' is attempted. This stance is often rejected by contemporary researchers as it is argued to be unrealistic or unachievable.

Chapter 4: Method

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In the current study, taking the stance of hermeneutic phenomenology and utilising the work of van Manen has both framed my research question and informed the chosen methods.

4.1 My approach: Hermeneutic phenomenology

There is understood to be more flexibility in the interviewing process with van Manen's approach to hermeneutic phenomenology than for example with using IPA. Following Gadamer (1985), interviewers may contribute more of their own views to the process to better encourage the production of meaning between interviewer and interviewee. This feature of flexibility of this version of phenomenology was particularly attractive considering the nature of the phenomenon under investigation and in particular the inclusion of children.

Data is also analysed thematically in hermeneutic phenomenology, much as it is with IPA. However, the process by which themes are generated is less prescriptive and guided more by the relationship between researcher and text – likened to having a dialogue with the text (Grenz 1996). There is a deliberate move away from a mechanical application of coding to discern meaning hermeneutically, recognizing the important role of the analyst in the construction of meaning. Van Manen (1990) talks of needing to capture our desire (to *'accept from the stars'*, p.79) for understanding, bringing our full attention to the material at hand, engaging in a *'free act of "seeing"'* (p79). Phenomenological themes in this context are understood as the structures of experience, experiential structures making up the experience. In accordance with the level of involvement needed on behalf of myself as the researcher, it would seem inappropriate for the data analysis to be merely a mechanical content analysis.

Van Manen (1990) asserts that hermeneutic phenomenology is a dynamic interplay among six research activities:

1. Turning to a phenomenon which seriously interests us and commits us to the world;
2. Investigating experience as we live it rather than as we conceptualise it;
3. Reflecting on the essential themes which characterize the phenomenon;
4. Describing the phenomenon through the art of writing and rewriting;
5. Maintaining a strong and oriented relation to the phenomenon; and
6. Balancing the research context by considering the parts and the whole.

The purpose of these six activities is to assist in gaining a deeper understanding of the nature of meaning of our everyday experiences. See Table 4.1 which shows which parts of the whole process of producing this thesis exemplify which activities.

Table 4.1 Research activities and related thesis parts.

RESEARCH ACTIVITY	THESIS PART	RELATED ACTIVITY DESCRIPTION
1. Turning to a phenomenon which seriously interests us and commits us to the world.	Introduction: choice of study, discussion of interest in the phenomenon and pre-understandings, the research question.	A true phenomenological question, according to van Manen (1990), is only possible once one has identified an interest in the nature of a human experience. Consequently, my desire to bring to the forefront the experience of life-limiting illness directed the questions 'what is it like to be a child living with a life-limiting condition?' and 'what is it like to be a parent of a child with a life limiting condition?' In doing so, the starting point for the study was formed.
2. Investigating experience as we live it rather than as we conceptualise it.	Literature review. Choice of participant sample, recruitment and methods of data collection. Interviewing.	A phenomenological description is always just one interpretation of that lived experience. It is realised that no one interpretation will exhaust all possible interpretations –others may be complimentary or deeper. This study aims to establish a renewed contact with the original experience and to explore it in all its guises.
3. Reflecting on the essential themes which characterize the phenomenon.	Analysis, Findings and Discussion.	A true reflection is considered to be a thoughtful grasp of what are the most important parts of an experience, the parts that make this experience so significant. In doing this the researcher makes a distinction between the appearance and essence of the findings. In other words the researcher can frame aspects of experience and also what it is that grounds these aspects of experience. Phenomenological research brings the obscure into focus. That which is not acknowledged in everyday life is unveiled. This study achieves this through identifying (through description and interpretation) the main themes and essences of the gathered data.
4.Describing the phenomenon through the art of writing and rewriting;	Reflexivity – provided in the Findings and Discussion.	What is it like to do phenomenological research? It is often really hard to actively separate language and thinking and to therefore be eloquent and true to our data in our writings. My experiences and related thoughts are documented in the Findings and Discussion chapters – where they are given they assist the reader in capturing research moments and in articulating my thoughts behind the discussed thematic areas.

RESEARCH ACTIVITY	THESIS PART	RELATED ACTIVITY DESCRIPTION
5. Maintaining a strong and oriented relation to the phenomenon.	Analysis, Findings & Discussion.	What is the purpose of this study? What is the application to practice? Theory? One's own being? The aim is to arrive at <u>better</u> understandings. I remained focused on the research question so not to deviate from the main purpose of study. By doing this I was able to determine themes and conclusions relevant to the lived experience of the phenomena under study that have research, practice and education implications.
6. Balancing the research context by considering the parts and the whole.	The research proposal, the methodological needs and nuances, the ethics of the study, the plan and context of the study.	There is a need for concrete research plans. The findings should illustrate the working of the text – chosen in this study to be analysed thematically, analytically and existentially. Themes and essences were drawn in this study as a result of considering parts of each interview/focus group against the nature of each full interview/focus group. In analyzing the data I made constant reference to the research question and related objectives.

4.2 Overall Design

The current study originally evolved from a funded service evaluation project. The service evaluation project involved focus groups with professionals and interviews with parents. The focus groups were conducted with a second researcher who assisted the facilitation of two focus groups and a third more experienced researcher who lead the facilitation of the focus group containing the GP and Paediatric Consultants. This project was funded by Kirkwood Hospice and The West Yorkshire Forget-Me-Not Trust. An academic panel and research steering group were established to provide support and guidance throughout the funded project (see appendix 1 for details of membership of these two groups). In addition, peer review was provided by two external academic psychologists, namely Dr. Jack Cadrenal of Leeds NHS teaching hospitals trust and Dr Dorothy Fielding of Newcastle University. They each reviewed the original research protocols.

The findings of the evaluation project were service needs oriented and utilised a descriptive level of analysis. For the purpose of this thesis further time was spent with the focus group data and findings to add more phenomenological description, thus evolving a new framework of themes. However, given the focus of this thesis the professional phase of the research is included but considered as background to the experience of parent and child. The parent data again was re-visited for the purpose of this thesis and deeper phenomenological interpretation was conducted, considering van Manen's four existential's (of temporality, spatiality, corporeality and sociality – see chapter 3, table 3.3) in the thematic analysis. For the third phase of this study which incorporates the parent-child dyads a separate research protocol was designed for the children and had to go through a separate ethics submission. One parent was utilised from the previous sample of parents with her child and a further four parents and their children were recruited for this phase. These data were specifically sought for the purpose of this PhD study and therefore were solely analysed using the outlined hermeneutic phenomenological activities.

The phenomenon of interest in this research was the experience of being a child with a LLC and of parenting such a child. The aim was to bring to light, through exploration within a hermeneutic phenomenological framework, these experiences and to also highlight the implications of these lived experiences for professional practice.

4.2.1 Samples & Recruitment

In phenomenological inquiry, purposive sampling is commonly used (Munhall 1994, Crotty 1996). This method of sampling selects individuals for study participation based on their particular knowledge of a phenomenon, for the purpose of sharing that knowledge.

Professionals

Local Paediatric health and social care community and acute teams and those working in specialist tertiary centres were invited to participate in the study. Professionals were recruited via a link worker who was a member of the research steering group. This group consisted of health and social care practitioners who were able to advise on the nature of illnesses and the appropriateness of methods for the population under study. Invitation letters and information sheets regarding participation in focus group discussions were forwarded to professionals via the link worker (see appendix 2 for copies of this material). Local Paediatric health and social care community and acute teams and those working in specialist tertiary centres were invited to participate in the study. A description of the researcher responsibilities, a note making them aware of their right to refuse participation and their right to withdraw their agreement at anytime before, during and following the interview was enclosed in the material for all participants.

Multi-disciplinary and multi-agency structured focus groups of between five to ten professionals were invited to discuss the strengths and weaknesses of current service provision for children with LLCs (details of participants can be found in Chapter 5).

Parents and children

Parents of either gender were considered potential participants if they lived within the locality under study, were able to speak English, and were the legal guardian of a child (5-16yrs) living with a LLC. The sample of parents included a mix of individuals who cared for children with: cancer and non-cancer life-limiting diagnoses, with different cognitive abilities and at different disease stages (details of each parent participant are given in Chapter 6 & 7).

Children (5-16yrs) of either gender were considered potential participants if they lived within the locality under study, were able to communicate and be understood, and were living with a LLC. The sample of children included a mix of individuals with cancer and non-cancer life-limiting diagnoses, with different cognitive abilities and at different disease stages (details of each child participant are given in Chapter 7).

Those who met the following criteria were excluded the study:

- Children in long term remission
- Children who had undergone successful curative treatment
- HIV positive children or those with A.I.D.S. (As professionals advised that the care of these children in the locality was of a different nature to other children with LLCs).
- Children with cystic fibrosis expected to live beyond eighteen years.
- Children who were unable to communicate verbally.

Recruitment of parent participants occurred through a team of paediatric palliative care professionals – recruited by link professionals from the research steering group. After explaining the aim of the study, the professionals approached potential participants and distributed an information sheet and consent form to release their name and contact details to the researcher if they were interested in participation. It is important to point out that participant selection was based on signed informed consent and a willingness to

discuss personal life experiences. Participants were made fully aware that if they chose not to participate this would not affect any health care services received. A description of the researcher's responsibilities, a note making them aware of their right to refuse participation and their right to withdraw their agreement at anytime before, during or following the interview was enclosed in the material for all participants (see appendix 3).

Parent-child dyads were actively sought. Children were recruited using the same process as parental recruitment. If the child was known to be able to communicate verbally, then the link professional included information about the research for the child – to be given by the parent if the parent consented to their child's involvement (see appendix 4). They excluded from the study any child whom they felt it would be inappropriate to interview (taking into consideration physical and psychological factors).

A description of the researcher responsibilities, a note making them aware of their right to refuse participation and their right to withdraw their agreement at anytime before, during and following the interview was enclosed in the material meant for all participants. As indicated, where information was enclosed for the child, there was also a form requesting the parent's written consent and permission for the researcher to make telephone contact. Following receipt of the researcher – contact consent form, I made telephone contact with the family/parent. The purpose of this contact was to:

- establish and reaffirm consent
- obtain information regarding the child's illness history
- obtain information regarding the child's current knowledge of their illness and prognosis
- obtain information regarding the child's level of functional independence
- arrange a pre-interview visit.

The pre-interview visit was an informal meeting with both parent and child. As stated within the DoH's 'Reference Guide to Consent for Examination or Treatment' (2001): *'Consent can be written, oral or non-verbal'* (p.2), this meeting created an opportunity to establish a degree of familiarity and trust and allowed me to ensure that the child's assent was voluntary. The following statement was given to the younger children to inform them of the study:

> *I would like to ask you some questions about being poorly and in hospital.*
> *We will do some writing and thinking, but if you get bored or just decide*
> *you don't want to carry on we will stop and no one will get upset with you.*

> *Is that O.K?*

And to question their understanding:

> *What are we going to do then?*

At this time, I was also able to roughly assess the language, communication and intellectual abilities of the child, thus informing the choice of interview schedule. A date and time for the interview was confirmed at this point. However, I made a number of informal visits to the homes of each interview participant, prior to the actual interview date. At the time of the interview/focus group each participant was given a further verbal explanation of the study, and invited again to participate. The following figure shows the process of recruitment, consent and data collection for the parents and children.

1. Health care professionals identified potential participants and provided the parent(s) with the written material

Letter of invitation and information sheet for parents	Letter of invitation and information sheet for children

2. Parent and/or Child agrees to participate

Researcher contact – consent form

3. A short telephone discussion with the parent

Reaffirm consent	Obtain information regarding: • Child's illness history • Child's knowledge of illness/prognosis • Child's functional independence	Arrange a pre-interview visit

4. Pre-interview visits

Discuss study and confirm child's assent	Roughly evaluate the child's intellectual abilities and develop an informal relationship with the child	If needed, further discuss the child's illness history, knowledge and independence	Confirm a date and time for interview

5. Interview conducted in the child's home

Interview schedules

Figure 4. The process of recruitment, consent and data collection.

Consent to interview was very much seen as a process rather than a one off event. Indeed contact with families spanned a number of weeks prior to any formal data collection. Readers may think that such prolonged involvement with families is unnecessary, however I would argue that in interpretive research the strength of relationships established prior to data collection have impact on both the progress and outcomes of studies (Flewitt, 2005). In addition, building relationships with participants allows time for them to reflect on their involvement in the research, to ask questions and disclose worries. Where children are involved, prolonged contact means they can reach a point of feeling comfortable and at ease to express themselves as they would ordinarily in their lifeworlds. Once data collection commences, the child is able to express their thoughts without too much difficulty or shyness.

4.2.2 Interview design and procedure

Each study used different interview methods and related procedures. These are detailed in the following sections.

Professionals

Three focus groups were conducted in this study and were deemed sufficient to detect trends and patterns across the groups. Morgan (1997:12) asserts that *'the hallmark of focus groups is the explicit use of group interaction to produce data and insights that would be less accessible without the interaction found in a group'*.

The group discussions took place at the University of Huddersfield. Participants were seated in a circle to facilitate interaction. Group introduction was standardised including a description of the selection process, the purpose of the study, data handling and dissemination. It was also clearly stated that all comments were important. Permission was requested to tape record the session and take notes and participants were assured of anonymity. The groups lasted between one-and-a-half and two hours, by which time all participants had had an opportunity to contribute their experiences to the discussion. As mentioned earlier, myself and a colleague working on the funded evaluation study co-

facilitated two out of the three focus groups. The third focus group contained only GPs and Consultant Paediatricians at this early stage in my research career I felt uncomfortable in leading the facilitation and therefore a more senior researcher lead the facilitation for this group and I assisted.

The focus group agendas were initially constructed from the findings of a literature review for the service evaluation study and notes taken from early research steering group meetings (see appendix 5 for a copy of the agenda). A number of open-ended questions were asked in an attempt to determine the services and support given to children with LLCs and their families. The professionals' perceptions of current services and the unmet needs for the child, family and themselves were also assessed. There were two main sections of questions within each agenda. The first section aimed to elicit the experiences and perceptions of professionals with regard to current service provision. It also aimed to determine if there was equal access to services for all families and to highlight any known or possible barriers to services for families and professionals. The second section aimed to elicit the experiences and perceptions of professionals with regard to current available support services for families and professionals. It also aimed to determine professional recognition of the holistic care needs of families and to highlight the current unmet occupational and emotional needs of professionals.

As a means of evaluating the focus group agendas an independent researcher from the academic panel with experience in focus group facilitation and with knowledge of the purpose of the study and the backgrounds of the participants, reviewed the questioning route. As a result, the agendas were further developed to include appropriate prompts and probes and a few questions were rephrased. Members of the Academic panel were chosen for their methodological or subject focus expertise and were in place to provide academic support and guidance.

As similar themes emerged in each group and since by the third group there were no new themes emerging, it was considered redundant to continue beyond this point. This was consistent with the guidelines by Krueger (1994) that recommend conducting more than

three groups only if new themes continue to emerge. In addition, Morse (1995) has argued that detailed descriptions are more important than the amount of data as excess groups do not necessarily enrich results; they may simply prolong the collection and analysis of the data.

Parents and children

All qualitative researchers need to consider the setting and context in which the research takes place. The context can often affect the research relationship. With children this consideration is paramount. The clinic/hospital environment can often be frightening for the child. Therefore, the child's own home was chosen to be the data collection site for both parent and child interviews, emphasising the non-clinical and non-interrogative nature of the inquiry (Ireland & Holloway 1996). In some instances parent(s) were present at their child's interview – this was agreed between me, parent and child on an individual needs basis. It was recognised that some parents and children could have been overwhelmed by the unfamiliar research context and so it was planned that in these circumstances the interview would be terminated. Fortunately this did not occur.

Individual interviews were chosen on the basis that they are fruitful in discussing personal experiences. However, efforts were made to adapt the process, employing methods that were fun and suitable for the child's cognitive development (Hill, Laybourn & Borland 1996). Alternative methods to the straight forward open-ended questions included for example, brain storming, sentence completion cards, pictorial vignettes, ranking exercises, fantasy wishes (for example, "list three things that would make Sara or Jack happy") and draw and write exercises. A system of red and yellow cards was also used to allow the children to make easy decisions about participation. Balen, Holroyd, Mountain & Wood (2001) successfully utilised this approach in their studies with young children that have aimed to evaluate children's understandings of cancer and infertility. It is important to note that the interview schedules were used as guides (see appendix 6 for a copy of the interview schedules). Other questions were added throughout the individual interview process as a result of the parent or child's response or questioning. And in some

cases particular activities/questioning routes were abandoned – as each child was given the freedom to lead each interview and talk about issues of interest to them.

The study was grounded in Interpretivism, which calls for a non-exploitive relationship between the researcher and the researched; one based on collaboration, cooperation, and mutual respect (Schwandt 1994). Furthermore, as an interpretive researcher, the aim was to create a dialogue between the participant's practical concerns (for example, trying to find funding for equipment needs or to be allowed out to play with friends) and their lived experience. This was achieved at times through engaged reasoning and imaginative dwelling in the immediacy of the participants' worlds (van Manen 1990).

Some authors claim that researchers should modify their interviewing techniques and questions to make them compatible with the individual linguistic and cognitive stage of development of each child. When preparing for the children's interviews, it was beneficial to find out about the language that the children use at their personal stage of development. Having informal meetings and discussions with participants helped me to establish such. Prior to the onset of the interview I could imagine how I could rephrase questions if needed in certain ways for certain children. The challenge for the formal schedule was to formulate questions about theoretical concepts into the kind of language that children understand and use (Shapiro & Carr 1991). In practice, reflective techniques were used to identify inconsistencies and to validate children's answers. For example, I would rephrase the children's answers and report them back to check what they really meant or said. According to Balen *et al* (2001), if the interview is carried out in a natural context, using open-ended questions and concrete accessories, children give more adequate and meaningful answers than when answering structured questions. However, in the given study I realised even with concrete accessories and a set of open questions, when interviewing the children I had to be prepared for an element of surprise and be willing to adopt a flexible questioning route to allow the interview to be lead by the child. By doing this, the child's voice and experience can be conveyed.

4.2.3 Analysis

The process of hermeneutical phenomenological data analysis was operationalised in the current study as follows:

1. The interviews were transcribed by myself verbatim. Each focus group/interview was in van Manen's (1990:99) words, a *'collaborative hermeneutic conversation'* that was transcribed as soon as possible after its conclusion.
2. Template analysis. Transcriptions were read with every effort being made on my behalf to totally submerge myself in the text to try to identify the implicit or essential basis of the experience, thus seeking the essential meaning of the experience. The thematic statements (essentials) were isolated.
3. Hermeneutic phenomenological writing.

All data was transcribed verbatim. Nonverbal information was documented immediately following each focus group/interview. I listened to participants' verbal descriptions, while reading and re-reading the transcriptions, to ensure their accuracy and to make any necessary corrections or additions. This approach also helped me to become immersed in the data.

Using the typed transcriptions, I read and re-read the text searching for themes. A line-by-line approach was followed during the thematic analysis of the data (van Manen 1990). Each sentence or sentence cluster was examined and re-examined as I tried to develop some insight into the phenomenon and to grasp an understanding of participants' experiences. The outcome of this initial approach to the data was the identification of statements, phrases, and paragraphs that seemed to reflect something essential about the phenomenon. All the units of general meanings gleaned from the text were noted, even redundant ones.

During the second phase of the analysis, I applied the research question to the general units of meaning to highlight those which seemed most relevant for participants'

experiences. Eventually, selected statements, labelled units of meaning, became the basis for constructing interpretive summaries and for developing hierarchical templates. The finalised templates aided the flow of the interpretive summaries. These summaries represented an attempt to explicate the meaning of the lived experience as described in the text, and were revised repeatedly to ensure that sufficient attention was being given to the essential themes.

Through the process of writing and rewriting, I developed a clearer understanding of emergent themes. Eventually, the written accounts of the themes organised in template form, culminated into a hermeneutical interpretation of the text. Van Manen (1990) provides the following commentary on this phase of the analysis: *'The inscribing, the writing of the text is the research; it is a relic of embodied reflections'* (p.128).

The final step in the analysis was what van Manen (1990) refers to as *'balancing the research context'*. That is, I constantly assessed the overall text in terms of the significance of the parts (themes) for the total structure or essence of the lived experience. Van Manen (1990) cautions that the researcher must be careful not to get caught up in writing the themes and lose site of the essence. In fact, at several points throughout the study, I found it necessary to step back, study the parts, and to assess how each part contributed to the total picture.

Template Analysis

The transcribed interviews became the phenomenological texts upon which the process of hermeneutic analysis was conducted. The scripts were analysed with the purpose of inducting the different meanings the experience had for each person. In order to organise the research text consistent with the methodological emphasis of the research approach, I selected a combination of three textual approaches to guide the analysis: the analytical approach; a thematical approach; and an existential approach. These were not separate approaches to Template Analysis but were orientations within the way I used Template Analysis.

Template Analysis (King 2004) was used to organise the findings. The method is commonly used in qualitative research as a form of thematic analysis. The theory is that the researcher develops a number of codes (a template), highlighting themes and constructs, which have been found within the textual data of their research. The template is then modified as the researcher repeatedly reads, codes, and provides interpretation to relevant text. It is therefore considered, that template analysis is similar to 'content analysis' (Weber 1985) and 'grounded theory' (Glaser & Strauss 1967). However, in content analysis, all codes are made prior to analysing the text, which is carried out statistically, and in grounded theory there are no preconceived ideas about the codes used. Template analysis appears to lie somewhere in the middle of these two theories. It is also much more flexible, allowing researchers to adapt the approach to their study (King 2004).

Initially I looked through the text of one or two transcripts (the first focus group, the first two parent interviews – Adele & Laura, and the first parent-child dyad interviews – Paula and Amy), adding annotation and simple, mainly descriptive coding. I then returned to the text and provided more interpretation by clustering codes together and ascribing meaning to each group. This began a process of hierarchical coding, with more general codes leading to more defined and specific ones. These themes are not considered to be merely objects or generalizations of a superficial analysis, but as van Manen (1990:90) states, more likened, metaphorically speaking to '... *knots in the webs of our experience, around which certain lived experiences are spun and thus lived through as meaningful wholes'*. From this point I adopted the analytical and existential approaches to data analysis. In developing my themes I considered the reviewed literature and the data's suitable fit (or not as the case may be). In considering the wider relevance of themes as essential structures of experience I also considered the existentials of corporeality (lived body), spatiality (lived space), temporality (lived time) and relationality (lived relationship to others).

From here, templates were gradually formulated. All remaining transcripts were then analysed via the process of coding, using the initial templates. The initial templates were

revised as a result of looking at the other transcripts. What was highlighted was the need for existing classifications to be adjusted, for further dimensions adding to codes, for areas to be deleted, and for new constructs to be used to create new sections of the template. The act of thematic analysis in the current study is more than a superficial reflection of the explicit meaning of the participant's descriptions; it is a method as a way of achieving a level of thoughtfulness that encourages the researcher to make a distinction between their first-hand impression of the participant's stories (the text) and the essence of the experience in question. In this sense, thematic analysis is a form of reflective enquiry that guides the uncovering of the essence or *'... a bringing into nearness that which tends to be obscured and elusive to the first hand superficial reflection of an experience'* (van Manen 1990:31).

The final templates for each participant sample are indexed and provide a tight and clear organisation of the data. I found these templates provided me with a well ordered structure to my data that I could interpret with ease once I came to write up my findings. In my writing I identified the themes within the templates that I found most relevant to the phenomena in question. This action draws upon the concept of the hermeneutic circle, in an effort to uncover the story's essence(s) and works with the understanding of the intersubject, interconnected nature of the interpretive interview. It is during this stage of the method that the essential themes are sifted from the non essential ones. What is and is not essential is again a choice made by the researcher and is relative to the context of their interpretation. A concerted effort is made during this stage to reflect critically on the choices made by repeatedly holding the identified theme (a part of the text) against the overall context of the story(s) being told and asking: does this interpretation fit the context of not only this particular section of the text but also the text as a whole? Is this interpretation succinct/in harmony/faithful with the overall context of the text? Is there a different way that the interpretation can be told so as to convey the meaning more justly?

Once identified the essential themes are called upon during the discussion of the interpretation to help guide the selected anecdotes from the participants' stories in an effort to further exemplify the essence(s) of the participants' lived experiences.

Hermeneutic Phenomenology aims to produce texts that are oriented, strong, rich, and deep (van Manen 1990). In my orientation as a psychological researcher, it was necessary to work creatively to present the voices of participants and their interpretation of the phenomenon.

The analysis and review process was completed when no new themes arose. Commonalities in essential themes between the various interviews were identified which guided the uncovering of two essences. These essences are seen to reveal the essential nature of the lived experience of the participants who have lived the experience of life-limiting illness, from the perspective of child sufferer, parent or professional, as understood by the researcher.

Hermeneutic phenomenological writing

Writing is an integral part of hermeneutic interpretation (van Manen, 1990), as is the process of noticing, collecting, and thinking about things that are interesting. To highlight the difference between phenomenology and other qualitative methodologies (for instance ethnography, ethnomethodology, symbolic interactionism, conceptual analysis, autoethnography) the dominance of the essential phenomenological question needs to be clear. No matter how any particular child lives through their illness, I want to know: How is this experience? Is this what it is like to have a LLC? Is this what it means to have a LLC?

The insight into the essence of phenomena involves a process of clarification, making explicit the structure of a meaning of a lived experience. Meaning is multi-dimensional and multi-layered; therefore writing is a difficult task. Soon I discovered that, as I began to write, there was no great schema on which I could draw to assist me in the process. Within this process, it was my role, as an interpretive inquirer, to ensure that writings of the interpretation of the participant's experience formed an adequate representation of their voices. Then I had to ensure that my writings would produce a text, which could readily be conveyed to readers. At times, writing had the effect that I could 'instantly' see something in a manner that enriched my understanding of experiences. To see, in this

context, is not a cognitive affair, but a reference to the creation of a text that speaks to our cognitive and non-cognitive sensibilities (van Manen 1990). Language is a major concern in phenomenological research because responsive-reflective writing is the very activity of doing phenomenology.

In my writings, I have made an attempt to incorporate lived throughness, evocativeness, intensity, tone and epiphany, as qualities central to phenomenological writing (van Manen 1996).

Lived throughness means that the phenomenon is placed concretely in the life world so that the reader of the text may experientially recognise it. The aim is to portray a phenomenon in such a way that, as a reader of the text, one may find continuity between portrayal of the phenomenon and the particulars of one's own life. In the next chapters experiences of life-limiting illness and the impact on life is discussed. Some of these experiences may be to a degree recognised by readers and so links may be found between the text and one's own experience for example of illness, pain, or hospitalisation.

Evocation means that the experience is brought vividly into presence, so that we can phenomenologically reflect on it. For example in the next chapters there are vivid descriptions of pain, an experience everyone can recognise. The challenge here is to produce writing that not only provides a concrete description, but also evokes vivid images and associations that prompt our thoughtful reflection.

Intensification refers to the use of poetry and art, for example, in order to produce certain poetic effects and understanding. In the next chapters some parts of some of the children's stories are conveyed through images and vignettes and the words of all participants are examples of finding meaning through living with a life-limiting condition. The purpose was to give certain meanings their full value, so that phenomenological meaning became embedded in the text.

Tone refers to translating intelligible experiences into 'feelingly understanding' interpretations. In the following chapters I aim to create and imagine for the reader, forms of being as a signification of humanness – I will provide examples to illustrate meaning and this may involve a degree of imaginative variation.

Epiphany means that the text must bring about a transformative effective, so that its deeper meaning makes an edifying appeal to the self of the reader, such that it provides sudden perception of the life meaning of something, so strong that it may stir us at the core of our being. I am hopeful that the text of the thesis will reveal itself to be rich, diverse, pertinent and of significant quality to open the experience for the readers' entry into a deeper understanding of the phenomena. Ultimately, the readers will decide whether this is achieved.

4.3 Ethics

The proposed study was submitted to and approved by the local research ethics committees of each participating centre prior to any written communication with any health professional or parent/guardian.

Focus groups necessitate the sharing of information with other participants and members of the research team. Therefore, privacy and confidentiality are important issues (Smith 1995). However, there is a dearth of literature surrounding the management of confidentiality within focus groups (Williams 1999). Smith (1995) implied that a researcher could never completely ensure confidentiality because they have no real control over what participants disclose to persons outside of the focus group situation. Therefore prior to the onset of discussion, it was important to discuss this issue with the participants, to provide general instructions (Williams 1999) and obtain participant agreement that they would not discuss any participant responses with persons outside of the focus group situation. The future use of the focus group data and the conditions of confidentiality were described in simple terms to avoid any participant anxiety or distress. The process of analysis was also described, highlighting that researchers would

not identify participants and although quotations would be used, there would be no means by which a participant could be traced. All data were anonymised at the point of data collection and stored and disposed of appropriately.

In qualitative interviews, feelings and thoughts are explored in depth; professionals, parents and children can sometimes recall upsetting experiences and need support and reassurance in dealing with such recollections. In the event of such circumstances, my first consideration was the welfare of the participant. I planned to stop the interview/focus group if necessary and deal with the participant's distress by providing support and reassurance or by seeking appropriate help, whether it be familial or professional (organised by the link professional). On one occasion this happened. I had visited the home of a mother who was very distressed with her situation and in the hours I was at her home she confessed to planning to take her own and her two children's lives. I remained at the home until I was comfortable in the knowledge that this participant was in no immediate danger of conducting this act and she had become calmer. Before leaving I explained that I would seek support for her due to the nature of her disclosure. On immediate return to the research office I consulted a member of the Academic Panel nominated for their Social Work expertise. After a short discussion it was decided that I should contact the appropriate link worker (from the research steering group). This person then visited the home of the participant and arranged appropriate support.

When providing participants with information regarding their participation, I did not promise absolute confidentiality, as this may not always be possible or practical. It was possible that I may (inadvertently) elicit comments that have professional and/or ethical implications (Milner & O'Byrne 1998). For example, a parent might have disclosed a concerning matter, for example abuse, during the course of the interview. As a result of such an event, I would have been under a moral and professional duty to report the incident to the relevant professionals/authorities. In addition, the participants were made aware that the findings from the study would be disseminated to a wider audience, although they and their responses would not be individually identified. The nature of the conditions of some of the children also restricted any description I could offer to

introduce participants in the findings chapter of the thesis. For example, a number of parents had children with very rare genetic conditions. To label such conditions or to detail too many of the disease characteristics or their disease trajectory would have inadvertently compromised both confidentiality and anonymity.

With these issues in mind, I adhered to all components of the Data Protection Act 1998, practically this involved:

♦ All data being anonymised at the point of data collection

♦ Appropriate storage, restricted access and disposal arrangement of participant names, contact details and tapes.

♦ No information released which allows the identification of parents, children, professionals or volunteers.

Pseudonyms were used in the written materials to protect participants' identities. The data were discussed in a professional and confidential way with supervisors. The tapes and transcripts were locked in a secure cabinet. The tapes will be erased and transcripts shredded after the completion of the thesis and subsequent publications.

Because of the sensitive nature of the semi-structured interview enquiry a certain level of researcher risk was required. The research procedure meant that the researcher visited the home of each parent and child interview participant, sometimes at evenings to conduct the interviews. A few interview precautions were established:

♦ The researcher used a private car, to avoid the vulnerability of walking in an unknown area.

♦ The researcher dressed casually to avoid appearing out of place.

♦ The researcher carried a mobile phone.

♦ The research supervisor was made aware of the address and time of interviews.

The recruitment procedures were designed so that local professionals knew all participants and telephone contact was made by the researcher prior to interview. This to a degree provided an opportunity for the researcher to assess the participant and their circumstances. I perceived myself to be able to cope with the possible sensitive content of the interviews. However, an employee of the University of Huddersfield with counseling skills was made available to provide support if needed. On the completion of each interview, the research supervision team reflected on the interviews to discuss any difficulties encountered.

4.4 Study quality

As already noted although there is no prescription of methods or fixed signposts, or a cookbook recipe, there is a tradition to follow in the use of methods that allows the demonstration of scholarship (van Manen, 1990). Because of concerns about the value of qualitative research methods, based on the constructs derived from quantitative research of the need to be able to generalise and show validity and reliability, there is a particular significance in the need to demonstrate scholarship that passes the 'so what?' test (Sandelowski 1997).

Regardless of the research approach selected, it must be congruent with the philosophical underpinnings supporting the research tradition endorsed. In interpretive research, it is essential to be aware of the philosophical underpinnings informing the particular approach being used and to adhere to these underpinnings consistently. Van Manen (1998) has stated that the researcher should be able to articulate the theoretical and / or epistemological tenets of phenomenology and hermeneutics. Consistency of the language used to discuss or describe the work is of crucial importance, as it informs others that the researcher understands the epistemic linkages supporting the approach being implemented, thus adding to the scientific adequacy of the work.

The meaning of scientific adequacy within a Gadamerian context implies that an expert and skillful technique is implemented with careful, systematic, and conscious intent of a reflective process as we conduct the interpretation of the text. This is relevant in the current context as my analysis is guided by my own interpretation of the text and my understanding of themes as related to previous literature and existentials. It is implied that the interpretation is sufficient, satisfactory and plausible. To ensure that scientific adequacy has been achieved, it must be embedded in the language used to describe or discuss the research approach and the understanding of the phenomenon of focus (Watson & Girard 2004). Meaning is derived from the context in which the experience (between the researcher and participant's story) has taken place, where it is both within and through the experience itself that meaning comes into being – through reading and re-reading meaning is constructed (Gadamer 1997).

I have chosen to go beyond the use of particular procedures or to follow defined criteria to ensure quality, as such are highly debated within the literature. Instead, I argue that a good phenomenological study achieves quality by highlighting the complexity, ambiguity and ambivalence of participants' experiences. As Dahlberg *et al* (2008) have cautioned, phenomenological researchers need to be cogniscent of making sure they do not make definite what is indefinite. Instead, Lifeworld research should be identified as such by its ability to both present paradoxes and integrate opposites, demonstrating holism (Dahlberg *et al* 2008).

In accordance, Wertz (2005:175) offers a succinct description of phenomenological study:

> Phenomenology is a low-hovering, in-dwelling, meditative philosophy
> that glories in the concreteness of person-world relations and accords
> lived experience, with all its indeterminacy and ambiguity, primacy
> over the known.

As a researcher and interpreter, I needed to be aware of my preunderstandings/prejudices and to understand how they could impact on data collection and interpretation. In addition, I was clear that the analysis of interpretive practice requires a level of patience to accept that there are incongruences and conflicting explanations of feelings and events. I understand that social life is messy in practice and if I was to not acknowledge such in my writings I could be accused of not adequately attending to my data. Through the many writings of the text and its related numerous interpretations, I was also aware of the language I used, making sure I did my best to reflect the meaning of the participant. In this respect I can argue that my research was achieved through a fusion of horizons and within the hermeneutic circle.

Another aspect of the implementation of the hermeneutic process is reflected in the report and dissemination of the study - written or oral. Garratt and Hodkinson's (1998) article discussing the dilemma of using criteria to assess qualitative research is of related importance here. They argue according to Gadamer that although the content and form of a research report is important, these are not central to the experience of reading and understanding that report. In accordance, a report cannot be fully understood by dividing it up. A summarised report or a number of papers from that report, represent parts of a whole, these parts cannot be understood clearly as parts; they are only fully understood as a related whole. Therefore, the report must tell a story in a sound manner where the experience can be recognised as plausible by the readers. Although, publications have evolved and are evolving from this work, the dominant focus of my writing was to ensure the full thesis formed a coherent whole. That the reader could piece all elements of this work together, with no gaps, forming a single coherent and believable story was of primary importance.

In addition, Gadamer (1997) would say that the readers or audience also bring their own prejudice(s) to the experience of understanding that text. Therefore each reader will have different interpretations or understandings they attach to the work. Indeed, Hermeneutic interpretation is never final or complete; it is always an approximation, but one version of that reality. As such, the findings of this work can be construed as a result of my own

interpretation and understanding of the experience which may differ from another researcher addressing the same phenomenon.

4.5 Conclusion

The research design and methods based on van Manen's hermeneutic phenomenology, presented in this chapter, have been selected as a means to highlight the day to day experience of living with a LLC. The presence of me as a researcher in the data means that my interpretation may well be different from that of another investigator. Phenomenology depends heavily on the researcher's use of self. Overall, the considerations I made in working with the participants, in designing and carrying out the interview processes, in the reflection on views about studying children, and the considerations of rigor and adequacy – I have been enabled to be reflective and mindful of my actions and interpretations.

Chapter 5: The professional focus groups

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This chapter details the findings of the professional focus groups. The membership of each focus group will be detailed and the main thematic areas will be outlined. The chapter will culminate with a discussion of these findings and how they have relevance for the following two chapters – the findings of the interviews with the parents and children. It is important to note that this data was gathered for a service evaluation study, therefore the nature of the data is less focused on personal experience and more on the views of services.

5.1 Overview

A total of twenty one professionals participated in the three focus groups. Included were health, social care and education professionals involved in the care of children with LLCs. Participants were from local Acute and Community services in West Yorkshire with one participant from a Tertiary children's service. Focus group one consisted of eleven professionals mainly working in multi-disciplinary or multi-agency teams including: learning disability nurses, a health visitor, an occupational therapist, physiotherapists, social workers and teachers. Some of the professionals involved in this focus group were also managers of key multi-disciplinary services. Focus group two consisted of five participants. They were all physicians, including Consultant Paediatricians and a GP. Focus group three consisted of five nurses, including a specialist outreach nurse, community paediatric nurses, a paediatric acute nurse and a children's hospice nurse. All groups lasted around an hour and half in duration. Discussion flowed and participants were happy to interact with each other. This meant I did not have to intervene with many questions. The focus groups provided a substantial amount of data and the participants stated that they had learnt a lot from each other.

Table 5.1 Participant characteristics – focus groups.

FOCUS GROUP	PARTICIPANT NAME	PROFESSION
1	Laura	Learning Disability Nurse
1	Diane	Health Visitor
1	Sarah	Paediatric Physiotherapist
1	Megan	Learning Disability Nurse
1	Gill	Social Worker
1	Jean	Learning Disability Nurse
1	Andrea	Occupational Therapist
1	Tina	Student Learning Disability Nurse
1	Marie	Special Needs Teacher
1	Kate	Special Needs Teacher
1	Lorraine	Paediatric Physiotherapist
2	Joanne	Paediatrician
2	David	Paediatrician
2	John	Paediatrician
2	Simon	GP
2	Louise	Paediatrician
3	Sally	Specialist Nurse
3	Gail	Community Paediatric Nurse
3	Tracey	Community Paediatric Nurse
3	Beryl	Paediatric Acute Nurse
3	Janine	Paediatric Hospice Nurse

NB. Please note all names used for participants are pseudonyms.

Participants reflected on their own professional experiences and the overlap of such into their everyday lives. They identified positive aspects of recent service developments as well as a range of problems and gaps associated with the current organisation and delivery of care for children with LLCs and their families.

Table 5.1b Summarised focus group coding template.

THEMATIC AREA	LOWER LEVEL THEMES

Service Planning, Delivery and Co-ordination	• Planning and delivery of care
	• Teamwork
	• Co-ordination and communication
	• Transition
	• Funding
	  o General
	  o Adaptations and equipment
	• Support for parents and families
	• Staff needs
	  o Training and education
	  o Support
	  o Bereavement

Specific Service Gaps	• Respite
	• Out of hours care
	• Challenging behaviour
	• Ethnic Minorities
	• Bereavement care
	  o Parent support
	  o Sibling support

5.2 Service planning, delivery and co-ordination

Participants in all three focus groups identified positive aspects of specific services, but also organisational and professional barriers associated with the planning and delivery of care. These barriers impacted upon their ability to provide or organise appropriate and timely interventions.

5.2.1 Planning and delivery of care and teamwork

There was overt frustration with the demands of services outside their remit and equally their reliance on these services and other professionals. Often referral and assessment processes and responsibility for action were a shared responsibility. The extent of the problems reported by participants did vary; with professionals working from a multi-agency/multi-disciplinary base reporting areas of good practice. Where the roles of key

services were clear and referral processes simple participants expressed the ease of planning services and care for children:

>**Gail (Community paediatric nurse):** From a nurse's point of view, my role, making a referral to (Hospice), I find is quite easy because if you've got the support of your Consultant then basically you just ring them up, have a chat with them. Sometimes they might write a letter about the family before they're accepted and then as long as you've got the support from the Consultant, you've discussed at a meeting with your multidisciplinary team and then you go for a visit… and my experience has always been very good and the families that I've talked to who thought that (Hospice) would be a place for them, then it always runs smoothly…
>
>**Janine (Paediatric hospice nurse):** I think the thing is that people have got more used to our criteria and we've been around a lot longer now. We very rarely do have to turn children down and sometimes you can do that on the first phone call if it definitely doesn't fit the criteria, so that very few families wouldn't get accepted, the majority of referrals are accepted. (Focus group 3).

Where there was contact with a well informed and approachable Consultant, care planning appeared to be more effective. Professionals appeared to be aware of hospice admission criteria but it was clear that at first they found it difficult to understand. Being able to be reliant on more experienced staff was the key to planning effective care. Participants recognised that planning ability varies according to diagnostic groups and the nature and complexity of the underlying medical condition. Where children receive care from tertiary centres, such as paediatric oncology units, there was a sense that provision was good:

> **Joanne (Paediatrician):** Well I think provision is patchy, very patchy.
> I think the oncology children in the main are relatively well provided
> for because there is a co-ordinated central service. (Focus Group 2).

Particular problems were posed in the planning and provision of services where the life-expectancy of the child was largely unknown or where no diagnosis has been made:

> **John (Paediatrician):** I think the oncology group, they've got some
> idea of how long they will need care and therefore you can kind of plan
> services. With the neurodegenerative conditions and in fact every other
> diagnosis…I mean the cases we have when we don't have a diagnosis
> and those are the most difficult ones because you don't know how long
> they are going to live. Therefore, people are reluctant to put in care
> without a diagnosis, so I think those are the difficult ones as well. Then
> there are children with severe cerebral palsy with severe and complex
> needs and yet they are not going to die and therefore they don't get all
> the help (Focus Group 2).

Where there was talk about reluctance to implement care due to there not being a diagnosis, it was clear to see that services were operating using the biomedical model. Without a diagnostic label, professionals were at a loss to know how to intervene. This was mainly for two reasons; individual professionals did not know what to do without a diagnosis and services were organised in such a way as to make it impossible to provide a suitable intervention without diagnosis.

Difficulties were also encountered where service sectors could opt in or out. Decisions are taken locally by one service and other agencies may then have to find a suitable alternative for the child and family. Individual schools, for example have autonomy to decide on the level of care they will implement for a given child:

John (Paediatrician): Because the unit I'm on, a lot of pre-schoolers go to school and they co-ordinate education before they go into school so we have a good system there. But, once they go to school, it depends what schools they are in really, if they are in a special needs school or a mainstream school. I think it's very variable, isn't it, how much co-operation you get from school, how much a school will do, you know, how much they'll input into the medical care and how helpful they'll be. Some schools are quite willing to help, some schools are incredibly helpful, and some schools are just awful (Focus group 2).

In summary, there was general agreement across the focus groups that there is inequity in the ability of professionals to plan and deliver services and care for children with LLCs and their families. This results from differences in service organisation based on location and diagnosis. Furthermore, certain services appear to be inflexible and healthcare overly focused on diagnostic labeling.

A difference in the ability to adopt a team approach for different diagnostic groups and age ranges was evident. Where teams were formalised within organisational structures such as Child Development Units, Children with Disability Teams and Shared Care arrangements, teamwork arrangements were valued and care provision reported to be well planned and co-ordinated, for example:

John (Paediatrician): I mean we have, the children who are ill in their first few years of life, I mean they are fairly well looked after in that there's the child development centre and every child with a disability goes through that service and we meet every six months for each child in that service and plan what we do (Focus group 2).

These teams have a routine, a protocol they are able to follow with each child that arrives on their case load. Having such streamlined practices removes the scope for error and allows the team to follow the care of each child. However, where teams are not

formalised within organisational structures this can result in poor co-ordination, for example:

> **Lorraine (Paediatric physiotherapist):** I had a little girl and she was only a year old and she had thirteen different professionals visiting the house and she hadn't even started with education yet, it was just health (Focus Group 1).

> **Joanne (Paediatrician):** I think the children who are in the other categories (non cancer) who require palliative care… it's whatever's happening locally that they get access to. That might be community nurses, Consultants, GPs, whoever, but there isn't really an overall co-ordinator of what happens. Often it is child by child and often crisis point occurs and you have to get as many people together as you possibly can to provide whatever service you can (Focus Group 2).

There is obviously a lack of organisation and co-ordination between services for children with non cancer conditions. But this situation points to other weaknesses in provision. Were these thirteen professionals not communicating? And why should a child be in a position of crisis before services are implemented? Whether it is from hospital or directly from the GP, irrespective of diagnosis one would expect a communication protocol to avoid certain children being contacted/given support by too many separate professionals in the system.

5.2.2 Co-ordination and communication

Participants in all three focus groups identified the importance of good communication and co-ordination between agencies and individual professionals, citing both strengths and weaknesses of current working arrangements and professional practice. The need to formalise a key worker for each child and family was identified in all focus groups. Reported advantages of such an approach included improved and proactive liaison to

maintain care in the home, co-ordination between agencies and protection of families from unnecessary duplication and intrusion:

> **John (Paediatrician):** With the acute trust yes and they'll go out [nurses] and see them and actually do quite well in liaising with GPs. They sit between the GP and do as much prescribing as possible and involve and support the GPs looking after children in the community rather than keeping them in hospital and…
>
> **Louise (Paediatrician):** They need somebody as a key worker who works with the families and primary care, maybe be part of primary care as a health visitor or something like that really to work with the family (Focus group 2).

Improved sharing of information between agencies was suggested. A co-ordinated record of professionals involved in the care of each child was an idea put forward - so that professionals involved with a specific child and family could be immediately identified. In addition, focus group participants were frank about their own inadequacies and those of others in relation to keeping other key professionals up-to-date through written communication across primary, secondary and tertiary medical care services. Some of these communication problems identified by participants were considered to be a result of office location. Multi-disciplinary professionals who share office accommodation identified the benefit of regular contact and informal direct communication. Problems were highlighted where communication is both across agencies (mainly across health and social care) and where teams use separate office accommodation. A further contributory factor to the lack of shared communication may be rooted in time constraints. In a shared office environment a team can 'get away' with less formalised systems and yet ensure services are co-ordinated. Where there is distance between professionals, effort is needed to complete formal records and to do this, professionals need space in their working day that can be focused on writing.

5.2.3 Transition and funding

There appeared to be a lot of chaos surrounding the organisation of transition from child to adult services. Differences in working practices were reported to present difficulties in providing and maintaining provision. Funding arrangements were also found to delay transitions. However, participants also identified recent developments in health care settings and spoke of setting up services for teenagers. Accordingly, different health, social and education services have different age criteria and the transition period can therefore result in care provision being provided by a combination of paediatric and adult services, for example:

> **Researcher:** How does the transition from child services to adult services… how does that work?
>
> **Lorraine (Paediatric physiotherapist):** It doesn't
>
> **Diane (Health visitor):** It's different for every service so …
>
> **Lorraine (Paediatric physiotherapist):** Our Paediatricians we have an agreement with the Duchene Muscular Dystrophy boys to stay with the Paediatricians
>
> **Diane (Health visitor):** And that's a reasonable thing
>
> **Sarah (Paediatric physiotherapist):** There's big issues around that, if we go onto nocturnal ventilation we're looking at extending their life for up to five years so looking at quality of life there you are going to have to change services
>
> **Diane (Health visitor):** That's right
>
> **Sarah (Paediatric physiotherapist):** You cannot you know, from a physio point of view we couldn't extend our service beyond that, even though the Muscular Dystrophy children throw up big issues (Focus group 1).

Still, there is obvious confusion that arises over specific cases/conditions. Here, we have a professional stating that the care of Muscular Dystrophy (MD) boys is held by Paediatricians. Whereas, we have others in the group arguing that such care can only be

of limited duration and that other services need to pass these boys on to adult services to provide the best care. Furthermore, participants report that currently during the transition period from child to adult services, the adolescent may be excluded from major components of support. This may include daily schooling for two to three years, prior to gaining any educational provision from adult services, for example:

> **Megan (Learning disability nurse):** Some do leave at sixteen in this area but they can't get a service till they're nineteen so…
>
> **Andrea (Occupational therapist):** We have had children leave at eighteen and they've gone into adult day services but
>
> **Jean (Learning disability nurse):** In the locality where I work they're leaving at eighteen so they can access places in this area
>
> **Andrea (Occupational therapist):** Only one of my cases, she's left a year early because if she stayed another twelve months she would lose her place, so she's left a year early
>
> **Megan (Learning disability nurse):** It's the same in my locality, if they left children's services at sixteen they wouldn't be able to access adult for another two years till they were eighteen… (Focus group 1).

Therefore, these children are being lost in the system and the children are failing to see the benefits that continuity of services provide. Participants argued that changes in routine can cause upset and losing activities can create more challenges for the patients and their families in terms of providing cares and stimulation. Indeed, problems in organising suitable arrangements for medical care through transition were identified by both focus group two (doctors) and focus group one (multi-disciplinary) participants, for example:

> **David (Paediatrician):** I see quite a number of patients with Cerebral Palsy; some of them are quite seriously affected. Also, some with Muscular Dystrophy and some with learning difficulties. I suppose the ones that come to grief are the ones with Muscular Dystrophy… it's a small number but there isn't an easy hand over process, you know at

seventeen or eighteen, there is nobody on the adult side (Focus group 2).

If there is no one within adult services to pick up the medical care of MD patients, paediatricians are left with awkward decisions to make. They either continue the care of an adult or leave the patient to struggle through a system that is in adequate and will not meet their medical needs. With technological advances some MD boys (and individuals with some other LLCs) are a number of years into their adulthood – if children's services were to continue to provide all their care there would be funding issues as spending would be taken away from other paediatric services. However, the multi-disciplinary group identified problems resulting from the sustained relationships children and their families have with their Consultant Paediatrician, and the difficulties in then withdrawing from such a supportive role, for example:

> **Jean (Learning disability nurse)**: But we've got three particular Paediatricians who are GPs … they act as GPs they are on call and that, now if you've got a child, if you've got someone with a learning disability that hasn't specifically got any problem and they get to eighteen and the parent goes to the GP, GP says well what do you want me to do I don't know her, I've never seen her, go back to your Paediatrician (Focus group 1).

However, participants did identify service developments in the area of teenagers and young adults. These included planned provision of a teenage unit at the regional Hospice, and a young adult team to be developed in the region, which will include therapists and a Consultant with a remit for young people with physical and/or learning disabilities. These developments further highlighted the need for local service developments.

Participants within each focus group identified funding issues including: insufficient or inappropriate use of funds, that there were various 'pots' of money and there were frustrations with a system they argued that was characterised by sluggish decision

making. Various participants suggested that funding for services was insufficient, although this was generally in relation to specific service provision including respite care, education, services for challenging behaviour, sibling support, psychology services, community nurses, equipment and adaptations, for example:

> **Beryl (Paediatric acute nurse):** Our biggest gap is for brothers and sisters, we've got nothing … and as much as we'd like to do something we haven't got the time. We would need bereavement people full time to be able to do it, but it is a massive gap and we've tried liaising with the adult hospice because they've got a group for children who've lost parents, but it hasn't really, it hasn't really happened…..and it's a massive gap that we're aware of but we're not in a position to do anything about it without funding someone to do it, which is incredibly sad and we know that but you know (Focus group 3).

> **Joanne (Paediatrician):** Yes they have Psychologists and Social Workers but it seemed from what they were saying that the services that they are offering certainly at the minute are relatively limited in that they've got a full case load and so (Focus group 2).

Where professionals were repeatedly acknowledging service needs, it was all the more frustrating that services were not being developed holistically – considering the life worlds of the affected children and their families. It was suggested, as previously noted, that funding arrangements do vary according to diagnostic group, for example:

> **Joanne (Paediatrician):** I think there is some kind of funding in that children with cancer from St James', they do have a separate pot of money so I think there is an issue there in that they have got the money to provide that service whereas perhaps locally we don't necessarily have the monies to provide as many community paediatric nurses for example (Focus group 2).

One starts realising that the services a child may be offered could be limited to their post code or diagnostic label, even where different children and their families have very similar needs.

In addition to problems with the decision making process as noted, participants highlighted a number of funding issues in relation to the provision of adaptations and equipment which impact on the day to day living, quality of life of children and families, and the ability of parents to care for their child at home. It was also recognised by professionals that parents who maintain work are further disadvantaged financially and have to make unrealistic contributions for equipment and adaptations.

General discontent with funding issues was highlighted, for example:

> **Andrea (Occupational therapist):** Well adaptations itself is a mine field, you have to jump through that many hoops to get anything, money wise to refer for an adaptation it's just unbelievable and it takes so so long and that's after I've got it through social services (Focus group 1).

In addition, problems associated with the provision of less than optimum equipment and changing the equipment as the needs of the child change were identified, for example:

> **Janine (Paediatric hospice nurse):** I think one of the things we've found is families at home, they have to have a certain bit of equipment and maybe that might not be the best chair for a child, I can imagine that's to do with the budget and restrictions and they then have had to have a chair that is less suited to their child or like an armchair, or they've already got an armchair and they've got to let that one wear out before (Focus group 3).

Indeed, participants recognised that problems associated with inadequate adaptation and equipment provision can impact greatly on the parents' ability to care for their child at home, particularly when their need is urgent. It is unclear in the example given whether the underlying problem was funding or the decision making process:

> **Janine (Paediatric hospice nurse):** I think the other problem which we do run across is trying to get equipment for a child who changes very dramatically very quickly before they die. The one I can think of had a brain tumour which was very progressive and very quick and the child actually died within I think about twelve weeks of being diagnosed but he was actually very heavy and it was a nightmare, trying to get that equipment into the house. The family wanted to keep him at home and even minor things were quite difficult to get. You had to rummage in adult stores to try and get things and in fact the family ended up paying for a bed and a device to get him up the stairs. Luckily they were in a position to be able to pay for those things whereas a lot of people wouldn't be…
>
> **Beryl (Paediatric acute nurse):** I can think of one family who couldn't get things in time (Focus group 3).

Participants highlighted the financial burden placed on parents for adaptations and equipment that are required for the care of their sick child in the home, particularly in long term care situations when they work. Parents who work are required to make substantial contributions to adaptations and equipment and it is suggested in this excerpt that this results in some parents making the choice to give up work:

> **Diane (Health visitor):** Because with the government change and regulations a few years ago the amount that families have to put in now is quite considerable for adaptations. You know, for an average family earning an ordinary wage the money is astronomical.

> **Megan (Learning disability nurse):** Because also that's why a lot of our families are dependent on benefits aren't they because
>
> **Jean (Learning disability nurse):** If you can pay for anything you're lucky
>
> **Andrea (Occupational therapist):** If you're on income support, you don't pay anything, it's when you work
>
> **Diane (Health visitor):** But giving up your job…and the other thing is if you haven't got the adaptations in and you haven't got the equipment in you can't put the services in. The families are allowed to lug them here and everywhere but you can't put carers in because of the lifting and handling regulations (Focus group 1).

This excerpt also illustrates the wider impact of a system where access to care provision in the home is dependant upon decisions about funding for adaptations and equipment. Furthermore, the situation whereby families are left to struggle because equipment is not in the home, highlights a lack of joined up thinking. If families were provided with what they needed as a matter of urgency and routine then there would be less risk of parental or child injury in them carrying out care unsafely. Furthermore, the stress experienced by families and professionals in organising funding neglects the potential for other services having to pick up the cost of psychological care and for children's services covering staff for burnout issues.

5.2.4 Support for parents and families

The focus group participants identified the need for parents and families to have general and specific support to cope with and adapt to the child's day to day needs, caring, and the need for back up services to deal with acute problems and family lifestyles. The ability of parents to establish a trusting and supportive relationship with a key professional, such as their GP, Consultant, community nurse, therapist or social worker, was identified as an essential component of the general support that families need to minimise the impact of caring for their child, for example:

Kate (Special needs teacher): But do you think that there's some difficulties around that because some families will only accept one person that they get on with, I think you need that and to perhaps have someone else there who can help out also if there's problems that arise

Andrea (Occupational therapist): I mean at the end of the day if you've got a severely disabled child or with a life threatening condition, the last thing you want is loads of different people. You know, you want to spend the time to make a relationship with them; you need to know that even if they can't solve a problem there and then they can do it on your behalf. You don't have to go through the same story from the word go. I think we should be thinking about that for our parents and our children (Focus group1).

These professionals really want to make services better. As reported elsewhere, they can see the gaps in services and are frustrated that nothing is being done. By referring to "our parents and children", one can infer that these professionals see the well-being of the families in their care as their responsibility. With prolonged involvement, the professional almost becomes a family member and it is upsetting for them to know that parents are having to repeatedly talk about distressing issues, when there could be a key worker allocated to families to co-ordinate care and shoulder the burden.

Because a key worker system has yet to be employed, participants identified the need to support parents in dealing with the conflict that arises when they deal with professionals and services not empathetic to their needs, for example:

Sally (Specialist nurse): Yes and I think sometimes they want to just use you as a sounding board to help them deal with the frustration with the system. Recently a family went to the doctor with needs and he just turned round and said "well there's people worse off than you", so you know, the family were upset and I think families do need support with working with the system (Focus group 3).

The need to respect the decisions parents make, when choice is available, was also identified. Parents often look to health care professionals for endorsement of their decisions and help in ensuring that appropriate care is in place, such as decisions about respite (home based or inpatient), for example:

> **Simon (GP):** Parents have different attitudes, some don't want any assistance, it's their child and that kind of attitude exists as well (Focus group 2).

> **John (Paediatrician):** '…From the parents' point of view an acute ward isn't necessarily the right place, but on saying that some families choose to stay with children. A couple of weeks ago a family wanted their child to stay on the ward even though they've got home care and all sorts of other things, they chose to stay. So I think we need to be aware that although we think it would be nice for them to be elsewhere or at home it does come down to their choices and that might not be what we might think it to be, so (Focus group 2).

Similarly, the need for general support for parents in the lifestyle decisions they make, such as family holidays, was recognised by participants, for example:

> **Gail (Community paediatric nurse):** I had one family and they said "they've told me my child is going to die". They didn't want to go to (Hospice), they had a supportive GP, spent very little time in hospital, was discharged thinking their child had got just two weeks to live. It got to the second week and they said well we're still here and you know is it going to happen? And I said yes it is. The week after they were going off to Bridlington in a caravan and their attitude was she could die at home or she could die in Bridlington, so I said well if you want to go as a family then you go, I'll make sure you've got everything to take. I contacted a GP in Bridlington and said you're obviously the nearest GP

to this caravan site, you know there's this child coming, you know where the nearest hospital is and you know (Focus Group 3).

Not only do some professionals recognise and accept family decisions, as illustrated in the above excerpt – they sometimes pull out all the stops to fulfill their wishes. Furthermore, the nurses described part of their professional role as supporting parents in expressing their needs and making decisions at critical times. For example:

> **Janine (Paediatric hospice nurse):** I think sometimes with some parents it's quite hard to make the decisions when their child is actually dying in front of them. What they want is to be parents and they actually, some families want you to initiate the discussion about the decision and when it's right to call the doctor and then you've got the time to go through the decision they've made (Focus Group 3).

Other types of support, such as parent support groups, were identified by all three focus groups, but mainly in the context of bereavement. The range of issues identified which affect the support of parents and families reflects the complexity of coping and adaptation and the need for co-ordination, continuity and confidence in service provision.

5.2.5 Staff needs

Participants from all focus groups identified a number of issues relating to their own education and training, the need for support structures including clinical supervision and specific issues relating to bereavement. Participants were very positive about the contribution of unqualified staff that with training provide very good clinical support for children and their families, for example:

> **David (Paediatrician):** We have a lad who's on a ventilator at home…he also has the ventilator at school. I mean when I first heard of this I said this is not going to work, it definitely will not work. But, it has worked and he goes and has an assistant at school and she knows

how to manage this very simple ventilator machine. She just plugs it in and he's fine and he can do his lessons being ventilated. You know an amazing level of care is possible if you have the right people…I mean I thought this thing with the ventilator was going to take some upgraded nurse and I mean the lady who does it is a (senior) health care assistant. So there are people who can be trained to do this and it worked (Focus group 2).

This also indicates, that there may be other areas of care or care tasks that could be conducted by less senior staff if only this was reviewed, acknowledged and the training was available. Participants also identified the benefits they had accrued from experience of working directly with children with LLCs in specialist Centres, for example:

> **Joanne (Paediatrician):** I've previously worked for quite a long time at (Regional Hospital) in the Paediatric Oncology Unit there and so I do have a reasonable amount of experience of paediatric palliative care in oncology (Focus group 2).

In relation to professional education and training, participants identified a general lack of training and education provision, whilst recognising the specialised nature of working with children with LLCs. Some difficulties were expressed in relation to funding for specialist conferences and it was suggested that training and education tends to be motivated by personal interest, for example:

> **Megan (Learning disability nurse):** Well I've done the ENB 931 the palliative care course. I did that because I felt it was very relevant to my job. I can remember when I did the course the tutor was quite surprised at me because I am from a learning difficulties background. It was 'what are you doing here?' sort of thing, but I did find that very useful (Focus group 1).

The lack of a planned approach to providing suitable training and education for professionals involved in the care of children with LLCs was identified as an issue which impacts upon self confidence, service delivery in relation to respite facilities, assessment of needs and bereavement, for example:

> **Tracey (Community paediatric nurse):** There's no surprise in relation to what they need. There are all sorts of challenges, if you look at gastrostomy feeds, you know over night feeds, social services are not prepared to take that sort of role on, yet parents are expected to care at home. It's not high tech in any way but it's difficult to get social services to understand that's how that child now feeds so that it's normal for that child and a small amount of training is all that would be required for them to actually take that on. But social services keep coming back to us and saying it's an indemnity issue and it's difficult for them (Focus group 3).

It seems that in many situations, there is a lack of joined up thinking which leads to families being left in potentially desperate situations. Also, in relation to home respite and home crisis management where agency staff are used, concerns were raised about training, for example:

> **Andrea (Occupational therapist):** Well how much is it for an agency nurse? Eighteen pound an hour? And they're going in four nights, five nights?
> **Diane (Health visitor):** And even the G grade with non-qualified staff, you're still paying above
> **Lorraine (Paediatric physiotherapist):** And you've no real control over quality have you? You don't know what training they've had; it's about us saying what about creating a team like this (Focus group 1).

The palliative care teams often need more support, but their needs are not always met by using agency staff that are not skilled in palliative care, or have experience in dealing with LLCs. Furthermore, they are expensive and if services were better evaluated service funders would see an opportunity for increasing team sizes with staff at lower grades. Indeed, participants in all focus groups identified the need for support, including clinical support to deal with situations they do not encounter often, clinical networks to share specialist experience, informal team support and clinical supervision.

There were positive comments made by some participants about clinical support networks relevant to this field of work, although these are generally not funded, for example:

> **Lorraine (Paediatric physiotherapist):** It's a new forum for therapists working with children with muscular problems and I think you get a lot of support. It would be nice if I could go because you get an awful lot of support…
>
> **Sarah (Paediatric physiotherapist):** What we try and do is, we get the room for free and we usually persuade people to actually lecture for free and then we get away with like asking for coffee and tea money. What we have left over we give in donation, for example we gave to (Hospice) for the new unit, that sort of thing. And that's worked very well, to get them things across and trying to get equality you know that we're all equal in the way we work, but that's just being a group
>
> **Lorraine (Paediatric physiotherapist):** Of just interested professionals really (Focus group 1).

There were also many positive comments about the use of clinical supervision to support staff involved in the care of children with LLCs, particularly in relation to bereavement. Participants reported various arrangements, some receiving no supervision, others reporting the inadequacies of supervision as well as formal supervision structures, for example:

Andrea (Occupational therapist): We learn so much from each other, but from a supervision point of view, I should say well I don't have

Lorraine (Paediatric physiotherapist): You don't have supervision?

Andrea (Occupational therapist): I don't have

Jean (Learning disability nurse): No

Lorraine (Paediatric physiotherapist): We have clinical supervision, very strong, very formal way

Diane (Health visitor): Formal

Lorraine (Paediatric physiotherapist): For all therapists in my locality

Researcher: Right

Lorraine (Paediatric physiotherapist): That's been set up recently

Researcher: And what are your views on that?

Lorraine (Paediatric physiotherapist): the staff get a lot out of it I think, because they choose who supervises them, it doesn't have to be a manager, it's not appraisal, its clinical supervision. It's quite a new concept to give a physio or OT (Focus group 1).

Interestingly, inadequacies in clinical supervision were mainly related to the use of managers as supervisors who were considered to be out of touch or have no expertise in this specialised area of practice. A key benefit to this supervision was it being viewed in different terms from appraisal. There was less of a feeling of being judged.

In addition to the education, training and support needs identified by participants, further needs were identified in relation to coping with the death of a child. Good support structures were reported within the children's hospice environment, but elsewhere support for staff was reported to be patchy. The infrequency of a child dying whilst in an acute setting was highlighted as one factor in coping particularly for therapists, ward based nurses and teaching staff. However, the long-term relationship professionals have with children and their families was associated with the loss they felt. The need for the

opportunity to discuss bereavement issues through team support, staff bereavement groups, clinical supervision and counseling was identified, for example:

Lorraine (Paediatric physiotherapist): My staff hasn't sort of been involved in the terminal phase of that (Muscular Dystrophy) and obviously they've known them since they were diagnosed usually. We had an incident in my locality which is similar which is based on my experience many years ago and it affected me really deeply. You know we had counselling and stuff after that and I think the staff have got to have some skills to help them to cope with the day to day bereavement issues and, what do you say to the family?, what are we going to say to mum you know?, he's dying how am I going to deal with it? And I think that's a really difficult one

Diane (Health visitor): It's hard afterwards

Lorraine (Paediatric physiotherapist): It is because you do your 'after death' visit don't you

Gill (Social worker): It's not just how do I deal with it professionally? What is my role? What is my role as a professional?

Lorraine (Paediatric physiotherapist): No it's not that, it's how you deal with it yourself as well

Gill (Social worker): Yes

Lorraine (Paediatric physiotherapist): And the support you get from within the team and I think that's one of the big issues for my staff

Gill (Social worker): Yes because I don't think, well I know that there's not enough recognition of that fact and I mean it happens a lot in hospices

Lorraine (Paediatric physiotherapist): Yes, yes it does

Gill (Social worker): It's done as a matter of course, that you know they recognise that staff need that, but it hasn't happened in this area

Lorraine (Paediatric physiotherapist): I think it's taken too lightly

Gill (Social worker): Yeah

> **Lorraine (Paediatric physiotherapist):** If you've worked very closely with a family for a long time and there was a time when the therapist was there literally at the end and it is a very traumatic event and I don't think you can dismiss it (Focus group1).

So there comes a conflict in role, once a child dies. Professionals are confused as to how they should act professionally when they are feeling the pain of bereavement personally, like a friend or family member, especially if their involvement with the family has spanned years. Participants also reported the benefits of saying 'goodbye' to the child by helping with and attending the funeral, for example:

> **Beryl (Paediatric acute nurse):** I think the other thing is that, if the family are happy we go to the funeral. We check if it's alright with the families first but we usually go and there's usually a few of us isn't there? If the community has been involved and other people, so that's quite nice and often the Consultant will go as well, so the whole team goes and you know it's quite therapeutic in some ways (Focus group 3).

With such words the services they provide are de-medicalised. These professionals are not hardened to grief and attending a funeral helps their perception of supporting the family and their own grief processes.

5.3 Specific service gaps

In addition to the general issues associated with service planning, delivery and co-ordination, participants highlighted specific gaps in service provision which need to be addressed.

5.3.1 Respite and out of hours care

Participants identified problems associated with access to and provision of respite care for children and their families, particularly in focus groups one (multi-disciplinary) and three (nurses). Whilst general problems have been noted in the previous sections

including referral, assessment, funding issues and delays in decision making, there was a consensus emanating from the focus groups that respite care provision is inadequate for children with high nursing and therapy needs, for example:

> **Andrea (Occupational therapist):** The only thing with respite is, even if it's there they get so little (noises of agreement). It's not really worth it you know you can't, I mean this area for any child with a disability not just the ones at the latter end of their disease you can't have a week's holiday
>
> **Diane (Health visitor):** And another thing is that all the money in this area is the respite care is social services isn't it? Health do not input into respite care at all
>
> **Megan (Learning disability nurse):** Social services employ nurses but don't employ them as nurses, they are nurses but their titles are residential social workers and they can't practice as nurses which again is an absolute shame (noises of agreement) you know
>
> **Diane (Health visitor):** It's a nonsense isn't it, but health I think fall down very badly there, them not having any commitment to respite at all (Focus group 1).

Participants went on to highlight inadequacies for crisis, short-term and long-term provision in both home and institutional settings and related difficulties in planning the appropriate care, for example:

> **Tracey (Community paediatric nurse):** Yes we do and I think, sometimes you come against things like this family could do with some help. Then you try phoning to get that family some help because you know that Mum's not quite at the end of her tether but if she just had a break then she'd be able to cope better
>
> **Researcher:** Yes

> **Tracey (Community paediatric nurse):** And then trying to find somebody that would say "yes alright then we'll take that on, we'll put somebody in there X number of times" just to let mum have a break and yet nobody. You end up banging your head up against a brick wall because nobody is listening … and nobody wants to take that on (Focus group 3).

Participants noted that there were different acceptance criteria for respite provision between different providers such as social services, acute wards, schools and hospice facilities. There were also many children who do not fulfill the criteria for any of these services, for example:

> **David (Paediatrician):** But then it is difficult to access other respite care for that group of clients because you're looking at social services then and really you need to say the cost of care a day, inhalators, you know, antibiotics and things, there's just no way. There's just nothing till you get to that point where you can go to (Hospice). It's so difficult for other people to take these children on board because of the package of care they need whilst they're with them, even for just over night (noises of agreement) it's, it's very difficult (Focus group 3).

Indeed many children and families lose out on accessing support because they do not quite fit the criteria. This takes me back to a previous point whereby I stated that services still appear to be adhering to a biomedical model of care and trying to fit children into boxes. All these children are different and the focus should be on their needs and supporting them. In addition, the majority of institutional settings, which are considered by many to provide respite, such as acute wards, schools and the children's hospice do not consider respite as their primary role, for example:

> **Laura (Learning disability nurse):** You can send them to hospital and not believe it because they'll be in the classroom the following morning. Yes there's a fine line between acknowledging the fact that

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parents do need respite care, they do need a break from their child because it's relentless but you are compromising the child's health. A lot of these kids have very complex needs, they need one to one attention

Kate (Special needs teacher): And at the end of the day you have to function as a school and not a care home (Focus group 1).

Furthermore, the use of the term 'respite care' is confusing in relation to the children's hospice and the distinction between terminal care and respite care is not clear. The hospice considers their primary role as a provider of symptom control and terminal care for children with life-limiting conditions, for example:

Janine (Paediatric hospice nurse): but what we don't see (Hospice) providing a respite service at all. Although that's part of it because of the number of children we have going the amount of respite you can give is quite limited. What you can say is maybe the symptom control, you're doing the best to get to know them before symptom control and terminal care because obviously it's a lot easier if you have that relationship with families (Focus group 3).

In contrast participants in focus groups one and two used the term respite when referring to children's hospice and terminal care, thus indicating the level of confusion amongst professionals, for example:

David (Paediatrician): and once they are ready for respite then it's (Hospice)…It's hard though sometimes of course … it's the responsible thing but it's like you are saying that death is the outcome here and depending how much they've understood about it…You know if you have a child whose spastic quadraplegic you probably won't have discussed death at all with these parents and even in the neonatal period they aren't even discussed then. Why? Because you're trying to

encourage them to be as active in their welfare in this child not discussions about death, so then you say respite care, well then you bring death into the equation so we have to have a discussion about that and what you'll do about it (Focus group 2).

The need for a range of options for children and their parents, including home based and institutional care was identified and discussed in all focus groups, for example:

Diane (Health visitor): Yes because I thought all the talk was about having a hospice style of model wasn't it. I mean with all the meetings they had with parents beforehand that they used to have, that was what parents were requesting, because that way you could opt in or out of family support, as well as the child just being taken to a place. And that's quite a big issue, especially for the younger children and for children with terminal conditions because there isn't always the expertise in a respite facility to do that

Megan (Learning disability nurse): And they also say don't they that having that physical building is the most expensive part, well if you had the right team of staff, interested, dedicated, skilled staff, willing to provide support services in the home, that would appease a lot of problems

Diane (Health visitor): It would

Megan (Learning disability nurse): And it's what a lot of families need, it's not always about physically going somewhere (Focus group 1).

Consideration of the needs of siblings in respite provision was again identified by participants in focus group three, for example:

Tracey (Community paediatric nurse): Yes, I think to be able to offer parents respite in their home when they need it but also for some

parents the respite has to be outside the home and allow them the opportunity, both parents to spend time with other siblings because often it's not. One parent has to stay at home and look after the child who has the needs while the other parent enjoys the healthy siblings (noises of agreement) and I think it's being able to recognise that you need both types of respite (Focus group 3).

Participants suggested that parents often bypass emergency medical services and contact the acute service direct for nursing or medical advice, prescriptions or supplies, for example:

Beryl (Paediatric acute nurse): I think what tends to happen with one bad experience with [out of hours GP service], they just access the hospital. We get mums saying can you get me this and so and so, but again if it's new nurses who don't know these children then it's difficult. But a lot of them certainly after five o'clock and at weekends, we get phone calls from families and that's what we do a lot of the time. It's just quicker and less traumatic for families to do that than it is to go through all this business from thread to needle that spans years. Well it's just not right to have to go over it every time the child is not very well (Focus group 3).

Overall participants identified the need to plan out of hours nursing and medical provision for children with LLCs, which can respond to their acute needs with minimal inconvenience and disruption. Accordingly, professionals will try and organize care so that parents are saved from the stress of dealing with professionals who have no knowledge of their child or the child's condition.

5.3.2 Challenging behaviour

Participants within each focus group also highlighted the lack of service provision for children with challenging behaviour. These children have high care needs; therefore providing a package of care can be very complex. At present there is arguably no suitable service or respite facility to cater for the complex needs of these children, for example:

> **Gill (Social worker):** We have a big problem in this area we have a big problem in having children with learning disability who need accommodating. You know those situations not necessarily with life threatening, life limiting… it's usually the challenging behaviour side of it (noises of agreement) and we just don't have anywhere. They end up being in our respite unit and staying there with huge problems and then they're there for a year or more which you know makes the whole system skew
>
> **Jean (Learning disability nurse):** I'm sorry but if you lived in this locality and you can't get through the day well, I'll ring you tomorrow just in case you have because there isn't anything (The participant is being damning of the support services in her locality)
>
> **Diane (Health visitor):** Other than the ward
>
> **Jean (Learning disability nurse):** Other than the ward
>
> **Lorraine (Paediatric physiotherapist):** We're desperate (Focus group 1).

This excerpt highlights the lack of provision for children with challenging behaviour and the professional frustration with the situation. The following example also illustrates the complexities that can be involved in providing care for these children and their families. Community care services will also not always have the staff with the skills and readiness to cope with and manage such behaviour, for example:

David (Paediatrician): He bites himself at any sort of frustration at all he'll bite himself, so much so that he's had to have all his teeth removed and he'll not only bite himself he'll bite the parents, so he is fine so long as he's strapped down … and he asks to be strapped because he knows he isn't responsible for his actions and he's not, so the lad himself wants to be put in straps… there was an incident where he was not kept in his straps at school and he gave himself a nasty eye injury with a pencil as a result (Focus group 2).

5.3.3 Ethnic minorities

Access and care provision for ethnic minority children and families was a question posed to each of the focus groups and participants raised a number of issues which affected their ability to support children and families. Focus group two (Doctors) made a distinction between the main (Asian) ethnic minority communities and smaller minority refugee communities – in terms of ease of communication. In particular, one doctor who could speak Asian languages commented on how he was now seeing the difficulties that non Asian language speaking doctors face when confronted with only Asian language speaking patients and families. This was because he was increasingly seeing patients from Eastern Europe who could not speak English and whose cultural heritage he was unaware of. All three focus groups identified efforts which had been made to improve access to services locally such as interpreting services, link workers and community development work to improve access to primary care and the children's hospice.

Indeed, participants reported access to and use of translator services and were very positive about their role and efforts, for example:

Tracey (Community paediatric nurse): Every interpreting service like most services they are very short staffed and very hard worked but at the drop of a hat they can quite often get you an interpreter quite quickly if they've got someone and we've got a situation that needs it (Focus Group 3).

However, despite best efforts within existing resources there remained concerns that at times there is an over reliance on English speaking family members and that information is at risk of being communicated inappropriately to families. There were also concerns expressed about the level of understanding of key family members and the absence of support networks within their own communities.

5.3.4 Bereavement care

Bereavement care provision was discussed mainly in focus groups 2 (doctors) and 3 (nurses) and various issues were highlighted. A clear distinction was made between the support in place for parents and the needs of the siblings of the sick child. The need for bereavement care and the value of parent and bereavement support groups and ongoing contact with health care professionals was recognised.

Participants thought that there were good support structures in place at the regional Hospice including support groups for parents, planned communication (such as birthday cards) and bereavement visits. Parents and siblings can return to Hospice to stay if they feel this may be helpful and attend an annual bereavement service. The professionals involved in this service have dedicated working time to follow up families and are rotated into the role for a two year period and are given the necessary support to undertake the role, such as clinical supervision and counseling services.

In the local area of Huddersfield, a bereavement service has evolved over time (in the acute hospital setting) with a core of five staff, largely on a goodwill basis. This includes a parent bereavement group, bereavement visits, planned communication (such as six week follow up and birthday cards), plus a telephone answer machine for parents to leave their contact details.

The main issue identified beyond the Hospice provision is that there is no dedicated bereavement care resource with psychologist input and local practice has developed largely on a goodwill and individual interest basis, for example:

David (Paediatrician): Things have not so much been set up, they've kind of evolved and developed. For example we have a liaison Health Visitor who has done the breaking bad news work over the years. I don't know what her job description is but she is the one if we want to give bad news to parents she's in on every single one of them, she's just a magic lady, but she's retiring soon so she's just had years of experience. Now that's a Health Visitor with years of experience of handling bad news and supporting parents after they've received that …now some of our Community Nursing team have moved into this area a bit to fill in the void (Focus group 2).

The need to consider bereavement from diagnosis, throughout the life of the child and during the transition period between active and palliative care was highlighted. Preparing parents for the terminal stage, particularly in non-cancer conditions where deterioration is gradual was said to be difficult by participants. In addition, parent support groups were valued highly by participants, although they also highlighted difficulties, which can occur and the collective sadness when a child dies, for example:

Sally (Specialist nurse): 'Parents get friendly with other parents and it must be difficult to see their friends lose their children, going to each other's funerals and they know that they will be there soon. They must sit there thinking, "I wonder who's going to be next" and so it's the effect of that and the support needed there as well (Focus Group 3).

The absence of good social support during the life of the child is highlighted in this excerpt:

John (Paediatrician): 'We had one little girl who was very ill and died by the age of seven and at that time her mum's only network of support were the health professionals. She had spent so much time either at school or in the hospital that she had no friends beyond that world. Once her daughter had died and she had no contact so you know I think

sometimes parents have enormous needs which are very very difficult to deal with, often on the bereavement side which are difficult to heal. We make one or two bereavement visits but after that it's (Focus group 2).

Professionals need to be able to prepare for a child's death to give the family adequate support but recognise there are often communication barriers, for example:

> **David (Paediatrician):** death and deterioration, that's a difficult area for us to go on about because we spend most of our time trying to get the child better and here we are saying that things have got worse suddenly…
>
> **John (Paediatrician):** You see usually with parents they don't really realise how really ill their child is and I'm beginning to realise that actually what the parents see is not what I'm seeing and you might have discussed it with them over four years, four times a year and you think wait a minute perhaps these parents are considering a future with their child (Focus group 2).

Problems also arise when it is difficult to determine the child's prognosis and the terminal phases are revisited. Parents and professionals prepare for death being imminent and then the child recovers to such a degree that they are no longer considered to be in the terminal phase. This can prove to be a massive strain on professionals, for example:

> **Janine (Paediatric hospice nurse):** I think one of the big issues for a lot of the families is that they often revisit the terminal care stage a number of times and that's actually quite difficult for them to realise to think it is actually happening this time because they've been there before and sometimes they're quite angry when it doesn't actually happen (noises of agreement) because they've prepared for it and then they bounce back and so they need an awful lot of support and you do

> **Gail:** You get complacent don't you sometimes with the ups and downs and then they're really are going to go this time (Focus group 3).

Overall, participants identified the need to develop this area of practice further in relation to better assessment of parent need and improved knowledge of therapeutic interventions which help parents through bereavement. Further, it was identified by participants that siblings have to go through difficult adjustment processes prior to and post death and their reactions can intensify the difficulty of the situation for parents. The scope of the current provision, which does not include groups for siblings of sick children and allows only limited follow up, is considered to be less than ideal. Hospice staff and participants from elsewhere identified provision for siblings as a service gap which they recognised but could not address within the existing 'goodwill' arrangements, for example:

> **Janine (Paediatric hospice nurse):** So we've actually started sibling groups as well and sadly we can only do that for children who've lost their brother or sister and that's a yearly (Focus group 3).

> **Beryl (Paediatric acute nurse):** Our biggest gap is for brothers and sisters, we've got nothing … and as much as we'd like to do something we haven't got the time. We would need bereavement people full time to be able to do it, but it is a massive gap and we've tried liaising with the adult hospice because they've got a group for children who've lost parents, but it hasn't really happened
> **Researcher:** Right
> **Beryl (Paediatric acute nurse):** And it's a massive gap that we're aware of but we're not in a position to do anything about it without funding someone to do it, which is incredibly sad and we know that (Focus group 3).

In summary, whilst there is a recognised need for support of siblings, service provision is considered to be resource limited.

5.4 Discussion

The focus groups provide an overview of the range of health, social care and education provision for the care of children with LLCs and their families in this region. The complex and often very individual nature of the needs of these children and their families is portrayed as is the highly specialised professional expertise and knowledge required to care for and support children in maximising and maintaining physical health, learning and quality of life. In addition, the focus group participants illustrate the complexity of needs these children have and their use of many services including primary, secondary and tertiary care facilities, mental health services (for example, learning disabilities and clinical psychology), hospice care, special education provision, social services and voluntary sector services.

The range of professionals involved is wide and the parents have to negotiate with the system on a continual basis as the needs of the child and family change. Repeatedly professionals and parents are met with diagnostic barriers in not fitting criteria which impede access to services and support. There are also reported to be many service shortfalls that result in professionals being unable to provide appropriate care for all children, especially those with challenging behaviours, from ethnic minority backgrounds and who may need support over a short period due to rapid deterioration.

Community teams such as those within Child Development Units/Children with Disability Teams/Community Nursing Teams describe elements of their role in which they negotiate within the system on behalf of parents. They report successes where appropriate care was provided but many frustrations with referral and assessment processes, the responsiveness of decision making, timely provision of essential interventions, and anomalies in the use of resources which are available to support both general and individual need. There appears to be a call for the recruitment of less qualified staff to widen local service provision and decrease spending. Furthermore, additional support and training is needed for professionals to deal with end of life communication and decision-making issues and to assist themselves and their patients with bereavement/grief issues.

Taking into consideration the views of these professionals and the knowledge gained through the analysis, a number of service recommendations can be put forward:

- It is evident, that employing one professional to work on the administration of joining up services, would be key to avoiding excessive spending and maintaining a coherent package of care.

- With so many inconsistencies between services regarding transition from child to adult services (and a lack of knowledge of what to do for the best), it is suggested that for children with LLCs there maybe a better option of 'shared care' and a service framework that could be structured around caring for those in their late teens (who have been cared for by children's services) until death. This being a service separate from both child and adult services.

- It is terrible to think there are families struggling to care for their children because they are not provided with appropriate or indeed safe equipment. Even more depressing is the realisation that, in fact, some of these children struggle dying without the equipment that would make the end of their life more comfortable. It is suggested that commissioners re-evaluate their budgets for children with equipment needs.

- Where there is a child with complex health needs it appears nonsensical for health services to not be involved in providing respite care. Hence, healthcare providers and services should be more involved in the allocation and delivery of respite services.

As stated in chapter 1 - partnership working is considered to be crucial and is a core principle in the following key policies: The Every Child Matters: Change for Children agenda (DoH 2004); The NSF for Children, Young People and Maternity Services (DoH 2004); Making it Better for Children and Young People (DoH 2007); Aiming High for Disabled Children (HM Treasury/Dept of Education and Skills 2007); The Children's

Plan (Dept for Children, Schools and Families 2007). In addition and also of relevance here - 'Better Care: Better Lives' (DoH, 2008) suggests

1. Equality of access to universal services
2. Responsible and accountable leadership
3. Choice in preferred place of care and widening of community services
4. Better end of life care
5. Stronger commissioning and value for money
6. Successful transition between children and adult services
7. Planning and developing an effective and responsive workforce

The 'End of life Care Strategy' (DoH, 2008) also echoes the understanding that the support these children and their families require is complex and as such a lot of careful planning is required by commissioners when considering transition to adult services and in planning end of life care services.

The findings of this phase of the research were disseminated at a consensus conference I organised. A number of positive outcomes evolved from this conference and are detailed in appendix 7.

These findings provide access to the professionals' views of services and practice and as such, do not provide so much insight on how they experience being a professional working with children with LLCs and their families. Thus, this analysis is not truly phenomenological and instead is included for setting the context of the subsequent studies. Before I interviewed the parents and children I was aware of the difficulties faced by professionals in providing care and the current shortcomings and strengths of services. To this end the scene is set for the hermeneutic phenomenological method. Its main purpose is to investigate and describe phenomena as these are experienced in life - to provide a voice to the human experience just as it is (Heidegger, 1962).

Phenomenology is oriented towards concrete experience and to people in relationship with others (embodiment, holism, intersubjectivity, and the life-world), to beliefs and practices (contextuality and shared history), and to the intent to understand the meaning of the person's experience (self-interpretation and intentionality). These premises hold interest for health and social care, where practice involves interactions and relationships with people through their experiences of health and illness (Benner 1985, 1994). In this setting, phenomenology is able to illuminate the types of human experiences that are possible, the context of these experiences, and how these experiences can be described (Spiegelberg 1965, Burch 1989, Hammond *et al*, 1991).

Through language, the phenomenological text has the power to convey the world 'as we live in it'. The results of a phenomenological study are descriptive in nature detailing a variety of possible experiences. All such phenomenological descriptions can be positioned against another phenomenological description, as the life-world is complex and remains in flux. Therefore, it is entirely understandable that alternative descriptions may continue to exist.

As a result, a full explanation of the world of palliative paediatric care, and more specifically Being and caring for a child with a LLC is not possible (Anderson, 1991) nor is it possible to dictate causal relationships, or produce law-like statements (Koch, 1995, van Manen, 1990). Instead, the phenomenological descriptions will be validated by mutual recognition given by the 'phenomenological nod' which says 'yes, that is an experience I could have' (van Manen, 1990). Taking on board the findings of this chapter, the conveyed lived experiences in the following chapters may contribute to the phenomenological nod and the reader being able to 'see' what life for these people is like.

Phenomenology's emphasis on the understanding of people in a non-reductionistic way, and on their experience within their environment, as well as on the professional–patient relationship, holds much interest for those wishing to find meaning in their practice. Thompson (1990) stated that phenomenological study allows subjective expression by both patient and professional, which also may allow entry into the world of social and

political contexts where professionals practice and patients live. The phenomenological text is produced to enable increased understanding of human experience such that health and social care practice can develop. To this end the phenomenological study of the lived experiences of children with LLCs and their parents will produce findings that will enable professionals to understand them better.

Chapter 6: The parent interviews

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This chapter presents the themes identified from an analysis of interviews with parents of children with LLCs. The participants' lived experiences are detailed and their voices illuminated in given excerpts.

6.1 Overview

From a total of twenty-five parents' responses, twenty parent interviews were successfully conducted (see Table 6.1). Ten interviews were conducted with parents in Huddersfield, six interviews were conducted in Halifax and four interviews were conducted in Dewsbury. Of these interviews, sixteen were with mothers and four with both parents. The remaining five interview arrangements were unsuccessful due to a number of factors, such as the child's hospital admittance, the deterioration of the child's condition and unsuccessful attempts to organise an interview date and time. These interviews are in addition to those conducted and discussed in chapter 7. However, 'Maria' is featured both in this chapter and chapter 7.

Table 6.1 Participant characteristics - parent interviews

PARTICIPANT NUMBER	PARTICIPANT NAME(S) *	CHILD AGE (YEARS)	CHILD'S CONDITION**	HOSPICE CARE RECEIVED (DAYS PER YEAR)
1	Adele	11	Non-cancer (Neurological condition)	✔
2	Laura	7	Non-cancer (Cerebral Palsy and related disorders)	✖
3	Bronwin	15	Non-cancer (Cerebral Palsy and related disorders)	0
4	Dawn & Lawrence	5	Cancer (Leukaemia)	0
5	Julie	6	Non-cancer (rare genetic condition)	0
6	Stephanie	5	Non-cancer (rare genetic condition)	0
7	Faye & Mark	10	Non-cancer (rare genetic condition)	✔
8	Mary	9	Non-cancer (rare genetic condition)	0
9	Clare	10	Non-cancer (rare genetic condition)	✔
10	Gina & Mick	6	Non-cancer (rare genetic condition)	✔
11	Rachael	2	Non-cancer (rare genetic condition)	0
12	Lindsay	15	Non-cancer (Muscular Dystrophy)	12
13	Haley	8	Non-cancer (rare genetic condition)	0
14	Catherine	2	Non-cancer (Heart condition)	0
15	Dee & James	4	Cancer (Brain tumour)	0
16	Maria	11	Cancer (Leukaemia)	0
17	Chloe	5	Non-cancer (rare genetic condition)	0
18	Belinda	9	Non-cancer (Cerebral Palsy and related disorders)	4
19	Kerry	12	Cancer (Bone cancer)	0
20	Tamsin	7	Non-cancer (rare genetic condition)	✖

*The given names are pseudonyms. ** Where a child has a rare genetic condition, the diagnosis is not given to avoid a compromise in anonymity and confidentiality.

The children of the parents' interviewed were aged between two and fifteen years. Four had been given a Cancer diagnosis and the remaining sixteen had been given other life-limiting diagnoses / prognoses. Of the twenty children, eight were reported to receive Hospice respite care. All of these seven children had non-cancer LLCs. The table below (6.1b) summarises the themes found across the interviews.

Table 6.1b Summarised parent interview coding template.

THEMATIC AREA	LOWER LEVEL THEMES
The beginning	The diagnosis & its immediate impact • Shock • Support • New meaning attached to episodes of acute illness New experiences • Provision • Recognition of professional focus New focus • Different outlook • Total concentration on sick child.

An inner incentive and drive to provide	Maintaining control
	• Putting full efforts into care
	   o Blame and guilt
	• Accepting lack of professional concern
	Parent-professional relations
	• Communicating needs
	   o Understanding of situations
	   o Information provision
	   o Maintaining good relations
	• Negotiating care
	   o Fighting for provision
	   o Needs not followed by provision
	   o Tick box criteria
	• Respite arrangements
	   o Insufficient provision
	   o Peer support
	   o Difficult times

Trying to maintain a life balance	Social life • No perceived social life • Peer support • End of life care Employment • Ceasing paid employment • Financial issues

THEMATIC AREA	LOWER LEVEL THEMES

Feeling responsible for others	Sibling care
	   • Lack of provision
	   • Struggles to meet needs
	   • guidance wanted for sensitive issues
	Open communication
	   • Prognosis disclosure guidance
	   • Truth telling
	Disrupted family functioning
	   • Stress
	   • Marital breakdown
	   • Sharing care

Psychological effects	Threatened self image
	   • Issues of identity
	   • Loss of control
	Social withdrawal
	   • Care demands
	   • Avoiding negativity
	       o Trying to maintain a normal life
	       o Being distant from unwanted attention
	       o Being comfortable
	   • Peer support
	Depression
	   • Difficult times
	   • Needing medical intervention
	Anxiety
	   • Frustrations
	   • Decision-making
	Fear for the future
	   • Degeneration
	   • Death
	   • Need for support interventions

Fear of reaching the bottom line	Communication with others
	   • Stress with periods of waiting
	   • Not knowing how one should feel
	   • Lack of support
	Struggling to cope
	   • Pain
	   • Questioning
	   • Maintaining control
	Facing the future
	   • Worries about energy levels
	   • Needing rest
	   • Uncertainty

6.2 The beginning

For many of these parents there had been concerns about the sinister nature of their child's condition far in advance of any given diagnosis. Where conditions were determined as rare and genetic, the journey to receiving a diagnosis was long and uncertain. Still, to be told that their child had a LLC no matter how far this was anticipated was experienced as devastating.

6.2.1 The diagnosis and its immediate impact

All these parents reported emotional struggles to be able to come near to accepting their child's diagnosis or in the event of there not yet being a confirmed diagnosis, their possible prognosis. For some parents, the stress of being given the bad news was heightened by their perceived lack of professional support:

> And we were really sort of given the prognosis which was quite… what's
> the word?… shocking and there was no follow up of any kind… not even
> information (Tamsin).

Interestingly, most parents recalled the bad news disclosure as being in a private office space in the hospital setting. The news was given by the child's Consultant and parents were then left to return to the ward/home to absorb this disclosure in their own time. The following two excerpts convey a sense of what the time of diagnosis and shortly afterwards, was like for these parents:

> We were in the office at the end of the ward… the door was shut by the
> nurse but but because there were windows out onto the ward, I could try
> and avoid the situation by looking out at the other children up and down
> the ward and the visitors moving around… the ward was very busy and
> alive that day… I remember the consultant seeming a bit tense and he
> was stood rather than sitting… the words 'there is nothing we can do'
> was what rang through my ears louder than anything else that was

> said...hmm… 'We will strive to make your child's life as comfortable
> as possible' … my heart was on the floor (Kerry).

And,

> I were just sat on my own and I remember sitting there… there were
> leaves falling off the trees and I can remember thinking all these trees
> are dying and (child) is going to die and I sat there planning her funeral
> (Catherine).

Immediately, the response for these parents was to focus on the end, on there being no hope and of their child dying. Little thought was on the here and the now. Through re-reading these excerpts I can see the professionals thinking behind conveying this news and then leaving parents to have the time to adjust. It is expected that over time questions are likely to evolve about the day to day care and treatment plans. However, I can remember in the interviews, being quite shocked at the thought of professionals almost sliding in, dropping bad news and sliding out. I viewed this as potentially unethical and insensitive. Indeed, some parents reported a lack of professional follow up despite their perceived need for guidance post diagnosis. Many parents spoke of having uncertainty; of not knowing the extent of what having this condition meant for them and their child and of feeling that they had or have no real conceptualisation of what the future may bring. Arguably, these issues were the focus of parent's thoughts, much later than the time of the bad news disclosure.

Adding to parental confusion is the fact that children with LLCs can go through a number of periods of ill health from which they can often rebound. Parents said that this can lead to a 'rollercoaster' effect on emotions, especially once they are aware of the life-limited nature of their child's illness, for example:

> But I mean it was worrying because everyday the Consultant came to me
> and there was something else not working, you just dreaded seeing him
> really… expecting we were going to be told that would be it… and then

there would be hope because actually 'this aspect is not actually as bad as we thought' or 'this has started to work again' (Julie).

Before a LLC is diagnosed, parents commented that they could cope with the illness phases better than once they are aware their child has a LLC. Without a diagnosis parents are striving for a label but once this is known, the parent is expecting the terminal phase to always be encroaching.

6.2.2 New experiences and foci

Often, it is not until a diagnosis is confirmed that appropriate treatment and packages of care can be implemented for children and their families. This may mean new experiences in terms of new procedures, of new professionals being involved in their care and sometimes different provision in terms of respite and education. Further to this, parents' reported that medical advances have meant that their children can now remain in their homes with relatively high level nursing needs. In one respect this is beneficial for families as they want their children to be in the comfort of their own homes and surrounded by family. At the same time, there is the added burden of parents trying to meet all the needs of their ill child. Although some families would receive help, there were many who stated that they received minimal assistance and felt they needed more professional input - especially when it came to their child needing to have complex procedures undertaking that were very nursing task oriented:

> When she had the peg put in, it took me a while to get my head around using that to feed her… we were sent home with all this equipment and feed and at first it was a bit of a case of trial and error… now knowing how things can go wrong with it… I think we should have had a lot more help at first and be shown a few times before we were left to have to do it ourselves (Belinda).

Child feeding is a maternal stress and pleasure. Being a mother I am fully aware of the stress incurred when my daughter refuses meals. However, there is a sense of pleasure

when she eats a full meal and when I can look back over the day and be satisfied that she has had a good balanced diet. Obviously, when there is a need for children to be fed by other means, mothers said that they had endured stress and worry due to the child's difficulty in eating by mouth. However, to then be faced with no longer being able to have the comfort of knowing your child has enjoyed their meal and will no longer eat a full meal you have prepared, is very difficult.

Parents acknowledge that after a LLC diagnosis they have new experiences in terms of caring for and parenting a dying child. Before the child was viewed to be chronically ill, but now the child is dying and as a result the lived experience is all the more emotional. Where there is contact with professionals, those that were said to go the extra mile and take time to sit and listen to what life is now like are more appreciated.

> The Consultant is very good… he will sometimes pop in to see how we are doing… it is nice to know that he cares, he has seen us struggling sometimes and has done his best to help us out when he can… sometimes him having the time for a quick coffee and to ask how are things going is a big help (Tamsin).

However, parents' reported that some other professionals can become too narrowly focused on the child's condition, and not be very considerate of the impact LLCs have on everyone's lives, for example:

> So, you know, but they're not interested because the (Specialist), like I've said, you could actually take her (organ) in on a dish and say right well is it ok today or do you need to operate on it, you don't need (child) and you don't need me …they're only interested in that (organ) bit …they're just not interested (Catherine).

This excerpt illustrates the doctors' focus as being purely biological, almost mechanistic and ignorant of other factors relating to the disease that impact on the child's well-being.

The parent separates the diseased organ from the child, signifying that the disease does not characterize her child; the child is a being without the organ or the disease. This way of thinking is not always recognised by the professionals. Such a condition impacts socially and psychologically on the full family unit, but the parent implies that this is not acknowledged in consultations. Indeed, parents in general reported that the lack of holistic concern by professionals could lead to family frustrations and upset. Parents argued that it is important that professionals work towards a more holistic approach to care in order to promote within family relationships, relationships with professionals and coping.

6.3 An inner incentive and drive to provide

These parents discussed events that were characterised by their 'inner incentives' and drives to provide for their ill children, to give their child the best possible quality of life they could.

6.3.1 Maintaining control

They described how knowing that they were putting full effort into caring for their child gave them a sense of satisfaction.

> He cannot do things for himself… he cannot do anything about his condition… and I do not want to be thinking after he has gone well I wish I had done this and I wish I had done that, because you cannot change things then… so as long as I know that I have given him the best quality of life he could have possibly had, then I have nothing to reproach myself for later (Haley).

Here we can see how this parent is living for the now, but at the same time imaginatively looking back at the 'now' from the future. This issue of temporality was present a lot in these parent interviews and will be discussed further in chapter 8. The above excerpt also indicates the worry or fear the parent has for potential reproach, if she was not to be totally focused on the ill child. The child is totally dependent on his parents for all his

cares, but there is a sense of frustration in having to meet all these cares. Meeting the day to day care demands are difficult for all these parents, they all reported to be tired and having little support. However, maintaining control over the day to day routines did give them a sense of purpose. In this case, the child is totally dependent. The mother implies this is not his fault and it is her duty as a good mother to make his life as comfortable as possible and thus his death easier to live with. Thus, further looms the question of whose fault is it? Where there were children with genetic conditions there were very delicate considerations about guilt.

Referring back to the parent's perceived lack of support; this was mainly directed towards professionals. Parents spoke of having very little space in their days to rest physically or mentally. They spoke of professionals who were aware of this and who were compassionate, but still this had caused frustration and at times, anger. Mary talks about how professionals try to support her with encouragement and praise for how well she is coping but such has served to be a great annoyance as she feels that by coping she is not receiving the support she needs:

> 'How you've got this far, you're doing a great job and carry on' and really
> I don't know why I go because sometimes I feel more cross (Mary).

Mick goes on to talk about the reality of the two worlds of the parent and the professional:

> So when we are struggling and they are full of empathy and sympathy, by
> the time they get home with their kids, yelling at them, they are at home,
> you know. They have got their own life and they are getting on with it. It
> is twenty-four hours, seven days a week, fifty-two weeks a year for the
> people that it affects. For the workers they have that escape and I do not
> think as such they can take it as serious as they need to. Why should they
> have to live the reality we are living, it's intolerable. It's horrible and I
> would not wish it on anyone (Mick).

These frustrations and points of anger were multi-dimensional. At one extreme, parents were annoyed that professionals can see that they are coping and commend their efforts – instead of inputting more professional assistance. Almost as if their ability as parents being in control of situations, was turned into a negative. By showing they could live through these experiences, they were not offered the support that might be available for those who might give up and show they are not coping. In the middle ground there is the recognition that professionals are not fully immersed in their lives, their involvement is in professional terms. This means that they are not going to be consumed by each family's plight – they are working within constraints and to be efficient they cannot afford to absorb everyone's problems. Whereas, at the other extreme there is almost a sense of naive jealousy in that parents want the lives of these professionals, perceiving these professionals to be happy in their careers. Indeed they have careers and these parents also want careers. These professionals can go home to healthy children and live relatively 'normal' and 'happy' lives.

The reference to life and the reality of their life being intolerable, horrible and something the parent would not wish on anyone was echoed, albeit in different terms across the interviews. Living with the knowledge that their child will most probably die in childhood was reported to sometimes cause physical pain, the sense of loss was felt so strongly.

> When I think of when the end comes… and we don't have her anymore
> oh I feel sick, I feel this indescribable pain and it is a physical pain
> (Kerry).

Still, there was said to be little time to ruminate on what will become of these children as their lives were so very busy. The everyday practicalities and random emergencies were exhausting and as such, enjoyment in life was said to now be only child focused. In that, a slight remission would be something to celebrate as would a smile, anything that signalled a fraction of hope and recognition that all their efforts were not for nothing. However, life was perceived as horrible and intolerable. Parents would long for a less

stressful life but there was cruelty experienced in knowing that life would only change or take a different route once the child has died.

> I get so fed up of living like this and then I have to give myself a good talking to… life is difficult but at least I have still got him (Maria).

6.3.2 Parent-professional relations

Parents described instances whereby professionals had lacked the communication skills to aid parental understanding in terms of disease trajectories. Professionals were reported to give insufficient time to families to ensure their understanding of their child's condition, treatment options and decisions, for example:

> We got a flow chart for every drug that she's on… and at the beginning we were told what each drug would do, we were told, we didn't have to read it… you take it in better when you're told, this is what's going to happen with this drug, this is what's going to happen with that… and then when you've got a second flow chart, we looked at it as if we were daft and there's no one there to tell you, there's no one is there? They haven't got the time, if there was someone to say this is what it's for and this is what's going to happen, but there isn't… you get support for the first sort of month and then that's it again (Dawn).

In terms of medication, these parents valued the chart but the chart only had meaning to them because they had the memory of the professionals talking them through the chart and explaining the characteristics of each drug. To then be given a subsequent chart with no additional verbal guidance was alien to them – the chart had no meaningful use, as without medical explanation, it could not be understood. A related issue was how some parents' claimed that the language used by some doctors also makes it difficult for them to absorb information and indeed fully understand the content of consultations. Some parents said that they have actively engaged in learning medical terminology to try and effectively communicate and understand the full content of consultations. Very few

professionals were reported to be able to engage in layman terms, in other words able to simplify medical terminology and procedures using more familiar words for the general public. As highlighted earlier, a few parents also commented that some doctors prioritize the mechanics and biology of the child's condition and ignore the consequent effects of the condition and its treatment on other aspects of the child's persona and the well being of other family members. Indeed, the lack of time afforded to parents and the lack of staff resources and skill has left parents in difficult situations. Often they have found themselves unable to understand the purpose or nature of their child's treatment and surgery for which they may have consented, for example:

> And also as well that, like the information they give you, I don't know whether it's just… the problem is when you've got a sick child… you're obviously worried about them and you don't always take in what they say … and hmm… and they just sort of assume that you've understood it all and I came out of hospital… when she'd had her first operation thinking she'd had (a particular operation)… she's actually got a scar here… like a, they call it a smiley face… and, I said to (husband) well how come they've done (a particular operation) if they've, if she's only got a scar down her side, how've they got into (organ) from side? And he says she hasn't had (a particular operation) and I, I felt really stupid because I thought she had (Catherine).

This excerpt highlights a number of practical ethical issues, in that the parent had not realised what she had consented to. It signifies the need for professionals to repeatedly discuss procedures/situations with parents to confirm their understanding. I can relate myself to being worried about something or tired and as a result have not been able to take in what is said about issues related or separate to such. I can trace situations whereby I have been in deep thought about something and so have not had full concentration on whatever else was happening at the time, resulting in me being told I had agreed to meetings I later did not attend for example. However, was I to be reminded of such facts prior to their enactment – on a different day my attention may be open to remembering

such. Hence, the need for professionals to be very repetitive and use layman speak with these parents.

However, despite the conflicts parents had with certain professionals, they stated that to provide their children with a good quality of life, they tried their best to maintain good relations with professionals. They realised that to receive many services or associated needs; key professionals were instrumental in assisting with decision-making processes. Still, parents' reported a number of instances where they had felt that professionals had not acknowledged their concerns. This had led to some parents' feeling inadequate and upset in that they felt their own opinions, views and experiences were not valued, as illustrated below:

> I knew that this particular drug was not suiting her… I wanted her to be tried on this other that had been mentioned a few weeks previous… anyway they kept her on this one and it wasn't until the tests they did showed she wasn't responding well, that they moved her on to this here other stuff… I was annoyed on that they didn't listen to us and listen to us saying we know our child, we know this isn't working (Lawrence).

It appeared to be commonplace, that professionals did not always acknowledge parental concern. Maybe this is a result of some parents being overprotective or unreasonable. However, parents cited having to shout to try and make professionals listen and to repeatedly do so. Indeed, a number of parents talked about fighting for statutory provision.

For many parents the hard work and demands of their life lead them to struggle to achieve a level of emotional balance. Keeping a balance involved trying to avoid ruminating on the emotional impact of the child's situation and the possible future. These parents described lives where they never stopped; they were always running from one task to another, often neglecting their own basic needs. It was almost felt if they had

stopped, the full realisation of the situation they were in would be too much to bear – as discussed earlier in terms of the physical pain felt when thoughts home in on this.

However, almost half of the parents interviewed commented that no professional had ever asked them about their needs. As a result, parents understood the professional concern to be directed only towards their child. In some cases, parents had had the opportunity to express their needs to health or social care professionals but were told that services available could not necessarily provide solutions. This had lead to the following comments:

> There's nothing, you get nothing at home, once you leave that ward…
> nothing, you're on your own basically (Bronwin).

> We need someone to consider the parents of these children that are like
> this twenty four hours a day, that don't come into anybody's bracket
> (Mary).

There appears to be a cry for services to start recognising the needs of these children and their families who do not fit neatly into a given service patient/client acceptance criteria. To feel alone is a difficult place to be, one may struggle to survive or give up because of a lack of confidence in ability or a lack of drive to care because no one else seems to.

Current respite service provision is perceived by parents to be reliant on their own consciences. Parents' reported that the current respite system is unable to cope with providing the care that all families need. As a result the health of many family units are perhaps at risk, which parents argue in the long run will not be cost effective, for example:

> And it just seems a little bit more of a pity for the health authority to turn
> round and say we are not having this funding when the end result will be
> two very damaged adults (Mick).

Professional attempts are reported by parents to encourage families to seek input from the voluntary sector, to complement services that are offered through statutory provision. However, two parents claimed that they had received no assistance or support and to date had not received any information from any professional regarding voluntary sector assistance. It appears that family's fare better if they are part of a parent support network where there is a sharing of information. However, where there are families that do not socialise with other like parents through hospice visits or as a result of acute admission, such families are very isolated and at risk of really struggling both practically and mentally. As stated in the above excerpt the mental struggle involved in just trying to achieve funding to meet basic needs is exhausting and can result in parents being affected and perhaps requiring health service funding to meet their resultant needs.

Indeed, many parents reported almost always having to endure a degree of conflict with professionals to be allocated respite services. The following excerpt highlights the major gaps in respite service provision:

> The only respite that I get, and it's not local, is the hospice… about
> three times a year… it is wonderful… yes…we go for four nights. The
> big school holiday is the problem… so we try to get a week away and a
> week at the hospice if we can… break it up, but it does get very hard
> (Lindsay).

Four nights, three times a year is little respite, yet this family received the most time at the hospice of all the participants. Some actually did not receive any hospice care. To think these parents have labour intensive duties over twenty four hours a day, having just twelve days break is minimal. Many families have had charity assistance, although most had found out about these organisations through peers. All parents interviewed perceived that there is inadequate funding for respite care both in and away from home. Parents reported provision and staffing to be limited, which was claimed to place the contact professional in an awkward position. Indeed, most parents interviewed had spent some time without any assistance, unaware of any respite services available to them:

We do now [have respite]… for a long time we didn't… and we are in a position now where we are receiving a small amount of care, more than we have ever had but we did really need it in the early years and there was nothing there… apart from when she started going to the child development centre, she was eighteen months old when she started going there… for two mornings a week… and that's the only kind of break… that I got (Laura).

Laura talks about how she would have benefited from more assistance in 'the early years'. Having no break takes its strain and having no one to pick up on this need or in not knowing that she could have maybe sought out some respite care meant that she had to learn to live without support. Looking back the family managed but Laura can reminisce over how life might have been easier with some help.

Most parents spoke of being admitted to hospital for acute care, complex procedures or surgical operations. In general, inpatient care was viewed to be for treatment purposes. However, inpatient care was said to be used as a respite facility for children with challenging behaviour, as the following excerpt indicates:

It makes you suicidal, I mean I said 'I'm going to kill myself' and he said 'what about the kids' and I said 'I'm going to kill them first', because I said 'I can't leave them with you lot because you can't even give me any help'… and then they said I was unstable, I says 'well you don't give me any help'… I don't get any help, it's when it gets that bad, so they took him in to hospital… and they said they were going to monitor him and assess him and all this… and they put him asleep half seven eight o'clock, because he was disrupting other kids on the ward because they put him on a normal ward… so I says 'well what good's that, you're not seeing what he's like twenty four hours a day'… 'So how can you assess him?'… so that went nowhere, I got nothing else off that …and that was only time I've had respite (Mary).

Desperation obviously led Mary to seek help from the professionals involved in the care of her child. Having had no respite due to there being none in the area for children with challenging behaviour and having no one listen to her pleas for help; Mary had to resort to exposing her desperation. Unfortunately, she felt let down in the care the hospital gave her child. She thought that if the hospital staff were to experience her child for just one day, they would realise how difficult things were at home, her being able to care for her child with no break. Instead, the staff gave him medication that she herself feels is cruel to administer.

As mentioned previously, for all parents the intense caring needed for these children was difficult and reported to be exhausting. In accordance, school holidays were perceived to be a big problem for parents whose children normally attended school. Suddenly parents are faced with the full time care for six weeks. Lack of available home carers was reported by parents, which meant that extra care hours cannot always be provided. This meant that parents would expect to incur very practical difficulties in the school holiday periods, for example:

> Because even though you have got equipment and hoists and that sort
> of thing… to physically put him in a sling is quite hard by itself…you
> know and then sort of like your hoist is on the bed and turning him,
> putting clothes on him is difficult (Faye).

Where there is no package of care to replace that which a child receives whilst in school parents are left to try and manage a situation that could be detrimental to their own health. Where there are lifting and handling issues, the parent had no choice but to try and continue with their child's care needs even if it was considered risky. Further to this, when there is no school and no additional provision implemented in school holiday periods, it may take a while for parents to readjust to their child's full care routine, thus increasing the risk for parental stress and upset.

6.4 Trying to maintain a life balance

Parents explained how they had had to revaluate their lives on knowing their child had a LLC. They began to prioritise activities and their time so that they could focus attention on their child. Often, LLCs and related health care procedures had meant that parents had to cease full time employment. Furthermore, they had had to reduce social life activities that they maybe had enjoyed and engaged in previously.

6.4.1 Social life and employment

Having a child with a LLC had brought new focuses that were centred on providing a good quality of life for the ill child, and this usually had meant neglecting their previous hopes and aspirations in terms of their families' and their own future, for example:

> I had wanted to go for promotion at work before all this happened… I haven't… I'm not wanting to spend anymore time at work than I have to, my time is with my child now… never mind going shooting or putting in a few more hours here and there… I want to enjoy the time we have got together (Lawrence).

Life has taken a different turn for these parents, than that which they had thought. Not a turn that could be forecast but a turn that now required time for parents to reprioritise the important things in their lives. This includes putting less attention on work and enjoyable past times and more attention on enjoying their children.

Few parents have room for a social life. Those who do, tend to socialise with new found friends rather than those they were close to prior to their child's illness or diagnosis. These new found friends can sympathise with these parents and understand their lives and constraints because they too have a child with a LLC. Often parents will befriend other parents through attending the same clinics, being on the same wards with their children or being at the hospice at the same time. Others may have made friends through support networks, for example through charities and related virtual message boards that enable parents with children with similar needs to converse. This had meant that the

parents of some children, especially those with the rarer genetic conditions, had made friends from different countries around the world. Often just receiving an email from another parent who had had a bad day made these parents realise they were not alone and they could find strength to support each other and remain positive.

> A lot of the time you can end up feeling very alone in the world… it is
> hard to keep up the will some of the time… having another mum to talk
> to has helped though… I log on sometimes in the middle of the night
> and she might be up having a bad night too or I can get all my
> frustrations down in an email and her do the same with me… it helps
> talking to someone who knows what it's like (Chloe).

There is comfort in knowing others are experiencing similar lives, it serves almost to make parents life styles seem more 'normal'. It was acknowledge that only other parents could really know what life was like.

It appeared that only in the presumed terminal phase would there be additional support offered via care agencies and a hospice community service. This sometimes included night sitters or sitters who would, for a few hours, be able to spend time holding the child and reading them stories. Interestingly, even when there was this support given few parents chose to leave their home in this time. They took this time as rest but remained to have a watchful eye over proceedings.

> I suppose I could leave her to hold him but I need to make sure
> everything is done ok, that he is not uncomfortable and that I am here if
> anything crucial happens (Clare).

Having trust in professionals entering their home was something that developed over time. Parents would not immediately leave their child in the care of others. This often meant that parents would only feel comfortable in leaving their child at night time with other relatives whom they knew would be quick to contact them in an emergency. Such

time was relished and parents talked of visiting the cinema or having a quick meal on the odd occasion.

Employment is also an issue for all of these parents. Many mothers have had to give up work because of their child's care needs. For those mothers who do still work they have flexible working arrangements or work within school hours. Further complications are said to arise if there are siblings. In such instances, fathers have found that they have to work many more hours to meet family expenditure or cut their hours to meet the needs of siblings. In some cases, fathers too have had to give up work because of the care/treatment needs of their child, for example:

> Well yes I work an hour a night (laughs) and I work on Sundays, I just do, I do some cleaning with a friend on an evening… I just clean a day nursery for an hour on an evening and I work at a local shop for four hours on a Sunday and that's my break… going to work, my husband's not working, he gave up work quite a long time ago and I got made redundant and then… I looked after and nursed his mum when she died and then his dad and then we had (sibling) and just going back to work is not a possibility… at the moment because I can't drive, ideally (husband) would go to work and I would look after the kids, (child) now is eight and I'm four foot eleven and nine stone, he's four foot four and he's five stone, I can't do it on my own any more (Haley).

Having a child with a LLC does not make these parents immune from other family issues and demands. Often trying to meet the needs of other family members, including siblings, alongside caring for the child with the LLC impacts on both parent's ability to engage in paid employment. Haley talks about finding respite in the few hours she goes to work, almost as if work has turned into a social activity for her. She herself labels her time working as a 'break'. Just having a few hours out of the heavy routine at home seems to lift her spirits. In contrast, Haley talks about her husband and how, although he would like a job, he is confined to their home. This is because their child needs to be lifted and

is too heavy for one person. Therefore, Haley needs the help of her husband to manage their son's care. Furthermore, parents report that they want to spend all the time they have with their sick child. This is sometimes difficult to achieve because of two reasons. Firstly, the financial implications – often if there is a way for parents to work this is needed so that they can meet the costs of care and equipment. Secondly, for some parents they can be at conflict with themselves regarding work. In one respect they want to dedicate their time to their child and in another respect they need time out and to leave work would also be an emotional wrench. Many of the parents interviewed were well educated and had established good careers, and so, to actually come to terms with leaving employment was difficult. For those parents who had given up employment, they reported to be more eligible than parents still working for funding and benefits. However, they did suffer worries with regard to the future and their ability and skill to return to their previous type and level of work.

Financially, having a child with a LLC has a great impact. Although many of the families had received assistance with funding for equipment and benefits, they still felt awkward and belittled with the constant 'fighting' they felt they had to do to receive any help, for example:

> We did have a little bit of trouble with the wheel chair and the pram, because he needed the wheelchair in school, they were taking the pram off us (James).

Equipment for these children was reported by parents to be very expensive and that not everything is provided. This leads to a lot of parents incurring financial difficulties. In addition, the parents who still manage to work reported to feel penalised, having to contribute large sums of money due to the means testing arrangements of funding applications.

6.5 Feeling responsible for others

Feeling responsible for everyone and everything was a common theme that permeated all interviews. Parents discussed occasions where they had forced themselves to try and fit more events in a day than was possible, in order to try and keep every one happy, to try and avoid a feeling of failure and failing others.

6.5.1 Sibling care

Also, there were many concerns surrounding sibling care and the lack of provision in place to help families.

> It is difficult to stretch yourself… I tell family 'look I can't do that really' but they do not always understand so I end up running around a lot… My eldest can sometimes feel left out so I try and make sure we have time to go shopping once a month and that I can have some time chatting about girls things… she is sensible but she needs her mum too and it is hard to be there for her as much as she needs me… services don't really think about this, the fact that we might want time out to be able to look after our other children better (Catherine).

Most parents with other children were aware of the current and potential struggles that face siblings who have to cope with their reactions to having a sick brother or sister. Most families have tried to normalise behaviours associated with their sick child's condition, such as the administering of medications and so on, but expressed worry about the psychological impact on their other children.

The following participant conveys her worries regarding her daughter's ability to cope with having a sick brother and her future worries in the event of her son's death:

> Actually, I wouldn't mind seeing a… you know a Psychologist on an odd occasion really for like support, well not support really, but advice for like with (sibling), because it is really difficult to… you know it is hard to

assess what understanding children have and what they are taking in and what they're not… and their reactions, you know and whether we are doing… the right thing with regard to what you are telling them… because you know it is very hard for her because she knows, you know, what is going to happen to (child) and also we lost both my parents over the last six years as well, which was quite… you know, it was quite a blow really because you know, they were supportive, they were close by and… Although (sibling) was only a baby when my Mum died, but my Dad he could see her more or less every day and… you know, that had a massive impact on her. You have only to talk about him now and she, you know, ends up in tears and so she has had a lot on her plate, you know (Clare).

Clare is acknowledging her daughter's struggles with the situation and worries she is already making the connection between her grandparents dying and how her brother will soon die. This situation is very traumatic as the nature of Clare's son's condition has meant a deterioration from a seemingly well and healthy child to a child who cannot function to do anything without assistance. This would be difficult for a sibling to understand and it is understandable that Clare worries about how her daughter will deal with her son's death. Indeed, most parents' reported that they felt siblings would perhaps benefit from direct therapy and parents would benefit from advice regarding issues such as prognosis disclosure to siblings.

6.5.2 Open communication

A number of parents expressed that their families would benefit from advice regarding issues such as prognosis disclosure to the sick child, for example:

Yes I mean we have never actually openly talked about the… what will happen ultimately, but I think he knows, you know… but it's sort of unspoken that sort of thing… what do we say to him? We are not sure and nobody has helped us with it (Lindsay).

Many parents' reported feeling uneasy at the thought of communicating openly with their child about prognosis. Some children had difficulty in communicating but appeared to understand what was being said to them. Others appeared to no longer have any capacity to communicate so it was unclear to their parents what they should do in terms of communication. For other children, who were still active and could communicate verbally there was still the difficulty of knowing what to say and to what extent the truth should be told or compromised if they asked very direct questions. For example, where children had knowledge of other similar children dying there had been comments as to whether they were facing the same fate. Parents had directed such communication down different avenues as they did not know what to say for the best.

6.5.3 Disrupted family functioning

Because there is so much for parents to think about and do they often focus less attention on themselves and their close marital relationships. Sometimes 'letting off steam' and releasing the stress of their responsibility was directed towards partners in temper and arguments:

> If I have had a really bad day… my instinct when he [husband] comes in is attack, I need to scream at somebody and he knows, he does… but it does not make for a good relationship (Bronwin).

Over time this repeated behaviour had lead to some couples getting to a point of mutual realisation that they needed to start sharing the burden more:

> Then as he got more ill and needing constant care, I said well, he will just have to sleep with me… so when he was small it was ok because the three of us could get in, now we cannot so (husband) has to sleep in the spare bed and occasionally he will relieve me and he will let me get a couple of hours, you know when I get really tired. But he needs his sleep because he has got to work you see… it is a huge problem for us, but there is nobody that can come in and give us the rest we need (Clare).

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Clare commented that living in such a way was not healthy, sleeping with her child and having broken sleep each night was exhausting. Whilst interviewing Clare I was at first unaware that her sick child was in our presence. It was only once he started choking, that Clare had to spring up out of her seat to suction his throat, that I realised he was there. She explained how she had to do this quickly to prevent him actually choking to death and as such I sat wondering how she ever manages to sleep with such worry.

Parents of children with LLCs have their way of life taken over by medical interventions, appointments, care tasks, holistic concerns and fights for better assistance. These combined stresses have been found to affect marital relationships, for example:

> I get fed up of fighting, I get fed up of having to prove a point we have to cope with it, all parents of these children, we have to do it because we've no choice... I mean that's why he left me, he couldn't cope with it all (Mary).

The daily workings of the family unit are disrupted by the health and social care needs of the sick child. Indeed, parents reported ways in which their family's previous routine had been forced to change due to the lack of support from health and social care services. As indicated by most of the parents, all family members have had to learn to adjust to the change of priorities, for example:

> I don't have time for anyone else it's as simple as that (Adele).

And,

> And I feel dead guilty because when you've got a child like (child) and you've got grandchildren, they miss out because all your time is taken up (Lindsay).

Parents talk as if life choices have been taken away from them. Using symbolism - their paths through the woods have now been set and they have to fight through the brambles

to negotiate any slight deviations. Even though the paths are set, these paths are not in straight lines, there are unexpected twists and turns.

6.6 Psychological effects

A number of psychological effects were reported or interpreted through these parents interviews. These appeared to stem from the overwhelming care demands and fears for the future.

6.6.1 Social withdrawal

Participants described how work had previously been an important part of their lives and identity. As caring demands had increased, it had become necessary for these parents to leave their workplace to care full time for their child. Such decisions had been felt to be enforced indicating a further loss of control over their own lives. Still, to maintain their identity it was as if all their energies were now focused on succeeding in caring and protecting and fighting for their child. Parents felt threatened but they were not going to loose their strong and able character, albeit that it was now focused down a different path:

> I used to manage a team of six workers, now I'm using similar skills to
> try and co-ordinate care and funding applications (Rachael).

However, as touched upon previously, over time it appears that the lifestyle of these parents necessitates a gradual cutting off from the outside world socially. Complications are reported by parents to arise from the ignorance of outsiders, for example:

> I don't know if you've been to Butlins but there's glass doors and there
> were loads of kids all stood round watching her and I just said I don't need
> this and I shut the curtains… it puts you off does that (Stephanie).

> His physical appearance affects him because of the reaction of other
> people… he's very conscious, and you go out and he knows if somebody
> is looking at him without them all commenting (Chloe).

The reported goal of all the parents interviewed is to try and achieve as normal a life as possible for their child. The negative perceptions of others as exemplified above, provides further barriers for these parents to overcome. Further, the difficulty in losing common interests with social companions has meant letting go and moving on to new ways of being:

> Our social life, I mean. I think people underestimate the impact that it has on your life, you are constricted in every way, in every sense of the word, you know, you are not able to go out, you are not able to function as a normal family. Your interactions with other people change, your social life… it finishes (Clare).

In a few of the interviews it was noted that parents had made a conscious decision to withdraw themselves from the social world. This effort was perceived to enable them to be able to care for their child better because their actions were in the best interests of their child. Others were accepting of their situation. However, whilst acknowledging that to manage the care needs of their child they had to withdraw from their 'ordinary' lifestyle, parents were annoyed at the lack of acknowledgement received. This intense focus on care duties made these parents also at risk of neglecting the warning signs of over exertion. Withdrawing socially from comforting activities, which had previously shaped their character had made them isolated and part of 'the inner circle'. This inner circle was occupied by those only who had similar experiences or were able to connect with their way of being. This meant friendships were valued with other families with children with LLCs and parents also strived to have less formal connections with the professionals that were now involved in their lives on a regular basis. Parents found increasingly, that if they communicated with people outside the family network, often, it would be another parent of a child with a life-limiting illness, the subject of the conversations being care related. This also helped parents to mentally normalise their behaviour and ways of life.

Most of the parents interviewed expressed the support they felt they received from their peers, for example:

> She's like me, she's got another one and like we go out and we make it so
> we get to go out for lunch and we discuss stuff together then (Stephanie).

> I'd rather mix with my special needs mates, which is quite peculiar but
> they do, the thing is if you're a special needs mum you just understand
> what it's like (Rachael).

This final excerpt is very poignant. Many parents' highlighted that perhaps no matter how far someone may try and educate themselves about children with 'special needs', only those who experience it really know what it is like and can empathise with regard to the highs and lows. But given the fact that their peers were going through similar struggles and stresses, it made it more difficult for these parents to recognise times where they really needed to rest and 'shoulder the load'. Indeed, a few of the parents interviewed explained how they had had times where they had been depressed. Low mood was something that was a particular issue shortly after diagnosis, but with time most parents had adapted to their current way of being. The general lack of control parents held over their situation was a source of deep upset:

> Now (child) could not wish for a better daddy, he is absolutely brilliant
> with him, but the first few years were hard for (husband) coming round
> to accepting 'this is my son, this is how it is going to be and there is
> nothing we can do about it'. That he could not cope with (Haley).

6.6.2 Depression, anxiety and fears for the future

Where there had been periods of child health deterioration however, some parents confessed that they had needed medical intervention to get them through. Not having the support to have time out had made them feel overloaded. Others explained that they refused to get depressed as if it was something they could control. They talked about all their worries and efforts being worthwhile in order to keep their child as comfortable and as 'well' as possible.

For some parents, no matter how exhausted they were, they had no vision of discontinuing their role as this was not a given choice. Life had become a set of duties that could not be reorganised irrespective of the prospect of a future emotional breakdown. Parents had spent hours, days and weeks fighting with the healthcare system and letting their energies be drained by it. Now, they continued their fight but were realistic in understanding the powers professionals had in light of the lack of available service provision. They had come to the understanding that they held the burden, no one cared as they do and no one is available like they are, for example:

> Because some of the things, I mean its only through living with him that you can spot the things, some of the things like I take him into hospital and I say I think his bloods are out because he has been vomiting and they say 'oh he looks fine to me' and he does look fine and then you take his bloods and they are completely all over the place, but its so difficult to spot unless you are watching him all the time, unless you know him really really well you just won't see it (Gina).

Parents openly discussed psychological manifestations and distress. Anxiety around new procedures was commonplace. Parents were hesitant to cause suffering to their child if it was unnecessary. They are caught within a paradox of wanting their child's life to be as long as possible but not wanting to accept treatments that will cause suffering in the short lives their children have. I can relate to this as I have had adult family members who have received palliative treatment, for example to lower levels of pain. However, these treatments were found to have side effects and with hindsight my family members may have chosen not to go ahead with such procedures. It was very difficult for parents to decide on palliative treatments for their children. They have the worry about doing the best thing and the anxiety of not knowing whether they had made the right decision if further but different suffering was then experienced. Privately dealing with managing this conflict and the general stressors of their lives was difficult and as stated earlier, frustrations were often vented towards partners.

Furthermore, emotional distress was evident when parents recounted events and discussed their worries in relation to anticipating the grief and future loss of their child. A common theme was that psychological support was provided at crisis points, rather than providing guidance from the beginning and throughout the child's illness. The excerpt below details a parent's worry over her son and his well-being:

> All them kids go through hell… and they get depressed, they get fed up… and withdrawn and (child) did just before Christmas and I did shout and scream about it if you know, his, his morale is so low it got to the point where he was questioning… his (major treatment) because he felt so poorly and in the end they decided to put him on antidepressants and they brought, I asked them to fetch the child psychologist in… bless him he's a lovely man but he just, he [the psychologist] can't split himself like he needs to… that's something else that's never… looked at as part of his, you know the treatment and his care it's not looked at, I mean if parents can get depressed and they're not going through the treatment… a lot of them have been at it years and years they must get… it's got to point where (child) is getting crafty with his tablets and if I don't watch him, he'll throw them away, he'll pour them down the sink, he's done it in hospital, he's been caught doing it (Maria).

There were also parents who commented upon past psychological input to help them deal with frustrations with their child's illness and in coping with the degeneration:

> **Mark:** You've had to go a couple of times haven't you? [to local mental health hospital]
>
> **Faye:** (laughs) yes, that was a big dip, a big dip… I was over there… about ten days… I'm his mum and I'm only human… I mean as well, it's like what another mother said to me at (Hospice), she's got a little girl with even more medical problems than (child) and she said to me 'when I was growing up I never wanted to be a nurse'.

'Growing up I never wanted to be a nurse' is a very telling phrase. These parents are nurses for their children. Yet of the twenty parent interviews, seventeen claimed they had received no formal counselling in any form, for example:

> We've never been offered any support, never, no, we've just got on with things, we've never been given the chance to have counselling if we had have needed it… sometimes I've wondered about having it… we were just told that he'd got this horrible condition, it were explained to us, that he might only live till whatever age and then we were left to come home and deal with it and that were it (Chloe).

This group of parents are almost like a forgotten group of patients. They get on with caring for their children and their efforts are not recognised. Unless they hit crisis point, psychological services are not concerned with their being.

6.7 Fear of reaching the bottom line

Stress with having to wait for interventions, the signaling of a lack of communication between and with professionals all add to the fear of reaching the 'bottom line'.

6.7.1 Communication with others

James (quoted below) details how having to wait for treatment caused so much stress that he felt it may have affected his ability to attend the unit again in a peaceful manner:

> I mean it's bad enough if you've got to wait for a straightforward operation, but not when you're on chemotherapy, you shouldn't even have to be warned that you might have to go home… I mean having a sick child for five hours on your lap in a corridor, it's not right… it's shocking, it's something you see on tele in third world countries (James).

Many parents reported feeling unsupported by professionals with regard to their own emotions. Parents described difficult experiences they had endured without a professional asking them if they needed support in any form. The following excerpts identify family experiences where little or no communication was initiated, although parents felt it was needed:

> There is nobody there to tell you how you are supposed to feel… there is nobody there to tell you that these feelings are normal or it is allowed for you to feel like this (Haley).

> **Dee:** He says there's no easy way to tell you this he says he's got
> **James:** And that were basically it… you know, they told us if you want you can stay in this room as long as you want, the phone's there if you want to ring anybody, other than that nothing really
> **Dee:** We'd just found out what were wrong with him, he's laid on bed, I'm sat there just crying me eyes out and nobody came near me… he wanted to know why I were crying and… he's still vomiting and all I'm thinking was… and they all just stood there and not, not helping me.

However, some of the parents interviewed did feel that they had received a level of good support regarding end of life issues, which was found to be readily accessible from certain sources, for example:

> Well (Hospice), they keep in close contact with us don't they, it's not just a children's Hospice they're there for us as well, you know I can ring them twenty four hours a day (Belinda).

6.7.2 Struggling to cope and facing the future

All participants described how in various ways they had at different times almost reached emotional breakdown. They discussed the endlessness of the inner pain and fight, which at times had got so severe that it had made them want to let go and break down:

> I mean I have done it a few times I have really thought all I need to do is kill us all, it would be finished… and nobody would have to look after us and I am not leaving any pressure on anybody else, it is a sad way to look at life but that is the way it makes you feel (Mary).

Parents' search for meaning was evident in questions such as 'why did it happen?' Many parents indirectly expressed their need to understand, try and predict, and control their family situation. Such mental reasoning gave parents a sense of meaning, assisting with their ability to cope with the situations they find themselves in. It was evident in some of the interviews that parents were managing to cope with what was happening to their child by focusing on their child's positive attributes, for example:

> Because she was very bright, we knew she had a lot of physical difficulties … but she was always very bright and alert so we were kind of hopeful that you know things would turn out alright so you know it did come as a bit of a shock (Laura).

Some parents are also able to cope by feeling that they are minimising any threats to their child, this may be in relation to wanting full control of medications, complying with all treatment options or exerting all efforts to protect their child. Some parents also provided examples of how their determination and perseverance resolved situations, for example:

> Yes we have become quite expert at presenting cases… yes it's things you learn as you go on, so I suppose on a positive note you do collect a lot of skills yourself along the way (Laura).

Once parents stop this struggle, they make themselves susceptible to the emotional decline.

> I need rest at present… I am talking in terms of time to rest to the point where we are rested… to get enough energy together to restart a social life … you know to actually see people that are not there as family or my family, to actually re-introduce ourselves to our friends… all around rest at the moment, I can't see any further than rest. I am sure there are lots of other needs but the priority at the moment is getting enough rest… last time I worked, I worked thirty six and a quarter hours, a standard week, and last weekend I was desperately trying to alleviate some of the work for Gina [wife] which I am not very successful at because at this stage of the pregnancy she should not really be… but we worked it out and I did thirty four and a half hours out of the forty eight which is a weekend and it is longer than a working week and that is just a weekend and you know you do it because you have to do it and there is no other way of… you could not live with yourself and I think this is the worst thing… that it is really left down to your own conscience and I do not think any person could turn their back on a child that needs… and not live with themselves then afterwards (Mick).

Many parents did not deny their child's illness but instead focused on more of a positive outlook or outcome, for example:

> Socially really it does affect her, that she has no speech, I think that is the biggest, the biggest social problem, although no she doesn't have social problems, she's a very sociable little girl (laughs) but that is the biggest bar (Laura).

> So we're lucky that he didn't die and everything, that he survived but, he is very badly disabled (Adele).

> We find ourselves lucky because we've got friends over there… a couple
>
> there and that, their poor son like he couldn't be operated (James).

The fact that these parents are able to find happiness in their lives and see that other families are in worse situations is a credit to their strength of characters. Each parent spoke vividly of their life, their child's condition and its impact. As a result, I have a lot of respect for these parents as they make life special for their children. They begin by compromising their happiness in stopping employment and previous activities. Their lives are difficult but enriched by their efforts and time spent with their dying children who are loved more than words can convey. These parents make real the phrase that people will do anything for love.

6.8 Discussion

The lived experience of parenting a child with a LLC has many dimensions as exemplified by the given thematic analysis. In the case of a child with a LLC, the whole family has the difficult task of trying to adjust to a situation which is dominated by the stresses of long lasting uncertainty and uncontrollability (Patenaude and Last 2001). This Being is one of feeling trapped, with an endless list of demanding challenges. However, where there is a hope in achieving a healthy balance of tasks, and where there is sufficient expert assistance or social support, the parent can continue comfortably in their caring role and be enriched by the experience. As illustrated in other studies, the pivotal role played by health professionals is critical to parents in coming to terms with their child's diagnosis, prognosis and associated health needs (Callery & Smith 1991, Casey 1995, Coyne 1997).

Parents struggle to meet the responsibilities they feel they have towards their ill child, to other family members, friends and work. As documented in the literature, parents may focus on the ill child to the exclusion of virtually everything else, including their relationships with each other, extended family, and friends (Gravelle 1997). Stein *et al* (1989) and Stein and Woolley (1990) discovered that families of children with a LLC had no time for social and leisure activities. It was also expressed in the current study that

parents were unable to do anything as a couple or as a family because all their focus was on the ill child who was unable to engage in 'normal' everyday activities. As a result, difficulties such as marital discord, sibling rivalry, inattention to other children, and loss of relationships with extended family and friends were reported here to often result. Interestingly, marital difficulties have been reported by other researchers who have investigated the impact of childhood chronic illness on family life (Thoma, Hockenberry-Eaton & Kemp 1993, Whyte 1992).

The parents' Being as individuals with their own wants and needs is threatened. Cutting themselves off from social activities and striving to get the best healthcare and support for their child leads to them neglecting their own essential needs, resulting in energy drain, as well as feelings of guilt towards oneself, family and others. In accordance, Baldwin & Carlisle (1994) revealed that mothers faced with such daily routines of care can become isolated, with considerably restricted social lives. Emerging psychological manifestations and overwhelming fatigue lead to a feeling of being trapped in a vicious circle; anticipating grief without a means to change any outcomes, culminating in a fear of reaching emotional breakdown or 'the bottom line', whereby they can no longer muster the emotional strength to continue with their everyday tasks.

There was a realisation that through all the struggles they face, there were times where emotional breakdown was in view. In these times parents needed to accept that they could not be all to everyone, they needed to stop the mental struggle. This letting go would enable motivation to rekindle; it marked the turning of the tide and a return to being able to see their purpose, their child's needs and the positive aspects of their Being. These parents talked of their lives being enriched by their children, of their children's drive enhancing their well-being and through meeting their children's needs they realised their many skills and their strength of character. This is a world they have been thrown into, but they have adapted to and developed both physically and emotionally towards.

Therefore, this lived experience can be seen to be illuminated by six thematic areas which can be viewed as continuous constituents: inner drive, maintaining a life balance, feeling

responsible, psychological affects, social withdrawal, and fear of reaching the bottom line. Central to this lived experience is enrichment. These parents gain strength from their children, their acts and exchanges and in doing so maintain an acceptance of their world (figure 6). As Frankl (1962) conveyed, people have a psychological need to seek meaning and purpose in their lives, and this drive alone can help them to face and get through really difficult life events and experiences. Folkman (2001) has also stressed the importance of trying to find benefit in a negative experience, arguing that successful coping and positive affect are a result of 'positive reappraisal', a so called cognitive reframing of an experience to be able to view it in a more positive way.
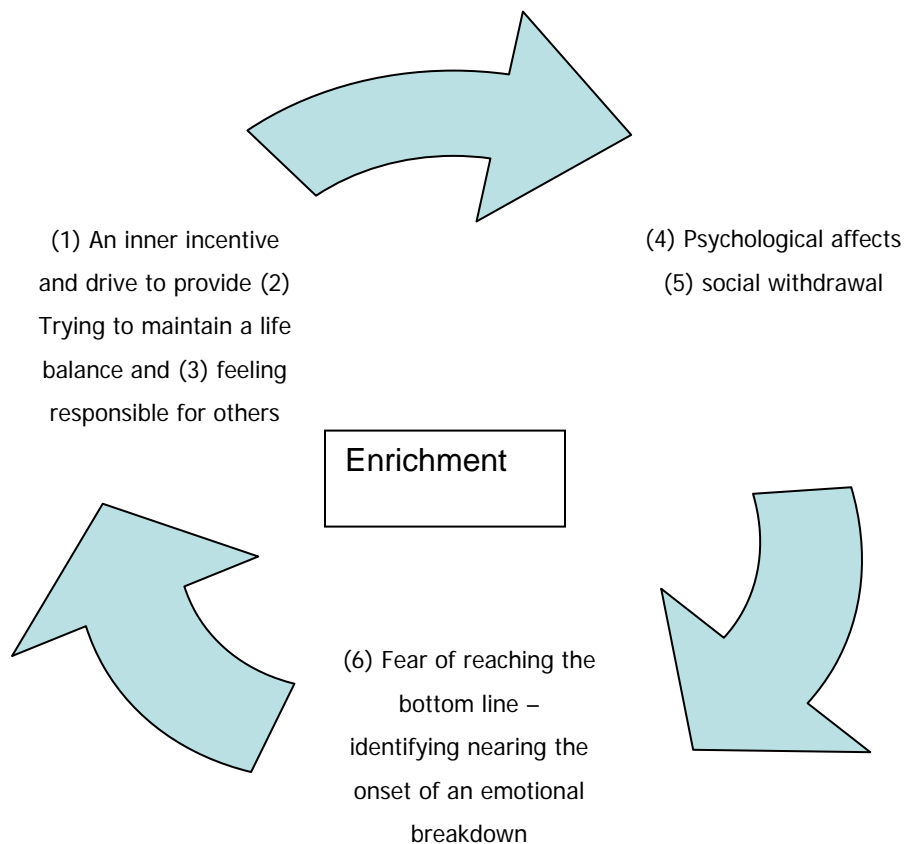
Figure 6. General structure of the lived experience of parenting a child with a LLC.

These constituents of the lived experience appear to be governed by the unique relationship that develops between parent and child to which Frank has alluded in patients and their caregivers more generally. He comments that *'the carer is the other half of the ill person'* (Frank 1995:6). As this relationship develops, the parents move away from their everyday familiar worlds and become immersed in a new shared world. A dominant aspect of this world is the vulnerability of the child, which makes them highly dependent on their parents and challenges parents to alleviate their suffering and to find ways to support them. This task is facilitated in one respect by the freedom that is inherent in a world where social conventions can be overlooked. Parents are allowed to act as they see fit, in a manner that aspires to authenticity.

Parenting a child with a LLC therefore fundamentally involves a move away from inauthentic behaviour that is governed by everyday social conventions, towards an authentic existence – governed by the reality of Being. This as indicated, is not an easy transition: the abandonment of social pretexts, conventions and norms of behaviour that stand in the way of authentic behaviour is difficult and there are bound to be lapses. For example, a lapse may be a time where parents find themselves dwelling on wanting to live alternative lifestyles. There is a need to move beyond the constraints imposed by society, and it is the parent's role to abandon these inhibitions and enter entirely into the world of parenting and caring, to immerse themselves into this world which is their child's world. In this respect parenting a child with a LLC consists of a fusion of interests. Parenting has the potential to open new directions in their life worlds, and through continual introspection in the phenomenological tradition, this process can be unending.

Chapter 7: The parent – child dyads

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This chapter presents the themes identified from an analysis of five parent-child dyads. The participants' stories represent a rich cluster of similar but disparate experiences. The themes that emerged from the descriptive commentaries reflected happiness but also the ongoing frustrations, as well as the challenges, involved with being a child with a LLC and of parenting a child with a LLC. Each parent and child was given pseudonyms. In one case the child's diagnosis is not stated as this would potentially enable the child to be identified.

7.1 Overview

At the beginning of each interview I asked each child to tell me a little bit about themselves. If the child was able to write, they were then given the opportunity to write a few lines about themselves. This was used as an ice breaker and a point of reference to discuss condition related issues throughout the interview. Sophie and Bobby were too young to be able to write down their thoughts and Peter and Amy were given the opportunity to use their own Personal Computers for this task, but both preferred to talk. Danny chose to write a few lines:

I am eleven and I have a brother and a sister. I don't go to school. I have alot of time in the hospital. We go to leeds for the treatment I'm used to it realy. I like Sausage like hot dogs but I eat what I can when I feel like it. My brother died and I miss him. My sister is annoying. My grandad is the best. I have a new cat I am having a big thing done Soon to save my life. The bone Marrow needs changing. I worry alot about my mum. Fish and chips from Kingfisher are good. Don't know what else to write. THE END.

This writing enabled me to go on and ask Danny about: his relationships with his siblings; his understanding and experiences of his condition and treatments; his relationships with his grandparents; why he worried about his mum; to gently ask about the loss of his brother, its impact and if he had thought about life after his transplant.

Similarly, all of the children provided detail of their likes, dislikes, being ill and observations of parental upset. Each child was very articulate and able to clearly describe their thoughts and experiences.

I began the parents' interviews by asking them to outline the sequence of events to date: detailing the time of diagnosis, age at diagnosis, diagnosis and how this had affected the daily lives of themselves and their child. Rich descriptions from all parents were received. They were very open about their experiences, thoughts and feelings.

Due to the differing viewpoints I wanted to obtain and because of the age ranges of the children, different interview schedules were used with different question areas. However, what was interesting to uncover was the reporting of similar incidents and the uncovering of lived experiences from the different viewpoints of the parent and child. To this end, the chapter will provide an overview of the findings.

Table 7.1 Summary of parent-child dyad analysis template.

THEMATIC AREA	THEMES
Tracing the early days	**Parental instinct** (Sandra & Bobby) **Diagnosis & its impact** (Paula & Amy), (Sandra & Bobby), (Edward & Sophie)

Interactions with professionals	**Age-related communication issues**
	 • Decision-making (Maria & Danny)
	 • Not considerate of child in consultations (Paula & Amy)
	 • Child lacks knowledge re: LLC (Sandra & Bobby)
	 Good relationship with key professionals (Gail & Peter)
	 Knowledge & uncertainty
	 • Child
	     o Lack of illness related knowledge (Paula & Amy), (Sandra & Bobby)
	     o Lack of ability to transfer knowledge to self (Gail & Peter)
	     o Desire for illness-related information (Paula & Amy), (Gail & Peter)
	     o Desire to talk about end-of-life issues (Gail & Peter)
	     o Concern for parents (Paula & Amy), (Gail & Peter), (Maria & Danny)
	     o Concern for siblings (Paula & Amy)
	 • Parent
	     o Lack of illness related knowledge (Paula & Amy), (Sandra & Bobby)
	     o Lack of ability to transfer knowledge to self (Gail & Peter)
	     o Desire for illness-related information (Paula & Amy), (Gail & Peter).
	     o Concern for siblings (Gail & Peter), (Maria & Danny), (Sandra & Bobby)
	 • Professional
	     o Lack of illness related knowledge amongst professionals in acute care (Sandra & Bobby)
	     o Lack of communication between professionals (Sandra & Bobby)

Critical incidents/life events	**Trials & tribulations**
	 • The body suit (Paula & Amy)
	 • The wheelchair (Paula & Amy)
	 • The unexpected (Sandra & Bobby)
	 Difficult times
	 • Bereavement
	     o When siblings die (Maria & Danny).
	     o When other children die (Edward & Sophie)
	     o Losing friends (Edward & Sophie)
	     o Childs concept of death (Edward & Sophie)
	 • Everyday issues
	     o Mum stops me playing(Sandra & Bobby)
	 • Pain & suffering
	     o Physical (Maria & Danny), (Edward & Sophie), (Gail & Peter).
	     o Mental (Maria & Danny), (Gail & Peter).
	     o Hospitalisation (Edward & Sophie)

THEMATIC AREA	THEMES
Issues of appearance	**Changes** • Degeneration (Gail & Peter), (Sandra & Bobby) • Losing hair (Sandra & Bobby), (Edward & Sophie) **External Prejudices** • Stares & comments (Paula & Amy), (Sandra & Bobby), (Gail & Peter) • Upset (Sandra & Bobby) • Child shelters parents (Sandra & Bobby)
Now and the future	**Changes** • Finishing work (Edward & Sophie) • Lack of social life (Gail & Peter) **Reality checks** • Prolonged disease trajectory (Maria & Danny) • Dashed hope (Maria & Danny) • Focus on negative outcomes (Maria & Danny) • The unknown (Paula & Amy) • Girlfriends (Gail & Peter) **Life is ok** • Because I was born like this (Paula & Amy) • Because it is all that is known (Maria & Danny), (Gail & Peter) **Hopes & dreams** (Paula & Amy), (Sandra & Bobby), (Edward & Sophie), (Maria & Danny), (Gail & Peter)
Integrative theme	**Protectiveness** • Truth-telling • Overprotection • Self-protection o Resiliency

Prior to outlining the emergent themes of the analysis, I will briefly provide a background to each parent/child dyad. The themes will then be discussed in terms of their relevance to each dyad. The integrative theme will be discussed in the final part of this chapter.

7.2 The Murphys: Paula and Amy

Paula and Richard have three children – Helen, Amy and Oliver. Both Helen and Amy have LLCs; however Helen is unable to communicate with words. Paula is the main carer for the children. Richard works away from home and so in the week, Paula's main source of support is her sister who lives nearby. Respite care is received for Helen. Paula is 40 years old and works part time from home. Amy is the middle child, she is 15 years old

(Helen is 17 and Oliver is 12) and she attends mainstream school. Amy has Cerebral palsy (CP). Amy suffers from seizures and has difficulty controlling her muscle coordination. Amy has Ataxic CP which means she has low muscle tone and poor coordination of movement; she looks shaky (tremor-like) when trying to perform a task, she has poor balance and is very unsteady when trying to walk.

7.2.1 Interview locations and characteristics

The downstairs of Amy's home was open plan; Paula chose to be interviewed at a time when her children were out of the home. I interviewed Paula at the dining table in the kitchen area. Amy chose to be interviewed in the lounge, with Helen laid on an adjacent sofa and mum in the kitchen preparing a meal. This lead to Helen (who also has CP) sometimes providing noise in reaction to what Amy had said or had been questioned and on occasion Amy's mum would also add comment. However, Amy was most comfortable with this arrangement and commented that she felt more at ease speaking with family members present than alone in her room. This was also thought by Paula to be a result of the untidiness of Amy's room.

(i)Tracing the early days

Being and caring for a child with a LLC involves many memorable experiences, some uplifting some upsetting. Entwined throughout these experiences are practical aspects – the delivery of care, communication, emotions, and their impact on others.

Paula was a bit nervous about being interviewed. She explained that she had had some negative experiences since the birth of her two daughters with health and social care services. She went on to explain how these services originally doubted her capacity to care for her children:

> I remember when Helen was born… she wasn't right… and yes I was
> devastated but she was my baby and no one was going to take her off
> me. I was a young mum but I was capable, but in them days things were

different and I suppose looking back their attitude was I could have had more of a life had I let someone else look after her… hmm and then with Amy, she has more ability but once I knew I did struggle with the why me? Again! I got depressed and selfish about it but again she was 'is' my baby and I wasn't going to be of any use to them moping about and feeling sorry for myself… they are beautiful children with really beautiful personalities… but the rotters wanted her off me too. In the end we had just had enough and it was agreed that if I had more family around me I would cope better and the health visitor and others were ok about things then. But I am telling you they made things so hard for me at first and if they had just been there to help and not tell me how to do everything I know the situation would have been easier for us all and I would look back now on happy times, but I can't (Paula).

Paula's husband was in the forces when the children were small and this meant she was living away from family and with minimal support from her husband. Further to this she commented that social workers and health visitors would initially assume her incapable due to looking younger than her years. In the first few years of her daughters' lives she talks about having to fight services to be able to maintain her daughters' care. Ironically, she is now in a position whereby she is living closer to extended family but has repeated struggles in trying to get help with any care:

Now the children are more grown up I feel more comfortable about letting go of their care a bit. Helen is looking towards going to college and Amy is now very independent anyway. I work from home but I'm starting to think it would help me to be able to open up a business, we would be better off really... Still, we need better advice about these colleges though and I need to know she will be ok… maybe just go for a trial run at first… but so far we have not been able to see in to that. Services are stretched and this means we end up having to wait around a lot or just trying to make do (Paula).

'Making do' seemed to be an attitude that kept occurring in the interviews with this mother and daughter.

(ii) Interactions with professionals

Healthcare relationships form a triad in paediatric care, the triad being the parent, the child and the professional(s). However the child, although involved in discussions and decisions appears to have a minimal contribution. Indeed the data pertaining to the hospitalisation of children, relates to issues of power. This is exemplified by the description of consultations, given by Amy:

> They talk to my parents and I will just sit there thinking yes I am here
> you can look at me when you are talking because actually you are
> talking about me.

Adults make decisions assuming no conflict of interest but on some occasion there is:

> My parents like to make all the decisions and they do that because they
> think they have my best interests at heart but sometimes I need them to
> just let me do what I want to do (Amy).

Amy gives the impression that she feels both the medical world and her parents are infantalising her, they are not acknowledging her maturity and ability to express her views and make her own choices. Amy is an adolescent not an adult so there will still be final treatment decisions to be made by her parents, however if Amy was to feel more included in consultations and that she had more control over her being, then she may not feel as side lined. Conversely, Paula has a different perception of consultations and Amy's level of independence from her parents:

> They are both independent girls… but Amy can be out alone and go in
> town shopping with friends and that's just like any girl of her age… and
> when she is shopping… I mean I don't worry; she's got good friends…

I know she is ok… she has been to a few parties too… I've let her…
but I've made sure I've dropped her off and picked her up but then
there were other parents doing same… with Amy I have the worries
that any mother has with any teenage daughter (Paula).

Now that Amy is getting older I think we all try and work around Amy
more… when she sees the paediatrician or the physio well then yes I am
there but they always give Amy the opportunity to talk and for her to
say what is happening and how she is going on… hmm… that has been
something they are doing more alately (Paula).

It is interesting to see that Paula felt Amy was having input to her care and the autonomy
to voice her opinions.

Linked to Amy wanting to be more involved in direct communication with professionals
were her illness related worries and her desire to protect her parents from them:

I do worry that one day I am going to have a massive fit and just die or
if it happens gradually where will I go? And how will it happen? There
is no book I can find to tell me what will happen but I'd like to know
what is possible and if I can plan for any of it. It would really upset my
mum if she thought I was thinking about things like this but it is on my
mind (Amy).

Amy had obviously been thinking a lot about potential outcomes if she had been
searching for literature on her condition and had not found anything on lifespan issues or
terminal care. It is hard to try and understand what it must be like for a fifteen year old
girl keeping these worries inside, wanting to be educated about her illness but not
wanting to cause her parents to start thinking too deeply about her requests. She is
expressing a desire privately for more knowledge and to plan the end, but I am presuming
this is not known to her parents or professionals involved in her care (at least Paula did

not touch upon this reality). Interestingly, Paula did mention at different times throughout the interview that she did not see the purpose of thinking about a negative future. This active 'blocking out' of potential outcomes could have lead to Paula denying any signals from her children to talk about lifespan issues and terminal care.

Amy's desire for further information about her condition flagged the issue that despite her maturity for her years, she did in fact lack knowledge about her illness and was uncertain about her future. I could see she was excited about becoming an adult and the responsibilities that may come with it but she was also in fear of getting ill. In this respect, she did not perceive her condition to be causing her illness at the moment but was aware that in the future things could change. Indeed, Paula made reference to not thinking about Amy becoming poorly. She sees Amy's disabilities and fights the struggles for care and equipment, but blocks out the notion that Amy has a LLC so is in fact not a 'well' child:

> Amy does brilliantly, she is just like any other teenager. I believe she
> has a bright future and I want to encourage that. I don't think it would
> help any of us to start talking about if she was to start not being well. I
> don't want to think down them lines with Amy (Paula).

It was awkward, listening to a parent of a child with a LLC talking about their child having a bright future. How could she have a bright future when her life was limited? Maybe this is rooted in our different conceptions of time. When I think of my future I think long term and maybe Paula looks at the future more in terms of her immediate years, for example in talking about family support Paula stated *'my older sister has a lot of input into this family and is happy to always be at hand'*.

(iii) Critical incidents/life events

Lessons had been learnt from past interactions with professionals and services and there were times when the family could be quite dismissive of situations whereby they had had to 'make do'. However, there were other times where this had caused really deep upset.

Two examples were cited by Paula and Amy. These were equipment related, to improve the daily lives of Amy and Helen. Paula talked about how as a mother she wanted to be at peace and know that she has tried her best for her children to give them the best quality of life she could. As Amy and Helen have grown up, Paula has realised that different equipment may give them more independence and indeed more life enjoyment. She feels that if she had ignored this knowledge, then she would have been failing her children. But, trying to get such aids to daily living meant a long process of bureaucracy and fund raising.

Amy is a very bright adolescent who talks about being hindered by her tremors and her mobility difficulties. With this in mind, both Amy and Paula have spent a lot of time researching treatments and aids to daily living. With interest they stumbled upon an Australian invention, a body suit that assisted with tremor. There were reports of fantastic results in children of various ages with developmental disabilities that had mobility difficulties. Items like this are not funded and are really expensive. Therefore, Paula and Amy knew that they would have to start fundraising again:

> The arm sleeve is very expensive so we had to do a lot of fundraising and when I grow and need another it will mean fundraising again… (Helen makes a noise and appears to laugh, I take her hand)… shut up Helen… (Helen squeezes my hand laughing)… She is laughing because I'm talking about growing and she knows I am trying to diet… Helen is naturally small but I have to work at my figure (all laugh)… so yes when I GROW, I will end up needing another one so we will have to start thinking up ideas to get some money to pay for it (Amy).

> It costs thousands but it makes such a difference to her. She can actually type when she's wearing it, which means her support assistant doesn't have to keep helping her out when she gets frustrated at not being able to hit the keys on an off day… It has given her a lot more confidence and because the tremor is less obvious when she has it on,

then she feels like she is fitting in more… the school have been very good actually… the have really helped us out and got on board with all the fundraising… they can really see a difference in her (Paula)

This is an example of a triumph in adversity. They worked as a family to find something that could help Amy and were not stopped in their tracks by formal services saying they were unable to fund it. They found strength in their purpose and the community worked together to help.

Wheelchairs are needed for most children with LLC at some point, if not throughout their illness trajectory. Children grow and develop, which necessitates different chairs and adaptations. Helen has very restricted mobility but was reported to be craving her independence. The family fund raised and purchased an electronic wheelchair via the occupational therapy services. They were really happy with the chair but there needed to be some adjustments so that Helen could operate the chair more easily herself. The family were refused further funding to adapt the chair. Out of desperation Helen's grandfather set to designing an invention that would allow Helen to operate her own chair. With success, Helen now has a chair with bits of wood and other materials attached to it so she can work the electronic controls due to her body positioning and restricted movement:

The wheelchair situation really really upset me. We waited for what seemed like forever to get it and Helen, she was so excited about getting it and then she couldn't use it. The support just wasn't enough and she tried her best but was all over the place in it and just couldn't operate it. I rang all around and explained how she couldn't use it… but no one was willing to budge and help us out, I ended up slamming the phone down on a woman. All this money and for something that would gather dust as she couldn't use it… my dad bless him thought I was going to have a breakdown over it. We both ended up in tears and Helen cried, she did cry… it took a few weeks but we have it sorted

now, it looks a bit funny but we can be creative with blankets and stuff (laughs) because we still have to consider fashion and not bringing unwanted attention really… but yes she whizzes all over the place in it… and I suppose seeing her ability to get about has made me feel a bit better about her going to college (Paula)

There are things that have caused a lot of stress. Helen's wheelchair got us all stressed out. It took ages for it coming and then it wasn't right. We thought that is it, she can't use it but granddad has seen to it so she can use it. It was a nightmare though cause I was upset about it but I got fed up of everyone getting stressed out over it and I kept thinking people just don't care (Amy).

When services are unable to meet care needs there appears to be communication breakdowns between services and families. Parents are not reassured that they can have their children's needs supported and can be left to try and work out situations in isolation. This wheelchair appears to have been instrumental to Helens independence and Paula's acceptance of Helen growing up and wanting her own space and distance from her family. These families cannot always contain their upset and in situations such as this illustrated one, all family members can be affected. My current focus is on the parent-child dyad, but 'their' experience is not just dyadic. Amy was upset by her perception of no one caring outside of her family. Was this a perception of no one caring about this situation or was it more generalised to their lives in their totality? At another point in the interview with Paula she commented: *'Nothing is automatically put in place, we do the chasing… we do the research and the asking'*. Grandad is reliable and fixed the situation, there is however an awareness in this family that those outside the family unit are not so helpful because they are not as emotionally involved in their lives.

(iv) Issues of appearance

Despite Amy's independence and her ability to attend mainstream school, she does not escape the public stares and teasing:

> I just wish that people would think a bit more about what they are doing – would they like it? No they don't cause when I stare back they turn away. Maybe that is embarrassment…. For god sake sometimes I just think get an education. Yes I might look different but I'm still a person with feelings (Amy).

> It doesn't happen in school but it does if I'm coming home from school and like when we go shopping. Everybody looks and I hear them (Amy).

> I have been teased for both the way I walk and talk in the past and because I have fitted at school. Things are OK now but I have been upset about it before. I've not always told my parents about it as they would have probably gone into school to sort it out and I didn't want it… I am over it now and I think ignoring it was best thing to do (Amy).

Paula did not really divulge any information regarding Amy being teased or discriminated against in any way because of her appearance. In a number of areas of her interview she talked about Amy being like any other fifteen year old girl. Sat on the sofa Amy did look like any other fifteen year old, but as she got up and walked into the kitchen her condition was then highlighted by her unusual walk. As human beings we are alerted to situations that are out of the ordinary. Perhaps Paula does not see this and now that Amy spends less time out with her parents and does not bring such up as an issue with her parents – then such is probably not seen as an issue by Paula. Or is it that Paula is choosing not to 'look' at this? Repeatedly, Paula appears to apply a conscious strategy to focus on the 'normal'. Several quotes included so far could be argued to suggest this.

(v) Now and the future

In the interview with Amy it was nice that Helen was present and could try and communicate where she saw appropriate. We discussed issues that had been memorable for both of them, including Helen's wheelchair incident as mentioned previously. The girls seemed very close, they had their own style of banter with each other but it was obvious they cared greatly about each other. I felt that had Helen not been present, then Amy may have discussed her sister's condition in depth as throughout Helens interview she would make reference to not being *'as affected as Helen'* or that things were *'more difficult for Helen'*. Looking at both girls and relying on my own prejudices in just seeing their outward disabilities I could relate to how this was probably the case. However, Helen would sometimes moan signaling she disagreed with the comments. If I had have had more time and scope within this study I would have liked to have spent longer with Helen to explore her world and perceptions. Furthermore, I would have liked to have had time to sit with Amy in private to ask her more about why things were harder for Helen. I felt uncomfortable to do this whilst Helen was present. I did not want to infantalise her or disregard her presence.

Amy did have concerns about her future in terms of the nature of her condition and how it may evolve over time. Still, she had hopes and dreams:

> I would really like to be a teacher but I know that that could be difficult for me. It would be hard to study and physically do it. Maybe a teaching assistant in a primary school is more realistic. It depends on how I go (Amy).

However, Amy refers to being realistic. She considers her future and gives herself options. Maybe this puts less pressure on herself physically and mentally. When asked about differences and if her life would be any different without her LLC, she actually found it difficult to imagine being different:

I was born like this and so I've never lived in a CP free body so I don't know any different. I think it is probably harder for kids who are able bodied from birth and then something happens to them causing them to have to lose… or stop doing things they have always done or been able to do (Amy).

I've always thought, better to be born like this than suddenly Oh No you wake up and can't walk or talk properly (Amy).

I had not spent much time thinking about this concept before – is it harder for children to experience a LLC after a period of healthy, illness free childhood? Thinking about it, these children may experience grief for their varied losses that do not occur to those children who only know a life of hospitalisation, strict medical regimens and more controls and barriers in their lives. Paula talks about things being difficult at first, but in terms of family coping rather than specific to her children with LLCs. She discusses specific upsetting experiences but these are not specific to the children's conditions, but rather they are related to care or equipment. Maybe, from the perspective of the parent if a child is born with a LLC they have the initial shock and diagnosis to gradually deal with but where a child has been relatively fit and then becomes ill, again the parent has the added grief for the lost future they presumed their child would have and the memories of a previously well child to deal with.

7.3 The Thomsons: Sandra and Bobby

Sandra and David have one child – Bobby. Sandra is the main carer for Bobby. David works full time but is with his family every evening and weekend. Both Sandra and David have received genetic counseling. Hospice provision has been suggested to the Thomson's but they have declined. Sandra is 32 years old and works part time in administration. Bobby is six years old and attends mainstream school. Bobby has a very rare genetic condition. Bobby is active but is smaller than his peers, has lost his hair, has tight skin and joint pains.

7.3.1 Interview location and characteristics

Sandra chose to be interviewed on one of her days off from work, whilst Bobby was at school. I interviewed Sandra in the lounge. Bobby was playing football with friends in the street when I arrived to conduct his interview. Bobby was excited at my arrival and immediately finished playing to enter his home with me. Bobby chose to be interviewed in the lounge, where he could play with a few toys out of his toy box in the corner of the room. This location also meant that when desired he could have full view out of the lounge window to observe his friends still playing in the street. Sandra remained in the lounge for the duration of the interview, assisting with responses when she saw fit.

(i)Tracing the early days

Parents talk about parental instinct a great deal. When a child is not born with obvious physical disabilities and does not appear to be overly sick, it can be very difficult for a parent to express their instinctual concerns to professionals. Sandra talks about how her pregnancy with Bobby went really smoothly, how she was supported in labour and how Bobby was seemingly a healthy child at birth. However, over the following weeks Sandra became increasingly concerned with Bobby's appearance, how his facial features were not similar to family, how his skin seemed a bit 'tight' and how he did not seem to be growing at the same rate as other babies attending the baby clinic. This instinctual feeling of something not being 'right' with Bobby's health was something over which Sandra had initial conflict with her husband and professionals. However, in time it was agreed that Bobby was failing to thrive and his body composition was not as robust as babies of similar months. Then came a series of tests for Bobby as Paediatricians were unable to immediately determine his condition. This was a period of concern for all the family but Sandra talks about how nothing could have really prepared them for the diagnosis and the related prognosis:

> He was almost a year old when we found out, which is apparently good… we have spoke to other families in other countries whereby it took a lot longer. It is strange, but it was actually only as a result of me suggesting this condition that we got the diagnosis. A friend abroad has

a friend with a child with the same condition… I got in contact with her and it seemed like Bobby was very similar, although I hoped beyond hope that he would have something slightly different that would mean he wouldn't eventually die from it… but these children are very similar… I suggested it to our Paediatrician and he took notice and we went into the testing for it. To be told he had this was devastating. The condition is very rare and I hoped beyond hope that it wasn't (Sandra).

Because some LLCs are genetic, they may be very rare which means Paediatricians may have never had to deal with a child's particular condition before. Therefore, providing a diagnosis (and prognosis) can be very much a matter of trial and error. As such, there are many children who are not diagnosed for a number of years and then parents can still be left with a degree of uncertainty.

(ii) Interactions with professionals

In interviewing Bobby I was unsure as to what degree he was aware of his prognosis. He knew he was different but I do not think he considered himself as ill: *'I would like to be like other children'* (Bobby). There had been a few occasions where he had needed to be taken into the accident and emergency department and later admitted to hospital, but he had been on acute care wards and not around very ill children. This is perhaps a reason as to why he was not expressing his condition to be of a serious nature. Still he could reminisce about consultations and talk about his limitations, his experiences and those around him – and he did so in a manner that illuminated his lived experience of being a child with a LLC. Sandra was open about her feelings and stated that she had not talked to Bobby about his condition and its severity:

He will be lucky to reach thirteen or so… if he reaches sixteen he's doing extremely well, so… I think the usual life expectancy is nine or ten year old. So, we sometimes think half his life has gone. You have just got to deal with it haven't you, and you can't be miserable…

Bobby… you know, you've just got to do it for Bobby… He doesn't
know (Sandra).

Bobby has intermittent checks with his Paediatrician. Difficulties arise when Bobby has
needed emergency care. This has meant Sandra having to explain his condition to every
member of medical personnel involved because they have not known how to take on his
care. Thus, highlighting the lack of shared notes between professionals and the lack of
knowledge around rare childhood LLCs in acute care settings. In talking about routine
appointments whereby the professionals are familiar with Bobby, it is interesting to note
Bobby's recollections of these consultations:

We don't see the doctor much but when we do he talks really loud and
slow. That's what I remember (Bobby).

I usually get the toys out and play with them when the doctor is
talking… mum or dad tells him how I'm feeling… at school we had a
story about a boy going to the doctor because he was poorly and I put
my hand up and said 'but sometimes you see the doctor when you are
not poorly'… because I do… that doctor with the fluffy hair, I think a
lot we go and I'm not poorly. But it is just because he wants to talk to
us and see I'm not poorly I think (Bobby).

Bobby is feeling 'well' most of the time and is trying to make sense out of needing to
keep making hospital visits to see the specialist Paediatrician. In mainstream education in
the primary school years there will be talk about the jobs of different people, the doctor
being one that makes children better when they are poorly. The lack of communication
Bobby appears to be having with the professional may contribute to his confusion and
need for meaning making.

(iii) Critical incidents/life events

Whilst interviewing Bobby, there was a point where Sandra had to leave and enter the kitchen to cry. At this point I got Bobby to put his coat on and encouraged him to rejoin his friends outside to play. I returned to speak with Sandra in private as I was worried I had caused her upset. I had not directly, but Bobby had started to talk about his appearance which had struck a nerve with Sandra. She then explained how she was in fact pregnant and worried about the birth of a sibling – how Bobby would be affected by this child being born healthy. We sat and had a warm drink. Although, this was not part of the formal interview and thus not tape recorded, Sandra gave me the permission to reflect on our conversation. It had not occurred to me that a parent with a child with a LLC would then be upset at having a healthy baby. My presuppositions would suggest it to be a relief rather than a burden. However, I can now see that having a subsequent healthy child can mean the parent can start the grieving process for the sick child and also a process of upset for the sick child – through making comparisons with the healthy child. Sandra queried how she would explain to Bobby why this baby did not need to keep going to the hospital, why this baby would grow taller, would have hair, would not start to degenerate. Sandra spoke about not having envisaged these feelings before getting pregnant and even spoke of how it may have been easier on everyone had she not got pregnant a second time. She made an interesting point, she talked about how the baby would have to experience the death of its older brother, but she also spoke of how she did not want to be childless and how she had always wanted more than one child. All I could do was listen and try my best to instill hope where I could. All the time I was thinking how devastating the situation in its entirety was. I am not a counselor, but I suggested that maybe the hospice could help her through this. It was at this point I realised the family had refused hospice care. I sat in hope that these services had maybe been offered too soon and that they would be offered again in the future. We later resumed the interview with Bobby.

Again, in her actual interview Sandra discussed her pregnancy and related fears. In this context she re-affirmed that Bobby was unaware of his prognosis and that this was something the whole family unit was struggling to come to terms with:

I'm pregnant and hopefully this child will be fine… I worry now, questions are starting to go through my mind now… I think because I'm, because I'm pregnant and Bobby is very inquisitive… and as this child develops and it's developing normally and Bobby's not (crying). My husband wouldn't even want to talk to anybody, he needs to get on with life and take each day as it comes… he doesn't want to know what's down the line, he's just dealing with the present (Sandra).

The trials and tribulations are recurrent in the lives of these families. Sometimes having longer term plans gives families something to focus on and give them the strength to live through the difficult times. For other families the reality is very hard to bear and to almost dismiss this reality is what they need to do to be able to enjoy their lives. Perhaps focusing on a future for these families is too difficult and living day by day means they can obtain as 'normal' a life as possible.

When I first met Bobby he was very quiet, although, I could see when he played with his friends he was almost like any other rough and tumble six year old boy, play fighting and moving around quickly. However, when we talked in the interview he displayed some frustrations with his mum:

I like playing out and dad lets me but not always mum… and when she does she keeps watching or coming out to see me. My friends at home are used to it but it makes me mad if I have a friend for tea… when I have a friend come I tell them its best to like play with building circuits or for me to be Spiderman and them the baddy but inside (Bobby).

If he starts running especially outside I think give up!, just go steady Bobby you know, you're going a bit too fast… when he's at school he doesn't get none of that, So (laughs)… because he has such a slight frame and he can get unsteady, and like if you've got eighty mile an hour winds outside and he goes outside, you're frightened of him being

knocked down by the winds or… err if he's playing out with his friends
on the street, you're frightened of and watching him because if one of
them just knocks him (Sandra).

Sandra has understandable anxiety. Due to the nature of Bobby's condition, a small fall could mean a broken bone. I can see how hard it would be to strike the balance in allowing Bobby the freedom to socialise freely with his peers and to experience a childhood as any other child can experience theirs, alongside the worry of an incident that may cause pain and suffering for Bobby and potentially impact on the duration of his condition. To this end, parents with children with LLCs may be accused of being over protective but to be carefree may result in negative health outcomes. Phenomenologically we can question how we judge appropriate levels of 'protectiveness' and what do we mean by the notion of 'over-protection'.

Bobby is just six years old now and I think most parents are protective of their children at this age anyway. Perhaps over-protection is illuminating amongst these parents purely because the child has a LLC. However, there are very real fears here – if Bobby was to fall there is a high risk of a bone breaking, much higher than in a healthy six year old child. To this end, do we then re-label Sandra's monitoring behaviour to just that – she is monitoring Bobby's behaviour in order to protect his health? To use imaginative variation we could consider how different we may behave if our child was in a swimming pool – would we be more observant if our child could not swim? I would argue that we would as the risk of our child coming into difficulty is far greater than a child who can swim. So then, is this over-protective behaviour? Or just being a good parent? I suppose, there may be a time whereby Sandra will perhaps need to try and let go a little bit, and especially if Bobby reaches adolescence as then independence from parents is more crucial to wellbeing and development. Bobby will then be more verbal about his wishes and behaviour, but will most probably be more educated about his condition and aware of risk.

(iv) Issues of appearance

As mentioned, being pregnant is proving to be a difficult time for Sandra. However, looking specifically at Bobby's lifespan, not including the time of diagnosis, the most difficult times have been associated with Bobby's appearance and him getting upset by it. This upset has hurt Sandra and has caused her to start thinking more about the future and what the future holds.

Most children of Bobby's age have a full head of hair. Unfortunately, due to the nature of Bobby's condition he lost all of his hair before he was two years old. This was an emotional time for Bobby's parents and now is a constant reminder of how ill he is:

> He knows he's different…but he's never… we don't hide it and we'll say the word (name of condition) or we'll talk about one of the other kids (with this condition)or something like that, but he never asks… The only thing he ever asks about is why he's no hair, because his hair fell out when he were eighteen month old… hmm… he never says, well if he says "well I'm only little aren't I?" I'll say "well it doesn't matter because people come in different sizes, because you know your Grandma's little isn't she?" you know (Sandra).

> His physical appearance affects him because of the reaction of other people. He's not like a little old man, but, he's different, and as he gets older, the older children that we've met, they are like little old people! You see, so… as he's getting older… It's affecting him more and because he knows, he's very conscious, and you go out and he knows if somebody's looking at him. Without them all commenting, because people are cruel and yeah, so… Hmm, so it does affect day to day living (Sandra).

A young bald child stands out in a crowd, attention can drift onto difference albeit unconsciously. These stares are not unnoticed and highlight Bobby's uniqueness. When

every other child around you has hair, trying to understand why you do not will be very difficult for a child aged six to comprehend:

> I am going bald… well it is all gone now but it might come back one day because I am still growing. I am the only one in my school without hair and even the teachers have all got hair (Bobby).

Via a support group for children with Bobby's condition worldwide he has met other children with his illness but does not make reference to these children when he is questioning his uniqueness. He is struggling to understand why he is different, the label of his condition is known and he is aware of the other children but he does not understand really why he is different. And this is something which anyone would find difficult to explain to a six year old child. When issues occur and the child is upset there appears to be little support available for families in tackling such difficult communication. Brushing off issues and encouraging the child to try and embrace their uniqueness appears to be the only favourable option to take.

Being different brings attention. As stated, attending public places elicits stares, and interactions with others highlight misconceptions:

> They stare at me a lot… people… sometimes I feel like people look at me as if I am an alien (Bobby).

> More than anything, it's the cruelty of other people and it's not mainly children, its adults… I remember this one time shopping and I had him in the pushchair and I had to listen to these two women surmise over what was up with him and one of them was saying she bet he didn't have long… that just made me feel terrible, my stomach just dropped and I couldn't challenge them, I just got away (Sandra).

Each dyad talked about them being more able to accept the condition and what may lie ahead, if they are not subjected to ignorant comments. '*Time is a healer'* was put forward by Sandra and other parents in this study. This is a cliché but was used to breach experience that parents appeared to find difficult to talk about or to put into words that would convey accurate meaning. Trying to imaginatively enter the child's or parent's world is difficult here. To have experienced prejudice in some other form may come near to this experience or having had a need to 'fit in' to a situation outside of one's ordinary experience. Sandra talked about getting used to people looking and making odd comments but still said that such comments can be upsetting. Sandra takes comfort in Bobby being accepted by his peers at school, but even at six years old Bobby is sheltering his parents from upset and not disclosing his struggles he has from time to time:

> I have lots of friends but they are not always kind. Sometimes I'm not the fastest and my legs hurt and they stop playing then… and they laugh sometimes because I'm going bald and I get upset (Bobby).

> He's very, he's very quiet is Bobby, extremely shy, painfully shy, hmm at first with people… but, he's getting better. Especially since he's had to go in to full time to school. Hmm… but I think, he has, he's had trouble mixing… because of his shyness and he tends to stick to the same two friends all the time, but he is getting better, I mean at one time he wouldn't have spoken to a stranger. Oh no, in fact when he were about two, eighteen months, two year old… if a stranger spoke to him he'd cry he was so shy, but he's a lot better now hmm… but no school's really good with him and just doing him good… And… Even though he's got all these physical disabilities that he can't keep up with the other kids he cannot get down on the floor… unaided, he can't get up unaided, he can't get changed for PE unaided, he can't fasten his own shoes, you know stuff like that he just, he manages it very well and the other kids they know… they're very good with him, they don't sort

of make him any different, they treat him well… To say that they're all
a similar age… you know, which I think is lovely (Sandra).

From what Sandra has seen Bobby is now fine at school, she has no real worries in terms of him being excluded. Bobby reports a different situation, whereby his disabilities are sometimes highlighted by the behaviour of his peers toward him. The being laughed at and the friends stopping playing are not issues that have been picked up by Sandra. Children can easily fall in and out of friendship and this may be a reason for Bobby either not disclosing upset or in Sandra not reporting such.

(v) Now and the future

Bobby is an only child but with a sibling on the way, Bobby has started thinking about what this may mean for him:

I am going to be having a baby brother or sister… yes… it will be nice… I've got friends that have brothers and they play. But if I have a brother he can have my toys and I will get some new ones. It will be nice to be the biggest and to tell my brother what to do… hmm… if I have a sister I'm not sure I will like it that much. I don't really like girls that much (laughs)… but Jacob has got a girlfriend (laughs) (Bobby).

This appears to be a reaction not unlike any other child of six may have to the prospect of a new sibling soon to be born. Interestingly, Bobby does not talk in a way that indicates he is foreseeing any of the issues Sandra is prophesizing.

Bobby was full of energy when we had the interview. He was excited that his friends were still outside playing and that maybe they would remain outside for him to join them later. He would keep running to the bay window and look out at them to monitor their presence. I asked him if he played out a lot: *'Most of the times I am playing football out there or like I play Spiderman or Power Rangers'*. (Bobby). I sat rooting through Bobby's toys with him commenting on all the good toys he had and I thought about what

a personality he is and how if it was not for his physical appearance I would see that he is no different to any other six year old child. Sandra made similar comments and talked about how she can cope with Bobby's physical restraints, but would maybe find things more difficult if he was to become mentally disabled by his degeneration:

> You know and hmm I mean if Bobby was, this is going to sound
> horrible and really cruel, but, if Bobby were mentally disabled as well
> as physically, life would be twice as bad, where as now, he has got a
> quality of life, he can do things hmm… and we do get out (Sandra).

The nature of Bobby's condition does in fact mean that Bobby could face mental deterioration in his final years of life. Sandra undoubtedly realises this is a probable aspect of Bobby's illness. Like other parents in this study, looking to the future may be more in the immediate sense than long term in order to be able to cope with their situation better.

As we have already touched upon with Sandra, the family is not really trying to look too far into the future as they find this too painful to comprehend. The more immediate future for Sandra is wrapped with worries about the new baby and Bobby's acceptance of it. There is also the covert anticipated upset of having the continual comparison of a healthy and very ill child in the family. To date, attention can be diverted away from this but the differences may be highlighted and verbalised by the children themselves. This remains to be seen. However, Bobby had a lot to say about his future:

> I'm looking forward to getting big…I'd like to be playing football for
> Leeds when I'm big but because my mum says I might stay little, I'm
> not sure if I could do a good job being little… I'd have to do some
> thinking again about it if I stay little.

And what things would be like if he did not have his LLC:

I would have more energy, I wouldn't hurt and… It would be nice to be able to go out and play in the street everyday and go swimming and to Mac Donald's for a Happy Meal and places.

Bobby has the same dreams as many other little boys of his age – to play football for his favourite professional team. Yet despite his young years he is aware of how he is different now and how he may remain different. He is cogniscent of his limitations and talks about how he would be able to do more and meet his ambitions if he had less pain and fewer disabilities. Bobby is different to his peers on many levels, his external appearance is frail and child like only in stature, he is small in height and will remain to have stunted growth over his lifespan. In this respect, the frailty will increase and so his ability to join in activities will lessen. Not being able to join in itself singles you out as different.

7.4 The Burtons: Edward and Sophie

Karen and Edward have one child – Sophie. Edward is the main carer for Sophie. Karen works full time but is with her family every evening and weekend. Edward is 38. Since Sophie's diagnosis Edward has not worked. Sophie is five years old and attends mainstream and hospital school, as dictated by treatment. Sophie has Acute Lymphoblastic Leukaemia (ALL). Sophie is currently going through treatment for ALL. Chemotherapy has induced significant hair loss and has enforced a reduction in her social network. Sophie is pale in appearance but still very active.

7.4.1 Interview location and characteristics

Edward chose to be interviewed with Karen, although Karen contributed little due to attending to Sophie who was also present. Sophie's interview commenced in her bedroom. Both parents were at home for the day and happy for us to conduct the interview upstairs. Throughout the interview Sophie played with her 'Barbie' dolls. This caused the interview to change locations a number of times, including going into the family bathroom whilst she bathed her dolls in the sink and then downstairs in the lounge

and conservatory whilst Sophie tried to find other clothes for the dolls and parts of her 'tea set' to prepare tea for them.

(i) Tracing the early days

In the Burton family difficulties were reported about having to get used to medical terminology, coming to terms with the diagnosis and trying to maintain hope. Sophie's illness commenced almost a year ago. What was first a concern over a lump in Sophie's neck soon was realised to be Leukemia. Sophie is currently on treatment so her movements outside the family home are limited. She frequently attends the regional oncology unit for more intense treatment administration but currently is being administered treatment by the community specialist nurse. Edward explains how he had to finish work because he needed to take so much time out to get Sophie to her hospital appointments and to be with her when she has needed to be admitted:

> Sophie is my life. There was no way I could keep up with work… I needed to be with her, Karen can't drive and when I was at work I couldn't concentrate. The situation has knocked me for six… we live each day as it comes and hope to God that she will get through this… it is really stressful, she has been through a lot… you'll have to prepare yourself for some harrowing stories, she'll tell you a lot, she remembers everything and she's not daft, she knows what's happening (Edward).

(ii) Critical incidents/life events

Edward went on to detail 'finding out' the diagnosis and how being in the hospital both helps and hinders their well-being as parents:

> When she has needed to be in the hospital it has been nice in so much as ideally we don't want to be there, but the staff are lovely and it is good to be with families going through the same… you know… especially when you see their kids getting better… it gives you hope… but on the other side of the coin you end up with more heartbreak…

we've ended up making friends with other parents, it's natural you are on the same ward… same ward day and night or you are bumping into them at clinic… but then things are not going so good so you worry for them and then quite recently we had the upset of one of Sophie's little friends passing away… it's not good… it's heartbreaking, heartbreaking… she was a similar age to Sophie and they really have ended up being friends. Sophie knows that Sarah has gone to heaven now but it is strange for her… and for us… well its heartbreaking… we have tried our best to be there for Sarah's parents… they come round now and again but you see it is hard for them now seeing Sophie. For us we are grateful to still have Sophie but losing Sarah has made us see how things can change… they can change quickly… you can think things are going ok and this cancer, it can fool them all and take kids just like that (clicks fingers) (Edward).

I wondered how Sophie had processed this reality. Had she gone to the funeral? Did she fully understand what had happened to her friend? And had she made any inferences?

Sophie knows her friend has died but we are unsure really how she has taken that in. She talks about seeing her again and we find that really hard (Edward).

Accordingly, Sophie had not attended the funeral. Karen and Edward said they had tried to explain to Sophie that Sarah had gone to heaven, that she was now with the angels and although Sophie could not see her anymore that maybe somewhere Sarah was happy, looking down and smiling. When interviewing Sophie she started making reference to one of her Barbie dolls going to heaven now and she kept lifting the doll up as if it was flying to heaven. I asked her what is heaven, indeed she explained it was where Jesus is and the angels and that Sarah is there now. I asked who Sarah was to which she just said: *'My friend'* (Sophie).Then quite out of the blue, she went on to say:

If I go to heaven I need to have my ears pierced. Sarah's mum told my mum that Sarah put her ear rings in before she went because she said ladies don't go to heaven without their ear rings… I want my ears pierced… will you tell my mum I want my ears pierced? (Sophie).

I found this upsetting but I tried not to overtly show it. I felt that Sophie had not fully understood the concept of death, yet she knew Sarah had gone, she knew Sarah had been poorly like herself and maybe in her own thoughts she was concluding that she could be going there too – hence wanting to have her ears pierced too. Conversely, she is a very feminine child and in a child with pretty clothes comes pretty makeup and ear-rings. Perhaps my immediate response of upset was adding more meaning to her words than what was a simple request to have her ears pierced, a request that is probably made by many young children. Looking back at my own childhood I had my ears pierced aged seven but I can remember that was after a very long time of asking.

Sophie goes on to talk about heaven as a physical place to go, which indicates that she either does not fully understand the reality of death or that such is in line with the belief system of her family. Sophie may have not seen her friend degenerate; her memories are undoubtedly of play and friendship. It would be difficult for her to imagine never seeing Sarah again. I also say this because as an adult I have lost friends and family through death and still I do not rule out seeing these people again. Is the reality of loss ever truly realised? And is this reality really that different in a child as compared to an adult? Perhaps as an adult we can communicate our thoughts and understandings better and these maybe be very much determined by our cultural belief systems and ways of being as passed on through generations. I do not know the full history of Sarah and of how Sarah's passing has been communicated to Sophie. However, my step father died a few years ago leaving my seven and nine year old siblings to come to terms with losing their father. As a family we explained that their father had gone to heaven and would now be in the company of other relatives that had died and would be with Jesus. I remember my siblings writing letters to their dad with illustrations of heaven with clouds and angels and big gates - these were buried with him. To this end, it was clear at that time that my

siblings understood heaven as a place and that their father would somehow be able to read their messages.

Times in hospital were reflected on with mixed feelings. Edward explained how when Sophie has needed to have long or even shorter term stays, they have taken her own bedding to the hospital and some of her soft toys to make the environment feel more home like. Meeting other children and parents following a similar journey was reported to provide support. However, when there have been hospital stays there has been periods of intense treatment and times whereby Sophie has been physically sick and complained of pain.

> Sophie has been really brave… she has taken it in her stride and even when she's had terrible sickness she hasn't cried with it… she has said she wished it would stop, but she hasn't cried with it… we have… different stuff has had it's different reactions and with one lot she got really bad mouth ulcers… they really were terrible… her little mouth was really sore and there were open wounds and she did go on a lot about when will it be better because it was hurting… when we know she is… she is or must be in pain that is really hard for a parent to have to sit through… but the staff at the hospital I mean they are very good and do their best helping her with that (Edward).

Sophie when reflecting about times in hospital talked mostly about the different children she sees and plays with. She did, however talk about having intravenous lines put in and such being painful and *'even when the cream is supposed to be working'* (Sophie), which I presumed must be something that is put on a child's skin to maybe numb the area before insertion. She also talked about not liking *'being sick'* or having *'sore mouths'* and that these times *'were the worstest bits'*. (Sophie).

(iii) Issues of appearance

For Sophie and Edward a big event was when Sophie lost her hair. The seriousness of Sophie's illness was now visible and Edward talked about how it was the point at which there was no more denying what was happening.

Edward showed me pictures of Sophie before the 'cancer'. Sophie had very long very blonde hair. He explained how when they were told the hair loss would happen, he had not realised how much it would upset him. He saw it as a means to end; this had to happen for Sophie to get better. But his emotions were still raw as he explained how Karen had one day started brushing Sophie's hair back in to a pony tail when the hair just was lifting off the scalp in thick clumps. He talks of how for a few days they tried not to brush the hair and just tie it back loosely, again trying to draw out the inevitable. But how each morning more and more hair was on the pillow:

> She takes it in her stride really… She's getting used to having to go into hospital and all the tablets as well; I think it's loosing her hair really that's been the worst for her… Being a girl it's not, obviously it's harder for a girl because most boys have no hair anyway; they have it shaved off any way. When it started coming out… we were told but it was awful… trying to do her hair… it all went over course of a couple of week and what we did in end to make it easier was to keep her having it cut that bit shorter so that what was ending up on the pillow was not as devastating (Edward).

> I have this Barbie hair and if I go out I ware it. It's nice. I'm going to ware it until my hair is back. You see these Barbies here I've cut their hair off and but they are still nice ones (Sophie).

As illustrated in these two excerpts, the event of Sophie losing her hair has been more devastating for her parents than Sophie. Sophie can see that hair is just hair, but for her parents this meant losing a piece of Sophie, her identity before the cancer.

(iv) Now and the future

In the literature there are studies that frequently discuss how mothers have to leave the labour market to focus their attention on their ill child. Comparatively less research has looked at the role of fathers in the care of children with LLCs. Karen's job is close to home whereas Edwards's work could mean he was involved in a lot of travel. Still needing a regular income it made practical sense for Karen to continue work as in the case of an emergency she could be granted leave and it would take just a few minutes to get home. Karen said it was difficult to work but in some respect it helped her to maintain normality in her life, whereas Edward was very open about the fact that he felt he could no longer concentrate on work and needed to spend his time with his child:

> I do worry, I worry about her getting infections about her falling ill and it going unnoticed… at least if I am around and this happens I have only myself to blame… but to be honest I am glad to just know I am here in case anything happens… it does Karen good to go out to work… but like I've said my mind won't take having to think about work and Sophie (Edward).

The downside of having cancer other than the obvious upset and illness related concerns all relate to the family reducing their previous social network and activities. Edward talks about friends becoming awkward around them, finding it difficult to talk about Sophie in case they say the wrong thing. He talks about feeling embarrassed because of the difficulty in wanting to have other things to talk about but also not wanting the subject of Sophie's condition to be totally avoided:

> I think a few of our friends have drifted… we have had to be careful about infection… infection… hmm and so we have had times when we have been worried and we've asked people to not to come if they have had colds or… you know if they have been feeling under the weather… and I'm not sure if they've understood or thought we've been being funny… but I think a few of our friends have now just took it that it's

best not to bother us… they stay away… others they don't know what to say, we don't know what to say and so on… increasingly like I say we make friends with people who are going through same… and we are sticking together so to speak… it's not that we think less of the friends we went about with before… it's just that we don't seem to have as much in common any more… we can't be going having bbqs or on holiday or out leaving Sophie all time and we don't want them to be upset or not knowing what to say… it is difficult and our social life… well it's practically stopped… but we're ok with it at the minute, I think it has gone down the road it was going to go down because of what's happening with Sophie (Edward).

Losing friends was not a situation I expected these families to be in. Now knowing the types of demands LLCs have on families I can see how having any form of social life will be difficult. These families befriend like families for support. Friends from a life without life-limiting illness can try to be compassionate but they are unable to know what this life is like. I am on the outside looking in and I can see the upset, the life disruption and the striving for 'normality' but because I am not a parent of a child with a LLC it is difficult for me to truly know their reality.

Sophie also talked about missing her nursery friends but having nice new friends. She mentioned how she would like to do more activities and go more places and could blame the cancer instead of her parents as the barrier that disallows such. Almost as if the cancer is like a wall she has to climb and once she is over it she will either be able to do all the activities she would like to do with all her friend or she will be going to see heaven to play with Sarah:

I have to try my best to get over it… the cancer… when I get over it it will be hard work… lots of times in the hospital I think and having more medicine… to when I do I know… I think I will be doing my dancing at dancing class and I want to go Disney land then… or if not

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when I've got over it… I will be going to heaven and I will be doing all
that there but with Sarah cause she is already there you see and she is
my best friend, I like Rebecca but really I like Sarah best (Sophie).

The words used in the beginning of this quotation seem quite adult like, almost as if she has listened to her parents' use these words and she has adopted them in her talk in how she will do her best to get over it.

Sophie's interview was really chaotic, I was up and down stairs, joining in the dolly washing and feeding and having to get in and out of play characters in order to try and gather some meaningful data. It is no wonder that when I asked about issues pertaining to what Sophie enjoyed in life, she made reference to the toys she was playing with:

Well… I enjoy playing with these Barbies. I want a Barbie horse and
carriage really though. I think that would make it better. And I like it
when I can have friends to play and I like parties and I like parties a lot
if there is a cake and I blow the candles (Sophie).

Having a party and being with a group of friends is probably something Sophie is looking forward to as she has had limited contact with friends recently due to treatment. Despite the difficulties in coming to terms with the illness and the demands and effects of treatment, Edward too commented that Sophie's energy and strength of character maintained the family's well-being;

This hasn't phased Sophie… not one bit… she is such a happy child,
she has not moaned with it all. She's had things happen to her which I
know will have hurt but she's kept that energy about her. She keeps us
going (Edward).

When asked what she was looking forward to, Sophie gave the following responses:

> Getting my long hair back… Well I want to be on TV dancing and if I wasn't poorly then I know that it would be easy… I would like to be a dancer. I have had to stop dancing classes but I can start them again on one day if I get better.

Now in ear shot, Karen and Edward both commented how Sophie was destined to be a dancer.

7.5 The Hills: Maria and Danny

Maria is divorced and is not in contact with the father of her children. Maria has three children – Adam, Laura (13 years) and Danny. Danny is the youngest child. Adam was the eldest and was tragically killed two years ago on a family holiday. Maria is the main carer for Danny. Maria's parents provide a considerable amount of support to the family. Maria is 36 years old and does not work. Danny is eleven years old and is currently educated in hospital. Danny has never attended mainstream education due to the constraints of treatment and as a result has difficulties socially interacting with other similarly aged children. Danny also has Acute Lymphoblastic Leukaemia (ALL). Danny has suffered with Leukaemia recurrently from the age of three years old and is now awaiting a bone marrow transplant. Danny is pale in appearance and is reserved in nature.

7.5.1 Interview location and characteristics

Maria chose to be interviewed in the lounge whilst her parents took Danny to their home for lunch. Danny chose to be interviewed in the family room, where he sat with his black kitten. At the request of Danny, his mum and grandparents remained in the lounge throughout the interview.

(i) Tracing the early days

Because Danny has been ill for so long, both Maria and Danny struggle to imagine a life without Leukemia. Maria talks about living through having hope and then having the hope repeatedly dashed:

We have struggled since his first diagnosis at three. He's had treatment he's got better and then it's come back again. When Adam died the shock of it was heavy and I have not really got through the bereavement because I am not free of worry... I am just thinking about what if I lose Danny now all the time because I know there is a high chance now… and to lose two boys, I am not sure I can deal with it. Laura is getting older now… she has a lot of worry on her shoulders… It's my parents who help me. We would all need care without them (Maria).

Because the illness has returned so many times the family really do not know of a life without worry, or at least cannot remember a time without worry.

(ii) Interactions with professionals

Throughout this study, in interviewing parents and children I have become increasingly aware of how sometimes decisions are made without consideration of what a child's perspective may be, for example:

Many many times I've said I don't want to carry on with it… and it has meant them waiting a bit longer before they can put me through it again... They do listen at first but then they go into persuasion overdrive and I end up giving in… Sometimes I get fed up with living like this and… I have stopped taking tablets before and even thought about taking them all at once, especially when my brother died (Danny).

I was saddened to be faced with such a young child who was depressed and grieving for his brother, in the face of his own cloudy future. Getting professionals to listen to him was a difficulty. Maria also touched on Danny not wanting to continue with his treatment:

We have had a lot of problems with him and him wanting to die. Like I have said he has wanted to refuse treatment in the past. I have to watch

he takes his tablets, everything. He is depressed, he's not had a childhood and he has had to go through his brother dying too. I haven't helped things as I have been very down. The kids don't know but I have tried taking my own life because there are times when I just can't cope with everything. I keep going for the two children I have living but it is hard (Maria).

The issue is not solved, so persuading Danny to be compliant with his treatment is an ongoing trial. Danny's grandparents are supportive and try to be involved in many of the day to day tasks, like helping Maria with the children and cooking and cleaning. The house is very clean but as I sat interviewing Danny, I wished I could interview the grandparents who are elderly and are having to have the worry of a very depressed daughter and grandchild.

Danny lacks enthusiasm for his own treatment but acknowledges his dilemma. He knows that to not adhere to treatment may result in his death. For him, that is not so big an issue as the potential impact his death would have on Maria:

> My brother died and my mum has taken it badly and so I do worry about what she would be like if I die… It is something she thinks about but she can't talk to me about it and I really don't want to talk to her about it. But then I would like to talk to someone about it. If I die I want to know that my things will go to who I want them to go to and stuff like that and I want to know if there will be help for mum with it… She doesn't really cope now so I dread to think what she would be like and I don't want her killing herself. I'm not scared of dying, I think I will… but I like to be organised and would like to know that my mum will be ok (Danny).

As can be inferred from this excerpt alone, Danny had a very adult like nature. He was reserved but talked in a way that suggested adult like reflection and rationale. This maybe

because of his interaction I an adult world and of learning about his illness and its eventualities. However, Danny needs reassurance that he may have a good life period in front of him and if not then there will be support available for his family. Danny is closed to his family with respect to talking about death and dying issues, yet he does want to talk about them.

(iii) Critical incidents/life events

This family are still grieving for Danny's brother Adam, who was tragically, killed a couple of years previous to the interview. There are photos everywhere of Adam. Danny implies that the death of Adam was very difficult because it was not expected:

> Adam… he was healthy so we didn't expect him to die… we were on holiday when it happened… being stupid jumping in the pool… he banged his head and that was it (Danny).

The death of Adam has made the possible eventuality of Danny's condition all the more real and unfair.

Few of the other children I interviewed talked in any depth about pain. They would briefly state how a particular treatment hurt at first but they then got used to it, how physiotherapy can be hard work but they can see the importance of it. Danny however was more direct about the memories of pain he had endured of the years: '*Every single needle that has gone in my body, I remember it… every pipe… every time I've been sick I remember it'*. And: '*From since I can remember I have had to look forward to pain 'to get me better' I'm hurting now but you can't see it'*. For an eleven year old child, Danny's comments were very deep and factual, almost adult like at times. Perhaps this was a result of his lack of socialization with other children. His writing definitely reflected his age, but was still very to the point and lacking child-like emotion, such as any indication of 'giddy' enthusiasm. Danny seems to go with the flow; he has tried communicating his discontent in continuing treatment. However, professionals and Maria

still push to continue with it and because he feels that his desires are not acknowledged when he voices them, perhaps he hides other feelings now as a result.

This family appear to have been suffering for years. Communication has broken down, they are grieving for a child lost and hope is diminishing for both Danny and Maria. Danny talks about how he has not enjoyed life as a child, but this is because he hasn't been able or encouraged to engage in child like activities. It transpires that Maria has been in and out of psychiatric care and caring for Danny has not been easy at least for the last two years: *'Since Adam has died it just seems like Danny doesn't want to live anymore either'* (Maria).

(iv) Now and the future

As mentioned, a lot of the family discussion is around Adam and keeping Adam's memory alive. Danny and Laura seem to have a typical brother and sister relationship:

> I enjoy playing chess with my granddad, getting on my sister's nerves and just sitting watching TV with my kitten (Danny).

> Danny and Laura, they fight like cat and dog sometimes but if anything was to happen to either one of them they would be devastated… Laura comes and still has a cuddle, we are close but Danny keeps to himself (Maria).

Danny did not mention any effects that his illness maybe having on Laura. Instead he spoke of how she annoyed him and so how he would do things to purposely annoy her. Maria talked about how Laura has had a difficult time in coping with Adam's death, Danny being ill and Maria being depressed. Accordingly, Laura is close with Maria but because her grandparent's home is closer to school she actually spends more time there. This is probably a refuge for Laura, away from the depression and conflict.

The future was a difficult area to talk to Maria and Danny about because they were so down beat. Maria smiled when thinking about what her future may hold and just said:

> If I could change anything, I would have a life I could look forward to.
> I'd live more for the future than I do now (Maria).

Again, Danny was very blunt:

> Fact is I'm probably not going to make it to working age so I don't see the point in thinking about jobs too much. I just look at each day and try and be happy and hope my mum is happy. If I start talking about what I want to be I think it will make her worse… she might start thinking of what if it don't happen (Danny).

Despite the fact that Maria perceived Danny to be distant from her, I think this is just a result of the experiences he has lived through. Danny loves his mum; he is not so positive about his own future but wants to protect his mum's. Perhaps this issue alone gives Danny the strength to continue his fight and to not enter a deeper depression.

Danny ccommented that he thought it is easier to accept having a LLC if it is something you have grown up with:

> I think those that get cancer as an adult or even at my age and they haven't had it before, it is harder for them. They find it harder to deal with because all of a sudden everything changes because of it. They are sick, can't go out, can't do things they have always done and don't know if they are going to get better or not. Whereas, these things are what I have grown up with (Danny).

Danny knows no different life and so cannot miss any activity he has never engaged in or be told he cannot do something he has always done. Danny only knows a life with

leukemia. To this end he is not upset that he has not always attended school or made friends of his own age:

> My friends tend to be older than me but that is because I've not really had much to do with kids my age. I tend to spend time with friends of my brother or sister and I spend a lot of time with my granddad. If I get through the transplant I will end up going to school and then making friends my age. It isn't a problem though as I like to be by myself a lot too (Danny).

Danny is very direct in the interview and so I believe him when he says that although his life is not ideal, he is content with how he has lived his life to date.

7.6 The Roberts': Gail and Peter

Gail is divorced. Gail has three children – Elizabeth (29 years), Sarah (25 years) and Peter. Peter is the youngest child. Gail is the main carer for Peter. Elizabeth and Sarah have both left home and have their own families. However, Gail does receive support from Peter's father and her two daughters. Gail is 52 years old and works part time. Peter is 14 years old and attends a special school. Peter has Duchenne Muscular Dystrophy (MD). Peter is mentally alert and is able to communicate but with slow slurred speech. Peters upper limbs have restricted movements, he can no longer walk and needs assistance in moving his lower limbs. Peter is mobile with the aide of a specialized electric powered wheelchair.

7.6.1 Interview location and characteristics

Gail chose to be interviewed in the lounge whilst Peter was at school. Peter chose for his interview to commence in the lounge whilst Gail prepared a meal in the kitchen. This was followed by a detailed tour of the full house given by Peter to illustrate a number of points made. This lead to the interview being conducted in most rooms of the house.

(i) Interactions with professionals

In other children's interviews there were comments about professionals not taking them seriously or neglecting their needs. However, Peter was one example of having struck up a good relationship over the years with his Paediatrician. The trials and tribulations he had experienced lead to a trusting bond developing between the two individuals: *'I know I can trust in him to tell me how things are and I feel comfortable in telling him how things are… it is just we don't always have a lot of time to talk about lots of stuff'* (Peter). This relationship was probably aided by Peter's perception of the professional being rather 'cool':

> James (Consultant) is really cool. He's not like a doctor he's not posh in any way and he doesn't talk using words we can't understand… he isn't time obsessed either. When we see him it is really relaxed, we talk about what is happening with me but it isn't dead serious and what I like is he knows me, knows me like a family friend really and he always listens to what I want to go on about. Mum is always there, if she wasn't I might even talk to him about the girl subject (laughs), well he's a man isn't he (Peter).

Peter talks of his consultant almost as if he is an exotic breed, something out of the ordinary because he is able to be relaxed and converse with him. Again though, an opportunity to arrange a consultation or chance meeting whereby he can discuss issues of importance to Peter is being missed – whether this is an opportunity neglected on the part of the consultant or whether this is something that is being blocked by Gail is unclear. The 'girl' issue is cited in the above excerpt but at other points in the discussion and indeed tour of the family home, Peter makes reference to wanting to talk about terminal phase issues and being remembered. These are areas of conversation he does not want to face immediately with his mum.

Peter is an intelligent child and realises Gail's awkwardness about facing the future. Interestingly, he does not attribute his own behavioural issues in terms of his own

struggles to cope with his degeneration. It is difficult for Peter to face his future but this is not just a selfish concern, he appears to mainly worry about how Gail will cope with his further degeneration and ultimately his death:*'I worry about when there is no me for my mum to worry about'. (Peter).*

A dichotomy of understanding was apparent in the interviews I held with Gail and Peter. Each was aware of the disease trajectory of MD, what tends to happen as the child ages and what tends to be the cause of death. Yet, in Peter's open desire to talk with professionals about what will happen and in how Gail commented on her uncertainty regarding Peters future, it made me realize that there was a barrier in place for them both. It was difficult for them to transfer their knowledge of the condition to their own being:

> MD takes all your functioning away in the end… moving ends up less and less… it gets harder to eat… all stuff to do with functioning slowing down… It would be difficult but better to know what was going to happen with me (Peter).

> All MD boys appear to degenerate the same way… we are now at this stage of Peter finding things increasingly difficult with his upper body movements… I am not sure how restrained his ability will get (Gail).

These excerpts clarify my meaning. Both Gail and Peter talk about knowing but later talk about not knowing. Is this self protection? Or is it simply the case of wanting to know more minute detail of their individual case?

Gail however, also notes the value of the relationship Peter has with his Consultant:

> James (Consultant) is a straightforward talking man, he tries not to mislead Peter and he tells him how things are… hmm… we both appreciate this and I know if anything was bothering Peter he would feel happy to talk to James about it (Gail).

Because Peter is mentally alert and well into puberty he has started to want relations with girls. This is a subject Gail is having difficulty in dealing with, not least because of the gender difference – as it could be seen as an easier subject to broach if she was having discussions about relationships to her daughters, in being a female herself. The present is being viewed as a difficult time by both mother and son because of this 'sex' issue:

> Sometimes it is hard being in this body. The mind works but the body don't. I want a girlfriend and some porn would be nice (laughs), but I can't exactly ask my mother to go and get it can I? My mate has a stash. But then I start thinking if I had a girlfriend what the hell would I do with this body I'm in? Are there people who I can talk to about this stuff? (Peter).

> He is raising issues like he wants to meet girls; he has got to meet girls. I don't know how to address this and there has been no one him or I can discuss these things with… there are big issues there really isn't there (Gail).

Gail's two daughters had left the family home but would visit regularly. Peter appeared to have a good relationship with them both:

> I can see that my sisters have had different experiences growing up than what I have but I'm not sure if their life has been much different or even better... Anyway, things will have been different for them being a girl… It has been a gradual process getting into this chair and I do miss the things I used to be able to do but then I might have stopped doing things like football as I got older anyway.

Peter compares his functioning with his siblings and reasons his acceptance of having to stop activities in terms of how this may have been the natural result of ageing. Thus, had he not had a LLC, then maybe his current pastimes would have been favoured anyway

and his childhood be as distinct from his sisters. It is interestingly to see how Peter makes sense of his own life dominated by a family made up of females. His upbringing he sees as different not because of his illness but because of his gender.

(ii) Critical incidents/ life events

MD is a degenerative condition, the deterioration is gradual but it is still difficult for the child and parent to experience:

> I worry alot about what he is thinking, he did used to have quite a lot of, not behaviour problems, but sort of a lot of frustrations to do with his illness and coping with things that have happened to him… I mean we have never actually openingly talked about the… What will happen ultimately, but I think he knows, you know… it's sort of unspoken sort of thing. (Gail).

The unfairness of the condition was internalized by Peter. Gail talked about how Peter tries to remain strong, but has had episodes of anger and heightened emotional outbursts. He blamed this on other issues at the time but reading between the lines Gail was aware that he was trying to hold on to his strength of character in facing times of adversity. With these degenerative nuances to deal with, Gail has feared talking about further degeneration and end of life care with Peter. Gail also sees this as a topic she would prefer to avoid.

(iii) Issues of appearance

The difficulty with Peter's condition has been its degenerative nature. This has been difficult for both Peter and Gail to come to terms with:

> Obviously over the years he has deteriorated and by the time he was nine he was in a wheelchair, an electric wheelchair. We went sort of using a manual chair from about five, but he went off his feet

completely at nine. And somewhere he was completely wheelchair bound and it's a condition that starts and the legs go first and then it just works through the body, so. At the moment he is sort of nearly fifteen he is sort of struggling with his upper body movement. He has got school obviously as well, so. He needs help sort of with food cutting up but he is still managing… he still manages (Gail).

Having a disability provokes stares from more able bodied people. Over time, Peter has realised this is something that makes up his life, he seemingly used to the stares and ignorance of outsiders. However, there are times when he has been upset because of people's lack of consideration for his feelings:

I know they don't mean to be cruel, they are just being nosey and having a good look because I look different. They probably try and work out what I've got… it just isn't nice being stared at, it just makes it clearer that I don't fit in… I suppose a lot of people work hard to stand out in a crowd (laughs). For me it is natural, a gift… I've heard lads at the youth centre say stupid things like 'I wonder if he can talk' or 'look at him he's spitting' and they laugh and it pisses me off. They are the ones who think they are hard and it would give me pleasure to kick their heads in if I could… rough justice…When you have what I have got I think you feel you have to prove yourself, to show that you can do things that people presume you can't do. But then everybody tries to prove themselves in some way (Peter).

This excerpt also illustrates how Peter tries to normalise his experience in his talk of how in some way everyone tries to prove themselves. By saying this he is saying his experience is not unique to him having a LLC, instead these times of conflict are part of ordinary life, of being a teenager, of being a 'normal' human being. Peter's ability to make fun of situations seems to help him through the difficulties he faces. Interestingly, Gail did not report any specific discriminatory event. This could be because she does not

notice these events, or simply she has not been present when they have happened. The alternative could be because they bear little relevance in her mind and their busy lives to go onto discuss, remains to be seen.

(iv) Now and the future

Further to this, there is reported to be very little in the locality that Peter can be involved in socially:

> He doesn't have a social life, basically. He goes to school… That's fine. He is at a special school and he enjoys it… And he actually mentally does not fit the criteria for special school, but he struggled so much with mainstream but his clinical needs are met much better at special school… But of course, he does not sort of have a lot of friends there because they are all…hmm… A lot more severe, a lot more mentally handicapped… But you see there is nothing locally either, cinemas that they can access locally, like you are looking at traveling to Leeds or Huddersfield… shopping, if it's winter time, you can't go shopping about town anyway because it's not very accessible so he likes to go to White Rose… I mean, it's got everything there, it's under cover and its, but hmm… so at the moment he is only going out once a month away from home, which is not enough (Gail).

Peter does go to a local youth club during the week but this the extent of his social activities. Gail has two older daughters and talked about how when they were younger she was able to take them dancing, let them go to the cinema and enjoy other activities. This is upsetting for Gail because despite Peters physical disabilities, he is very articulate but is not being able to express his mental abilities and enjoy his life to the full because of the lack of resources in the area. Peter did echo that there was a lack of things to do but he did get enjoyment out of attending the youth club and looked forward to his shopping centre visits.

Accordingly, Gail's life is circled around Peter. She has two older daughters but the focus of all her energies is Peter, whether it be attending to his daily cares, trying to organize further house adaptations or fundraising, her life is Peter. Peter recognizes this and talks about how going to college or attending respite facilities away from Gail may enable her to start building herself a separate life that is not focused on Peter. Thus, these focuses will remain after Peter's death and Peter will not then have the concern regarding Gail not having activities to help her through her grief. Although, time apart was discussed in a different context with Gail, it does appear that she would be willing to let go and free up more time for herself:

> For us both to have a little bit of time out, you know, I mean he needs it as well. I mean, yes I have got the van I can take him out, but he does not want to be going out with me all the time. He needs to be away from me (Gail).

Peter was the one child in this study phase that attended the regional hospice. This provision was valued by both Peter and Gail and they spoke of how they enjoyed their time spent there:

> I am sort of in contact with a couple of families, but not local. Families that I have met at Hospice… Most times we have now planned his visits so that we go with another family from the North who have also got a boy with MD, but it's the older boy that's not got MD that Peter pals up with… its great, you know and while he is there we don't fuss now we let him stay up while two or three in the morning if that's what he wants. Watching videos or the computer, you know and he is really enjoying his visits. Before he was really worried about 'what if there was nobody there that I know of? Is there anybody my age?' you know so… And so they are really good at now booking us in together. So it is really good… I mean quite often we have gone to the hospice when he has been poorly, rather than hospital (Gail).

Being around people in similar situations was reported to be of support to the parents in this study. Going to the hospice at the same time as other children with the same conditions allowed Gail the space to talk with other mothers about experiences. Gail also talked about being at ease whilst at the hospice because she knew all Peters care would be carried out with skill and attention and that she was surrounded by people who would allow her to rest and have time out. For Peter, time at the hospice was definitely viewed as a holiday. He felt unrestricted and happy to be with a friend for the duration of his stays. The hospice stays made life good.

As discussed under the rubric of other themes, looking into the future was difficult for Peter and Gail. When they did try and visualise the future, they realised they would like more information and support with dealing with different issues. Further to this, Peter struggled with trying to act like other able bodied teenagers, reflecting on his past and acknowledging his difficulties:

> I have sometimes gone out of way to show people I can do things and without anyone realising, sometimes I have hurt myself doing it… I have many arguments with people who find it reasonable to tell me what I can't do or shouldn't do. If I'm not here for long then I think I should be the one who decides what I can or shouldn't do… I'd love to be able to run again (Peter).

Planning for the future for Peter meant that he should aim to achieve and to not let his condition stop him in his tracks. Before, Gail had commented on his difficulty in schooling because he is mentally able:

> Whatever I end up doing I would like to leave home and study somewhere. Trouble is I need a carer and I refuse to take my mother to college with me (laughs), even though she will have heart failure if I leave her (Peter).

As noted, previously Gail acknowledges that they both need space. Perhaps, if Peter was to attend college in the future this would be a welcomed break for Gail. When asked about the future, Gail just talked about being able to have more breaks and worried about the growing up issues Peter was facing and how to deal with his degeneration. As a result, Gail opted for focusing more on the present than the future.

7.7 Integrative theme: Protectiveness

Through my analysis I identified a theme that was common to all the main themes. Therefore, this was conceptualised as an integrative theme, as it cuts across the categories and sub-categories of the final template. This theme enabled a more holistic analysis to be formulated.

Through out each interview issues of protectiveness appeared to transcend the lived experiences of both parents and children. All parents in the sample talked around issues of truth telling – in terms of what they should convey to their child or parent about their illness and if it is best to talk about such issues or not. Parents had had no support in terms of talking to their children about their prognosis but they had chosen to not broach this subject. Where other issues had occurred that the parents knew their child's degeneration would have impact, there had also been an opting out of talking about such issues truthfully. Maybe this was down to the parents finding their child's degeneration and death too difficult to comprehend themselves and too painful to consider talking about with their child. Instead, parents talked of being optimistic with their children and supporting their child's hopes and aspirations, no matter how these may not be possible to achieve.

Implicated were the parent's acts of over protectiveness. They were worried about the consequence of their child's actions in terms of their detriment to their child's health. For example, Sandra would be over vigilant in watching Bobby play, anxious of him falling and causing himself a sinister injury. Other parents talked of having difficulty in 'letting their child go', in terms of their child growing up and wanting independence from their

parents – just in case anything was to happen and them not be there. Interestingly, the children themselves showed similar protectiveness towards their parents. This could be exemplified in the children who wanted to talk about end of life care issues, of planning and of worrying about what would happen after their death (but to converse about these issues with professionals). And in the children who had had negative experiences with peers but had chosen not to worry their parents in talking about them. All these examples show the Childs strength of character in shouldering these burdens.

In addition, resilience with their life situations could be seen to develop from both the child and parent's acts of self protection. These were illustrated in parents actively not engaging in thoughts about the distant future, in not dwelling on their child having a limited life span and in thinking about the deterioration that their child was going to live through. Similarly, the children would reason their Being in talk of how they were happy with their life and although they could not do the activities more able bodied people could do, or the activities they could do if not on treatment, this was 'ok'. They rationalised this in a number of ways; by saying that without their condition they may have decided to stop doing these activities anyway, or they had no desire to do these activities, or they could maybe consider doing them in the future. Such visions helped them to deal with the now and to find happiness through other experiences and activities they were able to do.

7.8 Discussion

LLCs impact on a spectrum of issues within families. These may include issues relating to the child's autonomy, the activities they are able to be involved in and what realistic education and employment opportunities they may have. These are practical issues, but it was thought provoking to investigate the impact LLCs have on less concrete phenomena - such as verbalised thought processes, the reactions of others, and conceptualisations of the condition; of the prospect of the child dying and of future plans. It was interesting to examine the responses of both children and parents, to see how life is similarly or differently experienced and to identify how events may have shaped experiences or perceptions about the past, the present and the future. The parent-child relationship of

each dyad appeared to be strong. Parents had the needs of their children high on their agenda and the children were very supportive of their parents and their parent's actions. Parents sometimes had worries regarding how they were approaching issues as there was no 'cookbook' of guidance for them to draw upon. But children even when they were not in full agreement with how their parents were tackling issues would reciprocate support and would appear to consciously not add to the stress their parents were suffering by making them aware of any discontent. Even the younger children would hold back telling their parents about incidents that had made them upset. This is not to say that their relationships were weakened by a lack of openness to each other, instead I feel their relationships were stronger by trying to actively avoid conflict. Each participant was aware of the difficulty of their lives and their need to focus on happy times and positive outcomes was evident. Psychosocial support for parents and children extends beyond addressing concepts of death and medical decisions. By focusing attention on age-and developmentally-appropriate personal goals, parents and children could maximise the quality of their time together. Guilt and anguish arising from the parent's sense of responsibility was evident, especially in Sandra's case. As such I felt that more support could be offered to parents when their child's diagnosis has been given and when family dynamics change.

Hospitalisation was a significant feature of these participants' lives, yet few mused over it as being a main part of their lives. Interaction between children, parents and healthcare practitioners and systems however, was sometimes cited. Of course, what constitutes the best interests of the child can be debated. But one is left wondering how the child places themselves in this powerful adult dominated environment. Are they vulnerable? And do they have any say in what is happening to them? Perhaps the degree of child involvement in healthcare decisions is entirely dependant on the adults (parents and professionals) – in allowing such inclusion. In this study it was found that some of the children were actively contributing to healthcare decisions whereas others were excluded. It was understood however, that irrespective of the level of the child's involvement and their lack of desire for procedures, the potential consequences of not complying with professional advice outweighed any disgruntlements. Hence, children found themselves with few choices.

Accordingly, doctors were perceived as the most powerful and the most likely to exclude the child from conversations – yet this exclusion was not always acknowledged by parents.

Where previous studies have looked at the contribution of the child in consultations, they have provided a stereotypical view of the child's participation of that being confined to the provision of medical information and the upholding of a 'joking relationship' with the professional (Tates & Meeuwesen 2001). Indeed, there was evidence here that for a few of the children the interactions they had with medics were of an informal nature. However, this study demonstrates that services are moving forward in palliative paediatric care as children are establishing good relationships with their health care providers and wanting to have frank conversations with them, indicating their comfort in interacting with these professionals. Alliances can be made between professionals and children – but efforts are needed for this to happen. Even the younger children may benefit from talking about issues they have overheard from parents or cannot quite get to grips with, for example in the case of Sophie understanding the death of friend who had a similar condition. As stated by Stevens (1993), some of these children know a lot about their situation (irrespective of what they may convey), so it is ineffective and damaging to conceal information from them. He advocates, that questions should be answered truthfully, especially since it is claimed that the child often knows the answer and is just seeking confirmation. However, for some children and parents concealment from each other may actually strengthen their bond (parent-child). For many dying children it is argued that their primary concern is to have their parents near but to also be able to communicate their thoughts and fears with others (Liben & Goldman 1998). In addition, although children who are dying have levels of awareness about their status, they may find it hard to ask direct questions – for example Amy had desires to know about what may lie ahead but she did not know how to go about asking. This again may be in response to parental pretence or desire to avoid mentioning death (Pizzo & Popplack 1993). Children can feel more lonely and isolated by not being able to talk about their feelings in such circumstances (Dangel 1998). Moreover, the level of communication

dysfunction can impact on the grieving process, by leaving a sense of unfinished buisiness.

When professionals are interacting with families there is however, a call for the use of less technical language so that children and in some cases parents, can understand their situation better. This was something touched upon mainly by Amy and Paula, Edward and Gail and Peter. But at the same time there is a call for practitioners to avoid using language and a tone that is over simplistic, making the child feel patronised. As children get older they are increasingly involved in medical encounters but for children with LLCs, communication and learning disabilities might further reduce opportunities for involvement. Phenomenology provides important insights in to the lived bodily disruption that is intrinsic to the experience of LLCs. In particular, phenomenology discloses the ways in bodily changes alter the experience of surrounding space, disturbs taken for granted awareness of interaction with objects, disrupts corporeal identity, affects relations with others, and changes the experience of time.

What is really impressive in this study is that these children in recognising that they are viewed as being different, and they have to endure stares and societal assumptions, still hold onto a sense of self. The pressure to be 'normal' was felt by both the parents and the children in this study. This had caused efforts to try and reduce the impact of the condition. 'Normal' is a label inferred from discussions pertaining to these children not wanting to be characterised by their condition. These children did not display self pity about their life and either commented that such was the only life they knew or inferred that their condition was part of their identity, or that it was something that they had got used to and so was not a major difficulty for them. Furthermore, parents did not dwell on the loss of their 'healthy' or wished for 'healthy' child. They would instead talk about how their ill children had enriched their lives. In addition, the children did not express any sorrow for themselves and instead were on the whole very upbeat. It was inferred that these participants felt that 'this has happened, this is me and I'm going to live my life in the best ways I can'.

Indeed, this meant that for parents their energies would be focused on their ill child and providing them with the best quality of life they could. There is a large body of research which suggests that caring for a child with severe disability places families under financial strain as a direct result of the increased amount of care, particularly if that child also has additional medical needs (Bradshaw 1980, Baldwin 1985, Baldwin & Carlisle 1994). Recent work has focused on the reduced ability of the primary carer, predominantly the mother, to participate fully in the labour market (Shearn 1998). It has been noted that many mothers feel obliged to cease labour market participation on the birth of a child with a disability or at least reduce this participation (Shearn & Todd 1997, 2000). Interestingly, in this study we see the marked change in societal norms in a father leaving work to allow his wife to continue in the labour market and to allow him to be with his child. This was not perceived as an obligation but a need on the father's part (Edward) to be totally focused on his child (Sophie).

Furthermore, the children found it difficult to imagine living differently – something they conceptualised when asked to imagine life without their LLC. They were 'used to' a life of slow degeneration, of losing previously held capacity but for most of these children they struggled to fully imagine themselves in able bodies or having a life with no ill-health limits. In considering the meaning of living with a LLC here, it is useful to consider the phenomenological notion of the lived body (Sartre 1956, Merleau-Ponty 1962). As embodied subjects, these children do not experience their bodies as objects among other objects in their worlds. Instead, their bodies and how they live with their bodies represent their view on the world. They are embodied, not in terms of them having a body like they have a certain toy or possess a wheelchair, rather in terms of them existing or living their body (Toombs 1992). The body is therefore a vehicle for seeing or living rather than just the physiological body observed by others. In the case of progressive disability time may be disturbed in the sense that the future, rather than the present, assumes overriding significance. The assumption 'I can do it again' can no longer be taken for granted by someone whose physical capabilities are diminishing. This finding has relevance for the essential theme of the paradoxical temporality of the here and now which is discussed in the next chapter (chapter 8).

Frequently adults will ask children: 'What would you like to be when you grow up?' As the child grows up their desired roles become more realistic. What was interesting about these children was that they already they had realistic visions for their future. Although the youngest children had child like visions, they were still aware of the possibility of death or degeneration which would obviously affect their choices. However, one wonders about how deeply these children are affected by the fact that they may not meet their aspirations. Indeed the thought of adulthood is challenging especially for these children because they are aware that they may not reach adulthood, or indeed could need a lot of care if they do. As stated in the literature review, it is acknowledged that patterns of understanding in children are fluid; children's individual experiences, environment, including family environment, their intellectual capacities, their emotional profiles, ethnic, cultural and religious backgrounds – all contribute to how and when they come to fully understand the meanings of their illness and untimely death (Faulkner 1993).

Vygotsky's (1978) work was focused on the individual, like Piaget (1962) but in contrast he realised that to acquire an understanding of child development one needs to understand how and in what ways mental processes stem and develop via social interactions and different contexts, and of how mediating socio-cultural factors, particularly language can affect development (Rowe & Westch 2002). The children in this study were reflexive – they were critical and creative, they spoke of actively monitoring situations and people and as a consequence of their experiences they had accrued knowledge that had enabled them to modify or reject norms. Children in this study were aware of their illness and the limits it had put upon them. They were able to articulate their experiences and desires and in this respect each child appeared to be advanced cognitively in consideration of their age in years. Even Sophie was aware that death could happen to her which is in conflict with theory which suggests that children of her age do not usually sense that death is an event that happens to children, including themselves (Armstrong-Dailey & Zarbock 1993). However, the adolescents in the study would comment on their peers in hospital and how close they might also be to death, this invoked worry for them and they would express a desire to be able to plan for the eventuality. They were logical and consistent; they had each spent time thinking about

the meanings and impact of their own death and how they thought their death would affect those around them, in line with the ideas of Stillion & Papadatou (2002).

The children in this study were highly observant of adult behaviour and so were able to pick up clues about their situation. They saw that their peers find outward symptoms and signs of their illness or treatment, such as baldness, difficult to cope with. This was mainly exemplified in the accounts of Amy and Peter – and this realisation did seem to increase their isolation (Stillion and Papadatou 2002). However it was something that they had built resilience towards in order to try achieve a sense of Being normal. There is a large body of evidence suggesting children have high resilience, that they are able to draw strength from their experiences and successfully integrate themselves into society (Zani 1995).

With children dying from cancer, it has been found that there is a kind of 'mutual pretence' where, in order to protect their parents, children allow them to decide and set limits on open discussion about illness and death (Savins, 2002). This is not quite what was found in this data. Here, protectiveness was a significant theme that was present in all dyads. Of particular interest was how the adolescent children expressed that there were subjects they wanted to discuss with someone but felt that such were too awkward to talk about with their parents. These were mainly related to end-of-life issues. Throughout the child's life journey with a LLC it was made clear that their main concerns centred on the well-being of other family members. They were cogniscent of the upset their condition was causing their family and did not want to further add to this burden. Consequently, very few direct conversations had been held between parent and child about life-limiting issues. Adolescents are aware of their environment, of the potential consequences of their condition and their potential short life span. They want to be provided the opportunity to have private discussions with professionals to explore end-of-life issues, their cares, even their funeral and ways they could be remembered. These conversations are not conversations they immediately want to have with their parents. They do not want to be shielded from reality but they do not want their parents to have to face such too soon as they understand life is already hard for them.

Conversely, parents indicated their need to hold on to hope and to keep a focus on maintaining their child's quality of life and in extending their child's future. It was also interpreted that these parents impact upon the independence of their children. Children talked about how their parents were over protective as compared to the parents of their friends. They thought that their parents did to a degree understand what their lives were like but for the adolescents, it was felt that parents found it hard to let go a bit and to accept that they are growing up. This concept of over-protectiveness was acknowledged by parents themselves. Parents talked about being over vigilant and aligned such with their worry for further illness or injury in their children. They also displayed moments of self protection in their avoidance of direct conversations with their children regarding sensitive issues and in refusing to spend time thinking about the longer term future. Almost as if these parents were already at the edge of their coping ability and the nervousness and hurt that was possible in engaging with truth-telling and facing eventualities would be too much to handle and may be would have a deep effect on their ability to live life and extract the happiness they have in their current lifestyle.

However, it could be conceived that the difficulties these children do have, arise out of the concerns others including their parents, have for them. Childhood is thought to be a time full of fun and games, a time free of worry, although it is probably more complex than that we as adults may recall. These children however, were often kept from fully participating in normal life events and this was either as instructed by the demands of their treatment regimens, the illness itself, the over vigilance of their parents or their own conscience in not wanting to worry their caregivers. Interestingly though, these children were said to be happy and were enjoying their childhood in spite of all these barriers. They each spoke about their favourite pastime and what gave them the most pleasure in their lives.

Victor Frankl's (1962) seminal work, 'Man's search for meaning', conveyed that people have a psychological need to seek meaning and purpose in their lives, and this drive alone can help them to face and get through really difficult life events and experiences. As indicated in the literature review, in this area of study we can draw on existential

psychology. Freedom (Sartre, 1956), agency and responsibility (Heidegger, 1962, Levinas 1969), self-transcendence (Frankl, 1992), and the quest for meaning (Frankl 1961, 1988, 1992), each have significance for these parents and children in coming to terms with life while confronting imminent death. There is no greater existential crisis than that of facing one's own death or the death of your child.

The following chapter will go on to illuminate the essences of the lived experience of the parents and children of this study.

Chapter 8: Discussion of essential findings

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Previous chapters have detailed the thematic findings of this research and how these have held resonance with previous literature. The hermeneutic approach to inquiry seeks a deeper understanding of phenomena through analysing accounts of human experience in a particular context. It asks 'what is the essence of the phenomenon' through asking those who have experienced it to richly describe their experience (van Manen 1990:9). The intention of this study was to examine the meaning of the experience of Being and caring for a child with a LLC. Thus, the study asked children with LLCs, their parents and professionals involved in their care to describe their lived experiences. Using a hermeneutic phenomenological perspective, these descriptions were analysed to elicit the meaning of the phenomenon.

This chapter discusses the overall essential findings of this research, also highlighting the methods and limitations of the study. A number of recommendations for practice and education are outlined, and areas for further research are suggested. The chapter makes explicit the unique findings and contribution of this study and finally, a conclusion to the study is provided.

8.1 The essential themes

Van Manen (1990: 177) defines essence as ` ... *that which makes a thing what it is'.* Yet the essence of a lived experience can be quite ellusive and is forever changing.

Chapman equates the search for the essence(s) of an experience with ' ... *peeling an onion so that as one slowly and heedfully... unravels the multiple layers of the participants' experiences' the essence(s) are revealed*' (Chapman 1994:202). If this task is successfully invoked the language statement of the essence(s) is a description which Van Manen (1990:10) claims *'... reawakens or shows us the lived quality and significance of the experience in a fuller or deeper manner'.* In peeling away at the layers of the participants' experience in an effort to move beyond the words, I identified two

essences - Being normal in an abnormal unready world and the paradoxical temporality of the here and now - which I then wove into a single thematic statement aimed sententiously to capture the essential nature of the participants' lived experience:

> **The lived experience of paediatric life –limiting illness is expressed by an overt desire to be normal in an abnormal unready world, an illness and parenting experience that evokes the paradoxical temporality of the here and now.**

I will outline the process by which I reached this essential statement in section 8.1.1 and I will then reflect further on each of the essences it comprises. However in offering this single thematic statement I am cognisant of van Manen's words which state that:

> No conceptual formulation or single statement can possibly capture the full mystery of this experience. So a phenomenological theme is much less a singular statement (concept or category such as decision, vow or commitment) than a fuller description of the structure of lived experience. As such, a so called thematic phrase does not do justice to the fullness of the life of a phenomenon. A thematic phrase only serves to point at, to allude to, or hint at … the main significance of the text as a whole (van Manen 1990 p. 92–93).

With this statement one is drawn to concede that all research is yet another interpretation - another way of understanding the lifeworld.

According to van Manen (1990), a good phenomenological description is an adequate elucidation of some aspect of a person's lifeworld. To provide a good phenomenological description, one that captures the essence of what it means to live with a LLC, it was necessary to review and reflect on the themes derived from the rigorous process of data analysis, as these provided a means for an ontological description of the particular phenomenon in question (van Manen, 1990).

Hermeneutic phenomenology *'attempts to gain insightful descriptions of the way people experience the world pre-reflectively'* (van Manen 1990:9). It does not offer us the possibility of effective theory with which we can now explain the world, but rather *'it offers us the possibility of plausible insights that bring us in more direct contact with the world'* (van Manen 1990:9). Hermeneutic phenomenology has always had a special role in furthering knowledge. For children with LLCs and their parents, hermeneutic phenomenology had an important role to play in both reaching an understanding of the reality of participants' daily life and in creating a space for participants' voices to be heard.

For the participants, the experience of LLCs was not only personal, but was also transactional, communicative and profoundly social. A human being cannot be taken into account except as being an existent in the middle of a world amongst other things. The ontological question of 'what does it mean to be a child with a LLC or to parent a child with a LLC?' is also the key to Heidegger's (Annells, 1996) phenomenological view of the person. According to Heidegger (1996), Being - always capitalised - is that primordial state that enables everything else to come into existence.

Accordingly, Being a child with a LLC or parenting a child with a LLC literally means Being 'there' and 'there' means living as or caring for a child with a LLC. I understood that Being a child with a LLC or Being a parent of a child with a LLC is not extrinsic to participants' existence. In other words, the participants in this study are not isolated individuals who then enter into a relationship or subsequently take up dealing with the world. I understood the participants as Being present in the palliative paediatric care experience. According to Heidegger (1996), their existence has to be considered within the framework and against the background of the life-world into which they were 'thrown'. As such, these participants do not exist within palliative paediatric care without the other people, patients and professionals.

8.1.1 Process of developing the essential themes

The initial analysis undertaken revealed words and phrases that stood out as useful to the interpretation of the meanings attributed to the phenomenon. After highlighting these meaningful words and phrases from the individual transcripts (the parts), it was necessary to relate these back to the whole stories and look for shared meanings, and differences. Thus, the process of entering and re-entering the hermeneutic circle was evident, as my ongoing dialogue with the text. Through dialogue, I asked questions such as: How did certain events impact on the meaning of the experience? What was it like to be in this world? This dialogue enabled me to construct a phenomenological account that was rigorous. The hermeneutic process of reading, re-reading and dialoguing with the text revealed a number of themes that began to represent the shared experiences of the participants. This was an extremely time consuming and involved process, as I found that I was continually reflecting, questioning and re-reading, to ensure that I was being true to the experience and disclosed meanings as faithfully as possible.

Once I had completed my thematic analysis of the data I still felt that there were aspects of the lived experience not being illuminated or adequately revealed. There were words of the participants spinning around my head that I felt were key to revealing the essential nature of their experience. By essential themes I am not referring to a Husserlian notion of essences whereby I needed to engage in a level of imaginative variation to strip back concrete examples to their essential features. Instead, in adopting hermeneutic phenomenology, I tried to remain close to the participants experience. As argued by van Manen (1990), grasping a thematic understanding is not a rule bound process; I knew I could almost touch the experience, get closer to its reality if I was able to provide the reader with a fuller description and interpretation – my thematic analysis was uncovering the lived reality of life limiting illness but it was not telling all that was there. The 'ah-ha' moment of my research was in drawing together the essential themes. I cannot describe my thinking that brought me to articulating these themes but now they are articulated I can describe their meaning. Their understanding was evoked by my internal dwelling on the parts and the wholes of the texts and on the templates of the thematic findings.

8.1.2 Being normal in an abnormal unready world

Although the presence of pain, discomfort and loss of control featured across the interviews, and should not be underestimated, these aspects were overshadowed by participants' struggle and search to make sense and meaning of their experience and the world that they are part of. The study showed that participants strive to achieve normality; however they felt thrown into a world that was out of touch with the everyday world. It is interesting to note that the concept of 'throwness' is a key concept in Heidegger's phenomenology. It refers to basic conditions of the world that humans are thrown into. Throwness is Heidegger's way of revealing and expressing the existential experience of 'Dasein', as thrown humans submit to the world, and exist tactically with others (Heidegger 1996)

Gadamer (1985) distinguishes three modes of engagement that people have with their surroundings. He uses the example of a hammer. When using a hammer, we have no need for focal awareness of ourselves and our tool. The skills and practices we bring to our activity are so familiar to us, that we are simply unaware of their experience. This is the ready-to-hand mode of activity. However, when some problem is encountered such as the hammer may prove too heavy for the job, its weightiness becomes salient. This breakdown of action represents the un-ready-to-hand mode. The present-at-hand mode is entered only when people detach themselves from an ongoing practical involvement in a project at hand. People have to stand back and reflect. The hammer becomes an independent entity, removed from all tasks pursued. In ready-to-hand mode, participants' life was familiar and normal because their behaviours and situations fit other people and they were able to go about a usual lifestyle. But for example, being told or becoming aware of the life-limiting diagnosis, difficult phases in the disease trajectory (biological, social or psychological) or hospital admission moved them to the unready-to-hand mode. These events/lived experiences brought the awareness of being in an abnormal unready world and participants felt their life did not continue as before. The use of the term 'abnormal unready world' is awkward but deliberate in that the experience of the participants was fundamentally one of contrast from their pre-known everyday world or the perceived everyday world of others. From awareness comes understanding and the

participants were then moved to the third form of engagement, present-at-hand, where the participants reflected on the meaning of Being a child with a LLC or in parenting a child with a LLC. The need to be seen as normal developed the awareness of being in an abnormal unready world and participants felt their life did not continue on as before or like others and therefore their world would always be 'different'.

Entering into an unready world can be likened to embarking upon an adventure; the endpoint of which is both mobile and invisible. The journey is not determined but instead unfolds allowing the future to slowly reveal itself as it releases the present (Heidegger 1962). In this context, feelings of powerlessness, uncertainty, and isolation are lost in the parent and child's perceptions. They respond by trying to retain their Being in a ready world or in other words retaining normality.

Each parent spoke about how their child was just like other children but intermittently their comments would flag differences. For example, in both Sandra's and Bobby's interviews they made reference to how Bobby cannot join in all activities with his friends because of his disabilities, this within itself was acknowledged to single him out as different. Some of the children tried to reason their constraints, for example Peter in his desire to be perceived to be like any other teenage boy commented: *'It has been a gradual process getting into this chair and I do miss the things I used to be able to do but then I might have stopped doing things like football as I got older anyway'*. But it was not just the children who had been thrown into this abnormal unready world – it was the parents too. Living life knowing your child will die before you is within itself part and parcel of Being within an abnormal unready world. This knowledge had brought many changes to their life worlds they had previously known. Some parents for example, had continued to work to try and maintain some normality in life whereas others had been ejected from the world of work either because they could not cope with dividing their attention or because the care requirements of their child demanded it. As a result, social networks decreased or changed and families found themselves increasingly in the company of other families going through similar circumstances.

Van Manen (1990:102) suggests that we take on and become the space we are in. For example, as the home is a known familiar space where people feel secure and comfortable, home is a place where we can be ourselves and be what we are. In contrast, van Manen (1990) uses the example of walking alone in an unknown, foreign and busy city as creating feelings of lostness, strangeness, vulnerability and even excitement. For the people in this research study, they felt displaced from a usual everyday world. The uneverydayness and sometime unfamiliarality of life sometimes rendered them unable to derive understanding of context in any meaningful way. As van Manen (1990) points out, there are cultural and social dimensions associated with lived space that we learn through experience. However, nothing really prepares people for the world and space of living with a LLC, as many of the dimensions are so unfamiliar.

8.1.3 Paradoxical temporality of the here and now

Paradoxical temporality here refers mainly to how the participants of this study actively blocked out the future despite everything about their here and now being conditioned by it.

The awareness of events in our lives as before and after life stages is one of the formal characteristics of temporal experience and a fundamental aspect of the sense a person has of his or her continuity. Most of the events that we might place on the 'timeline' of one's life are routine. Some, however, mark major changes: marriage, the birth of a child, the death of a parent, retirement. After such events, things are not what they were before. This is particularly true in the case of a LLC. Scannel (2000:56) writes that when she learned that she might have cancer, *I felt my life organising into a sharply divided 'before' and 'after', with cancer cleaving the middle"*. The experience of before and after presumes the temporal continuity of our lives, but such news, portending not merely a change in life but intimating its closure, may signal the end of one self and the beginning of another, thus challenging the very sense of continuity that time-consciousness constitutes.

In the presence of a LLC patients/parents thus realise that everything has changed and that they now have a new life with 'a different view of the future'. But just as the dilated now presumes past and future, the shattering of one's self in illness, as real and painful as it may be, still depends on the deep and abiding sense of the self's continuity established in time consciousness. It is always against the background of this continuous sense of self that all of our experiences announce themselves in the now, even the most disturbing.

Participants discussed objective and subjective time and were very much focused on the now. If their thoughts ventured into the future, often it was the immediate future rather than the long term, and then talk would move back to the now, in a sense that they would talk of the future and reflect on the current now – as they (parents and some of the children) could reflect on the past as being very different to the now. Time was discussed on many levels, on the level of life routine, and specifically what it feels like to experience that routine, but also on the level of existential realisation of the contingent character of what we do and what we count on, and finally on the realisation of mortality. It was with this focus that parents especially were able to continue the care in the face of adversity and fearing 'reaching the bottom line'.

Paula mentioned at different points throughout her interview that she did not see the purpose of thinking about a negative future – the focus was on the time they have together in the here and now without too much concentration on what the future will bring. Indeed when the future was considered, it was the immediate future that reference was made to rather than any long term possibilities. Her daughter Amy however, was more open about her future and the uncertainty it held for her – she was excited about becoming an adult but was in fear of getting ill. In this respect she was aware of how time could change her Being in the world. For each of the parents involved in this research having a future focus would often give them the strength to live through the difficult times, but in direct opposition was the inability of parents to confront the reality of how time will bring death. Living in the here and now was evident as a coping mechanism in the interviews I held with both parents and children, for example Edward commented: '*we live each day as it comes and hope to God that she will get through this*'.

'Otherwise' was written when Kenyon (1996) was in good health – a poem about her day routine. A few years later, she learned that she had an aggressive form of leukaemia. She died fifteen months later at the age of 47. One of the few poems she wrote during her illness was 'The sick wife', in which she expresses her sense of lost freedom and vitality against the background of the seeming freedom of everything that she simultaneously experiences around her – children, retired couples, dry cleaning swinging on hangers – as she waits in the car for her husband in a shopping centre car park: *'How easily they moved/with such freedom/even the old and relatively infirm'.* The last lines of the poem formulate and reveal her inner state: *'the cars on either side of her/pulled away so briskly/that it made her sick at heart'* (Kenyon, 1996:221). Simultaneity is a temporal form we all share, but how we take what appears in it can differ greatly depending on whether we are well or ill. Simultaneity has the capacity to bring individuals together in a common experience, but the illness of the sick housewife serves to isolate her painfully from those with whom she shares the same time. She knows they have the benefit of the ordinary and routine that she once had but that might have been otherwise then and that now is otherwise. They have the freedom that freedom from her illness would restore (Brough, 2001). The participants of this research expressed similar sentiments, life continues at speed around them and although objective time is realised, their subjective time is at a different pace to those outside of their experience. To represent the paradoxical temporality of the here and now, I have taken some excerpts and merged them together to form two short poems. These are displayed in table 8.1.

Table 8.1 Poems representing the paradoxical temporality of the here and now.

Parents	Children
There is nothing else we can do	I just look at each day and try and be happy
My child is going to die	These things are what I have grown up with
I sat planning her funeral	If it happens gradually where will I go?
Everyday there was something else not working	And how will it happen?
Over the years he has deteriorated	If I'm not here for long then I think I should be the one who decides
We sometimes think half of his life has gone	I would really like to be a teacher but I know that that could be difficult for me
When I think of when the end comes, I feel sick; I feel this indescribable pain	I am going bald… but it might come back one day
We have never actually openly talked about what will happen ultimately	I am still growing
I don't want to think down them lines	I'm looking forward to getting big
Its 24 hours a day	I have had to stop dancing classes but I can start them again… if I get better
All your time is taken up	I have to try my best to get over it
	I'd love to be able to run again
	I'm not scared of dying
	If I go to heaven I need to have my ears pierced.

8.2 Reflection on methodology

Van Manen (1990:31) identified activities which provided me with a methodical structure that promoted freedom and initiative in my involvement with the dynamic process of hermeneutic phenomenological inquiry. Here I will reflect on the research process and how these intertwined activities were considered.

Through telling their stories and describing their lived experiences, the participants in this research divulged the history surrounding their experience. These are histories which are suffused with an illness experience, which when hermeneutically analysed can reveal an

understanding of the experience as lived by the participants. The illness is therefore seen to be the lived experience of the disease or of caring, from its onset (Kleinman 1988). This aspect of 'turning to the nature of lived experience' (van Manen, 1990) utilises the understanding that all experience can be seen as temporal in nature. Hence, a person's experience of being told the prognosis is an experience that is imbued with a history of this moment's `becoming'; a history of past experiences that all roll into one and influence the interpretation of the present moment.

When I commenced this research I knew the data gathering phase would be difficult, not quite as active as I might have thought with the children, but difficult. I put plans in place that I felt would make the process easier for the participants to enter in to and would allow a greater depth of material to be gleaned for later analysis. Particularly for the parent and child studies, I had to attend a number of ethics board meetings to argue the basis of my work and why I wanted to talk in depth with these 'vulnerable' groups. I can remember on receipt of my first few 'researcher consent to contact' forms, colleagues telling me "you are brave" and me thinking "what they talking about, I am just the researcher in this dynamic". Maybe I started out a little naïve. To develop a level of trust with these parents and children I would make visits to their homes and engage in general conversation and play. I wanted the interviews to start out with these people being comfortable in talking with me. I think this actually worked and that my research findings have benefited from this stance. However, I had not considered how by doing this, I was making myself more vulnerable. My status as the researcher became less formal and I suppose I became something more than an acquaintance. Increasingly, parents would talk about quite private topics such as their feelings for their husbands or annoyance with their own parents, almost as if to some degree I was evolving into a counseling figure, someone who could listen. I did not get to know these people well enough or long enough to become friends with them, but my prolonged contact made me feel emotionally involved. I would find myself in tears after interviews and would ruminate a lot on what had been said. I also struggled to reduce my contact. Through establishing a relationship with these participants prior to data collection I allowed myself to enter their life worlds and to genuinely be caught up very strongly in the emotion of their lives.

The essence of the participants' experience is given within the language of the stories that arise once the taped interviews have been transcribed. The method chosen supports the unraveling of this meaning so as to present it in a manner that is conducive to others taking meaning from it. To mine the meaning from open-ended interviews is an enormous task and one that takes considerable time and care. Taylor (1994) speaks of the enormity of this qualitative process, but also of the outcomes that can be achieved so long as this interpretive process is approached with the high degree of mindfulness that it deserves:

> It is the responsibility of any researcher doing interpretive work to sift through the gathered information very carefully, so that the essence of its meaning can be salvaged. Other details that have no contextual bearing on the main intentions of the research are put to one side. The salvaging of qualitative information is reminiscent of searching for gemstones of a certain type; some gems are of a desired type, others are precious but they are not the type being sought, and some of the other stones are clearly pieces of gravel stones and grit (Taylor 1994: 187).

The transcribed interviews became the phenomenological texts upon which the process of hermeneutic analysis was made. The interviews were analysed with the purpose of inducting the different meanings the experience had for each person. With each reading I was back there, back in the participant's home, remembering the sequence of events we engaged in, the body language and the emotion. Considering all these memories that alluded to all my senses I was able to arrive at interpretations of experience. These memories helped me to illuminate the experiences through writing.

The analysis process was messy. I wanted to report everything that was said, I felt that it all held meaning and so was worthy of an audience. Over time I moved away from wanting to report everything and I searched for what I perceived to be the most meaningful parts of the whole. But then I still found that I wanted to look at the whole but more academically, to allow the essential nature of this lived experience to be shared

with my audience. To do this, I set about trying to find what I considered to be the essential themes. Through all the everyday moments I had captured, I asked myself what was the commonality of this experience? How were thought processes and related comments framed? And how did this then impact upon behaviours? And the lived experience of Being and caring for a child with a LLC? As I have stated earlier, once I had got to this level of description and interpretation I had a 'ah – ha' moment. I was always looking for parts of the text that echoed a sense of an individuals experience of their illness or of caring for their child. I am excited about how I can now get across to other people better this lived reality. It has been a time consuming process and I know that I could keep going back to my thematic templates and keep rearranging titles and sub themes because with every read and re read of the data I see different things. However, I do think that I cannot move beyond the data any further than I have. According to Van Manen, essential themes are not:

> Objects or generalisations; metaphorically speaking they are more like knots in the webs of our experience, around which certain lived experiences are spun and thus lived through as meaningful wholes. Themes are the stars that make up the universes of meaning we live through. By the light of these stars we can navigate and explore such universes (van Manen 1990:90).

The themes identified are relative to my context of engagement with the text and therefore accepted as simply one amongst many ways of understanding these experience(s). Other people will see other things and maybe will draw other conclusions.

Rather than me conceptualising and theorising about what it would be like to experience life-limiting illness, I have sought to understand this experience from those who live it as an intimate part of their being-in-the-world. Commonalities in essential themes between the various interviews were identified which guided the uncovering of two essences. These essences were later called upon in the formulation of a single sententious phrase that captured the cardinal nature of the participants' lived experience. The analysis and

review process was completed when no more new themes arose. The outcome gained from following the six stages of this method was the uncovering of two essences: Being normal in an abnormal unready world and the paradoxical temporality of the here and now. These essences are seen to illuminate the essential nature of the lived experience of Being and caring for a child with a LLC.

This activity of the research method attests to the value of seeking a greater understanding of a human experience by treating the people who are actually living the experience as the experts. This again, was something I had to keep a strong ground on when it came to putting together ethic proposals and attending ethics board meetings. I had to repeatedly argue my case for wanting to speak with parents and children living this experience. On completion of this thesis, I feel I have remained oriented to the phenomenon and my chosen methodology throughout.

8.3 Strengths and limitations

A variety of strengths and limitations are identifiable within this research. These relate to issues such as my status as the researcher, the chosen methodology and methods and the research findings.

I acknowledge that I am a novice researcher but although this is a limitation in itself I feel it has been to a degree compensated by my interest in the phenomenon under study and in phenomenological methodology and methods. This interest has led to information being gathered from established researchers and professional health and social care workers and I have engaged in wide reading that has helped me to concentrate on both the phenomenon under study and the research approach.

Roberts and Taylor (1998) argue that to be credible, phenomenological researchers must research areas where they have expertise. My knowledge of palliative care and paediatrics was limited before I commenced this research. I had had experience of adult family members requiring palliative care and I had been an informal carer for these individuals. I had worked for a few months in a palliative care setting, conducted a

locally funded paediatric palliative care service evaluation study and had experience of working overseas at a summer camp with children with developmental disabilities. Throughout this work I have lost loved ones and I have also become a mother. Although these experiences do not qualify me as someone having expertise in the phenomenon under study, I believe each experience has helped me to empathise with my participants and to develop a sense of what their lives are like. I am aware that there is still so much I have yet to learn and discover.

I believe that I have a number of inherent strengths that have helped me with this research. I am at ease and able to have in depth conversations with people irrespective of their age, standing and level of previous contact I have had with them. Through my life to date, both professionally and socially I have learnt to listen closely to people and be guided by my intuition so that through interaction we can resolve difficulties or get to the heart of an issue. For example, this is evident in helping a student determine what it is about a subject they are having difficulty with. These skills or abilities I have developed, have allowed me to engage in this research with confidence. Furthermore, I believe these abilities coupled with my openness made participants feel comfortable in my presence which led them to be very open about their lives. Lived experience material in this study was gathered and reflected upon by means of in-depth interviews. The relationships formed with each person were trusting, adding a large degree of depth and richness to the data. The quality of the gathered data I believe was dependent upon forming these trusting relationships.

The chosen methodology helped me to recognise the importance of the influences that I bring to the research and the impact of these in generating data. I aimed to channel all my internal and external resources to produce a phenomenological answer to the research question: 'What is it like to be and care for a child with a LLC?' This was demanding in terms of there being no direct path to follow. Hermeneutic phenomenology is a philosophy and not a methodology, and so he researcher is required to read and extract the principles of this and apply them to their study. This leaves the researcher open to criticism that the process of translating philosophy into practice involves the researcher's

interpretation. In seeking to make the decision trail clear to others, I have tried to distill the philosophical principles and have set them out in a way that I believe is accessible and open to scrutiny. The lack of methodological framework meant that I had to use high levels of interpretation to achieve credible findings. I had to keep assessing whether the research design I was using was leading to the uncovering or illumination of the phenomenon. Whilst it is not the type of study from which strong probabilistic generalisations can be made, and there is no wish (or need) to generalise any of these findings, it is possible that the views of the participants may correspond with the views of others in similar circumstances.

I acknowledge that the process of setting out my horizon can never be complete or fully understood by others, but that I have taken this direction as far as possible in working towards the development of a fusion of horizons. The principles of the hermeneutic circle have served to highlight the value of analysing the data at a macro and micro level over a number of years, living with the data, and acknowledging the evolution of the data over time, both through conducting further interviews with participants and through awareness of changes in social, political and personal contexts. The methodology served to guide the level of interpretation undertaken, advocating that analysis should move beyond description but that interpretation should not move beyond the data and out of the hermeneutic circle.

A further factor to consider is the appropriateness of the sample of participants. My epistemological approach was to seek knowledge from those who live the experience. Therefore, all participants were either a child with a LLC or someone who cared for them, including parents and professionals. A gate keeper process was used as advised by the research steering group and academic panel. This meant that key professionals originally invited participants to participate. One then has to consider the strengths and weaknesses of such an approach in terms of the final sample and my control over it. The sample achieved may be or may not be representative of the population of children with LLCs and their carers. The gatekeeper may have only approached families they 'liked' or they felt had experiences that would enrich my findings. However, the premise was that

there would be no bias and the gatekeeper would send out information packs to all families that met the given research criteria. Still, one can say the research was limited to accessing the insider perspectives of those chosen by the gatekeeper. However, the research is unique in it in-depth focus on children with LLCs themselves and their parents.

A limitation was imposed by the lack of participant diversity. People who were part of an ethnic or racial minority were absent in this study. The issues of ethnicity and race and how it impacts on everyday life are important and require further research and understanding within this domain. The breadth of the study is itself also a limitation. It was frustrating not to have the scope to go into much more depth and to interview the participants longitudinally and to also go on to interview other family members. The challenge now is to explore in separate detailed studies, some of the issues that this study has raised at a general level, such as the lived experience of protectiveness.

I propose that the study's inherent strengths, limitations and quality must be viewed against the methodological goal of bringing Being into view. The strength of the presentation of the actual thesis is also important in achieving this goal. To this end, the reader can judge how well the document has been crafted as a phenomenological text.

8.4 Implications

While the general structure of a doctoral study should conclude with a series of specific recommendations for practice, education and research, a list of prescriptive recommendations is considered by some to be inappropriate for an interpretive phenomenological study (Darbyshire 1994), the aim of which is to deepen understanding by illuminating and interpreting important themes. It does not describe an objective reality or discover generalisable rules about a particular situation. However, the findings of this research do have practical implications for those working within palliative paediatric care. My intent is to enhance awareness of Being and caring for a child with a LLC and the possibilities for change within our practice, education and further research.

Indeed, this research has provided a rich interpretation of the meaning of living with a LLC to children patients and their parents. As stated, interpretative inquiry does not lend itself to generalisation. However, the implications for practice that have arisen from the participants' experiences in this study may be significant and resonate in similar populations. The suggestions I make have not been proven to be statistically significant to a large cohort of participants, instead they are drawn from the interpretation of the few participants in this study. However, the findings provide unique insight for planning and implementing appropriate health and social care services and adding significant evidence on which to base practice and education that should be enhanced by further research. This section discusses these implications and provides a number of recommendations aimed at improving practice.

There are a number of issues, which can be addressed by individual professionals in their day to day practice. The findings illustrate the inter-dependant nature of relationships with professionals and parental evaluations of life events. The findings highlight the importance of inter-personal skills, communication skills, and provision of information to parents and children using appropriate terminology, respecting parent's views, adopting a holistic family centred approach and developing trusting relationships. A number of current service strengths were identified including: the contribution of some professionals who were perceived to be dedicated to the care of children and the contribution of specific services such as the children's hospice. Service development needs to build on the strength of services such as the children's hospice and advocate its philosophy to other areas of provision. However, a number of more specific practice recommendations can be seen to evolve from this research.

It is advocated that professionals adopt a subjective approach when working with children with LLCs and their families. The reason for this is twofold. Firstly, what parents and children know and what they talk about can be varied. The implication here is that professionals should not rush in with generic rules or protocols regarding bad news disclosure or other aspects of information relating to the prognosis. They need to approach each child and parent individually as they are each unique with their own

histories and dynamics. Secondly, the notion of 'protectiveness' in families needs to be considered. In essence this might be viewed as mutual deception/denial which is frowned upon in the literature. However, the way it is lived is actually embedded within caring for each other. So again, for professionals to rush in would force a break in their protectiveness. Here, professionals need to act as a third party to explore what each person wants to share with the other and to how to go about this. This is a difficult job to work out but professionals need to try to avoid the jump from silence to whole truth-telling prior to interacting with families (see Langsdown 1996). Both points lead us to realise that this holistic understanding can only be achieved if the professional has a relationship with the family and knowledge of the child.

In forging friendships with other like families, miscommunication can occur and so it is felt important that professionals could afford the time to talk with families regarding their specific situation and to offer any support they me need to deal with the impact of issues in other families – for example in cases of loss.

Participants here talked about having their days filled with care and medical related tasks, or in being constrained by such. Achieving a life balance can be difficult. Both parents and children benefited from being part of a social network and having time out from their everyday situations. Even when families do not talk about their discontent it does not mean they would not benefit from receiving more help. Here, participants were managing but there was a definite cry for more practical help, assistance and holistic care like that offered by the children's hospice. The hospice provides social activity for both children and parents and peace of mind in knowing staff who work within it are well trained and able to meet the needs of all those who they care for. Parents want to be with their children so they expressed a desire to be able to be accommodated in the majority of any respite activities they could be afforded.

The findings from this study provided valuable information and knowledge for those involved in the care of paediatric patients with LLCs. The findings also represented possible areas for further research.

8.5 Recommendations for further research

The study suggested that there are many aspects of the care of children with LLCs that require further consideration. Any research endeavour that seeks an increase in understanding and awareness of the needs of children with LLCs, their families and carers, is helpful as many potential research directions exist. The following topics may provide additional insight into the nature of the phenomenon:

- A systematic comparison could be carried out between patient groups; for example, comparing those with cancer conditions against those with non cancer conditions. This may provide a deeper understanding at a practice and commissioning level of needs, in relation to needed available systems of support. At a theoretical level the issues inherent with different conditions and their impact on the lived experience of life-limiting illness could be explored.

- A number of further in-depth studies could be focused upon the integrative themes of the current research – including the issues of truth-telling, protectiveness and resiliency. With concentration on these elements of experience a greater understanding of their existence could be conveyed.

- In the literature review and subsequent findings I discussed the notion of 'a good death'. Accordingly, one of the most difficult challenges faced by end-of-life care providers is helping patients achieve or maintain a sense of dignity. There is mounting evidence that suffering and distress are major issues facing dying adult patients and some studies suggest that psychosocial and existential issues may be of even greater concern to patients than pain and physical symptoms (Field & Cassel, 1997 & Breitbart, Rosenfeld & Passik, 1996). Dignity therapy is designed to address psychosocial and existential distress among terminally ill patients. The therapy engages patients in a brief, individualised intervention designed to engender a sense of meaning and purpose, thereby reducing suffering in patients nearing death (Chochinov, Hack, Hassard, Kristjanson, McClement & Harlos, 2005). To date I am not aware of whether or how this intervention has been used

with children with LLCs. It would be interesting to conduct a piece of action research to evaluate the worth of such.

- It would be interesting to return to my sample of parents and children (if they are still living) to investigate issues of long term coping and any changes in their lived experiences that have occurred over time. In addition, I would take the opportunity to engage with wider family members for example siblings and grandparents to achieve a sense of what life is like for them.

- A bereavement study could also be initiated; looking at parents' life worlds after their child has died, bringing to the fore issues of spirituality and religiosity.

- I am also interested in the lived experiences of those with LLCs and their carers in other countries, whereby socio-political systems and models of care may be very different. Through such research a number of interesting findings could be shared to develop practice both here and abroad.

8.6 Unique contribution

The contribution of the study goes beyond the individual elements that constitute the findings. This study provides a rich ontological interpretation, rather than a mere discussion of the lived experience of the phenomenon; underpinned by the philosophical hermeneutic of Heidegger (1962) as well as the ideas of van Manen (1990/1996).

Nature of the sample

Few studies have conducted in-depth qualitative research with parents of children with LLCs. I am unaware of a hermeneutic phenomenological study that has involved parent-child dyads, or any phenomenological study that has looked at the perspectives of professionals, parents and children. This study can therefore be considered unique in its focus. The sample was difficult to achieve and I stand privileged to hear their stories and

have been touched by the generosity of parents especially as they talked candidly about their experiences.

New and original findings

This research hopefully encourages readers to thoughtfully reflect on what it is like for families and those involved in their care and to consider practice improvements that may enhance the family and professional experiences. The full significance of such reflection will ideally promote further questioning and inquiry about this and related human phenomena, as the phenomenological quest can never be conclusive nor complete but is provisional. As van Manen (1990) noted: *'It should only make people wonder – that's the point'*.

No other study has formulated such a myriad of thematic findings and none to date have described the essential nature of the experience for children and their parents.

Connectedness to recent policy initiatives

A number of comments throughout the interviews and focus groups pertained to a lack of co-ordination, whether it is in terms of referral to appropriate services or in terms of poor communication systems. As previously stated partnership working is considered to be crucial and is a core principle in the following key policies, and as such should help services work towards achieving better standards of care:

- The Every Child Matters: Change for Children agenda (DoH 2004)
- The NSF for Children, Young People and Maternity Services (DoH 2004)
- Making it Better for Children and Young People (DoH 2007)
- Aiming High for Disabled Children (HM Treasury/Dept of Education and Skills 2007)
- The Children's Plan (Dept for Children, Schools and Families 2007)

In addition, a number of funding issues were highlighted in this research. The 2005 manifesto commitment to double funding for end of life care will therefore be appreciated by children's services. To try and ensure children's palliative care services are given priority and planned well, the following eight goals are put forward by 'Better Care: Better Lives'. In accordance this research will add to the knowledge base, allowing service providers and commissioners to understand the child and their family's experience of palliative care better and thus put appropriate plans in place to meet the given goals:

- Improved data
- Equality of access to universal services
- Responsible and accountable leadership
- Choice in preferred place of care and widening of community services
- Better end of life care
- Stronger commissioning and value for money
- Successful transition between children and adult services
- Planning and developing an effective and responsive workforce

Furthermore the findings of this research have significance for the 'End of Life Care Strategy' (2008) – community services are still not comprehensive for many children with LLCs, as such this may be contributing to more children dying in hospital. Parents and children spoke of how they enjoyed visiting the children's hospice but they received very few days respite there. Other respite services were patchy in the provision they offered and there were families in this sample who received very little or no support. Parents and children do prefer to either be at home or in the hospice setting, this research therefore does not advocate that the family's choice for the child would be to die in hospital. Bereavement services were rarely mentioned – where they were it was evident that provision needs to be developed locally, as in line with the recommendation of the 'End of Life Care Strategy'.

Peer reviewed work

To date, I have had one paper accepted by an international peer reviewed journal and I have presented parts of this research at a number of conferences both nationally and internationally. It is planned that I will submit a number of further papers to peer reviewed journals. These papers will focus on the procedural issues of conducting research with life-limited children and will further disseminate the unique findings of my research. A further abstract has been submitted to the 11th Congress of The European Association for Palliative Care, being held in Vienna May 2009. I am awaiting a decision on this submission - the focus of the paper is on truth-telling from the perspective of the adolescent.

New projects

As stated earlier, I am interested in the lived experiences of those with LLCs and their carers in other countries, whereby socio-political systems and models of care may be very different. Recently, I was successful in achieving school innovation funding (School of Human & Health Sciences, The University of Huddersfield). This money is funding a trip to Cuba, whereby I will initially investigate ethics in research and practice. I have made a number of links with Cuban professionals and academics and will be visiting a number of polyclinics who provide palliative care. It is proposed that an external bid for funding will be formulated in collaboration with my Cuban counterparts that will have a mixed method design and will evaluate palliative care provision and the lived experiences of patients and their families.

8.7 Conclusion

This study reinforces the value of hermeneutic phenomenological research that aims to explore the experience of Being and caring for a child with a LLC. The findings of this study have provided insights into the world of palliative paediatric care and the world of the patients and their families implicated in it. The challenge is one of Being thrown into an abnormal unready world which compels one to consider the paradoxical temporality of the here and now. This brings recognition of being the same as others in a lived space but

also being different in a fundamental way that has a significant impact. The challenge is met by adapting to the environment to find ways of Being.

It is my hope that other academics and professionals who read this work can appreciate and be informed by the interpretations presented in the findings and discussion chapters of this thesis. This study has helped me to understand the lived experience of Being and caring for a child with a LLC. I trust that the findings of this research contribute to the study's aim.

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APPENDIX TWO: Ethics material regarding participation in the professional focus group discussions

Letter of Invitation to Professionals

(University/Hospital headed paper)

Date

Dear

Care Provision for Children with Serious and Life-Limiting Conditions in Calderdale and Kirklees: A Service Review and Needs Assessment.

I am inviting you, on behalf of the Centre for Evidence Based Health Care, to take part in a research study looking at the care needs of children with serious and life-limiting conditions.

Your participation is requested as a health, social care or educational professional to one of a combination of uni-professional, multi-disciplinary and multi-agency structured focus groups. Further Details of the study can be found in the information letter enclosed.

With best wishes

Yours sincerely

Name and Title

(Researcher / Health Care Professional)

.

Information Sheet to Professionals

(University headed paper)

Information Sheet for Health, Social and Education Professionals

.

Care Provision for Children with Serious and Life-Limiting Conditions in Calderdale and Kirklees: A Service Review and Needs Assessment

You are being invited to take part in a research study. Whether or not you take part is entirely voluntary. We have summarised the main objectives and methods being employed and hope that this enables you to make a decision about your participation in the research. If you require further information or a copy of the research protocol please contact the project lead Alison Timlin

If you do decide to take part but subsequently wish to withdraw you will remain free to do so at any time, without giving a reason and such a decision will remain confidential.

Project Aims

The overall project aims are to review current access arrangements and service provision for children with serious and life-limiting conditions and their families in Calderdale and Kirklees, to identify unmet needs in provision and make recommendations for service development. Information on the present services available will be gathered through talking to children, parents (and carers) and service providers. A full research report including recommendations for the development and improvement of services for children and their families will be published.

Research Objectives

1. To estimate the number of children with life-limiting conditions within the Calderdale and Kirklees population.
2. To review current access arrangements and service provision for children with life-limiting conditions and their families in Calderdale and Kirklees.
3. To assess the needs of children with life-limiting conditions and their families in Calderdale and Kirklees.
4. To identify unmet needs in current care provision in Calderdale and Kirklees for children with life-limiting conditions.

Your Participation

Your participation is requested in one of a combination of uniprofessional, multi-disciplinary and multi-agency structured focus groups of between 7-10 health, social care and education professionals. The focus groups will discuss the strengths and weaknesses of current service provision for children with serious and life-limiting conditions, and in addition offer opinion regarding what level and type of service you would like to see.

Sampling is purposive reflecting the need for health, social and education professionals with experience of caring for children with serious and life-limiting conditions.

Management and ethical approval for staff to participate has been agreed within all relevant organisations prior to the start of the study. There will be no fee paid for participation and each participant will need to negotiate/plan attendance within the course of other duties and commitments.

Recruitment and Consent of Professionals

You have been identified and approached by the link Consultant Paediatrician or Community Paediatric Nurse and invited to participate. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to complete an initial contact form agreeing for the researcher to

contact you. If you decide to take part you are still free to withdraw at any time and without giving a reason.

Following receipt of your contact details you will be invited in writing to participate in a focus group in advance. Another information leaflet will be included with the invitation together with a consent/confidentiality form and confirmation slip of attendance.

The focus groups will have an independent, experienced facilitator with a structured discussion format. As a participant you will be alerted to tape recording equipment and the confidential nature of the group.

Data Analysis

The data generated from the focus groups will be transcribed anonymously by a member of the research team and analysed using template analysis. In order to address quality issues the template will be verified by an independent person and upon completion a provisional report will be sent to two nominated members of each focus group to provide clarification and to ensure the research remains participative.

The final report will be sent to all professionals involved in the focus groups.

Confidentiality

The Centre for Evidence Based Health Care will comply with all aspects of the Data Protection Act 1998 and operationally this will include:

- All data will be anonymised at the point of data collection
- Appropriate storage, restricted access and disposal arrangements of participant names, contact details and tapes.
- Any information which will allow individual professionals or volunteers to be identified, will not be released.

In the analysis and presentation of the results of the focus groups particular consideration has been given to maintaining anonymity of the participants. The composition of the group will be described but participants will be given pseudonyms (false names) with no direct reference made to profession or job title. Where direct quotes are used care will be taken to ensure individual anonymity is maintained.

In addition, you will be asked to keep the names of any other group member confidential and will be asked to sign an agreement to keep all information discussed within the group as confidential.

Research Organisation

The research study was initiated and is sponsored by Kirkwood Hospice and the West Yorksire Forget-Me-Not Trust. The research is being conducted by the Centre for Evidenced Based Health Care, University of Huddersfield under the direction of Dr Jane Nixon, Karen Warner and Alison Timlin.

If you have any questions or would like further information please do not hesitate to contact Alison Timlin on 01484 472670.

Health, Social and Education Professionals - Agreement to Researcher Contact

(University headed paper)

Health, Social and Education Professionals - Agreement to Researcher Contact

Name of Researcher: Karen Warner / Alison Timlin

Name of Consultant/nurse: ……………………

Title of Project: Care Provision for Children with Serious and Life-Limiting

Conditions in Calderdale and Kirklees: A service Review and Needs Assessment

- **I have read the information sheet and kept a copy**

Please complete your contact details in the space provided

Date   ………………….

Name   ………………….

Signature of professional   …………………

Job Title   ………………….

Contact details   ………………….   Tel no./bleep no.

                              ………………….   Address

                              ………………….

                              ………………….   Best time to contact

Professional Consent Form and Confirmation of Attendance

(University headed paper)

Consent Form and Confidentiality Agreement for Professionals

Name of Researcher: Karen Warner / Alison Timlin

Title of Project: Paediatric Palliative Care Provision in Calderdale and Kirklees Service Review and Needs Assessment

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

2. I understand that my participation is voluntary and that I am free to ☐
 withdraw
 • at any time
 • without giving any reason

3. I understand that the focus group will be tape recorded. ☐

4. I agree to take part in the above study ☐

5. I will not disclose confidential details discussed during the focus group ☐
or disclose the names of other involved without their prior agreement.

------------------------- ----------------- ------------------------
Name   Date   Signature

APPENDIX THREE: Ethics materials regarding participation in the parent interviews

Letter of Invitation to Parents

(Hospital headed paper)

Date

Dear

Care Provision for Children with Serious and Life-Limiting Conditions in Calderdale and Kirklees: A Service Review and Needs Assessment.

I am inviting you, on behalf of the Centre for Evidence Based Health Care, to take part in a research study looking at the care needs of children with serious and life-limiting conditions. One part of the study involves interviewing parents (or carers) of children with serious and life-limiting conditions to find out about your experiences.

Whether or not you take part is entirely voluntary and if you do not wish to take part this will not affect your child's care in any way.

Find enclosed an information leaflet explaining the study and what to do if you want to be involved.

With best wishes

Yours sincerely

Name and Title
(Health Care Professional)

Parent Information Sheet

(Hospital headed paper)

Parent (Carer) Information Sheet

Care Provision for Children with Serious and Life-Limiting Conditions in Calderdale and Kirklees: A Service Review and Needs Assessment.

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with relatives if you wish. Ask us if there is anything that is not clear or if you would like more information.

Whether or not you take part is entirely voluntary. You will remain free to withdraw at any time, without giving a reason and this will not affect any aspect of your child's care. If you do not wish to take part this will not affect your child's care.

What is the purpose of this research?

The research projects aims to find out how easy or difficult it is for parents to access care in Calderdale and Kirklees, to identify unmet needs and make recommendations for future development. Information on the present services available will be gathered through talking to parents (or main carers) and health, social and education professionals involved in the care of children with serious and life-limiting conditions.

A full research report including recommendations for the development and improvement of services for children and their families will be published in May 2002.

Who are we?

The research study was initiated and is sponsored by Kirkwood Hospice and the West Yorksire Forget-Me-Not Trust (a charitable trust which raises funds to improve the services for children with life-limiting illnesses). The research is being conducted by Dr Jane Nixon, Karen Warner and Alison Timlin from the Centre for Evidenced Based Health Care, University of Huddersfield.

Why have I been chosen?

A selection of parents (and main carers) of children with serious and life-limiting conditions from the Kirklees and Calderdale region have been invited to take part in the study by either their hospital Consultant Paediatrician, Community Children's Nurse or the Forget-Me-Not Trust. We are hoping to carry out 40 interviews.

What will I have to do?

If you think you might want to take part please complete the initial contact form. A member of the research team will then contact you. If you still wish to take part a convenient time and place to conduct the interview will be arranged. At the beginning of the interview you will be asked to confirm that you are still happy to proceed with the interview and sign a consent form.

The interview will consist of a number of questions regarding your experiences in caring for your child. This will include discussing the help and support you and your family have or would like to have. There are no right or wrong answers, we are simply interested in your opinions. You can stop the interview at any point to ask questions or clarify the

meaning of any of the questions asked. If you change your mind at any time and do not wish the interview to continue the interview will be stopped. It is expected that the interviews will last approximately 1 hour. The interviews will be tape-recorded so that we are able to analyse their content in detail.

Will my taking part in the study be kept confidential?

All information that is collected from you during the course of the research will be kept strictly confidential in line with the 1998 Data Protection Act. Each interview will be given a code so that names are not used. Your name and contact details will be shredded following the interview. Tapes and interview transcripts will be kept locked away and only the research team members will have access to this information. No names will be used in the final report and no one will be able to identify you. The tapes will be erased at the end of the research.

What will happen to the information we collect?

The information we collect from all parents/carers will be summarised in a report and presented to the Health Authority.

If you want to know more, what should you do?

If you have any questions or would like further information please do not hesitate to contact **Alison Timlin at the University of Huddersfield on telephone number 01484 472670**.

Parent (Carer) Agreement for Researcher Contact

Name of Researcher: Alison Timlin

Name of Consultant/nurse:

Title of Project: Care Provision for Children with Serious and Life-Limiting

Conditions in Calderdale and Kirklees: A Service Review and Needs Assessment.

- **I have read the information sheet and kept a copy**

- **I am happy to be contacted by telephone by the researcher to arrange an interview**.

Please complete your contact details in the space provided

Your name   Your child's name

 Address

                                                            Postcode

 Telephone Number

Preferred contact time

Thank you for completing this form.

Please return it to Alison Timlin in the addressed envelope provided.

Centre for Evidence Based Healthcare

University of Huddersfield, Harold Wilson Building, Queensgate, Huddersfield HD1 3DH

Name of Researcher: Karen Warner / Alison Timlin

Title of Project: Care Provision for Children with Serious and Life-Limiting Conditions in Calderdale and Kirklees: A Service Review and Needs Assessment.

1. I confirm that I have read and understand the information sheet ☐
for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to ☐
withdraw
- at any time
- without giving any reason
- without affecting my child's future care.

3. I understand that the interview will be tape recorded. ☐

4. I agree to take part in the above study. ☐

------------------------- ---------------- -----------------------
Name of Parent (Carer) Date Signature

------------------------- ---------------- --------------------------
Researcher Date Signature

APPENDIX FOUR: Ethics material regarding participation in the children's interviews.

(Hospital/University Headed)

Dear

With reference to the following project:

Care provision for children with serious and life limiting conditions in Calderdale and Kirklees

I am inviting you and your child, on behalf of the Centre for Evidence Based Health Care, to take part in a research study looking at the care needs of children with serious and life-limiting conditions. One part of the study involves interviewing children with serious and life-limiting conditions to find out about their experiences.

Whether or not you allow your child to take part is entirely voluntary and if you decide to not allow your child to take part this will not affect your child's care in any way.

Find enclosed some information explaining the study and what to do if you consent to your childs involvement.

With best wishes

Yours sincerely

Sister Ann Brady

(Children's Community Nurse).

Experiences of children with serious and life-limiting conditions in Calderdale and Kirklees.

You are being invited to allow your child to take part in a research study. Before you decide whether or not to give your consent, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with relatives if you wish. Please do not hesitate to ask if there is anything that is not clear or if you would like more information.

Whether or not you allow your child to take part is entirely voluntary. You will remain free to withdraw your child at any time, without giving a reason and this will not affect any aspect of your child's care. If you do not wish your child to take part this will not affect your child's care.

What is the purpose of this research?

The research projects aims to find out how children experience, understand and cope with serious and life limiting conditions and hospitalisation, and to identify unmet service needs and make recommendations for future health care development. Information on these issues will be gathered through talking to children with serious and life-limiting conditions.

Who are we?

The research study was initiated and is sponsored by Kirkwood Hospice and the Forget–me-not trust. The research is being conducted by Alison Timlin from the Centre for Evidence Based Health Care, University of Huddersfield.

Why has my child been chosen?

A selection of children with serious and life limiting conditions from the Kirklees and Calderdale region are being invited to take part in the study by recommendation of their consultant. We are hoping to carry out 15 to 20 interviews.

What will I have to do?

Please also read the information enclosed for your child, and if you agree to your child's participation then give the information to your child. However, if you feel that your child is too young to understand this information, then it is thought most appropriate for you to disclose information regarding the study and their possible involvement in your own words. Ask your child if they would like to participate and if they agree then complete the enclosed researcher contact - consent form and return. Once your consent form is received, a member of the research team will then contact you. If your child still wishes to take part a convenient date and time will be arranged to meet prior to the interview. At this point, the researcher will also ask you about your child's illness history, how much they know about their illness and how it affects their daily life. It is proposed that the researcher will be given the opportunity to meet your child prior to the interview so that they can establish a degree of familiarity with your child and to determine your child's understanding of the research. A suitable date and time will be confirmed for the interview to be conducted at your home address. At the interview you will be asked to confirm that you are still happy to allow your child to be interviewed.

The interview will consist of a number of questions regarding your child's experiences of being ill and needing health care. This will include using child led activities to discuss the help and support your child has had or would like to have. There are no right or wrong answers; we are simply interested in your child's opinions. It is expected that the interviews will last around 1 hr, but this will depend on the child's age and concentration. The interviews will be tape-recorded so that we are able to analyse their content in detail.

Will my child taking part in the study be kept confidential?

Each interview will be given a code so that names are not used. Your names and contact details will be shredded following the interview report. Tapes and interview transcripts will be kept locked away and only the research team members will have access to this information. No names will be used in the final report and no one will be able to identify you or your child. The tapes will be erased at the end of the research.

What will happen to the information we collect?

The information we collect from all parents and children will be summarised in a report and presented to the Health Authority. A shortened copy will be provided to all involved.

If you want to know more, what should you do?

If you have any questions or would like further information please do not hesitate to contact **Alison Timlin at the University of Huddersfield on telephone number 01484 472670.**

Parent consent and agreement for researcher contact

Name of researcher: Alison Timlin

Name of Consultant/nurse:

Title of project: **Care provision for children with serious and life-limiting conditions in Calderdale and Kirklees**

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions_____ ☐
2. I understand that my parental consent is voluntary and that I am free to withdraw my childs participation
- At any time_____ ☐
- Without giving any reason _____ ☐
- Without affecting my childs future care _____ ☐
3. I understand that the interview will be tape recorded _____ ☐
4. I agree to allow my child to take part in the above study_____ ☐
5. I am happy to be contacted by telephone by the researcher to provide the researcher with some information about my childs illness and to arrange an interview_____ ☐

Please complete your details in the space provided

Your name -------------   Date ------------   Signature --------------

Your Childs name -----------

Address ---

Post code -----------   telephone number ---------------------

Thank you for completing this form. Please return the form to **Alison Timlin** in the envelope provided. Centre for Evidence Based Health Care. The University of Huddersfield, Harold Wilson Building, Queensgate, Huddersfield HD1 3DH.

Dear

I am inviting you, on behalf of the Centre for Evidence Based Health Care, to take part in a research study looking at the health care needs of children. One part of the study involves talking with children to find out about their experiences.

Your parent(s) has agreed to let you take part in this study if you want to. The decision to take part is now yours. If you decide that you do not want to take part your care will not be affected.

Please find enclosed some information explaining the study and what you will be asked to do if you agree to be involved.

With best wishes

Yours sincerely

Sister Ann Brady

(Children's Community Nurse).

Child Information Sheet

You are being invited to take part in a research study. Before you decide whether or not to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read, or ask your parent to read you - the following information. Please ask if there is anything that you do not understand or if you would like some more information.

Your involvement is voluntary. You can decide not to take part at any time, without giving a reason and this will not affect any aspect of your care.

What is the purpose of this research?
The research projects aims to find out how children experience, understand and cope with being ill and needing hospital care, so that services can be improved. Information on these issues will be gathered through talking to children with particular health care needs.

Who are we?
The research is being carried out by Alison Timlin from the Centre for Evidence Based Health Care, the University of Huddersfield.

Why have I been chosen?
A selection of children from the local region are being invited to take part in the study. We are interested in your experiences of care and are hoping to carry out 15 to 20 interviews.

What will I have to do?
If you would like to take part, the researcher will meet you so that you can be certain that you want to take part. At the interview you will be asked to confirm that you are still happy to be interviewed.

The interview will consist of a number of questions and activities relating to your experiences of being ill and needing health care. There are no right or wrong answers; we are simply interested in your opinions. It is expected that the interviews will last approximately 1 hour. The interviews will be tape-recorded so that we are able to look at our conversation in detail.

What will happen to the information we collect?

The information collected from all the interviews will be looked at and a report will be written summarising all our findings.

Will anyone know who you are?

No, all the taped interviews will be given a code; no names are going to be used. Therefore, no one will be able to identify who you are.

If you want to know more, what should you do?

If you have any questions or would like further information please do not hesitate to ask your parent or contact **Alison Timlin at the University of Huddersfield on telephone number 01484 472670**.

APPENDIX FIVE: The focus group agendas

FOCUS GROUP AGENDA

1. Introduce self

2. Thank all for attending and invite all to introduce themselves

3. Following introduction:

   'The overall project aims are to review current access arrangements and service provision for children with serious and life-limiting conditions and their families in Calderdale and Kirklees, to identify unmet needs in provision and make recommendations for service development. Therefore, it is important that today we try and explore these issues, focusing on current practice and suggestions for improvement with regards to children receiving palliative care for their terminal illness and the services in place or required for their families'.

Learning Disabilities Group

1. **How successful are the current access and referral systems?**
   - How are services accessed and patients referred
   - How quick are the procedures and once refereed do parents have direct contact with the professionals
   - Views on current education facilities for these children
   - Views on current financial support for families
   - Views on other provision and ideas to improve current practice

2. **How accessible and efficient are your services for patients from ethnic minorities?**
   - Are there issues also relating to the uptake of services?

3. **What respite services are available?**
   - How do parents access these
   - What are the views on these current arrangements
   - How could these services be improved - ideas

4. **How are the children's and their families needs assessed?**
   - Individually - by each professional for their own service
   - Collectively – all professionals coming together to plan care
   - How successful is communication between agencies

5. **How do your services achieve normalisation of life for these children?**
   - What services / professionals are involved with these processes
   - Could these services be improved

6. **How efficient are your transition services?**
   - For instance in catering for adolescents / transferring children to adult services

7. **What are your views on current staff training? And expertise? And supervision?**

8. **Other issues?**

GP/Medics

1. **What is the level of your involvement with these children?**
   - Involvement in care and care planning
   - Do you think your skills and knowledge are used to their full potential
   - How efficient is the communication between local consultants, tertiary consultants and GPs and the multidisciplinary team

2. **What provisions are in place regarding psychosocial support for patients, relatives and staff?**
   - Views on current provision
   - Ideas for future provision

3. **What provision are in place regarding respite care?**
   - Is this sufficient
   - Who supplies the service
   - What is the level of availability
   - How do parents access these
   - What are the views on these current arrangements
   - How could these services be improved – ideas

4. **How satisfied are you with current bereavement care?**
   - What information and services are offered to parents and siblings

5. **How accessible and efficient are your services for patients from ethnic minority communities?**
   - Are there issues also relating to the uptake of services?

6. **What are your views on current staff training? And expertise?**
And supervision?

7. **How could inpatient / outpatient services be improved?**

8. **Other issues?**

Nurses

1. How successful are the current access and referral systems?

- How are services accessed and patients referred
- How quick are the procedures and once refereed do parents have direct contact with the professionals
- Are key worker systems efficient and reliable
- Do you have multidisciplinary records

2. How accessible and efficient are your services for patients from ethnic minorities?

- Are there issues also relating to the uptake of services?

3. What respite services are available?

- How do parents access these
- What are the views on these current arrangements
- How could these services be improved - ideas

4. How are the children's and their families needs assessed?

- Individually - by each professional for their own service
- Collectively – all professionals coming together to plan care
- How successful is communication between agencies

5. What are your views on current staff training? And expertise? And supervision? And support?

- Views regarding psychosocial support for the family

6. Other issues?

APPENDIX SIX: Parent and child interview schedules.

Interview Schedule for Parent(s)

1. Participant identification number   …………………
2. Interviewer initials   ………………….
3. Date of interview   ………………….
4. Location of interview   ………………….

Socio-demographic details.

5. D.O.B of child/children   ……….../………..
6. Sex of child/children   ……….../………..
7. Sex of parent(s)   ……….../………...
8. Ethnic group(s)   ……….../…………
9. Religion(s)   ……….../…………
10. Relationship to child/children   ……….../………..
11. Occupation of parent(s)   …………/……….

History of illness

12. Could you tell me a little about what has been happening?

    Prompts

- ◆ Time of diagnosis
- ◆ Age at diagnosis
- ◆ Diagnosis

13. Can you tell me about how this has this affected the daily life of your child?
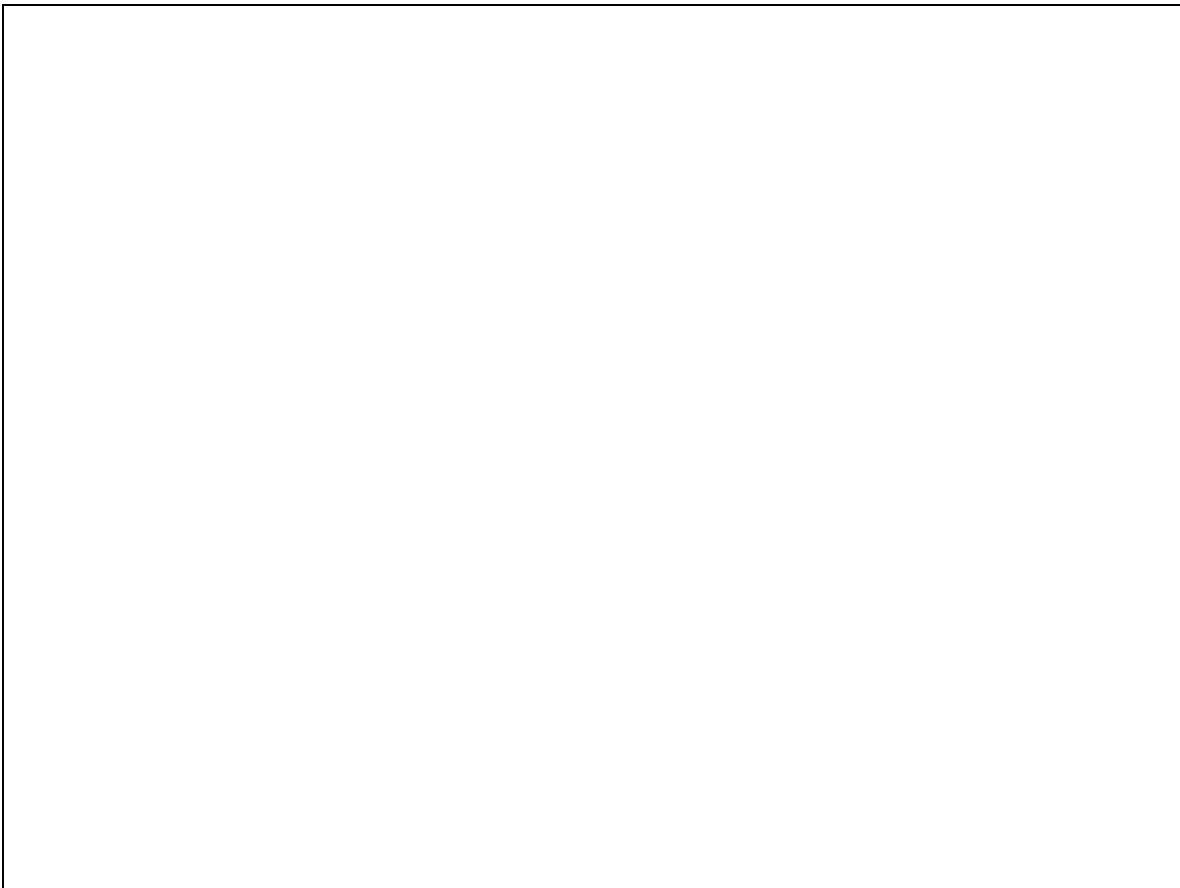
Prompts

♦ Activities of daily living (washing, personal care, dressing, going to toilet, eating and drinking, mobilising, getting in and out of bed)

♦ Medication.

♦ Technical nursing care/medical care

14. How do these affect other aspects of your child's life?

   Prompts

   ♦ Social life

   ♦ Friends

   ♦ Schooling

   ♦ Leisure including holidays

   ♦ Independence.
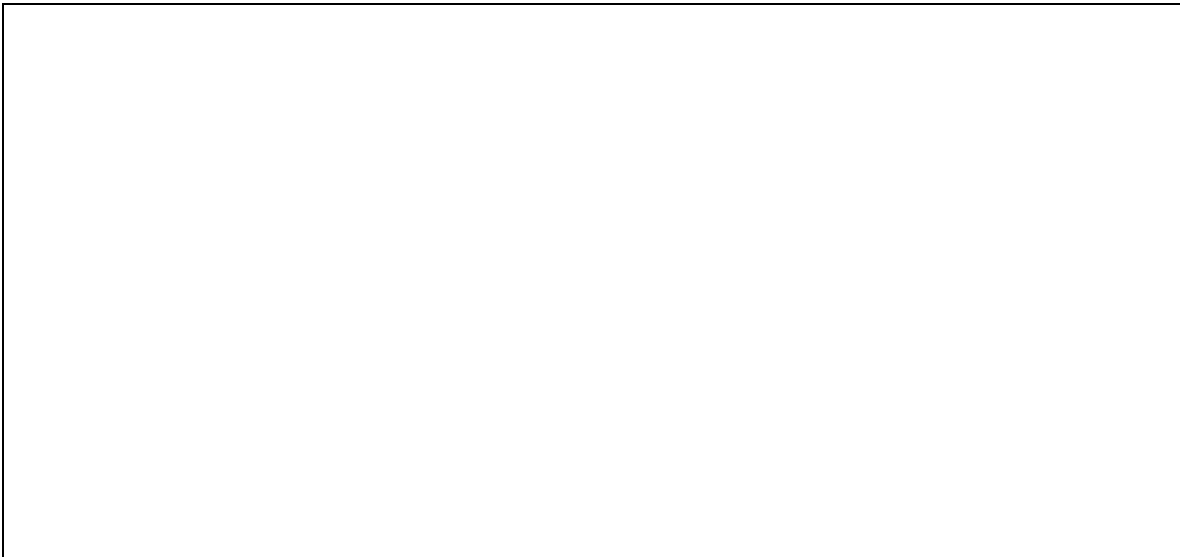
15. Can you tell me a bit about the help you receive at the moment?

	Frequency	Who initiates contact	Location	Payment	Key-worker
GP					
Con. Paed. Local/Specialist					
Comm. Paed nurse Outreach spec. nurse					
Health visitor					
Social worker					
Specialist teacher					
Psychologist					
Speech therapy					
Counsellor					
Alternative therapist – specify					
Physiotherapist					
OT					
Dietician					
Voluntary sector – specify					
Respite care – specify **Home** ♦ Voluntary ♦ Nursing ♦ SS Away from home School/nursery ♦ Residential/ Daycare ♦ Type Inpatient ♦ Hospital ♦ Hospice (child/adult) Holidays Other					

16. How has your child's needs affected the day to day life of your family?

Prompts

- ♦ Social life
- ♦ Leisure activities including holidays
- ♦ Finances
- ♦ Housing adaptation
- ♦ Transport issues
- ♦ Employment
- ♦ siblings
- ♦ Other difficulties

17. Has anyone talked to you about **your own** needs?
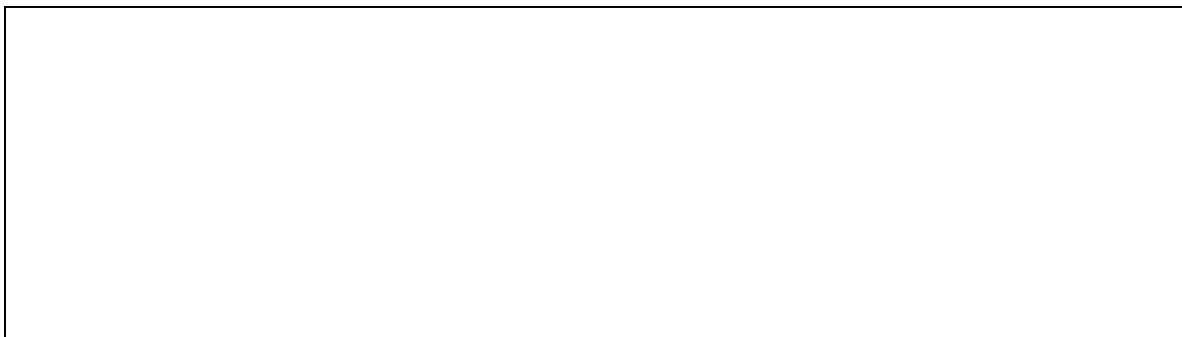
18. As a carer what do you consider are your needs?

    Prompts
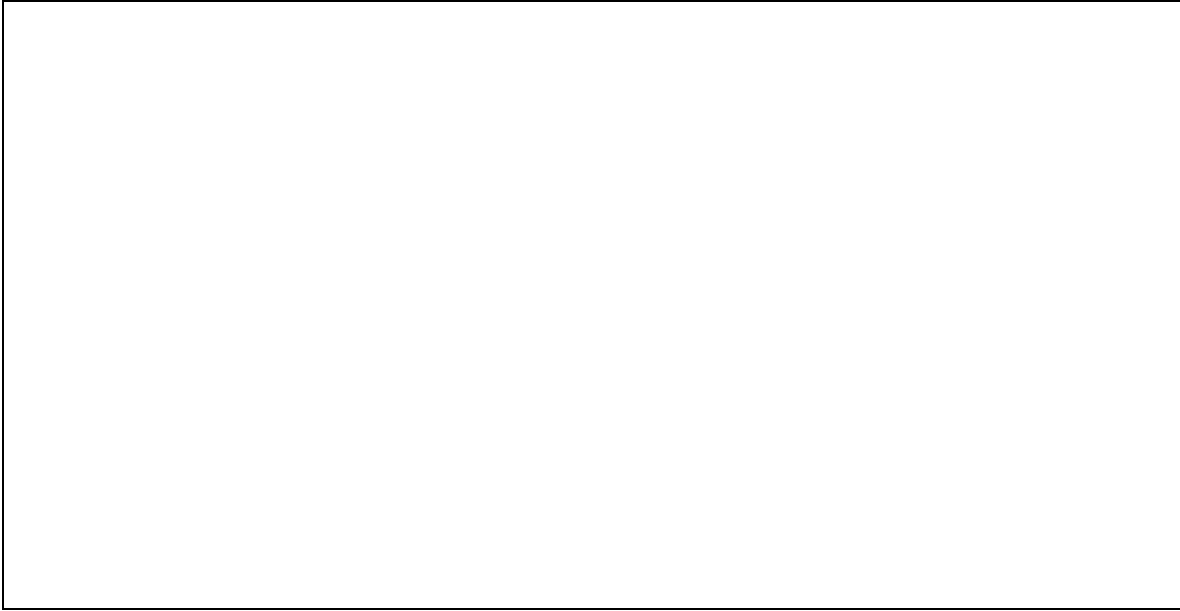
♦   Psychological, spiritual, religious

♦   Practical support

♦   Financial

♦   Information

♦   Respite
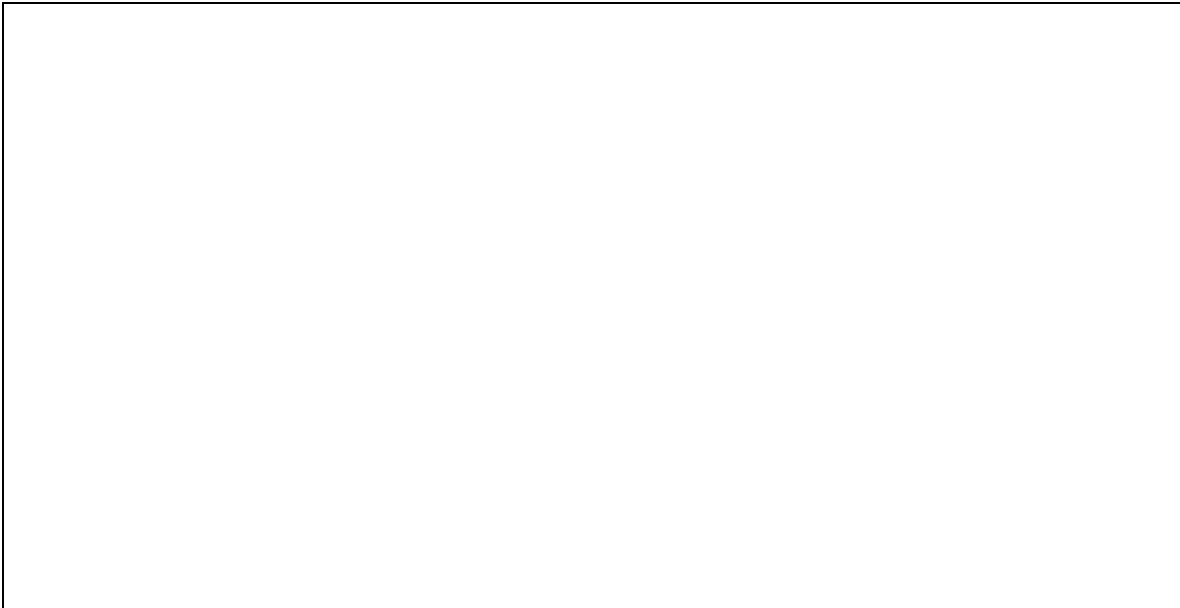
19. Of the needs discussed which one is the most important for you?

20. What additional help have you tried to get but couldn't?

21. Are there any other comments you would like to make?
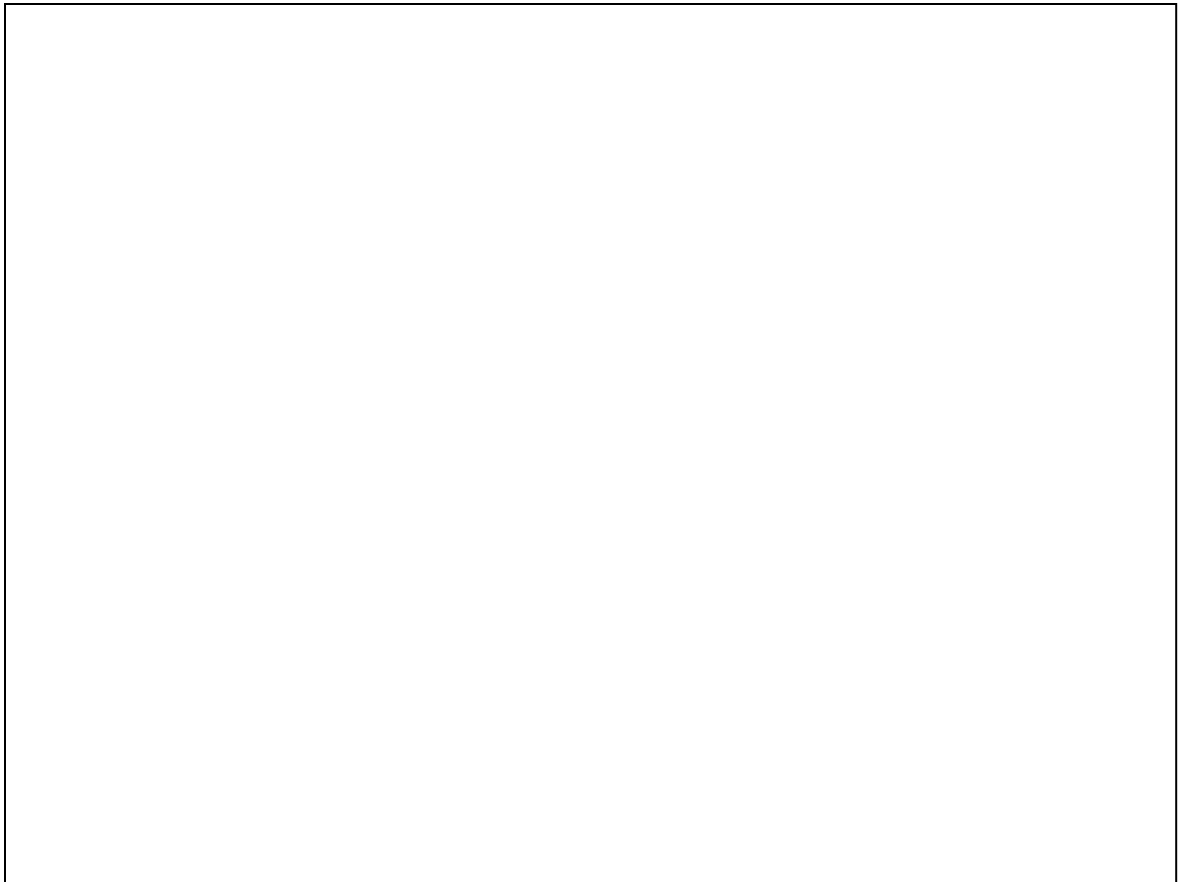
22. Would you like to read a summary of our findings when the study is finished

YES/NO

Thank you very much for all your help.

Interview schedule for younger children

1. Participant I.D. number   -----------

2. Interviewer initials   -----------

3. Date of interview   -----------

4. DOB of child   -----------

5. Sex of child   -----------

6. Ethnic group   -----------

7. Religion   -----------

8. History of illness and child's knowledge (obtained from parent)

9. Hello, is it OK if we have a little chat and do some writing today?

10. Do you mind if I tape record our conversation today?
(Here, the rules of the yellow and red card will also be discussed).

Personal factors

11. As a mechanism for getting to know the child in an unthreatening way, an **'about me'** sheet where the child can write (or ask the researcher to write) some basic details about themselves, and their likes and dislikes (for example, about food and pop stars, school, what happens at hospital) will be initially used. This will also reinforce the notion that the interview is about their perceptions, not right or wrong answers.

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│                   ABOUT ME                      │
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Social-ecological factors

12. Then the child will be assisted to compile an ecomap, which is a chart of people who the child views as important. This will help the researcher to understand the childs social context. The ecomap will be referred to at different points in the interview when discussing who might be told about or help with specific emotions/tasks.

The charts will be filled in to indicate the people nominated by the child as the 'easiest to talk to', 'best helpers' and 'most fun' – about personal things.

People	Easiest to talk to	Best helpers	Most fun

Speculated interpersonal factors, personal factors, adjustment/adaptation

13. Outline faces displaying various emotions will be used to stimulate a listing and brief discussion of key emotions and situations that give or have given rise to them.
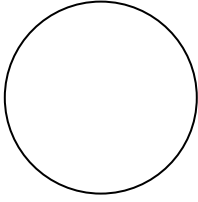
Shocked
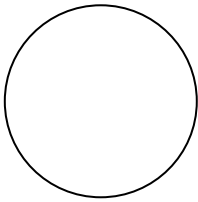
Happy
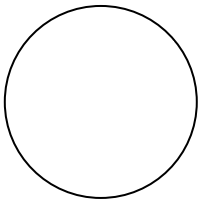
Sad
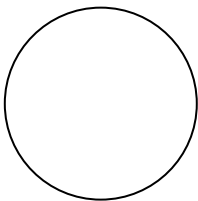
Angry
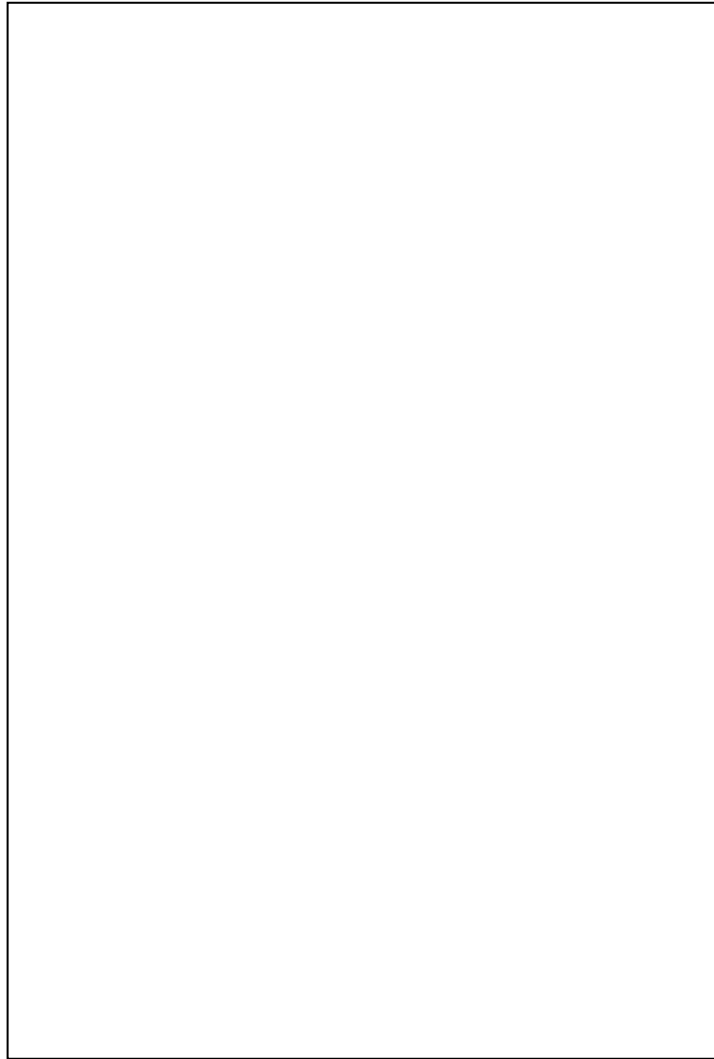
Adjustment/adaptation, personal factors, social-ecological factors

14. Next, the children will be asked to turn over sentence completion cards, which will ask about intense feelings.

These cards will have several functions:

- to elicit actual examples of extreme emotions
- to explore who in practice children turn to in specific situations
- to ascertain which responses of other people in those situations were perceived to be helpful or unhelpful.
- To ask what else could have been done or who else might have helped.

I feel really safe when…	The saddest I've ever felt was…	The happiest I have ever been was…	I feel scared when…

Psychosocial stress, stress processing, personal factors.

Now a ranking exercise will be included to specifically look at particular problems and coping strategies.

Problems – questioned in a way that pertains to child's specific illness

disease related, e.g. trouble breathing

15. If you had trouble breathing what do you think you might do?

What other troubles are caused by your illness?

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disease related pain, e.g. leg pain

16. If you had leg pain what do you think you might do?

What other troubles are caused by the pain?

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medical procedure related pains, e.g. injections hurt
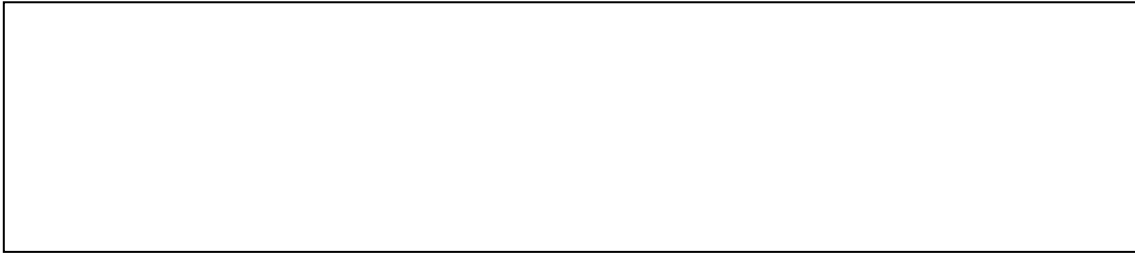
17. If you were given an injection that hurt what do you think you might do?

What other troubles are caused by the different medical procedures?

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hospital related problems, e.g. being kept awake at night by other children, lack of privacy

18. If other children kept you awake at night what do you think you might do?

What other troubles are there when you are in hospital?

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common problems, e.g. school, parents, friends.

19. If you were having arguments with your friends, what might you do?

What other troubles do you have with school or your family or friends?

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Possible coping strategies could include

- distraction
- social withdrawal
- wishful thinking
- self-criticism
- blaming others
- problem solving
- emotional regulation
- cognitive restructuring
- social support
- resignation

Taken from Spirito *et al* (1995).

Personal factors, adjustment/adaptation, stress processing

20. A pictorial vignette will now be used – showing a child in hospital –
The vignette will be matched to the age, gender and race of each child interviewed

'Sara/Jack is in hospital, she/he is not well, can you list three things that would make Sara /Jack happy?'
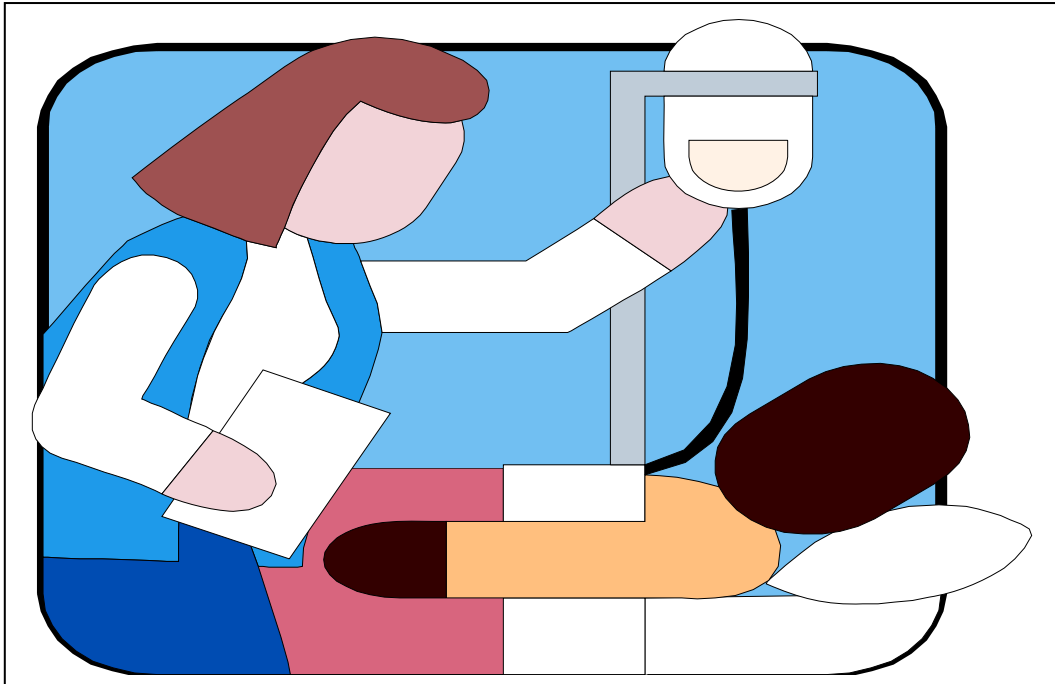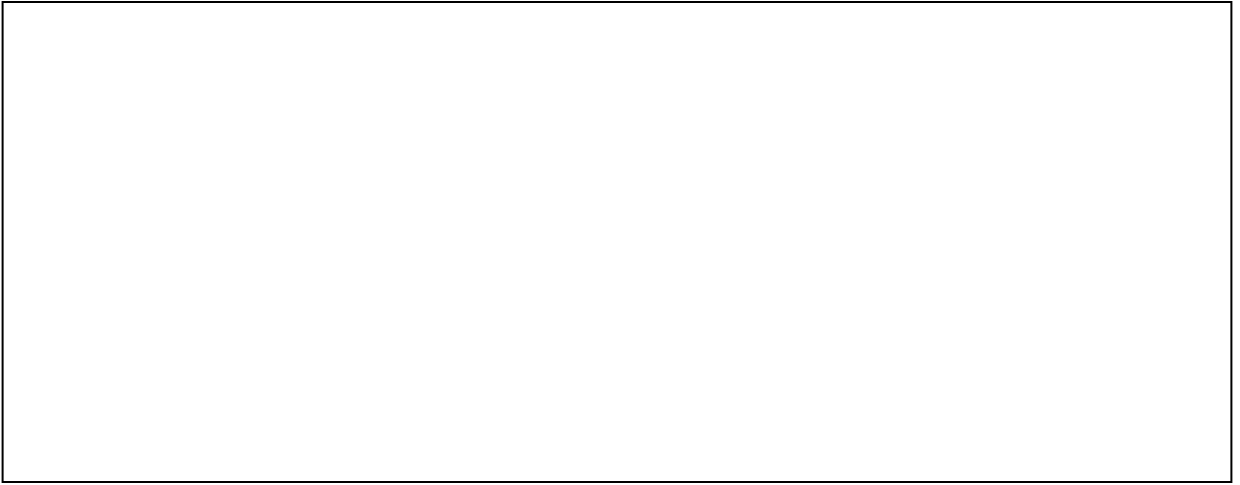
Adjustment/adaptation, service evaluation.

21. Finally a brain storming exercise will be carried out – to determine what they understand and have experienced so far throughout their illness and hospital visits.

What have been the best things / worst things about hospital?

What have been the best things / worst things about being ill?

22. Would you like to ask me any questions?

Thank you for helping me.

Interview schedule for older children

1. Participant I.D. number   ----------

2. Interviewer initials   ----------

3. Date of interview   ----------

4. DOB of child   ----------

5. Sex of child   ----------

6. Ethnic group   ----------

7. Religion   ----------

8. History of illness and child's knowledge (obtained from parent)

9. Hello,

As you know, I'm here so that we can have a short discussion on topics related to your illness, is that ok?

10. Do you mind if I tape record our conversation today?

(Here the rules of the yellow and red card will also be discussed).

Personal factors

11. Can you give me some basic details about yourself?

- What are you three most favourite things?
- What are your three least favourite things?
- Do you enjoy school?
- Do you have any hobbies?
- What foods do you like or dislike?
- What things annoy you?
- What makes you laugh?
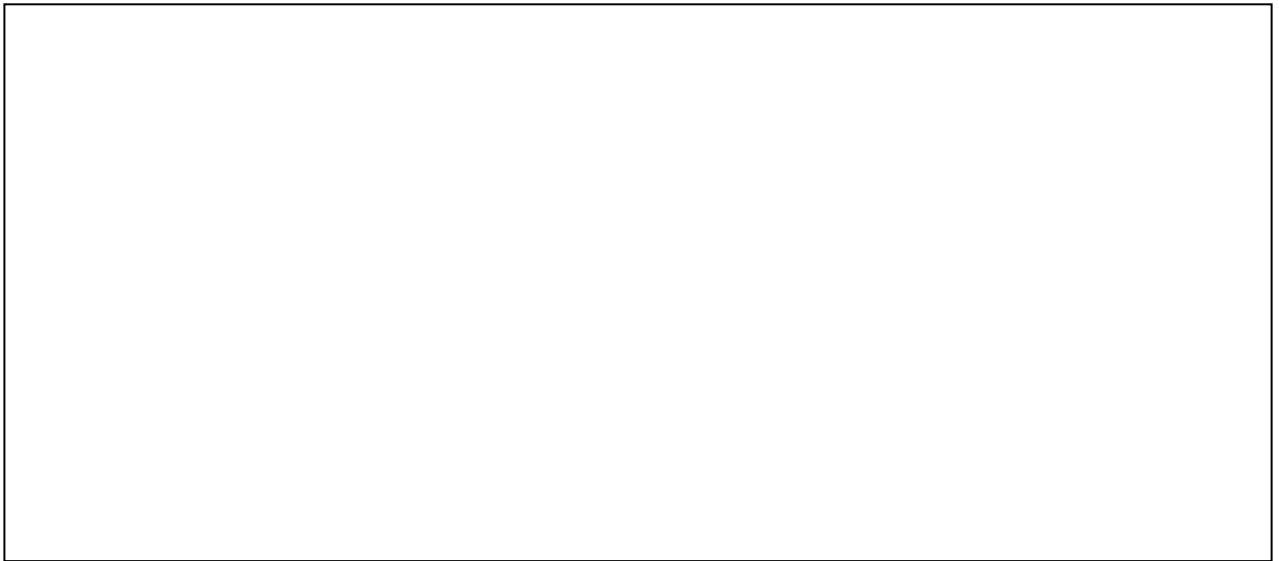
Social-ecological factors

12. Can you give me some information about your family?

- Do you live at home with your parents?

- If you think of the way they are with you – what words would you use to describe them?

- Are they supportive?

- Do you always agree?
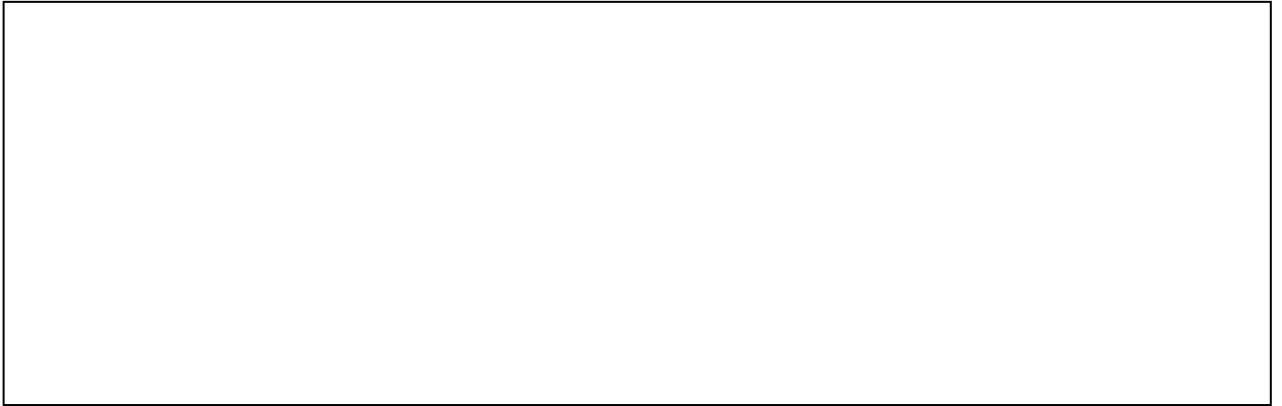
13. Is there anyone else outside your family who is important to you?

- Why?

14. In considering all your family and friends, who do you find it the easiest to talk to?

- Do you feel that you could talk to them about most things?
- Are there any things that you couldn't/wouldn't talk to them about?
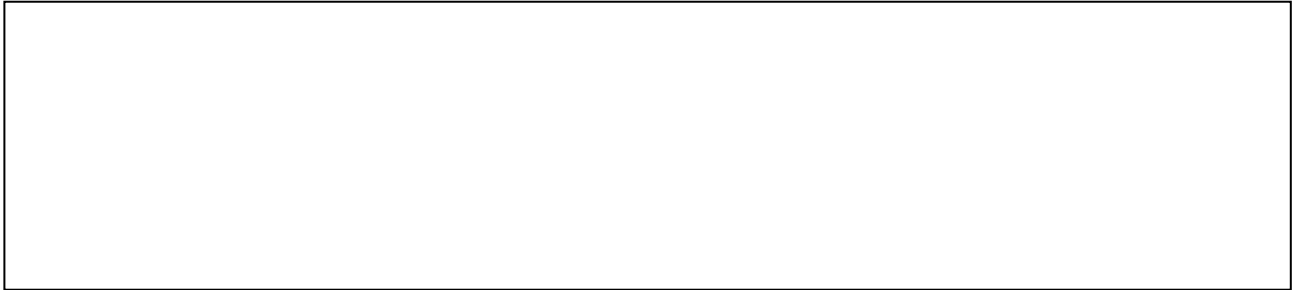
15. Who do you consider to be your best helper?

- Why?
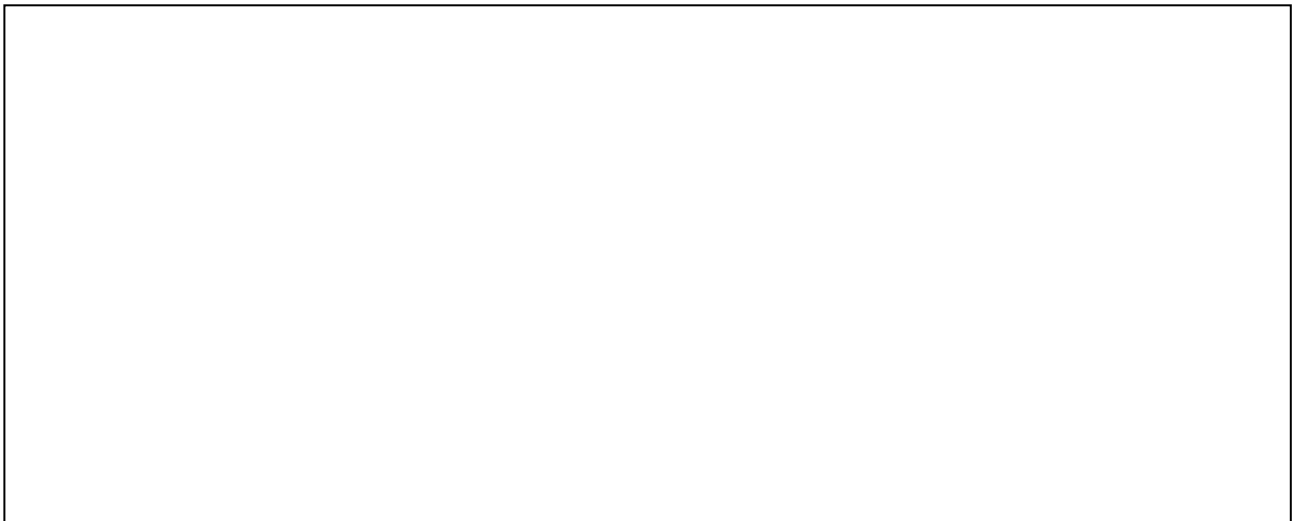
16. Who do you consider to be the most fun?

- Why?

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- Have there ever been any difficulties for them do you think?
- Is there always someone you can rely on for support?

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Speculated interpersonal factors, personal factors, adjustment/adaptation

18. Now, for a bit of fun I'm going to show you some outline faces displaying various emotions, I would like you to tell me what feelings you see in these faces and I would like you to try and relate to a situation recently where you too felt that emotion – What feelings do you see in these faces and perhaps you could tell me a time where you felt like that.
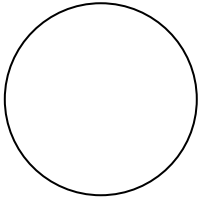
Shocked
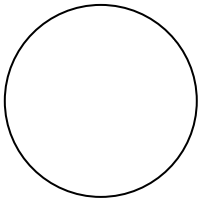
Happy
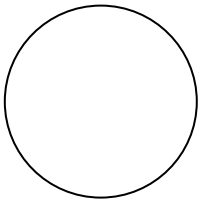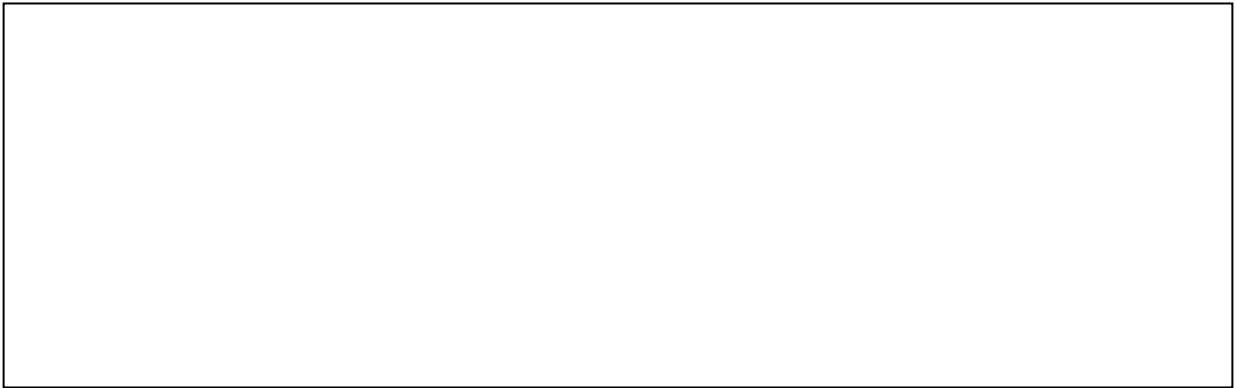
Sad
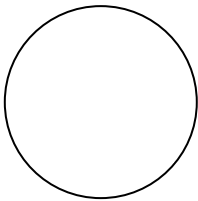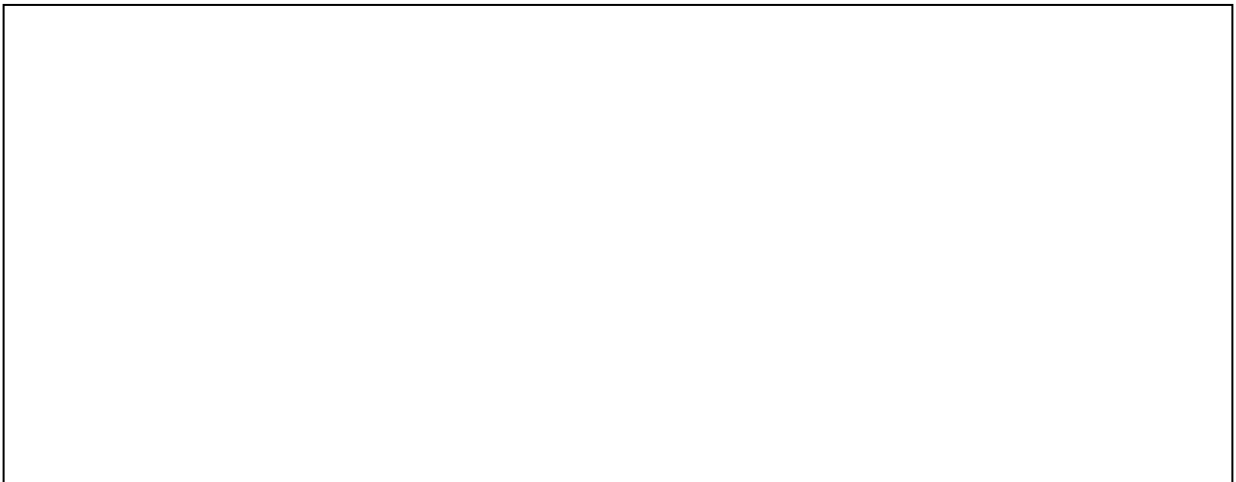
Angry
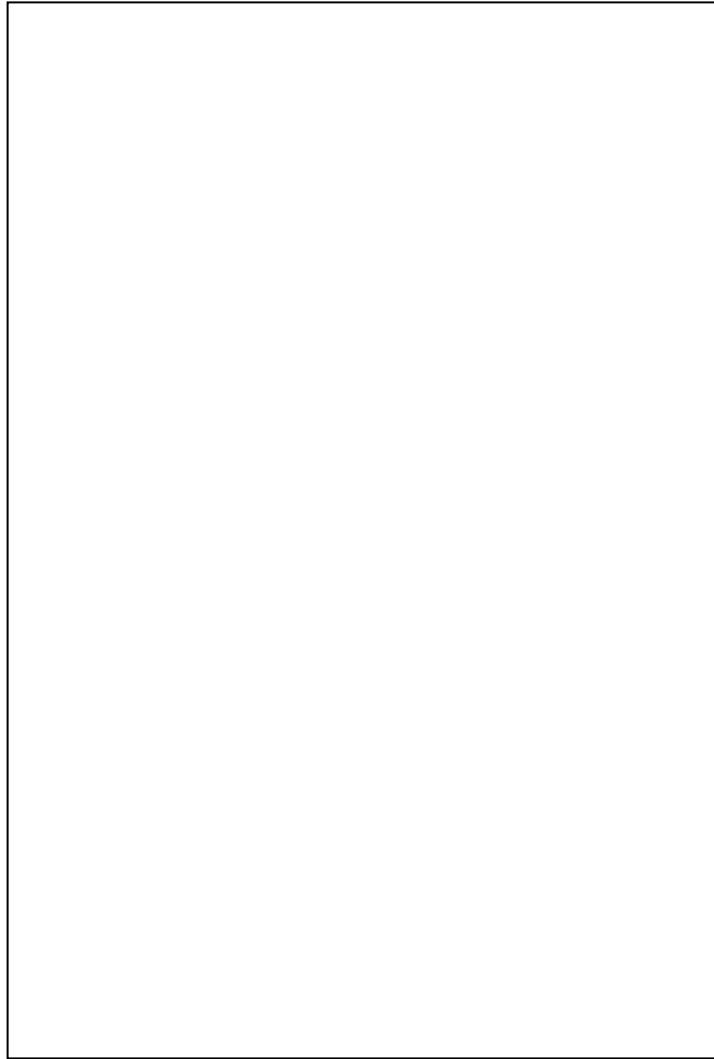
19. Do you always feel in control of your emotions?

20. Do you think you get enough support?

Adjustment/adaptation, personal factors, social-ecological factors

21. Next, the children will be asked to turn over sentence completion cards which will ask about intense feelings.

These cards will have several functions:

- to elicit actual examples of extreme emotions
- to find out which people children turn to in these situations
- to ascertain which responses of other people in those situations were perceived to be helpful or unhelpful.
- To ask what else could have been done or who else might have helped.

I feel really safe when…	The saddest I've ever felt was…	The happiest I have ever been was…	I feel scared when…

Psychosocial stress, stress processing, personal factors.

Now a ranking exercise will be included to specifically look at particular problems and coping strategies.

Problems – questioned in a way that pertains to childs specific illness

Disease related, e.g. trouble breathing

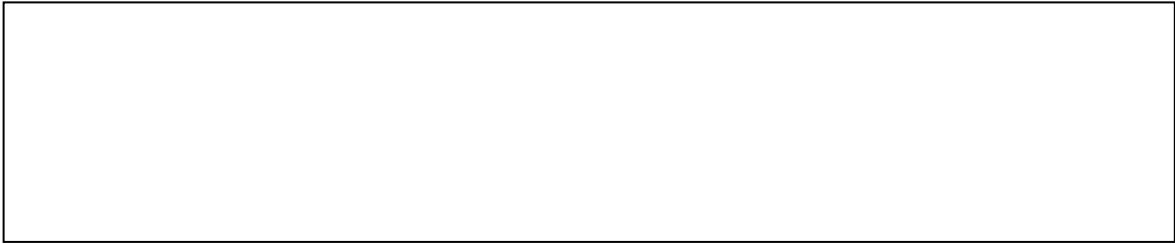22. If you had trouble breathing what do you think you might do?
What other troubles are caused by your illness?

Disease related pain, e.g. leg pain
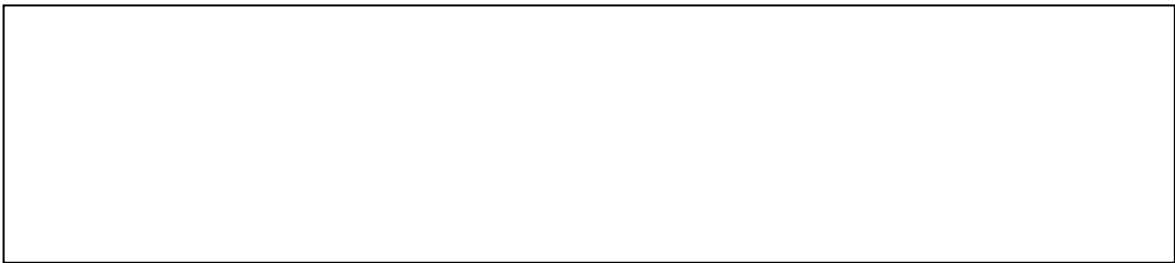
23. If you had leg pain what do you think you might do?

What other troubles are caused by the pain?

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Medical procedure related pains, e.g. injections hurt

24. If you were given an injection that hurt what do you think you might do?

What other troubles are caused by the different medical procedures?

```

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Hospital related problems, e.g. being kept awake at night by other children, lack of privacy

25. If other children kept you awake at night what do you think you might do?

What other troubles are there when you are in hospital?

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Common problems, e.g. school, parents, friends.

26. If you were having arguments with your friends, what might you do?

What other troubles do you have with school or your family or friends?

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Possible coping strategies could include

- distraction
- social withdrawal
- wishful thinking
- self-criticism
- blaming others
- problem solving
- emotional regulation
- cognitive restructuring
- social support
- resignation

Taken from Spirito *et al* (1995)

Personal factors, adjustment/adaptation, stress processing
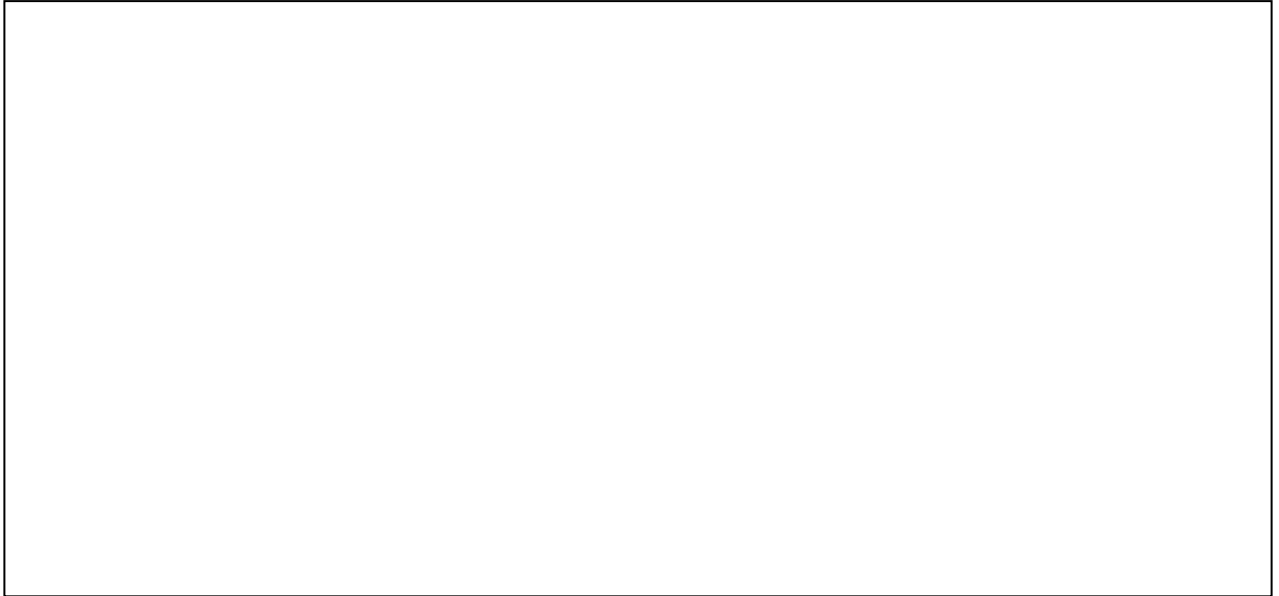
27. What gets you stressed?

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28. Do you think that since you have been ill you have become you have become more or less patient of situations and people?
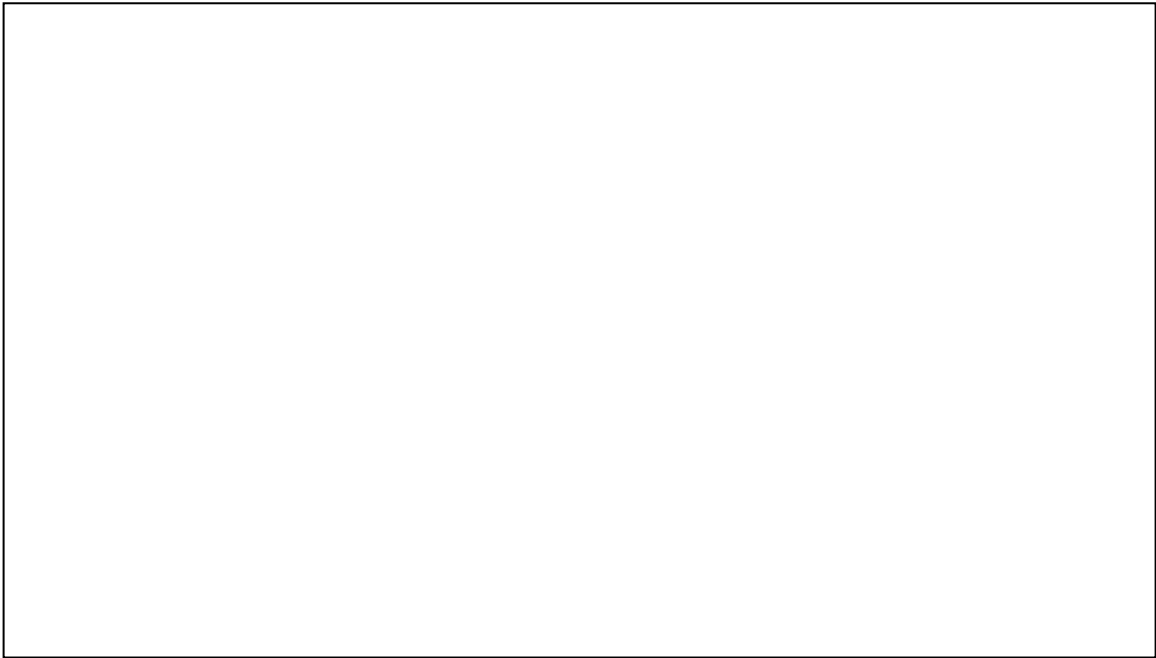
- Why?

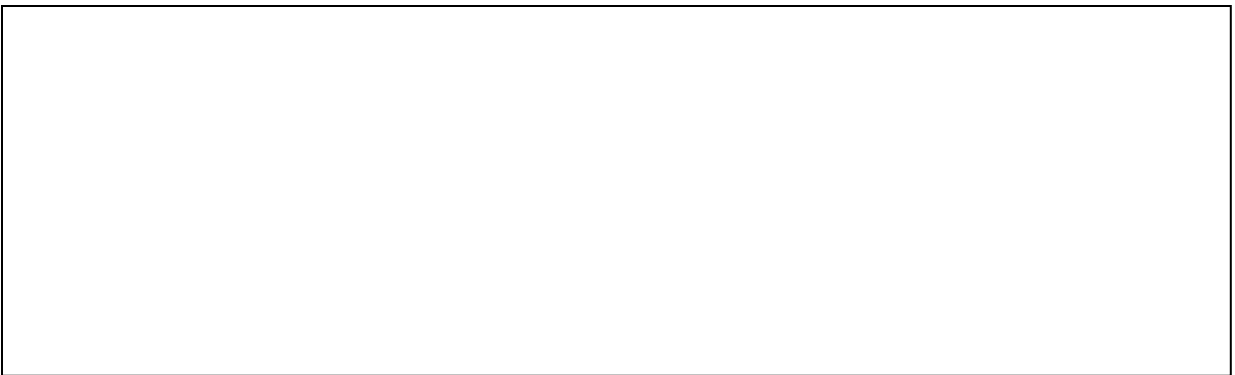29. Do you think you have adjusted well to being ill and having to attend hospital?

Adjustment/adaptation, service evaluation.

30. I would like to finish with a brain storming exercise.

a. To see what you have experienced and understood regarding your illness.

b. To look at how you think the services you have received could be improved

c. To think about other services that you haven't received but that you think could help you.

31. Would you like to ask me any questions?

Thank you, for helping me with this research.

APPENDIX SEVEN: Outcomes of the consensus conference.

The Consensus Conference

<center>✳✳✳</center>

As mentioned, this PhD study evolved from a small scale funded palliative paediatric care evaluation study. After the surface level analysis of the professional and parent interview data I presented these findings at a consensus conference. There was two thousand pounds remaining in the project budget so I organised a local venue and invited parents who had been involved in the study and professionals from across the region involved in palliative paediatric care and service funding. In addition, I asked key professionals to do presentations detailing their services and expressing practical needs as they saw fit. Thankfully, these professionals agreed to participate without being given financial gain. In the afternoon, we spent time in small groups considering action points.

Organising the conference was very time consuming, not least constructing a large mail merge and individual names badges. However, I feel that the day went smoothly and there were a number of positive outcomes. Please see below the summarised outcomes:

Consensus Conference: Feedback and Action Plan

The consensus conference aimed to:

a) Present the findings of a locally commissioned research project exploring the needs of children with LLCs and their families across Calderdale and Kirklees.

b) Provide examples of innovative service developments in health and social care which support children and families with life-limiting conditions.

c) Identify areas of service which require development.

d) Secure agreement from the commissioners and managers of health, social and education services to develop local provision to address needs.

It was agreed that a summary of the group work and action points concluded at the Consensus Conference would be circulated to participants. These are summarised in the

following sections. There were six group work sessions including strategy and commissioning; communication and co-ordination; social and psychological support; education, training and staff support and respite and supportive care.

Strategy and Commissioning

In order to address multi-agency and boundary issues in a strategic, cohesive and co-ordinated way it was recommended that a Calderdale and Kirklees 'Strategy Sub-Group' be established to review models of good practice, redesign services and secure appropriate funding through the business planning process for children with LLCs.

Action A: Establish a Calderdale and Kirklees 'Strategy Sub-Group' for Children with Life-Limiting Conditions.
Lead responsibility: Manager, Partnership Commissioning Team (Contact details omitted here).

Communication and Co-ordination

Two action points emerged in relation to communication and co-ordination. General issues associated with communication and co-ordination such as the need to simplify language, clearly define roles, services and responsibilities, map services and links, establish key working and single assessment were identified. It was agreed that the Calderdale and Kirklees 'Strategy Sub-Group' would address these issues as detailed above.

Action: as Action A above

In addition the difficulty for parents in influencing service development and decisions at a strategic level were identified and it was agreed that a parent council should be established with appropriate links with the 'Strategy Sub-Group', Kirklees Partnership Board and Calderdale Children with Disabilities Strategy Group.

Action B: Establish a Parent Council

Lead responsibility: (parent) and (Community Sister), Huddersfield.

Social and Psychological Support

The general issues raised by the research were emphasised within the group work and the need to consider the social support needs of children with LLCs, their parents and families in the planning and development of services.

Action: as Action A above

Education, Training and Staff Support

The group work identified various actions required to improve the education, training and support for staff involved in the care of children with LLCs. These included:

- Learning from 'champions'.
- Learning from others involved in the care of a child – communication, multi-disciplinary training, open days and training days.
- Pre and post registration training.
- Dissemination of good practice.
- Generic training for all professionals across health, social services and education.
- Contracting education and training on a multi-disciplinary basis.

It was agreed that the commissioners of education and training (Confederations), providers of education and training (University and service) and purchasers of education and training (health, social, school and voluntary sectors) need to be better informed about the needs of children with LLCs.

Action C: Improve links between and awareness of commissioners, providers and purchasers of education and training.

Lead responsibility: (Senior Nurse Paediatrics), Calderdale Royal Hospital.

Respite and Supportive Care

Two groups considered respite and supportive care and highlighted issues raised by the research. A number of recommendations were made by the groups which also overlap with other group work, including the need to strengthen parent and child consultation and involvement in planning and service development.

Specific recommendations included:

- Needs led service development.
- Involving parents in training.
- Exposing strategic planners and commissioners to parents and children's needs.
- Innovative use of existing facilities, such as schools during weekends and holidays.
- Increase choice.
- Ability for parents and children to dip in and dip out.
- Services that foster independence rather than dependence.

Action: As Action A and B above

Summary

The funded project was conducted within the given time constraints. Left over project monies were utilized effectively in order to bring staff, parents and service funders together. This was done to explore service development and to try and ensure a better future and support locally - for both professionals working within palliative paediatric care and for parents and the children with LLCs themselves.