

UNIVERSITY OF DERBY

**ROLLER COASTERS AND UPHILL STRUGGLES:
THE IMPACT OF THE MEDICAL MANAGEMENT
OF CHILDHOOD LIFE-THREATENING AND
LIFE-SHORTENING CONDITIONS ON FAMILY
RELATIONSHIPS, ROLES AND EMOTIONAL
WELLBEING**

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ABSTRACT

This study is the result of observations and questions that stem from my professional role as a senior key worker with families where a child has a life-threatening or life-shortening illness. This project explores the cultures of families where a child has been diagnosed with a potentially fatal medical condition. By examining parents' accounts, other family members' accounts and professionals' accounts of the ways treatment regimes are experienced, the study indicates typical differences in the ways life-threatening and life-shortening illnesses affect family relationships. The study also examines variations in what these illnesses 'mean' for families and the ways that treatment regimes help to shape these meanings. A combination of qualitative research methods was used via in depth, semi-structured and informal interviews with families and professionals, and included participant observation. Data was collected from five informant groups: a) mothers where a child had been diagnosed with cancer or was living with a life-shortening condition; b) families of the ill children, suffering from both cancer and from a number of severe chronic medical conditions; c) well siblings living alongside an ill sibling; d) ill children themselves; e) professionals from health and psychosocial backgrounds who worked with the families. A detailed summary of the sample may be found in Appendix 1 page 291. Although limited, the findings have helped to provide a hypothesis outlining typical differences in the ways life-threatening illnesses and life-shortening illnesses affect family relationships. They also offer health professionals and others working with ill children insight into the crises and challenges which might typically face families during the course of their children's treatment.

Medical technology is successfully prolonging the lives of children diagnosed with life-threatening and life-shortening illnesses who would not have survived the same illness some years ago. In the light of these improvements, findings from this study indicate that when the illness is *life-threatening* as in childhood cancer, the treatment regimes and the sudden and frequent hospitalisation of the mother and ill child impact on the daily life of the family, changing the family dynamic and creating a sense of an emotional roller-coaster ride - with horror, hope, fear, relapse and remission all part of their journey. Conversely, findings suggest that in cases of rare, often difficult to diagnose, *life-shortening* conditions, the family is drawn into a life-long up-hill struggle where the medical management of the child takes priority over, and increasingly dictates, other

family members' relationships, roles and activities. Unlike the intermittent but extreme crises of life-threatening illnesses such as cancer, life-shortening conditions continue for the lifetime of the child, creating enduring long-term pressures on the family. However, in both categories of illness the families' lives are entwined with various professionals who appear largely unaware of how the medical management of these illnesses drain the practical, financial and emotional resources of the family.

The findings of this research raise implications for practice and future policy. I conclude by suggesting that there is a need for an increased understanding, acknowledgement and respect from professionals that the primary carers in both categories of illness are to a greater or lesser extent, experts in their own children's illnesses. NHS Trusts, Children's Hospices and Children's Agencies produce a variety of care pathways for sick children, and although training in communication with patients is already in place, there is considerable room for improving the day-to day skills and approaches of the various professionals, particularly health professionals involved in paediatrics and their communication with the parents *and* the ill child. There is also a need for increased understanding by professionals of the particular daily challenges faced by families with children undergoing treatment for these conditions.

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CHAPTER, 1

INTRODUCTION

The initial aim of the research was to investigate how the diagnosis of a sibling with a life-threatening or life-shortening illness impacts on well siblings within the family. Since the 1960s there have been a large number of studies that have related to the difficulties that well siblings face (Bendor, 1990; Chesler et al, 1991; Parson and Fox, 1968; Share, 1972; Sloper, 2000; Spinetta et al, 1999; Taylor, 1980). The majority of these studies concentrated on well siblings living with a brother or sister diagnosed with a childhood cancer, and looked for an adverse psychological reaction to the illness (Dixon-Woods, 2005). The concentration of research in the area of siblings and childhood cancer continues to focus on the emotional and behavioural difficulties that the illness may create in a family (Houtager et al, 2005). Fewer studies have been conducted on the issues relating to the difficulties for siblings following the diagnosis of a life-shortening illness, but the findings of these also continue to highlight an adverse reaction (Bluebond-Langer, 1996; Breslau, 1982; Ferrari, 1984; San Martino and Newman, 1974). More recent studies have used self-reports of siblings as their primary data. These findings have shown a difference between the reports from mothers, which note anxiety and behavioural difficulties, and the reports from siblings themselves, which recognize that although they do not live in a 'normal' family they do not perceive any greater anxiety in themselves (Batte et al, 2006; Waite-Jones and Madill, 2008; Wood et al, 2008). However, as far as I can tell, no previous studies have compared these two categories of illness in terms of their impact on well siblings. Therefore, the issues of similarities or differences in the trajectory of the treatment regimes and time span of the illness on well siblings' lives have been largely overlooked. The following thesis sees this initial aim having grown into a much wider consideration of the impact of illness and treatment regimes on families as a whole. I will explain how this broader concern has emerged by briefly outlining my own role as both practitioner and researcher.

BACKGROUND TO THE RESEARCH AND MY PROFESSIONAL ROLE

During the mid 1990s the then Branton Health Authority, now Branton Primary Care Trust undertook a research project to look at improving the availability of additional services to adult cancer patients within the Metropolitan Borough of Branton. It became evident via the findings that a number of children were also receiving treatment locally

for various childhood cancers. A recommendation within the report was that a borough-wide bereavement co-ordinator should facilitate and provide the support to these children and their families. I began my role in July of 1995. At this time within Branton no emotional support services were available to the families where a child had been diagnosed with a life-shortening illness. Further to this, there were no recommendations to provide such a service.

The original recommendations involved creating a working relationship within the paediatric department of the local acute hospital. As I was already involved in the support of bereaved parents it was reasonably easy to begin the process of working in conjunction with the paediatric oncology department, which was a shared care centre under the direction of specialist hospitals. It was agreed by the clinicians that I would approach the parents to explore what they felt would support them and their family during and following treatment. Two main areas for support were identified and requested. Firstly, the provision of a parent support group not held within the hospital but with medical expertise available on an informal basis, and secondly, a support group for the well siblings. It was agreed by the parents that the professionals would organize and facilitate the two groups for one year, at which point the families would take ownership. The groups were held on a monthly basis, both on the same evening. Between ten and twelve parents attended, the majority being mothers, with my involvement mainly centred on the well siblings, who were between 8 and 14 years of age. The groups continued for approximately 3 years and then discontinued. As the original focus of the research was to be the difficulties of well siblings, it will be useful to describe how the research began.

THE RESEARCH BEGINNINGS

It was through my involvement with the siblings that the original focus of the research was identified. At that time there was a perceived lack of published research that explored the impact on well siblings of living with a brother or sister with either a life-threatening illness or a life-shortening medical condition. However, I had to acknowledge that the well siblings are part of a family unit and the impact of a child's serious illness changes relationships between family members and therefore changes the whole family dynamic. It was whilst working with a community project that the focus of the original research changed from the siblings to the family as a whole. The shift from just the well siblings to the whole family occurred when, as part of my working role I began to act as a

senior key worker with a community project. The Project works with the whole family within the categories of life-threatening and life-shortening illnesses. I began to witness first hand how the illnesses impacted on individuals within the family, and how in turn that impacted on the family as a unit. This was compounded by continually hearing the parents' stories from both categories of illness and how their perceptions frequently focused on how little understanding professionals had of how they [the family] managed the illness at home or how it impacted on family life. These stories also contained feelings of powerlessness that both the illness and health professionals' attitudes imposed on the family as a unit. It also became apparent that there were differences between life-threatening and life-shortening illnesses, especially in relation to the trajectories of the patients' 'careers', their key turning points, their duration and their engagement with medical professionals. Importantly, though, there were also many similarities such as the problems of negotiating with the medical interface. A common feature was that both categories of illness affected each member of that family and played a significant part in the wellbeing of the well siblings. However, the tendency for life-threatening illnesses to 'fragment' family relationships, and for life-shortening illnesses to 'consolidate' family relationships suggested that the experience of its treatment played a part in the 'meanings' which family members came to give to the illness itself.

Hence, the **RESEARCH AIM** of this study developed into an examination of how the diagnoses, the subsequent treatment regimes and the trajectories of the families' contact with medical and other professionals, affected their family dynamics, their respective roles as mothers and fathers, and their relationships with well siblings and with the ill child themselves.

The **OBJECTIVES** of this study were to:

1. Describe processes of change in family relationships following a) diagnosis and treatment of life-threatening childhood disease - notably cancer, and b) diagnosis and treatment of complex, severely disabling and life-shortening childhood conditions.
2. Explore patterns of responses - both between and within families - to diagnosis and treatment regimes and the interface with medical and other professional support workers in a) life-threatening illness and b) complex, life-shortening conditions.

3. Identify factors that help family members adapt to the social, emotional and physical challenges of living with life-threatening and life-shortening conditions, and to identify factors which may hinder such adaptations.

4. Review models of family adaptation which may contribute towards enhancing the interface between families of severely ill children and a range of medical and other support workers.

In order to meet these objectives, the following **RESEARCH QUESTIONS** were identified:

1. In what ways do the illnesses impact on families, and, as a part of this exploration, how do different medical conditions affect family roles and relationships? More specifically, in what ways might enduring incurable life-shortening conditions differ from potentially curable but nevertheless seriously life-threatening illnesses in their effects on family dynamics?
2. What are the consequences, for the emotional wellbeing of families, of diagnosis in the light of differences between the ways in which life-shortening and life-threatening conditions are diagnosed, and the differences between their 'typical' treatment trajectories?
3. In what ways do medical and other 'professional' workers interact with families and how might 'cultures' of cancer regimes differ from the cultures surrounding the treatment of a severe disability?
4. What are the implications for service provision and future research in relation to these families?

In order to explain the ways these aims and questions relate to the context in which my study has taken place, it is important that I sketch out the changing nature of treatment regimes and the impact of medical advances for both life-threatening and life-shortening conditions. Following this, I shall outline difficulties encountered in establishing a consistent definition of these terms and clarify exactly how I have used them in this study.

CHILDHOOD LIFE-THREATENING AND LIFE-SHORTENING ILLNESS IN THE CONTEXT OF THIS STUDY

In Britain today, through advances in medical technology, many babies who would have died from premature birth, complications at birth, or congenital abnormalities, now survive. These advances and the increased development of disease specific drugs and medical research have seen a significant rise in the number of children diagnosed in childhood with a life-threatening illness - such as cancer, or shortly following birth with a life-shortening illness - such as Cystic Fibrosis, now surviving into adult life. For example, in the mid 1990s children with Cystic Fibrosis had a life expectancy of twenty years. Through medical research into the disease and new treatment, life expectancy is now estimated to be in the mid to late thirties. Children diagnosed with childhood cancer in the 1950s were expected to live no longer than four months, now the success rate for childhood leukaemia is 80% 'cure' at five years, post treatment. The continued success of expanded life expectancy has created some confusion regarding the definition of a life-shortening and life-threatening illness: treatment of life-shortening illnesses now means some children live into later adulthood, whilst the prognosis for many childhood cancers is also much improved and is often described within recent research as a chronic rather than an acute condition. Thus, the definitions tend to blur what are actually very different conditions and treatment regimes in terms of the medical power and expertise experienced by the families.

It is possible to outline some of the main differences in families' experiences of these treatment regimes. Firstly, the treatment regimes of both conditions are different in as much as childhood cancer requires primarily a hospital based treatment that can include chemotherapy, radiotherapy, and in certain instances, surgery. The treatment is reliant on the expertise of the paediatric oncologist and administered by health professionals. Secondly, life-shortening complex medical needs (including chronic conditions) are, by their very nature, primarily treated at home with the primary carer becoming an expert in their child's condition, though there are also likely to be periods of hospitalisation, some lengthy, depending on the condition. Some of the conditions are rare with extensive underlying health issues that require a number of consultant paediatricians specialising in various aspects of paediatrics to be involved in the medical management of the individual child. Thirdly, the aim of the treatment regime for childhood cancer is 'treatment in order to cure', whereas treatment for life-shortening illnesses is largely amelioration of the

condition in order to improve the quality and length of the child's life. There is no cure as such, and treatment takes the form of medically managing the condition so as to provide ways of living more 'normally'.

Whatever the diagnosis and outcome, on receiving 'bad news', it is my experience of working closely with these families that they enter a world controlled and regulated by treatment procedures, drugs, hospitals and operations. This changing environment within the family unit now resides includes the loss of private lives, the constant fear of relapse and/or increased illnesses with the ever-present possibility of the death of the child. Regardless of how long the child survives (and as noted, increasing numbers do survive into adulthood and beyond), the relationship between the ill child and the rest of the family is affected both by the possibility of the child's death and by the impact of the treatment regime.

DEFINITION OF LIFE-THREATENING AND LIFE-SHORTENING ILLNESSES

The epidemiology of life-threatening diseases in childhood has been well documented for cancer, but is less well described for non-malignant conditions (Lenton et al, 2001). There appears to be no clear definition of a life-threatening illness. However, research does appear to be in agreement about it being a condition such as cancer, or irreversible organ failure of heart, kidney, or liver, where curative treatment may be available but could fail, leading to the probability of death in childhood (ACT 1997: 12; Field & Behrman 2003: 37). In more recent years childhood cancer has been described as a chronic condition. This is mainly due to the number of children now progressing to the status of survivorship. However, for the purposes of this research, childhood cancer continues to be described as a *life-threatening* illness. One of its key characteristics is the widely held perception that the illness carries an immediate and critical risk to the survival of the child.

A *life-shortening* condition is defined, for the purposes of this research, as a condition characterised as being of long duration or frequent recurrence that disrupts normal physical, psychological or social functioning (Copley and Bodensteiner, 1987: 67) such as Cystic Fibrosis, Spina Bifida, various neurological and other rare conditions and associated illnesses. The definition also includes severe disability, representing a broad group of neurologically handicapped or medically fragile children where there is no cure

and where the condition will result in the premature death of the child usually before or on reaching early adulthood. However, although the illnesses and physiological complications associated with this condition are widely seen to be severely disabling, and ultimately fatal, they are generally (and often incorrectly) not seen to carry an immediate and critical risk to the survival of the child (as opposed to a baby born with severe physiological complications).

Following on from these definitions of the two conditions as used in this research it is also important to outline, through the use of diagnostic and statistical information, typical patterns of childhood cancer and a number of complex medical conditions that families live with and which are part of my working practice, and which have been part of this research.

DIAGNOSTIC AND STATISTICAL INFORMATION – CHILDHOOD CANCER

The term ‘childhood cancer’ includes a wide range of illnesses and relates to children diagnosed with cancer under the age of fifteen years and is a term which represents some of the most serious illnesses affecting children, and continues to be a major focus of medical research and of widely publicised charity funding. In recent years although the success rate for childhood leukaemia is 80% of children ‘cured,’ it includes a difficult treatment period. The parents have to rely on the expertise of the paediatric oncologist to guide them through the different trials and treatment protocols that are now available. The treatments are regimented and typically consist of two years for girls and three years for boys. This leaves the parents with little choice or control over the expert consultants’ expectations regarding their acceptance of the treatment offered. At this time the parents only other choice is no treatment which they know, would lead inevitably to palliative care. With the threat of death or choice of survival the vast majority of parents quickly consent to the treatment recommended by the consultant, unaware at the time that they are placing themselves within a constricting regime and under the control of the culture of medicine and illness.

Writing on the epidemiology and genetics of childhood cancer, Stiller, (2004) states:

“...there are 12 major groups of childhood cancer and include, leukaemia, lymphomas, brain and spinal tumours, sympathetic nervous system tumours,

retinoblastoma, kidney tumours, liver tumours, bone tumours, soft tissue sarcomas, gonadal and germ-cell tumours, epithelial tumours and other and unspecified malignant neoplasms...” (Stiller, 2004: 6429).

The types of childhood cancers that develop are different from adult cancer, and usually respond better to chemotherapy. However, the treatment is aggressive and the chemotherapy and other drugs used in the treatment can have long-term effects, with those who survive childhood cancer carefully followed up in their adult life at the specialist centre where they were treated as a child. Statistical data relating to various aspects of childhood cancer is collected via Cancer Research UK and provides an indication of new cases, types of cancer, sex of the child and deaths. This information is useful in indicating the number of families that become part of the culture of childhood cancer.

INCIDENT STATISTICS

Incidence statistics provided by Cancer Research UK, suggest that in the UK there are approximately 1,500 new cases of childhood cancer diagnosed each year, of which there are about 20% more boys than girls. The risk for an individual child in Britain of being diagnosed with cancer before the age of fifteen is around 1 in 500. This according to Cancer Research UK, is made up of risks of about 1 in 1600 for leukaemia, 1 in 2200 for brain or spinal tumours, and 1 in 1100 for all other cancers combined (www.cancerresearchuk.org). Childhood leukaemia is a malignant disease of the bone marrow and blood. It is characterized by the uncontrolled accumulation of blood cells, divided into subtypes of, myelogenous or lymphocytic, each of which can be acute or chronic (www.lukemia-lymphoma.org), Acute Lymphoblastic Leukaemia, abbreviated to ALL, being the most common type. ALL makes up about four-fifths of childhood leukaemia, making it a quarter of all childhood cancers, and is about 30% more frequent in boys than girls. Acute Myeloid Leukaemia (AML) is about 15% of childhood leukaemia and is about 20% more frequent in boys than girls. Chronic Myeloid Leukaemia is less than 4%. Lymphomas are more than twice as common in boys than girls, and rarely occur before the age of two. There are two types of lymphomas, Hodgkin's Disease and non-Hodgkin Lymphomas (NHL) the occurrence of Hodgkin's Disease increases steadily with age. Brain and spinal tumours can either be Astrocytoma, Primitive Neuroectodermal Tumour (PNET) or Ependymoma. The most common type of

PNET is Medulloblastoma. Astrocytoma is equally frequent in boys and girls, whereas PNET is 60% more common in boys than girls (Cancer Research UK). In recent years children diagnosed with childhood cancer survival rate has increased dramatically with long-term survivors of leukaemia now reaching adulthood. However, success rates for other cancers according to the National Cancer Register for paediatrics are still unpredictable as the following information indicates.

PROGNOSIS

It was during the 1980s, according to Stiller et al, (2004), that reliable statistics were first produced via the National Cancer Register (Paediatrics). For the first time statistics covering the whole of Great Britain were available that listed children from birth to fourteen years who had been diagnosed with childhood cancer. At that time 11,479 children were registered and it was estimated that two-thirds were likely to survive for five years. In 2009, it is predicted that if the child with leukaemia gets beyond five years post treatment without an 'event' from the original diagnosis (so five years without a relapse), he or she will be amongst the approximate 80% of children who are considered 'cured' and who should survive into adult life. Brain tumours are amongst the most common form of malignancies in childhood and account for 20%, and are second to leukaemia. Treatment for a brain tumour depends on location, rate of growth, and the child's age. The general treatments are surgery, radiation therapy, and chemotherapy. However, radiotherapy is not used on children under five years of age in the UK, but with many of the children with brain tumours there is a 90% success rate of cure. Where Neuro-Blastoma is concerned, children are now surviving beyond the end of treatment although there are still a relatively high number of children who relapse. Whilst the death rates have been considerably reduced in recent years, there are children who unfortunately do not respond to treatment as the following death statistics indicate.

CHILDHOOD CANCER DEATH RATES

Although the survival for childhood leukaemia is now 80% of children 'cured', children do unfortunately still die. However, data provided by Cancer Research UK, suggests that at the end of 1961, there were probably fewer than 2,500 people of all ages living in Britain who at some time in the past had been diagnosed with childhood cancer, but by the end of 2001 there were more than 26,000. Whilst acknowledging the advances and success rate in the treatment of childhood cancer since the early 1960s, the reality is that

not all children and young people survive the treatment. Although the death rates have fallen, according to the UK Childhood Cancer Research Group National Registry of Childhood Tumours (2004) www.ccr.org.uk, on average by 2.6% per year between 1962 and 2001, a reduction of more than half, an average of 300 deaths per year from cancer in children under the age of fifteen years were still recorded in the UK in the three year period 2000-2002.

Nearly a quarter of all deaths in the age group 5-14 years in England and Wales, 2000-2002, were recorded as being caused by cancer. In this age group, cancer was the most common form of death in girls, and the second most common after accidents in boys. In the age group 1-4 years, cancer caused nearly 15% of deaths (Cancer Research UK). As noted earlier whilst death rates have fallen, registration rates have increased by 0.8% per year on average between 1962 and 1998, a total increase of 35%. Figures provided by the ONS Mortality database for the years 2001-2004, show that 7,055 children and young people aged 0-30 years died from causes likely to have required palliative and end of life care which include cancer and other life-shortening illnesses and/or complex medical needs.

DESCRIPTION AND STATISTICAL INFORMATION OF LIFE-SHORTENING CONDITIONS

Whilst there are reliable data attached to childhood cancer via the National Cancer Registry, for the myriad of other illnesses and syndromes, accurate information about the epidemiology of children with life-shortening conditions is still sketchy, though improving (ACT & RCPCH; 1997). Unlike childhood cancer statistics which are recorded nationally, the accurate incidence of severely ill children with life-shortening conditions is not. Estimated figures from the Department of Health (2004b) suggest there are approximately 700,000 children in the UK with disabilities and/or complex medical needs living in 25,000 families. The following descriptions are of a number of life-shortening conditions that are included within my practice and of families interviewed.

One family interviewed consisted of 4 children, the two youngest [now young adults] have life-shortening/complex medical conditions. The youngest son was diagnosed with Prader Willi syndrome shortly following his birth. Professor A. Prader and Dr H. Willi noted that this condition had unique and definable characteristics and first described

Prader-Willi Syndrome in 1956. Prader-Willi Syndrome affects around 1 in 1500 and is present at birth. PWS is caused by an abnormality on chromosome 15 that occurs around the time of conception. The majority of cases, about 70%, are caused by a deletion on the chromosome 15 inherited from the father, whilst about 25% are caused by inheriting two chromosome 15s from the mother, instead of one from the mother and one from the father. According to the Prader-Willi Syndrome Association, it is thought that the part of the brain that is affected by PWS is the hypothalamus, which is the 'control centre' of the body, and regulates things like appetite, growth, sexual development, and emotional stability, which in PWS, do not work properly (www.pwsa-uk). There are also additional learning difficulties. One of the stresses for the family associated with Prader-Willi Syndrome is that unless children are very closely monitored and the intake of food controlled, they can develop an insatiable appetite. As an example, I have known this particular family for 8 years and I am aware that they have to monitor their son's food intake closely. As he has grown older he also is aware of what food will increase his weight. During a visit to the family the mother reported an incident where during the summer they decided to go out for a pub lunch with the two ill children [daughter in a wheelchair]. They had ordered the meal, and while waiting a waitress had brought out the meal for people at the next table. On seeing that there were chips on the plates, their son believing they were for him and knowing he is not allowed them, had an explosion of temper knocking the plates off the tray and onto the floor. Further embarrassment followed whilst trying to explain to those present, eventually the family left without having their meal (Field work diary, August 2004).

Although Chiari Malformation is present at birth, it is not usually diagnosed until early childhood. The daughter of one family in my sample was around 3 years of age when she had a stroke and was diagnosed with the condition. Her mother reported that she had been a 'funny' baby and toddler, always appearing unhappy with life but had been told by the GP and health visitor that some children are like that. Chiari Malformation is a congenital anomaly, a condition present at birth, in which parts of the brain protrude through the opening in the base of the skull into the spinal column. There are four types of Chiari Malformation. Type 1 is where the lower portions of the cerebellum, known as the cerebellum tonsils protrude through the opening in the skull known as the foramen magnum and into the spinal cord canal. It is often accompanied by a condition known as syringomyelia, [which this child also has], where pockets of CSF form in the spinal cord.

Type 11 malformation, also known as Arnold Chiari Malformation, is more severe than type 1 and involves herniation of a more significant part of the cerebellum, part of the fourth ventricle and part of the brain cell. The brain tissues protrude further into the spinal column than in type 1.

Apert Syndrome as one mother explained is a cranial, facial condition, which involves major surgery early in life and is a life-threatening condition, affecting approximately 1 per 160,000 to 200,000 live births. The bones in the head are fused before birth rather than at around eighteen months. So the children are born with large heads and an odd-looking head shape. Fingers and toes are usually fused together. Sometimes it is the bones that are fused, and sometimes it is the skin between the fingers and toes. The children have breathing difficulties as all the mid-facial bones are too small, as are the ears and nose bones. They have a cleft in the soft palate, and the jaw is small creating severe overcrowding of teeth. The condition does involve learning delays in varying degrees. The majority of Aperts children undergo surgery in the early years of life, with further re-constructive surgery in the late teenage years which is a decision they can make themselves (Information from a mother with a child with Apert Syndrome).

Most cases of Apert Syndrome result from a mutation of a gene [the fibroblast growth factor receptor 2-FGFR2-gene] on chromosome 10. The affected gene is inherited in an autosomal dominant way, which means that each child of a person with Apert Syndrome has a 50% chance of inheriting the condition. However, in the past few years people with Apert Syndrome have had children and about 98% of babies with the condition are born to unaffected parents as the result of a new mutation. This mutation usually occurs in a sperm and although the father in this particular study was in his twenties when his son was born, Apert Syndrome is one of the few genetic conditions linked to older fathers, particularly men over the age of 50 www.bbc.co.uk/health/conditions.

Spina Bifida literally means 'split spine' (www.asbah.org) and the youngest of three children in the family in this study was diagnosed with the condition shortly before his birth. Spina Bifida is a fault in the development of the spinal cord and surrounding bones leaving a gap or split in the spine. It occurs when the foetus is growing in the womb and the spine does not form correctly. The central nervous system and the spine develops between the 14th and 23rd day after conception. Spina Bifida occurs when the neural tube

fails to close correctly to make the normal ring shapes around the spinal cord. Children born with Spina Bifida may have other nervous system disorders such as Hydrocephalus or Chiari-Malformation. There is no complete cure for Spina Bifida, although the spine can be closed surgically either before or after birth, and this will reduce its effects on the body. The life expectancy for these children has changed dramatically over the years. A study by Bowman (2001) found that with appropriate medical care at least 75% of children born with the most severe form of Spina Bifida will most likely live until their early adult years.

The eldest child in a further family interviewed was diagnosed with Steven Johnson Syndrome at around three years of age and the Syndrome affects her eyes and lungs. Paediatricians A.M. Stevens and S.C. Johnson discovered the disease in 1922. Stevens-Johnson Syndrome is a rare, acute exfoliative disease involving the skin and mucous membranes. The incidence of SJS is approximately 6 cases per million persons per year and is more common in females than males. A significant majority of patients will have ophthalmic pathology mainly involving the conjunctiva, both bulbar and palpebral, but it can also involve the cornea, lid margins, eyelashes, and eyelid skin. In children the most common causes are infections, immunisation and many drugs have been implicated such as penicillin (www.patient.co.uk). The disease typically starts with a non-specific upper respiratory tract infection and the patient may experience flu-like symptoms. In severe cases, the lesions can cause significant scarring of the involved organs, which often leads to loss of function of the organ systems, for example, restriction of the oesophagus and of the respiratory tract. This can occur due to lesions and scarring (www.righthealth.com).

A number of families supported by the Community Project, some of which appear in my sample, have children diagnosed with Cystic Fibrosis, [CF] and this also is a life-shortening chronic condition. As yet no cure has been found, although through medical research life expectancy is now extended into the mid thirties. During 1989 the precise location of the gene was found on the seventh chromosome. The disease occurs as a result of mutations affecting a gene which encodes for chloride channel known as cystic fibrosis transmembrane conductance regulator which is essential for the regulation of sodium and chloride transport across epithelium cell membranes in the airway, gut and biliary tract (Cystic Fibrosis Nurse Specialist). Faulty regulation results in thickened

secretions in these areas. Other complications include pancreatic insufficiency, diabetes and liver cirrhosis (Esmond 2000).

The life-shortening conditions experienced by families in my study have been outlined above in order to illustrate the complex, often rare and varied nature of the physical challenges faced by these children. It is also important to note that each of these conditions frequently involve a number of physical and mental problems affecting development and normal functioning and which may only become apparent as the child grows older.

Having discussed definitions and offered a brief background to the main distinctions between life-threatening and life-shortening conditions I now aim to outline the structure of this research report. It is grounded in the experiences of families where a child has been diagnosed with a life-shortening or life-threatening illness. It is also sensitive to the perceptions of individual family members who see a need for greater awareness amongst professionals of the important social and psychological changes that such a diagnosis and subsequent treatment create within the family unit. Therefore, this research seeks to describe and explain some of the principle difficulties that such conditions have for family relationships, communication, functioning, and levels of control over medical treatments and services. The thesis is divided into ten chapters, which are as follows:

In Chapter 2, I explore the literature and focus on the extent to which research has investigated the adjustment of families and individual family members following a diagnosis of a life-threatening or life-shortening illness in a child. The review is divided into the two categories of illness. In the first section I examine how previous research has examined the difficulties families face when childhood cancer has been diagnosed, and how once a confirmed diagnosis is made the parents may be involved in decisions regarding treatment and associated factors such as fertility. The diagnosis places the family into a crisis situation followed by the immediate hospitalization of the ill child, usually accompanied by the mother. The literature review notes how this 'hospitalization' of the mother raises issues regarding her loss of self-identity and previous roles, and the surrender of the child to the medical culture leaving her feeling powerless and isolated. Marital difficulties at this time are reviewed, and although limited, the literature notes how previous research viewed the father's perspective, often considered to be on the

outside of the illness whilst continuing to work. The review continues with well siblings and their adaptation to their 'new' family life following a diagnosis of a brother or sister with cancer. Throughout the literature from the late 1950s onwards concerns have been raised regarding the wellbeing of the well sibling with research concentrating on emotional and psychological problems. Earlier research often presents ambiguous results, in which well siblings' perceptions of parents' withdrawal of attention and lack of clear honest information are cited as possible sources of their anxiety and anger. However, more recent findings of Alderfer et al, (2010), consisting largely of siblings' self-reports, found that there was no evidence of anxiety or depression, although over half the siblings did report that they had experienced more cancer-related post-traumatic stress symptoms, which was a higher number than in a previous study (Alderfer et al, 2003). In this section I also explore literature relating to difficulties at the end of treatment, palliative care, and more recent research on 'survivorship'. The final section on childhood cancer reviews recent contribution to the theories of grief and issues associated with bereaved parents and siblings.

The second section examines the published literature on families where a child has been diagnosed with a life-shortening illness and includes aspects from anti-natal screening for abnormalities, to the loss associated with the birth of a non-healthy baby and the responses of health professionals. I explore how the lack of clear and honest information impacts on general parental coping and family adjustment. This includes the long-term psychological consequences for the individual, the parents and their relationship. I further examine the literature that focuses on the perceived difficulties of adjustment for the well sibling, but much of the literature reflects disagreement over conclusions, with often contradictory findings regarding the degree of stress and anxiety that the illness may create. However, more recent research, from 2005 onwards, has drawn increasingly on qualitative methods, often using the self reports of siblings, with some surprising results in comparison to the reports of parents. For example, although the sibling in one study thought his family was different to 'normal' families, and he was aware of the distress felt by his ill brother, he did not express any strong negative feelings about himself. This more recent research suggests that how the rest of the family reacts to a child's illness had a greater impact on the well sibling than previously recognised, and that professionals should adapt the support offered to encompass all members of the family.

In Chapter 3 I outline the methodology, and explain why qualitative research methods have been used in conducting this research. As the research aim is to describe through the stories of families their lived experiences of the culture of childhood illness, an ethnographic approach has been used. In helping to make sense of the ethnographic data a narrative approach was used to explore sense and meaning-making in families' daily coping with the illnesses. Open-ended, semi and unstructured interviews were the basis of the data collection of these families' stories. Complementing the narrative approach, and central to an ethnographic approach, I explore how participant observation has allowed for the collection of further data that may otherwise have been overlooked or ignored. This chapter also explores the ethical concerns associated with researching such emotionally sensitive experiences with vulnerable adults and children.

Chapter 4 examines the data collected from families who have become involved in what Ball terms 'the culture of childhood cancer' (Ball et al, 1996). Here, I develop the metaphor of a 'roller-coaster' to help characterise the feelings and experiences reported by many parents in this research. The parents' responses indicate that the reactions to the diagnosis of childhood cancer and the consequences of the immediate 'hospitalization' of mother and ill child leave parents feeling confused and isolated. The mothers also suggest that hospitalization places them in a subordinate role, which along with their loss of identity to the hospital regime and the loss of control of the child to the medical world, results in a roller-coaster experience of family life which challenges parental roles and marital relationships. The chapter also examines how the illness is largely perceived as a 'destroyer' of the 'normal' daily life experienced by the family prior to the illness (Katz and Krulik, 1999). The roller coaster metaphor reflects the dependency of parents on those who are 'expert' in treating the illness and the extreme ups and downs of their child's progress through it. Even when the treatment is at an end, the metaphor of the roller-coaster captures the mixed sense of relief and deep seated anxiety that parents continue to feel. Survivorship, palliative care and loss of the child are also examined in this chapter.

In Chapter 5 I explore data collected from families experiencing the emotional and life-long challenge of living with a child diagnosed with a life-shortening illness. The findings include how, through the continued advance of modern medical technology, a number of conditions are diagnosed during pregnancy, and babies who would have died

shortly following birth are now surviving into their teens and early adulthood. I use the metaphor of 'Sisyphus and the up-hill struggle' to describe how the findings have shown that for many families, life is a continual up-hill struggle. This includes for many families the responsibility for the medical care of the ill child and the many demands coming from the interventions of professionals, particularly health professionals. The findings also explore how parents often experience specialist treatment as assuming ownership' of their child, thus subordinating the role of the mother. In particular, the chapter examines how the activities of some health professionals appear to devalue the expertise involved in the parental care role or the expert knowledge parents have of their child's day to day health and wellbeing. The meanings which parents give to the child's condition indicate that they feel that they are on a continuous up-hill struggle with each member having to find their own pathway into a new form of family life quite unlike the one they knew before.

In Chapter 6 I examine the data from the siblings of ill children from both categories of illness and include mothers' perceptions of how healthy siblings coped with the many changes that the illness brought to family life. Published research has documented that siblings often receive less attention as the parent becomes more absorbed with the ill child, and further research suggests that siblings are a population at risk (Spinetta, 1981). A number of issues are considered within the data. These include debates about the value of finding a temporary replacement home for a well sibling and disappointments for parents whose expectations that well siblings' schools would offer support to the well child were rarely met during the illness. The findings also explore how pre-existing ambivalent relationships between siblings continue throughout diagnosis and treatment for life-threatening illnesses, and how the realisation of imminent death may bring them closer together. These findings indicate that not all sibling issues should be attributed to a child's illness and may in fact have always been present within the life of that family. As a young adult, one sibling in this study reported that it was during his late teens that he realized the full impact of living with two ill siblings and although his perception was of personal failure, sought professional support. On reaching adulthood he began to recognize the pressures this placed on decisions he made regarding his future life and the wellbeing of his ill siblings.

In Chapter 7 I explore data collected from ill children who report personal perceptions of their care whilst in hospital and/or out-patient clinics. In particular, it examines how health professionals appear not to recognise the child as possessing any expertise in their own illness or treatment, and how they fail to perceive 'children' as active users of health services until approximately 17 years of age.

In Chapter 8 I present data that offers insights into how families maintain some form of 'family life' within the treatment regimes of cancer and of severe disability whilst co-existing within the culture of professionals that include health workers, social workers, and counselling/emotional support workers who have become involved in the lives of families with ill children. The data in this chapter explores some of these practitioner cultures and their interface with families, and continues to examine the difficulties of partnership working within paediatrics, and health professionals' limited perceptions of the considerable expertise which parents possess in their own children's illnesses.

In Chapter 9 I discuss how I place the research within the context of existing literature and suggest ways in which my study has contributed to the meanings which families give to life-threatening and life-shortening illnesses diagnosed in childhood. It also argues that the treatment regimes they experience have a greater impact on the roles, relationships, and wellbeing of families than is appreciated by the professionals involved in the care of their ill child. This discussion focuses on the ways in which 'expertise' is perceived, both by family carers and by professional workers, and leads to substantially different relationships between life-threatening and life-shortening illnesses and the families that are trying to cope with them.

Chapter 10 is the final conclusion that draws the argument of the thesis together. It proposes that diagnosis of a life-threatening or life-shortening illness during childhood changes the family dynamics through its different effects on individual members, and that the primary carer, often the mother, is in danger of losing her expertise and her role to the cultures of illness and the regimes of treatment which take control of the ill child. The limitations of the research, its implications and its principal findings are presented along with a set of recommendations for improving care of children with life-limiting and life-shortening conditions and their families.

CHAPTER 2

LITERATURE REVIEW

The aim of this chapter is to focus on the extent to which published research has investigated the problems of families and individual family members following a diagnosis of a child with a life-threatening or life-shortening illness. Whilst an initial review reveals extensive literature, much of this research has been undertaken using quantitative methods, and is largely from a psychological perspective (Dixon-Woods, Young and Heney 2005). Conceptually, there has been little comparison of life-threatening and life-shortening illnesses, particularly from a sociological point of view. Published studies tend to focus on the separate domains of childhood cancer, chronic illness, and severe multiple disabilities. Davies (1999: 98) states that the “majority of research in the area of childhood life-threatening illness continues to focus on children with cancer, as this remains the leading cause of death due to childhood life-threatening illness”. Research has also concentrated on the relative levels of parental distress, particularly maternal mental wellbeing in relation to the illness, and on the mother and ill child relationship. There has, until more recent times, been little research on the ways in which fathers, well siblings, and the family as a whole adapt to these conditions.

In the following sections, I aim to examine published research associated with the following: anti-natal screening for abnormalities during pregnancy; parents’ response to a diagnosis of a life-shortening illness during pregnancy, birth, or in early childhood; the impact of the loss of a health baby; parental coping and adjustment following the diagnosis; and how the lack of clear communication from medical professionals may affect the ways in which parents cope. This is followed by a review of the difficulties associated with a life-shortening illness and how these may impact on family life and the relationships within the family. I also examine how the research findings generally appear to be contradictory regarding the long-term consequences on psychological wellbeing and whether the marriage survives or fails. Three aspects of the literature are explored relating to the well sibling: the concerns of what is now quite old research into the well sibling; the contradictory nature of the research regarding well sibling’s coping and adjustment; and the changes for the well siblings in their family life. I also explore three areas of the research concerning factors that may influence sibling reaction to the illness: the stress and anxiety that illness creates for the well sibling; relationship issues such as birth order; and the positive aspects of life with an ill sibling.

I continue the literature review by examining how research has dealt with difficulties in diagnosing childhood cancer. This includes the problem of delay in confirming diagnosis due to the symptoms reflecting common childhood ailments. I also examine literature which considers the crisis situation in which parents find themselves following a confirmed diagnosis, the decisions they have to make regarding treatment and the future, and the effects of hospitalization on parents. I also consider how traditional gender roles tend to come to the fore with fathers continuing to work while mothers become the primary carer with implications for loss of previously held identities. The hospitalization of the ill child impacts on family roles and responsibilities, on the marital relationship, and on the emotional wellbeing of the family as a whole.

I continue by examining research findings into three areas associated with the well sibling: siblings' perceptions of inequalities in parental attention; the desire by the well sibling to protect their parents; and the lack of accessible or honest information regarding the seriousness of their ill sibling's condition. I review the literature that highlights the difficulties that are faced by families following the end of treatment, and, for those families where palliative care is the only option, the consequences of survivorship and the long-term health and social problems that this brings. The final part of this chapter examines the literature in relation to recent theories of grief, and issues for bereaved parents and siblings.

FAMILIES WITH A CHILD WITH A LIFE-SHORTENING ILLNESS AND COMPLEX MEDICAL NEEDS PREGNANCY, BIRTH, AND THE LOSS OF A HEALTHY BABY: ANTINATAL SCREENING

In the last fifty years the development of paediatric medicine and medical technology has helped to increase the understanding and treatment of childhood illness and disease. The major paediatric health problems are due to genetic disorder or congenital malformation, and studies indicated that more than a quarter of all deaths in the first year of life are due to foetal abnormalities (Atkins and Hey, 1991). Relatively recent technological developments now allow many potentially fatal conditions to be diagnosed pre-natal and have extended the point of diagnosis some months before birth (Field and Behrman, Eds. 2003). Antenatal screening and diagnostic techniques are almost the norm with the probability of 90% of women in the United Kingdom undergoing one of these procedures

at some time during pregnancy (Whittle, 1991: 35-43). Other studies suggest that antenatal testing has changed the experience of pregnancy:

“Before the development of antenatal testing for foetal abnormalities the foetus was assumed to be healthy, unless there was evidence to the contrary. The presence of antenatal testing and monitoring shifts the balance towards having to prove the health or normality of a foetus (Marteau, T. M, 1991: 234-54).

Statistical information is now used to help identify so-called high-risk groups within the general routine of antenatal screening. Tests are primarily to screen for Down’s Syndrome (incurable), Edwards’ Syndrome (most babies die within the first few weeks of life) and Cystic Fibrosis, (treatable but not curable). Mothers-to-be are given a high or low percentage of risk, especially for Down’s Syndrome as the mother’s age at pregnancy is thought to increase the risk of having a baby with Down’s Syndrome. Figures show that at the age of twenty years the risk is approximately 1 in 1529, at thirty years of age, 1 in 910, rising to 1 in 28 at the age of forty-five years, with 1 in 700 babies born with Down’s syndrome (www.intellectualdisabilities.info/diagnosis/antenatal). A study by D’Amico et al, (1992) examined the reproductive choices of couples with experience of a child affected with a genetic disease and found that a higher percentage of couples (65.5%) avoided further pregnancies than those who continued with subsequent pregnancies (34.5%).

However, the antenatal screening that has helped to diagnose certain conditions prior to birth has also placed parents in the unenviable position of having to choose whether to continue with the pregnancy, or abort. If the parents continue with the pregnancy studies have shown that there is little consideration from the medical world to offer emotional support for either short or long-term stress placed on the parents following the ultrasound diagnosis (Cox et al, 2007). The medical technology that has helped to reduce infant disease and mortality rate has also helped to increase the present high rate of children with a severe disability and/or complex medical needs now surviving into adulthood. The expansion of treatment creates a paradox of a reduction of fatal outcomes and an increase of life-shortening illness (Bury 1991: 457). With the increased population of children, two recent surveys give estimates of 700,000 children under the age of 16 years with disabilities and complex medical needs now living in the UK (DOH, 2004b;

The Family Resource Survey, 2002-3). A further more recent report by ACT (December 2006) estimated that there are approximately 25,000 families in the UK coping with the morbidity of a child, adolescent or young adult. A significant and growing number of these children have a severe disability.

COMPLICATIONS AT BIRTH AND THE LOSS OF A HEALTHY BABY

Archer (1999) suggests that as soon as parents decide to extend their family they begin planning their future child's life and construct a mental image of their perfect child. Seligman and Darling (1997: 40) point out that for many reasons pregnancy and birth, even when the baby is healthy, are stress-producing situations. However, most parents' expectations are such that as they approach the birth, they are anticipating a healthy child, and are therefore not at all prepared for the birth of a child with a disability or chronic illness. Following the birth, or indeed a diagnosis in early childhood, the parents face a multitude of losses. These include the re-defining of roles and re-organization of a different life and future to the one they had planned prior to the birth, and grief for the 'normal' baby they had hoped for (Goodman, 1964: 92; Cohen, 1962: 137; Bristor, 1984). Investigating parental grief following the birth of a special needs child, Solnit and Stark (1961) list three stages of grief: numbness, disappointment, and re-experience, suggesting that the grieving is a reaction to the loss of a wished for child. The notion of 're-experience' – the development of a 'new kind of normal' following the crisis of a special needs diagnosis is significant in the light of my own findings. Rapoport, (1970: 277) concludes that the loss is experienced as a form of mourning and frequently accompanied by depression.

Writing from a counselling background of working with parents following the birth of a special needs child, Olshansky (1962) suggests that chronic sorrow is a normal reaction and that parents suffer from chronic sorrow for the rest of their lives with the intensity varying from time to time, from one parent to another, and from one family to another (Olshansky, 1962: 190). Kennedy points out that although a mother may recognize her grief for the wished for child, she may be reluctant to allow others to share her grief because of the lack of encouragement from society (Kennedy, 1970: 416). Writing some years later, Doka (1989) suggests that there are certain types of grief that are not socially sanctioned and cannot be openly acknowledged or publicly mourned and refers to this as 'disenfranchised grief'. I will suggest that disenfranchised grief 'fits' the parental

situation not only following the birth of a child with disabilities or special needs, but for the rest of the child's life. The societal perception is one that if the child is considered not to be 'normal', or physically not perfect, and the disability is clearly visible, there is a general avoidance of the child and therefore, the parent(s) become a target for sympathy or blame, and although contradictory, the child remains invisible to those around them (for example the famous quote 'does he take sugar?' from the film about Christie Brown's life - *My Left Foot*). Whilst loss is part of everyday life, the potential loss of the anticipated birth of a 'normal' child is rarely considered. Society ignores parental grief for the wished for child, and therefore the grief cannot be acknowledged. However, Carpenter (1997) cites Wills (1994) who draws attention to whose opinion is it being referred to by the term 'society', with many positive outcomes for the family being overlooked:

“The most important thing that happens when a child is born with disabilities is that a child is born. The most important thing that happens when a couple become parents of a child with disabilities is that the couple become parents” (Wills, 1994: 248).

Copley and Bodensteiner (1987: 68) continue the discussion of 'chronic sorrow' in response to life with a disabled child, and suggest that even before parents can cope with their own feelings sufficiently to be able to accept the fact that their child has special needs, they are placed under considerable stress. In their review of the literature 1964-1984, Fortier and Wanlass (1984: 13) point to the anticipated happy event that becomes a tragedy. Parents may find themselves in a situation that they cannot cope with and do not possess sufficient coping skills to handle the diagnosis they have been given. Following their review Fortier and Wanlass propose a five-stage model that clarifies and incorporates stages of crisis in terms of behaviour, affect, sensation, interpersonal relationships and cognition. Featherstone (1980: 232) states that “only when the truth becomes inescapable can the parents acknowledge their special needs child and the long-term significance”.

PARENTAL COPING AND ADJUSTMENT

Much research since the 1950s has concentrated on parental adjustment following the birth of a chronically ill or disabled child, focussing until more recent years on the

negative psychological effects on the mental wellbeing of the mother. There is, however, a general agreement within the research that parents of children with disabilities or chronic illness are more likely to suffer from stress, anxiety, and depression than other parents (Parad and Caplan, 1960; Brantley and Clifford, 1980; Philip and Duckworth, 1982; Quittner et al, 1992, 1998; Lever and Drotar, 1996; Emond and Eaton, 2004). There is similar agreement that parents are more likely to experience marital discord (Eddy and Walker, 1999; Neil-Urban and Jones 2002), suggesting that high levels of distress is found in the parents of severely disabled children. Sloper and Turner (1993: 170) gave figures of up to 70% of mothers and 40% of fathers reporting such problems. They do, however, continue to state that this may be more to do with the professional's prediction of negative effects than of the parents' objective distress, with little comparison of marital discord amongst parents following the birth of a baby without any disability. These findings too are significant to my own data, suggesting that too much emphasis may have been placed on expected negative psychological effects whilst possibly overlooking more positive sociological outcomes for overall family cohesion. These positive effects may well be a reaction to challenges from the outside world, and greater member identification around the characteristics of the 'special' child.

FACTORS RELATING TO PARENTAL COPING

In instances where parents are concerned that something is wrong with the child, but there is no clear evidence of a particular symptom, they usually turn to a health professional for information and advice - normally the family GP (Neill, 2000). However, due to the limited time that a GP can give, parents may often leave the surgery without any detailed information, leading to more anxiety. Eventually the parents may find themselves in a consulting room hearing that their child has a diagnosis of a life-shortening illness. Research suggests that the way in which parents are informed of such a diagnosis impacts on their subsequent coping (Davis, 1993; Lynch and Staloch, 1988; Moynihan and Haig, 1989). Field and Behrman (2003: 106) comment on how health care professionals may be inadequately trained or prepared, and often dread the delivery of a diagnosis so much so that they fail to provide a complete, accurate, and time-framed picture of the child's condition and prognosis. The medical practitioner may be unaware of the parents' capacity to take and digest 'bad news' and complicated treatment information. According to Bury (1997) poor communication, indecisiveness and lack of information, particularly by the GP, crushes parents' hopes for the future. A further factor

in coping which often is taken for granted by health professionals is the future management of the child's illness, where its effectiveness is dependent on the family's ability to provide the care (Jerrett, 1994).

Much published research concentrates on the 'inside' world of a family and how individual parents cope both emotionally and financially with having a child who has a physical or mental disability. This approach tends to overlook how the 'outside' world places an additional burden on the family by the negative attitude of the public towards disability (Leiter et al, 2004). An additional factor affecting families' ability to cope is the level of emotional support offered and the level of financial resources provided at a national level to support what is an expensive and time consuming task of caring for these children (McKeever and Miller, 2004; Redman and Richardson, 2003). This lack of financial and emotional backup, lack of apparent concern by others for the challenges faced in caring for severely disabled children, and the day to day coping with often arduous, physically demanding tasks may well hinder the positive adjustment of parents (O'Hagan et al, 1984).

FATHERS OF CHILDREN WITH A LIFE-SHORTENING ILLNESS

The role of parents, particularly the role of fathers, has changed dramatically since early research investigated how the diagnosis of children's life-shortening illnesses impacted largely on mothers' coping ability (Anderson, 1996; Katz and Krulik, 1999; Katz, 2002; Seligman and Darling 1997). Post-war and into the 1970s mothers were thought to be the main object of attachment with the child, and the father was assumed to be in a supportive role to the mother, and less emotionally involved with the child (Bowlby, 1951). Despite the changing role of women and the increasing numbers of children with life-limiting illnesses who survive into young adulthood, few studies have focused attention on how the diagnosis, birth and ongoing care for the ill child impacts on the father's life and ability to adjust (Davies et al, 2004; Katz and Krulik, 1999; Katz, 2002; May, 1996; Seligman and Darling, 1997). As a result of the scarcity of research in this area, even less is known about how fathers cope when their ill child dies (Davies et al, 2004; Riches and Dawson, 2000).

A number of researchers (McKeever, 1981; Meyer, 1986; Katz and Krulik, 1999) suggest that although fathers are emotionally affected by their children's life-shortening illnesses,

they appear to have greater difficulty than mothers in accepting and adjusting realistically to the children's limitations. Goble's study (2004) theorised that by not being able to fulfil the 'fatherly' role with the ill child, for example, playing football, and riding bikes, the relationship was not as close as to the well child. The same study also found that the fathers believed that the financial and social demands of the illness also dramatically changed their relationships with their wives and well children. One father in the study suggested that he had isolated himself from family and friends as he felt that no one really understood his situation (Goble, 2004: 159). McKeever (1981) reported that fathers found it difficult and distressing to discuss their concerns for the ill child. The lack of family and social support appeared to increase some fathers' sense of being overwhelmed by their children's illnesses (Cayse, 1994). Other studies reported that fathers appear to gain little satisfaction from the ill child and lacked confidence in their own ability to care for them, gradually becoming less involved with this care and more detached from the child (Eiser, 1990; Lillie, 1993; Turner-Henson et al, 1992). Whilst undoubtedly this pattern is still in evidence in my own research, little attention has been given to the ways in which the demands imposed upon a family by a severely disabled child may increase father's involvement in the care of all his children. Neither does it explore the extent to which the presence of such a child within a family may 'consolidate' the family's identity around the challenges which disability presents. In short, this earlier research tended to 'pathologise' fathers' responses to the birth of a child with special needs, overlooking evidence that, although crises are central to coping with the needs of children with life-shortening conditions, over the longer term those families that stay intact may also form relationships around the defence of their 'special family'. These studies may also be criticised for not recognising similar relationship stresses when fathers feel excluded following the birth of a so-called 'normal' baby.

THE SURVIVAL OF MARITAL RELATIONSHIPS

The literature relating to marital satisfaction following diagnosis of a child's life-shortening condition appears to report the same negative findings as research into the impact on parental coping (Bristol, 1987; Eiser, 1990; Noh, Dumas, Wolf and Fisman 1989). Whilst giving only the diagnosis as a possible reason, early research suggests that there is increased marital tension and a lack of intra-couple interaction in couples parenting a child with chronic medical needs (Gath, 1972; McAlister et al, 1973). Tavormina, Boll and Dunn (1981) suggest that as increased parental stress is to be found

in all types of chronic illness or disability and this may have an impact on marital relations. Other research criticises these conclusions, arguing that there is no reliable or valid research that offers a convincing causal link between birth of a severely disabled child and either family dysfunction or marital conflict (Wright and Leahey 1987). However, in comparison studies, researchers have found marital satisfaction to be lower in parents of chronically ill children than parents of well children (Fisman and Wolf, 1991; Konstantareas and Homitidis, 1991; Shek and Tsang, 1993). Eddy and Walker (1999) state that there is no straightforward link between the child's diagnosis and whether there is either a marital problem or marital stability. They do, however, suggest that the diagnosis could be associated with reasons for the parents to both stay together or to break up (Eddy and Walker, 1999: 10), suggesting that, like a child's death, coping with a severely disabled child can either 'break or make' a couple relationship. It is also possible for marriages to be unhappy but stable (Heaton, 1991), but this also is not confined to couples with special needs children.

THE WELL SIBLING

The sibling relationship is possibly the longest of all relationships (Cicirelli 1995) and one where the well sibling will live the longest with disease related memories and concerns (Spinetta, 1981). The relationship is one that not only enriches play and socialization, but also offers a variety of experiences that aid psychosocial development and self-definition. Because of this, according to Parsons and Fox (1968) an illness in a sibling shifts the focus of family solicitude and concern, creating disequilibria within the family. This they conclude intensifies sibling rivalries and decreases the beneficial aspect of the sibling relationship.

Early pioneers who in the late 1950s and early 1960s showed concern for sibling adjustment included Cobb (1956), Farber (1959, 1960, 1963), and Natterson and Knudson (1960). Yet, paradoxically, later research has all but ignored the sibling relationship within the complexities of childhood illness. Faux (1993) suggests that sibling relationships are reciprocal by their very nature, yet few researchers have studied them from this perspective. Rather than concentrating on the relationship between the well and ill sibling and the possible long term effects, research has continued to concentrate on adolescents who are either the sibling of a dying child (Birenbaum, et al, 1990; Hogan and DeSantis, 1992; Martinson and Campos, 1991) or siblings who are

bereaved (Blinder, 1972; Heiney, 1991; McCowen and Pratt, 1985; Packman et al, 2006). Whilst the well siblings face issues that are uniquely theirs (Meyer and Vadasy, 1997), professionals working with the families of special needs children may not be aware of sibling concerns, or know how to address the well siblings in their work. Cicirelli (1995) states that:

“Researchers are just now beginning to determine how the (sibling) relationship is affected by various life cycle changes as well as by critical life events. By taking a life span perspective one is enabled to see implications of early events for later relationships and to appreciate the natural cycle of change in the sibling relationship...”(Cicirelli 1995).

WELL SIBLING COPING AND ADJUSTMENT TO THE ILLNESS

Damiani (1999) in her update and review of the research literature on responsibility and adjustment of siblings of children with disabilities highlights the disagreement amongst professionals regarding the diagnosis and whether this is a factor in sibling adjustment. She cites the work of Lobato (1990) as one who believes that sibling reaction is similar regardless of a specific diagnosis of a child with disabilities. She continues to cite Donovan (1985) and Stoneman et al, (1988) in reporting that there is growing evidence that different symptomatology relates to differences in care-giving levels and therefore, indirectly to sibling reactions. Damiani concludes that the body of literature on siblings is a mixture, with some studies suggesting that there is no effect on the well sibling, whilst other studies identifying a changed relationship between siblings combined with an increase in psychological problems.

CHANGES IN FAMILY LIFE FOR WELL SIBLINGS

Illness in a family disrupts the routine of family life as it used to be. Changes can include the disruption of individual and family routines such as chores, meal times, bedtime, and the well sibling's play patterns (Chesler and Barbarin, 1987). Some siblings experience what Iles (1979) describes as the 'empty house' and the presence of parental substitutes during hospitalizations of the ill child. Tiller et al, (1977) note the pattern within some families for an older sibling (usually a sister) taking on the mothering role for younger siblings in the family. However, McHale and Gamble (1987), Gold (1993), and Damiani

(1993) found that in families even without a child with disabilities, girls had significantly more responsibilities that could be seen as part of a 'mothering role' than boys.

In Taylor's (1980) study of well siblings in families where one child had severe medical needs it was suggested that, regardless of the changing roles and responsibilities within the family, there was a lack of touch and physical closeness which these children felt to be predominant deprivations. These experiences can lead to feelings of isolation and loneliness (Bendor, 1990; Cairns, et al, 1979). When these two dynamics are joined, siblings may have difficulty expressing the anxiety or jealousy they feel at the lack of parental attention, or of maintaining family rules. A concern for all siblings is whether their brothers or sisters are treated more favourably by parents, and they frequently monitor their parents' behaviour towards themselves and their siblings carefully (Bendor, 1990; Dunn and Stocker, 1989). McHale and Pawletko (1992) suggest that when mothers devote more time and attention to younger or disabled siblings, older children may feel that their parents' behaviour is legitimate, but still may feel left out or neglected. Chesler et al, (1991) state that when parental concern for the ill child seems out of proportion to the explanations given, the sibling's anxieties about favouritism and rejection may escalate.

Bringing the published findings up to date, it is possible to note the tendency of these earlier studies to pathologise sibling relationships with ill children in similar ways to those with the father. A study by Read et al, (2010) found a link between the parent-reported psychological issues of well siblings and the severity of the illness and the extent of wheelchair use by the ill child. Although a third of siblings in the study reported that the illness had had a substantial effect on their family and individual life, the unaffected siblings had only a slightly higher risk of emotional difficulties than the general population. Closeness in age between siblings was a further issue that linked parental psychological difficulties and emotional symptoms reported by the siblings themselves. This may be due to lower parental attention to the well sibling and the adverse changes and care demands of the ill child. Read et al conclude that future consideration should include factors such as disadvantaged social backgrounds, adverse life-events, and how families function and communicate with each other. In other words, factors which commonly affect the functioning of so-called 'normal' families and which produce marital breakdown and sibling conflict, may have been interpreted in these studies solely

as the consequence of stresses arising from the needs of the special child. Hence, earlier studies which tended to pathologise relationship problems in 'special needs' families may not be helpful, bearing in mind the relatively high incidence of divorce in the population at large.

For example, in her study of twenty-five well siblings, Taylor (1980) reported that a number felt that they could never do anything right or 'good enough' to get parental attention. The same study found that they occasionally reported they had wished for the death of their ill siblings. However, it is important to note that in addition, all respondents appeared enthusiastic when told that the researcher would share what they were saying with other children in a similar situation, and said that they wished someone had been available to talk to them earlier.

The more complex link between sibling involvement and positive coping is highlighted in a more recent study in which Waite-Jones and Madill (2008) found that healthy siblings of children with juvenile idiopathic arthritis tended to see their families as different to 'normal' families. They appeared to spend less time with their friends, identified strongly with the experiences of their ill siblings and felt as though they had too little information about the illness and its possible outcomes. The authors argued that these experiences exaggerated the conflicts normally felt between siblings, feelings especially vulnerable to the stigma of physical disability. Interestingly – and this supports the notion of the whole family being involved in the care of a disabled child – Waite-Jones and Madill argue that siblings often appear to be more aware of the social distress felt by their ill brothers and sisters than were their parents. Feelings of responsibility for an ill sibling and time taken out from normal adolescent activities to help with their care appear to lead to feelings of frustration which are difficult to admit to. The authors suggested that problems of adolescent adjustment in well siblings can be reduced through strong extended family support networks, particularly where good communication allows children to understand the family's situation and the detailed nature of the ill child's medical condition. Waite-Jones and Madill argue that, where such support is in evidence, this can lead to increased independence, maturity and self-direction in both the well and ill sibling.

However, Giallo and Gavidia-Payne (2006) found that the siblings in their study had significantly higher adjustment difficulties and emotional symptoms compared to the

normative group. This, they note, is consistent with previous research reporting on siblings of children with disabilities, and cite (Summers et al, 1994; Lamorey, 1999; Rossiter and Sharpe, 2001). They continue to suggest that siblings who are from families where there is a higher risk of family and parental stress and fewer resources may have an increased risk of difficult adjustment. The siblings from families who had reported consistent family routines and used effective communication appeared to have better adjustment outcomes. This study found parental stress was a predictor of sibling adjustment and this, Giallo and Gavidia-Payne argue, raises questions regarding the benefits of sibling support groups which may have a limited impact on some siblings, adding that professional support may increase family stress. Giallo and Gavidia-Payne's study also revealed that families who had a more positive experience of the illness may also have an important role in the positive adjustment for the well siblings.

STRESS AND ANXIETY IN THE WELL SIBLING

In their study of fifty-four well siblings Tritt and Esses (1988) state that one of the most revealing questions asked was "who in the family do you think is most unhappy because of your brother's or sister's illness"? Although justifying the response with comments indicative of their worry, and feelings of exclusion, the answer was a very clear, 'themselves'. The researchers continued to suggest that the results of the study give a clear indication that the life-shortening illness of a sibling is a profound experience, with many siblings experiencing feelings of abandonment and distress. In concluding Tritt and Esses point to the illness as having some impact on all healthy siblings and argued that it may alter or distort normal development and adjustment. A number of studies in discussing the difficulties of well siblings (for example, Drotar and Crawford, 1985) suggest that well sibling of chronically ill children are a population at risk, not necessarily for mental health problems, but for anxiety, confusion, and personal suffering. The anxiety for the well sibling increases as they themselves grow older along with an awareness of what future plans their parents have, or have not made, in the care of the ill sibling (McCullough, 1981). The well sibling also faces new challenges when their thoughts are around their own future of relationships and child bearing potential, especially if the illness or disability of the sibling is hereditary. Often these fears are unfounded (Parfit, 1975). However, well siblings as they get older, need the opportunity to receive information and genetic counselling on the implications of the disease or disability for their own lives (Murphy, 1979).

Although these earlier studies focussed on child illness and its apparent consequences of anxiety and depression for well siblings, recent studies have found more positive outcomes, especially from the self-reports of well siblings. Wood et al, (2008) found on the basis of self-reports of siblings of children with intractable epilepsy and other neurological disabilities that overall they were functioning well, and that no sibling showed signs of depression. They continue to report in their study, that, possibly due to care-giving demands, maternal depression rates were very high. Because of this factor, Wood et al, were expecting a poorer quality of life and greater psychopathology in the siblings, but were surprised to find no significant correlation with maternal depression as previous studies had shown (Downey and Coyne 1990). Overall, Wood et al, conclude that the siblings had a good quality of life and were functioning well and that consideration should now be given to support programs that place an emphasis on helping parents as the programs that concentrate on supporting siblings may have a lesser impact. Although the study of Batte et al, (2006) did not provide results that indicated statistical differences between the well siblings and the normative group, the well siblings did have concerns regarding being left out, and away from parents during hospitalization of the ill child. Continuing, they suggest that a positive aspect for the well siblings is that they may become emotionally stronger through their experience of having a brother or sister with renal failure. They conclude that the paediatric team should encourage parental communication with well siblings and aim to recognize the family as a whole, identifying their coping strategies and strengths rather than concentrating on the anticipated worsening of specific family relationships. Hames and Appleton (2009) reported that in the early stages of the illness negative feelings were common for the well siblings, but were frequently overcome by a caring approach. A limited number of siblings felt considerable responsibility towards the ill sibling. The study was based on self-reports of siblings who emphasised the benefits of clear information directed specifically at siblings, noting that it would have been particularly supportive in the light of parents' poor or selective information-giving, especially when they were stressed. A study by Hastings (2007), based on maternal reports, found no significant difference in the behavioural adjustment of siblings of children with disabilities. The mothers reported that the siblings were well adjusted when compared to a normative sample. The study did provide evidence that the child with development disabilities who themselves had behaviour problems may place the well sibling at risk of having similar problems. It is

suggested that the well sibling may be affected by the ill sibling's unusual public behaviour, and thus contributed to lowered self-esteem which could place them at risk for other problems. Hastings concludes that the findings do not support a hypothesis that well siblings of children with developmental disabilities are at risk of adjustment problems, and continues to suggest that his study illustrates how little is known on how or why some siblings adjust well and others appear to have difficulties.

BIRTH ORDER, GENDER, AND OTHER FACTORS

Although limited, there are research studies that have identified the complexity of factors that could affect the well sibling in their medium to long-term futures. In line with more recent studies, early research by Ferrari (1984) disagrees with the more general view that siblings of chronically ill children are at greater risk of psychological impairment than siblings of healthy children. However, his study did provide supportive evidence that siblings of same sex chronically ill children have higher rates of maladjustment than opposite-sex pairs. Other variables were found to influence the sibling's adjustment. According to Ferrari these related largely to the nature of the illness, the age at diagnosis of the ill child, and the amount of time that had elapsed since the diagnosis while the sibling was alive. More recent research unfortunately appears not to have investigated Ferrari's particular area of interest, yet these findings may be crucial in explaining how well siblings cope. This may be particularly important when comparing siblings of children with life-shortening conditions with siblings of children with cancer or leukaemia. There may be real differences in adjustment when the diagnosis comes out of the blue, and appears to have a greater initial impact along with an almost immediate separation of the mother and ill child from the rest of the family. For the well siblings of children with severe long-term medical needs there may not be this separation experience following a diagnosis, but, on the other hand, they do have to live with a slow decline over the ill child's lifetime.

Early research has suggested that a sibling's birth-order in relation to that of the ill child has an effect on their psychological functioning (Lavigne and Ryan, 1979; Tew and Laurence, 1973). However, Breslau's (1982) study of birth-order and age-spacing effects found that birth-order had opposite affects on the psychological functioning of male and female siblings. Among males, those younger than the disabled child showed greater

psychological difficulties than those who were older. With females, those younger than the disabled child fared better than those who were older.

POSITIVE ASPECTS OF LIVING WITH AN ILL SIBLING

The review so far illustrates that over the years much research on well siblings has concentrated on the largely negative psychological effects of living with an ill sibling. However, whilst the well sibling may generally have to take on additional responsibilities within the home such as caring for the ill child, and undoubtedly extraordinary stresses will be faced by these children, there also appear to be a number of positive responses to living with an ill sibling. These may be linked to the willingness of the parents to keep the well sibling informed regarding the illness and treatment and to the quality of adjustment within the parents' marital relationship. In addition, according to DeMeyer (1979), well siblings can act as change agents in helping reduce parents' frustration with the ill child and hence contribute actively to the quality of the marital and parental relationship. DeMeyer reports that well siblings often are more effective in motivating their disabled brother or sister than parents themselves, and may help 'dilute' the pressures generated by the disability, both by sharing in the care, and in making their own non-medical demands on parents. These processes were observed in my own research, with a number of well siblings appearing to accept both a role in and considerable responsibility for, the welfare of the wider family. On the whole, most studies in the latter decades of the 20th century overlooked these positive aspects because of understandable but possibly exaggerated assumptions about the stresses involved in coping with a child with complex medical conditions.

FAMILIES WHERE A CHILD IS DIAGNOSED WITH CANCER

Having focussed so far on research into families with severely disabled children with life-shortening conditions, I now move onto looking at studies of families where a child is diagnosed with a life-threatening illness. Since the 1950s much has changed regarding the treatment and survival of a child diagnosed with cancer. For example, this has changed from a prognosis of death within four months of diagnosis to what is now approaching an 80% survival rate for children diagnosed with leukaemia. However what has not changed is that, following a diagnosis of childhood cancer, the parents and other family members are thrown into crisis and their ordinary daily lives are severely disrupted (Allen et al, 1997; Boman et al, 2003; Maguire, 1983; Sloper, 1996; Young et

al, 2002). The distress that the diagnosis creates has the “potential to disrupt permanently parents’ and children’s biographies (Young et al, 2002: 1836). Although the medical understanding of the disease has grown, the medical understanding of how the disease and its treatment affect families has failed to keep pace with the improvements in treatment. The Institute of Medicine’s report *When Children Die* (Field and Behrman, 2002), suggest that there are gaps in health care providers’ knowledge regarding the support of children and families, and that often they fail to accurately assess the needs of the family unit as a complex system of roles.

DIFFICULTIES IN OBTAINING A DIAGNOSIS

The diagnosis often comes some time following the onset of symptoms which at the time parents may view as ordinary and common to childhood, such as tiredness, lack of appetite, and general aches and pains, often referred to as ‘growing pains’. One mother assumed her son had eaten too much:

“...my son David, who is seven years old, had woken up complaining of a pain in his stomach. There didn’t seem anything remarkable about this at the time, since the day before he had been to a friend’s birthday party and eaten too much chocolate cake!” (Burn, J. 2005: 8).

The stomach-ache continued. The GP, who thought it was a grumbling appendix, sent him for a scan. This indicated that his appendix was healthy, but showed a tumour on his kidney that was later diagnosed as being malignant.

Because of the innocuous symptoms many parents delay seeking medical attention but once the diagnosis has been made, perhaps feel guilty for disbelieving the child or for criticising the child for complaining. Self blame by the parent often follows. For example, “Was it something in pregnancy?” “Was it where we lived?” and for not realizing the seriousness of the situation (Comaroff and Maguire, 1981; Edgeworth et al, 1996). In some circumstances where there is a family history of cancer, this self-blame may have a clearer source. There are suggestions that acute leukaemia may result from a lack of exposure to infection (Stiller et al, 2004). However, for many parents, even when seeking medical attention, their child’s confirmed diagnosis is often still some time away. A number of studies have reported that the family GP can, and often is, dismissive of the

symptoms described to them by the parent (Comaroff and Maguire, 1981; Eiser et al, 1994; Dixon-Woods et al, 2001; Holm et al, 2003).

57% of parents in Sloper's 1996 study reported a delay in first taking the ill child to the GP before the diagnosis of the cancer was made. He further states that the shortest time for the diagnosis was for children with leukaemia at 4.8 weeks. Ibrahim's (2004) study of children with brain tumours reported that there was a delay of between two weeks to two years. Bone tumour diagnosis was found to be between eleven and twenty weeks (Pollock et al, 1991). Parents often feel that they are dismissed by the GP or other health professional for wasting their time, or are perceived as being over anxious or neurotic mothers (Dixon-Woods et al, 2005; Holm et al, 2003; Sloper, 1996). The majority of childhood cancers are, in the first instance, identified within primary care, with the majority of GPs seeing many children at their surgery with symptoms similar to those children who will later be diagnosed with leukaemia. However, a family GP will have very limited experience of the subtle symptoms and signs attributed to childhood leukaemia and may only see one or two patients throughout their career. This indicates the importance of the family doctor being able to recognize what is more than a minor illness (Dixon-Woods et al, 2005: 32).

RECEIVING A CONFIRMED DIAGNOSIS

Having to inform parents that their child has a potentially fatal condition is difficult for the consultant. The diagnosis, treatment protocols, and prognosis information are generally all given at the same time and frequently important information gets lost in the shock reaction of parents to the emotive 'Cancer' word (Christakis and Iwashyna, 1998). This is quickly followed by the signing of consent forms at a time when parents are still disorientated or disbelieving and may lead to misunderstanding of the information they have been given. This may impair their capacity to face the decisions they are expected to make (Downer, 1996; Field and Behrman, 2003; Sourkes, 1995a). These decisions may include taking part in clinical trials, alternative treatment protocols and fertility safeguards such as storing eggs and sperm for the future, as chemotherapy and other associated treatments are likely to create infertility in both males and females (Lackner et al, 2000).

Health professionals and parents may decide that the ill child is too young to be involved in a discussion of issues connected with sex and fertility. Although the general consensus would agree that this is right for children under ten years of age, consideration should be given to the fact that children and young people are now sexually aware much younger than twenty years ago. Research has shown that a number of children are sexually active from 12 years of age (Doss et al, 2006). Albert et al (2003) found that approximately one in five teenagers have had sex before their 15th birthday. In both clinical practice and quality of life research the sexual, interpersonal, and reproductive late effects of treatment often are not addressed adequately or are not addressed at all (Thaler-DeMers, 2001).

This poses the question of whose problem is it to make decisions about egg or sperm banking in older children? The lack of a clear answer could be as much to do with the inadequacies of the health professionals' communication skills as it is to do with the reluctance of young patients to discuss it with their parents (Hautamaki and Nojonen, 2001; Zmuda, 2001a). Nurse's knowledge regarding sperm banking may be inadequate and influence their ability and willingness to discuss this opinion with young male patients (Reebals et al, 2006). Shover, Bray, Lichtin, Lipshultz and Jeha (2002) noted that 91% of doctors agreed that, where there is a risk of infertility, males should be offered sperm banking, yet only 10% of these doctors had offered this to all eligible males.

When parents receive the news from a clinician that their child has been diagnosed with a form of childhood cancer, they also experience the distress that their whole world has been turned upside down (Allen et al, 1997). A father in Katz and Krulik's study (1999: 306) described how the illness had changed family life. "The child's illness has destroyed the normal life we used to have as a family". Clarke-Steffen (1993a) describes the diagnosis as a fracturing of reality, followed by a need to reconstruct reality in the light of long-term uncertainty. Sloper (1996: 187) states that "the diagnosis of cancer in a child presents a crisis for family members". Other studies suggest that the diagnosis and illness poses such a threat that it transforms all family life and affects each family member in different ways (Binger et al, 1969; Kaplan, 1971). For some parents the diagnosis actually marks the end of what may have been a frustrating period of time, especially when the parental perception was that no one believed the child was ill. Following the diagnosis, which for all concerned is a distressing time, the ill child is hospitalized almost

immediately for what will be a prolonged, intensive, often very invasive period of treatment (Allen et al, 1997).

Although the horror of the initial diagnosis and situation may reduce over time, a number of studies have suggested that high levels of distress have been found in some parents one and more years later (Boman Lindahl and Bjork, 2003; Fife, Norton and Groom, 1987; Maguire, 1983; Sawyer, Antoniou, Toogood, Rice and Baghurst, 1993). There are, however, noticeable variations within studies regarding the levels and sources of distress, with some studies suggesting that there is no difference in stress levels between families with an ill child and families of healthy children (Brown et al, 1992; Norberg, Lindblad, and Boman, 2005). A further study by Townes et al, (1974) reported no difference in families, although the families of children with cancer reported more stressful events. There appears to be some agreement within the research findings that family factors such as, social support, relationships, and socioeconomic factors are related to outcome (Knussen and Sloper, 1992; Sloper, 2000). In *Rethinking Experiences of Childhood Cancer*, Dixon-Woods et al, (2005: 15-16) criticise how children and their families have been presented within psychological studies of childhood cancer. These researchers, they argue, have been preoccupied with measuring psychopathology or maladjustment and that children with cancer and their families are portrayed as being victimised psychologically as well as being victims of a physically malign disease.

HOSPITALISATION OF THE MOTHER AND ILL CHILD: THE IMPACT ON MOTHERS, FATHERS AND OTHER FAMILY MEMBERS

Immediately following the diagnosis, complete reorganization of family life and care of other children, has to take place. With few exceptions this usually results in the mother having to give up work or reduce her hours in paid employment to be with the hospitalized ill child. For women in particular, motherhood acts as both a regulator of their lives and a major component of their self-identity (Richardson, 1993). In a study by Young et al (2003: 305-9) the mothers, on receiving a confirmed diagnosis, began a process which over time led to a changed identity. This identity revolved primarily around the ill child and that brought about new responsibilities, roles and a rapid growth in expertise based on close observation of the treatment effects on her child. Yet, whilst still a wife and mother to other children, the associated roles and responsibilities are

partly relinquished in order to become the primary carer for the ill child (Clarke-Steffen, 1997).

Young et al, (2002) suggest that when there is little else a parent can do to help in the ill child's recovery, by continually being at the hospital bedside she demonstrates adequate parenting to those around. This could mean that some mothers find themselves entrenched within a hospital over many weeks:

“...And she's holding my hand day and night to say don't go away, don't leave me alone, and I couldn't leave her like that so I was there with her until they allowed me to come home with her. And I was there for more than 2 months.”
(Mother of female patient, aged 4, cited in Young et al, 2002: 1838).

Generally, whilst the mother remains at the child's bedside, the father continues to work. Raey et al, (1998: 41) suggest that the more traditional gender roles and responsibilities which always lurk beneath the surface of everyday family life re-surface with the diagnosis of cancer. Continuing this theme Williams and Bendelow suggest that even in the 'post-modern' 1990s traditional conceptions of 'masculinity' and 'femininity' were still widespread and exerted a powerful and pervasive impact on people's lives (Williams and Bendelow, 1996: 149). Dixon-Woods et al, (2005) argue that the social state of childhood, especially in relation to serious childhood illness, tends to push adults back towards traditional roles.

The gender roles become more evident during the treatment and hospitalization of the child diagnosed with cancer, with the father as primary financial supporter of the family having to continue working and visiting the hospital when paid work permits (Brown and Barbarin, 1996; Yeh, 2002). This, however, does not indicate that fathers do not wish to be involved and often the lack of involvement is more to do with the working hours of the medical professionals. For example, out-patient appointments are during the day, and during the child's hospitalization, consultants are usually only available throughout the week-day whilst the father is working, but not in the evening or week-ends when the father may be visiting:

“All of us who work in paediatrics need to be aware of our potential to contribute to this pattern, which makes fathers feel excluded and inadequate, and to do everything we can to counteract it by showing respect to fathers, as well as to mothers and children. To act as if fathers’ opinions, feelings, and presence are unimportant is to disrespect them” (Seagull, 2000: 167).

Katz and Krulik (1999) state that research on how a child’s life-threatening illness impacts on a fathers’ role is limited and inconclusive. Early research suggests that the lack of participation in the treatment and care of the ill child was a primary difficulty for fathers (Binger et al, 1969). Other studies (Eiser, 1990; Lillie, 1993; Turner-Henson et al, 1992) indicate that fathers seem to gain little satisfaction from the ill child and feel inadequate in their care and knowledge of the child’s illness. There is, however, acknowledgement within the research that the role of the father in the care of the ill child is increasing (Anderson, 1996) yet mothers are far more likely to maintain a heightened sensitivity to the changing condition of their children if they are the ones most concerned with the day-to-day care.

On entering the hospital the medical practitioner’s priority is to treat the illness and the parents soon grasp that they have little control over what happens to their child. Dixon-Woods et al, (2001: 73) state that: “...the submission to the requirements of the medical regime places children with cancer (and their families) in a potentially very subordinate position in relation to medical staff and organizational routines”. Clarke-Steffen’s study (1997: 282) suggests that parents encounter barriers in relation to information, such as complex technical language, reluctance to disclose information, and difficulties in the attitude of the person providing the information. With the medical focus primarily on the ill child the stress and pressure the parent is under may go unnoticed by staff. Field and Behrman (2003: 30) point out that: “although parents may cherish every minute of care they provide to an ill child, other caregivers should be alert to excessive strain on parents from a physically, emotionally, or technically demanding regime of care-giving”. As parents continue to witness their child’s pain and distress it is difficult for the family to continue functioning ‘normally’ and plan for the future (Haas, 1990; Rolland, 1994; Sloper, 2000).

THE EFFECTS ON MARITAL RELATIONSHIPS

Following the diagnosis of cancer and the inevitable hospitalization of the ill child, there is likely to be a growing physical separation of the parents and a distancing of their relationship. Sloper's (1996) study of parents' responses to childhood cancer reported that marital tension as a result of the illness had been mentioned in 30% of families. However, it is important to note that 56% of the respondents reported no change in their relationship, whilst 29% felt more positive and only 15% felt less positive. Sloper suggests that "the comments indicate that the changes related to the quality and strength of the pre-existing relationship." Many fathers where a child had been diagnosed with cancer reported that their marital relationship had been placed on hold and that they had not been out socially alone with their wives since the diagnosis and that the passion and sex had disappeared from their relationship (Davies et al, 2004; Neil-Urban and Jones, 2002). Sloper (1996) suggests that because of their preoccupation with their own emotional state, fathers find it difficult to provide social support to their spouse and child. A consequence of the treatment, separation of the parents, and the father's perception of not being part of the medical care is that as the treatment intensifies the mother does not have time or energy to be the 'wife'. The husband then may find it difficult to accept the withdrawal of their wives' attention:

"They [fathers] were unable to cope but they were also unable to accept the fact that their wives were having to give the child 100% of their attention, which is awful to think that the men wouldn't like that, but I don't think a lot of men do"
(Linda Lewis, cited in Raey, Bignold, Ball and Cribb, 1998: 43).

When the primary focus of family life becomes caring for the sick child as it inevitably does in childhood cancer, then women rather than men will be seen as coping (William and Bendelow 1996).

MOTHERS AS CARER 'EXPERTS'

A further consequence of the mothers' immersion in hospital life and the medical world of treatment is that quite quickly they learn medical language, have a knowledge of the drugs and, more importantly, they know their child. Over a short period of time they become a 'lay expert' in the treatment of their child. The traditional role of medical expert is now being challenged with the government promoting patient centred NHS

initiatives such as the expert patient programme first announced in *Saving Lives: Our Healthier Nation* (DOH, 1999), and *The expert patient: a new approach to chronic disease management in the 21st century* (2001). It is now generally recognised that the patient has more long-term insight into their own illness than the consultant who originally made the diagnosis. Holman and Lorig (2000) suggest that, “in the field of chronic illnesses ... patients are recognized to hold an important understanding of their condition”. Although the parents in childhood cancer are not the patients they are closely involved in the treatment. Although this does not make them (generally the mothers) an ‘expert’, in medical terms it does give them more than a basic understanding of the illness and treatment.

Further to this, times have changed regarding medical information in relation to disease and treatment with advice freely available in magazines, newspapers, and television programmes. Fathers as well as mothers have considerably more access to medical conditions and their treatment through the internet. Therefore, the media is now a major source of health information. Williams and Calnan state that “the media play a powerful role not only in shaping of lay views and evaluations of modern medicine, but also in the profiling of risks in contemporary society” (Williams and Calnan, 1996: 259). Rogers et al, 1999 argue that new ideas about acceptable and controversial treatment have been found to reach the layperson before the professional and to act as a source of information via laypeople to *professionals*. Parents within childhood cancer frequently search the internet for new research and the availability of alternative treatments, particularly from the United States of America.

END OF TREATMENT

The end of treatment can and does bring some relief to the family. However, following a number of years concentrating on the ill child’s needs, the end of treatment raises possible issues with the needs of both the primary carer and the family as a whole. During the treatment period, the carer - usually the mother - has less time to attend to her own health needs. Problems may arise due to reduced sleep patterns and irregular, frequently unhealthy meals often snatched within the hospital stays, compounded by the emotional roller-coaster of guilt and anxiety (James et al, 2002). Other circumstances, such as an accident or witnessing a serious crime, would place her at risk medically, and yet the care of a seriously ill child is not considered to be a potential source of post

traumatic stress disorder. Stuber et al, (1996) found continuing evidence of mother's PTSD symptoms at an average of five years after cessation of treatment of their child's cancer.

LONG-TERM EFFECTS OF TREATMENT AND SURVIVORSHIP

With the significant advances in the treatment of childhood cancers, survivors are now reaching adulthood. However, studies have shown that cancer and its treatment can create treatment-related complications and may significantly impact on the physical functioning of the survivors of childhood cancer (Green et al, 1999; Dryer et al, 2002; Marina, 1997; Mertens et al, 2001). Further studies suggest that for many years there has been an awareness that the treatment that has helped in the survival of childhood cancer patients can also be the source of long-term health problems and a reduction in the survivors' quality of life (Friedman and Meadows, 2002: 1083). Cancer Reference Information (www.cancer.org) point to what is known as the "late effects" that are caused by the injury that cancer treatment causes to the healthy cells in the body. As a result of radiation therapy, some chemotherapy medicines, bone marrow transplantation, and in some instances surgery, may create damage to organs and tissues such as the heart, lungs, bladder, kidneys, ears, liver, breasts and thyroid. Other tissues and systems that could be affected include eyes, teeth, skin, bones, brain, ovaries, testes, and immune system (Prouty, Ward-Smith, and Hutto, 2006: 143).

At the present time the earliest survivors of acute Lymphoblastic leukaemia are well into adult life. These children have been exposed to chemotherapy and radiotherapy and many of the late effects will not be discovered for many years. A UK regional follow-up service found that 58% of survivors had at least one 'chronic medical problem' and 32% had two or more (Stevens et al, 1998). The Childhood Cancer Survivor Study www.ccss.uk provides evidence that second neoplasms are strongly associated with the use of therapeutic radiation for the treatment of the original cancer. MacArthur et al, (2007) found that 5 year survivors of all childhood cancers had a nine-fold higher risk of death compared with the general population. In a twenty-five year follow up Li et al, (2008) reported that survivors with a history of relapse reported more chronic medical conditions. Survivors from the USA reported lower academic attainment, higher use of special educational services, lower marriage and higher divorce rates, and lower employment rates (Pui, Cheng and Leung et al, 2003; Mitby et al, 2003).

Although the health monitoring of the survivors continues throughout adulthood a parallel emerges that whilst the survivor is checked for adverse effects of the treatment, the survivor's awareness is raised relating to their own vulnerability regarding their future health (Eiser et al, 2000b). A further concern following the end of treatment and the survivorship of the once ill child is the psychological impact of the illness. Whilst there is medical follow-up as discussed above, there appears to be little emotional follow-up or support offered in relation to the child's or young person's personal experience of the illness and their long-term mental wellbeing. Some studies suggesting that the self-esteem of the survivors is not affected (Felder-Puig et al, 1998; Langeveld et al, 2004), whilst other studies have suggested that survivors are at risk of adverse psychological outcomes (Lansky et al, 1986; Koocher and O'Malley, 1981). Two more recent studies suggest that the survivors are at greater risk of psychological distress than their siblings (Hudson et al, 2003; Zebrack et al, 2002b). There have, over the years, been a number of studies that present contradictory findings regarding the psychological consequences of the illness for well siblings.

PALLIATIVE CARE

For a limited number of families, their child's cancer reaches a point where treatment ends and palliative care has to begin. Children's palliative care is concerned with the treatment of children where 'cure' is no longer possible and the goal becomes maintaining their quality of life. During more recent years there have been several definitions put forward in pursuit of providing quality palliative care:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual” (World Health Organization, 2002).

“Palliative care for children and young people with life limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancements of quality of life for the child and support for the family and includes the management of distressing symptoms,

provision of respite care through death and bereavement” (Association for Children with Life Threatening or Terminal Conditions and Royal college of Paediatrics and Child Health Care [ACT] 2003).

In the United States of America the definition of palliative care although similar, appears to be flexible in its approach:

“Palliative care seeks to prevent or relieve the physical and emotional distress produced by a life-threatening medical condition or its treatment, to help patients with such conditions and their families live as normally as possible, and to provide them with timely and accurate information and support decision making. Such care and assistance is not limited to people thought to be dying and can be provided concurrently with curative or life-prolonging treatment” (IOM Report Field and Behrman, 2003).

The children requiring paediatric palliative care are a diverse population, with less than half dying from malignancies. The remaining children have a range of life-shortening illnesses and rare conditions that include congenital abnormalities, chromosomal disorders and neurodegenerative disorders (Goldman, 1998). Although paediatric palliative care is a relatively new and emerging concept, Wolfe et al, suggest that “it is known that some children in the terminal phase of illness suffer significantly from inadequate recognition and treatment of symptoms and aggressive attempts at cure” (Wolfe et al, 2000: 326-333).

LIVING WITH AN ILLNESS – THE IMPACT ON THE WELL SIBLINGS

Writing on the sibling relationship across the life span Cicirelli (1995: 9) suggests that a child with any form of serious illness can have a significant effect on other well siblings in the family and on the family system as a whole, as parents tend to be preoccupied with the ill child and consequently give other children less attention. An illness in a sibling, according to Parson and Fox (1968), shifts the focus of family comfort and concern, creating an imbalance within the family. This they conclude intensifies sibling rivalries and decreases the beneficial aspect of the sibling relationship. Sloper (2000: 302) states that the withdrawal of one child from the usual sibling relationship through hospitalization or inability to take part in normal activities can leave a considerable gap in

the life of the other sibling. Yet research has all but ignored the sibling relationship within the complexities of a childhood life-threatening illness.

Bendor (1990) suggests that siblings of paediatric cancer patients suffer in response to the disease process and that their needs are usually overlooked by parents and professionals. Early studies (Fife and Lancaster, 1984; Gogan et al, 1977; Iles, 1979; Lindsay and MacCarthy, 1974) point to the risk to the well sibling of parental preoccupation with the ill child. Whether or not this is actually the case, if well siblings perceive this to be true, feelings of resentment and rejection would appear to be a natural consequence. They are concerned that their siblings are treated more favourably by their parents, and at a young age begin to scrutinise their parents' behaviour in an effort to detect potential inequalities in treatment (Dunn and Stocker, 1989; McHale and Pawletko 1992). The apparent inequality of parental attention and the excusing of the ill child from normal family rules can be sources of anger and jealousy (Bendor, 1990; Gogan and Slavin, 1981). Chesler et al, presented the thoughts of one well sibling:

“I might get mad when he gets away with things, especially the way he treats mom. Sometimes I think he should be grabbed and smacked, but nobody has the nerve to do it” (Chesler, Allswede, and Barbarin, 1991: 27).

Nolbris et al, (2007) point out that the diagnosis of a child with cancer not only changes the family but it also changes the relationship between the well and ill siblings. The study consists of self-reports of well siblings who suggested that the relationship was closer and stronger, although following the diagnosis they had experienced more anxiety about the loss of the ill child to cancer. Nolbris et al, reported that the siblings appeared to take responsibility to protect their ill brother or sister and to always try and see that their needs were met by them personally and felt guilty when they did not.

More recent studies also concentrate on the emotional and psychological problems that well siblings may experience following the diagnosis of a sibling with cancer. Houtzager et al, (2005) found that approximately 50% of the children in their study experienced significant emotional difficulties, which was more than twice as high as the reference group. The majority of siblings of children who had been diagnosed

with cancer one month previously reported that they had feelings of anger, sadness, jealousy and fear, and that feelings that were positive such as being content, relaxed, happy or glad were absent in comparison to their peers. As well as adolescent siblings appearing to be more at risk, the study suggests that girls seemed to have greater difficulties in their social relationships. The study suggests that this may be due to the fact that girls may be expected to take on more home responsibilities and, therefore, social activities become more restricted. Houtzager et al, stress that the diagnosis of the illness brings about uncontrollable consequences for the siblings, but those siblings who could maintain more positive expectations adjusted to the illness better. A study by Alderfer et al, (2010) noted parents reporting that a substantial number of well siblings experienced problem behaviours that included anxiety, depression, aggression and somatic complaints. However, the self-reports from the same study did not show anxiety or depression as a concern, but over half the siblings in the study revealed that they experienced moderate to severe cancer-related post-traumatic stress symptoms, which were higher than previous research findings (Alderfer et al, 2003). Siblings also felt that the support they received from parents and teachers were similar in both amount and importance, and that support from classmates accompanied fewer symptoms of withdrawal and depression and greater motivation and social skills in the classroom. Whilst clearly the siblings were at risk for adjustment problems, the findings in this study show that social support from school sources in addition to family support provides a positive environment for the siblings of children diagnosed with cancer (Alderfer et al, 2010).

SIBLING CONSIDERATION OF PARENTS

The well siblings, although possibly angry at parents for their lack of attention, have a desire to protect their parents by not making additional demands. Sibling concern for their parents, according to Chesler et al, (1991) often led to providing additional practical support, for example, helping round the house. They suggest that some siblings also tried to be “extra good” to avoid upsetting their parents further:

“Sometimes when things aren’t going well, you can’t misbehave because they have too much on their minds to worry about you” (Chesler, Allswede and Barbarin 1991: 29).

Other studies (Fife and Lancaster, 1984; Gogan and Slavin, 1981) reflect similar findings and the conscious decision made by siblings to be “good”. Taylor (1980) suggests that siblings in her study were remarkably in tune with their parents’ feelings and tried to adjust their own behaviour accordingly.

SIBLING PERCEPTION OF THE LACK OF INFORMATION REGARDING THE ILLNESS AND THE WELLBEING OF THEIR SIBLING

Many healthy children experience the feelings of being “outside” of the family not because of the changes that occur within their home life through the ill-child’s hospitalization, but also because of the lack of information they are given about their sibling’s illness. Taylor’s study (1980) found that many of the well siblings felt isolated from the medical regimes through which their ill sibling was treated. Unlike the mothers who became increasingly involved with the ill-child’s care, well siblings reported feelings of being peripheral to the family on clinic visits, and also felt generally ignored by the health professionals. Share (1972) writes that the leukaemic child and their siblings need an environment in which they can feel free to ask questions and express concerns, with the knowledge that they will receive honest answers. Siblings almost universally express worry and are distressed in relation to how their ill sibling copes with the illness, treatment and pain (Alderfer et al, 2010; Chesler et al, 1991; Nobris, 2007). It has also been found that well siblings when left alone to deal with their thoughts, secretly believe that they too might become seriously ill or die, just like their brother or sister (Bendor, 1990; Binger et al, 1969; McCullum and Schwartz, 1972; Spinetta et al, 1999). At the same time, the research also counsels caution regarding the passing on of all information to siblings in the relation to the diagnosis and treatment. Bluebond-Langer (1996) argues strongly that factors relating to age and developmental stage must be taken into account when providing information and support to well siblings. Spinetta et al, (1999: 396) stress that “children remain children, and communication about diagnosis and treatment issues should take into account the siblings’ social, emotional, and cognitive capacity”. Young et al, (2003: 114) conclude that whilst research advises professionals to remind parents of the needs of well siblings it may be asking the impossible to expect them to be this sensitive - and unless appropriately timed and sensitively handled, such advice may merely undermine parents.

LOSS AND BEREAVEMENT

THE DEATH OF A CHILD IN THE FAMILY

Grief can be an all consuming experience and a death within the family creates even more disruption to the everyday life experienced throughout the illness journey. The roles and positions of family members that may have changed with the illness are now recognized as being permanent. Not only does the death threaten the wellbeing and cohesiveness of the family, it may well lead to even more disruption and suffering. Death from an illness, particularly childhood cancer, can and does increase the vulnerability of individual family members and may create conflict within the family as a whole (James and Andershed, 2007; Wennman-Larsen and Tishelman, 2002). This is especially so in relation to how the family coped with the chaotic situation of a childhood life-threatening illness, the relationships between parents and well sibling and how the family typically cope with loss. Bowlby (1980) in the final volume of his trilogy on loss, suggests that patterns of grieving are influenced by the experiences a person had from their family of origin.

OVERVIEW OF THE THEORIES ASSOCIATED WITH GRIEF

“Much of the writing on the subject of bereavement during the first three quarters of the twentieth century were written from the point of view of the western psychiatrist” (Parkes, 2003: 1). Freud is generally referred to as the originator of contemporary theories of grief and mourning with many models deriving from his article *Mourning and Melancholia* (1917/1957). This link is identified by many writers including Klass, Silverman and Nickman, (1996); Packman, Horsley, Davies and Kramer, (2006); Rando, (1995); Valentine, (2006); and Walter, (1996). This has led to an underlying assumption that the bereaved person has to work through a series of phases or tasks in order to eventually emotionally detach from the deceased. Lindemann’s (1944) study of the survivors of the Coconut Grove disaster was influential in promoting Freud’s theory that the ultimate goal of grief work was to break the emotional ties with the deceased in order that the bereaved can move on in their life. Kubler-Ross (1969) suggested five stages of death and dying, and these stages are still widely referred to by health professionals. These stages were developed and based on her work with dying patients but did not, however, take into account the feelings of grieving relatives. Parks (1970) based his work on widows in the East End of London and suggests that bereaved people experienced different phases of grief that has led to a lasting perception that there is a fixed pathway

bereaved people follow in order to 'recover' (Walter, 1999; Wortman and Silver, 1989). At the beginning of the 1980s Worden (1982) developed his theory of tasks that the bereaved had to work through with the fourth task mirroring Freud's original work of breaking the emotional ties to the deceased. However, by 1991, Worden had reconsidered the fourth task and amended his original work to read "relocate the dead person within one's life and find ways to memorialize the person" (Worden, 1996: 15). Throughout these years the directive was that grief could only be resolved with the severing of the emotional ties to the deceased. If the individual appeared distressed some years later, it would be considered that he or she had a complicated or unresolved grief reaction to the death that would require the intervention of a mental health practitioner.

However, in more recent years these conventional models of grief have been challenged. There is now a generally accepted acknowledgement within the so-called "new" models of grief that people's grief varies enormously, and that some individuals reach no absolute resolution. Here, the emotional ties that bind us to the living are not severed with death, but continue to remain in one form or another with the bereaved (Klass, Silverman, and Nickman 1996; Riches and Dawson, 2000; Stroebe and Schut, 1999; Walter, 1996). To a greater extent grief is now viewed from a more holistic perspective that recognizes other factors that may impact on the individual reactions to the death and grief. Stroebe and Schuts' Dual Process model (1999) suggest that both expressing and controlling emotions are important and that the bereaved oscillate between coping behaviours that are attached to the grief following the death described as loss orientation, and the restoration orientation that focuses on the associated losses created by the death. The authors however, continue with a discussion on complicated grief that tends to reflect the more conventional theories and maintains the medicalised approach to grief. Moules et al, (2007: 138) states that "...models around grief work abound, but what might be the more important quest is finding a way to suspend models and consider how we describe and teach the sacred and privileged work of helping the bereaved."

BEREAVED PARENTS

The 20th century has seen many social changes and infant and child mortality is considerably lower than in previous centuries www.nationalcentrehealthstatistics.org.uk (2005). However, this perception that child death is rare increases the tragedy for bereaved parents and is painful for anyone to witness. The early studies of parental

bereavement (Binger, 1969; Cain and Cain, 1964; Kaplan et al, 1973; Natterson and Knudson, 1960; Solnit and Green, 1959; Townes et al, 1974), concentrated on the death of a child from cancer at a time when the chances of survival for these children was minimal. The inconsistency of the findings from these studies may reflect that the approximate time from diagnosis to death was then four months, with studies often based on clinical observations of parents shortly following the death. In the previous section I examined the theories of grief where it was generally suggested that there had to be a detachment from the person who died. Typical of this view was Feifel (1977: 9) who stated, "...the dead must die before we are able to redefine and reintegrate ourselves into life". The consequences of a continuing bond with the dead would then have been considered an abnormal or unresolved grief reaction to the death. However, Rando's (1985, 1986, 1991) studies that focused on parental grief argues that abnormal or unresolved grief was actually a part of most parents' experiences and that their grief may not diminish over time, but may intensify and warns against the over- pathologizing of parental grief. In more recent years research has begun to question the theoretical models and to reconsider how bereavement research has been undertaken. Early models, Valentine argues ".....occurred within a positivist paradigm in which the prioritizing of quantitative methods has excluded the subjective experiences of self-reflecting individuals and how they make sense of their world (Valentine, 2006: 57)." Similarly, Davies (2004) suggests that:

"...there has been a shift away from a positivistic approach to research with the bereaved to a nonpositivistic one focusing on how people themselves experience grief and make meaning, whilst taking into account their social world" (Davies, 2004: 511).

It is suggested that the death of a child is the most painful of all losses and almost impossible to describe the feelings of grief that follows. In a study by Corr et al (1996) parental grief is described as:

"... boundless. It touches every aspect of the parent's being...The range of expression of parental grief is wide...Some parents will express tears and hysteria openly. Others will silence these expressions and grieve inwardly...Despite the volumes of work on grief, the experience of grief seems

to defy description...Definitions touch the fringes of grief but do not embrace its totality or reach its core...Grief is a complicated, evolving human process. Grief is a binding experience; its universality binds sufferers together. More is shared than is different” (Corr et al, 1996: 50-52).

The death of a child is a family tragedy affecting all members in individual ways whilst they continue to interact with each other (Nadeau, 1998). Whilst research has acknowledged the individuality of grief (Cowles 1996) particular emphasis has been placed on the grief differences between mothers and fathers (Dyregrov, 1990; Moriarty et al, 1996; Sanders, 1978; Wallerstedt and Higgins, 1996; Cook and Cohler, 1986). Much of the literature suggests that the primary differences between men’s and women’s grieving processes is that women appear to have a greater ability to express their feelings, and a greater willingness to talk (Kavanaugh et al, 2004; Riches and Dawson, 2000). However, some studies suggest mothers experience a greater intensity and longer lasting grief (Gilbert, 1996; Johnson, 1987; Kavanaugh, 1997; Littlewood et al, 1991). However, Vance, Boyle, Najman, and Thearle (1995: 806-11) reported that whereas fathers appeared to experience briefer and less intense anxiety reactions, they more often used alcohol to cope with the death of a child. Within the extended family the father’s grief is often overlooked. Traditionally, it is generally assumed that the man will remain strong and be there to support his family (Worth, 1997). A number of studies found that the husbands became frustrated with their wives’ intense grief, and the wives became angry with their husbands for not sharing their grief. This often led to a breakdown in communication and loss of sexual intimacy (Kavanaugh, 1997; Riches and Dawson, 2000; Schwab, 1992). There has been much written about bereavement following the loss of a child, with much of that research concentrating on a children’s deaths from cancer. There has, however, been little written about parents’ reactions when the child who died had a life-shortening illness and/or complex medical needs. Yet their loss is two-fold: first learning that their child has a disability and often developing incredibly close links through extended caring, and then losing that child to death.

BEREAVED SIBLINGS

Interest in sibling bereavement has grown since the 1970s with a concentration of the research during the 1980’s and ‘90’s. This included studies that focused mainly on adolescents where a sibling had died from a life-threatening illness such as cancer (Balk,

1983a; 1983b; Hogan and De Santis, 1992; Kandt, 1994; Martinson and Campos, 1991). Unfortunately, there have been very few studies that have investigated how the death of a child with a life-shortening illness impacts on individual family members including siblings. The research of Cobb (1956) was cited by Davies (1999: 47) as the first study that drew attention to the needs of well siblings. This was at a time when most children died in hospital, and where, although parents would be there, the well sibling was excluded, and often distanced from their parents. Following the death, health professionals would have been unlikely to consider the needs of well siblings as they were generally outside of the clinical setting.

Since that time, although the body of literature on childhood bereavement has grown, research has mainly focused on children following the death of a parent (Dyregrov, 1991; Furman, 1974; Raphael, 1983; Silverman, 2000; Smith and Pennells, 1995; Smith, 1999). The same tends to be the case for bereaved adolescents although some work has focussed on loss of a sibling (Balk, 1991; Hogan and DeSantis, 1994; Martinson and Campos, 1991). According to Hogan and DeSantis (1994) adolescent siblings are thought to be particularly at risk from medical, psychiatric, social and behavioural dysfunction.

Research into the bereavement responses of well siblings of all ages has been relatively neglected, and this is markedly so in the literature relating to the well sibling of a deceased child with a life-shortening illness. Davies (1999: 98) suggests there is a notable deficit of published literature relating to sibling bereavement responses when the cause of death is other than cancer or cystic fibrosis. In their study of siblings following a sibling death from cystic fibrosis 9-10 years previously, Fanos and Nickerson (1991) suggest that the siblings who had experienced the loss in adolescence had significantly more guilt, anxiety, and depression than those whose loss was in childhood or young adulthood. Cicirelli (1995: 189) states that:

“...when a sibling dies as a result of a chronic or life-threatening disease, the dying process can extend over months or even years. Although there is more time for family members to adjust to the impending loss, the disruption in the lives of the surviving siblings can be great.” (Cicirelli 1995: 189)

Yet, there have been very few studies that have investigated how the death of a child with a life-shortening illness changes the family dynamics, or indeed how the death impacts on individual family members including siblings (Hunt and Bourne, 1995).

During the later stages of an illness well siblings may not be informed by parents of the seriousness of the situation or of the possibility that their brother or sister might die. In most instances parents are not only consumed by what will happen next, but do everything they believe to be right in protecting the remaining sibling(s) by not giving them full information. However, this attempt to protect them may be interpreted by siblings as once again being shut out from the family. They are also excluded from what will be a critical turning point in the family's history, and from opportunities to be supported prior to the death. Early research suggests that this loss and perceived exclusion may be a crucial factor in their future adjustment:

“...Following the death of a child most discussions regarding grief and feelings are focused primarily on the parents, who are at times so consumed by their grief that they fail to recognize that the surviving siblings are also grieving. With the lack of family support resources, to verbally communicate feelings and concerns regarding the death inhibits positive sibling behaviour and ability to speak about the death in the future. This may have lifelong effects on the sibling...” (Solnit and Green, 1959).

Later, an Institute of Medicine Report published in 1984 (Osterweis, Solomon, and Green) suggested that information on sibling bereavement excluded a section devoted to sibling grief. Balk (1991: 8), in his review of the literature concluded that “theoretical models of adolescent bereavement await construction”. The issue, however, for siblings of all ages is that ‘models’ of grief often place the bereaved sibling on the periphery of their concerns. As Bowlby (1963) writing on the effects of separation and loss in early childhood warns:

“Not every child who experiences either permanent or temporary loss grows up a disturbed person” (Bowlby 1963: 527).

An element of caution needs to be considered when bereaved siblings are referred for counselling or support to the various agencies or to staff within a children's hospice. Acknowledgement should be made that the intervention will have implications for relationships with other members of the family and for the future of the family as a whole.

CONCLUSION

This literature review has established that the first research on the effects on families of childhood cancer began to be published in the mid 1950s, and since that time there has been a growing body of literature relating to the difficulties that parents and family members face following the diagnosis of a child with childhood cancer. Since then, much progress in medical treatment has occurred from the time when childhood cancer had a poor prognosis with the majority of children dying within four months of being diagnosed to the current position where 80% of children now diagnosed with leukaemia and following a five year event free period, are considered 'cured'. This has led to emerging research that investigates the long-term health and social problems of survivors of childhood cancer. In addition, a number of studies now describe childhood cancer as being a chronic illness which is misleading and ignores the fact that children still die from childhood cancer.

The literature relating to childhood cancer has grown out of mainly quantitative research methods based on a psychological perspective that has provided findings that are sometimes contradictory and that tend to concentrate on the perceived psychopathology of parents, siblings and the ill child. This focus has led much research to continue emphasising the mother's ability to cope, and the potential for maladjustment of the family leading to difficulties in the marital relationship. In more recent years, this focus has broadened to the psychological impact of the illness on well siblings and fathers. Many of the research articles are orientated towards the ill child in the family, rather than towards an understanding of how the family as a whole is affected. Much of the work done on family relationships concentrates on the mother and ill-child bond, with less emphasis on fathers and well siblings (Brannen and O'Brien, 1996; cited in Dixon-Woods et al, 2005). Moreover, research that does exist into family outcomes tend to overlook 'non-traditional' families such as a single parent with an ill child, and the impact on fathers who are separated from the family but still have contact with their

children, and the difficulties of being a step-parent in a family where a step-child has cancer.

Although in more recent years the literature concentrating on the impact on families when a child has been diagnosed with a life-shortening illness is increasing, it remains more limited than research relating to the issues surrounding childhood cancer. The early research of the 1960s discussed and acknowledged that parents experience chronic sorrow following the birth of a baby that had some form of disability. At the time the findings stressed this was a normal reaction for parents to grieve for the loss of a 'normal' baby and that chronic sorrow would continue for the rest of the parents' lives. Yet in practice this is an area that remains overlooked by professionals and until more recently, has been of major research interest. Limited findings indicate that the mother although recognizing her grief, may be reluctant to share this with others because of societal influences regarding disabilities. Other research findings point to how an anticipated happy event becomes a tragedy and as there is little preparation, the parents have less ability to cope in the short-term. Over the years research had been in general agreement that parents of children with disabilities and/or complex medical needs are more likely to suffer from stress, anxiety, and depression. According to a number of studies this may be related to how information is relayed to parents by the health professional and that the health professional may not give complete and accurate diagnosis and prognosis. The literature relating to marital relationships often offered no clear reason other than the diagnosis, as to why there may be a breakdown in the relationship. In comparison studies, contradictory findings show that marital satisfaction appears lower in parents of chronically ill children, whilst other studies suggest that there are no clear links to marital disharmony and that a diagnosis could be associated either with parents staying together or breaking up, or that the marriage may be unhappy but stable.

The role of fathers has changed dramatically since the early years of the research and yet this area remains limited within the research. The findings have, however, shown that fathers are greatly affected by their child's illness but have greater difficulty than mothers in accepting and adjusting to the child's limitations and cannot fully fulfil the 'fatherly' role. Some studies show that the lack of family and social support appeared to increase some fathers' sense of being overwhelmed by the illness and that the fathers found it more difficult to discuss their concerns.

The literature relating to well-siblings of severely ill children has grown considerably since the early years of the late 1950s and 1960s. Since the sixties, the research in this field has been largely influenced by medical and quantitative approaches that tend to take for granted that well siblings, especially those siblings where there has been a diagnosis of childhood cancer, are at risk of some form of psychopathology. Hence findings have focused on siblings' general feelings of being treated unfavourably by parents in comparison to the ill child, on the lack of parental attention, and on concern over the wellbeing of the ill sibling. Although the results from these studies have often been contradictory, a number of studies continue to suggest that the illness may distort or alter the normal development of siblings and that they are a population at risk. However, since 2005, a number of qualitative research studies of siblings, particularly those where a child has a life-shortening illness, have provided findings that indicate less negative outcomes. It appears that well siblings have the ability to be more resilient when the family itself is more positively disposed towards the care of the ill child and where all family members have a role to play in that care. Based far more on extended self-reporting by siblings themselves, these studies also suggest that families' social backgrounds and parental coping strategies have a strong influence on siblings' wellbeing and resilience. Early research suggested that the provision of support should be concentrated on the well sibling, whereas a number of later findings suggest that this support may be misdirected, with more benefit deriving from working with the family as a whole unit, and taking account of parental coping and quality of family communication patterns. Overall, the literature on bereaved siblings' remains concentrated on death from childhood cancer, with minimal research that investigates the affects on bereaved siblings where the death is other than childhood cancer.

The literature review on childhood life-threatening and life-shortening illness is similarly dominated by quantitative research methods, usually from a clinical background of psychology and nursing with the research concentrating on the psychopathology of individuals within the family. In line with more recent qualitative approaches to families' experiences of living with cancer (for example Grinyer, 2002) consideration should now be given to using more self-reporting research methods into the impact of caring for a child with complex life-shortening condition on family systems. These should be more inclusive involving families with single parents and step-parents. The reported

contradictory perceptions of well-siblings and parents with children with cancer, suggest that more attention should be given to the range of 'expertise' of parents and other family members, to the voices of both ill and well children, and to the difficulties and parental stresses surrounding the educational needs of children with life-shortening illnesses, especially following the last government's legislation of *Inclusion for all*.

CHAPTER, 3

METHODOLOGY

Through my review of the literature I am aware that a large part of both professional and academic research has concentrated on the effects and difficulties that families face following a confirmed diagnosis of a child with cancer. This is especially so in relation to childhood mortality, which according to Davies (1999: 26) is a persistent interest for researchers as childhood cancer is the leading cause of death from disease in children. Although, there is a range of literature pertaining to children with disability and/or complex medical needs, research into these conditions is far less comprehensive than research into childhood cancer. A further point is that research rarely compares these different medical conditions or the effects on families, where the focus is generally restricted to the condition itself. Even where social factors are examined, research tends to be limited to the impact of the illness on the mother. Working for a considerable time with families where a child has a life-shortening illness I have become increasingly aware of the long-term difficulties these families face. The literature in this area of illness, however, unlike childhood cancer, has not considered in any depth the well or bereaved siblings. It was the absence of research into the impact on the wider family that led me to propose a study that concentrated on the well siblings where there is a child with a confirmed diagnosis of either a life-threatening or a life-shortening illness. Given the major difficulties of access to such families, I was also conscious that as a practitioner, I was in a position to explore this deficit in the literature, believing that such research could be very beneficial not only for support workers such as myself, but also for medical staff involved in treating ill children.

Moreover, once the project was underway, as senior key worker for a Children's and Families' Project I soon realized that the original focus of the research needed to broaden out from the well sibling to include the whole family dynamic within the 'settings' of childhood medical conditions in which there was a chance of a shortened life or premature death. My role has provided me with first hand experience of how life-threatening and life-shortening illness has a continual impact on individuals within the family, and how in turn that impacts on the family as a unit. My interest in this issue was compounded by continually hearing parents' stories from both categories of 'illness' that reflected their feelings that key practitioners, particularly from the medical world and

social work, had little understanding of how the illness impacted on family life twenty-four hours a day. These stories also contained feelings of powerlessness and a lack of control over the impact the illness appears to exert on the family as a unit. It became apparent that there were differences between life-threatening and life-shortening illnesses, especially in relation to the trajectories of the patients' and family's 'illness career', their key turning points, their duration and the family's engagement with medical professionals. Importantly, though, there were also many similarities such as the problems of negotiating with the medical interface, and the common feature that both categories of illness affected each member of the family on an individual level and played a significant part in the wellbeing of the well siblings.

Hence this research project is grounded in parents' perceptions of a need for greater awareness amongst professionals of the important social and psychological changes that such a diagnosis and subsequent treatment creates within the family unit. Therefore, this research seeks to describe and explain some of the principle difficulties that such health conditions have for family relationships, self-identity, communication, family functioning, and lack of control over medical treatments and services.

WHAT METHODS WERE CHOSEN AND WHY

Bryman gives a very succinct and distinctive definition of quantitative and qualitative methods and suggests that "on the face of it, there would seem to be little to the quantitative/qualitative distinction other than the fact that quantitative researchers employ measurement and qualitative researchers do not" (Bryman, 2001: 20). I was therefore aware that quantitative methods could more accurately describe the nature and extent of problems faced by families, but that qualitative methods would give a deeper and richer approach to understanding more about families and their lives, particularly in relation to emotionally challenging issues such as bereavement or the treatment of very ill children. I also felt this to be appropriate because, in relation to children with life-threatening and life-shortening illness, research methods have until more recent years concentrated on quantitative methods. According to Dixon Woods et al, "...research on the psychosocial aspects of childhood cancer has been of poor quality, and has often produced widely conflicting findings that do little to prove enlightenment, or been so inconclusive as to be uninformative" (Dixon Woods et al, 2005: 161).

Over the years there have been debates about the limitations of both quantitative and qualitative research methods. These include criticism that quantitative methods based on a natural science model are inappropriate for studying the social world, and that qualitative methods are too subjective and their findings are difficult to generalize as usually they are based on small samples (Bryman, 2001). However, I have followed what is now a generally accepted argument amongst researchers that in order to understand how people live their lives (and this includes the difficulties families perceive they face when living with a seriously ill child) the most appropriate method for me to adopt was an ethnographic qualitative approach. “Qualitative methods were developed for understanding the experience and lives of others” (Morse, 2000: 539). By listening to participants and observing them over time within social settings, researchers can piece together an understanding of their lives, especially over the long-term. Anderson (1987) points out that:

“The purpose of qualitative research is to explain social action in everyday life and if explanation is contextually bound, then clearly the ordinary and everyday must be the context of the qualitative inquiry. The research has to be where it happens” (Anderson 1987: 53)

THE APPROPRIATENESS OF THE CHOSEN METHODS FOR THE RESEARCH

Ethnography, according to Hammersley and Atkinson (2007) does not have a standard well defined meaning due to its complex history which grew out of nineteenth-century anthropology, where the aim was a descriptive account of a community or culture, usually located outside the West. To a large extent, ethnography still aims to describe the experiences of a culture from the perspective of those who are members of it. Hence this approach assumes that time and trust are both necessary for the researcher to gain entry to the social worlds of those being researched. For example, in Wolf’s (1991) study of bikers he had spent three years in their company before he approached the subject of research. Ethnography also rests on principles which see the value of the researcher ‘perceiving’ participants’ social worlds as much as possible as they themselves see it. This involves ‘sharing’ experiences, both as they happen (participant observation) and after they have happened but in ways that allow the person who experienced them to ‘recount’ them in their own words, in their own time, and in ways that enable them to express feelings as well as events. However, to be of value, it is suggested by

Hammersley and Atkinson (2007: 12) who cite Gewirtz and Cribb (2006) that ethnographic research should be concerned not simply with understanding the world but with applying its findings to bring about change.

This approach also assumes that in order to understand a different culture, the researcher has first to learn the 'language' of that culture. In this particular research I believed that I was entering more than one culture, each containing its own language and norms. The culture of families with chronically ill children crosses both middle-class and working-class backgrounds. Through these parents I was to enter the social world of long-term illness, and the professional cultures of paediatrics, education and social work. Because of the protracted nature of their child's illness, parents eventually learn the language of the illness, procedures, treatment and drugs that 'fit' their particular child illness. They do not, however, learn the complex language contained within the culture of medicine. I had enjoyed considerable contact with the families prior to the start of the research and therefore had a limited awareness of the different languages used and made the decision that I would continue as I had always done, and that was, when I didn't understand I'd ask for an explanation from the parent. I hoped this would help if I unintentionally gave any of the parents the impression that I understood and knew 'everything' about their child's illness. Brannen (1988) suggests that if informants perceive themselves to be of equal status with the interviewer, they are more likely to volunteer spontaneous material, accepting the interview as a two-way process. It is a problem for the ethnographer in deciding how much self-disclosure is appropriate, especially when I as researcher expect 'honesty' from the participants (Hammersley and Atkinson, 2007).

However, language is far more than just vocabulary, and access to any culture requires the researcher to 'bracket out' their own assumptions and pre-conceptions in order to begin to grasp the 'meanings' which these social situations have for those who live their lives within them. Therefore, the ethnographic researcher has to be aware that the difficulties of over-identification with the respondents during the fieldwork can lead to a distorted perspective of the culture that is being studied. Hammersley and Atkinson (1995) are particularly critical of Paul Willis's study *Learning to Labour* (1977). His study was primarily based on conversations with twelve adolescent boys who had 'anti-school' attitudes and could only see themselves obtaining working class employment. Willis argued that their school counterculture fitted with the culture of the working-

classes and the factory as a workplace. Hammersley and Atkinson (1995) suggested that the researcher over-identified with his respondents and became a spokesman for the boys and their social world, rather than being a researcher of it. Because of this, Willis, according to Hammersley and Atkinson gave a distorted description of schooling and an uncritical partial perspective on working-class culture. Therefore, they argue, his analysis was flawed. Flawed or not, one cannot underestimate the impact of this study which, like Goffman's study of Asylums presented a memorable account of a social setting as perceived by those 'inside it'. Amanda Coffey (1999) in *The Ethnographic Self* describes how as a researcher within a large UK accountancy firm she "found that it became increasingly difficult to separate my life outside the firm from my life within it...by actively participating in the everyday life of the setting, I found it impossible to divorce my fieldwork self from my other selves" (Coffey, 1999: 30). This was particularly true of my own research. As I have previously stated, the major difficulty I had was to 'see', and more importantly, to understand that I was not 'bracketing' out my working relationship with the families, and for some considerable time I remained 'fighting' on behalf of the families. It was only through a slow and gradual process that I became aware and came to the realization that there had to be another side to the families' stories. I would however, suggest that this learning process became an enabling tool to better anticipate the ways in which the research may suffer from biases.

A NARRATIVE APPROACH

Narrative analysis provides a matching approach to organising and making sense of ethnographic data. Although it isn't the only approach which informed my data collection and analysis, it is one which has helped shape this practical study. It was helpful in this case because the research primarily aimed to understand families' experiences of being inside regimes of treatment and cultures of life-shortening/life-threatening medical conditions. Narrative analysis focuses very much on the ways in which participants 'tell' their stories and the ways in which they ascribe meaning and significance to the events, crises, relationships and outcomes of their interface with the illnesses, medical staff and treatment regimes and procedures. Narrative analysis rests on an epistemological stance in which the universal truth or objective accuracy of these events is not at issue. People do not have to reveal everything about themselves; the interviewee chooses the aspects of her life that she is most interested in telling (Charmaz, 1995). The interview assumes that participants' accounts are just that - 'accounts' or stories which represent, as far as the

participant is able, the meaning around their experiences, in relation to a particular audience. It represents the subjective 'truth' of their lives as they are making sense of it at the point the accounts are given. Redwood states that:

“...An analysis of narratives cannot reveal what someone 'really' thinks or feels because any truth is simply a construction, and narratives are skilfully woven to bring into being versions of the self that serve specific purposes. Thus in a medical encounter narratives can describe the narrator as consumer, concerned parent or resistor of medical domination” (Redwood, 1999: 674).

Nunokoosing (2007) points to the purpose of the interview as primarily to construct stories and versions of events that can have the possibility of generating theories. Riessman cites White (1973) as suggesting that “narrativization tells not only about past actions but how individuals understand those actions - that is, meaning. Plots vary in type: tragedy, comedy, romance, and satire” (Riessman, 1993: 19). It is accepted in this research approach that they, the stories, may change over time, that significance of events and relationships may also change and that even with the telling of a story, greater insight and therefore changed meaning may occur. Gubrium and Holstein (1997b) suggest that narrative practice has two competing concerns; how a story is told and what it contains:

“We use the term 'narrative practice' to characterize simultaneously the activities of story telling, the sources used to tell stories, and the auspices under which stories are told. Considering personal stories and their coherence as matter of practice centres attention on the relation between these 'hows' and 'whats' of narration.... Orienting to practice allows us to see the storytelling process as both actively constructive and locally constrained” (Gubrium and Holstein, 1997b: 164).

Nevertheless, the analytical approach relies for its validity on acquiring sufficient 'stories' from sufficient participants experiencing common events for the researcher to identify recurring patterns of experiences and meanings. It also relies on accounts which identify critical, extreme and challenging events, regular milestones and unfolding stories which would be recognisable to most of the participants that have gone through them. Therefore, in examining participants' stories the researcher is looking for issues and

themes that appear common, for problems that are regularly experienced, for crises and supports that appear to recur within families facing similar medical conditions and regimes of treatment. In addition, the researcher is sensitive to the nuances of the language participants' use, the metaphors, images, explanations and stresses they place upon specific experiences and events which appear to be central in creating the meaning they give to these experiences. Bury, (2001) discussing illness narratives as fact or fiction suggests that:

“...the importance (and, to some extent, the limitations) of studying narratives in circumstances where the ‘unfolding’ of illness, particularly chronic illness comes to dominate people’s experience of everyday life. Here, time is important in a mundane as well as an existential sense... such illness constitutes a major instance of ‘biographical disruption’ (Bury 1991) in which the relations between body, mind and everyday life are threatened” (Bury, 2001: 264).

It is assumed in illness narratives that the researcher is healthy, therefore the ill person as interviewee is often placed into a position of justifying the illness to avoid the accusation of being a malingerer or continual complainer (Radley and Billig, 1996). Talcott Parsons (1978) discusses the ‘sick role’ as one where the person is exempt from social obligation and performance expected of healthy individuals. In this research although most of the interviewees were not themselves ill, they were reporting as parents their experience of having a child with a life-shortening or life-threatening illness, and are therefore, to an extent tolerated and exempt from social obligation by the community around them. Frequently in this research the parent justified their position as being a good parent, and stressed how they loved their children, as if the serious illness or disability of the child reflected in some way ‘bad’ parenting skills, and perhaps how the community around them failed to understand how they could love a child with a severe disability. Riessman (1993), discussing narrative structures, likens them to weight bearing walls:

“...personal narratives depend on certain structures to hold them together. Stories told in conversation share common parameters, although they may be put together in contrasting ways and, as a result, point to different interpretations. Events become meaningful because of their placement in a narrative.” (Riessman, 1993: 18).

PARTICIPANT OBSERVATION

Participant observation is central to an ethnographic approach and, arguably, complements a narrative perspective on the data collected and analysed. Participant observation techniques make it possible to collect many kinds of data which otherwise are ignored or considered off limits, while respecting accepted standards of research ethics (Carnevale et al, 2008). Savage (2000: 324) notes that participant observation is often described as a method, but it incorporates a range of approaches to data collection, including what she calls “participative observation”, in which physical involvement in the field cannot be divorced from the researcher’s theoretical or epistemological suppositions. She continues to suggest that:

“There are certain parallels between participant observation and practice-based professions or occupations such as nursing, which suggests that an examination of one might increase our understanding of the other” (Savage 2000: 325).

This ‘participative observation’ certainly applied in my case. As a researcher whose role was already to work alongside families, my major research task was not to gain entry to their worlds, but to disentangle my role as supporter and advocate from my role as objective researcher and collector of data. Savage in her introduction to *Participative Observation: Standing in the Shoes of Others* warns of the dangers of attempting to wear someone else’s shoes, inasmuch as they [the shoes] retain the form of the previous occupant, and although we as researchers may believe that the shoes are the right size, we cannot assume they will fit (Savage, 2000: 324). Kohn (1994) points out that although the researcher may come close to experiencing the worlds of informants, they will always be experiencing this through the filter of their own cultural worlds:

“...we are stuck knowing that we are working with second-hand experiences....We have the ability to imagine our informant’s pains, joys and first impressions because we are often painfully aware of our own, even if we cannot find words that fully describe them. (Kohn, 1994: 13-27 in Hastrup and Hervik *Social Experience and Anthropological Knowledge*. London: Routledge)

At one level, I was already a participant, if not within the culture of families with children with life-shortening/ life-threatening conditions, then at least as a participating

professional within the wider service provision built around these medical conditions. Within these wider service provisions participant observation was particularly useful in providing what would have been invisible data contained within interviews alone. Observing what happens in the homes of the participants who continually stress that they strive very hard in difficult circumstances to provide a 'normal' life for their children provides different kinds of data to that gained solely through interview. For example during an interview at the home of one family they had a delivery of nappies for their seven-year old daughter. There were ten large boxes that had to be taken upstairs and placed within the loft in order, according to the mother, that there was no visible evidence that she [the daughter] had to wear a nappy, and suffer that embarrassment. Similarly, Bluebond-Lannger's (1996) analysis of observations made in the daily life of families where a child had Cystic Fibrosis highlighted how they attempted to manage the disruption that the disease brought to their lives by adapting their conception of what was a 'normal' life. Carnevale et al, suggests that "participant observation techniques may be suited better to examining some complex phenomena regarding the health of children and their families than more structured methods" (Carnevale et al, 2008: 21). Hammersley and Atkinson, point out that:

"...there is a sense in which all social research takes the form of participant observation: it involves participating in the social world, in whatever role, and reflecting on the products of that participation" (Hammersley and Atkinson, 2007: 15).

It has been important for me as both researcher and practitioner to have an understanding of the location - whether that is in the home, school or clinical setting - of how the person responds to others who may be a significant player in that particular location. As participant observer it is important to note obvious or subtle changes whether this is linked to the home setting (for example, untidy house when it is usually very tidy), or to the individual (such as clothes that are not particularly clean or signs that the person has been crying and perhaps more stressed than usual). However, in the role of practitioner I would take action whereas in the role as researcher, I would not, but may, however, be faced with a dilemma of observing a situation where action should be taken. Goodwin as a researcher and former nurse, found herself in an ethical dilemma which she described as two pronged: one side that pertained to her former role as a nurse, and the other to her

present role as researcher. This followed her presence as a participant observer when she noticed that a patient's blood pressure had fallen, and the fluid infusion was empty with the end of the anaesthetic infusion imminent and nobody appeared to have noticed, although an anaesthetist was present in the room:

“The role of patient advocate is one deeply embedded in nursing culture; it was part of my legacy and, therefore, not a role I could easily relinquish whatever identity I was now assuming. To my relief, however, any action on my part was rendered unnecessary by a timely response by the anaesthetist...” (Goodwin, Pope, Mort and Smith, 2003: 572-3).

I have already indicated the problems experienced disentangling my practice role from my researcher role. Access to settings as a practitioner was a natural part of my daily routine, but the writing up of observations had to occur after leaving these settings and had to include any professional input made as part of my practice role. Hence, the field-work diary was a crucial tool in systematically compiling observations of events that until that point I would have taken for granted as self-explanatory. I began the field-work diary prior to the interviews with families who had returned the consent forms. The observations began within the homes noting how siblings reacted towards each other, how the ill child and mother coped with medical procedures that had to be undertaken at home and often linked to a recent operation, and/or the administering of drugs. The observations also highlighted other family events that brought the family, extended family and friends together. For example, I attended the 21st birthday party of a young person with complex medical needs, [field-work diary August 2004] watching how people other than the immediate family responded to the young person and how she responded to them. This was particularly relevant towards the end of the party when more photographs were required and Debbie was no longer interested in taking part. Her father stood in front of her and began to sing, ‘Hey, Baby...’ [from Dirty Dancing, performed by Bruce Channel]. She absolutely beamed, everyone got their photograph and everyone was in tears.

The diary was particularly useful for me as a participant observer in situations where consent could not have been realistically acquired, for example, in the course of my everyday work, such as professional meetings in the hospital and/or school settings. This

is where I found my field-work diary especially useful, not only to record my impressions of how professionals respond to the parent(s) but also to note the parent's attitude and responses both during and following the meeting. Without doubt, a major challenge to me has been to 'bracket out' my desire to speak on behalf of these families, and to get out from under the inevitable contaminations of frustration, partiality and identification I felt at the outset. The field-work diary was a valuable reflective tool. As it would have been unethical to use literal data from these meetings, my reflections on patterns of interaction I had seen many times without formally noting them, helped inform my thinking and validate my interpretation enormously. I began by setting out complete 'stories' – my own, medical staff, siblings, parents and ill children – alongside each other. The reflective diary helped me identify where they overlapped, where they contradicted, and where, frequently, they reflected different priorities, providing a unique perspective on events. My role within this research has, I hope, shifted from my own stance from one of practitioner through that of participating observer to one of observing participant.

I have consciously sought to avoid the role of complete participant. 'Complete participation' according to Hammersley and Atkinson (2007: 83) may seem very attractive. Such identification and immersion in the setting appear to offer safety: one can travel incognito, obtain 'inside' knowledge, and avoid the trouble of access negotiations. As a key worker I am often requested by a parent or professional to attend what are generally called professionals meetings that are linked to the progress of the illness, change in treatment, future difficulties, and in some instances, reviews of a child's school statement. I have also visited two families when their child has been hospitalized, one in a local acute hospital setting and the other in a specialist children's hospital. It is in these routine practitioner meetings that participation has given me privileged access to the practices of a range of professionals, and how in certain instances the parents attending the meetings, (usually the mother) may appear to become subservient to the professionals involved. However, I have been very conscious of the ethical implications of this research, and although such privileged access to rich data has inevitably shaped my thinking, without full, informed consent, none of this material has been included in the data upon which my findings are based.

OBSERVING PARTICIPANT

One of the criticisms of qualitative research is that the findings rely too much on the researcher's often unsystematic views about what is significant and important, and upon the close personal relationships that the researcher frequently strikes up with the people studied (Bryman, 2001: 282). Sieber (1993) states that "the researcher is a central part of the research process and her own feelings and experiences should be analyzed as an integral part of it." Coffey (1999) points out that:

"...in fieldwork the professional, research relationship also has a far more personal quality. It is not enough to simply go through the motions of politeness and professional courtesy. Fieldwork simply will not generate good data and interesting analyses without personal investment in the relations of the field."
(Coffey, 1999: 39/40).

In order to reduce subjectivity, and provide as much transparency as possible to the bias that grows from my professional role, I have undertaken three clear strategies to limit this. Firstly, I have sought regular supervision, within my work role, which has enabled the venting of frustration and over-identification with families whose emotional problems I am paid to support. This has enabled a cooler and longer term appraisal of my own issues as distinct from those of my clients. Secondly, I have maintained a field-work diary in which I have entered observations, conversations, methodological and theoretical notes, along with dates and descriptions of settings and events so that, with the benefit of hindsight, I can review and objectify to a certain extent, impressions formed at the time they happened. Thirdly, and most usefully, I have had myself interviewed using the same pattern of questioning I have used with other professional workers, allowing me to add my own 'stories' and those 'accounts' which I, like the others I have interviewed, feel to be 'significant' in representing the 'truth' of our clients' experiences.

My mid-programme progress report and evaluation (RD7) presented to an independent assessor and peer-audience included the background to the research, assumptions and progress. The short presentation illustrated how the diagnosis of a life-threatening or life-shortening illness impacts on the family as a unit. It identified changes in the individual relationships within the family unit, the loss of identity, and how the relationship between the family and the medical professional was perceived by parents to be one of power and

control. Following the presentation I found the discussion useful as it raised issues that I had not fully considered. Whilst I had acknowledged the close relationship I had with the families I realized later that I actually called them *my families*, and at that time almost refused to change the statement as that was my perceived relationship with the families. What I had not considered was that the relationship could create bias in favour of the families and create identification with families in the research against the professionals involved and therefore, invalidating the findings. Following the discussion, and as the researcher, I was able to consider my role as practitioner and the influence it may have on the research and findings. However, even though I put into place arrangements with my supervisor to denote any partiality in the future, I found it very difficult to separate from the families and it was only through time that “the penny dropped” and I began to separate myself out of the mind-set of an advocate voice for the families and became the voice of a researcher. Nevertheless as Max Weber (1946) pointed out in the early years of the twentieth century, all research is contaminated to some extent by the values of the researcher.

From my own perspective as researcher, I was aware that the study included a number of different cultural worlds, notably the families themselves, the social and emotional conditions imposed by the differing illnesses, and the various treatment regimes they encountered. I understood that these worlds were characterized by their own cultures. However, what I did not consider was that within each culture there were different levels at which I could be involved both emotionally and intellectually. There was the research itself, and my needs for data collection, but also it was difficult to ‘bracket out’ my perceptions as practitioner and counsellor. There was also the complication that I was known to the families and professionals involved, but largely *as* a practitioner or counsellor. Importantly, there was also a language difference between these worlds. As the researcher I am very aware that following a diagnosis and for some considerable time afterwards, an initial problem for the families is the medical language that surrounds the illness and drugs and their inability to understand medical terminology. However, as the illness progresses the family have a greater understanding of the language and eventually it is incorporated into their everyday language. At this point the family may consider that others such as extended family, friends, and the researcher, are now incapable of understanding them. I acknowledge that as a researcher I had not considered the language dimension of research or that time has to be invested in becoming familiar with the

specialist or characteristic languages of medical and social practitioners, individual families, both common and rare, but always severe medical conditions, and regimes of treatment both within the hospital and home setting.

HOW THE PROCESS WAS UNDERTAKEN - INITIAL PLANS FOR THE SAMPLE - HOW IT WORKED IN REALITY

Sampling procedures in qualitative research according to Marvasti (2004: 9) are “sometimes referred to as purposive, meaning that the theoretical purpose of the project, rather than the strict methodological mandate, determines the selection process”. As I had chosen ethnography as the preferred approach to collecting my data, my participants were recruited from the substantial case load of families already known to me professionally as a qualified counsellor in my dual role as Director of the Bereavement Centre and key worker for a project working with families where a child had been diagnosed with a life-threatening or life-shortening illness. Whilst carefully considering other options with my supervisor, purposive sampling enabled me to draw participants from those known to me and from whom my request for their involvement was least likely to be rejected. Whilst this inevitably means the sample was limited and the sample frame itself based on ‘convenience’, given the highly emotive and private nature of the focus of inquiry, what was lost in representativeness, was compensated for by the depth of access achieved. Denzin and Lincoln (1994) state that:

“Many qualitative researchers employ...purposive, and not random, sampling methods. They seek out groups, settings and individuals where...the processes being studied are most likely to occur. (Denzin and Lincoln (1994: 202. cited in Silverman 2001: 250).

Initially, I intended the research focus to be around the difficulties [if any] that well siblings face when living with a sibling who has been diagnosed with a life-threatening or life-shortening illness. The original sample included various family members and a number of well siblings. However, as the research began to progress it became more evident that the original focus on the well siblings was beginning to shift more and more towards the family as a whole. Hammersley and Atkinson (2007: 25) state that “change in research can derive from several sources, it may be discovered that the original formulation was founded on mistaken assumption.” It was important for me to

acknowledge that although it was possible to continue to separate out one particular type of difficulty within each family, by continuing that particular thematic approach I was ignoring the insight that the illness actually became an integral part of the family and its daily life and therefore appeared to impact on all family members as part of a social unit. It also appeared that the way individual members of the family responded to the illness, in turn, impacted on the family as a whole. Therefore, the original focus of the research shifted to a broader examination of how life-shortening and life-threatening medical conditions impact on the family and the extent to which the stresses involved are taken into account by health professionals in their dealings with them.

SAMPLE

My sample involved various family members from nine families in all, of whom six included children with life-shortening illnesses and three with life-threatening illnesses. From these nine families, six mothers, two with children with life-threatening illness, two with life-shortening illness, provided significant sources of the accounts on which I draw in the early chapters, with a further two mothers providing additional material. Initially an additional family in the life-threatening condition category had been approached. However prior to the formal letters being sent out an additional health scare had occurred within the family and I felt at that time it would create additional stress to commit to the research. Within the nine families I interviewed, two adult well siblings (including one sister who described herself as a 'replacement' child following her brother's death some years prior to her birth from a brain tumour), and a brother who had two siblings with life-shortening conditions, were included in the sample. I had approached two further brothers of ill children, but one declined as he wished to leave his brother's death behind, believing the research would raise issues he did not wish to confront, and the other who had agreed but pulled out at the last moment implying that to talk about his sibling would be too distressing. As the research began to change shape I recognised that it was lacking a view of the family from the 'outside'. I therefore, decided to include in my sample four professionals who I had worked with over a number of years. All the professionals were employed in practitioner roles specific to the needs of the families interviewed. They included a paediatric oncology nurse specialist, and a paediatric cystic fibrosis nurse specialist, who at the time of the interviews worked in clinical settings within two children's hospitals that included home visits as part of their role. A children's social worker attached to a children's community nursing team and the CEO of a community

project supporting families with children with life-threatening and/or life-shortening illnesses were also interviewed. Towards the end of the research I realised that I had omitted the voices of ill children and approached one of the mothers in my sample regarding interviewing her children [both were used to taking part in clinical research]. Permission was given with the proviso that the eldest child would not answer questions but would draw and write about her feelings. A further young person was approached who had received support from the project since she was six years of age. As part of the medical management of the two conditions a letter had been sent to a paediatric consultant with an explanation of the research and requesting a meeting with the possibility of an interview. Unfortunately, I had no reply to the letter.

The CEO of the children's and families' community project acted as 'gate keeper', and through the collaborative arrangements with the project the CEO was available to discuss any issues or problems that arose from the interviewees. The socio-economic areas from which the sample was drawn - a city 'wedge' from inner centre to outer suburbs - is probably typical of medical conditions across many large urban conurbations in the UK.

The interviews began in 2005 and I finished collecting data in 2009. A number of informants were interviewed more than once. In addition, I have drawn on participant observation experience since the onset of this project, having access to a number of settings, the primary one being the home of the individual families, the secondary source being the project in which I work. For a summary of the sample used, please see Appendix 1 page 291.

The participants were drawn from families already known to me, and therefore the sample was entirely 'opportunistic' with selection of subjects based primarily on the length of time I had known the family. This ranged from between two and ten years, and my relationship with them was close enough to judge that their experiences were not untypical of the larger set of families with whom I have worked over the last seventeen years. In selecting the sample, consideration was also given to the age of the ill child, the medical condition and variations in the length of time since the diagnosis. At the beginning of the research the ill children ranged from three to eighteen years of age. The children's illnesses included childhood leukaemia, Apert Syndrome, holoprosencephaly and complex medical needs including chronic idiopathic thrombocytopenic purpura,

Prader Willi syndrome with additional special needs, a kidney transplant with additional complex medical needs, Stevenson-Johnson syndrome, and Arnold Chiari Malformation.

Whilst acknowledging that the sample was small and opportunity based, having worked with the families in the sample over a number of years, I was aware that I would be trusted in ways which would give me access to both delicate and emotionally challenging information regarding the illness and the impact it had on everyday life and relationships. Whilst the sample may not be demonstrably representative of all families, it does offer in-depth longitudinal data which illustrates the treatment trajectories experienced by nine families, and includes three ill children. The four in-depth interviews which, when added to the longer term participant observation, provides a 'hypothetical' model of the major crises affecting families in these particular circumstances. The professionals interviewed were again an opportunity sample to help counterbalance and check the perceptions reported by the mothers. As professionals we had worked together with families over a number of years which had helped to build a trusting relationship that I believed would provide data that would likely to be valid. Whilst there is often criticism of small opportunity samples providing limited generalisation, Morse, (1999) contends that:

In qualitative research, each participant in the relatively small sample has been selected purposefully for the contribution he or she can make toward the emerging theory. It is this selecting that ensures that the theory is comprehensive, complete, saturated, and accounts for negative cases. The knowledge gained from the theory should fit all scenarios that may be identified in the larger population. The theory also is applicable beyond this immediate group and is applicable to all similar situations, questions, and problems, regardless of the comparability of the demographic composition of the groups. (Morse, 1999: 5).

Therefore, I believe that this study, whilst based on only a small sample, would, using similar methods, 'fit' research linked to adults with chronic illnesses and other services provided by the NHS, particularly maternity services and educational requirements such as appropriate secondary schools for children with complex medical needs.

I encountered a range of problems accessing data from siblings within the sample families. In one family both siblings were ill, and hence were a special, but very interesting, case. Although parents were happy to take part in the research themselves I suspect they may have acted as a barrier in regards to the well siblings participating in the interviews by not passing on my request. Previous research has demonstrated that children are more than capable of reporting different opinions of their medical treatment to those of their parents who traditionally speak on their behalf (Greene and Hogan, 2005; Hill, 2006). Bluebond-Langner (1996: 160) points out that “Some parents are reluctant to have their children participate in studies, lest it raise issues that they would prefer to avoid...”

ETHICS

“Ethics is an ever-present concern for all researchers; it pervades every aspect of the research process from conception and design, through to research practice and continues to require consideration during dissemination of the results. In health care settings, one of the first formal ethical hurdles is attaining ethical committee approval” (Goodwin et al, 2003: 567). Research ethics emerged from the Universal Declaration of Human Rights (1948) following the Second World War and the atrocities committed against prisoners of war in the name of research. In 1964 the Declaration of Helsinki according to Bell, “illustrates an ongoing commitment to the protection and promotion of human rights through the implementation of research ethics” (Bell, 2008: 9). However, following a hospital’s retention of children’s organs without parental consent for the purpose of research, one of the conclusions of the subsequent inquiry was that there had been a failure of research governance (House of Commons, 2001). Following on from this, the Department of Health decided that new guidance would apply to *all* types of research conducted in England not just clinical trials, and continued to state that “it was to avoid confusion that could arise from the use of different systems” (Department of Health 2005a, cited in Meenaghan et al, 2007: 150). In respect of the present study, it was decided following much discussion with supervisors, that as the research was already in progress with participants included in the study of families of children with life-shortening or life-limiting illness who are part of my working practice and were not accessed via the NHS, or would not throughout the research process be interviewed on NHS premises, that approval from a NHS ethics committee would not in this instance be practical. However, I do acknowledge that if I were beginning this research in 2010, I

would have to complete a University RD5 ethics protocol and risk assessment form, in addition to the formal proposal which I submitted in 2003. This process would also guarantee that the need for any further formal approval from NHS or other relevant body would be explored fully during the registration process.

Given the extension of the sample to include NHS staff, it is likely that I would have needed NHS ethical approval, even though interviews were not conducted on NHS premises. Had this been the case, I would have needed to submit all letters, consent forms, safeguards for the protection of collected data, rationale for the inclusion of NHS staff in the sample and so on, as well as providing a presentation in person to the relevant NHS Ethics committee(s) to gain both approval and research governance. I have completed the current University ethics and risk assessment forms in relation to my research and included them in Appendix 2 page 293.

As it was, I presented a detailed proposal during the registration process which included the ethical principles to which I was working, and a set of procedures designed to ensure that no harm was done to participants and that all aspects of confidentiality and anonymity were safeguarded. The initial proposal and the long-term conduct of the research has been informed by the British Sociological Association guidelines (2005), and with reference to the *Ethical guidelines for researching counselling and psychotherapy* (BACP, 2004), the British Association of Counselling and Psychotherapy (2010) Ethical framework for providing a good standard of practice, and The British Psychological Society (BPS, 2006) Code of conduct ethical principles and guidelines. It has, however, been suggested that ethical codes are inherently ambiguous and indeterminate, and that the researcher will continue to be faced with difficulties in the interpretation of whether he or she will be judged to have acted ethically (Dingwell, 1980; Goode, 1996/99). I am able to summarise the ethical safeguards and procedures I have used at each stage of this project. Initially, permission had to be obtained through the University's Faculty Research Committee, and later through the mid-term progression report (RD7) assessed independently of the supervision team under the auspices of the Faculty Research Committee. Furthermore, my supervisory team includes a qualified senior nurse with extensive research and publication experience in the field of childhood cancer. She has provided very clear advice on a number of occasions.

As a qualified counsellor and senior practitioner [enhanced CRB] I have been working with families and children over a number of years, therefore, as a practitioner working alongside the various families, ethical working is, and always has been ingrained in my working practice. As a researcher, I sought to ensure prior to the start of the research that the rights and interests of those who would be asked to take part were of utmost importance. Above all else, I strove to meet the primary requirement of doing no harm. In the first instance I approached the CEO of the community project to grant approval for me approaching the University with a research proposal. We also agreed, following discussion of this and my gaining provisional permission, that she would make additional support available for the families and individuals within my sample if at any time the interviews raised emotional or other issues. Given the sensitive nature of the subject matter, I was particularly concerned that any distress arising from involvement with the research was supported over and above my own involvement with these families. Following the CEO agreement I began to approach individual families and verbally explained my intended research. At the same time I asked their permission to send a formal letter with an attached consent form requesting that they be part of the research [appendix 3/4 page 296/297], emphasizing that if they did not wish to take part or wished to withdraw at a later stage it would not in any way change the service they received or place them at a disadvantage in our working relationship. Costley and Gibbs (2006: 90) point out that the work of a “practitioner researcher takes place on the inside of the political context of work, where the researcher may be in a powerful position in relation to the subjects, caused by the research methodology used”. It was therefore, essential that the families had the confidence and trust that our working relationship remained stable. I also offered assurances that all tape-recordings would be retained in a secure place and destroyed once the research was complete.

Having verbally agreed to take part the letter and consent form were initially sent to 5 families explaining further the research aims and objectives to help give them a clear understanding of why I was requesting the interview. Consent forms were attached to the letter to be returned to me in a stamped addressed envelope. The letter clearly stated that all participants would have the right to *remove* their contribution to the research at any stage and prior to completion. Participants were guaranteed anonymity and confidentiality at all stages of the research with the use of pseudonyms. However, at the interview stage this created an issue much as it did in Grinyer’s study (2002: 20) of

Cancer in young adults: “perhaps surprisingly, the majority of contributors very much wanted their real names used”. A number of the participants interviewed stated that they did not wish their names to be changed. However, following advice and direction from my supervisor I continued with the use of pseudonyms. This was to guarantee anonymity to other members of the family, the extended family and those who knew the participants, but who could not be covered by the informed consent process. It also guaranteed that any comments participants wished later they had not expressed could not be traced back to them personally. This anonymity was also extended to the organisations and to geographical locations for similar reasons.

Working as a counsellor with the families in my study over a number of years I inevitably have privileged and totally confidential background information about them that in my role as a research practitioner I could not, and would not, use in any part of the research. Assurance that this information would never be disclosed, unless volunteered as part of the data collection, was emphasised at the outset, both verbally and in writing. A further ethical consideration for this research was the possibility that any of the children with cancer could relapse, and any of the children with complex medical needs could face hospitalization and operations from which they might not survive. Infact I made the decision prior to the interview stage that in one family there was too much ‘going on’ and the letter and consent form were not sent. I verbally explained to the mother why I believed at that time an interview may have added more stress to her family. Ethical principles also apply to the researcher’s wellbeing, who also should not be exposed to emotional or physical harm. Given the challenging nature of this project, I was also increasingly aware of my own emotional commitment to these families and that my role as practitioner sat uneasily alongside the demands of my role as researcher, particularly as the research itself was likely to raise issues which I would be required to deal with in my professional role as counsellor and supporter. Therefore, it was essential that I had an outlet where I could freely talk through my relationship with the families, their perceived treatment by professionals and my own role as researcher. This was essential for me to begin to untangle my roles as researcher and practitioner. This required an understanding of both the work and the research environment and was achieved in two ways; firstly, the established link via the CEO of the community project who agreed to meet on a regular basis to discuss my part in the work and the research, and secondly, regular supervision (over and above research supervision with my Director of Studies) was timetabled and

adhered to throughout the duration of the research study, including the writing up period. This was provided by a qualified counsellor with extensive consultative experience in the field of child psychology and development,

Because of the subject content of the research, including possible children's deaths, complex family relationships and potential criticism of professional colleagues, ethical considerations also demanded that I as researcher was aware of the stresses involved in undertaking research in 'sensitive' areas (Lee and Renzetti, 1993). Cowles (1988) suggests that 'sensitive topics' are those that have the potential to arouse emotional responses. As I already had a relationship with the families and was aware of the illnesses and possible outcomes the 'stories' that the mother's told me did not have as much emotional effect as they might have had on a researcher with no background in the subject. This was both a strength – in that families were used to trusting me with quite personal and distressing information – and a weakness – in that all too easily my role of interviewer and researcher could slip into that of counsellor and family supporter. It was therefore ethically important to constantly remind 'interviewees' that when I was working in my role of counsellor I was not conducting research, and that if they felt highly relevant information could be used in the study, they needed to make this explicit. Therefore, boundaries were put in place from the outset, and with substantial support from all supervisors, I began to recognise the importance of comfortably shifting from the perspective of practitioner and advocate on behalf of clients to a more objective inquiring research perspective. Johnson and Clarke (2003: 428) note that "Some researchers felt confused about their role as interviewer...one or two talked about the need to behave as a friend and felt that in doing so, they almost lost sight of their professional role". This has been an ongoing dilemma in my own research approach, but through regular supervision and use of my reflective field-work notes I have worked systematically to maintain clear boundaries between the roles of practitioner and researcher.

Because the respondents in the research were well-known to me, ethnography was the most appropriate research methodology to adopt to capitalise on the rich data and privileged access which my role as practitioner afforded. There are a number of key issues relating to the ethics of ethnography as Hammersley and Atkinson (2007: 209) point out "...Most of the ethical issues we discuss apply to social research generally, but the particular characteristics of ethnography give them a distinct accent...consider them

under five headings: informed consent, privacy, harm, exploitation, and consequences for future research”. Even with these five headings in place one of the difficulties of ethnography is that the research frequently changes direction once the research has started. Murphy and Dingwall (2007) state that:

“In ethnography, both the research focus and the research design typically emerge during the course of the research...the researcher is rarely able to give a full account at the outset of what the research will involve. Flexibility of research design...are distinctive contributions of ethnography, but complicate the process of obtaining prior informed consent (Murphy and Dingwell 2007: 2227).

This quote is particularly relevant to my own research project. It began with an emphasis on the well sibling within the families with whom I work. However, as the research developed, it was almost as if the research problem itself forced a shift in emphasis to that of the family as a social system. This changing focus necessitated the addition of four professionals - two paediatric clinical nurse specialists, a paediatric social worker, and the CEO of a community project. I felt this was important to counter-balance the narratives of parents, many of which were particularly critical of medical staff. In addition, an adult sibling who had heard about the research from a family made contact with me and asked if I would be interested in her perceptions of being a ‘replacement child’. Towards the very end of the research I realised that the voices of ill children themselves were missing and decided to include three ill children in my sample in an effort to address the problem from their point of view. As the project grew, at each change letters and consent forms were sent to the relevant people in a similar way to the original participants. I also sent additional letters to the original five families explaining the change of direction asking if they still wished to be involved [appendix 5 page 298]. In the case of the three children, I first verbally approached parents, then, with the parent present asked the two children who were 10 years and 7 years of age if they would take part [both children were used to being part of clinical trials] in my research that involved drawing their thoughts and telling me their experiences. Once agreed a letter and parental consent form were sent out [appendix 6/7 page 299/300]. The other young person was 17 years of age, but I followed the same principle of speaking to the parent first, then I approached the young person. Letters and consent forms were sent to both. Throughout the research, whether children

were present or not I continued to work alongside the Child Protection policy of the project ensuring that everyone continued to be aware that this was the only area that my role as a key-worker overlapped that of a researcher and that it was the only area where if I had any concerns confidentiality would be broken and I would report my concerns to the CEO of the project. Ethnography appears to present particularly difficult problems of gaining ethical approval in as much as whatever permission and approval are acquired at the planning stage, it is not entirely possible to predict, once in the field, how the research questions and the sample population will develop.

DATA COLLECTION

In order to obtain accounts of participants' perceptions of how their lives had changed since the diagnosis I planned for in-depth interviews as my main method of data collection. The interviews I undertook were either semi or unstructured to the extent that I had a working set of categories I wished to explore with each participant, but remained flexible over the order in which I explored them. The questions were open-ended and non-interrogational, and arose naturally from the conversation throughout the interview. Interviews varied in length and frequency, in as much as I saw these participants on a relatively regular basis as part of my work. Interviews were lengthy and in many cases produced between two and three hours of tape recorded and fully transcribed data. The participants were given the choice of where the interviews were to be carried out, in the home and/or in my office where participants were already familiar with the setting. In recent years there has been a growing interest in qualitative literature regarding where interviews take place and acknowledging that face-to-face interviews reveal a wealth of information to both the researcher and researched. Adler and Adler (2002) suggest that the:

“...subject of the interview should be the determining factor in terms of location. Interviews dealing with highly emotional, sensitive or private issues are best conducted in the home of the participant since such a setting offers a sense of intimacy and friendliness.” (Adler and Adler, 2002: 528)

OPEN-ENDED, SEMI AND UNSTRUCTURED INTERVIEWS

Semi and unstructured interviews working from a pre-determined but loose 'agenda' or set of categories formed the basis of the data collection of stories from participants involved in my research. Johnson summarises how this process is organised:

“... [in-depth interviewing] begins with common sense perceptions, explanations and understandings of some lived cultural experience...and aims to explore the contextual boundaries of that experience or perception, to uncover what is usually hidden from ordinary view or reflection or to penetrate to more reflective understandings about the nature of that experience”. (Johnson, 2002: 106; cited in Marvasti, 2004: 21).

To provide some 'shape' to the interviews I began all the interviews with 'can you tell me your story from when the diagnosis was made?'. Cotterill and Letherby (1993) argue that the "narrative technique" is a sociological method for gathering data about people's lives, making the distinction between researchers who *work on people*, and those who *work with people*. Although it has been suggested that interviews contain no more than topics of interesting conversation (Ackroyd and Hughes, 1981), Giddens points out that "conversation and talk, after all, are universal features of social activity in both informal and more structured setting of interaction" (Giddens, 1989: 462). The purpose of the interview is primarily to offer participants an opportunity to rehearse constructions of their stories and accounts of events that can possibly help in the generation of broader theoretical explanations of what is happening (Nunokoosing, 2005). Because of the sensitive area of my research it was essential that the families of children with either a life-threatening or life-shortening illness were allowed to tell their story in their own way. By allowing the respondent's to tell their story, they hope as Cole (1989) suggests, tell them well enough so that we can understand the 'truth' of their lives. They, the families, assume that we know how to interpret their stories correctly and it is the goal of ethnography to spend long enough within the 'culture' of participants to reflect descriptions of their lives which they would recognize as 'true'.

Cortazzi (2001) suggests that the collection of narratives as data is not limited to the examination of the respondents' lives but can also be applied to those experiences of the researcher, and that it is reasonable to pose the same questions about the researcher as the

ones directed at the respondents, that means asking: how does the researcher view the world and tell her/his story? Oakley (1981) states that:

“The goal of finding out about people through interviewing is best achieved when the relationship of the interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship. Thus, it is neither possible nor desirable to attempt to retain ‘neutrality’ as one conducts research.” (Oakley, 1981: 41).

As the exchange of personal information is part of the relationship I have established as a practitioner with the families, I believe that their responses have been shaped and supported by their knowledge that I have always been willing to answer their questions openly and honestly. They are also aware that I possess a sympathetic understanding of the difficulties they face. But as Charmaz, (1995) states “People do not want to, and do not have to, reveal everything about themselves.” Continuing, Nunkoosing, (2005) suggests that the interviewee chooses the aspects of his or her life that he or she is most interested in telling. Holstein and Gubrium state that:

“Meaning is not elicited merely by apt questioning, nor simply transported through respondent replies; it is actively and communicatively assembled in the interview encounter. Respondents are not so much repositories of knowledge - treasuries of information awaiting excavation, so to speak - as they are constructors of knowledge in collaboration with interviewers.” (Holstein and Gubrium, 1997: 114).

Arguably, the interview is, or should be, an empathic relationship between the interviewee and interviewer, and it should be of mutual benefit to both parties. For the researcher it is the gathering of information, and although the research interview should not be considered therapeutic the interviewee may find the process therapeutic and empowering. However, there has been discussion in recent years particularly from feminist researchers, that the research method of interviewing produces a potentially exploitative relationship. Although I do not consider my research as being a feminist research project, I do have to acknowledge that the majority of the interviewees in this research were women being interviewed by a woman. This relates to the power

differential within interviews noted particularly in the feminist literature regarding women interviewing women. Oakley, (1981), argued that because women have a shared understanding of gender subordination, it provides a ‘non-hierarchical’ relationship. Despite this understanding other feminist writers suggest that there are other social attributes that contribute to differences in a power relationship of women interviewing women (Edwards, 1993; Maynard and Purvis, 1994; Riessman, 1987). Ribbens, (1989) suggests that “ultimately, research interviews may inescapably involve power imbalances, stemming from public domains.” Whilst I have no personal sense of an imbalance of power during the interviews, this belief is partly linked to the relationship I had with all the interviewees prior to the research. Needless to say it did make me re-think one particular mother who I have known since 2002, who constantly stresses that she is not ‘intelligent’ because she left school without qualifications. I would want to stress that this is only her perception of herself, and in my experience others see her differently. But she does relate this to anyone who she believes has a ‘paper qualification’, which in another dimension would include me. Tang (2002) in the conclusion to her paper *Interviewer and interviewee relationships* however states that:

“The interviewees’ as well as interviewer’s perception of social, cultural and personal differences have an important impact on the power dynamics in the interview. In whatever way the power relationship plays out in an interview, it is not simply an issue concerning the goal of the interview but also the dynamics between the interview pair, because interview is a social encounter...”(Tang, 2002: 719)

Regardless of what we believe we are leaving outside of the interview, as researchers we have to acknowledge at some point that “then as now the lives and emotions of researchers and research participants are thoroughly entwined in interlocking relationships and identities. It is inevitable that fieldwork affects the researcher and the researcher affects the field” (Coffey, 1999: 56).

In recent years there has been a growing awareness in qualitative literature regarding where interviews take place. Herzog (2005: 27) suggests that among the most neglected components of the interview process is the choice of location and who selects the location. Seymour, (2007) suggests that the setting in which an interview is conducted is

a potent source of information in its own right. As I stated earlier, the interviewees in this research were given the choice of location for the interview, their home, my office, or where-ever they thought convenient. The interviewer is, according to Herzog (2005), the “taker” and the participant is the “giver”, hence, the interviewer must be flexible and willing to adapt him or herself to the preferences of the participant. By giving my respondents the choice of location, eventually leads to an interesting point that Herzog suggests should be examined and included in a study, that is, “what takes place *around* the logistics of the interview and include this as part of the study” (Herzog, 200: 28). By offering choice the mothers of children with life-shortening illness all took place within their homes, which Jordan (2006) suggests as being an intimate setting, and one that I was already familiar with. The interviews with the mothers of children with life-threatening illness took place in my office. Although I have not investigated this further by asking them to provide a reason for their decision, these particular respondents and I had a common ground in the past of meeting within the hospital setting and/or my office. It may be for future consideration that as Herzog suggests “...these social locations are part of our knowledge production and therefore must be part of our research analysis” (Herzog, 2005: 45).

DATA ANALYSIS

Initially all interviews were transcribed verbatim. From this, continual re-reading of the transcripts and of field-work diary notes allowed me to identify a number of themes and categories into which recurring or significant aspects of participants’ stories could be classified. This was achieved in the first instance by carefully sifting through the transcripts and observations. I began by colour coding accounts according to who were the main actors within the various conditions of illness: mothers, fathers, siblings, ill child, and health professionals. I then extended the colour coding to identify common themes, for example, fathers’ sense of exclusion and the isolation of mothers following hospitalization. Initially I transferred this information into headings using paper files placing them into shoe boxes [I had to have a physical box]. These also included relevant quotes from the literature. As the paper files grew I transferred them to word files. Key interview quotes that I judged to represent significant turning points or critical incidents were placed into ‘boxes’ with other unconnected quotes that were to be eventually shuffled to begin to create a logical order. Through this new order, new headings and sub-headings for the data categorisation began to be established and developed.

RESEARCH WITH ILL CHILDREN

The technological advances in medicine that has helped to increase the life chances of many of the children born with a life-shortening illness or are diagnosed with a life-threatening illness during childhood have considerably overtaken how health professionals appear to recognise the child as a person, how they communicate with the child, and the extent to which they acknowledge the expertise the child possesses about their own symptoms. The children themselves have a greater awareness of their own condition than is generally recognised by professionals and yet their voices are seldom heard. Alderson, in her discussion of the dilemmas around informed consent in researching aspects of children's bodies, health and illness, suggests that:

“...Adults make mistakes and children may be able to make wise choices besides having unique and essential embodied knowledge, which adults need to understand if the decisions they make for and with children are to be informed. Orthopaedic surgery, for example, aims to relieve pain, immobility or deformity, about which the child who lives in and is the body in question knows most...” (Alderson, 2007: 2282)

Without the voices of ill children how do attitudes and procedures that are carried out change? Research with children is a relatively new concept which throws up major problems of access and consent, always involving ethical dilemmas of whose permission is to be sought, and more importantly, who safeguards the child against any long-term emotional damage that might be triggered by the research? This was the uppermost thought when I decided to approach the parents in the hope of interviewing children and young people. I felt that if it were possible, it was of importance to include the voices of the ill children, as they are central to this research.

In researching children, consideration has to be given to whether the researcher has previous experience of working with children, particularly seriously ill children, as reported by Davis et al, (2004):

“...despite his previous experience of working with children, John found his initial entry into the school extremely difficult which related to his lack of experience working with disabled children...” (Davis et al, 2004: 207/8)

As a counsellor I have worked with children that have included bereaved children, well siblings and ill children for almost twenty years. During those years the children/young people have taught me that ‘talking’ is not the only way to elicit information regarding their thoughts and feelings. It is a trusting relationship that makes the difference. In taking the decision to approach ill children I considered certain factors. Firstly, I have known the families over a number of years. Secondly, the younger children are used to me making home visits. Thirdly, I have an established relationship with the girls I interviewed and have been involved in their play, piano practice, visiting them in hospital, and have a close enough relationship to be told their guinea-pig had died, but that they have a new one. Their mother is very much aware of the research as she was also an interviewee. I approached her regarding consent which she gave, and completed the consent form. In the case of the young person interviewed, I first asked permission from the mother to approach her in regards to the research and interview and, following an explanation of the research, both mother and daughter agreed, with the interview contained in the findings, Chapter 7. The two sisters were slightly different inasmuch as the older of the two girls will not speak of her disability and/or condition, but following my request and explanation of what I was doing and why, she agreed to draw and write her thoughts which are included in the appendices. Her younger sister who is very verbal and confident in her condition, agreed to do both the interview contained within Chapter 7, with the addition of a drawings in appendices. I informed both families that following the interviews if a problem arose, arrangements had been made for them to speak to a colleague who also has counselling experience of working with children.

CHAPTER, 4

THE ROLLER COASTER RIDE OF CHILDHOOD CANCER

The aim of this chapter is to outline the emotionally challenging changes that families face following the diagnosis of a child with cancer. The 'roller-coaster' metaphor is useful in representing the feelings and experiences reported by many parents in this research and convey the many ups and downs that characterise families' experiences during the diagnosis and treatment of childhood cancer. This includes the sense of helplessness, fear, loss of control, and dependence on others, with additional challenges to marital and well sibling relationships. At the centre of these findings lies the struggle parents have to bridge the gap between 'normal' family life as experienced before the onset of the cancer and the major changes arising from the treatment regime. Subsequently, during remission, the gap between loss of the discipline of the treatment regime and a possible return to 'normality' also provides serious challenges to the family's wellbeing.

I examine two aspects of the disease's early stages and parents' reactions to a probable diagnosis, from the point of view of both the consultants who have to give the bad news and explain treatment protocols, and of the parents who have to receive this information. I continue with three consequences of the child's hospitalization: the impact of the immersion and subordination for the mother and child in the hospital regime; the direct affects this has on marital relationships; and the affects these changes have on family life, parental roles, and early losses. The challenges and threats of treatment are also divided into three areas: early decisions about treatment and the realization of their consequences; the child's perceptions of his or her treatment; and the parents' experiences of their children's treatment. Two further issues relate to the end of treatment. Firstly I note the loss of normal family routines which the medical regime brought about but which fail to return with any sense of real security; and, secondly, ways in which relief that treatment has ended and that the child in remission is tinged with anxiety regarding the future. The final section looks directly at the long-term effects, exploring how families respond when their worst fears are realised and palliative care and the child's death have to be coped with.

THE FAMILY'S RESPONSE TO A PROBABLE DIAGNOSIS OF CHILDHOOD CANCER

The following excerpts from parents' stories illustrate how they attempt to represent in words their emotional reaction to receiving the diagnosis and the impact on their perceptions of themselves, their family and the 'normal' life they had been living until the onset of the illness. One mother's automatic response on arriving home following her son's probable diagnosis of leukaemia was to cling to her 'normal' family life:

"...I went straight to the freezer. I got a pound of mince and stuck a Dolmia sauce over it and I had spaghetti bolognaise cooked within minutes, and my mum and dad came over and said 'what are you doing?' and I said 'I am feeding my family'. Richard was sitting crying saying he had to go to hospital and he didn't know why, Matt was crying because he thought it was the best thing to do, my world has collapsed but its dinner time..." (Mother, family one - April 2006)

Whilst almost immediately recognizing that the world she knew was threatened, the mother in this instance, albeit for a short period of time, maintained order, her position and identification as the carer to her family by providing food. The diagnosis also served as a significant marker for the mother as the beginning of her transformation of self-identity, from a mother of a healthy child to that of a mother of a child with cancer, and of her subordination to the medical world. It also began a new journey leading to her eventual identification as 'carer' of a seriously ill child. Other research studies suggest that, for women in particular, motherhood acts as both a regulator of their lives and as a major component of their self-identity.

A number of the mothers in my research also reported pressures placed upon them that reflected the traditional views of selfless devotion to the care of their ill child, such as continually being at the hospital bedside. One mother spoke of how difficult it had been:

"...I had been with her every day, every night every waking hour when it was just the fracture to the spine ..." (Mother, family two - April 2006)

For this particular mother, the seriousness of the diagnosis, the uncertainty and the overwhelming fear of cancer seems to have differentiated between the child's serious

injury and that of her life-threatening illness. Although the parent had already experienced some re-ordering of family life during the hospitalization and treatment of the fracture to her daughter's spine, it appears that nothing could begin to compare with the diagnosis of cancer, and what the future held. She reported that:

“...When they said they were 90% sure, my world fell apart, I can remember it like it was yesterday, not knowing what I was going to walk into... and until it happens to you, it doesn't happen in your world and suddenly there is all this information...” (Mother, family two - April 2006)

In this sample, the interviews indicate that mothers unlike fathers appear to have the ability to focus more clearly on the ill child and the seriousness of the diagnosis and appeared not to question if it was a correct diagnosis, whereas the father appeared to look for an alternative answer for the illness. One mother described what happened:

“...I rang Mark up at work and said ‘I have the GP here, it's not good, come home’, his first thing was ‘well that's ridiculous’, and when we were driving to the hospital he kept turning round and saying ‘cause your alright aren't you, there is nothing wrong is there Richard?’...” (Mother, family one - April 2006)

The reaction to the possible diagnosis by this father appears to be in conflict with the information that he has been given. It appears to be one of disbelief, or rather an attempt to minimize or look for an alternative to the information given first by his wife, followed by confirmation from the paediatric consultant. She reported that:

“...Dr Smith said ‘well we are 99.9% sure it's leukaemia’, so he said ‘well what could the other 1% be?’ ‘Well it could be a virus.’ ‘Well there you are. It could be a virus...’” (Mother, family one - April 2006)

GIVING AND RECEIVING OF A CONFIRMED DIAGNOSIS

Having to disclose to parents that their child has a potentially fatal condition is difficult for the consultant to confirm, and for the parents to hear. The shock of the diagnosis, the prognosis and outline of the probable treatment all given at the same time frequently prevent any clear information being conveyed in the news the parents first hear. This is

quickly followed by treatment decisions that have to be made and consent forms signed, when in fact the parents are still recovering from disbelief of the initial diagnosis. The numbness and confusion that follows often leads to a misunderstanding of the information they have been given by the consultant and at this stage it may impair the decisions parents are expected to make, as this nurse reported:

“...I think at diagnosis there is so much overwhelming information that they have heard it, and I would guarantee they would say they haven’t, its been said but they haven’t heard it...”(Paediatric oncology nurse specialist - May 2006)

Evidence from my research shows how vital it is that those giving the information have good communication skills and that part of this requirement would include an understanding of the impact of the news on the family. This nurse reported that:

“...one mother said, ‘you never forget the words of the consultant who tells you that news no matter how they say it, good or bad, you never forget it...’”
(Paediatric oncology nurse specialist - May 2006)

Perhaps understandably, consultants on occasions do not fully relay the seriousness of a diagnosis until they have the clinical evidence confirmed. This may be appropriate for the consultant, but in this research, it appears that the majority of the families needed as much information as possible not only to help prepare them for what happens next, but also to gain an insight into the future of their child, as this social worker confirms:

“...I think they are very reluctant to give parents a life-limiting, life-threatening diagnosis and I think they will only do that when they are absolutely 100% certain. My experience of doctors is varied. Some of them have great skills in communicating the families’ very bad news, but other can’t manage it for themselves, let alone communicate that to the families, and that does make it very difficult...Because I think families often have had really bad thoughts. ‘Oh they might die’, and they want someone to confirm that and then the doctors say, ‘Well it’s likely to be’, because families feel better with actualities rather than myths but they don’t get it...”(Social Worker, Home Supportive Care Team - January 2007).

One mother reflected on the diagnosis, hospitalization, and her first night alone on a hospital ward following her son's diagnosis of leukaemia, noting her absolute shock in the early hours of the morning after being given a leaflet that discussed childhood cancer. Faced with the sudden realization that whilst the consultant had been discussing leukaemia, it had never occurred to her that her son's diagnosis was in fact a life-threatening form of cancer, as she reported:

“...I was sitting there in a daze ...then they gave me some brochures that talked of neutropenia. These brochures included cancer and the school child. And I looked at them and thought why have they given me these, it's got nothing to do with Richard? Then I thought yes he has got some form of cancer and it was wow. Oh my goodness”. (Mother, family one - April 2006)

The seriousness of the diagnosis and the change this inevitably brings to the lives of parents and other family members is reflected in the way in which the mothers reported how the medical regime takes control almost immediately:

“...then we had 14 ambulance rides backwards and forwards to different hospitals for MRIs, CT scans, and up to specialist hospital A and to hospital B for her back and it was all just, just too much really, and you just muddle on, you do just muddle on in your own little world ...” (Mother, family two - April 2006)

Following diagnosis and in the following weeks the role of the mother is redefined. “Muddling on in her own little world” could be identified as a strategy for coping with the stress of the diagnosis. The mothers in this research inevitably become part of the medical culture separating them increasingly from their families.

In conclusion to this section it is useful to sum up the key points. For the family, the diagnosis of childhood cancer not only threatens the life of the ill child, but also the ‘normal’ family life that they have, until now, taken for granted. Almost immediately ‘normal’ routines disappear and the medical world takes control of the ill child's life, with little detailed predictions regarding treatment, prognosis or eventual outcome. For the parents, the loss of control brings fear for the future. Closely following diagnosis the ill child enters the medical world for treatment with the parents still reeling from the

shock of diagnosis and the information they have been given. At the same time there are assumptions from family, friends and the medical world that the mother will automatically assume the role of carer and remain at the ill child's bedside regardless of how long that will be. The mother generally also has the same expectations. Although some fathers found it difficult to accept the initial diagnosis, the confirmation and hospitalization of the ill child represented a marker for the separation of the parents' lives into home and hospital. Within a short period of time it appears that through the hospitalization of the ill child the mother's identity begins shift from mother to carer of a child with cancer.

HOSPITALISATION: ENTRY INTO A MEDICAL CULTURE AND TREATMENT REGIME

Parents report that on first entering the hospital, the treatment regime focuses almost exclusively on the physical needs of the ill child. Outside of the hospital setting, the primary carer, usually the mother, soon grasps that although as a parent she is required to give formal permission for treatment to begin, she has little power or control over what happens to her child, and quickly realize that the medical world and its treatment regime dictates the shape of all their future lives. A paediatric oncology nurse illustrated this:

“...I think oncology trials and treatment are so regimented and these families have no choices, they fit into a slot that fits this way. If you don't do this, you go down that way... certainly palliative care.... there is not a beginning and there isn't an end...I think parents certainly feel stifled within that because they lose all their power and they lose all their control...” (Paediatric oncology nurse specialist - May 2007)

Mothers, who in this study were usually the primary carers, are thrust into the world of childhood cancer. All respondents in this research indicated that this new world is characterised by fear for the future, medical intervention, hospital routine, and separation from the family. Therefore, the original structure of the family is de-stabilized and a reformation of the family unit begins, continuing throughout the treatment, as this mother reported:

“...in and out of our shared-care for just weeks... weeks in, weeks out, days home then back in again with another infection and that is what they expect in the first year of ALL because the treatment is so intense and you just have to go with it really...” (Mother, family two - April 2006)

This is in fact, the beginning of a very long ‘roller coaster’ ride that takes families on to heights of relief, only to suddenly drop to the lows brought about by periodic separation or the news that the child is not responding to treatment. In parallel to this, is the fight with daily life, which means the washing and ironing still have to be done, bills have to be paid, birthdays come and go, and the weekly shopping still continues. However, even shopping gains new significance with a different meaning placed upon it. Some parents reported that they not only did their weekly shopping bill increase as they seemed always to be forward planning for hospitalization, but others saw it as a gamble on nothing going wrong, as this mother suggested:

“...my weekly shop was my omen in the end because I would do the weekly shop and the fridge would be stocked and then she would spike a temperature and we would end up in our shared care...” (Mother, family two - April 2006)

At this time although one might expect all family members, including extended family, to ‘pull together’, one mother reported that although this generally occurred, the heightened tension led to far more arguments, surprisingly with her own sibling:

“...I had a few big blows, even though Annie was ill... real big issues, which we obviously go through. It was hurtful at the time. Really, really big issues...I have never rowed with her [mother’s sister] like that before but through Annie’s illness we did...” (Mother, family two - April 2006)

AFFECTS ON MARITAL RELATIONSHIPS

In normal circumstances the strength of the marital relationship may help tie a family together. In this research, however, following a child’s diagnosis, marriage was often reported as becoming secondary to the illness and what was normal and expected in that relationship often disappeared without time to adjust to the new roles and demands that the illness created. Therefore, the continual familiar demands of the everyday are brought

into conflict with the new and more strident demands of the illness and hospitalization. This mother described how her husband viewed the separation:

“...he [husband] hated me not being there, hated completely. But what can you do? ...Obviously at the time his place in the status quo had changed, like all of ours had. But, and you feel like saying well ‘it’s not just you’...” (Mother, family two - April 2006)

Most of the fathers in my research continued to work in order to meet the families’ financial commitments. A consequence of this is that fathers may feel left out and not part of the medical care, and as the intensity of care increases, mothers do not have time to be the “wife”, and over the treatment period husbands may find it difficult to accept the withdrawal of their wives’ attention:

“...they [fathers] were unable to cope but they were also unable to accept the fact that their wives had to give the child 100% of their attention...” (Raey et al, 1998: 43).

The parents in my research who maintained the role of caring for the ill child reported that they had to quickly learn to adjust to the language of medical staff and the names and administration of drugs, and so begin a journey that would ultimately lead them to becoming relatively expert in their children’s illnesses. They also had to become familiar with the general routine of the particular ward where, for a period of time, in a paradoxical way, they find themselves living for a limited time in a “home-from-home” room on a hospital ward. However, what cannot be provided is privacy for the couple, and nurses on duty become “watchers”, “judges” and “reporters” of their perception of how the parents are coping. This mother spoke of how a nurse told her that her husband was not coping:

“One of the nurses said to me the following morning (Sean had stayed over night) ‘Your husband is not coping is he, not coping very well? and I said, ‘I don’t know what you compare it with’, and she said ‘it’s the dads, all dads are like that, they all go into denial especially when it’s their little girls’”. (Mother, family two - April 2006)

The nurse's perception of fathers not coping was reinforced by one mother who during the interview described her experience of staying on the ward with her ill son and how mothers would be supportive to each other. These conversations would often include how they collectively believed that their husbands were not coping with their child's cancer and treatment. This mother continued:

“...I don't know what it is about these dads, when you talk to other mums it's the dads who see these bald headed children and run out saying 'My son does not belong here', and they can't take it...” (Mother, family one - April 2006)

Other mothers reported that they could cope better as it was already part of their role as a mother to care for a child who is ill, as this mother suggested:

“...I think a mum just goes, 'Oh I have got this to deal with now. How do I fit this in with everything else I have to deal with?' With men they leave all the children. If the children have got a headache or the mum takes them to the doctors with a sore throat or tonsillitis they don't really get involved with the illness...” (Mother, family one - April 2006)

The parents of cancer children are forced to struggle with this new disorder in their lives, along with the new roles that have been constructed by the illness, thus creating different problems for each parent and individual members of the family. This mother described what her husband could and could not do:

“...He's not that way. I mean he can fry an egg but that is about it, so he was round my mother's house for dinners and things, which was fine and that worked, but if I didn't have that support on the doorstep ...” (Mother, family two - April 2006)

CHANGING ROLES AND EARLY LOSSES

For many families over the period of hospitalization they will become reliant on extended family members to “fill in” the gaps that have appeared through the absence of parents, particularly the mother. They struggle to provide some sort of ‘normal’ routine for the

immediate family, from caring for the well sibling(s), helping with home work and giving out information regarding the ill child, to reassuring the absent parent that everything at home is fine and everyone is coping well. This includes maintaining the basic everyday chores of proving meals and making sure there are clean clothes, as this mother reported:

“...my mum was doing all the washing and ironing and things like that, but again if she hadn't been there he [husband] could have put the washing machine on but he certainly wouldn't have ironed anything ...” (Mother, family two - April 2006)

A number of mothers also reported that on returning home from the hospital stay, they realized that as parents they had themselves become institutionalized, part of the medical culture, and an 'expert' in their child's condition. During this time they had not been involved in anything 'domestic' and others were in control of their home. There had been no school run and the mother's routine had been based on a ward routine. In fact everything according to this mother had more or less been made orderly by the medical world:

“...you become institutionalized. When you come out it's like 'Wow', it's like it's not been happening. Everything comes to a grinding halt when you are in a place like that, but it actually doesn't. When you come home you have to pick up the pieces...and every time you come home you think what am I going home to...?” (Mother, family two - April 2006)

For some mothers it may come as a shock on returning home to discover that the family is coping in a newly created environment of different routines and rituals. They [mothers] may on returning home find themselves in the position of having to re-learn their own family domestic routine. For example, one mother reported that in the past the family celebrated children's birthdays with a party at home with the mother organizing everything. Following the illness and her absence, this was now being held at McDonald's.

With the onset of a child's serious illness the traditional mother role often appears to come to the fore, with an assumption that she will relinquish other roles to become the primary carer. With few exceptions, in this research this usually resulted in the mother

having to give up work or reduce her hours in paid employment to be with the hospitalized child, as this mother described:

“...when it’s major it’s ‘Wow, he (the father) better had get involved in this’, but it’s ‘I’ve got to go to work that’s my department’ - you deal with that...” (Mother, family one - April 2006)

Therefore, the father generally appears to have less direct involvement in the care and treatment process. In contrast, mothers often spend long periods of time with the ill child becoming the ‘expert’ carer and hence become more isolated from the world outside the hospital, as this mother suggested.

“...Sean had to carry on working. At the time he was rushing up every night after work. By the time he got to us in London the maximum he was with us was a couple of hours and then it was time for him to go. That was awful. I just remember the nights, so long and lonely in hospital... it was awful...” (Mother, family two - April 2006)

It is useful to sum up the following points. Following the diagnosis and hospitalization of the ill child and mother it appears that the marriage takes second place to the illness with little or no time to adjust to the new roles bringing conflict to the demands of everyday life and other family members. With the fathers continuing to work to meet financial commitments they become less involved with the medical care of the ill child and may feel on the ‘outside’ of the treatment. The mother’s full concentration is given over to the ill child and that brings additional difficulties to the marriage, especially with the extended separation during hospitalization. The isolation and loneliness that night-time hospital caring brings helps to underscore the loss of the ‘old life’. It shatters parental belief that they could keep family members safe and well, and that their children would outlive them. In this study, some mothers noted that life up to this point had not prepared them for the responsibility they felt during these long periods in hospital. Not only are old familiar routines and assumptions about the future threatened, the isolation gives the parents few opportunities to share a joint sense of a reality that captures what is happening to them. The sense of isolation fragments the couple’s relationship with the demands of work on the father, and the demands of the treatment regime and

hospitalization on the mother, and leaves little distraction from the fear in their minds of the consequences of the treatment failing. Mothers spend long periods of time in hospital with their ill child becoming 'expert' in their care, whilst fathers visit when work permits. This pattern appears to be common indicating that the culture of cancer frequently takes over the lives of mothers, whilst less directly affecting the working lives of fathers, but having a major impact on home routines.

THE TRIALS AND TRIBULATION OF TREATMENT EARLY DECISIONS: THE IMPLICATIONS OF TREATMENT SIDE EFFECTS

Following a confirmed diagnosis of leukaemia, treatment generally takes place immediately. However, prior to treatment many decisions have to be made by parents. These discussions are usually about treatment protocols, and the possibility of taking part in trials. Other decisions, if raised by the consultant, may be governed by the age of the ill child. For example, issues regarding fertility have to be considered prior to chemotherapy, such as whether or not to store eggs and sperm for future use. This is primarily a safeguard as chemotherapy and other treatments associated with childhood cancer are likely to create infertility in both male and females.

Whilst the immediate treatment usually begins in the shared-care hospital, it was reported in this research that the ill child was quickly transferred to a major cancer centre, to begin the treatment protocol that consists of two years for girls and three years for boys. It was reported in the interviews that a basic explanation is given to the child about leukaemia, and a description of the treatment such as how chemotherapy will affect them, including one of the consequences of the treatment being hair loss. One mother described this:

“...she [paediatric oncology nurse specialist] sat down with Annie and said this is what it means and probably one of the side effects you will lose your hair and Annie was only eight and a half at the time and I remember she sat on the bed and said sometimes the hair comes back a different colour and Annie just said “but I don’t want blue hair...” (Mother, family two - April 2006)

THE ILL CHILDREN'S PERSPECTIVE AND FEAR OF THE UNKNOWN

It was reported that initially, the mother's and nurse's response to the hair loss had been to laugh off this relatively minor side-effect for the child's benefit, stressing that it would grow back. To the child, however, it was just one frightening indication of the unknown future to hear that her hair would drop out or change colour. The information given by the nurse was ambiguous, and although she meant that when it grew back there would be a variation in the natural colouring, the child imagined the worst scenario. This information, given confusingly, added to the child's serious fear of the unknown, rather than reassuring her. For other children, information about the affects of the treatment raises not only fear of the unknown, but also the fear of what you know you do not like. The following report from the interviews is how an eleven year old, on admission, viewed his new surroundings, the patients with no hair, the thought of being sick, and how easy it was for him to ask the question that the parents could not bear to think:

“...I was sitting there in a daze, they [nurses] went away and he said to me, Mum I really do not like the idea of losing my hair because that boy's head over there is all shiny. Am I going to look like that?’ And I said ‘Possibly’, and he said, ‘I don't like being sick and the medicine is going to make me sick and I feel a bit tired, shall we go home now, or am I going to die...?’” (Mother, family one - April 2006)

Death appears to be the shadow that follows parents from the moment they are informed of their child's diagnosis, as the CEO of a Community Project reported:

“...its mum's reaction. Mum's reaction is strong on this. Her little girl, who is now off treatment..... and they went to New Zealand..... The mum was completely hooked up to the fact that her daughter was going to die and couldn't see anything else...” (CEO, Community Project - February 2007)

However, ill children may not have been informed directly of the possibility that the treatment will not be successful and that they may die from the illness. The children do, however, ‘tune in’ to what their parents and medical staff are reluctant to talk to them about. Many children, through their own experiences of being on a hospital ward, have a

full understanding that they could die from their disease even though the adults in their lives fail to discuss this possibility with them.

“...what we were told fairly early on is that commonly quite often you do not lose them to leukaemia, its secondary infection and that was our fear...” (Mother, family two - April 2006)

PARENTAL PERCEPTION OF MEDICAL CARE

Although parents appeared to value the medical knowledge and input from the main cancer centre, there was common disillusionment regarding the care of the ill child during hospitalization at the locally based shared-care hospital which, during the long process of treatment, brought additional stress for the parents. One mother’s perception was that the medical treatment and attention the child was receiving was too general and that the actual daily care on the ward was lax, as she reported:

“...(in) the specialist hospital the requirements are better, the knowledge, the noticing it was needed, certainly was there....But again, I think it all fell apart at our shared-care because, as I say, it was a general ward and you have nurses who are doing tonsillectomies one minute and then they would have to turn their hat around and talk to oncology parents about issues, and nurses used to say, ‘Well I’m not really, I don’t specialize, or I am not familiar with this...’” (Mother, family two - April 2006)

Some parents spoke of mistakes made by health professionals during the hospital stay that could have led to disastrous results for the ill child. One parent reported that following her daughter’s allergic reaction to weekly transfusions it was decided to give her anti-histamine:

“...right on the front of her notes big red letters – ‘Must have cover before transfusion’, so the nurse went off - and I had seen it on the front of her book in red in big capital letters: ‘Next time she had a transfusion didn’t give her cover’... and had it not been for me they were just about to put the bag up, and I said ‘She hasn’t had her anti-histamine’, ‘Oh right, yea, yea, that’s right I did read that’,

‘Well why haven’t you done it then?’ It’s just incompetence...” (Mother, family two - April 2006)

Whilst in this instance the mistake had been avoided through the mother’s watchfulness, parental anxiety is often criticized and misunderstood by staff, as noted by the following two mothers:

“...sometimes they do talk to you as if you are neurotic or paranoid and there has been a good few times when we have persisted over something and it’s turned out right, whether it’s medicine dosage or you are double checking - and checking all the time and that’s exhausting...” (Mother, family one - April 2006)

“...the whole, whole concept... all the hospital business, it’s just exhausting and just to have somebody being a bit more responsive, a bit more respectful all the way through, to know it’s just not what you do, to take the pressure off.. You are just watching points all the time and you don’t want to leave them because of it, because you are worried that they are going to come in and do something detrimental, give them something they shouldn’t have, get the wrong notes, not to read something that is written up...” (Mother, family two - April 2006)

In his *Essays on the Welfare State* Richard Titmuss discusses how illness can play tricks with the thoughts and behaviour of the patient:

“This does not mean, as some all too easily suppose, that they are neurotic. In being querulous and ungrateful, and demanding and apathetic in turn, we are in fact behaving as ill people” (Titmuss, 1958: 124).

Whilst in his essay Titmuss referred to patient behaviour in hospital, there is an interesting parallel that it is not only ill patients that behave in a way that they would not outside of the hospital environment, but it is also how mothers of hospitalized seriously ill children may behave as this mother reported:

“...I went (noise like an explosion) on the moment she started her treatment... because she was so anxious and they were trying to get a needle vein...and she is now needle phobic...” (Mother, family two - April 2006)

The ward staff are busy with a continual lack of resources and more demands placed on them. Nursing staff may hold information that is privy to them long before the ‘bad news’ is relayed to parents. This can create avoidance or frustration with the parents especially if they are pressurizing the staff for information, or clearly making plans for the future that the ward staff are aware may not be possible.

However, medical staff at all levels must begin to understand, and more importantly, accept that they are not only there to treat the disease, but to work with the whole family whose only concern is with their child, and perhaps have completely different ideas of parenting than is the acceptable ‘norm’. More awareness and acceptance that parents have a greater understanding of their own child, and that by being continually watchful at the bedside they become an expert in their own child’s illness, is important. They must begin to realize that the “don’t worry” conversations with health professionals are not authentic, with the long-term prognosis being cloaked in false reassurance:

“... actually in your own little world life is a bitch, and you’re dealing with that, then the way they (medics) minimalize everything in hospitals does make you think it’s not a big deal, which isn’t right...” (Mother, family two - April 2006)

It appears from my research that many parents, especially with childhood leukaemia, do not stop at the Consultant’s explanation of the disease but explore all avenues of information open to them regarding the aetiology and possible alternative treatment. Although this additional information has usually been accessed via the internet, it is part of the increasing knowledge base of the expert parent that, if acknowledged by health professionals, would make them less patronizing in their communication. Information makes the basis for a genuine discussion about the children’s illness, as this nurse suggested:

“...I have found this on the internet and in America. Outside New Jersey there is this trial and it’s cured all leukaemia. What we would do then is say ‘Why don’t

you bring it next time you go to the clinic...it could quite rightly be a bono-fide trial that this child might be eligible for', One family was talking about a drug that is now used in chronic leukaemia. It was on trial in America but was used for their son's type of leukaemia, and dad had researched it very well and had sent to the drug company, had spoken to America... We did know about it but it wasn't licensed here..." (Paediatric Oncology Nurse Specialist - May 2007)

In summarising this section it is useful to review the key points. Firstly, the rigid protocols that have to be followed in the treatment of childhood cancer are often explained to the parents and the ill child when they are struggling emotionally with the shock of the diagnosis. Secondly, whilst the parents are fearful for the future, the ill children have their own fears of the treatment that include such details as being told that the chemotherapy will almost certainly create hair loss and that the hair will grow back a different colour. At the time of admission to hospital the ill child is perhaps best described as "walking wounded", and for them to see other very ill children who have no hair, vomiting, and hooked up to machinery fills them with even more fear of what will happen to them. Thirdly, whilst the parents cannot voice their ultimate fear, that is, their child will die, the ill child has a sense that this could happen to them. Fourthly, the parents in my study reported that they found the care of their child more acceptable at the main cancer centre than at the local acute NHS trust where they found services lax. This included the lack of nurses' experience of working with cancer children and the loss of continuity from paediatric Registrars and Consultants. The parents felt that they had to continually be watchful to avoid mistakes being made by the nursing staff who seemed to either ignore or appeared not to read new instructions that had been made in the child's notes. Fifthly, on the ward, the mother's perception was of being judged as being either neurotic or paranoid and found a lack of respect by the medical professionals who also appeared to understate the seriousness of the situation. Sixthly, parents did not entirely rely on the information they had received from the consultant and frequently searched the internet for information that further increased their knowledge and own expertise. Whilst the parents in my research are not the patients, they are closely involved in the treatment of their children, having an understanding of blood counts, platelets, medical language, drugs, and chemotherapy. These points may not make them a medical expert in the eyes of practitioners but it does produce expertise in their own child's illness that should be acknowledged.

ENCOUNTERING A NEW PHASE OF JOY AND FEAR: THE END OF TREATMENT, TRAUMA AND 'CURE'

After a period of intense medical treatment that is characterised by uncertainty for the future, the child who has remained in remission receives a specific date when treatment is considered to be at an end. This is the day that everyone has waited for, a day of celebration. There is active encouragement from nursing staff for families to have a party to mark the day, and many families do. Yet many parents I interviewed reported that throughout the celebration there is a "shadow" of fear. This is also the day when the medical regime upon which they have come to rely is removed, along with the structure to their lives which the treatment has created. The family are overjoyed that they have reached this stage but when the celebration is over they realise that they are on their own, and from this point onwards the parents begin a waiting and watching phase:

“...the other day she had a nose bleed and it rung alarm bells for us so it takes you right back to the very beginning when things like that happen...” (Mother, family two - April 2006)

LOSS OF THE MEDICAL STRUCTURE WITHOUT REGAINING CONTROL

The loss of structure which accompanies the end of treatment is appreciated by some of the medical staff. One cancer nurse explained her view of the loss of the two to three years of treatment as follows:

“...and literally you go from week to week and this and that and the other, and that gets less frequent but you are still going and you have all the structure in your life, then suddenly on a given day somebody says it's all finished...” (Paediatric oncology nurse specialist - April 2006)

For many families, the experience of regular treatment that has continued over a number of years and is an integral part of the family's routine, is now ended. Not only has the treatment ended, but the support network of other parents formed at clinics and hospital stays also disappear. The family finds itself at the beginning of a new phase in its life in which the end of chemotherapy creates its own anxieties:

“...when you see the parents getting anxious it’s towards the end of treatment when they are coming back for follow up, there isn’t any more chemotherapy and it’s a watch and wait now...” (Paediatric oncology nurse specialist - May 2007)

For many parents at this time, happiness is balanced in equal measure by fear and anxiety. Some parents reported that they considered it as bad as receiving the initial diagnosis. The structure and control for which the medical establishment has taken responsibility for many months is given back to the parents who are often unprepared for it. One mother reported finding herself very much on her own:

“...then you come off treatment and that is a scary thing. Your safety net has gone and you’re left floundering a little bit. I mean you are looking forward to the day, but you feel in limbo...” (Mother, family two - April 2006)

For the parents interviewed, there was also the additional pressure from the expectations of wider friends and family that they could now ‘get back to normal’ This mother described how that made her feel:

“...and people would say to you, ‘Oh get back to normal now then’, and I just felt like smacking them in the mouth really, because no, my life as I know it has gone, I have another life now...” (Mother, family two - April 2006)

The new life that the illness and treatment has created tends only to be obvious to the immediate family. Those on the outside of the family unit, for example extended family and friends, may not be aware of all the changes, but possibly will excuse visible changes in behaviour of family members, including marital relations as being down to the illness. ‘Back to normal’ may not be an option for all individuals within the family. From the interviews in my research the illness had been viewed as a source of change that no one person in the family had control over, often leading to anger and resentment:

“...no, no, not at all, and I resent it [cancer] for that...” (Mother, family two - April 2006)

A FORM OF RELIEF

From the mothers' stories in this research the end of treatment can and does bring some relief to the family. What has been clear from the interviews is that throughout the treatment period, parental concentration has been firmly placed on the ill child, with the greatest stress being experienced by the main carer. It is at this point, when the family begins to relax a little, that their neglect of their own health-care needs may come to the fore. During the treatment the main carer has had less time to attend to her own health care needs, and reduced sleep patterns over a prolonged period of time, irregular, often unhealthy meals snatched within hospital stays and the emotional roller-coaster of remission and relapse, can take their toll. Physically and emotionally, the family is generally in a weaker state than before the illness.

On reflection, the parents in this research were not really aware of how they had managed to cope. They did recognize, however, that it was basically left to each parent and family member to deal with whatever the situation demanded on a daily basis in their own way. They also acknowledged that no manual or leaflet would have helped, as they were already overloaded with information. One mother suggested that:

“Yes it was a bit of a game and one hell of a roller coaster. You can't imagine. Lots of my friends now say I don't know how you got through it, but you do day-to-day and you just cope with everything that is thrown at you in your own little fashion...” (Mother, family two - April 2006)

To summarise this section, it is useful to list the key points. Firstly, on a given date the treatment comes to an end. Although there is relief for the family there are also anxieties as the medical support that has structured the family's life for so long disappears, along with the support network of other carers usually created by mothers within the hospital setting. Whilst the medical staff encourages the family to celebrate, parents do so with a certain amount of trepidation as they begin a period of watching the child who is now in remission for any sign that the illness has come back. Secondly, with the end of treatment control is given back to the family, indicating that they have to yet again restructure family life to accommodate the new status of the once ill child. At this time families often reflect on how they had coped for so long on what at times seemed to be a roller-coaster of emotions. Thirdly, whilst the family may not be able to pinpoint how they coped with

the changes brought about by the illness. For some, it is a time when resentment against the illness comes to the fore. Those on the outside of the family can only see the positive outcome of being off treatment and continually talk of getting 'back to normal'. The immediate family know this to be impossible, and are in fact at the start of having to restructure a new family life following treatment. Routines adapted to the ill-child and main carer being a part of the culture of childhood cancer, disappear, leaving both parts of the family to find ways of coming back together.

THE FUTURE AND UNKNOWN FEARS: THE LONG TERM EFFECTS OF CHILDHOOD CANCER AND ITS TREATMENT

One mother described her feelings on her daughter's future, especially when considering the drugs that were involved in the treatment:

“...20 years down the line, I don't know what or how she is going to be, the medicines she had, the repercussions of that, reading now it's about side effects...”(Mother, family two - April 2006)

Cancer Reference Information (www.cancer.org) points to what are known as the “late effects”. These are caused by the injury that cancer treatment causes to the healthy cells in the body. A paediatric oncology nurse reported that:

“...so although you won't necessarily relapse from your original disease, if you have had certain types of drugs it can prove ...you know....brain tumour. Parents know that during treatment, because you have to tell them before they sign the consent form, but I think if we did a study to see how many parents remembered it at the end of treatment very few would” (Paediatric Oncology Nurse Specialist - May 2007).

PALLIATIVE AND END OF LIFE CARE

During this research and over the longer period that I have been employed as bereavement co-ordinator I have worked with families for whom the treatment regime has not been successful. Families who have learned that treatment no longer is having any effect, face palliative and end of life care which can last from a relatively short to an extended period of time, with ongoing hope that some new 'cure' might be found:

“...one family are a prime example of this, dad searched for a cure during the palliative stage and his son was actively dying and it wasn't that he was un-accepting or had no faith in services both locally and at the tertiary centre, it was yearning to do something practical to try and save his son's life, there was never any other motive than to do that...” (Paediatric clinical nurse specialist - May 2007)

Families find it difficult to understand how the original treatment which at the time appeared to be providing a 'cure' and which led to an extended period of what was viewed as recovery, is now replaced by, and is the possible cause of, impending death. One mother explained this:

“...it was a brain tumour, so having read the small print, a cranial boost could cause a brain tumour and it jolly well did ...it seems so stupid that radio therapy gives the brain tumour and you have radio therapy to get rid of the tumour it doesn't make sense”... (Mother, family one - April 2006)

Throughout the period of treatment and remission it appears from the sample that the mother as primary carer remains strong and positive regarding the future of their child with fathers being less involved and often more negative. Whilst a number of families were interviewed for this study, in only one family had the young person died. It is from this interview that the mother reported a situation that highlighted how during the illness and treatment the father had little opportunity to participate in the care of the young person, and yet when the parents were given the information that there was nothing more medically that could be done, and that their son would die, the father, although distraught, came to the fore and took charge:

“...Mark did it beautifully and he said, 'I am ever so sorry mate, medical science has failed you and our time together is going to be short.' And he said, 'There is nothing more to do', and Richard said, 'There is nothing? They are not going to do any treatment?' and we said, 'No, there is nothing left love, and do you understand what that means?'. And he said, 'Yes...’ (Mother, family one - April 2006)

From the interview there is no clear evidence that there had been further conversations with Richard regarding his impending death or with other members of the family regarding their feelings attached to the future. However, from working with the family at that time and for some years following Richard's death I am aware that the family fragmented into three separate units with little discussion associated with the death of their son and brother.

At that time, what future Richard had left was to be filled with concerts, balloon flights, and time out at the Youth Cancer Trust. He used this time to say his goodbyes to his best friend and brother and in some ways to create a sibling bond that had been tenuous throughout their previous lives:

“...the Youth Cancer Trust offered him a holiday. He went for a week with Alex his best friend and then he had a week in the March with Matt and that was really good because they talked and I don't know what was said, but there was a real bonding that was good. Then he got to the stage where he went into the local hospice where he died...” (Mother, family one - April 2006)

LIFE FOLLOWING THE DEATH OF A CHILD

Like the illness, the long-term consequences of the death continue to influence every part of family life and relationships. For some families the ability to talk to each other is non-existent and the gap created by the illness and death fragments them further. Although the death affects all individuals in the family differently, family members do interact and influence each other as they continue with their lives. However, the child or young person who died can remain the centre of attention within the family. Marital relationships that may have cracked during the illness can begin to break down through frustration that one person's perception of the other's grief is not the same. One mother described the lack of understanding of differing coping strategies:

“...it is very much me, me, me. You know if I was to cry or want a cuddle, no way. It would be, ‘Oh for goodness sake, we are all having to cope with it, in our own way’. And that's it, you are not allowed to get upset, and there are times when I have thought, ‘I want out...’” (Mother, family one - April 2006)

“...I think, ‘Hang on a minute that’s not very fair is it...I would like a man, I want a man on a charger to scoop me up and say I will look after you, he hasn’t arrived yet...”(Mother, family one - April 2006)

“...and what you want from your partner is to be cherished and loved, and probably courted. I can remember saying to my husband ‘I want to be courted’...and he couldn’t do that...He hadn’t the reserves to do that.” (Riches and Dawson, 1996: 13).

Summarising this section it is useful to review the key points. For a small number of families, treatment is no longer an option and they are informed that there is nothing more that can be done for their child. Parents at times find it difficult to understand how the original treatment may be the cause of the impending death. Throughout the treatment fathers seem to be on the outside of the medical care. However, they appear to come to the fore at this time to take control of the situation by passing on this information to the dying young person whilst other fathers continue the search for a cure. It can also be a time when siblings put the disagreements to one side and perhaps for the first time come together. Following the death the once ill child still maintains a ‘presence’ within the lives of family members. Survival for some families means living together but all pulling in different directions, consumed by their own individual grief and unable to communicate their personal feelings with other family members. Marital relationships can become more fragmented through the misunderstanding of each other’s grief, especially when one parent appears to be coping and the other’s grief is more prolonged. It also seems that at this time the wife requires some form of attention that includes comfort and protection. Other families make a determined effort to be positive and live life to the full, whilst some parents feel compelled to ‘give back’ in some way, supporting other families who are now in the situation they previously found themselves, that is, having a child diagnosed with cancer.

CONCLUSION

As soon as a confirmed diagnosis of childhood cancer is made, the ‘normal’ routines of family life are shattered and the medical regime takes control over the ill child. The parents who are still shocked from this news have little time to digest the further

information they are given regarding treatment and prognosis. The parents have little choice but to agree to the treatment. The only other alternative is usually palliative care. At this time assumptions are made that the mother will assume the role of carer and remain at the ill child's bed-side. This change marks the start of the separation of marital/family life and hospital life. This is also a time when the mother begins to lose her self-identity as wife and mother to a narrower identity that represents primary carer and 'mother of a child with cancer'. The impact of the diagnosis can produce a trauma that de-stabilises the original structure of the family and fractures the family dynamic requiring the building of new routines. The fathers continue to work, visiting when work allows, often appearing to be on the outside of the illness, indicating that the culture of cancer primarily takes over the lives of mothers. During the hospitalization the mothers growing expertise in the illness and its treatment help them recognise that the child was better cared for at the main cancer centre than at the local acute hospital. They are increasingly sensitive to mistakes which, if it were not for their own observations, their child might have been placed in jeopardy. However, raising these complaints with the health professionals also created conflict, often attracting the criticism of being neurotic. It was not recognised by health professionals that over time parents have an increasing understanding of the treatment and procedures involved, and becomes an 'expert' in their own child's illness. On a given date the treatment comes to a close and although there is relief for the family there is also an anxiety that the medically structured life that they have led comes to a close. Simultaneously, whilst there is a celebration that the treatment has finished, there is also fear for the future, including fear of relapse. There is also the challenge of having to reconstruct a new 'normal' in their family life that is now independent of the treatment regime.

CHAPTER, 5

THE CONTINUED UP-HILL STRUGGLE OF FAMILIES WITH CHILDREN WITH A LIFE-SHORTENING ILLNESS

The aim of this chapter is to outline the emotional and life long challenges that families face following a diagnosis either before birth, following birth or in early childhood of a child with a life-shortening illness. This diagnosis confirms that the child's development and life expectancy will be limited. The Sisyphus metaphor is used in this chapter to illustrate the continued up-hill struggle of families who are living with the awareness that there will be no cure for their child's condition. Family life will not become easier as the years go by, but additional pressures mean that the family have to continually adapt to the original condition and to additional illnesses that are at times created by a life time of drugs, and a weakened immune system.

I examine how modern technology enables a problem to be diagnosed before birth, parents' reaction to the information and the choices that they then have to make regarding the continuation of the pregnancy. I outline the trauma of 'problems with the baby', detected at birth, the loss of control of parents-to-be in the medical environment of the delivery room, and a perceived lack of information regarding the problem. Three issues regarding a diagnosis of complex medical needs are examined: the difficulties in obtaining a diagnosis when there are non-specific symptoms; the reluctance of doctors to give a diagnosis without certainty; and parent's perception of the limited information that leads to the separation of mother and baby for life-saving surgery.

I continue with how hospitalization appears to be the beginning of a long up-hill struggle which includes the medical culture's supervision of the ill child and the subordination of the parents who may not always feel supported by medical staff. I examine two further issues, the life long consequences of a life-shortening diagnosis which for many means that the medical world becomes an integral part of family life. The primary carers become committed to a struggle for information, attention and resources, particularly when there are learning difficulties attached to the illness. Also, I consider how the medical management of the illness at home restricts family life.

BETWEEN A (TECHNOLOGICAL) ROCK AND THE HARD PLACE OF MOTHERHOOD: DILEMMAS OF ABNORMAL DIAGNOSIS PRIOR TO BIRTH

During the early weeks of pregnancy antenatal testing can confirm that the pregnancy is viable. However, it can also identify many rare and possible fatal conditions months before birth (Field and Behrman 2003). One mother recalled:

“...when I was twelve weeks pregnant they scanned me and so I went to King’s she had got one kidney but the kidney she had got was very dilated that was at twelve weeks...” (Mother, family four - January 2006)

A government document published by the DHSS in 1977: 48 *Reducing the Risk: Safer Pregnancy and Childbirth*, suggests the possibility that the tests may have been developed with more than the interest of women in mind and includes the economics of the care involved when a child has a disability and/or complex medical diagnosis:

“...because caring for the handicapped can impose great burdens on our society the prevention of handicaps...in addition to its other benefits may save money...would be more than offset by the economic benefits in terms of savings of expenditure on children and adults with Down’s Syndrome and Spina-bifida” (DHSS, 1977: 48).

Whilst the continued developments of antenatal testing can be viewed as medically positive, it does appear from the sample that a number of mothers of children with life-shortening conditions experienced pressure from the medical profession because they were not going to produce the “perfect baby”, as this mother suggested:

“...so all through the pregnancy they talked about abortion...” (Mother, family four - January 2006)

From a medical and probably a societal perspective, abortion may be thought to be the better option for the parents to consider, especially when informed of a disability or rare syndrome prior to birth. Whilst there had been a number of discussions with the parent regarding the possible negative outcome of the diagnosis and that the chances of the baby’s survival would be slim, the discussions were perceived by this particular mother

as pressure to conform to what was right for the medical professional. Throughout the remainder of the pregnancy, there appears to have been little attempt from the health professionals to offer emotional support for the emotional stress placed on the parents by the antenatal ultrasound diagnosis. However, although scans are routinely used, and abnormalities in the majority of cases detected, there are occasions when even severe abnormalities go unnoticed:

“...if I look at my scan it just looks completely normal, but by the time he was born his head was an odd shape, it was one of the most severe they had seen, but no, they did not spot it on the scan, thank goodness...” (Mother, family three - June 2006)

I asked the mother why “thank goodness”? In this particular instance, if the abnormality had been detected via the scan, and an abortion offered, the mother would not have taken long to consider her choices, and as she suggests that is still how she feels:

“...Well it’s a mixed blessing really, I wouldn’t have had him, I wouldn’t have had him, again if I could go back and I knew, I still would make the same decision I wouldn’t have had him, even though my life would be nothing without him...” (Mother, family three - June 2006)

The statement, “I wouldn’t have had him, even though my life would be nothing without him...” may give us an insight into how a parent identifies with a particular child as an extension of herself, and how her role becomes one of primary care provider for their ill child. In turn she herself becomes identified with the illness and ill child:

“...a lot of people [at the hospital] do not recognize me without Steven. Sometimes I have to say, I am Steven’s mum, I met you and they go, oh yes ...” (Mother, family three - June 2006)

A further factor could be the possible mental anguish that has been created over the years by the experience of caring for a child who will continue to be physically, socially and emotionally dependent upon her for many years to come. It can also be assumed that the parent, knowing that she would have aborted the pregnancy may have feelings of guilt,

yet it is as if she has turned this positively around to say “my life would be nothing without him”, without saying what her life is like with him.

Unlike the parents of a child diagnosed with cancer, where the illness and treatment create the hope of a cure, the parents and the family of a child with complex medical needs learn only gradually the full implications of the physical problems and disabilities. They also have to live with concerns about their own capacity to cope with a situation that will not change and in many instances, will get worse.

For those parents in this study who made the decision to continue with the pregnancy, it was reported that lack of support from medical staff continued throughout the pregnancy:

“...she might have died but no-one cared. They don't care, you are just a number, not a baby, and then they said, ‘well if the baby survives will you bring it back and show us’, do you think I ever took the baby back...” (Mother, family four - January 2006)

In summarising this section, it is useful to sum up the key points. These are: ultra sound and amniocentesis tests are now an accepted part of pregnancy, not only to confirm a viable pregnancy but also in detecting whether or not the baby is healthy or has one of the many conditions where it is considered more beneficial to offer an abortion. It appears that when an abortion is rejected by the mother the medical profession do not always offer hope or sensitivity for the remainder of the pregnancy, and continue with the suggestion that it would be better for all to reconsider the decision not to abort. Although the majority of pregnancy screening detects abnormalities, there is always an exception when the routine scan is clear but should in fact read a severe abnormality. In this instance although not having a choice at the time, the mother would, even though her son in now nine years old have chosen an abortion. For those who continue with the pregnancy, the perception is that the medical world has little or no compassion towards the parents, and little hope for the baby's survival.

RECEIVING A DIAGNOSIS IMMEDIATELY FOLLOWING THE BIRTH

In the sample most parents-to-be have had little experience of children with a disability or complex medical needs and approach the birth with the expectation that their baby will be

healthy, and are not at all prepared for the birth of a child with a disability or chronic illness. Throughout the pregnancy the parents create a mental image of the baby that consists of expectations and their own dreams for the future. Along with the expected delivery of a 'normal' healthy baby which has been promoted throughout pregnancy and within anti-natal classes, where any discussion of babies born with disabilities and/or illness would be rare, this mother reported that:

“...well I had a emergency caesarean you know that big head was not coming out so after about 24 hours in labour they said right they are going to do it they took me down and as soon as he was born they whisk him off into the corner...”
(Mother, family three - June 2006)

No matter how prepared the parents are for the actual birth, in the medically controlled delivery room, their personal power and control of the situation is taken over by the professional. In addition, the transition to parenthood is filled with conflicting emotions that further strengthen the vulnerability of parents to environmental and professional reactions. These feelings become more evident when, following the birth, problems with the baby are detected, but no clear information is given as this mother reported:

“...I said, ‘What’s happening?’ One of the midwives said to me, ‘He’s got a few deformities’ and I said, ‘Is he going to live?’...they called Lewis over and said there are problems and we are going to take him up to NICU (neonatal intensive care unit) saying we don’t know what the problem is, but he is having breathing problems and poor Leroy was looking at him from where he was lying with his head and he said to me he looked like an alien...” (Mother, family three - June 2006)

In this instance as in many others, this data reflects the experience of a number of parents. This contrasts with advice given in *Sharing the News*, a NHS manual produced to help improve the way in which medical professionals convey the news to parents that all is not well with the baby:

“...The memories of these early hours can be devastating. Be sensitive and supportive, avoid hurtful terms such as “he looks a little funny...” (South Essex Mental Health and Community Care Trust 2000: 8)

Parents who may have no understanding of medical terminology or procedures during labour and delivery do have an awareness of what is happening around them and continually monitor the behaviour and responses of the staff involved as indicators that all is well, or as the first sign that something is wrong. Julia Hollander recalls the birth of her second child:

“...third push and she slides out. ‘Beautiful, beautiful,’ I hear. Then silence. Horrible silence. My screams have stopped, but **Nothing** has taken their place...”
(Hollander, 2008: 10)

For the mother in my research, her baby had not been given to her but quickly whisked away by the midwives with no clear honest information passed directly to the mother. Yet it was visibly obvious to all who were present that it was more than a “few deformities”, and left to the husband to explain and describe the situation in which they as a couple found themselves, following the birth of their first child:

“...I remember him [husband] saying not so much at the time but since, he has said to me ... not wishing him to die but saying it would be better for him not to survive...” (Mother, family three - June 2006)

The impending birth of any child creates change for the couple and means that both parents have to adjust their relationship roles in order to assume the responsibility of caring for that child. The assumed feelings of happiness and joy that follow the birth of a healthy baby are dashed with the news that all is not right, and places the parents into a crisis situation. This mother spoke of what happened following the birth:

:

“...I didn’t see the baby for 24 hours because my husband could not stop crying and I was just so scared to go and see him and they brought me a picture up and he was huge 9lb 10oz so he’s there in the cot next to all these 2lb babies...”
(Mother, family three - June 2006)

Following the initial crisis and on seeing her baby for the first time the mother could only think of her baby:

“...I can remember sitting next to him crying, my poor baby and sitting there and I was post caesarean and I wasn’t able to move a lot so I was just stroking his hand...” (Mother, family three - June 2006)

However distressing the birth and the diagnosis, there comes a point when “you just have to get on with it” (Apert Syndrome mother). The baby is taken home and the new family begins to make what will be a lifetime of adjustments in their newly created “routines” that revolve around the medical and social needs of the new addition to their family. One mother reported that:

“...I was so desperate to get home and start to live my normal life - even though normal was not quite the same as normal, let’s be fair (both laughing) to a certain extent just sort of getting on and looking after my baby, it was just sort of hazy...” (Mother, family three - June 2006)

In summarising this section, it is useful to sum up the key points. Throughout the pregnancy the majority of parents assume that their baby will be healthy, and they have little or no experience of disabilities or complex medical needs. Within the labour and delivery ward parents have no control over what is happening, this is especially so when following the birth it becomes obvious that things are not as they should be. It seems that the parents are not clearly informed by the maternity staff about what is happening, with platitudes frequently used by staff to describe the situation. The baby appears to be quickly whisked away without a reasonable explanation, and it is often left to a shocked father to relay the “bad news” to the mother. The next step for the parents is to take the baby home and to begin what for many is a life time of adjustments, hospital admissions, surgery and drugs in the care of their child.

FROM HEALTHY TO COMPLEX MEDICAL NEEDS: DIAGNOSIS IN EARLY CHILDHOOD

When young children become sick it can be very difficult to distinguish between “a trivial problem such as a viral infection and a much more serious condition such as meningitis” (Ill Child Standard, NSF DOH 2004: 6). Likewise, not all disabilities and complex medical conditions are possible to diagnose at birth and in some instances the medical professionals delay the communication of a diagnosis to parents because of the lack of clinical evidence. In some cases of rare conditions not obvious at birth, it is often parents who are the first to realize that something is not quite right with their child. It may be that the child is not meeting the clinical, or parents’ developmental expectations, such as sitting-up unaided, or that they are disinterested in the environment around them. Such observations may instigate the parents to make an appointment with the family GP.

There are, however, a number of children that display non-specific symptoms that continue over a number of years to hide a serious condition. In the following example it was approximately three and half years that culminated with the child suffering a stroke that instigated serious clinical investigations that eventually led to a diagnosis of Arnold Chiari malformation with extensive syrinx, neuromuscular scoliosis convex to the right and previous left sided cerebral infarct. The mother reported that:

“...she was a weird child you couldn’t cuddle her, she would find it irritating, you couldn’t bath her, she was irritated, everything bugged her, life bugged her...”(mother, family four - January 2006)

A number of parents in my research noted that the first visit to the family doctor may result in further hospital tests that eventually lead to a confirmed diagnosis. For other parents the first visit may result in being dismissed as worrying too much and requires repeated visits to the GP before a referral is made to the hospital. For some parents even following a visit to the paediatric specialist, it may be a long and frustrating wait filled with uncertainty before a diagnosis can be discovered. During this period of uncertainty the many specialists that the families are in contact with may not always be prepared to inform the family honestly as to what they need to know to make decisions and plan for the future. This social worker suggested that:

“...I think they [doctors] are very reluctant to give parents a life limiting/life-threatening diagnosis and I think they will only do that when they are absolutely 100% certain, and my experience of doctors is varied, some of them have great skills in communicating the families’ very bad news but others can’t manage it for themselves...” (Social Worker - July 2007).

For one mother, even though her awareness was of a very serious situation, having been informed during pregnancy that the baby’s chance of survival would be slim, the mother’s perception was that no-one had given her clear information on what would happen if the baby survived, or how her life would change. It seems from the interview that the expectation of death by the medical specialists outweighed their expectation of life, as the mother suggested:

“...not even 24 hours old her first operation and she did really well and got out of that, then you see all the tubes, and never once did they tell me that she was very, very ill...” (Mother, family four - January 2006)

It is probable that the doctors had confirmed throughout the pregnancy that if the baby survived the birth there would have to be a major operation shortly after birth if the baby were to continue to survive. However, there was little or no discussion regarding major surgery as the medical expectation was that the baby would die. As it was a live birth at a local acute NHS trust, it may be assumed that there had to be an almost immediate decision to transfer the baby to a major London hospital with possibly the briefest of time for explanations to the parents. In this instance the father had left the hospital following the birth to care for an older daughter. The mother reported that she was informed that there was no room in the ambulance for her to travel with her baby daughter and was left to organize her own travel arrangements a matter of hours following the birth. She continued to report that:

“...after twelve hours of giving birth to Alice they said she had got to go to Specialist Hospital, but you can’t go in the ambulance there is no room, so not only was I deprived of my baby, no cuddles they take her away to the specialist hospital...” (Mother, family four - January 2006)

However, for the mothers who find themselves in circumstances where the baby is taken away with no time to say hello or goodbye, the birth trauma is magnified with the possible addition of guilt and self-blame at giving birth to a baby who may not be the healthy baby wished for. In addition, it is probable that the birth occurred at a local hospital where the obstetric and paediatric knowledge revolves around a reasonably straightforward birth and a healthy child. When this does not happen there can be further difficulties and delay in obtaining information as to what the problem may be. At times even when the baby has been born at a dedicated Children's Hospital a diagnosis can be difficult if the condition is very rare, as this mother suggested:

“...It was about 6 in the morning when he was born and someone came up, a paediatrician came up about 2 in the afternoon and said right we have found out what it is, and it's Apert Syndrome and he had printed off some bits from a medical thing which was all but it had a couple of pictures in it...” (Mother, family three - June 2006)

With the increasing number of rare syndromes, it is becoming more difficult for doctors at local level to have a complete awareness of these conditions. However, at these times it would be more useful for the parents if the information they receive is honest information instead of information that appears primarily to make medical staff feel better. In this instance, the reality was that the problem, as described by the doctor, could not be fixed. The mother continued to say:

“...he tried to tell us a little bit about it and said he (baby) would probably go straight from hospital (the local hospital) to the specialist hospital and do plastic surgery on him, and make him look normal...they would fix him basically, fix all the bits that weren't right that was the impression he gave us...” (Mother, family three - June 2006)

At this time the mother said that she was given the impression that the medical professionals felt that the delivery and birth of her child with Aperts had, in fact, been as traumatic for them as it had been for her. It appears that there had been little thought from the medical team regarding the impact on the parents and the long-term consequences of the child's health on family life, as the mother reported:

“...I think I have said before, one of the doctors came to me a couple of days later and sat down on my bed and (making a big sighing noise...) it was a big shock for all of us. In a slightly different world I think...” Mother, family three - June 2006)

Whilst there are numerous examples of negative experiences with medical staff's thoughtless comments, there are also examples of when a positive relationship can become empowering, and help to begin the process of re-building parents' confidence and an ability to face the prospect of continuing medical care. One mother mentioned the value of a consultant's belief in her ability to be a successful parent of a 'challenging' baby:

“...the consultant, I was really impressed with her, she was quite empowering. I felt she trusted us with our own baby, you know it sounds silly to say trust you with your own baby but she had confidence in us...” (Mother, family three - June 2006)

Unlike the majority of 'new' parents, instead of returning home with a healthy baby to the adoration of family and friends, the parents of ill children have to accept that the birth of their child may alienate some family and friends who are unable to cope with the situation, as this mother suggested:

“...I don't think they could cope with it, it's a shame for Lewis because one of them was his best man at our wedding and we just have not heard from him.... sort of a couple of times since he was born, he came to see us and we never saw him again...” (Mother, family three - June 2006)

In addition, parents now find themselves thrown into a culture of medical treatment including hospitalization, operations, drugs and the acquisition of specialised technical language. They also come to realise that they are now being encouraged to identify themselves as members of a culture of childhood disabilities and complex medical needs.

In summarising this section, it is useful to sum up the key points. Following the shock of the birth and the sudden separation of baby and parent the information and the way it is

communicated can be confusing. This is especially so when the information comes on top of medical warnings given during the pregnancy regarding the baby's survival, and the inevitability of surgery should the baby survive. There is further confusion when the condition is extremely rare and hospital staff lack the experience to recognise or identify it. The lack of expertise and knowledge of medical staff increases the distress when the information that is given to parents appears to understate the severity of the problem and incorrectly implies that it can be fixed with a little surgery. Conversely, the shocked reaction of staff to a visible disability at the time of the birth increases parents' distress, especially when this information is given with little acknowledgement that they will have the experience for a life time. However, positive support from paediatric neo-natal specialists can help make a very difficult situation easier for the parents to begin to trust themselves in the care of their baby. Not all complex medical conditions are possible to diagnose at birth and it may be weeks, months or even years following birth before a condition is confirmed. The further difficulty for parents is gaining a clear diagnosis when the baby's symptoms are non-specific and it takes many visits to the family GP before a referral is made to a paediatric specialist. Communication between the medical professionals and the family on occasions appears to lack sensitivity and caring.

THE BEGINNING OF THE UP-HILL STRUGGLE: HOSPITALISATION OF THE ILL BABY AND MOTHER

The previous chapter presented data that illustrated how mothers of children hospitalized during their cancer treatment experienced isolation and loss of control over their own and their children's lives. This experience is similar for mothers whose babies are born with acute medical complications, especially when their babies are transferred to specialized units for intensive medical care. In her book *When the Bough Breaks*, Julia Hollander writes of how she felt the neonatal consultant had taken ownership of her daughter following her birth:

“...And as far as she was concerned, Imogene was *her* baby. ‘My babies’ she kept on saying as she ushered us into the ‘family room’ with its bamboo furniture and pastel prints. ‘My babies are carefully monitored’ My babies need time...’
(Hollander 2008: 23)

As with the cancer treatment, parents' dependency on medical expertise forces them to sacrifice 'normal' family relationships with their child in exchange for the promise of the child's survival. The added complication with new-born babies is that this occurs before any physical relationship between mother and baby (much less father and baby) can be established. In my own data, the issue of 'giving up' the baby to the greater expertise of medical specialists is evident:

"...because when I go up to Children's Specialist Hospital, Alice is not my property, I know that sounds really awful to say property, but it's true, once you are there you've got to ask permission to go out, you have lost all control, all power and they say yea or nay..." (Mother, family four - January 2006)

It appears from the interviews that parents not only sense that they are powerless within the hospital setting but are also made to feel as though they are of low intelligence by medical staff when dealing with the complications of their child's illness, and that they, as professionals know best. This mother suggested:

"...but you say something and they are all on your case, they make innuendoes like you're thick..." (Mother, family four - January 2006)

"...Locally not brilliant, walk into A&E and say, '...you know my child? I think my child's shunt is blocked'. And because they know shunts they then think they know about shunts in an Aperts child and it's a completely different story and they kinda like dismiss you ..." (Mother, family three - June 2006)

In addition to feelings of inadequacy picked up from medical staff's comments, the parents interviewed suggested that they are also powerless to argue their point of view and have no choice but to put up with the attitudes they encounter whilst they are staying at the hospital during their child's prolonged treatment. They are in fact reduced to being compliant but not through choice, as reported by this mother:

"...we (parents) are frightened of jeopardizing our children's care so we don't, we put up with dirty hospitals, we put up with doctors and their attitude, and we put up with being second class citizens..." (Mother, family four - October 2006)

This reluctant acceptance appears to continue whenever there is contact with health professionals, but only for so long. As parents' knowledge of the condition grows, so does their confidence to assert themselves and trust more and more in their own expertise in their child's condition to make, agree or disagree with decisions regarding the way forward in the health care of their child. One mother suggested that:

“...he [the Consultant] said he has ways to make me change my mind ... that he hoped we could work as a family and hopes he knows me enough to be able to sway me to go... yeah, but I am not stupid... it's an operation on the spinal cord...I've got all the data on it saying it's only a short term measure but he said it's a long term measure...” (Mother, family four - October 2006)

In summarising this section, it is useful to sum up the key points. Not only do the parents feel that they lose control but feel in some instances that the medical professionals take ownership of their child and they, as parents, become subordinate to the professional. They become powerless within the hospital setting and the attitude of the staff towards them reinforces their sense of inadequacy. There is also a perception by parents that if they challenge the authority of the medical professional or go against a suggestion made by them regarding treatment, they are jeopardizing their children's care and their future. Parents' experience of treatment for rare conditions in local NHS Trusts is not good, with a clear view that expertise exists only in specialist hospitals. Nevertheless, health professionals at the local A&E appear unreasonably sure of their ability to treat the child simply because they work within paediatrics. Parents' own knowledge of their child and the condition is frequently dismissed. However, the treatment received at the major teaching hospital for the majority of parents in my sample, was considered to be of a good standard.

THE LONG CLIMB UP THE HILL: LIFE WITH AN ONGOING DIAGNOSIS

The majority of parents continue to follow an up-hill trajectory in which they endure countless hospital appointments and, for many, continuing major surgery. Throughout this time parents' close knowledge of their child and recognition when all is not well, develops an expertise in their child's condition and treatment outcomes. Most importantly, they come to realise that whatever the treatment or surgery undertaken, it

will never produce a “cure”. However, they do monitor carefully how the treatment outcomes might contribute to prolonging the child’s life, or to making it a little easier for the child to live in a society where any form of abnormality is unacceptable. One mother stated that:

“...at 4 months he had his adenoids out and then at 5 months he had the re-modelling of his skull, which they peel back the face take it all apart and put it back together again in a different shape, he’s had his fingers separated, adenoids and tonsils, re-modelling and most others [operations] are on shunt replacements...” (Mother, family three - June 2006)

All the families interviewed recounted numerous operations since the child’s birth either to fix physical malfunctions or to reconstruct physical appearance in order that their children might have a chance of experiencing some sort of a ‘normal’ life. In some instances there were regular smaller operations for blocked cerebral shunts, and for the majority of families, these operations have continued – and will continue – over many years:

“...he will have to have head surgery ‘cause the bones still grow back into their odd shape once they have been moved, because that is whatever the map says.... so he will have that, they try and leave it until they are about 17 and they still cover them at Specialist Hospital, and then they have a frame on and stuff...” (Mother, family three - June 2006)

On occasions the people who surround the family, whether health professionals, extended family or friends, unintentionally fall into the trap of confirming how well the parents are managing their new role, in a way that they and others could not. Whilst being very positive, and empowering to hear, significantly, for the parent this removes the choice of having days when they understandably feel they are not coping and the stress and strain begins to take effect, as Julia Hollander reported:

“Not even two months into my second child’s life, the pressures of caring for her were starting to get on top of me. The relentless broken nights made me grumpy

and impatient, the constant screaming meant I was permanently on edge...”
(Hollander 2008: 65).

Having to continually live up to these expectations of coping reduces parents’ opportunity on bad days to say to someone “I can’t do this anymore”, “I’ve had enough”, “why me?”. This leads to a perception, possibly created by statements shortly following the birth such as, ‘you will have to be strong, or, you will get through this’, that if they allow their feelings to be made public, it shows a weakness in their ability to cope with their situation and the care of their children. This creates a situation noted a number of times in this research and in my own professional experience where a mother feels she has to become a “super mother”:

“...my health visitor was wonderful, special needs health visitor, although there is one criticism I have of her, she built us up so every time we were these wonderful parents which was really nice in a way, but it was really a lot to live up to, so she was really lovely and gushy but some times it was a bit overwhelming, it was a bit too much, sort of I had to live up to this, I could never show any signs of weakness in front of her. There were times when she probably would have been the ideal person for me to have a sit down and a cry with or moan...” (Mother, family three - June 2006)

This mother had a relatively positive relationship with her health visitor and she clearly indicates the additional benefits that could have been brought to the relationship. This is, however, dependant on how the health professional copes personally with the child’s disability or complex medical needs, the family’s situation, and, importantly the relationship between the parent(s) and the professionals, especially when a family is either one that is defined as dysfunctional or one that questions medical decisions. This Chief Executive suggested that:

“...the medical staff surely can’t cope; they like the white middle class, the squeaky clean type family. I don’t think they give them preferential treatment necessarily, but you can hear when you go to meetings the way that they are talking about families they don’t like, how critical they are...” (CEO Voluntary Project for children and families - February 2007)

In some instances, the mother's perception of being part of the health and social care system can be anything but positive and at times the perception is either 'you are making it all up', or that 'you cannot cope and may be a threat to your children', as she continued to say:

"...you feel like Munchausen's by Proxy, because I have two ill children, right? I feel people are looking at me and thinking she can't manage because its so rare to have two ill children with two different.... you know you feel like they think you would smoother them..." (Mother, family four - October 2006)

The above statement made by this mother was not clear as to who she was referring to, so, in order to clarify, I asked if the mother's feeling had been created by people she had met who have had no personal experience of a disabled or seriously ill child, but before I could finish the question there was an emphatic answer:

"...(agitated) no no no! It's the professional's it's the professionals who have made me feel like this..." (Mother, family four - October 2006)

The mother continued to give other examples particularly of insensitivity from social workers who are usually assigned to families to support them with forms such as DLA, equipment and education and most of the practical issues that should make life a little easier for the family. Unfortunately, it appears that there is a rapid turn around of social workers giving very little continuity to the families and little acknowledgement that the main carer (usually the mother) of the ill child is not necessarily typical of families that they may be used to visiting within their experience of a 'typical case load'. This mother pointed out that:

"...she is very sweet but she's just left school and she's asking me if I am aware of danger around my children... I looked at her and said 'Obviously I cook with my children..'.... but [pause], Pam, I could have killed Alice with the drugs I have to administer. But for them it's all text book, it's all come out of a text book. 'But we must ask these questions'..... Right go, 'Well I won't ask her that question

because she looks pretty clued up, let's not insult the woman', but they don't..... I find it so insulting..." (Mother, family four - October 2006)

Mothers or the main carers find themselves in a number of demanding roles, and the role that revolves around the medical care of their child requires considerable skill, confidence and nursing ability. It may include enteral feeding, administering drugs, injections, and judging the status of their child's condition. However valid this mother's feelings were, it is important to point out that although her children have very serious and complex medical conditions, these are, in the main, internal and generally invisible. Her daughters look for most of the time, healthy and well. For the many professionals who have contact with a family such as this, it is on occasions difficult to see beyond the surface and therefore it is all too easy to respond in a way that would be described as 'normal'. This reflects the barrier that professionals can impose upon themselves due to their own personal inability to cope with situations that some families find themselves living in on a daily basis:

..."the biggest thing I hate about all this when you've got children...[is that] there are other agencies and..... especially with special needs.... you have got all these people involved who are doing nothing really... they do their penny worth and then leave. No one is tying up the strings and making me bows, and yet they are all everywhere.... all these untied laces.... and they are getting on your nerves and they are going to be dumped ...there are families out there who have been dumped on the slag heap because of their bloody lack of tying up bows..." (Mother, family four - October 2006)

It is useful to sum up the key points. For many of these parents, surgery, hospital appointments, and drugs become part of everyday life, with the family increasingly aware that whatever treatment or surgery is undertaken, there will be no cure, and that all medical procedures are about the management of the condition. As time goes by, family, friends and health professionals adapt to the disability and/or condition and may on occasions praise the parents for being wonderful and thereby unknowingly discourage expression of the desperation and inadequacy they sometimes feel. However, parents often feel there is no understanding of the stress they are under and have little choice but to continue with the care of their child, usually presenting a positive and coping persona

on a daily basis. This places the primary carer in a position where they feel they have to live up to an image that is hard to maintain, and reduces the opportunity of seeking support, especially from the health professionals and social workers who should recognize that on occasions, cracks may appear in the carers' coping mechanisms. From the accounts of some mothers in this study, it appears that their experience of the health and social care system is depressingly negative. It is also, at times, perceived as threatening in as much as professionals are often only around for a short period of time before leaving them once again to fight alone. It seems that a further problem occurs when numerous agencies are involved but still nothing appears to get done for the families as these agencies either fail to talk to each other, or do not complete the work for which each is responsible.

OUTSIDE THE SECURITY OF HOME

For those parents where the child has a visible disability such as facial disfigurement, life can be made more difficult by the societal attitudes of the general public who perhaps find it difficult not to stare, and at times have great difficulty in not showing how shocked they are, as these two mothers described:

“...in the beginning when I went out with her everyone was staring, so it got to the point where I did not go out with her...” (Mother, family six - August 2006)

“...yes if I am out with him it is.... with some people its consistent, completely consistent... well you have to walk around with blinkers on... you just have to not notice it.... you have to make yourself not notice it. Some days you notice more than others...I was saying to a friend the other day I didn't want to go to a particular park because it was further away..... it wasn't in my sort of little safety zone where..... in my local park... where one or two people have seen him before...” (Mother, family three - June 2006)

These feelings of embarrassment and self-consciousness can be overwhelming with parents reporting that they feel everyone is looking at them and talking about their child's physical deformity. Noting in my field work diary following a home visit [July 2005] a father, although not taking part in the research had reported that when out with his severely disabled daughter who is confined to a wheelchair, when realizing that people

are staring, says that he will make a point of saying, “her name is Vickie please say hello”, but it has taken many years of frustration for him to make his point. One mother reported that she felt it was harder for her husband to cope with other people’s reactions when he was out with his son:

“...so when you go out to different places it can be harder, but if I go out with Lewis I notice it a lot more because I am a lot more used to being out with him and my blinkers are bigger than his. He is a lot more sensitive to it than I am and notices it more...” (Mother, family three - June 2006)

Additional problems occur as the child gets older, linked to their growing size, behaviour, and how, regardless of the child’s chronological age, the mother has to be as vigilant as with a toddler. It is at these times that the loss of what would be considered a ‘normal’ child becomes ever more evident especially when in the park:

“...What I find hard day-to-day as he is getting older, behaviourally, if I am out with him and he doesn’t want to do something or he wonders off or he runs offsay we are in the park.... I have to be with him like a 2 year old... I have to be with him. Whereas by now I should be able to sit on a blanket...” (Mother, family three - June 2006)

“...if we go into a shop or something he will wonder off, run off, or he will pick things up and if you try and pick him up his arms go up [showing me] and because he is eight, its not like doing it with a three year old, although he is not very big or heavy he is still bigger and I am not that big [about 5’ 1”] so trying to control him when we are out...” (Mother, family three - June 2006)

As the children with additional learning difficulties grow older they increasingly have fixed ideas about what they will or will not do. This is particularly so on days out, and although for others hearing a report of a day’s events may sound very funny, for the mother it can be frustrating as she has no control of the situation:

“...we went to a Farm Park in the holiday but Steven wanted to be in the pig shed so I spent the whole day in the pig shed... [I ask why the pig shed]...he just loves

pigs... thought they were great... so I had to sit there for the day. It was really stinky as well. There are loads of things he feels strongly about, he really wanted to be with the pigs and thought they were fascinating..." (Mother, family three - June 2006)

Although some parents find it difficult at times to be out of their 'safe' zone, a number of the families find themselves completely restricted in where they can go and what they can do. This is because the ill child cannot be separated from the equipment and drugs that have to be taken, as this mother reported:

"...everyone else takes a picnic basket we take a basket of drugs, its like when we go to friends, we cannot stay late or stay over because of everything we have to take with us and everything that needs to be done. There are over 15 drugs during the day - that's not counting night time drugs, machine feeds, colostomy to be changed, and catheter and that's only the beginning..." (Mother, family five - September 2006)

The families have a continual struggle in the attempt to be 'normal' and do 'normal' activities that most other families do not even have to think about apart from where to go and which transport they will use. As one mother reported:

"... [big sigh] if only life was that easy..." (Mother, family four - October 2006)

It is useful to sum up the key points. The small geographical area around home provides a comfort zone for many of the parents, especially when their child has a very visible disability. To leave this comfort area creates additional pressure and frustration as people continue to stare more out of curiosity than rudeness. At times this may become a greater difficulty for the father as he is less used to being with the child in the outside world, and is, therefore, less used to the public response. As the child grows older the condition and/or disability does not get any easier, but in fact becomes more difficult, as the parents are not only dealing with the growing size of their child but, developmentally, the child may be far less advanced than the chronological age and hence acts accordingly. However, despite the developmental delay the child often feels very strongly about certain activities or whatever they feel drawn to, which again can create a problem for the

parent who feels caught between the child's demands and the expectations of 'normal' social settings. A number of families are restricted by the drugs and care the child requires throughout the day, often making a day out or visit to friends difficult, and at times, almost impossible.

CONCLUSION

From the early weeks of pregnancy parents can be informed that their baby has a disability and/or rare life-shortening condition. This places parents in the unenviable position of having to choose whether to continue with the pregnancy or to abort. Alternatively, parents discover at, or very soon after the birth, that something is wrong with their baby. In both instances parents report that health professionals rarely communicate this information in a sensitive way, failing often to consider the feelings of parents or to offer appropriate emotional support. Grief for the loss of the anticipated 'normal' baby appears not to be acknowledged, whilst the stress on the paediatric team may be all too obvious. Eventually the parents take their baby home to begin a family life for which they have little preparation. For some of these parents, this family life begins in a paediatric intensive care unit following surgery or for specialised treatment. Whatever the treatment, the parents are aware that, at best, their child's problems will only be ameliorated and their child will never be cured. Gradually parents become experts in their child's condition and are aware that whatever the treatment, it is geared towards improving the quality and length of the life of the child. The family realise that they are on an up-hill journey that includes the medical management of the illness at home with periods of hospitalisation that will continue for the life-time of their child.

CHAPTER, 6

THE IMPACT ON SIBLINGS' CHILDHOOD EXPERIENCES: ROLLER COASTER PASSENGERS AND UP-HILL STRUGGLERS.

The aim of this chapter is to present the different challenges faced by well children living with siblings diagnosed with a life-threatening illness such as childhood cancer, or a life-shortening illness and/or complex medical condition. The chapter draws on accounts from mothers and well siblings and outlines the ways in which the diagnosis affects the life and emotional wellbeing of well sibling(s) in the family. The metaphors used in the previous two chapters of 'A Roller Coaster Ride' and 'Sisyphus and the Uphill Struggle' continue to be used to describe the well siblings' journeys with the illness and includes their experience of loss, identity, isolation, and hope.

In this chapter I consider one mother's account of her perceptions of the difficulties that a well sibling had to face through his absence from the family home - and the unsupportive attitude of his school - following his sister's diagnosis of leukaemia. Also I present another mother's account of how a younger brother reacted to the news that his sibling, with whom there was already a strained relationship, had been diagnosed with cancer. This mother describes the difficulties that were faced by the well sibling throughout the original illness, two relapses, and finally as a donor for his brother's bone-marrow transplantation. It was during the sibling's late teens that his brother eventually died from a brain tumour possibly connected to his original treatment.

I then go on to explore how, following the death of a child, the family's narrative is badly disrupted. I examine one particular case in which, subsequent to the death, another child was born into the family. At one level, this was seen as a joyous occasion, and the birth was considered by family and friends as a distraction from the family's grief, and a contribution to making things 'better' for the family. However, as a child born after the death of her brother, the informant in this section looks back from adulthood at how her birth appeared to affect family relationships and how, in later years, although she never knew her brother, she has taken on the responsibility of keeping his memory alive.

In the next section, I move on to examine the account of an adult sibling who is the oldest of three, two of whom have complex medical needs. This well sibling discusses how during the past 25 years he has taken responsibility for everyone in the family, and

because of his ill siblings he became a high achiever and strived to be the 'best' at everything. He also gives his views on the joy that his sister and brother bring, his fear for his sibling's future and the changes he knows he will have to make with regards to his own life and aspirations.

THE FAMILY WITH WELL AND ILL SIBLINGS: FELLOW PASSENGERS ON THE CANCER ROLLER-COASTER

It has been reported in much of the published research that siblings are overlooked by parents, and it is well documented that when a child within a family has been diagnosed with a life-threatening illness such as leukaemia, the well siblings often receive less attention from parents (Sidhu and Passmore, 2005). The parents become absorbed by the ill child's treatment, hospitalization and their future. Even though most parents reported that they strive to treat the ill child as 'normal', the relationship with the well sibling inevitably appears to change. However, any disproportionate attention given to the ill child is likely to place increased stress onto the well sibling, increasing their risk of developing emotional difficulties. Not only will a child's illness disrupt family life as it used to be, it threatens parental assumption that they can keep all family members safe and well. In the case of serious illness, the well sibling will probably be the family member who spends the longest time living with disease related memories and concerns (Spinetta, 1981). An illness in a sibling will shift the focus of family comfort and concern and help to create an imbalance within the family unit (Parsons and Fox, 1968). The illness, even for a short period of time, helps to intensify sibling rivalries and could reduce the positive aspect of the sibling relationship.

DIFFICULTIES OUTSIDE HOME FOR WELL SIBLINGS

Treatment for childhood cancer can range from a few months to several years depending on the intensity of treatment and the extent of the disease. The impact of a confirmed diagnosis on the family system is significant, with family life irrevocably changed. Amongst these changes are the loss of certain 'normally' predictable aspects of family life such as routines, meal times, chores, and birthdays. With a sudden shift in parental and marital roles affecting all family members, parents have limited time and energy to meet everyone's needs other than the ill child's. For the well sibling this frequently leads to significant anxiety regarding the future and in certain instances concerns the well sibling's own health. One mother spoke of the difficulties of not being at home:

“...I wasn’t at home - so my sudden absence from home was difficult especially on Sam who was ten and a half at the time and carrying on at primary school...”
(Mother, family two - June 2005)

This mother began to describe the difficulties her son had experienced at school following his sister’s diagnosis and her own absence from home. These included struggles with his peer group, and instead of the parental expectation of him being supported by the school the opposite had occurred, creating additional stress on the family that continued throughout his time at the Primary unit. She continued to say:

“...last year at Primary school was not a good time for him and we were in countless times, not me to start with, because I was away from it all. But my husband and my parents had to go into the school to talk to his teacher about what had gone on the day before with other kids in his class. And the Head Teacher actually said in the end, ‘I think Sam is.... it’s just his sensitivity...’, as if that’s the answer, you know he’s being over sensitive. Well sorry but his sister has just been, she’s in hospital plus mum’s away as well, and people just have no idea, even though you.... sit down... and obviously we had kept the school informed of Annie’s illness...but I will never forget him saying that its just his sensitivity...”
(Mother, family two - June 2005)

From the previous findings of parents’ accounts of the initial diagnosis it seems that in the immediacy and shock of a diagnosis, along with all the information received in a short space of time, it is difficult for parents to have a clear understanding of what leukaemia and the treatment for the disease actually entails. Although it is imperative that siblings receive clear information from parents, it is understandable that parents may leave gaps in the information they pass on to the well siblings. This may largely be due to the parents own limited understanding probably based on a single conversation with a consultant that is usually medically factual, but often incomplete. The distress, confusion and lack of time for a clear explanation of what the well siblings are being told, can create very different interpretations in the siblings’ minds about what the treatment of leukaemia actually means. This mother reported how her son’s impression from what he had been told was that everything was going to happen at once:

“...well he came out of school. Mum had him straight away. We were in Specialist Hospital on the Wednesday for the diagnosis and mum remembers him running out of school to her at the gates saying, What does she look like, is she all white, what does she look like?’ because he thought straight away she would be bald...so his whole concept at 10 was that she was going to die...” (Mother, family two – June 2005)

A REPLACEMENT HOME

At the same time, the well sibling may have to be temporarily sent to stay with grandparents or other relatives simply because mother is not there to look after him or her. Some siblings might interpret this ‘removal’ as a further rejection of parental affection and attention, even though the parent may not have any choice:

“...Sam had to stay at my parent’s house because Sean had to carry on working at the time...” (Mother, family two - June 2005)

Whilst the parent may have difficulty and question themselves at leaving the siblings to be cared for by someone else, for a short time at least the well sibling may enjoy the experience of being the focus of attention which from the time of the diagnosis has usually been placed on and around the ill child. This mother’s perception as she continued her interview was that staying at his grandparent’s house was an experience her son was not used to, but enjoyed:

“...and he goes home to nanny, which he actually did thinking it was fantastic - staying at nannies and granddads was like staying at a hotel. You know he gets up in a morning and his cereal bowl is full. I say it’s in the cupboard help yourself love, but nanny waited on him so staying wasn’t an issue, it was normality changing for him as well, which was difficult...” (Mother, family two - June 2005)

For this well sibling amidst all the changes at home it also seems, from the mother’s account, that the hospital staff did not take any notice of him either:

“...the tertiary hospital gave him a book and it was spot on, but apart from that nobody spoke to him, he came to visit her in the shared care, but it was, ‘Is this your brother?’ - and brother goes home to nanny...” (Mother, family two - June 2005)

FUTURE CONSEQUENCES FOR THE WELL SIBLING

I asked the same mother “Do you think there has been - or will there be - an effect on him from his sister’s illness?” In response the mother stated that:

“...I don’t know if it’s all to do with that but he has issues and I just put it down to his disposition because he is so easy going and tolerates an awful lot and he is a red-head so he has had all the jibbing in the world to the point where he will then blow, so whether its something to do with it I don’t know, or whether he has just learnt to be tolerant...” (Mother, family two - June 2005)

This mother continued to say that she now believes that when brother and sister are ‘having a go at each other’ she has contributed to the ‘problem’ because of her concern for her daughter. Nevertheless, her response also shows her frustration at not being able to elicit a more sympathetic response from her son:

“...he can wind people up, and he winds his sister up no end, and when they are indoors sometimes they have a bit of a go and now I have started to shut the door on it, where as before I would say, ‘what’s going on’ and you feel like saying she is here with us, all that we have been through! Don’t you think we should be nice to each other? ...but that’s not life is it...?” (Mother, family two - June 2005)

In summarising this section it is useful to note the key points. As soon as a diagnosis of childhood cancer is confirmed hospitalization occurs almost immediately and for a number of well siblings this will be their first experience of separation from the rest of the family. Having little choice the well sibling may be transferred to a replacement home, and even when this ‘new’ home is a grandparent’s - and for a while may even feel like a holiday - it is not home. It is not long before the well sibling realizes that the outside world does not change because your sibling is in hospital. School, which could be a source of valuable support at this time, may also appear unsympathetic to the well

sibling, and although parents' may do their best to provide information to the school, this may not always work out as hoped. No matter how much discussion occurs with the staff, the well sibling's peer group may react in a way that creates more distress than support.

HIGH PARENTAL EXPECTATIONS OF A WELL SIBLING: RESPONSE TO A DIAGNOSIS

For many well siblings, their priorities and behaviour may not quite meet their own parents' expectations of how they should have responded on hearing the news that their sibling is seriously ill. As well sibling witness the distress and crying of others in the family, they could assume that as everyone else is upset, that it is the best thing for them to do. However, at certain points in a young child's life, to be told that your sibling is very ill is not quite as important as going out to play. Although the well sibling may not be aware of it, this news may for the foreseeable future dictate how the illness will occupy parental attention and concern. One mother spoke of how the well sibling reacted to the news:

[Richard's first diagnosis] ...Matt then 8 was crying because he thought it was the best thing to do, and said well I don't want this [spaghetti bolognese] because I want to play with my friends and I've been called in and it's a lovely sunny day ...” (Mother, family one - June 2005)

From the interviews and my observations it appears that the possibility of relapse following treatment and remission is a hidden fear and a constant shadow that follows parents in their daily lives. This is particularly so for mothers as they usually have the major contact with the nurse specialist, checking blood counts, attending out-patient appointments with the consultants, and are, therefore, usually the first to hear “something is not right”. Throughout the treatment, even though a possibility in the first year, relapse remains the parents' greatest fear.

IMPLICATIONS OF RELAPSE ON SIBLINGS

Following treatment for cancer and discharge of the child from hospital, family routines adapt to the return of child and the presence of the mother. If relapse occurs, these routines established in the early months are shattered, and the family is back at the beginning. One mother spoke of how she was given this information:

“...he had relapsed again on treatment and they took me on one side and said we do not have a child in this hospital that has survived a relapse on treatment so things are now very urgent...” (Mother, family one - June 2005)

On these occasions the well sibling has a greater awareness of what this actually means, and in this instant the well sibling had been away for a week on the Isle of Wight trip with school and on his return home was informed of his brother’s relapse, and according to the mother’s report, his reaction was not particularly sympathetic:

“(Richard’s 1st relapse)”...and he [Matt] got off the coach with me saying I am sorry but I have some bad news for you - your brother is poorly again and back in hospital, and it was oh no, and he threw a bit of a tantrum and it was oh we have got to go through all that again...so we went straight up to the hospital” (Mother, family one - June 2005)

In this situation a bone-marrow transplant may be the only remaining hope of survival but with life-long consequences for siblings. These consequences include the distress for the donor and parents following bone marrow transplantation, especially when it is the only hope for the ill-child’s survival. When this course of action is recommended, family members are the first potential donors to be identified and each is requested to have a blood test to check for a positive match. As siblings usually have the closest match and a higher success rate, there is an expectation from the medical team that siblings will willingly go through the procedure. If the match is positive the well sibling will be encouraged to become the donor. But this is not always an easy and straightforward decision to be made, as this mother reported:

“...I had got this child who could die and this child who could give his bone marrow but we could not get the blood for a match...” (Mother, family one - June 2005)

THE WELL SIBLING’S ENTRY INTO THE MEDICAL WORLD

The donor is usually given a clear explanation of why the transplant is necessary, what the procedure will entail, and how this will possibly help to save the recipient’s life.

There are times, however, when other people's expectations are too high and old sibling conflicts come to the fore, as this mother described:

“...it took one and half hours to get blood out of Matt to get a match, he screamed the place down, they tried every trick in the book...they were saying you want to help your brother and he was saying no I don't, I hate him, and you're not having my hand.... Well you will be able to help..... I don't want to help anybody. Oh dear me he screamed and he was rude, and he kept saying you're fat and you're horrible...it was so embarrassing” (Mother, family one - June 2005)

Whilst there is no straightforward answer to why at times there is sibling conflict, differential treatment by parents has been shown to be a major contributor (Daniels et al, 1986; Dunn and Stocker, 1989). In Matt's family his mum had reported that there had always been a closer relationship between the older brother and Matt's father. Even before Richard became ill, he was the father's preferred child, whereas Matt was the outgoing mischievous one, who according to the mum, in his father's view could never do anything right. As the years have passed by, Matt more and more proved his father right by leaving school without qualifications and by dropping out of college. Even now, with Matt settled in employment, he still cannot please his father. Yet according to the mother, dad in his youth was more like Matt, but he and Richard had been very close from the moment Richard was born. The mother explained that:

“...Matt and I were very much on the outside...and we were not allowed to join that exclusive club...and there would always have been dad and Richard... and then Matt...” (Mother, family one - June 2005)

From a medical and family perspective the urgency was that the bone marrow transplant happened quickly. Eventually a blood test was taken and the family received the results, and although there appeared to be satisfaction from the medical team at the match, Matt's reluctance to co-operate stands out as a major feature of this stressful time. As the mother reported, they maybe had a match, but the donor is only remembered in an unfavourable way:

“...the doctor came back and said, ‘Richard you know that brat of a brother, that pain in the butt brother, that awful snotty nosed brother you’ve got? He is a 6 on 6 perfect match...’ (Mother, family one - June 2005)

Although generally there seems to be a consensus by health and social professionals that parents pay little attention to the well siblings in an illness situation, this may not be the case with a bone-marrow transplant, and a positive result can cause very mixed emotions in the parents, as this mum reported:

“...he is a 6 on 6 perfect match and I sat there and thought, oh my gosh he’s got to have an operation and he’s not even ill... and there was relief that there was a match but, oh my poor Matt, and I sat there and cried...” (Mother, family one - June 2005)

Even though the sibling was a ‘perfect’ match, and viewed by others as the life saver for his brother, the mother’s impression was that Matt was not actually acknowledged by the medical professionals as being important enough even to be referred to by name. She described a visit to the ward:

“...taken round the ward and the nurse said oh this is Richard and he’s coming onto the ward soon for a transplant and this is his mum and this is so and so and this is the donor, I said excuse me the donor has a name and I thought I wasn’t very happy about that...” (Mother, family one - June 2005)

WHEN CHOICE BECOMES NO CHOICE

It seems that whilst the parents experienced conflicting feelings about giving permission for the procedure to take place knowing that Matt was still reluctant to take part in the procedure, the bone-marrow transplantation went ahead anyway. The mother described how difficult it was:

“...with Matt saying I have changed my mind, please do not make me do this...”
(Mother, family one - June 2005)

Additional stress is placed on the family by the very nature of the transplant. The donor can be hospitalised for up to two months, with restrictions after discharge on who can visit because of the poor immune system. For the parent, the watching and waiting that they experienced during the early years of the illness is intensified. For this family, following a successful bone marrow transplantation, family life relaxed for the next four to five years into some form of normality with the recipient attending University. Unfortunately, at the age of twenty a brain tumour was diagnosed and the family were again in the situation of hospitalization, operation, and intensive treatment. For the parents there was the added stress of not being included in hospital consultation's as their son was now an adult. For Matt, the donor sibling, he again found himself isolated from the family with the old feelings of anger and resentment returning. During the last few months of Richard's life the parents organized a holiday for their dying son and Matt through the Youth Cancer Trust. On their return the mother's impression was that the two siblings had at last become closer than they had ever been:

“...and then in the March he had a week with Matt (holiday-Youth Cancer Trust) and that was really good because they talked and I don't know what was said but there was a real bonding that was good...” (Mother, family one - June 2005)

Following the death of the older sibling it can be assumed that no-one will ever know just how close these two siblings were at the end of the holiday, but throughout their lives Richard and Matt had not had a close relationship. However, the mother confirms that the gap between the well and ill sibling had existed prior to the illness, with the father and ill sibling having an 'exclusive' relationship. Therefore, the illness in this instance had not created the rift between brothers as it had always been there. The mother continued to say that the father's relationship with the surviving son had not grown any closer over the years since the eldest son's death:

“...there would always have been Mark and Richard and then Matt, and now Martin will say I just don't understand that boy I try and understand him but he is so alien to me...” (Mother, family one - June 2005)

SUMMARY

In summary, the key points can be listed. There are times when playing with friends seems far more important than hearing that one's sibling has been diagnosed with cancer. Following treatment, if a relapse occurs, there is an expectation by medical staff and parents that the well sibling will happily consent to a blood test in order to donate his bone-marrow. However, it cannot be assumed that a sibling will willingly go through with the procedure and this places parents in the dilemma of having to balance the distress and threat to the health of a well child against the certain death of the ill child. Although the transplant was successful in the case-study described in this chapter, and for some years family life resumed with some sort of order, this does not guarantee the survival of the ill child, especially over the longer term. Family alliances and their hidden implications were made explicit in this case, and it is possible to recognise that in many similar cases, sibling rivalry and resentment can lead to significant fragmentation of the whole family. Normal jealousy and resentment, often managed successfully in healthy families, may be amplified by the extended absence and return of ill-child and mother. The pressure on well siblings to provide a bone-marrow donation following a relapse may represent 'the last straw'.

SIBLING DEATH FOLLOWED BY A BIRTH: A RETROSPECTIVE VIEW OF THE IMPACT ON FAMILY AND SIBLING LIFE

Sibling bonds develop because of the interaction between siblings, and according to Bank and Kahn (1982), play a crucial role in identity development and in helping to understand the world around them. When a sibling dies, the effects on a surviving sibling can have life-long effects on survivor identity especially if there was a close relationship between the siblings. After a period of time following the death, many parents make the decision to have another child. Whether or not this decision is taken consciously to 'fill the gap' which the deceased child has left, the subsequent child rarely fails to become aware of their deceased sibling. Although limited, studies have investigated the experiences of children born after the death of a brother or sister (Cain et al, 1964; Legg and Sherick, 1976; Grout and Romanoff, 2000). Amongst their findings is the possibility that the 'replacement child' may be expected to live up to an idealized image of the dead sibling, and that they may be willing to attempt this role to ease parental grief. They may, however, be doomed to an impossible task (Cicirelli 1995). The following case example

describes the experiences of one such sister, Molly, born a number of years after the death of her brother from cancer.

A SIBLING'S PERCEPTION OF BEING A REPLACEMENT CHILD

Born following the death of her sibling, Molly had always known of her brother's existence before her birth, but had only recently come to see herself as a 'replacement child':

"...I was actually thinking about this yesterday as I was driving round...and I have always maintained that I was a replacement child...but I never actually felt like that, it's an assumption that I have come to as an adult, and looking back I was never made to feel like that..." (Sibling, family seven - April 2005)

Throughout her life she has had to rely on relatives, including a very reluctant elder sister, Kate, who was born before he died, for information regarding her brother:

"...my brother then aged 8 years developed a brain tumour, no chance of treatment, I don't think there would be now for that type of brain tumour actually, so he presented with bumping into furniture. He was taken to the optician, the optician sent him straight to the Specialist Hospital, the Specialist Hospital had him in and discovered what it was and sent him home and I think he died in 6 weeks...throughout the illness my sister used to come in and sit with him, and play games with him, talk to him, she has never discussed this with me ever..." (Sibling, family seven - April 2005)

SEEN BUT NOT HEARD: A DIFFERENT TYPE OF CHILDHOOD

The death of Molly's brother occurred over sixty years ago when children were not involved in such family matters as death and, as previous research has suggested, the emotions that are raised by a death were not made public. "Traditionally, British parents find it embarrassing to talk to their children on subjects of deep emotional importance, and traditionally they try to hide their own deep emotions from their children's observation..." (Gorer, 1965). In fact it was thought at the time that children under the age of 10 years had no cognitive grasp of what death meant or of expressing their feelings, and although the majority of children at that time died in hospital, this sibling

reported that she had been told that unusually at that time her brother had been sent home to die:

“...What I got [information] from my mum, she’s been dead 23 years...my mum died when I was 20... mum did say that Kate really did not know he was so ill and they did not want to tell her so the outcome of that was he died at home in the bedroom that subsequently was mine and my sister came home from school and threw things, screamed and shouted she did not know he was going to die and she sat with him until he died...” (Sibling, family seven - April 2005)

INFORMATION GATHERING

The sibling continued to report that in more recent years she has asked relatives their perception of what had occurred in her immediate family between her brother’s death and her birth in order to try and understand her sister’s difficult attitude not only towards herself, but her mother, and life in general:

“..my cousins are in their 60s and they remember when Phil died... how bereft she [older sister] was, she was like very in shock like a little lost soul, but they do remember her wanting mum to have another baby, she was involved in it and it wasn’t like putting one past her, she wanted it and I don’t think she realized what she could get, maybe she thought it would be a boy and she could look after it like Phil...I think they were very grateful to have me, I lifted a lot of the gloom, I didn’t replace him...” (Sibling, family seven - April 2005)

It would seem from the interview that the brother’s death and the arrival of herself as a new sister also changed Kate’s attitude towards her mother, who Kate appeared to blame for what happened in the past. This attitude persisted throughout the remainder of her mother’s life:

“...but I get the impression it was when my brother died...she (Kate) took it out especially on mum, they never resolved it. She was 29 when mum died and even now she speaks quite scathingly about mum...” (Sibling, family seven - April 2005)

Over the years siblings grow and change with the new relationships that they encounter, but for some siblings their thoughts and memories of the sibling that had died remain as ‘frozen images’ (Bank and Kahn, 1982). This is especially so when the sibling has not been allowed to express emotions or ask questions regarding the illness or death, which in the 1950s would not be conceivable. Rochlin (1965), points out that “the object is never truly given up; it is made into a part of the self. In this way figures that appear to be given up or lost are permanently held with bonds that are impervious to being severed”. With no social support for their grief, siblings at that time would either have to suppress their feelings or deny they had them, perhaps only to have them acknowledged many years later in adult life. When the death experience is at a very young age, often the surviving sibling lives with a fear that illness and death will occur again to either themselves or other close members of the family. When the family has been in turmoil for a number of years and another baby is then born, the responsibility and fear for the surviving sibling and family life increases. Molly spoke of how life might have been:

“... I think life could have been quite nice and it could have been better. My main issue is always my sister you know, and it hurts me... and it still hurts me even though I have distanced myself from her...but the animosity that woman feels for me...I am sad, really, it happened that way and I am sure if she could have got help prior to Philip’s death things may have been different...” (Sibling, family seven - April 2005)

The new sibling who has only other peoples’ accounts of the life and death, either finds that they have expectations placed upon them by family members, or that they willingly accept responsibility for trying to make things better within the family, as Molly explained:

“...I once described myself to someone else as this big Elastoplast that is put on to make things better and heal...” (Sibling, family seven - April 2005)

Much later as adults, the two siblings faced the death of their mother, and Molly at that time, felt that the only source of information relating to the brother had died as well:

“...I have heard nothing as I said from her (Kate), not a lot from dad, but mum used to tell me things which were relevant to me at the time but not enough...”
(Sibling, family seven - April 2005)

This was followed by the re-marriage of their father and she continued to speak of how it felt that there was a possibility and fear that her brother would be lost too:

“...and we grieved him at that point. I sort of picked him up because I’ve always loved him and I have always known him which sounds really odd. I don’t remember the day when they said you’ve got a brother but he died, because he was always there and (yet) the house wasn’t covered in pictures of him. There was a crucifix he’d made and put together and made a cross and a Jesus out of clay...but I have always known him and always loved him and when mum died it was like who grieves for him now...?” (Sibling, family seven - April 2005)

REMAINING IN THE FAMILY: CONTINUING BONDS

For the remaining years and up to the present time Molly reported that although she never knew her brother she has taken on the responsibility of keeping him in the present. Her own children, who are now young adults, are aware of Philip and what happened to him. She has the crucifix and the clay figure that Philip made at school. The sadness is that there are few remaining people who are willing or able to provide her with the missing pieces of information regarding her deceased brother. She continued:

“...Yes it is sad but it’s born out of tragedy which was Philip being such a stunning wonderful little boy that everyone loved - and dying from a hideous brain tumour and ruining lives really, but it was born out of tragedy I am born out of tragedy...but the sibling thing has been mishandled and to see the damage it can do is quite astounding and there is probably quite a lot of that generation with baggage and grief ...” (Sibling, family seven - April 2005)

In summing up the key points of this section, studies have shown that following the death of child the birth of a subsequent child is often viewed as a replacement to fill the gap that has been left. In this case study, with the birth of this baby, the surviving elder sister’s relationship with the mother and new sister appears to have deteriorated and this

still continued following the mother's death. At this time the younger sister's fear was that her primary source of information had died, as neither her father nor older sister spoke directly to her about her brother. Her other fear was that no-one would now actively grieve for the brother she never knew. This was especially so following her father's re-marriage, and so she decided that she and her own family would take on this responsibility. On reflection, the younger sibling's impression was that throughout the years, her sister's attitude towards her may have been less negative if she had been told the truth by her parents that her brother was dying. Following the death of the brother the respondent's perception was that the older sister would have benefitted greatly if she had received some form of bereavement support external to the family. Whilst many changes have occurred since the 1950s in relation to the support of bereaved children, this sibling's story reflects what may happen when a well sibling is not given honest and/or clear information of what is happening in the family and to the ill sibling. This sibling relationship fractured on the birth of the sister, whether that is because she was not a boy for her sister to care for, or because all attention turned to this new baby as bringing happiness back to the family, will never be known.

The foregoing case-studies illustrate in detail the roller-coaster effects of living through a sibling's cancer treatment. It shows that for many of these well children, the illness comes to mean a loss of parental attention, loss of normal family life, and emotional distancing from both the ill sibling and from the primary carer. It may also mean having to pretend emotions that are not felt, or to feel distressing emotions without the information through which to make sense of them. It may mean having to watch while a sibling who has always been a competitor for parental attention gets all the love, concern and gifts, and it might also mean having to face the real possibility that what is happening to him or her might also happen to the well child. In a few cases, this might even come physically all too close if a bone marrow donation is required. Furthermore, these case studies illustrate that even though the treatment is finished, the ride might not be over. Relapse, or even longer term onset of other tumours linked to earlier treatment always remain a possibility. Finally, it is clear that the fragmentation of families into smaller emotional alliances between individual parents and individual children, or the isolating of particular children through death and grief for a beloved sibling may create long-term disharmony, resentments and loss of memories of deceased loved ones.

THE SIBLING'S WORLD OF LIFE-SHORTENING ILLNESS AND COMPLEX MEDICAL NEEDS: FELLOW TRAVELLERS ON THE UP-HILL STRUGGLE

The numbers of children in this category of illness is increasing in the UK and according to the Department of Health figures there are approximately 700,000 (DOH, 2004b) children living with a life-shortening illness, and who are cared for in approximately 25,000 families (ACT, Dec 2006). The majority of these children are cared for at home, but the number of siblings living with an ill sibling is unknown. The illness not only impacts on the sibling's day-to-day living but has a powerful impact on them as individuals and continues throughout the whole of the well sibling's life. Over the years much of the research that has investigated the effects on well siblings has been contradictory (Cox et al, 2003). The literature has indicated that the relationship may well be a negative one, with possible long-term psychological problems creating a "population at risk" (McKeever, 1983; Sharpe and Rossiter, 2002). The majority of studies focus on the stress placed upon well siblings through the additional demands and household responsibilities that may be expected of them by parents as a result of having a brother or sister with complex health needs. Conversely however, McHale and Gamble, (1987) warn against this conclusion and suggest that tension may actually arise from how the ill child responds when they are cared for by a well sibling. There is little information on the long-term effects on siblings, and practically nothing on consequences of living with a child with chronic medical needs after the well sibling has entered young adulthood. From the well siblings' accounts in this study, it is possible that they experience considerable guilt at the advantages they have over the ill sibling by being healthy. Further issues at this time may emerge such as ageing parents and increasing responsibility for care being placed on the siblings.

Whilst acknowledging that a number of children living with an ill sibling may feel the experience has had a negative impact on their lives, there are well siblings in my research who consider the experience as being more positive. This may be due to how the parents manage the illness within the family environment and how the well sibling continues with their own life. Bury, (1982), describes the onset of adult chronic illness as a 'biographical disruption', but when a child is born with such an illness or disability it is not the ill person whose biography is disrupted but that of the well sibling and the family as a whole. It may be important therefore to contrast the meanings which family members

give to a life-shortening illness diagnosed at birth, with the meanings which family members give to a life-threatening illness which strikes, unexpectedly, in childhood or adolescence. Even at this point, it is possible to draw attention to the findings presented so far which show how the 'bread-winning' parents and well siblings are distanced from both the child and from its treatment for cancer. Yet, as noted at the start of this section, the chronically ill child is 'treated' primarily at home, and this takes place over the child's life-time rather than over a hospital-based 'course' of treatment.

RECOLLECTIONS OF A WELL SIBLING: THE TURNING POINT

Stephen is now 25 years of age and eldest of four siblings. He and his subsequent brother, Bill, were born without any physical problems, but the two younger siblings, a brother and sister, were born with complex medical needs and severe disabilities. His interview illustrates longer-term effects of the stress of living with chronically ill children in the family. He recognized at the end of his time at University that the stress and strain of having two siblings with chronic illnesses had eventually caught up with him. Although he said it felt like an admission of personal failure in coping with his situation, he spoke of how he realized that he could not continue without support and made the decision to make an appointment with a counsellor to explore his feelings regarding his siblings, his life and his future expectations:

“...I have been struggling to deal with what I suppose has built up over the years...if I look back throughout my teens, things used to get on top of me, and I think maybe something was always bubbling away, I think leaving university was definitely a turning point for the worst because up till then you're almost like on a tread mill, you know primary, secondary, Uni, then you have to start making adult decisions...home is where you can control everything as soon as you step out of the door...there is something about home...” (Sibling, family eight - September 2005)

Studies have indicated that parental pressure may be placed on well siblings to achieve the unfulfilled hopes of the parents (Cleveland and Miller, 1977). Whilst this sibling spoke about high expectations, these were expectations he had placed upon himself for the advantages he had over his ill siblings, and to a degree those personal expectations remain and are, on occasions, a further source of stress as he suggested:

“...it’s was almost like admission [of failure], you know I am so competitive, so wanted like to be perfect and best at everything, and that’s unobtainable, expectations so high you don’t know where to choose them or that sort of fear of not achieving them, it twists you up in knots at times...” (Sibling, family eight - September 2005)

However, he continued to speak of how he now recognized that perhaps there is an alternative place for him to be:

“...I think the best route for me with everything that has gone on is somewhere in the middle... but that makes up who we are and you are probably never going to change that.... but maybe trying to get more to the middle ground...” (Sibling, family eight - September 2005)

On leaving for University the distance away from home raised a greater awareness that he personally could not control home, and that he could not continue without emotional support. However, what he did discover was that he could conceal information regarding his own health and wellbeing from his parents in order not to worry them. His impression was that by revealing his own problems to his parents he would then become an additional burden:

“...I think it’s also admitting that you need help personally. It took me a long time... I never wanted to be a burden, an extra burden on mum and dad. They have more than enough to worry about, so I found myself not telling them things... down from stuff like how I was feeling, to when I was at Uni I had a mole removed and stuff like that... and for a week or so, I told them afterwards...” (Sibling, family eight - September 2005)

THE EARLY YEARS

I asked Simon if he had any recollection of his sister’s birth, 20 years previously. He recalled the only memory that he had of that time:

“...I was 5 and I don’t really remember a great deal of when she was born. The only thing I remember was that Kit Kat had an offer, you know when you collect wrappers and I got my prize and I sat at the hospital putting it together...”
(Sibling, family eight - September 2005)

The non-disabled child may experience a strong sense of identification with the ill or disabled sibling which may lead to feelings of being overly responsible. This is especially so when the disability is very visible and when other children or adults are thought to be staring or laughing at the ill sibling. When asked when he first became aware that his sister was different to himself and his friends he reported that:

“...I can almost say there was never a time when there was an awareness. ‘Cause we were so young we didn’t know any different, so we just learnt to deal with it. And that is where some of my problems stem from...coping mechanisms when you’re ...you know... 8-9-10 years old. They work for you then, but they don’t work for you when you are 25...” (Sibling, family eight - September 2005)

When there has been a diagnosis of childhood cancer it seems that the illness is thrust upon the family with little or no time for adjustment. This continues throughout the treatment, where periods of the ill sibling being in remission and later, possibly, relapse, and disrupted family life as described in previous chapters, reflects the instability of an emotional roller-coaster. In contrast, many families with children who have chronic, life-shortening medical conditions have a greater opportunity to adjust and ‘come to terms’ with the condition, as this sibling suggested:

“...we didn’t know any different so we just learnt to deal with it...” (Sibling, family eight - September 2005)

The perception is that this sibling had a more positive and time balanced attitude towards the illness and his particular home situation. Previous research has suggested that increasing the well siblings’ awareness of their brothers or sisters disability may improve feelings of connectedness with them (Lobato and Kao, 2002). An earlier study confirms the problems resulting from absence of awareness, suggesting that those siblings who are

poorly informed about their ill siblings' condition may be confused with their own identity (Wasserman, 1983).

During the interview when discussing coping strategies, it seems that Simon's anxieties may have arisen precisely because of his awareness of his younger siblings' problems and his commitment to them that led him to be personally driven to achieve his full potential – almost as if he had to 'make up for' the disadvantages of his younger sister and brother. He continued to speak of how he and his other 'well' brother may have developed this highly ambitious attitude:

“...both me and my brother are both very driven, want to achieve.... and an element of that is we take advantage of opportunities that my sister and brother never had, and I suppose there is also an element... that when you are that sort of age....sort of like attention seeking. You know Jimmy and Vickie were very much... especially Vickie when we were younger... was very much... as I said you could see physically and mentally she had problems, and I suppose me and Theo's competing never ... sub-consciously thought, [but] yea that is what I did...”
(Sibling, family eight - September 2005)

COMMUNICATION OF INFORMATION: FROM PARENT TO WELL SIBLINGS

When there are well children in the family, one of the many difficulties for parents is how they maintain a balance of how much, or how little information they give them regarding the condition of the ill sibling. Some siblings appear to only want to know when something serious is happening to the ill child, others would like to hear all relevant information regarding their ill sibling. As a 'worrier' Stephen spoke of how he felt sure that in the early years, information had not always been forthcoming regarding the ill siblings:

“...there have been times when mum and dad have withheld [information]..... like without a doubt they have not told us...I can remember in the early 90's when I suppose that mum and dad's careers have always been.... mum less so, she was an air stewardess ...very much ad hoc jobs...finances were very tough and I used to worry sick ...and for weeks and weeks I would worry myself because I

didn't see the bigger picture, everyone was screaming, dropping right, left and centre..." (Sibling, family eight - September 2005)

However, he continued to report that if there were serious health problems he and his brother were given the information together, but he could also see how that may not work in all families:

"...I think me and Theo have always been [together]... if there has been anything serious mum and dad have always sat us down together.... I can't remember a time when I did and Theo didn't. I can see if there was a 5-6 year gap between us, I was in my mid teens and Theo was 9, 10, 11 definitely see how that could happen but there is only 18 months difference between me and Bill..." (Sibling, family eight - September 2005)

REMAINING ON THE 'INSIDE' OF THE FAMILY: RESPONSIBILITY AND ROLES

Feelings of being left out are quite common amongst well siblings and whilst some will understand the reason why this happens, even in the best of circumstances it's possible that they will attempt to gain that parental attention. Stephen has already alluded to his experience of this: "there is also an element that when you are that sort of age sort of like attention seeking..." and I asked if he realised at the time that he did not get as much attention from his parent. He quickly responded by saying:

"...I don't think so, we were quite fortunate in the sort of work Mum and Dad did, they you know... well more so dad... once my sister and brother were born he got modelling shoots [at] set periods of time where it was a day here or a week there, so he was around a lot especially in the 90's in my teenage years. He was always around.... available for sport.... just to be there you know...games or cricket...Mum and Dad they couldn't have given us any more. There was always support there if we needed it. The question was not wanting to burden them, but Mum and Dad have been fantastic. I think circumstances definitely helped..." (Sibling, family eight - September 2005)

I am aware from my observations of this family over a number of years, that when the sister was born with major medical problems, neither parent although employed, had a

typical nine to five working life. Following the youngest brother's birth approximately four years later the father appeared to jointly take on the role of carer. The parents appear to have worked a reasonable balance between the well and ill siblings. Stephen continued to report that as the eldest child he believed he had had it 'easier' than his other well sibling who before the youngest brother was born was the middle child:

"...well I can only speak for myself. I think he [Theo] as the middle child had a rougher ride. Obviously I was the first to do things... although there is only 18 months between us. As we were growing up there were times when he got a rough deal 'cause the two youngest took up a lot of time and being the first to go through GCSE's and 'A' levels it's always like a bench mark. I was always very sporty when I was young... a lot of the time travelling around and I spent a lot of time with Dad through that.... I can remember times when dad was off doing something [photo shoot] Mum had to take me to football - Charlton somewhere like that... on a rainy Tuesday night the other two would be stuck in the back of a car..." (Sibling, family eight - September 2005)

The well sibling's sense of solidarity with the family grows from his concern for his disabled younger sister and brother, but his perception of their needs is likely to differ significantly from his younger brother's response and adjustment. Each sibling will have had a different relationship with each other member of the family. Describing the different relationship he and his brother have with the two younger siblings Stephen continued to say:

"...I see myself responsible definitely, not only for my [able-bodied] brother, but for everyone. [But] I think, like my ex-girlfriend used to say, that his [Theo's] relationship with our younger [disabled] brother is more like brothers [than mine], like teasing him, beating him up, winding him up, where I would be sat down helping him with his home work maybe I would have a more fatherly relationship..." (Sibling, family eight - September 2005)

He continued to report on his perceptions of the individual personalities of his family:

“...I just think that my brothers and dad are all quite similar - more aggressive, moody and that’s how they deal with it. My mum and my sister and me are more passive, and ...you know... let things go over my head, or I pretend that they do. But as a worrier and a thinker ...until they don’t resemble reality, so you are worrying about things that will never happen...” (Sibling, family eight - September 2005)

This older sibling has always been part of his younger siblings’ lives, and has a clear picture of what poses the greatest problem to the family, particularly with regards to his sister and her shortened life expectancy. In fact, she has now lived longer than either professionals or parents believed possible. Stephen summed up the long journey they have all taken to get to this point:

“...I am sure, I think if Mum and Dad were in this room as well and if you had sat down 20 years ago and gone this is what is going to happen in the next 20 years time, it would be ‘No way!’, but it isn’t like that, it’s every separate illness, it’s every day at a time, you can’t look into the future...” (Sibling, family eight - September 2005)

SIBLING JOY

If, as he has suggested, it has been difficult and stressful over the years with a consistent inability to look into the future, could there be any benefits to having siblings like his younger sister and brother? Without hesitation he spoke of the joy that they brought to him:

“...[a resounding] oh yes they are so rewarding. Obviously Jimmy is more frustrating at times, but it’s so rewarding just seeing a smile on Vickie’s faceand [seeing] Jimmy get pleasure out of something ... I could talk forever on that side of things...” (Sibling, family eight - September 2005)

Whilst Simon continues to live at home, his sense of responsibility for two ill siblings remains. At the request of the family I attended a meeting with the Consultant to discuss end of life treatment for the family to think about - being realistic that there may come a time when the decision has to be made ‘to resuscitate or not’. This meeting had a

profound effect on all members of the family with the realization that treatment and care are not going to get any easier. As the eldest sibling he realized that he had to accept that this is the reality of the situation at home. He recognized that as an individual within the family he had to continue to live his own life, and he continued to speak of his own future:

“...yes I think that definitely, the realization, you know before I went travelling [Australia] I said my goodbyes to her and didn’t expect her to be here when I got back...I think that’s a perfect example where I could have said I am not going to go travelling in case it happens, and nothing happened, she could live another day another 10-15 years you don’t know...I love family, my brothers and sister but I’ve reached that stage now, definitely reached that stage where I need to move on in my life...staying at home... it’s so in your face... the whole time.... it’s constantly, especially for me who is a worrier... when it’s there in front of your face all the time...” (Sibling, family eight - September 2005)

WHAT THE FUTURE HOLDS

It has taken Simon many years to acknowledge that he has in many ways taken on the responsibility not only of his ill siblings, but also of his parents in trying not to be an additional burden and always striving to be the ‘best’:

“...whereas you are never realizing any of that, it builds up, builds up definitely, that’s definitely me, blow out type of thing definitely, it’s not sustainable...moving out would help as well, I pretend that they do [thoughts go over the top of his head] but as a worrier and a thinker...until they don’t resemble reality, so you are worrying about things that will never happen, you have just taken those little bit of facts...” (Sibling, family eight - September 2005)

There comes a time when it takes someone outside of the family to put your life into the right perspective and to help you recognize that you are not responsible for the ‘family’ but only yourself. He spoke of how an ex-girl friend brought him to this view:

“...and that’s exactly what she [ex-girlfriend] said, she was almost quite blunt, she can be blunt, she said your mum and dad decided to have more children, ok

they turned out not as a normal person, or not as a person considered normal and it's their responsibility, and for quite a long time I have taken responsibility..." (Sibling, family eight - September 2005)

Although he had personally felt responsibility for his siblings, it has to be noted that the responsibility had not been thrust upon him at any time by his parents. In fact they had expressed concerns regarding his wellbeing for some time and suggested that he should seek support which he eventually agreed to. I asked him how as a young man he had managed his life over the years with the weight of responsibility that he had taken on particularly since leaving University. He explained:

"...girlfriends have never been my priority. I suppose if you could put your life into a pie chart, it would be the girlfriend - and sometimes my friends – sectionthat would suffer, whether it's obviously now it's work that's a big part of that chart, family always been big to me, then there is my sport..." (Sibling, family eight - September 2005)

Sport has always been a large part of his life, especially cricket as he played both locally and for the County. His younger brother is also a keen sportsman. Simon described how change in his own life will affect his ill brother:

"...for so long much of my life has been what he does, so he loves going up to the cricket club on a Saturday, pottering around for the day, they put on an extra plate for tea he loves it up there, there will be a time when I don't play cricket up there, he has his own life to lead..." (Sibling, family eight - September 2005)

Whilst he still has real concerns regarding the future for his sister and brother he has recognized that the responsibility for them lies with his parents and that at 25 years of age he must look towards his own future which will probably involve leaving home. The final question that I asked him was "for siblings who find themselves in a similar family to yours both now and in the future what do you think would help?" He responded by saying:

“...support and counselling should be there from the age of 11/12 onwards whenever that sibling has a need to talk...” (Sibling, family eight - September 2005)

Since the interview this sibling has left home and lives not too far away from the family home. Although still very much connected to his ill siblings, it does appear that he now has a greater awareness and understanding of how they fit into his own life that is separate from theirs. There will, for Stephen always be concerns about his ill siblings' welfare especially as they are getting older, and time, especially for his sister, is running out. He spoke of what he thought may be a positive move for his disabled brother:

“...I don't like the thought of him just wrapped up in cotton wool It would do Mum and Dad a great deal of good, and he would get the stimulation and interaction with his peers, to go to some boarding [...] whether it would be one night a week or say two or three nights a week...” (Sibling, family eight - September 2005)

SUMMARY

It is useful to sum up the key points in this section. The uphill journey that parents struggle with on a daily basis also affects the lives of well siblings, and, although they may be on the same hill, the well siblings travel on a different pathway. Their perception of this journey changes as they themselves mature and develop a greater understanding of the illness, its consequences on life expectancy, and the financial and emotional drain on their parents. In many ways the well sibling's journey may be personally driven to achieve and strive to be the best and take all the opportunities that are not available to the ill siblings. As the well siblings mature, they themselves still have great difficulties to overcome as they learn to adjust and balance their family circumstances, especially when they come to the decision that they have their own lives to lead, and leave the family home.

CONCLUSION

The sibling relationship is conducted through what is not always an easy and happy journey, and, following a diagnosis of cancer in a brother or sister the relationship may become distant and even more ambivalent, albeit for the duration of the illness. The well

siblings appear to have limited choice over how involved they become in their brother or sister's illness and treatment. Like many of the fathers, they appear to be on the outside of the illness, with the main focus of attention throughout treatment and remission remaining on the ill child. Because of the likelihood of separation of mother and ill child following the diagnosis, there is little time for the well sibling to adjust to the many changes in their home life that occur throughout the treatment period.

For the brothers and sisters of children with a life-shortening medical condition, their journeys reflect more those of their parents. That is, they are part of the uphill climb that becomes part of the whole family's daily life that is characterised by frustration, stress, responsibility and hard-work, but also a sense of joy. Unlike the siblings of children with cancer, these siblings have far more opportunity – and pressure – to be closely involved with the illness and care of their brother or sister. Although they may take on additional roles and responsibilities at a young age, and their lives are far from 'normal', they are more likely to remain part of the family unit. It appears from the findings that the difficulty for these siblings is that, as they reach young adulthood, they are torn between their life within the family and their desire for independence and a future of their own.

CHAPTER, 7

WE HAVE VOICES TOO: ILL CHILDREN'S PERCEPTION OF MEDICAL CARE

Using the stories from ill children's accounts to illustrate the analysis, this chapter examines how ill children and young people as active users of the health care system perceive the care and attention that they receive from health professionals during hospitalisation and out-patient visits. Whatever the diagnosis, the children themselves 'live' the illness experience. For some children it is for a lifetime, for others it can be a number of years of treatment with always the possibility of 'cure'. Yet the relationship between health professional and patient is often overlooked, sometimes even ignored, with the decisions over treatment being exclusively between the health professional and parent.

Since Cobb's study (1956) of how the death of a child from cancer may create a problem for the continued stability of the family, there has been much research that has focused on how the diagnosis of a life-threatening or life-shortening illness impacts on family members with particular reference to the mother. Although limited, in recent years research has also begun to focus on the reactions of siblings, fathers and grandparents. However, in relation to the ill child themselves, research is sparse. Whilst there are difficulties undertaking research with children, especially very ill children, they do have voices that need to be heard regarding treatment relating to their own illness, what the illness means to them, and at times it is important to listen to their experiences of health professionals' attitudes towards them.

A CHILD'S UNDERSTANDING OF TREATMENT ISSUES

Within childhood cancer the issue of control over treatment is virtually non-negotiable. There is very little room for discussion and once diagnosed, the treatment is urgent. Therefore, parental 'choice' and involvement in treatment is very limited, with a 'cure' being the main aim of the medical culture and, understandably, of the parents, generally, at any cost regardless of what the child may want. Entering a children's oncology ward for the first time is a confusing and often frightening experience especially for the ill child who has perhaps been given little or no explanation of what happens next. Some children will resist admission once they see what is in store for them, whilst others become a compliant patient from the beginning:

“...ok mum if that is what we have got to do then that’s what we have got to do...” (Mother, family one - April 2006)

Although explanation is given to the parents regarding the side-effects of the treatment, to be told that sometimes your hair can grow back a different colour means something totally different to a 9 year old than it does to the adult:

“...but I don’t want blue hair...” (Mother, family two - April 2006)

As the child grows older and has been in remission for a little while, they are continuing having to adjust to life with regular check-ups and with the fear of relapse ever present. Even though parents may not openly acknowledge that relapse may ultimately lead to the death of their child, one 12 year old in remission was aware what she would choose if she found herself having to go through treatment again:

“...I said to mum I would like this song played at my funeral...” (Ill child, family two - field work diary April 2007)

In his book, “*They Never Want to Tell You*” Bearison recalls a number of interviews with children and young people on their thoughts and feelings regarding their diagnosis and treatment of cancer. One 16 year old explains why she decided not to continue with treatment:

“...I was supposed to come in for chemo last Wednesday but on Tuesday night I decided not to go in. I didn’t want to go in at all ‘cause I was fed up with it. I was tired, I’m sick of this. I hate it and I don’t want to do it any more...I am tired of people making decisions for me. They speak for me, they answer for me, I never could say anything, ‘cause I’m underage, I’m still a human, I’m allowed to make decisions...” (Bearison, 1991: 78).

These comments reflect the personal feelings of children and young people diagnosed with cancer, and illustrate how as an individual person they become secondary to the illness. Health professionals, and at times parents, give little explanation of the condition to the ill child, often believing that they are unaware of the seriousness of their illness,

without considering that they ‘live’ the illness and treatment on a daily basis, and they are on wards where other children die. These children may have cancer they are also acutely aware of what is going on around them. They need to be treated as active patients who have a clearer grasp of what is happening to them than is often appreciated.

ILLNESS IS PART OF MY LIFE

In contrast, for children with a life-shortening illness and/or complex medical needs, ‘cure’ is never really an option, and treatment and hospitalization is often integral to their lives, although, as they get older and remain relatively well with home-based treatment, hospitalization may well be reduced. A number of these children have since birth or early childhood become part of the medical culture that is involved with their illness. It must be acknowledged that a number of children and young people in this category of illness are unable to speak for themselves. However, there are some who can and do gain the confidence to speak for themselves. Many of these children gain a greater awareness of their own condition, but from this study it appears that some are never too sure if they are being told the truth about their illness by the health professional and, on occasion, by their parents. This doesn’t just relate to children where hospitalization is part of their life, but to others who find themselves on a general paediatric ward. As Carney et al’s study (2003) and Stewart’s study (2003) indicate, it appears that it is normal to give little information to children during their treatment for cancer:

“...I didn’t think they told you enough about what was wrong or what was happening and why they were doing things...” (Carney et al, 2003: 33).

“...But I didn’t know what it was at first, I didn’t really know what it was, I was like huh? I didn’t have a clue...” (Stewart 203: 399).

It is often only when the child who has a specific chronic medical condition has reached an age when health professionals recognise that they can be directly involved in discussions regarding their own health and treatment that these now young people may feel they are given correct information. As this seventeen year old, diagnosed with Steven-Johnson Syndrome at around three years of age, reported:

“...I know that they are telling me the truth and that they’re telling me in my best interests. Obviously that wasn’t so good not so long ago when I was a bit younger...I went through a phase where I didn’t think what they were telling me was true... the operation... I decided not to have it done, also I felt I’d had enough of having stuff done to me that I didn’t want any more...” (Ill child, family nine - November 2009)

Whilst few in number, studies have shown that children have a similar capability to adults when making choices regarding health care (Alderson, 1993). Further studies (Runeson et al, 2002), suggest the need for children to be encouraged to voice their opinions, but this opportunity has been slow to develop. The control of information remains with the health professional and even though the following young person reports that she now has choices as they [the consultants] have got to know her, she has in fact been in the health care system for over 14 years:

“...I think that they treat me more now like an adult, like I’m an adult, they give me more choice, so I feel I can say no if I want to, its got to be up to me, especially with the consultant about my contact lenses now that we have got to know each other. They know me and they’ve got to trust me. It’s not so much like in a hospital, do you know we are more like friends, a laugh and a joke...” (Ill child, family nine - November 2009)

EXPERT PATIENT

The longer the child remains in the health care system, the more they (like their parents) become ‘expert’ in their own condition. Although their expertise is not always acknowledged, these children have become accustomed to the environment in which they are being treated. This often leads to an increase in their confidence, especially when they are also able to access emotional support. This can encourage empowerment enabling them to speak for themselves, as this young person described:

“...I’ve got this sort of new confident streak in myself. I tell them what I want, and not in a bossy way...I feel more confident in hospital. I suppose I go there a lot and I suppose I know what I want there, and I suppose, I don’t think I like

being in hospital but I like that kind of atmosphere where people are helping people...” (Ill child, family nine - November 2009)

When a rare condition has been diagnosed from early childhood it is not only a lonely position for a child to be in, it is also difficult for them to appreciate that there are others who may have similar problems, especially when there is no-one with the condition in their own geographical area. This may make them feel even more different. One child reported that:

“...Like at specialist hospital with the eyes (eye problems are a characteristic of her condition) I like seeing people with similar conditions...[it] makes me realize I’m not the only one, makes me see...that I’m not the only one, fascinates me, especially with the eyes as well...” (Ill child, family nine - November 2009)

YOU DON’T KNOW HOW I FEEL

The relationship between the child with a life shortening condition and the health professional spans a lifetime and each knows the other very well, but knowing the patient and knowing how they feel are not necessarily the same thing and this level of need is not always recognized by the professional:

“...the doctors and nurses say that they know.....well they don’t know.... how I feel, but they come across as though they do know how I’m feeling and what it’s like, and I think because they are dealing with patients all the time with certain conditions, seeing people like me before, then they should know how awful it is...” (Ill child, family nine - November 2009)

A further difficulty in the lives of the children and young people who may be constantly ill or attending hospital is that, no matter how hard they try, others around them in their daily life cannot begin to understand how the illness impacts on them personally, or on their family, as this young adult explained:

“...they [people] have no idea, the struggle, getting people to understand how you are, how you are feeling, the difficulties...if they saw what I go through and what

the families were going through and what life's about, then I think they would be quite different..." (Ill child, family nine - November 2009)

GROWING FRUSTRATIONS

A further problem for most people who attend hospital appointments, whether it is the first appointment or one of many, is that it is common for notes to have been misplaced or lost and that consultants have second thoughts regarding their original treatment and frequently change their minds without a great deal of explanation:

"[it's]...hard for me. I feel that sometimes with doctors they say one thing one moment.... they've lost my notes or not got my notes or something...and then they say another thing.... and when I go back they have changed their minds, and I say 'Wow what's going on?' Sometimes even with Ms Smith she keeps changing her mind as to what's going on [re: lenses] and I sort of find that quite confusing, and I think I'd rather you say one thing and I know what's going to happen rather than changing your mind..." (Ill child, family nine - November 2009)

Respondents report that they feel there is a tendency for health professionals to talk in a patronising way to their patients. In the following example it is difficult to distinguish whether the consultant is actually talking down to the young person or whether he is just not thinking or listening to himself. In either case it does not help the young person to make decisions regarding her health or indeed her life:

"...Dr Walker sometimes says to me 'your lungs are pretty bad, you've got to take it pretty easy', then in the next breath he's going 'have you been out much lately? I've heard of this holiday you can go on and it's trekking' and you know he's just said my lungs are bad, contradicting himself..." (Ill child, family nine - November 2009)

A YOUNG PERSON'S PERCEPTION OF TRANSITION TO ADULT CARE

During the last few years there has been much discussion of the difficulties that are encountered by patients and parents during the transition from paediatrics to adult services. This includes the lack of consultants working in the adult sector that have the level of specialist expertise that can be found in paediatric services. There can also be

confusion around when (and indeed if) this transfer has occurred, especially at the young person's local hospital:

“...going over to adults has been hard. Dr Walker has been... not really having a go at me... but saying, ‘You know we’ve really got to think, you are 17 now’, and then all of a sudden we hadn’t heard whether I was (transferring) or not. My GP decided to send an e-mail to the other consultant’s secretary who said ‘Oh I’ve got a letter here. She has been seen by her’. I was like, ‘NO I haven’t... I’ve never seen or heard from her, I don’t even know what she looks like’, and the letter did state that I had been seen in her clinic. Mum said to Dr Walker about it, and he just said ‘Oh yea, we’ve talked about that’ - brushed it aside, now he’s saying there is no rush to go over... We didn’t want to make a complaint as a family, us, we don’t know who to contact or who to complain to or anything. The letter that the GP received - it wasn’t true, so we weren’t very happy with that. As mum said, even if she had just talked about us, she should have known that, she should have put that... I’m not even aware that they’ve been talking about me. I’ve not had any information feedback to me...” (Ill child, family nine - November 2009)

This young patient decided to take matters into her own hands, ignoring the local hospital and wrote to her previous paediatric consultant at the specialist eye hospital where her request appears to have been positively received:

“...the specialist hospital was more straightforward, well I just wrote to Dr Davies and said, ‘Would you take me back as your patient?’...and he wrote back and said ‘Yes...’ (Ill child, family nine - November 2009)

Although she had been transferred to adult services at the eye hospital, she felt that the relationship between herself and the consultant was not a positive one and she had the confidence to act for herself:

“...I had gone over to Mr Lamb who had totally different opinions, different views, different ideas, about my eyes, Davies was a paediatric eye consultant, Lamb had different views, ‘think we’ll just try and get your lenses sorted’. There was no sort of, you can do this with your eyes, you know what I mean, it will

make them better sort of thing'. He was just slow, he didn't have that kind of, not like Davies, he's kind of bmp, bmp, you've got to do this, he sorts it out, we weren't really getting anywhere. I wrote to Davies and said 'please take me back on' and he wrote back and said 'yes no problem'. It was nice because the first time I went to see him in the adult clinic, even though I was a child, and there were adults around me, it was nice he sort of put my notes to the top and he called me first, he knows me..." (Ill child, family nine - November 2009)

A further difficulty of this transition period is that within the NHS once a patient reaches the age of 16 years their notes are closed and it is the responsibility of the local hospital to ensure that the patient is transferred to adult services. This can leave them feeling nervous, especially when the patient has already experienced a lack of professionalism in relation to the transfer:

"...as I said it's mainly just hospitals with my lungs, although now I'm going over to Specialist hospital 1 or Specialist hospital 2. I'm happier with that because I was under Specialist hospital 2 for the lungs and there again they just kind of wiped me off. I got to 16 and then I never heard anything else whereas I feel that I should still be under a Capital City hospital, just in case..." (Ill child, family nine - November 2009)

CONTINUED FRUSTRATIONS

After countless hospital admissions and appointments over the years the parents of children with life-shortening illnesses can get frustrated with the carelessness of health professionals and their apparent lack of consideration, thus creating even more stress for the family:

"...there again the family get frustrated, my dad rings the hospital to see if the lenses are in, then they come in and they're not the right size, not the right thickness. He says, 'Why is this? Do you know what I mean? Surely you've ordered them in the right size, the right thickness?' And then, there again, my dad has to ring up.... and they should ring back, and it never happens and it's just quite stressful..." (Ill child, family nine - November 2009)

This frustration and stress is also experienced by young people as in some cases the health professional appears to expect them as patients to remember what they as professionals have forgotten. Most times the missing information is associated with the patient's drugs and one young woman expressed her annoyance because she felt it was not her responsibility because she is the patient:

“...I get a bit upset really and quite annoyed. It's always up to me to give them the dosage or any information...it shouldn't be up to me, you're the one who prescribed it to me so you should know. I don't go round looking at the bottles thinking oh that's 4.5% or whatever [laughing] quite annoying for me and for the family. Its like going to A&E sometimes and dad says, 'Just find her notes it'll be in there', but it's not there...” (Ill child, family nine - November 2009)

However, in certain circumstances this loss of notes can be dangerous, and places other health professionals in difficult situations, as the following experience shows:

“...the other thing we've always found is that every time we see a new doctor we have to see them afresh, we have to give them all the information, all the medication I'm on...every time they've lost my notesthey haven't got them. I know when I had the first operation this year, the anaesthetist said I was going to be put to sleep and then she listened to my chest and said my lungs were too bad, but she wanted to know what happened previously when I'd had my other operation, but they'd filed my notes away so they couldn't find them. So she wasn't happy. She said I need to know about this patient, I'm about to give her a general anaesthetic...I kind of gave her the information, but she said my lungs were too bad, I needed sedation instead...” (Ill child family nine - November 2009)

EVERYDAY IMPACT OF THE ILLNESS

It had been noted throughout the interview that this young person spoke of how her dad had to telephone the hospital, or take her to A&E where the notes had been frequently lost, and although she reported her own frustration, she had not related how her dad responded. I ask the question, “Frustrating for you. Your dad sounds as though he's the one who shows it?”

“...Yeah, and even for the little ones, for everyone really...” (Ill child, family nine - November 2009)

The frustration permeates the whole family, and for the younger siblings this is the only life they have known. Described as the ‘little ones’ they are the two younger siblings aged 7 and 4 years of age. Their lives are often constrained by the illness. For example, at any time - often without warning - there can be a problem with their sister’s eyes. It may be that the lens has come out, or the eyelashes are growing inwards. In these instances if there is no-one available to look after the siblings they have to accompany their sister to the hospital. On these occasions these family members clearly illustrate how the medical condition has become a ‘normal’ part of everyone’s daily routines.

This young person’s health has, over the years, created increasing difficulties for her education and social life. This is especially so since secondary school where the perception of her peer group in the 6th form was that she has had hectic, fun week-ends similar to most of them. Following the week-end, friends asked what she has done. The answer was often anything but exciting:

“...Like my friends go, what did you do at the weekend? I say I didn’t go to the cinema, I went to hospital, I suppose it’s a bit the same [laughing]...” (Ill child, family nine - November 2009)

THE DIFFICULTY OF HOSPITALISATION FOR YOUNGER CHILDREN

Two further children were interviewed. The two girls are sisters, both diagnosed with different life-shortening/complex medical conditions. I asked them to draw their thoughts and feelings on paper, and whilst they were doing this I asked them questions about their drawings. The eldest sister who is 9 years of age will not discuss her condition in any detail, but agreed to draw and write her thoughts. The younger sister is 7 years of age. She is very verbal, confident, and has had continual surgery from birth that includes reconstruction surgery for internal female organs, bowel and bladder, and a kidney transplant two years ago. These children are very aware of their conditions and how they are treated when hospitalised:

“...they don’t listen to what I say to them... they don’t look at me... they just do things...” (Youngest ill child, family four - November 2009)

TELL ME THE TRUTH: BUT UNDERSTAND THAT I DO GET SCARED

The perception appears to be that when the nursing/medical staff are taking bloods, conducting observations and other procedures, the child can be ignored as a person and becomes more of an object. Further to this, from the child’s perspective of being told to always tell the truth, it can be confusing when they are informed that anything that includes a needle or surgery will not hurt, as the 7 year old reported:

“...they say it won’t hurt, it’s like a scratch. It’s not, it hurts and I want to cry but I don’t...and they keep saying I’m getting too old to sit on mum’s knee when they stick a needle in. Mum said I’m not...” (Youngest ill child, family four - November 2009)

This particular child is familiar with surgery, and from a time when she was quite young her mother has always given her an age appropriate explanation as to why she has to undergo these procedures. However, it is difficult to explain to a child when a mistake has been made by not removing a stint following a major operation, and you have to undergo further surgery to remove it:

“...I’m not telling you.... it’s horrible...” [She continued to show me and made a movement like opening a zip the length of her body] (Youngest ill child, family four - November 2009)

As reported in an earlier section, there is a knack to placing a cannula in a child’s hand which not all doctors/registrars appear to have, and after many years of experiencing difficulties with this procedure the youngest of the two children now has a phobia about the procedure and will not even say the word. It is always spoken as the ‘C’ word, even when writing she has just written ‘C’ [appendix 8 page301]:

“...when I am in hospital and hear the trolley [blood trolley] I start to shake, and it was funny because a doctor came to do it and he was shaking more than me...” (Youngest ill child, family four - November 2009)

Mum intervened and informed me that this Registrar had to have two attempts before she [mum] then said, 'Enough', and at the same time a nurse had fetched someone else to do it. It seems that these problems not only happen on the wards, but children's perceptions of professional insensitivity extend to out-patient visits. One such visit was described by the 7 year old:

“...she told us to hurry up because she [consultant] had a meeting and we had been waiting ages, and it was lunch time and we had to see another doctor in the afternoon and I wanted to go and have a quick curry, 'cause I like curry - it's my favourite, and this person [out-patient nurse] said no you can't and it was tea-time when we saw her [the doctor] and I was really hungry...” (Youngest ill child, family four - November 2009)

Whilst it can be said it is not that important that children go without food for a few hours, this particular child had not eaten solids until she had the kidney transplant when she was 5 years of age. It was only after some considerable time following the transplant that she began to eat small sized meals. Even now she is partially machine fed with pressure constantly being placed on the family regarding her eating, and is a further example of the often contradictory attitude of the health professional. From the writings of the older sister [see appendix 9 page 302] it is clear that she could not quite understand why nurses asked which hand she wrote with and then “put the needle in the wrong hand”. This reinforces what the children have previously reported, that no one explains what is going to happen next. Otherwise this particular child would understand the reason why the needle was put, as she saw it, “in the wrong hand”.

THERE ARE GOOD THINGS TOO

However, the children did not only recount negative experiences they also described what they liked about hospital:

“...I like going to (hospital) school. It's better than school...the teacher is kinder...” (Youngest ill child, family four - November 2009)

“...the man nurse makes me laugh...” (Youngest ill child, family four - November 2009)

The 7 year old also reported that other changes have occurred recently that she approves of and which appear similar to changes in the adult sector - primarily at meal times:

“...they don’t observe me at dinner times now, I used to be eating my dinner and they would ask me to pee when I am having dinner. They don’t now, but they do take hours...” (Youngest ill child, family four - November 2009)

Although this is a very small sample, the views of the children and the one young person interviewed have reflected the findings of the published studies (Dell’Api et al, 2007; Runeson et al, 2002; Wise, 2002) regarding the responses of children who are frequent users of the health care system.

SUMMARY

The findings have shown that ill children have the ability to understand their illness, hospitalisation and the procedures that have to be carried out. The younger children would have a greater understanding if the health professional gave an explanation of what they are going to do. Health professionals do appear to recognise that, as the child matures, they should be more directly included in the health discussions. However, with the growing maturity, the child begins to experience similar frustrations to their parents that mainly concerns lost medical notes or notes that cannot be accessed and the lack of communication between the professionals and the different hospitals that they attend. On occasions the lost health records can create additional difficulty for other health professionals, especially when it involves anaesthetics as it seems from the findings that the anaesthetist was reliant on the young person’s recollection of what drugs they had taken. Additional frustration noted in the findings is when health professionals voice that they ‘know how you feel’ when they do not. The transition from paediatrics to adult service can create additional stress and difficulties for young people that appear to originate with the lack of communication between the paediatric and adult services. As the confidence and maturity of the young person increases they realize that they can make decisions regarding their own health care, and on occasions take control of who they wish their consultant to be. The findings have shown how the long-term illnesses become part

of 'normal' everyday family life affecting all family members with the ill young person recognising that their week-ends are not always the same as their friends.

CONCLUSION

Although ill children have the capacity to understand their condition and treatment, it needs to be set in an appropriate developmental context for them to understand the changing nature of this treatment and the progression of the illness. For the younger child this may require different methods of communication, and may involve collaboration between the play worker and the health professional to identify age appropriate ways of presenting information. More recognition should be given to the ill children - especially those children where hospital has always been part of their lives - and are continually learning from their experience of hospital treatment and care. In similar ways to their parents, children too become 'experts' in their own condition. They do know what hurts, they are aware when staff are rude to them, they do know who can or cannot place a cannula in their hand and it is no longer acceptable for health professionals to have an attitude that reflects 'children should be seen but not heard'.

CHAPTER, 8

'AT THE INTERFACE': RECIPROCAL PERCEPTIONS OF COMPETENCE, CARE AND EXPERTISE

The overall aim of this thesis has been to describe families' experiences of living (and in some cases dying) with children whose medical conditions seriously threaten the length and quality of their lives. In the first findings chapter I explored data collected from families experiencing what Ball et al, (1996) called 'the culture of childhood cancer'. In doing this, I stressed the ways in which medical regimes were experienced by many as a 'roller-coaster ride' in which parents' control over normal family life was replaced by the demands of treatment and hospital routines. In the second findings chapter I explored data collected from families experiencing what a number of writers have called 'the culture of disability', but primarily from the point of view of how diagnosis and treatment of a severely life-shortening condition moulded family interaction and shaped the interface with health and other professional services. I characterised this culture as an uphill struggle.

In this chapter, I aim to present data which will offer insights into the 'cultures' of professional service workers who help determine the experiences of families with seriously ill children. In the terms of metaphors I have been using, some professionals appear to be like the operators of the roller-coaster, some like the attendants who secure the harnesses, some like fellow travellers who help push the stone up the hill, some like obstacles that have to be surmounted on the way up the hill and yet others like bystanders who offer first-aid, advice and refreshment on the journeys. In the previous two findings chapters, I noted differences between a life-threatening illness, more often diagnosed during childhood or adolescence, and a life-shortening illness, often diagnosed at, or soon after birth. I characterised these differences very much on the one hand in terms of cancers in which medical regimes 'take over' family life for the duration of the treatment, and on the other hand, as chronic disabling conditions in which medical care is one component of a wider adjustment to more or less permanently challenging circumstances. Parents' perceptions of professionals vary, especially between notions of the 'expert' oncologist, in whose hands parents generally have to place the survival of their child, and the wider array of potential 'specialists' (medical and otherwise) who might join the family in finding better ways of caring for and extending the life of a severely disabled child. Hence this chapter explores aspects of the professional cultures that interact with

families of very ill children, aiming to distinguish between those practitioners whose priorities focus exclusively on treatment of the illness at one end, and those whose roles take them into wider care and welfare of the family at the other.

PROFESSIONAL EXPERTISE AND THE 'EXPERT' PARENT

In the preceding chapters I have noted that most parents perceive a lack of understanding amongst professionals of the social, psychological and emotional impact of the various treatment regimes on their families. This leads to variation in the nature of relationships between family members and different practitioners involved in the care of these children. It also leads to variation in the perceptions of who possesses the appropriate 'expertise' for a range of different situations. In the case of children with complex medical needs, especially when these conditions are rare and diagnosis is difficult and drawn out over time, exasperation with the failure of the health service to effectively manage the condition contrasts dramatically with cases of childhood cancer where parents' reliance on the expertise of the oncologist is virtually unquestioned. Further down the line, however, the level of expertise of the parents deepens as they come to understand the child's cancer and its treatment intimately through many hours by the bedside, intelligent involvement in discussion, further on-line research and careful observation of the regime in operation. This awareness may be accepted as quite formidable by the professional.

It is important therefore to explore professionals' perceptions of how families themselves cope with the illness, treatment and service provision. It is also important to explore how they recognise expertise amongst families when it comes to 'knowing' their child's responses, and understanding their particular treatments, and being involved in their care. The families I interviewed used the term 'professional' regularly, but often they used it loosely to 'donate' people who provide any form of organised support - such as a volunteer within formal service provision who may work in a professional way but who may not belong to a professional body. Respect for and trust in these 'professionals' was not necessarily a reflection of their medical status - the issue always was related to perceptions of 'expertise' - that is to what extent did this practitioner understand their child's condition, their child's wellbeing, their family's needs and the impact of their interaction with the family?

The concept of 'expert' and expertise was recognised in the *Expert Patient* initiative – “A New Approach to Chronic Disease Management for the 21st Century”. This was launched during 2001 by the Department of Health, to encourage patients [adults] with chronic illness to become more actively involved in their treatment. Commenting in the BMJ Liam Donaldson, Chief Medical Officer stated that “the patient as expert and partner in care is an idea whose time has come, and has the potential to create a new generation of patients who are empowered to take action to improve their health in an unprecedented way” (Donaldson, 2003: 1280).

Whilst the Department of Health documents relate to adults with chronic conditions such as arthritis many of the mothers in my research spoke about themselves as 'experts' in their own child's condition:

“For the families of children with complex and continuing health needs, and the children themselves, soon become experts in their care. They [the family] are often far more knowledgeable about the practicalities and intricacies of care and the underlying disease processes than many healthcare professionals” (Hewitt-Taylor, 2008: 29).

One mother in my research reported that when her son attended for his regular blood tests the “registrar would appear with a number of people and they would teach on him”. After hearing on numerous occasions how it was taught, this mum approached the subject with the specialist hospital:

“...I said, 'This isn't fair, we are still coping with all this trauma and he is being a guinea pig', so when we went up to the tertiary hospital I said, 'Can I learn?' and they said, 'Of course', so I got my certificate, I was certified to do the blood tests at home which worked out really well...” (Mother, family one - April 2006)

Therefore, in the 21st century, traditional perceptions that patients are incapable of decision-making due to illness or lack of knowledge are increasingly being challenged. Health professionals are now expected to share their expertise with others and to work in partnership with users of health services. In my research, it was clear that for this to work effectively within paediatrics partnerships, working has to go one step further. That is,

parents have to be taken seriously in terms of what they are relaying to the doctor regarding their child's symptoms. In Carter's 2002 study of children and pain it was noted that:

“One of the aspects of the medical encounter that the children and their families found particularly difficult and stressful was the feeling of being judged and often disbelieved. Families often felt that their own explanations were often interpreted through a variety of different professional lenses. The interpretations made by professionals did not usually fit with their own beliefs about their child's pain.” (Carter, 2002: 33).

Bury (2003) discusses the tensions that can arise between the experts and lay people when strong feelings are expressed and gives the example of parents' preference for vaccination of their children with a particular single injection instead of the MMR combined injection. He continues:

“It is clear from this and other examples that from a professional or political viewpoint, patient or lay views may be important and worth emphasising in the development of health policy, but are only likely to be allowed to influence practice under certain circumstances...an official rhetoric will grow up emphasising patient involvement and 'expertise' while on the ground patients will remain passive recipients of professional care” (Bury, 2003: 1-2).

KNOWLEDGE IS POWER: PROFESSIONAL CONTROL OF A CHILD'S ILLNESS. PARENT AND PROFESSIONAL CONFLICT IN THE TREATMENT AND CARE OF A CHILD

Traditionally parents have a powerful influence over decisions that children attempt to make in their daily lives. There is little doubt however, that during a severe illness such as childhood cancer, the perception is that decision making over the child's health is given over to the medical professional who freely discuss with the parents 'what is best'. The parent is left to actively manage what and how children are told about their illness, without always asking or including the child's point of view (Young et al, 2003). Certainly in the interviews conducted for this research there is no reported evidence that the doctors consulted directly with the child. All discussions regarding treatment took

place between the doctor and the parent, usually the mother, even though by the end of treatment a number of the children with cancer were in their teens. One mother of a child with complex medical needs, did however, describe a situation that occurred during an out-patient appointment when her 7 year old daughter was having an examination of her genitalia. No curtains were drawn around her and a nurse entered the room leaving the door open and her daughter exposed to anyone walking by. The point this mother was making was that the medical professionals do not appear to see her daughter as a person, and that they did not appear to have the same respect for a child's body as they would for an adult's. In cases of severe disability and complex medical conditions the division of power between parent and medical expert is not so clear cut and lines of control less obviously demarcated between home and hospital. Once cancer is suspected, diagnosis is swift and supported by both technology and established medical experience. In contrast, with severe and multiple disability, whilst one condition might be diagnosed, others producing subtler symptoms of which only the parent is suspicious, may take considerable time to be heard and ultimately diagnosed. One parent reported how her eldest daughter, who at four years of age was diagnosed with Arnold Chiara malformation with extensive syrinx neuromuscular scoliosis following a stroke, was an oddly behaved baby and child but had repeatedly been told that some children are like that:

“...she was a weird child you couldn't cuddle her, she would find it irritating...I used to say to mum, 'Take this baby away from me', because she was so miserable.... and [there were] very, very, very few times she was chilled and relaxed but them times we had good times. She would leave me like all stressed [screwing herself up] and I used to think I know children are not perfect but she's just got this stiff way [using her body to show me stiff]...” (Mother, family four - January 2006)

There is evidence which suggests that doctors sometimes fail to recognize that parents may be better at the identification of a serious illness or disability than the professional as parents tend to know their child best (Dixon-Woods et al, 2001). As a paediatrician, Spencer (1984: 103) states, “the ability to judge what is normal or abnormal for their own child is a skill which parents alone possess.” In certain instances it may take a period of

continual observation of the child before, as one parent reported, she knew something was wrong but “just couldn’t put her finger on it”:

“...he had just returned from the Isle of Wight on a school trip and he got off the bus, very pale and dirty like the rest of them, but he did not pick up. He was tired and I couldn’t put my finger on it...he was off his food, but the weather was hot so I rang the doctor and made an appointment for the following Monday ...He had quite a few bruises on his legs so we were sent for a blood test in the morning and I was a little concerned but ok, he came out with his badge and it said I have passed my blood test, and I was driving him back to school and I looked across at him and thought you have not passed this blood test you have got leukaemia...By the end of school the doctor had telephoned to say the results are not good ...and I said he’s got leukaemia hasn’t he, and she went, oh, every indication looks that way, doctor speak that was.” (Mother, family one - April 2006)

Once a confirmed diagnosis has been received, whether it is one of a childhood cancer or one of complex medical needs, the parents in both instances of illness enter an unfamiliar environment of a hospital and find themselves in a position of powerlessness and dependency. They are reliant on the medical professional for information and the hope that their expert knowledge will make everything right for their child. However, some parents reported that their first experience was not as good as they expected, and that they encountered additional problems for the ill child throughout the treatment period. A mother described what she called “the most traumatic afternoon of her life”:

“...she started her treatment at the specialist hospital on the Thursday but we couldn’t get a vein ‘till Friday because she was anxious and all her veins were popping every time they got a needle in and on the Friday afternoon they started at 2pm to try and get a vein and at 7.30pm I couldn’t cope anymore. I could see them almost strapping her down to the bed just to try and get a cannula in and literally... as we walked he (the hospital chaplain) took me to a room and he didn’t talk about what they were doing to her we just had a cup of tea and sat...it was the most traumatic afternoon of my life and she is now needle phobic...” (Mother, family two - April 2006)

The mother continued to explain that since that afternoon she had discovered that not all doctors have the aptitude, especially with children, to quickly complete the procedure of placing a cannula in the hand:

“...some people since then who actually specialise say it’s a knack that some people have and surely if you are coming to canulate a child at that age [8 years] then send a specialist - don’t send somebody who is a bit, sometimes I am alright, sometimes I’m not, that was not helpful and it just went on from there really...”
(Mother, family two - January 2006)

Since the Platt Report in 1959 parental presence in hospital has been advocated within paediatric care and since those early years accommodation is now provided for the parent(s) to ‘live’ at the hospital for the duration of their child’s hospitalization. At these times the primary carer’s relationship is more linked to the nurses on the ward than with the consultant who is often in the background except when they are on their ward rounds. A number of studies indicate that there is an expectation from nursing staff that parents will be involved in the nursing care of their child and often this assumption is not fully discussed with the parent (Algren, 1985; Brown and Richie, 1990). Regardless of this, the distribution of power remains uneven, with the nursing staff making the decision whether or not to negotiate the care-giving roles.

Therefore, the parent, considering nothing but the wellbeing of their child, remains at the bedside, as identified by Coyne’s study (1995) where parents often viewed their participation as essential for their child’s emotional and physical welfare. One mother reported that she stayed partly in order to be reassured that the doctors and nurses could be trusted with the care of her child:

“...the knowledge and of course you know your own child, they, they [eyes raised] medical people, professionals, people in general.... try and treat everybody the same, where you do, they say mother’s instinct...some times they do talk to you as if you are neurotic or paranoid, and there have been a good few times when we have persisted over something and it’s turned out right, whether its medicine dosage or you are double checkingand you are double checking all the time and that’s exhausting...” (Mother, family two - April 2006)

Although this mother talks about the professionals generally treating everyone the same, she was not alluding to the treatment where there is little flexibility in the protocols for childhood leukaemia, but to the health care professionals who appear not to see the patient as an individual within their own illness. Neither do they see the reactions of parents who are worried about their child's prognosis and of being caught up in the hospital system. However, for another mother who spoke about her daughter having had a brain operation to amputate the cerebellum tonsils, her impression was that everyone was treated the same because that was what the text book said would work. In fact - what had perhaps worked for others - in her daughter's case failed:

“...when she had that brain operation and tonsils amputated the CF fluid that's absorbed in the brain go down into the spinal cord and actually drains away, where hers hasn't. It's the lesion and adhesions that have kinda built up that have caused the cavities and not the cerebellum tonsils, so in hindsight, text books said if you have these amputated the CF's flow, but it hasn't happened in her case...” (Mother, family four - January 2006)

Whilst acknowledging that the families of the cancer children are on a roller-coaster ride, within the hospital setting the primary carer quickly has to adjust to the new environment and begin to learn the treatment process. Although they cannot change or control the protocol, the more the carer understands about the disease, particularly from the internet and from watching the nurses, the more it appears that the mother's self-confidence around the medical professional increases. The increased confidence and knowledge of the disease was often a personal development in response to frustration with the health care system and the fact that they personally felt helpless. However, a number of respondents in this research reported that with their increased confidence the lack of trust in the nursing and medical staff had grown rather than diminishing. One mother described her experience of staying with her daughter on the ward of the local shared-care hospital:

“...you are just watching points all the time and you don't want to leave them because of it, because you are worried that they are going to come in and do something detrimental, give them something they shouldn't have, get the wrong notes.... not read something that is written up...for people to be a bit more

switched on generally in the caring profession, that we have just a bit more sensitivity just to be what I would expect to find, people who care. To some it's just a job..." (Mother, family two - April 2006)

One mother reported that through her increased knowledge, awareness and confidence she not only challenged everyone concerned in the care of her son but, following one incident on the ward, insisted on new boundaries for ward staff regarding any tests that had to be carried out. She also pointed out that whilst challenging is right, there are times when it can work against you, and how what she had said had been taken literally by the nurses to the detriment of her son:

"...I went back one day and Richard was upset because they had done a thumb prick and he didn't like thumb pricks because they hurt and he was really distressed, so I said 'I don't want you doing anything like that unless I am here', so the next day I go to work at 11.30am and back again at 2.30pm and he was sitting there. Remember he was in isolation, and he said, 'I am really hungry, I have had no dinner', so I went down and said, 'I know I said don't do anything to my son unless I am there, but I did mean for you to feed him..." (Mother, family one - April 2006)

She continued to say that eventually through her acquired knowledge and her belief that it was right not to just accept what is being said by the ward professionals her son's confidence increased and he too began to question everything that the nurses said when his mum was not present:

"...one day they came in with a syringe behind their backs, saying 'It's that time again and you hate this don't you?' he said, 'What are you talking about?' they said, 'Your injection'. Richard said, 'But I don't have injections', 'Oh yes you do', again, 'I do not have injections, I have a portacath, there is no reason for me to have an injection', and she went, 'Oh sorry Richard, this is for Robin next door..." (Mother, family one - April 2006)

Often in the circumstances of children with complex medical conditions there is a power conflict between the parent and professional, especially during the hospitalization of the

child. Often, this is where parents are expected to relinquish control of their child to the professional, and yet are competent and confident in caring for their child at home. In fact they are expert in their child's condition. One mother described how she felt having to do certain procedures on her daughter following a reconstruction operation:

“...the stuff I have had to do for her, Pam, is mind blowing and my concern and dread is that as she gets older will she remember that I have done these things to her that were painful and I had to hold her down to do them...” (Mother, family four - January 2006)

Some parents' accounts show that, whilst on the wards when they have challenged the health care professionals for a variety of reasons, they have seemingly stopped mistakes being made. As reported earlier though, such intervention appears to have a detrimental effect on the relationship between staff, patient, and parent. Two mothers recalled how, when they were both on the same ward with their children who have different but similar complex medical needs, they became quite a powerful team who challenged the boundaries of how ward staff perceived parents should behave when on the ward:

“...well we just spoke out about the attitude of the nurses and doctors towards us mums and how they spoke to us and our children. When they were going to carry out procedures, they would just come and stick a needle in, so we spoke out. In the end they [the staff] put the beds at each end of the ward and told us we were not allowed to talk to each other whilst we were on the ward...” (This episode was reported in the interviews of family four [January] and family six [May] - 2006)

Unlike childhood cancer, hospital life and treatment for the children with a life-shortening illness and/or complex medical needs, cannot follow an established regime of treatment as in the majority of cases the conditions are so very rare. For these children there never will be a cure and treatment is more to do with the management of the illness. Even with the rarity of certain conditions, the primary carer is aware that a nurse or doctor may have some experience in treating one aspect, such as cerebral shunts. The difficulty for parents is that the nurses or doctors appear to be unaware that their proficiency does not extend to every child and they continue to follow the guidelines for

the procedure not recognising that not all children are the same. It seems that although the mother lives with, and cares for her child, the hospital staff still disregard her knowledge of the condition and she remains on the outside of their culture where they remain the professional, and seemingly still knowing best. One mother spoke of the difficulties she faced when taking her son with Aperts to her local children's A&E:

“...locally it's not brilliant. You walk into A&E and say, 'I think my child's shunt [cerebral] is blocked', and because they know about shunts then they think they know about shunts in a Aperts child, and it's a completely different story and they kinda like dismiss you...and I have been there 3-4 hours and ending up having to be in hospital overnight and I don't think they understand, and if they don't understand that's fine, I don't expect them to know all about Aperts, they can't know everything...” (Mother, family three - June 2006)

The child may be under a number of expert consultants, for example, a paediatric neurology surgeon who works with a number of rare conditions that are linked to the brain. Unfortunately, at times, the way that this expert knowledge is communicated to parents can feel more like a threat and they sometimes feel coerced into agreeing to treatment or an operation that they themselves are unsure about. One mother spoke of a time when she felt she was being coerced - and possibly threatened with social services - if she didn't agree with the surgeon regarding a brain and spinal cord operation on her daughter. She had undertaken her own research on the procedure and recognized that the information she had been given was different to the information she had researched:

“...the neuro-surgeon said he had ways to make me change my mind but that he hoped we could work as a family and hopes he knows me enough to be able to sway me to go yes.... But I'm not stupid. This operation, it's the spinal cord, I'm not going to jump in...I've got all the data on it, it says it's only a short term measure but he said it's a long-term measure...” (Mother, family four - January 2006)

Over time the families increasingly learn the language, the procedures, and medication linked to a specific illness or condition that eventually leads them to become an expert in their own child's illness. As this knowledge increases it enables them to take more

control and to have the confidence to challenge the medical expert. However, regardless of their increasing expertise in their own child's condition which can actually be more sensitive and detailed than the healthcare professional, they remain on the outside of the medical culture.

PARTNERSHIP WORKING: PARENTS' RELATIONSHIP WITH PROFESSIONALS

The idea of partnership working between patients and their doctors is now a key element in the modernization of the health service. However, what has been given little attention is how the partnership will work when the patients are children. In their paper *'It takes three to tango': a framework for understanding patient partnership in paediatric clinics*, Gabe et al, (2004: 1071-1079) points to the case of children and that the partnership in this instance is shaped by organizational and legal settings that create boundaries. Ultimately, they suggest, there are three parties involved; child, doctor, parent. Children are normally present during a paediatric consultation and although the doctor may rely on the child for information regarding what hurts, how they feel, they may be excluded from the actual discussion between the doctor and parent regarding treatment issues. There is, however, evidence that doctors do spend time talking to a child or adolescent patient, but this 'talk' is more geared towards a joking relationship (Tates and Meeuwesen, 2001). In this three way partnership the parents often feel powerless in the face of doctors' expertise, with an additional impression that "nurses are being paternalistic and perpetually 'busy' leading to intimidation and further loss of control..." (Langton, 2000: 27). The question is, given the opportunity would a child's comments actively be heard? The answer is perhaps reflected in the case of a 15 year old girl who had her decision to refuse a heart transplant overruled by the High Court who advised the heart transplant doctors to act on their clinical judgement and overrule lack of consent. McHale and Gallagher (2003) suggest that in the past both parents and children may disagree with medical advice, and in these situations the courts have generally overridden the parental wishes.

There is an impression that parents exclude their children from treatment related discussion with the doctor. However, three points have to be considered: firstly, for the majority of parents who have a child with a life-threatening illness, their only concern is that on treatment advice from the doctor their child may have a greater chance of survival regardless of what that treatment is. Secondly, that within cancer trials there is little room

for discussion, it is treatment or palliative care, and given the opportunity, the ill child would probably agree with the decision that their parents have made. The third point is that children are very astute in their understanding of what is expected of them within a clinical setting and behave accordingly. In his book *"They Never Want to Tell You"*, Bearison, (1991) states that:

"Children who have cancer become masters at perceiving what others are reluctant to talk with them about. When these children decline to talk about their condition in the presence of adults, it does not reflect their lack of concern or their innocence but their sense that adults are unable to talk candidly about it" (Bearison, 1991: 12).

As suggested earlier in this research, none of the parents reported that they included their child regarding their cancer treatment procedures, although, a nurse specialist did report an instance when a child who had for the second time relapsed, and against the doctors' and initially his parents' wishes, refused to continue with the treatment for his cancer. The specialist nurse continued to describe how following several interviews the young patient was deemed to be 'Gillick' competent and treatment did not proceed and he died shortly after:

"...you see them [the children] start to protect the parents, so you see children go along with whatever the parents decide, I think I've only ever come across one child who said 'I've had enough, I want this to be over, I don't want any more, it's my life', but he's the only person ever in my career..." (Paediatric Oncology Nurse Specialist - May 2007).

In the situations of a child with complex medical needs the relationships between doctor, child and parent is somewhat different inasmuch as it is an extended relationship that for a large number of children begins at birth or shortly after and lasts throughout childhood into young adult life. Problems occur when these children reach 16 years of age and are no longer viewed by the NHS as being a paediatric patient and are transferred to adult medicine. This problem has been mainly created by the advances in medical technology that maintains the life of the child who some years ago would have died either at birth or shortly after. The consultants are often working with very rare conditions where there has

been little advance in the knowledge of the illness since the discovery of the original condition. Therefore, from a medical perspective, no-one is sure what the next step will be regarding the treatment. In these circumstances especially when there are a number of different consultants involved, each having their own perspective of the 'right' treatment for a particular child, the parent may be left feeling that treatment is more to do with guesswork than knowledge. One mother gave her opinion as,

“...if its one condition then that’s fine, but when you get into complex needs I feel that my child and others are used as guinea pigs...” (Mother, family six - May 2006)

In contrast to the specialist treatment which children with cancer receive, life-shortening conditions which are the result of rare illnesses or a complex set of physical abnormalities appear to some parents as though they are as much a financial nuisance as a medical challenge. One mother, with two children with complex needs expressed this as:

“...its like you are a waste of NHS money...I don’t know what we need as well, so how much am I using of the NHS and I think they might be resentful...” (Mother, family four - January 2006)

Further to this another mother spoke of her frustration at having so many different health and social professionals involved in the care of her daughter:

“...it’s a circus, demented.... I hate it.... that is the biggest thing I hate about all this, when you’ve got children there are other agencies, and especially with special needs you have all these people involved who are doing nothing really, they do their penny worth and then leave. No-one is tying up the strings and making me bows and yet they are all everywhere - all these untied laces and they are getting on your nerves and they are going to be dumped in the middle. There are families out there who have been dumped on the slag heap because of their [the medical/health/social/ care providers] bloody lack of tying up bows...” (Mother, family four - January 2006)

Partnership working between the consultant and parents within childhood cancer has to a large extent been present for some years because of the very prescriptive nature of the treatment. With the ever-present goal for doctor-patient-parent of knowing that achieving 5 years in remission now equals 'cure', it is as if the parents at diagnosis are given a check-list of facts such as, 'if there is no deviation from the list and we all work together, all should be well'. Oncology consultants and families work within a protocol based on a well-funded research base, whereas treatment for many life-shortening conditions is more likely to be highly individual and geared to each child's particular and often highly specialised needs. For the parents of children with complex medical needs, partnership working, like the condition itself, may take many years to achieve some sort of 'working together' relationship. One mother reported that for her it had taken almost eight years to reach the stage of having an open discussion with consultants:

“...the consultants now don't tell me, but now give me the space to hear me out then they give their opinions, most of them now have respect...” (Mother, family four - September 2006)

It appears that many of these families find themselves having to fight not only for service provision, but also for respect and space to be heard, whether that is to agree with a consultant or other professional, or to disagree with what has been suggested for the care of their ill child.

SUMMARY

I have considered data from families where a child has a life-threatening and life-shortening illness and their perceptions of how the professionals care for their child. I have noted that some perceive an apparent lack of understanding of how the illness and associated procedures impact on daily life. Few parents would acknowledge that following the original diagnosis they have any awareness of the treatment or medical culture. However, over time many parents too become an 'expert' in their child's illness. Although the Department of Health launched the *Expert patient* initiative during 2001, from accounts of many parents in this research this appears not to have been clearly transferred to paediatrics. The parent 'expertise' seems to either be ignored or overlooked by the professionals in control of their individual child's treatment and care.

It appears that, from the outset of the illness, parents who feel that they know their child best can encounter difficulties in convincing a medical professional that something is wrong with their child, especially when there are no obvious symptoms. Even when a confirmed diagnosis is achieved and parents become involved, the child still appears to be left out of any discussion concerning what occurs next regarding treatment. Once the child is hospitalized the parent and ill child are faced with an unfamiliar medical environment that they are reliant on for care, treatment, and information. From the reports of parents from both categories of illness – life threatening and life-shortening - their expectations of care do not appear always to be met. Moreover, a number also have encountered mistakes made by nurses and other medical staff that increase their anxiety, vigilance and demands.

Within the modernization of the Health Service there is much discussion on partnership working between patients and their doctors. However, little attention has been given to how this will work within paediatrics with the growth of children's rights attached to the Children Act (1989) and their developmental understanding of what the treatment involves. A further issue that has been raised in mothers' accounts is their perception of how the medical culture of the NHS views their particular child in financial terms regarding long-term treatment and care. Issues were also raised about the apparent number of professionals involved in their children's care and how there was no apparent connectedness between the services the professionals worked for. With regards to partnership working it appears from the accounts of mothers from both categories of illness that it takes a number of years to achieve a level of 'working together' partnership.

THE PROFESSIONALS'S PERCEPTIONS OF THE DIFFICULTIES THAT FAMILIES FACE

Following a confirmed diagnosis of either childhood cancer or a complex medical condition the lives of the ill child and their family become, over the years of the illness, entwined with a range of professionals from health and psychosocial care. For the families the treatment and care of their ill child means that almost every part of their life is open to scrutiny. Nurses come into their homes to provide treatment and health professionals within the hospital may question the ability of the family to cope with the care of the ill child. Forms for Direct Living Allowance have to be completed that request personal information that often leads to a family's perception that others are making

judgements on whether or not they are coping with their particular illness situation. The professional's role is to be supportive to all members of the ill child's family in the many varied situations that they may find themselves. However, it is not always as easy or straightforward as it may sound.

THE SOCIAL WORKER – FRIEND OR FOE?

It was the perception of some of the interviewees that the diagnosis of their child's illness conjured up a number of strangers who entered their lives and often dictated how they should act in order to cope better with the illness. These strangers are professionals, but this sense of intrusion into their family life may be heightened because there is usually a social worker attached to specialist departments of paediatrics, such as a renal or heart unit, or within the community working along side the children's community nurses. Although the role of the social worker is to be supportive, some family members saw their role as one that 'fitted' the stereo-typical view of someone who 'takes children away', and where possible the families seemed to try very hard to retain their privacy which at times was actually detrimental to their needs, as one social worker reported:

“...there are some families when you go in and you do the initial assessment they get very cross because you have written it down, but you have to assess their circumstances, and you ask about how are the children managing, what other people are doing...families are very private and they do think you are going round looking at bruises and other things like that and expecting them to fall apart at the seams as it were...” (Social worker - January 2007)

Whilst a number of families strive for privacy and 'get on with it', by continuing in this way and by not being too vocal regarding the daily difficulties that the illness has brought to the family, they almost select themselves out of receiving the practical support they need. However, there are families that are very vocal and very demanding, not only in relation to the medical care, but also regarding what is available from agencies such as social services, and while these families succeed in obtaining more, there are the undemanding families who may, unfairly, receive less, as this social worker reported:

“...part of the difficulties within social services is to rationalize why some people get more than others.....and it's only recently [become obvious] with the

disabilities resource panel having an eligibility criteria. The families are weighted, there is a scoring system now, so when they get what they get they have been involved in a scoring system that gives us a fairer idea of who is most in need of those resources, and in terms of allocating you can say, 'Well I'm sorry but you can't have this because of X, Y, Z, and your need isn't as great'. It's the real world and resources are finite. There are extenuating circumstances, some times people demand more and they need it, ...more resources are needed, but I don't think there are enough, I think there are families who just live on the edge of what they can manage and cope with..." (Social worker - January 2007)

Regardless of the situation, the majority of the families preferred to be told the truth, whether this is to be told there are no more resources available, or more importantly, as the social worker continued to report, that little more can be done in the treatment of their child:

"...families feel better with actualities rather than myths but they [doctors] don't get it, and sometimes when they ask the doctor a direct question I don't think they get a direct answer...I've heard that doctors are getting better personal skills in their training about breaking bad news...I have known cases where doctors have agreed that something is hopeless for a child and are not expected to live very long and that child goes on to live for a very long time..."(Social worker - January 2007)

A perception is often formed throughout the illness by professionals and others that the families are well supported by their extended family. Unfortunately, and for different reasons, support is not always available as this social worker pointed out:

"...I think the hardest thing for families is confiding in their own [extended] families. I sometimes find that they are not best supported by their own families for a variety of reasons. Sometimes they don't even ask people, they just assume they are not going to get it..."(Social worker - January 2007)

The frustration for professionals is that when they can see a member of the family is in need of practical or emotional support, even when it is offered, it is frequently refused:

“...I have to tell you sometimes you can’t even work with the ill child. You don’t always get the access from the parents to be able to see a child...One mum never gives me any time with her child at all. It’s very hard to sit and chat with him on his own. I go in, have a little word, she stands there then I am almost ushered out. She has not got to the point where she thinks her son could benefit from talking about it, she is very keen in saying to me ‘I do not want you to upset him’...”(Social worker – January 2007)

As both life-limiting and life-shortening illnesses are considered ‘long-term’ there are bound to be frustrations for both the families and the professionals, for a variety of reasons:

“...it depends on what access you get, you can’t always get access to dads, they are at work, some find it uncomfortable but not all of them do, they are all different. You can’t say there is one family you go and see and do A, B, C and I will do all this bit and this will be the result of it, it doesn’t work like that at all. So you go in there and you go ‘That doesn’t work, this isn’t how its going to be...” (Social worker - January 2007)

Frustratingly for many families, it frequently seems that there is no continuity of care from the social workers due to the high turnover of staff. This social worker confirmed in her interview that this was a problem:

“...staff turn-over is very high so you don’t always have that continuity...”(Social worker - January 2007)

In the role of providing emotional support to families there is always the possibility of having to deal with ‘bad news’, never more so than when treatment fails and a death occurs. Regardless of the success rate in childhood cancer and the large number of children with life-shortening illness that survive into adult life, there are deaths within both categories of illness. The impact of this on those who work with the families - whatever that role involves, can be both emotionally and physically draining, and on

occasions devastating, and yet few receive workplace support. Therefore the question is 'who supports the supporter?'

"...Supervision, I have supervision with my team leader which is every four to six weeks, but I think within the team there is a lot of support for talking about it. Although I have been there two years, in my personal case load there hasn't been a large number of deaths, although there have been deaths, it was too late for me to become involved because the hospital hadn't informed us..."(Social worker - January 2007)

It is fair to say that the aim of all the professionals who work with these families is to help make their life easier. To do this effectively, the many different professional groups involved in the care and treatment of these children have to communicate with each other and work together. The social-worker spoke of how there are gaps in communication between professional groups and how this lack of inter-professional working also extends out to the families, often excluding them from support:

"...one of the big problems is ...three deaths that have happened really quickly and the communication between the hospital and the team in getting the social worker hasn't been good, and that's largely, sometimes they [specialist hospital] don't know that the post exists. That can't obviously be explained for the local hospital because they know and they don't always refer through straight away so you don't get that information...but what I think is difficult is when they [the families] don't get a link on to the other services..." (Social worker - January 2007)

Although local organizations offering support to the families provide information leaflets to the hospitals involved with the ill child, this information seems not to be passed on to either the families or other relevant professionals outside of the hospital. No one would argue that the medical management of the child is vital but for the families there is more to manage than the illness. Hospital staff appear to ignore the demands of these families' everyday lives which create further hurdles for the families to manage. This social worker reported how basic communication for families is often ignored by hospitals:

“... I don't think consultants always think about it because there is always the medical management going on...there isn't even a psychosocial case meeting before they move on [the family] and once they have moved on, people aren't thinking, 'Oh well if the worse happens they might want local support', and there is a lot of movement between the local and specialist hospitals and that fragments things then nobody takes it on board...”(Social worker - January 2007)

Families appear to become isolated within the medical setting because information is clearly not passed on. This is regardless of the professional support services that are available within the community. This too tends to confirm parents' views of the continued paternalistic approach by hospital staff.

THE TERRITORIAL PROVISION OF SERVICES: MEDICAL EXCLUSION OF SUPPORT

From the parents' perceptions reported in previous chapters some health care professionals appear to work from an insular position of medical management. Their failure to understand that families may require someone other than hospital staff to provide support in the early stage of an illness helps to create additional hurdles. Also, when nursing staff become too involved with emotional support of family members, their professional boundaries may become blurred. These members of the medical team may at times experience a conflict of interest between their professional role and their commitment to the family. This close relationship as reported earlier can lead to a failure to refer the family elsewhere or to provide information relating to emotional support external to the NHS, as this CEO reported:

“...it's the medical that I have a 'tussle' with, if that's the right word. They close the triangle, they form a relationship with the families and then expect the families when they can't work with them anymore to pick up a referral to the project, and by that time the family has formed a close bond with the medical staff that it's nigh impossible for a third party to come in...” (CEO - February 2007)

Unfortunately a perception by many health professionals is that, other than themselves, the only other professionals who can support families in an effective way are those who hold a degree in psychology. However, this barrier of 'in-house professionalism' does not

always work for the family as in many cases all the medical team appear to see is a 'patient' and not the family. This serious lack of understanding of how the family cope on a daily basis helps to create a greater problem regarding the provision of emotional support:

"...I think I had been working with this particular family off and on for about four or five years, the child had been quite poorly and she went to a hospital visit and the consultant picked up she was feeling low and referred her to the psychologist. I think it was from the family that I heard about it, I spoke to the consultant and informed him that I could no longer continue with the family. He didn't understand several things, how we worked, how I was working with the whole family, because he saw it as a family issue and not the child issue. I had to end the work because professionally I cannot work in parallel when someone else is offering therapy. We lost contact with the family for about six months then bumped into mum who was hopping mad about the psychologist who had basically blamed the parents for how their daughter was feeling, and, apparently at a cognitive behavioural level, noted that the parents were the issue, the parents were the problem; none of the family felt that was true at all so they had come out but remained very angry. Happily they eventually came back to the project and I have been working with them ever since..."(CEO - February 2007)

Many parents have developed an impression that professionals can extend their roles to cover all of their possible needs. This leaves the families confused about basic information about the illness, treatment and available support, and about which person does what, as this CEO confirmed:

"...its around confusion of roles ...so what is the role? People see social workers as coming in to take their children away or whatever, and social workers will say that isn't their role and in actual fact I'm not 100% convinced what their role should be or is. A hospital social work team are doing complete therapy group work, individual work, parent's group, father's group. Families need help they need help with finance and equipment and all sort of stuff, and again crossing the line and in becoming therapists what happens to their case load..."(CEO - February 2007)

The provision of emotional support can be difficult for families to access and at times very difficult to accept. Although this may be more to do with the societal and external family attitude towards counselling, at times it comes down to whether or not a professional believes that a family is coping:

“...partly an assumption about the need for emotional supportand it could make people realize the impact of the illness... but I also think counselling, emotional support, is stigmatized, you know whatever you call it, how ever you wrap it up its still the same at the end of the day...”(CEO - February 2007)

Staff within all organizations working with families, whether the NHS or a community service, have to be grounded enough to accept that there will be times when the child is dying and will be receiving only palliative care. These situations are difficult for all concerned and there are times when it seems that the staff can be ‘sanctified’ by the general public, especially within a children’s hospice setting, because of their involvement with dying children, as confirmed by the CEO:

“...there’s a lot of martyrdom about working in the area there is a lot of vying for position, again bereavement is territorial but when you get into palliative care its even more so if that’s possible...”(CEO - February 2007)

The majority of families attending hospital with their child present a coping ‘face’ to the professionals who at times make assumptions that whatever they see in front of them is a true reflection of how the family is actually working. Conversely some families can be labelled as dysfunctional, when in fact the particular family may have always thrived on chaos, or live a life that is not viewed as acceptable because it does not ‘fit’ the professional’s view of ‘normal’:

“...a lot of health professionals, possibly all professionals.... I don’t know, have this assumption of this vulnerable family with a child with a chronic illness of some description who will be very grateful for their help who will have everything else in their life sorted out. You walk into a lot of the houses - the issues have been around for years, whether the family is together or separated or

whatever.... it's something you pick up really quickly. I think much quicker going into the home than in an office but you pick them up none the less, and the medical staff surely can't cope...they like the white middle class, the squeaky clean type family, I don't think they give them preferential treatment necessarily. You can hear when you go to meetings the way that they are talking about families they don't like.... how critical they are.... and however much some of it might be true its not the way that they are talking about anybodyand that family has got to that position with an ill child. Its not of their choosing, it's the make-up of the family and what right have the medical staff got to criticise them how they are as a family...?"(CEO - February 2007)

Assumptions made by professionals are often based on a distorted picture of family life. The 21st century family frequently includes a step-parent living within the home of the ill child. Although the separated birth parent lives outside the family home, there is every probability that there is still a relationship between the parent and child. By not accepting the whole picture people continue to be excluded:

"...I have tried with one referral from a social worker.... offered to support the dad who didn't want support at that time but may come back in the future. What he was really concerned about was adaptations to his family home because the family was split and his daughter visited at weekends. I went back to the social worker and said you know this is part of what he wants....that family flagged it up to me, since then it seems to be a recurring theme because so many families have split now..." (CEO - February 2007)

It is through a professional assessment of needs that decisions are now made regarding what support is required by a family. It is a method by which individuals in the family can be easily over looked:

"...I think they [dads] are quite receptive. I think it's a bit of a myth.... I think it's who gets referred... I think they are much more receptive...[It's] siblings who are ignored, [or] fathers who are ignored or don't want to talk, I am not sure necessarily want to talk I think that's an assumed need these days, I think the

dad's, again I think its something to do with the referral sometimes its availability..."(CEO - February 2007)

THE MECHANICS OF MEDICAL CARE: THE LYNCH-PIN BETWEEN HOSPITAL AND HOME: PAEDIATRIC CLINICAL ONCOLOGY NURSE SPECIALIST

Receiving a diagnosis of childhood cancer affects everyone's relationship within the family and inevitably affects the family dynamics. One of the many difficulties the family has to face is that there is very little time to digest the news and information they have been given. They are often helped in this by support from the paediatric clinical oncology nurse specialist. The nurse I interviewed noted that:

"...as the symptom care team we are really the family's lynch-pin between the hospital and home...we see all newly diagnosed oncology children as a out-reach service in hospital before they are discharged and arrange a home visit...we also manage palliative care..."(Paediatric oncology nurse specialist - May 2007)

As previously stated, at the initial treatment phase there is so much information for the parents to digest that they frequently approach the clinical nurse specialist to clarify what they think they have been told. The nurse specialist spoke of how parents approach her regarding information:

"...you have to be very clear about information, you cannot misinform them [parents] and you can't say I don't think so...when a parent asks me any treatment directive question. If I don't know the answer I say, 'I don't know the answer'. If it comes down to specifics [such as] 'Why not use this drug instead of that drug?' it's a case of, 'Let me go back and raise it', or what is best for parents is 'Why don't you raise it at your next appointment...?'" (Paediatric oncology nurse specialist – May 2007)

She continued to report that the family have choices removed from them:

"...I think oncology trials and treatment are so regimented, these families have no choices, they fit into a slot that fit this way, if you don't do this you go down that way, certain palliative care..."(Paediatric oncology nurse specialist – May 2007)

Following the shock of diagnosis there comes a period of time when the family create a new routine of home, treatment, home. It is around this time that the parents become more confident in their own awareness of the disease, and begin to use the internet as a resource for information to discover new treatment trials or drugs from other countries, especially the USA. It is through this additional source of information that parents often become more confident and demanding. This is especially so if the parents' perception is that the health professionals and/or cancer centre they attend are not doing their 'best' for their child. At this stage the parents begin to challenge the professional decisions of what happens next. The nurse specialist continued to report that:

“...that’s quite common...they will talk about them, ‘Oh I have found this on the internet and in America outside New Jersey there is this trial that’s cured all leukaemia’...the consultant usually knows because it’s a universal network, it could be a bona-fide trial, for example one family spoke about a drug that is now used and on trial in America, and we did know about it but it was not licensed here so it was a case of, ‘This is not available the best treatment we can offer is this...’”(Paediatric oncology nurse specialist - May 2007)

The treatment continues and the ill child moves closer to the time when they are in remission and treatment comes to a close. Whilst everyone is delighted that this point has been reached there is for the parent an element of trepidation, as the nurse specialist points out:

“...when parents come back to clinic even throughout treatment you see their relief getting easier the more clinic visits they make, it means that things are going along the right path, you are having chemotherapy when you should and you are on a treatment path and when you see parents getting anxious its towards the end of treatment when they come back for follow-up, there isn’t any more chemotherapy and it’s a watch and wait...”(Paediatric oncology nurse specialist - May 2007)

For the majority of families they continue with the treatment that is now up to 80% successful for childhood leukaemia. There are, however, a percentage of children with

leukaemia and other forms of cancer and tumours where treatment fails. It then rests with the consultant to relay the 'bad news' that no more treatment is available that will cure their child. By the time the parents receive this information the child has been cared for by a consultant and team that consists of registrars, nurses and specialist nurses, I asked 'Who finds it more difficult, the team or consultant?' The nurse specialist reported that:

"...consultants every time, because they are there to cure, and the families often see the consultant. They see more children that they cure than children that die and they have built up a rapport with the family, I think it is [difficult] for the consultant to do because it's the consultant who has to sit down with the families..."(Paediatric oncology nurse specialist - May 2007)

At the time of being informed there is no cure, the families enter a new phase of their child's illness which not all parents can accept or believe. The clinical nurse specialist pointed out:

"...the difficulty with palliative care, it's getting them [the parents] to accept that cure is not an option and for me that's par for the course, and you get to know these families quite well and you would like to support them in their quest for a cure..."(Paediatric oncology nurse specialist - May 2007)

She continued to give an example of a father who found it difficult to accept his son was dying:

"...the family are a prime example, dad searched for a cure during the palliative stage and his son was actively dying and it wasn't that he was unaccepting or had no faith in services.... it was the yearning to do something practical to try and save his son's life. There was never any other motive than to do that..." (Paediatric oncology nurse specialist - May 2007)

The palliative care of the child usually takes place at home and perhaps for the first time during the illness the parents are in control of what happens next. On occasions the parent may begin to direct the professional, who does not always agree with what is happening.

It is then that the question should be asked, whose needs are we here for? As the nurse specialist reported:

“...we are visitors in their homes, we offer the service.... they don't have to take it. If they want to close the door and not talk to anyone that's their right, and less experienced staff would see that as a child protection issue, but that's because the medical has been so much in control. This child belongs to the parents and if they are caring and loving the child and providing the things the child needs, then who are we to say that they are wrong? I had to have a conversation which was difficult as he was a professional saying, 'Whose needs are we addressing here? Are we addressing the family's needs or are we addressing our own?' Just because it doesn't sit comfortable within our normal model of working it doesn't mean to say it's the wrong model...” (Paediatric oncology nurse specialist - May 2007)

I asked the question 'in that case whose problem is it?' She responded by saying:

“...oh the professionals...I think professionals do find it hard, certainly doctors who aim to cure.”(Paediatric oncology nurse specialist - May 2007)

The majority of children diagnosed with cancer are in contact with a paediatric clinical oncology nurse specialist both at the shared care hospital and at the main treatment centre. In building up a relationship with the families they often have a difficult role in combining treatment alongside an understanding of the emotional impact of the diagnosis on the family. The nurse specialist often acts as a lynch pin between hospital and home. This is particularly so when no further treatment is available and palliative care is undertaken at home. In these unfortunate circumstances the nurse specialist is part of a team which has to work with, and support the parents through their child's final stage of the illness. This may include parents who continually strive to find a cure via the internet.

CYSTIC FIBROSIS PAEDIATRIC NURSE SPECIALIST

Cystic Fibrosis is probably one of the few life-shortening childhood illnesses that most people have an awareness of, and may even know of a family where a child has been diagnosed. Although there is no cure, through medical research life expectancy now often

extends into mid to late thirties. Although deaths still occur in childhood and as young adults, since July 2007 a major advance in the diagnosis is that all babies born in the UK are now screened at birth. The Guthrie Test detects Cystic Fibrosis offering a confirmed diagnosis at around three weeks of age. It is at this stage that the paediatric Cystic Fibrosis nurse specialist becomes involved with the family for the rest of the child's life regardless of how long that will be:

“...I know the family from the very beginning when the first diagnosis is given and I almost become accepted as a friend of the family, so I know what is going on and I look at it [CF] holistically and I am privileged to information that wouldn't be given to anyone else...so its actually understanding what is going on in that family from all directions not just the episodes of admission...”(Cystic fibrosis nurse specialist - June 2007)

Although babies now have the Guthrie Test there are children who were born prior to 2007 that are diagnosed much later than three weeks of age, and in certain instances a diagnosis is confirmed well into adulthood often with surprising results as the PCFS nurse confirmed:

“...it can happen... well, adults can be diagnosed, oh yes, yes at times you know they have been ok during childhood... the less severe mutation... they suddenly become unwell, or with men 95% of CF men are infertile and this gets picked up in fertility clinics because there is a particular defect that shows up, and if it shows up then they do the test for CF, so you get quite a few adults picked up who suddenly start to show some symptoms...”(CF nurse specialist - June 2007)

However, parents who following the birth assumed they had a healthy child were shocked when they were informed after only a few weeks that their child had Cystic Fibrosis. The parents face a very confusing time and a succession of losses that include the re-organization of their life, re-defining of their roles and grief for the healthy baby they no longer have (Bristor, 1984; Olshansky, 1962; Seligman and Darling, 1997). Although there are similarities between the family's experience of childhood oncology and a life-shortening illness, for example, becoming part of medical culture, isolation, and the loss

of 'normal' family life, the major difference is that the life-shortening condition lasts for the life time of the child as the CF nurse reported:

“...I think you get to know both [conditions] the difference being with CF you are working with this condition that is going to last the whole of their life and you probably become more involved, there are always ups and downs with oncology. The plan is, the child is diagnosed, they have the treatment and there are times when these children are in hospital but you are working towards remission, you are working towards that episode, not something that will carry on. And the other thing I think is with CF you are doing a lot of prophylactic, you are keeping them well, most of the treatment is preventative. With oncology you work with the positive, but with CF the negative is always there and you don't know what is going to happen. Oncology, you have a time then after treatment they go into remission then you see them for a very short time after and then they get on with their lives. If they are not successful, they go down-hill and that can happen very quickly. With CF you never have that time really or very, very, rarely, and you can never say when, you can't predict, it's just living with it, living with something that is shortening the life of their child...” (CF nurse specialist - June 2007)

The other major difference between the two conditions is that CF is a genetic condition where in certain instances blame may be quickly apportioned:

“...its both [mother/father] sides but you get... because the mums have the baby... you can get - I don't think so much now, people are much better educated - but we start off straight away saying, 'This is genetic, it happens', but it has to be both parents, but we have, particularly in the past, the father's family say, 'Oh it's not in our family so its not his fault...’” (CF nurse specialist - June 2007)

The CF nurse becomes involved in the life of the family, sometimes as early as three weeks into the baby's life, and as stated earlier she is privileged to information that others are not. This includes how parents can present a different 'face' to other health professionals at out-patient clinics and how this does not always just relate to the parent as she continued to report:

“...they don’t tell the doctor anything...this mum said we don’t want people to know that we are not coping, but we want you to know that so when we come up to clinic we put our make-up on, we walk into clinic and they say to us how’s it going and yep, yep, we are fine, actually we are not, we are absolutely shattered. We don’t let them see that, but that is the side I see, ...their son died at 17, and I would visit him and towards the end he died at home which is unusual for CF and it was all planned and he knew he wasn’t going to get a transplant so we were able to do palliative care with him and towards the end he put a big front on. Everyone who saw him had no idea how upset he was underneath, just this big front...I said to the ward nurses because they knew him quite well, and I said to them if you want to see him you had better go around...and they went to see him and he still put this big front on. I was there, but as soon as they left, he just crumpled, absolutely crumpled. I saw them the next day and they said, ‘Oh he’s not as bad as we thought he would be’, I said ‘Believe me he is’. That’s how they do it, that’s how they cope with it...”(CF nurse specialist - June 2007)

The above account describes a side to the families that they have chosen to keep private. However, there is a side to the illness that remains public, where on occasions the parents can be a target for criticism from health professionals along with parents of other sick children on the hospital ward as the CFNS suggested:

“...these children accept that their mothers can’t be there all the time because it’s a ongoing thing all their lives, which sometimes on the ward the nurses find really difficult to accept...there are sick children on the ward and the parents are with them, but it’s only for one episode...even some parents are critical of the [CF] parents where this child is in hospital, but the family have to carry on because its not just this episode, it’s an ongoing thing and the work that is done at home with these children before they come into hospital is most tiring, so parents have got to get some rest. People don’t appreciate that they have probably been up for nights on end and they are absolutely shattered, so they need to recharge their batteries because they are going to go home and carry on with this treatment all the time because its part of their life...”(CF nurse specialist - June 2007)

Although the criticisms of the nurses and other parents are not openly directed at the CF parents, they are aware of the thoughts of others and see it as yet another obstacle for them to cope with, as the nurse reported:

“...I’ve had some of my families say, ‘It’s all very well for the nurses to say that, but they are going home, they are having a break from it’ I never get a break...”
(CF nurse specialist - June 2007)

Because of the advances in the treatment of CF in recent years most of the children now live beyond childhood, which places an even greater pressure on the families especially the relationship between the parents:

“...most of the children now grow up and they are getting to adulthood and it really takes its toll on the families, so you have a lot of marriages break up. They have their ups and downs and they have to put so much attention on the child...sometimes it happens really quick, like the dad can’t take it on board, its partly his fault...and sometimes its later because of all the pressure...”(CF nurse specialist - June 2007)

At times the medical advances whilst helping the ill child can remove an element of support from the families that in the past has been invaluable in supporting family-to-family, as the nurse described:

“...there are a lot of things that these families learn to do and the way they manage that we don’t know. We have no idea what they are going through and they have all these tips which they share with another family but they don’t share with us because there is no need to share with us because its part of their life, and we don’t know all the bits and pieces and that’s why they need to be in contact with each other. It used to be like that with CF, [but] they don’t any more because of cross-infections [between Cystic Fibrosis patients]. They had very good support between themselves but because of cross-infection they can’t do that anymore, even in clinic they don’t mix, they go into the room and everyone goes and sees them in the room and they go home, they don’t go in the play-room or waiting room and chat to each other...”(CF nurse specialist - June 2007)

In summarizing this section it is useful to note the key points. Since 2007, all babies are screened at birth for Cystic Fibrosis with a diagnosis confirmed at around three weeks of age. It is a genetic disease where both parents can be the source. Children born prior to 2007 have a much later diagnosis that on occasions is in adulthood. Whenever the diagnosis is confirmed the Cystic Fibrosis paediatric specialist nurse becomes part of the family's life and similar to the oncology nurse specialist is a lynchpin between the hospital and the home. Because of the relationship they are often party to information that other health professionals are not aware, such as the parents often appearing to be coping when in fact they are not. For the majority of the time the children are cared for at home which places an enormous amount of pressure on the rest of the family and can be the source of marital breakdown. Although medical advances in the understanding and treatment of certain childhood diseases such as Cystic Fibrosis can only be viewed as positive, this advance can also remove what was a positive aspect of family support - that is the opportunity to mix with other CF families.

CONCLUSION

Although acknowledging the expert knowledge that is required in the treatment, surgery, and drugs that help to 'cure' in the case of childhood leukaemia, or, prolong life in the cases of life-shortening illness, the findings show that the actual care that the child received in hospital falls below the expectations of parents. On the ward it is reported that nurses are careless, sometimes making mistakes, such as wrong notes, incorrect medication, and ignoring procedures with regards to cross infection. This leads to the mother being constantly vigilant. This is often misinterpreted by nurses who view this practice as mothers being neurotic and/or paranoid. The reports of mothers suggest the placing of a cannula in a child's hand can be easy, but some medical staff find it a difficult procedure and not everyone has the knack of doing it. Both children and parents were critical of registrars and doctors who place the children under more distress and pain by attempting the procedure more than the suggested three times. Already feeling isolated, the mothers on the ward felt that they were controlled by the treatments and the ward regime. They were often restricted in when they are allowed to leave the bedside of their child. Hospital staff appear to sometimes hold a paternalistic attitude towards the parents, even though these parents care for their child at home and often possess more expertise than some of the health professionals on the ward. The findings show that the

parents' perception of some health professionals is that they are sometimes insensitive and uninterested in the daily difficulties and stress that the illness places on each family member.

Whilst the Department of Health advocates Partnership Working and the Expert Patient initiative, little has been achieved in taking this forward within paediatrics where there needs to be an extended partnership consisting of parent, doctor, and child. This relationship has been reported as being one where the doctor may joke and ask how the child is, but any discussion regarding treatment is always between the doctor and parent. Very rarely is the child included or eye contact made. The mothers reported that they felt that the health professionals had, in general, showed little respect for their expertise as parents and it was only in the instance of life-shortening illness when one mother reported that although it had taken around eight years, she did feel that she was listened to by the consultants. From the findings, it appears that the relationship between professionals and families can be difficult at times. This, is particularly so in the case of social workers where there is a belief that the social workers only look for bruises and take children away from the family. However, without the social worker the family may be cutting themselves off from the additional financial and practical support that is available to them. Communication between professionals and families appears to be lacking especially with regard to psychosocial support external to the hospital. This, in the long-term, excludes families from services that may be available to them locally. From the findings, health professionals appear to attempt to provide exclusive support for the family in addition to their health care role, which can both confuse the family and may create a conflict of interest regarding treatment of the ill child.

In certain instances of illness there are nurse specialists, for example, childhood cancer and Cystic Fibrosis nurses. Although both roles act as a lynchpin between hospital and home there are major differences. The oncology nurse specialist is part of the family for the life of the illness that on occasion includes palliative care. However, the cystic fibrosis nurse specialist becomes part of the family from soon after the baby's birth and for the rest of the child's life, whenever that may end. The nurse specialist unlike the ward nurses often see the family at home and are more aware of the difficulties of everyday life that the illness brings to the family, and she can recognise the reality of the situation that is often different to the 'presenting' face that the consultants see at out-

patients appointments or on the ward. Although we do not live in a perfect world, more could be achieved within paediatrics especially for the families of children with a life-threatening or life-shortening illness, such as the inclusion of the ill child [regardless of age] in treatment discussions, better communication between health professionals and parents and acknowledgement that these families live the illness twenty-four hours a day.

CHAPTER, 9

DISCUSSION

The findings from the accounts of families from both categories of illness (life-threatening or life-shortening) suggest that their experiences of the illness and its treatment affected the identity of each family member and, therefore, changed the nature of the family unit as a whole. Data suggest that the ‘shocking’ diagnosis of childhood cancer followed by the temporary removal of mother and ill child from the family through hospitalization and ongoing treatment helps to set up an emotional roller-coaster ride that continues throughout the trajectory of the illness and its treatment in order to ‘cure’. In contrast, the diagnosis of a life-shortening illness, whether that is prior to birth, at birth, or early childhood, is the first step on an emotional uphill struggle where family members gradually come to an understanding of the full implications of the condition, to a realization that cure is impossible, and to a recognition that their future pathway is likely to culminate, sooner or later (maybe in adolescence or even early adulthood), in the death of the child.

THE ROLLER-COASTER RIDE OF CHILDHOOD CANCER

Whilst studies in the literature review have indicated that the diagnosis of childhood leukaemia may take some time to be clinically diagnosed (Comaroff and Maguire, 1981; Dixon-Woods et al, 2001) this had not occurred in this research. Although some mothers reported that they had recognized their child was not well and there had been non-specific symptoms (Dixon-Woods et al, 2005; Holm et al, 2003), generally, the diagnosis itself was a ‘shock’ and in no way offered relief from any longer term anxiety. At best it only confirmed the worst of their fears. One mother noted that she had little difficulty in accepting the consultant’s report that he was 99.9% certain the diagnosis was leukaemia, whilst it was the father who found great difficulty in accepting that there was anything so seriously wrong with their son. This father’s resistance to the diagnosis continued, even when the consultant further confirmed it was leukaemia. His clinging to the 0.1% possibility of something else – whether for his own sake or for that of his wife – was merely the first of many differences in the way they constructed the meaning of their child’s illness.

My data reflected the findings of Christakis and Iwashyna, (1998) that, following a clinical diagnosis, the parents had little time to digest the information they had been

given. This suggests that they often failed to grasp explanations about the treatment protocols, and the effects of the treatment (such as fertility). It also suggests that the signing of consent forms occurred before the implications of the treatment for the child or the family were fully recognized. This is born out by some parents' accounts of the later stage in the illness when 'cure' is no longer a possibility and when the child/young person is palliative, that they recall certain information noted on the consent form such as 'radiation may lead to secondary tumours'. Most of the accounts from the cancer sample of parents indicate that following the child's hospitalization the medical regime assumes comprehensive control of the child's care. At this time the traditional gender roles comes to the fore and the findings confirm that mothers set aside their previous roles of wife and mother to be at the bedside of their ill child. Generally, the illness and the treatment regime acts to separate mothers from their family (Brown and Barbarin, 1996; Yeh, 2002) fragmenting the family dynamic, which, as the illness progresses may be resented by other family members.

On first admission to the hospital the participants in this research entered two previously unknown cultures, the medical world and the world of childhood cancer. With no past experience of these cultures and the loss of familiar routines and surroundings, the mothers appear to begin a process of constructing a new identity. The findings suggest that this identity revolves around the role of primary carer closely linked to their identity as a mother of a child with cancer. The old identity of mother and wife in a 'normal' household tends to be replaced by a narrower identity based on care and concern for the one ill family member. At the same time, it seems from the findings that other family members who remain at home also acquire new roles, and additional responsibilities and obligations are generated. All of the fathers in this research continued to work, visiting the hospital whenever they could. Accounts suggest that support from the extended family is of immense value at this stage, from providing a replacement home for the well siblings to picking up some of the everyday chores that may be difficult for the parent remaining at home to complete, such as ironing, cooking and the school run.

A number of studies have reported marital difficulties during or following a child's serious illness (Davies et al, 2004; Sloper, 1996; Raey et al, 1998), and evidence within this research also confirms that this had also occurred in the families interviewed. The mothers reported that there were periods of difficulties within the marital relationship that

had escalated due to the continual separation and uncertainty of treatment and relapse, and that the intimate side of married life had been placed 'on hold'. The findings indicate that although the mothers had overwhelming feelings of loneliness and isolation, heightened by a sense of loss of the 'old' life, within the hospital setting they quickly adjusted to a 'new' life, with the main focus of attention remaining on the ill child. The husband/father by having to continue to work carries on as 'normal', with the findings indicating that fathers appear to be on the outside of the illness having less direct involvement in the care of the ill child. Therefore, the separation and the withdrawal of their wives' attention become more difficult. This 'together but apart' relationship of the couple continues when mother and child return home. Even when treatment has been completed, the uncertainty of the illness may draw the parental focus of attention towards continual vigilance for infections and the possible relapse of the child, leaving little time or energy for the couple to adjust and begin to reconstruct their relationship.

The findings indicate that it is not only the relationship between husband and wife that is changed but also life for the family as a unit. For the mother, who has remained in hospital, there is a growing realization that she has not only become subordinate to the medical culture, she has also become institutionalized with limited responsibility other than the ill child. She has been involved in far less domestic work, with less cooking of meals and little part in family life other than hospital visits by members of the family. In her place, either a family member or a number of friends have taken on her role at home, and with other family members in charge, changes may have been made to her 'normal' daily routines. The findings indicate that it is the mother that now has to 'adapt' to the newly constructed routine of home life, and for one mother in this research there was almost a disappointment when she reported that, although her impression whilst in hospital was that everything would come to a halt, she had discovered that most domestic duties within her home had carried on without her. It was her physical presence that had been missed the most.

During the hospital phase of the illness it is assumed that family members will be supportive in practical ways, which from the findings, the majority were. However, one mother reported that she and her well daughter, throughout her other daughter's illness, continually argued and in one instance had a disagreement so great that for a time they did not speak, which was something they had not done before. This may reflect the well

and ill sibling's relationship during the illness especially as all attention is on the ill child. This deserves further investigation from future research as relationships between parent and their siblings, and the relationship between the well and ill sibling during a serious illness, appears to have drawn little or no attention.

Whilst the mothers valued the medical knowledge and care at the main cancer centre the findings have shown that they were critical of the medical treatment and attitude of some health professionals when on the ward of the local shared care hospital. These findings are limited in as much as all the ill children in this research were based at the same shared-care facility, although the main cancer centre they attended was divided between two major teaching hospitals. At the shared-care hospital the mothers reported that they continually had to watch the nurses as mistakes were being made on a regular basis, from their child not being given a cover drug before a transfusion or the wrong dosage of chemotherapy, to the wrong notes. They also suggested that the nurses lacked experience of working with oncology children and failed to follow the procedures that helped to eliminate cross-infection (Field and Behrman, 2003). The findings show that the mothers vigilance over treatment leads to health professionals seeing them as neurotic, paranoid or of lesser intelligence. This leaves the parent with a sense of spoiled identity. Mothers reported that health professionals at all levels showed them little or no respect as intelligent adults, and little acknowledgement that, for a variety of reasons, including internet research, knowledge of their children and observation of nursing procedures, provided them with considerable expertise in their children's illnesses.

The emotional roller-coaster effect, triggered by the original diagnosis, continues and reaches a high point following the required period of time in remission when the child is given a specific date where treatment is considered to be at an end. Whilst everyone is delighted to have reached this day, the findings show that the family are in fact hesitant, as the structured life that the diagnosis created and had been in place for so long, disappears. The adjustment to the 'new normal' family life that the illness created, the support of other mothers whilst in hospital, along with the reassurance of medical contact comes to a close. The families enter a new phase of family life with the shadow of relapse continually present. The findings show that although this is a time of reflection it is also a time of resentment towards the cancer for the disruption and anxiety it created for the family. At this time according to the findings there is a perception that extended family

and friends believe the family will now return to 'normal'. This made one mother very angry, as she recognized that the family life they had before the cancer diagnosis had disappeared. This process had been entirely outside of her control.

With the advances in the treatment of childhood cancer many children now have significantly improved chances of long-term survival even though that future may contain a constant shadow of the unknown. Although the survivors are regularly monitored the late effects of treatment can occur at any time up to and including adulthood, and are generally associated with the original cancer treatment. The findings reflected those of the Childhood Cancer Survivor Study which point to the use of therapeutic radiation in the treatment of the original cancer and how this may be linked to secondary neoplasms. The only family in this research where a survivor of childhood leukaemia had died received therapeutic radiation in the form of a cranial boost around the age of 13 years. He died of a brain tumour at the age of 21 years. Although the father may have been less involved during the treatment period, it is at this time that the findings show that they become much more active, whether through searching the web for possible cures, or through sitting down with the ill young adult to talk through the implications of changes in treatment.

The findings have suggested that during the illness the marital relationship can experience difficult times, but somehow survives (Davies et al, 2004; Grinyer, 2002; Neil-Urban and Jones, 2002). Following the death of the child or young person the marital difficulties may again come to the fore, often created by the misunderstanding that as parents, both will grieve their child in a similar way (Rosenblatt, 2000a). However, a number of studies show that the differences in the way that mothers and fathers experience their grief can create rifts in the marital relationship (Kalnins et al, 1983; Schwab, 1998). The findings suggest that although problems occurred in one marriage following the death of a son, the coming back together required the reconstruction of a new identity (Riches and Dawson, 1997). The findings, however, indicate that in this particular marriage the reconstruction also included a different style of relationship:

“...I would like a man, I want a man on a charger to scoop me up and say I will look after you, he hasn't arrived yet...” (Mother/wife, family one - April 2006)

The roller-coaster ride continues following the death of a child, with couples struggling at times to survive. Many do survive and eventually reconstruct a new identity creating new ways of living whilst keeping the dead child within the family (Klass et al, 1996).

Where the ill child survives, the data indicates that the family remain on the roller-coaster ride, the difference being that it is no longer geared around the illness and treatment. The family as a unit once again have to reconstruct family life and begin to learn to live together and as individuals they discover that they have changed. For one mother it was to recognize that although her daughter had been through a devastating illness, the daughter and her sibling should be allowed to argue without her interference, which in the past and certainly throughout the illness she would not have allowed. As the family progresses, the shadow of the illness and that of an unknown future recedes but does not disappear. Relapse is still possible and additional illnesses may be diagnosed. The data also shows that many family members are aware that the drugs used in the original treatment may be the source of a new condition in the future, leaving them 'holding on', waiting for the next corner that may ultimately lead them to hearing once again 'bad news'.

THE UP-HILL STRUGGLE OF A LIFE-SHORTENING ILLNESS

Major paediatric health problems are mainly due to either a disability and/or congenital malformation, which less than 50 years ago would be considered fatal (Atkins, 1991). Through the advances in modern medicine and medical technology, a large number of children with complex medical needs are now surviving into early adult life. A further advance in recent years is the diagnosis of medical conditions during pregnancy. Once a condition is detected the parents find themselves in the unenviable position of having to choose between continuing with the pregnancy or to terminate. For other parents where the diagnosis has gone undetected it is only at birth or shortly after, that a diagnosis is confirmed. The exception to this is that at some point during delivery an incident occurs that leads the baby to sustain a brain injury. Whatever the cause of disability, with the expansion of treatment the number of fatal outcomes has been reduced which has increased the population of children with disabilities and/or complex medical needs to approximately 700,000 (DOH, 2004b). For the families of these children life becomes a

life-long uphill struggle not only because of the continuous surgery, treatment, and hospitalization, but also because of the daily challenges of life itself.

The data suggests that a number of obstacles increased the already difficult situation that the parents found themselves in. These included insensitive or unhelpful reactions of health professionals at all levels who were involved in the pregnancy, the birth, and or in the early weeks following the birth. It was reported in the findings that one mother felt continually pressurized by the health professionals to end the pregnancy following the scan at twelve weeks that indicated the baby had only one malfunctioning kidney. Another mother reported a 'normal' scan that resulted in the birth of her son who was diagnosed with Apert Syndrome. The findings show that had this mother been aware of the condition during the pregnancy she would have terminated the pregnancy. Further criticisms raised in the data included the mothers' perceptions of not being treated as individuals and everything attached to pregnancy feeling impersonal. In one reported instance the health professionals did not appear to care whether the baby lived or died. One mother reported that having survived the birth, the baby was transferred by ambulance to a specialist hospital, whilst she had to find her own transport, as there was no room in the ambulance. The data shows that there appears to be a lack of clear information from health professionals to the parents regarding the condition of their babies. One mother's perception was that following her daughter's first operation no one had clearly explained how seriously ill she was. Another mother who asked if everything was OK following delivery was told by the midwife that 'he had a few deformities' and the baby was removed immediately to NICU without further explanation (Avery, 1999).

Previous research has indicated that how the health professional communicate 'bad news' influences the coping ability of the parents (Bury, 2001). The data from this research also shows the extent of parents' distress during this time – in one instance following the shock of the birth and on seeing his son for the first time, it all became all too difficult for one father who could not stop crying. This reaction by her husband, and the lack of clear information or support from the health professionals, resulted in the mother feeling too frightened to see her baby for 24 hours. The first information she received came approximately 8 hours later when a paediatrician arrived at her bedside with pictures and extracts from a medical book. The frustration for the parents grew as the paediatrician continued to describe how the baby would be transferred to a major Children's Hospital

to have plastic surgery, which would make him look 'normal'. Which even at this early stage in their son's life the parents realized would be impossible.

The findings also indicate little positive communication between the medical professionals and the parents at this time, with the mothers' impression often being that no one really cared about them or their children. This is often reinforced by the failure of any health professional to sit down with the parents to speak with them, or approach the subject of counselling, and/or emotional support. In the case of the Aperts baby, there had been no further explanation of the condition at the local Children's Hospital, although one doctor did speak to the mother regarding the shock and difficulty the birth had been for the team involved in the delivery, with no apparent consideration of her feelings.

The value of positive support from hospital staff was reported by one mother who said that prior to leaving hospital, the female consultant was the one person who had actively encouraged and empowered them as parents to believe that they had the capacity to take their baby home and successfully care for him. Although the health visitor continued this encouragement at home, the data suggests that by her continually telling the mother that she was a wonderful mother and coping very well, [which is not disputed] the mother felt that she could not inform the health visitor on those days when she was finding it all too much and just wanted to have a good cry.

Within the hospital setting the mothers of children with complex medical needs felt that they surrendered their children to the medical world and that their child no longer 'belonged' to them. A number of mothers of children with complex medical needs also reported that when hospitalized with their child they felt subordinate to the Consultant and the regime of the hospital ward. The data shows that they experienced a sense of powerlessness and a lack of control with the professional always knowing what was 'best' for their child. As parents, the data suggests that they had little or no choice but to go with the medical advice, otherwise they may jeopardize their child's care. One mother's perception was that her daughter's consultant pressurized her in an attempt to agree with him in relation to an operation that she did not want her daughter to have at that time. From the findings, although a number of mothers had cared both emotionally and medically for their child over a number of years, the health professionals did not

always listen to what the parent were saying in regards to their child's health and wellbeing.

The findings also suggested that the range of professionals attached to and working with the family created additional hurdles for the families. The parental perception of the multi-agency working was that the different agencies did not talk to each other, which often left the families feeling stranded. One mother felt that the social workers did not use common sense but relied on 'textbook procedures', which often did not relate to the ability or experience of the mothers caring for ill and disabled children. In addition to this, because of the continual turn-around of staff, nothing that the social worker had instigated ever came to fruition, leaving the family feeling even more frustrated.

The experience of the struggle in everyday life for the family was reflected in the findings by the reports of parents, particularly when out with their child. They recounted how personally difficult it was when their child had a visible disability and they were out of the geographical area where people were used to seeing their child. One mother reported that it had been more difficult for the father who was less used to the responses of the public, whilst another father tried to instigate communication between those that stared at his daughter. As the child with disabilities and special needs develops, additional difficulties on a daily basis have to be dealt with by the family such as when out shopping and even when the family are out on a day trip. The constant watchfulness, trying to persuade the child to do what the parent prefers in order to keep them safe, is never ending. A further restriction for a number of the families is that wherever they go, whether that is a day trip or to friends, the care has to continue along with the administering of drugs.

PASSENGERS ON THE ROLLER-COASTER: WELL SIBLINGS

The impact of a confirmed diagnosis of childhood cancer on the family system is significant with family life irrevocably changed. The data suggest this includes the growing unpredictability of certain aspects of family life such as routines, meal times and chores. With a sudden shift in parental and marital roles affecting all family members, parents have limited time and energy to meet everyone's needs other than the ill child. The well siblings often received less attention from parents as they became more absorbed by the ill child's treatment, hospitalization and the future of the ill child. Even

though the parents strive to treat the ill child as 'normal' the relationship with the well sibling cannot remain the same (Riches and Dawson, 2000). However, the disproportionate attention could place increased stress onto the well sibling increasing their risk of developing emotional difficulties. There is other research evidence that suggests siblings of children with cancer have significantly higher emotional and adjustment difficulties than siblings of children with chronic illness (Houtzager et al, 2005; Spinetta and Deasy-Spinetta, 1981). For the well sibling this frequently leads to significant anxiety regarding the future, and in certain instances anxiety about the well sibling's own health. Therefore, continuing the roller-coaster effect of the illness.

The findings of this research have shown that following a diagnosis of childhood cancer it is often the sudden disappearance of the mother and ill child from home, the lack of clear and honest information regarding the illness that helps to create the initial difficulties and misunderstanding for the well sibling. Previous findings suggest that the well siblings require an environment where they feel free to ask questions (Share, 1972). Unfortunately the primary source of information, that is the health professionals involved, appear from this data not to be available to the well sibling in an informative or supportive way and in general they continually go unnoticed (Taylor, 1980). At this time the findings show that parental assumptions and expectations may be unachievable, inasmuch that not all well siblings are concerned that their brother or sister is ill, and wish to carry on with what they were doing. Also, regardless of how much information is passed on to well siblings' school regarding what is happening at home, teaching staff may not always provide the pastoral care that the parents hope for. Yet the findings in the study by Alderfer et al (2010) indicated that social support from school sources, in addition to family support, provided a positive environment for the siblings of children with cancer. However, the findings in this study suggest that it is the disruption to the family life, the loss of normality and the lack of the physical presence of the mother, along with the negative responses of school and peer group, that places increased stress onto the well siblings.

Following the ill child's discharge from hospital a form of 'new' normality is returned to family life with no guarantee of how long this will last. This is often a more challenging phase of the illness with the shadow of relapse ever present, highlighting that the family are still experiencing the roller-coaster effect of the illness. The findings have shown that

at the time of relapse the well sibling has a greater understanding of the illness and a growing awareness that stems from his or her previous experience of how the family will respond, and once again the family fragments with re-occurring hospitalization. Therefore, the well sibling may not always be sympathetic or responsive when informed that the ill sibling is back in hospital. This seems to be especially so during adolescence when there appears to be a greater risk to the individual sibling, especially when there are additional home responsibilities and less time for outside social activities (Houtzager et al, 2005).

For a small number of ill siblings the second or third relapse may indicate that the only hope of 'cure' is a bone marrow transplant. This is the point at which health professionals are more likely to become involved with the well sibling as they can be the source of a possible match for transplantation. The findings in this study, although very limited to the case study presented, have illustrated that, regardless of what other people may think or feel at this time, the well sibling may make no effort to hide his or her resentment and dislike of the ill sibling. The need for the transplant also created a conflict of interest for the mother as she had a son who could die, and a son who was a match but had to undergo an operation when he was not ill. In the case study presented the health professionals provided all the relevant information to the donor sibling regarding the transplant, but paid little attention to his emotional wellbeing, and the data suggests that he appeared to be invisible to the staff whose main concern was for the ill child. Studies have only recently acknowledged the psychological impact of becoming a sibling bone-marrow donor. From my long-term relationship with this particular family I know that the sibling donor believed that he was a hero for saving his brother's life, and found it difficult to accept that everyone appeared to ignore what he had gone through for his brother [see drawing appendix 10 page 303]

As noted, only one family in this research had experienced the death of their child as a young adult from cancer, occurring some ten years following his original diagnosis. He was 21 years of age when he was diagnosed with brain tumours that were linked to the cranial boost required in preparation for the bone-marrow transplant. The data shows that the parents arranged a holiday for the two siblings prior to his death. On their return the mother had recognised that her two sons, having always suffered a strained relationship, now appeared closer on their return. She continued to stress that her husband would

always be closer to the eldest son, and that had been the relationship since the day he was born, with her and the youngest son always remaining on the outside. This finding indicates that it is not always the illness that creates the difficulty for a well sibling. Life and relationships prior to the illness should be considered in any form of emotional support, as the illness may have acted as a catalyst for problems already present within the family.

STRUGGLERS ON THE UP-HILL JOURNEY: WELL SIBLINGS

Within the families that care for a child with a life-shortening illness, there are a substantial number of well siblings who are considered to be a 'population at risk' (Sharpe and Rossiter, 2002); with research suggesting that it is a negative experience (McCullough, 1981). Other research points out that an illness in a sibling shifts the focus of family concern, creating disequilibria within the family (Parsons and Fox, 1968). It has been suggested that increasing the well sibling's awareness of their brother's or sister's illness may actually improve the sibling's feelings of connectedness. There is also criticism that the professionals working with the families of special needs children may not be aware of the concerns of siblings and/or do not know how to address them (Cicirelli, 1995).

The findings of this research have indicated that the sibling responses and ability to cope with their ill sibling may be linked to how the parents manage the illness within the family environment during the lifetime of the ill child (Giallo and Gavidia-Payne, 2006; Wood et al, 2008). Firstly, how the family responded to the birth of an ill or disabled child, whether the grief of not having the anticipated healthy baby was acknowledged, and secondly, how the family adjusted to their situation. Unlike the children with a life-threatening illness where there is a sudden disappearance of the mother and ill child, in the situations of a life-shortening illness, the illness along with the child grows into, and becomes part of family life. Although there are periods when the ill child and mother are hospitalized, the effect on the family appears not to have such a fragmenting effect as with a life-threatening illness, with the attachment remaining intact. The findings have produced one family where the parents' employment allowed them to equally share domestic and caring roles, enabling them to explicitly balance the needs of well and ill siblings, and thereby maintain the well sibling's sense of security, worth and involvement.

Although sparse, there is research that considers birth order and other factors such as same and opposite-sexed pairs that may have an influence on how a sibling copes in their medium to long-term future with an ill sibling (Ferrari, 1984; Read et al, 2010). In the study by Read et al (2010), they suggested that the sibling's closeness in age and emotional symptoms were more linked to parental psychological difficulties than the illness. In my own research the eldest brother of four siblings, the youngest two having chronic life-shortening conditions, felt that his younger well brother had experienced the more difficult journey as he had a shorter time period with his parents when life was 'normal' and without the ill siblings. The data from this family's account and from others in my study illustrates how closely involved well siblings become in the defence of brothers and sisters with special medical needs. Unlike siblings of children with cancer, the evidence presented suggests that life-shortening illnesses provide opportunities for siblings and fathers to 'accept' the condition as a routine (if not 'normal') part of their family. Because this is not just for the (hopefully) short period of treatment as in the case of life-threatening illnesses, but for the foreseeable future, the family has time to 'internalise' both the illness and the ways in which it is a part of the ill child's character. It also presents far more opportunities for all family members to identify with the ill child and to come to see themselves and the family as a whole as having the characteristic of the particular medical condition with which they are all struggling.

This may not be a wholly positive process, and the data suggests that depending on the severity of the illness, the well siblings may have additional responsibilities and concerns attached to the ill sibling that helps to create anxiety and personal suffering (McKeever, 1983). This occurred in this study when a sibling realized as a young adult that the coping strategies he used between 8 to 10 years of age no longer worked as he reach his early twenties, and as a worrier he had to find external support in the way of counselling even though he saw this as a personal failure. In addition, the sibling recognized that on leaving home for university he could no longer control what was happening at home, but what he could control was information regarding his own health and how and when he relayed health concerns to his parents.

Findings from this study also illustrate the importance of good and open communication in families. Previous research has noted that limited information given by parents to well siblings about their brother or sister's illness and/or disability can create difficulties, such

as feeling responsible for the condition, struggling with peer group reactions to the ill sibling, and anxiety over implications the illness has for their own future (Seligman and Darling, 1997). The findings of this research found that many siblings were given appropriate information by parents regarding the illness, but were generally excluded from concerns about other crises such as lack of financial support, parental disharmony and anxieties over the long-term future of the ill child as they progressed into adulthood.

More research is needed into how the well siblings cope as they themselves move closer to adulthood. However, the findings in this research indicate that as the siblings reach young adulthood there is a sense of personal conflict between moving forward in their own life and yet remaining closely attached to the life of the ill sibling who may also be reaching an age that was thought not to be possible some years before. This very conflict illustrates the difference between life-threatening and life-shortening conditions. For the child with a life-shortening illness, death, which has been ever present, becomes a greater reality for all members of the family. This is especially so when the well siblings begin to take into consideration the age of their parents in deciding where their own future responsibility towards the ill sibling lies. This issue is less likely to arise with siblings of older children with cancer, as there is a much lower likelihood of care or treatment lasting over years or being centred on the home rather than hospital. Where it might arise is during the final stages of an untreatable cancer, where the child remains at home. It seems far less likely for siblings or parents to identify with the illness, or to see it as a 'characteristic' of their family, even though they may have struggled very hard to live with its consequences.

With a life-shortening illness, the up-hill struggle for the family begins when a child is born with complex medical needs. With a life-threatening illness, the roller-coaster ride only begins when the cancer is diagnosed, often well into a family's established and 'normal' development. As most children with life-shortening conditions are now cared for at home, involvement with the illness, its treatment and its impact on siblings can be considerable. The illness has a long-term effect and therefore, the siblings have a continuous up-hill struggle along with other family members that is not only connected to the illness but also with everything associated with daily life. Whilst the parents struggle up the hill on one pathway, the well siblings experience their own struggle on the same hill but on their own path. From the findings of this research the more positive the parents

are towards the illness and the ill child and more inclusive of the well sibling, the less the risk to the family as a whole (Batte et al, 2006; Read et al, 2010; Wood et al, 2008). Further findings from recent research suggested that it may be more beneficial to well siblings if support is offered to the whole family, particularly the parents, instead of assuming the individual well sibling requires support that may not be necessary or have a lesser impact than support to the family as a whole (Read et al, 2010; Waite-Jones and Madill, 2008; Wood et al, 2008).

ENTERING THE CULTURE OF PROFESSIONAL SERVICE WORKERS

The findings have shown that from the diagnosis of a child's serious illness the family enter and work in parallel with the culture of professional service workers. These range from medical, health care and social workers, to providers of emotional and practical support. Primarily, the relationship between the family and the professional should be one of care and support, although these relationships may not always run smoothly. Initially the parents view the consultant as the medical expert and one in whom they have placed their trust and hopes that their child will be cured or made 'better', and at the same time they trust that other health professionals will give care and attention to their ill child. The social worker role is to assist the family with form filling and practical help, unfortunately this initial relationship is often overshadowed by the perception that social workers take children away, and by retaining this opinion the family often restrict themselves from the much needed practical support that social workers can often access from local authorities. Emotional support is offered from a variety of different sources such as the nurses on the ward, psychologists within the NHS, the social workers, children and families projects based within the community and external to the NHS.

The family often view many of the people they are in contact with and who are supportive towards them, as 'professionals' even though they may be volunteers in a community service. Although the primary carers, usually the mothers, would not consider themselves as professionals, they are quick to learn the medical language, the names of drugs and eventually, may consider themselves as 'experts' in their own child's illness. As Ball et al, (1996) point out "Parents begin to acquire language, skills, and knowledge not even possessed by other professionals". Regardless of this, the expertise, power, and control remain within the culture of medicine and other relevant professionals.

EXPERTISE, POWER, AND CONTROL

In the majority of families, parents hold a powerful position in decisions that relate to the daily life of their children. The findings have shown that for the families of both categories of illness it is more often the medical professional who holds the greater control in the life of the ill child and therefore, to an extent, the life of the parent. The findings suggest that in most cases of childhood leukaemia once cancer is suspected the diagnosis was swift with the ill child and mother hospitalized. Mothers reported that on entering the medical culture they as parents lost control not only of their child to the treatment but also of their own life to the regime of the ward which often dictated when they could leave the bedside of the ill child (Coyne, 1995). The data shows that amongst families of children with a life-threatening illness, it is this very 'threat' which provides the rationale for the various sacrifices each family member has to make in order for treatment to have its best chance of success. Hence, power lies firmly within the hands of the consultant, health and nursing staffs that supervise and administer treatment.

However, the findings also indicate that mothers in this research whose children were receiving treatment for cancer gain sufficient expertise of their own to observe that, whilst in the shared-care hospital, there were frequent mistakes made by the nursing staff that placed their children in danger, and that whilst their child was in isolation the protocols regarding cross-infections were often ignored, reflecting the findings of previous published research:

“parents were instructed about the need for reverse isolation procedures, yet they saw ancillary personnel not washing their hands, not wearing masks and gloves and coming in [to the room] coughing”...’ (Moore and Kordick, 2006: 89).

It was the very lack of expertise in some of the nursing staff that created an obstacle for the mothers who felt they had to be continually vigilant to avoid mistakes being made with their children. Rather than accepting that these mothers did have expertise in their own children's treatment and condition, this was often interpreted by the ward staff as the mothers being neurotic and/or paranoid (Avis and Reardon, 2008). Further to this, some mothers' growing disillusionment with the medical expertise was expressed in their view that professionals tended to follow set procedures and often ignored the mothers when they had suggested something that related specifically to their own child's problems.

Amongst the findings is an example of disagreement between a consultant and mother over the necessity for an operation on a child with a life-shortening condition. Only after the operation failed to produce what the consultant predicted did the mother feel vindicated. Feeling let down by what the consultant had promised, the relationship between the parents and professional deteriorated further, increasing the lack of parental trust at a time when the health and wellbeing of the child should have been paramount.

As noted earlier, whilst the expertise of parents tends to be overlooked, the insights and understanding of ill children themselves is rarely acknowledged by either medical staff or parents. Reference has been made to the *Expert Patient* (2001) initiative which encourages patients with chronic illness to be more involved in their own treatment. However, from the findings of this study, partnership working within paediatrics appears to be somewhat one-sided, with an unquestioned assumption that expertise lies solely in the hands of the health professionals. The additional difficulty of partnership working within paediatrics is that the patients are children, and little reference has been made to how their involvement could be achieved. This particular patient partnership is three-fold, the doctor-parent-child, and includes a number of legal requirements relating to children, as Gabe et al, (2004: 1071-79) in their discussion paper on the subject, '*it takes three to tango*' note. The data in this research show that although present, the children as patients were not directly asked or questioned regarding their own illness and treatment, particularly in relation to those children diagnosed with leukaemia (Pantell and Lewis, 1993; Tates and Meeuwesen, 2001). The doctors may have had a conversation with the child but it rarely covered details about their condition or its treatment. The study of Dickinson et al, (2006) suggests that this is especially so with the older children:

“I find that many doctors just treat me like a kid, as if I don't know anything and it is not like that! They just want to talk to my parents and they don't tell me what is happening” (Lynda cited in Dickinson et al, 2006: 315)

All discussion in both life-threatening and life-shortening illnesses remained between the doctor and the mother and father. Nevertheless, one nurse specialist's account shows that she worked with children who know far more about the severity of their illness than they shared with their parents, holding back in order to protect them. This confirms the findings of Bearison (1991), which indicates that children themselves have far more

expertise in their condition than is commonly accepted. The findings have also indicated that on rare occasions once a child with cancer has made up his or her mind not to continue with the treatment it can, following much discussion with family and health professionals, reach a conclusion whereby the ill child achieves his or her goal. It was reported by one mother with a child with complex medical needs that the medical professionals appeared not to respect her daughter's body when being examined as they would if she was an adult.

Because of the many medical advances in the care of children with life-shortening illnesses the relationship between consultants and parents differs from the relationship between consultants and parents of children with cancer, inasmuch as it is an extended relationship over the life-time of the illness *and* of the child. The data shows that frequently a number of different consultants take 'ownership' of their particular specialism in the body of the child. With the majority of these ill children not only are there often a number of underlying conditions, but little is still known about the main diagnosis. This often leaves the parent with a sense that there is guesswork on the part of the health professional, and that her child is being used as a guinea pig in order to advance medical knowledge. Hence, with life-shortening illnesses, parents appear to be much more willing to criticise medical staff than with life-threatening illness. They may not be able to voice these anxieties, but findings illustrate that at least one mother's impression was that she and her ill children were felt by medical staff to be wasting NHS money and resources. The findings also indicate that because there were so many different health and social professionals involved, mothers felt that inter-professional teams rarely delivered what they had promised. Because of this, many families felt they were left stranded having to struggle through on their own. However, it is possible to argue that, because of the extended relationship between these families and the health professionals, it may be possible in time for them to engage in a more egalitarian partnership although this may take a number of years to achieve.

SUPPORTIVE SYSTEMS AND PARENTS' DISEMPOWERMENT

There are further factors to be taken into account regarding the disempowering of parents within the health care system. The findings have shown that following a confirmed diagnosis the once private lives of the families of ill children become open to professional scrutiny. Social workers are one such profession that parents found to be intrusive.

Although they are part of the support systems in place to provide the much needed practical support such as help in completing direct living allowance forms, educational statements, and additional services available from the local authority, the findings show that some parents resent the power social workers have in judging the quality of the home-life of the ill child. They also reported how important it was to 'present' a coping front to outsiders, and contact with social services was too intermittent for these professionals to be considered a part of the family.

Although it is understandable for parents to feel this way, the findings indicate that to obtain the extra resources available, the family have to meet eligibility criteria that are required by a local disabilities' resource panel. This consists of a scoring system to help with the demand and to help highlight which family is in greater need. However, the data shows that one of the difficulties with this system is that there are families who 'just get on with it' and make very few demands on social services and partly exclude themselves from the available extras which in the medium to long term would make their life easier. At the same time, there are other families who appear to receive more attention and resources because they make themselves very visible and make far more demanding requests.

The findings have indicated that often the availability of psychosocial support at a local level is overlooked and often ignored by health professionals. Because of the fragmentation between hospitals, and hospitals teams, the support available to the families regarding alternative services is neither passed on nor acknowledged. However, the data has shown that health professionals do not hesitate to refer a family, or individual family member to a psychologist, which may be right professionally for the referrer, but may not be the 'right' supportive referral for the family. This exclusion of services other than the NHS whether that is within the acute or primary sectors can create additional difficulties for the families. Moreover, it confirms that the only expertise that counts is 'medical' expertise. This 'in-house' professionalism as the findings show can lead to a blurring of boundaries to an extent that the families find themselves unsure where a professional role begins or ends. This may place some professionals, nurses particularly who get 'close' to a family, in a situation where there can be a conflict of interest between their role, who they work for and what is in the best interest of the family.

It is the nurse specialists above all other professional health workers, who form a different, more personalized relationship with the ill child and their families. The specialist role is one which is often located between the hospital and the home, and they will, therefore, have a greater insight into how the families are *actually* coping instead of the 'coping' face that parents frequently show to the consultants and ward staff. The relationship between the paediatric oncology nurse specialist and the family lasts for the career span of the illness and their relationship is one that focuses more on treatment, pain control and palliative care. The findings show that following the diagnosis the nurse specialist ensures that the parents have received the correct information and importantly, that the parents clearly understand what the treatment entails. This includes the consent form, and is not only about the treatment but how the illness can be managed in relation to the family's daily life, and extends to the ill child with an explanation of what the treatment entails and the side effects of the chemotherapy. The treatment of childhood oncology is so regimented that as the findings indicate the parents lose the power of choice. It is at this time that parents often decide to research the availability of new or alternative treatments via the internet and frequently wish to discuss this with the consultant, but may take the opportunity to talk it through with the nurse specialist first. It is at this time that the nurse specialist's role becomes a lynchpin between the parent and consultant.

Where treatment has failed, the family enter a phase that includes the palliative care of the ill child. As most children in the terminal phase of the illness are cared for at home, it perhaps is the first time when the parents feel that they have control of what happens next. The findings suggest that although palliative care is part of the nurse specialist's role, the family have a choice in whether they accept this care or not. Rejection of this nurse specialist involvement can prove to be difficult for some health professionals to accept and, in the first instance, may be viewed as a child protection issue which can only add to the stress already created by the illness. Palliative care of children is stressful for all concerned and the findings indicate that professionals' own emotional needs may get in the way of what the family feel is appropriate. Hinds et al, (1990) identify oncology nurses as being vulnerable and an occupationally stressed professional group, although Bulley, (2000) suggests that the research attached to paediatric oncology nurses indicates the sources of stress are similar for all nurses specializing in cancer care. The data shows

that the anxiety of families is raised considerably as they move towards the end of treatment and it becomes a watch and wait situation.

Unlike the paediatric oncology nurse specialist, where the relationship with the family extends for the career of the illness, the Cystic Fibrosis nurse specialist enters the life of the family for the duration of the illness, which is the lifetime of the child. As the findings show, the families accept the CF nurse almost as a family friend. By working holistically she can become privileged to family information that under different circumstances, such as out-patients clinics, the family would attempt to keep secret from health professionals. Parents often present at the out-patient clinics as being in full control of the situation and coping well, even when they are not. As the nurse specialist visits the ill child at home she has a far more intimate view of what is happening in the family not just in relation to the illness, but also in relation to the family's changing dynamics, its stresses and its crises. This gives the CF nurse a greater understanding of the needs of all members of the family. Hence, although her expertise lies initially in her qualifications as a Cystic Fibrosis nurse, it extends to her growing trust, insight and understanding within the family's own dynamic.

The data has shown that the health professionals working with childhood cancer are continually working towards remission and cure. Although there are negative periods during the illness such as relapse, there is a greater positive outcome for the majority of children. In contrast, the treatment for Cystic Fibrosis is mainly prophylactic, trying to keep the child well. CF is such an illness where the health professionals are continually working with the negative aspect of knowing that at present there is no cure, and for the families they are living with an illness that is shortening the life of their child. This recognition, as much as anything, qualifies the CF nurse as a 'honorary' family member in as much as she, like the other family members, are in for the long haul, and therefore can legitimately act as a guide on the uphill struggle. Without doubt, much of the expertise parents and siblings develop in the care of a child with CF is learned from watching and working alongside the CF nurse.

THE 'MEANING' OF ILLNESS

There are a number of studies that have directed attention to the 'meaning' of a life-threatening illness. For example, breast cancer has been studied for its affects on certain

aspects of an individual's life such as their understanding of, and adjustment to the illness and the perception by the individual of their future, whilst living with the experience of cancer (Fife, 1995; Frank, 1998; O'Conner et al, 1990). The majority of these studies focus on an adult's personal illness experience. As yet, few studies have focused on the 'meaning' of different conditions of serious illness of a child to the family as a whole and to individual members of the family unit.

In this thesis the data indicates that both life-threatening and life-shortening conditions significantly affect and change family relationships, family roles and family members emotional wellbeing – with a widening gap at the interface between the families and the professionals. They are perceived to be largely insensitive to the social, emotional and financial consequences for the whole family, as their focus remains solely on the physical wellbeing of the ill child. However, the 'meaning' of illness for childhood cancer differs from the 'meaning' of illness for a child diagnosed with a life-shortening illness such as Apert Syndrome or Cystic Fibrosis. Each medical condition affects the family dynamic in different ways. In cancer the family has a tendency to be more fragmented, largely due to the sudden shock of the diagnosis and the almost immediate separation from the family of the mother and ill child that adds to the trauma. The majority of these families have, up to the diagnosis, lived what is considered to be a 'normal' family life. However, the treatment and separation leads to a sub-system of mother and ill child, that may exclude the husband and well siblings who remain at home, and to a greater extent on the outside of the illness. In severe chronic life-shortening conditions, the family remain to a greater degree 'intact'. The family attachments are likely to be less fragmented in the immediacy of the diagnosis, and although initial treatment and/or surgery may split parents' division of labour, the condition will remain and the child will return home over the longer term. Thus, the family have a tendency to be more fully involved with the treatment at home and so are more likely to consolidate around the characteristics of the illness. The treatment regimes differ in each of the conditions, with cancer primarily treated in hospital with health professionals administering the treatment and care. Whilst children with life-shortening illness, even given hospitalisation for operations, are mainly cared for at home, offering more opportunities for family members to be involved in the ill child's treatment and care.

The treatment regime for cancer is rigid, based on expert knowledge that offers little room for negotiation with the primary and often overriding concern of 'cure'. In the first instance the only choice open to parents is consent to treatment or consent to palliative care and ultimately the death of their child. This leaves little time for the parents to digest the information that they have been given before the family are separated through hospitalisation. The data also shows that at this time there is a loss of the mother's normal identity to one that is much narrower and concentrated on two aspects; a) the care of the ill child and b) created by the illness - a new identity of a mother of a child with cancer. Initially and throughout the treatment for cancer the ill child and the family relies on the expert knowledge of the consultant although the primary carer, usually the mother, quickly learns at the bedside the technicalities of treatment. Conversely, the treatments for life-shortening illnesses are varied and differ between the often rare conditions that can take a number of years for the full implications of the condition and underlying problems to be fully clinically diagnosed. Throughout this time the medical professional maintains the expertise required for the physical wellbeing of the ill child. However, with the majority of these children cared for at home, the mother becomes more proficient in the child's medical care and often become 'expert' in their child's condition, along with the family who also have a fuller knowledge of all aspects of the child's life. Whilst the treatment may be technologically based, it is only amelioration, as there can be no cure. Although the family may initially fragment, once the crisis around the birth or diagnosis has been confirmed there is the potential for family members to be included in the daily care of the ill child. However, the mother's identity becomes partially attached to the illness particularly within the hospital setting.

The majority of the mothers in both categories of illness reported a growing frustration with the health professionals and that the actual care that their child received did not meet their expectations, with frequent mistakes made by the nursing staff in the care of the child that confined the mothers even more to the bedside of their child. The data suggests that the mothers felt that they could not speak out against the attitude of the staff towards themselves and the ill child, as they believed it might impact on the care received. The actual role of the illness differs in the two conditions. Childhood cancer is viewed more as a threat to be fought and overcome, and a threat that is dependent on a 'medical solution' for its cure. Unlike adult cancer, there is no stigma attached to childhood cancer, with the family often viewed as martyrs with the ill child described as an 'angel'

or 'brave soldier'. However, the primary and overriding concern for the family is a potential failure of the medical regime to produce a cure, and that will ultimately lead to the death of the child. It is this threat which in most cases guarantees the subordination of family relationships and wellbeing during treatment to the medical 'cure'. In total contrast, the life-shortening condition can at best only be managed or ameliorated, and although medical advance has increased the life chances of the child by medical technology, surgery and drugs, the condition can never be 'cured'. Being aware that there is no cure, neither the family nor the health professionals are aware when the child's life will end, only that it is likely to be shortened by the illness. The reality of the child's death has to be lived with. Over time the premature death and the condition itself become part of the family's identity in which all members to a greater or lesser extent struggle to cope and endure a series of challenges that continue to affect the family's dynamic and the roles which each member plays in relation to the ill child's care. The illness becomes part of family life with each member having to reconstruct his or her life and roles in order to 'fit' with the ill child.

The families reported that they felt continually frustrated and let down by the professions who often fail to communicate with each other and the family. This supports the family's notion that the health professionals have only one focus that is the medical management of the illness. This perception is extended where a child has a rare condition and was reported by mothers, that their child was used as a 'guinea pig' for the advance of medical understanding. The data collected from the families regarding the professional involvement was that relatively few professionals had any understanding or interest in how the illness had impacted and changed the life of the family. Or indeed, for the families, how the illness continues to place increased pressure on all relationships within the family on a daily basis.

CHAPTER, 10

CONCLUSION

This thesis has sought to explore the perceived difficulties that families experience following a child's diagnosis of a life-threatening or life-shortening illness. Central to this is their relationship with the professionals who are involved in the medical management and psychosocial care of the ill child and other family members. I have argued that families in each category of child illness experience similarities *and* distinctive crises and stresses depending on the illness trajectory. I have argued that following a diagnosis of a *life-threatening* illness such as childhood cancer, families experience an almost immediate surrender of the ill child to the expert medical professional thus subordinating the family relationships to a treatment regime of 'cure' as the 'failure to cure' will result in the death of the child. The affects of the illness permeate throughout the family creating changed roles and responsibilities for all members, impacting on the everyday life of the individual family members, therefore changing the family's whole dynamic. This, I have argued, includes well siblings who appear to have greater difficulty in their ability to cope with the sudden separation from the mother and the additional total focus by both parents on the ill child. Although this is often characterised by marked 'swings' between periods of hospital based treatment and periods of relative home based 'normality', between crises of anxiety and periods of relative calm during remission.

I have continued to argue that families experience a very different set of crises and pressures following a diagnosis of a *life-shortening illness*, often beginning with a much longer drawn-out diagnosis in which the full implications of the condition take time to emerge. The extent to which family members are going to have to adapt to the care of a child with a life-shortening condition emerges only during their struggle to understand the diagnoses, to understand the potential and limits of medical 'treatment' for the child's survival, and their ongoing struggles to obtain the 'best' medical, social and educational resources for the child's life-chances. Although the family become part of the culture of medicine and childhood illness, relying on the medical professional for the medical management of the condition, the mothers are usually the primary carers within the home setting and this care often continues during hospital treatment, and consider themselves 'expert' in their child's condition. Although often perceived to have difficulty in coping, well siblings within these families often appear to have the ability to 'grow' with the

changed family environment that the ill child's condition ultimately brings, this is especially so, when the parents have a positive attitude towards the ill child and are supportive towards other family members.

In both life-threatening and life-shortening illnesses the 'expertise' varies from family member to family member and from medical staff to medical staff. With childhood cancer it is the mother who is likely to come to know the details of the treatment her child is receiving as she is the primary carer. In contrast, with life-shortening conditions, the expertise often lies more evenly distributed amongst all the close family members, though obviously to a greater or lesser extent, depending on the illness and the age of the siblings. This reflects the ways in which a life-shortening condition is more likely to encourage the family to pull together in taking responsibility for the day to day care.

In both categories of illness communication from the birth or diagnosis of the child is a continuing issue for parents and ill children. For the parent it can be a lack of clear, honest information, or information given in a way that can be patronising or interpreted as a threat if there is no agreement with the expert. For the ill children, communication between themselves and health professionals appears almost non-existent. There is also a perception by professionals, and to a certain extent by most families, that *all* well siblings will have psychological difficulties following a diagnosis, yet frequently no one takes the time to ask the well sibling if they understand what is happening. It is this lack of communication with the well sibling, or inadequate or misdirected information, that may create long-term issues. In both categories of illness the families' perception is that the health and other professionals are only interested in the particular illness that may, with success, advance their professional career but have little understanding of, or interest in, the families' daily struggle with the illness.

AUTHOR'S CONTRIBUTION

The following summary outlines the contribution which I feel this study has made to the area of children's life-shortening and life-limiting illnesses and how the illness and the medical management of the illness impact on the life of the family and their relationships with each other. It needs to be read in conjunction with the next section which notes the limitations surrounding the status of this contribution.

1. In order to describe the experience of living with childhood cancer and the experience of living with life-shortening illness, I have examined similarities and differences in the 'family cultures' of these two categories of medical condition. Inevitably, these have been oversimplified in order to highlight some fundamental ways in which the different treatment regimes differentially impact on family roles and relationships. As a consequence of my data analysis, I have characterised childhood cancer as a 'roller-coaster', using this metaphor to foreground those aspects of cancer treatment that appear to have the greatest consequences for family relationships and wellbeing. Similarly, I have characterised the experience of living with a life-shortening illness as a 'constant uphill struggle'. These metaphors have provided the basis for two distinctive conceptual frameworks which help explain how the diagnosis and treatment of the illnesses systematically affect family roles, relationships, emotions and communication, including different ways in which families 'make sense' of the illness, and different values which the treatment regimes place upon family members' 'expertise'.
2. Amongst the meanings which treatment for a *life-threatening* illness, such as childhood cancer, provides, is the inevitability of a dependency on medical expertise and hospitalisation which *fragments* the family, emphasising the role of mother in her relationship with the ill child, but often demoting her role as wife and mother of her well children. Along with the extreme anxiety which the diagnosis of cancer invokes, this treatment regime can add to family communication problems and can all too easily make siblings resentful though a sense of increasing exclusion. It may place social and emotional pressures on the family which tend to isolate their previous relationships and which create a new pattern based around the separate locations of home and hospital ward. The placing of the mother and ill child in what initially is an alien treatment culture, makes it difficult for marital and parental relations with well children to be maintained as normal, and which fails to find ways in which the mother's expertise in her ill child's condition might be recognised and integrated within the treatment regime.
3. In contrast, the meanings which often unique *life-shortening* conditions provide are developed over a much longer period of time as parents struggle to understand the full implication of caring for a child with a condition such as cystic fibrosis.

Social and emotional pressures are placed on couples and on families which tend to present challenges to the family as a whole, which, if survived, tend to change the character of the family around the treatment regime, integrating contributions by various family members to the treatment and to the defence of the family unit as a whole. The family's involvement in this treatment regime provides for the opportunity to care for their children in conjunction with medical professionals whose role operates over the child's lifetime, usually as much within the home as in the hospital environment. Hence, in contrast to life-threatening illnesses, *life-shortening* medical conditions have a tendency to *cohere* or *unite* family relationships around the illness, providing a 'care project' with which all members have an opportunity to identify, and a set of activities in which all members can, to a greater or lesser extent, take part.

4. The experience of a life-threatening condition, because of its dependency on medical intervention, hospital based treatment and technical expertise, and the acute threat to the child's life, is likened to an emotional roller coaster, with little control over the crises and stresses which the trajectory of the illness presents. Medical staff need to be aware of the emotional and social vulnerability of families at diagnosis, during treatment and, importantly, when treatment has ceased and families are left 'on their own'. The experience of a life-shortening condition by contrast, because of its long-term and often gradual unfolding of complex conditions and social challenges, is more like a life-time's uphill struggle. Medical staff need to be aware of ways in which the illness may itself present a challenge which, if met, generates a family identity within which various members may develop expertise in the child's condition and in the quality and continuity of care provided by various medical and support services.
5. Parents of children with *life-threatening* illnesses appear to often feel dependent on medical expertise, sidelined by professionals and often split in their division of labour between father/breadwinner and mother/auxiliary 'nurse'. However, because of this role, mothers gain increasing expertise in their child's medication. They become aware of the dangers to the immune system following chemotherapy, and may become particularly anxious about the possible failure by nursing staff to care for their children according to the exact protocols they have become very familiar with, particularly in the specialist children's hospitals, where nursing staff may change frequently. However, at the same time, they

appear to be reluctant to express criticism of medical staff because of the dependency they feel for their good-will and total commitment to the 'cure' of their child. In contrast, parents of children with life-*shortening* conditions may have had to struggle for some time to gain a clear diagnosis and honest information regarding their child's condition, and continue to struggle to get the medical attention, treatment, social, economic and emotional support that they require in the care of their child. That 'something is wrong' with the child may have been intimated before its birth, and the full extent of the medical problems and their implications for the child's survival and quality of life may take months, or even years to be fully recognised. In surmounting a range of challenges that families of 'normal' children do not face, it is likely that a 'culture' of family struggle and care may develop in which each member has a role to play. Individual family members are also more likely to develop considerable expertise in their child's condition and become experts in any changes in that condition. They are also likely to feel the need to present a 'united front' to the outside world in the face of the difficulties they face, regardless of the internal tensions generated by the ill child's needs.

6. Professional medical staff, especially specialist nursing staff, may over time come to be seen as allies and even 'honorary' family members. Hence, in the case of paediatric oncology nurses, their absence following the end of treatment and remission may leave families feeling isolated and even 'abandoned' with the threat of the illness returning playing on their minds. Conversely, specialist nurses in life-shortening conditions such as cystic fibrosis will be involved with the family for the duration of the child's life. He or she will also involve the family in the treatment itself, with all members having a chance to be a part of the 'care team'.
7. All medical and associated staff involved in the treatment of severely ill children need to be aware of the social and emotional consequences of the treatment regimes for the family as a whole as well as for the child patient. The degree to which family expertise is utilised varies from one illness to another, from one family to another, and the actual meanings which the illness has for families also varies according to the degree to which each member may be able to be involved in the treatment. Fundamentally, however, these two categories of child illness present very different meanings – cancer particularly carrying clear associations

of immediate and serious threat to life, with the only real hope being utter reliance on medical expertise. The sacrifice of normal family relationships during treatment seems a small price to pay, yet the dependency on professional knowledge and medical technology also has a cost in terms of the families' loss of control and of a safe predictable future. In contrast, life-shortening conditions are far less well publicised and less understood. Many life-shortening conditions are complex and their various interactions may take considerable time to diagnose and manage. The full implications of these various conditions may take a considerable time for the family to comprehend. The fact that the child's illness may almost certainly also lead to a premature death features far less significantly in the range of challenges faced by the family. Each illness has a small, but often quite active parent support self-help group or web-site. The characteristics of the condition, its frequent rarity, the struggle to gain support and appropriate treatment, and the general ignorance of the population of its consequences all serve to promote a sense of the families' difference from 'ordinary' families, providing a 'defensive' identity to which each family member may, to a greater or lesser extent, become committed.

LIMITATIONS OF THE STUDY

Ethnography as the chosen methodology combined with my practice allowed access to families where there was already a trusting relationship that had been built up over a number of years. The families were used to seeing me in their home settings, and on occasions, accompanying them to what are known as 'professional's meetings' and visiting them when the child was hospitalised. Therefore, the methodology allowed greater access to understanding the typical ways, particularly on a day-to-day basis, in which a diagnosis and treatment of both life-threatening and life-shortening illnesses affect family relationships, roles and wellbeing. However, there are limitations to the thesis which need to be acknowledged:

Firstly, the sample is small and gained through opportunity sampling methods, and therefore needs further research to demonstrate its representiveness. Secondly, the families all reside in a narrow but heavily populated geographical area, and may therefore not be typical. Thirdly, all parental perceptions of the illness, treatment and care of the ill child were based on accounts by mothers, and hence fathers' perceptions are absent from this study. Fourthly, the ethnic origins of the families were all white British from low and

middle income groups. I acknowledge that the study would have been further enhanced by the inclusion of fathers and their perception of how the illness impacts on their marital and family relationships - and their relationships with male friends who are fathers of healthy children. Unfortunately the majority of the fathers in this study worked full-time, and hence were unavailable, although I did suggest that I could interview them in the evenings, but no father came forward. I also acknowledge that the study draws heavily on the participant observational view I have as a practitioner in this field. I did not seek interviews with those who make decisions on the nature of the treatment regimes, although I believe that the interviews with the paediatric nurse specialists who have the responsibility to carry through those clinical decisions and have a closer relationship with the families helped to give a broader perspective of the medical culture involved with the families. Whilst these limitations need to be born in mind, there are, from the perspective of mothers and siblings involved in this study, important recommendations for practice and future research.

IMPLICATIONS FOR FUTURE RESEARCH, POLICY AND PRACTICE RESEARCH

This thesis provides evidence of the difficulties that families face in their adjustment to the diagnosis of a life-threatening or life-shortening illness. The study indicates that the families will often 'put on a coping face'. This 'coping response' in front of strangers - especially strangers asking questions - challenges whether certain research methods are providing a clear indication of the problems associated with long-term childhood illness. There are previous studies that draw on the experiences of children with cancer and Cystic Fibrosis, and the same attention should be given to other children with life-shortening conditions who are active long-term users of the health care system. Drawing on the findings, future research should also place more focus on the affects of the illness on well siblings as they reach adulthood, and the long-term relationship between the ill and well siblings. This is especially so with childhood cancer patients as they are now surviving well into adulthood. With research in this area in its infancy, studies have concentrated on the survivors with little or no focus on how the relationship between the ill and well siblings has been maintained or what problems have evolved over the years following the diagnosis. A primary concern for families with children diagnosed with a life-shortening condition is that, now they are living much longer than the original prognosis, the question of who will take responsibility for the ill child when the parents die becomes particularly significant for the well siblings. Arguably, the focus of support

should not be the responsibility of any one individual within the family, whether that is a well sibling or a parent. More emphasis should be placed on supporting the family as a social unit, including their emotional and financial wellbeing. More emphasis should also be placed on how the illness and ill child are viewed and on whether the meanings given to the illness enhance or detract from the identity of the family. It also needs to take account of the opportunities provided for its members to 'sign up' to that identity. Although not reported in this research, but deserving investigation, is the difficulty of meeting the educational needs of children with life-shortening illnesses. Although government legislates for inclusion for all, in reality this does not work unless the child has only minor special medical needs, hence creating additional stress for the families throughout the child's educational life, especially on transfer to Secondary school.

POLICY

Over recent years there have been numerous policies and documents regarding care pathways that stem from the Department of Health such as *Meeting the health needs of children and young people* (2007), NICE guidelines, local NHS Trusts and charitable organisations that act on behalf of families with seriously ill children relating to the various issues of care and wellbeing of the ill child, the transition into adult care, and educational needs. In practice it seems that the documents are too general and are left to interpretation by individual organisations at management level, and are diluted again at ground level by those individuals providing the care. More consistent and workable guidelines are required that leave the families feeling supported instead of the frustrations they currently experience. Where possible incorporated within policies should be a key-worker policy where they are placed with a family and remain until a time when the family [not the professional] feel that they no longer require that support. Although not raised in the interviews, I have, as a participant observer, witnessed a major source of stress that has increased over recent years. This is the difficulty parents have in accessing appropriate schools for the ill child. Therefore, an educational review should be considered for children with complex medical needs who do not fall into the category of 'special needs'. Whilst there are excellent special schools they are not always appropriate for a large number of children with life-shortening conditions – neither are most secondary schools who cannot provide the medical input of providing drugs, catheterisations, and the changing of continent pads. Many schools are built over two or three levels which means that the child has to leave lessons early to avoid the crush in the

corridors. These children require schools that 'fit' between the special and secondary schools that can provide the individual care, attention, and education that the children deserve.

PRACTICE

The findings in this study indicate that for the parents in both categories of illness, miscommunication, including the lack of clear, honest information and often patronising and uncaring attitude of health and other professionals, adds to the already difficult everyday life of these families. Health professionals in their contact with the ill child also need to recognise and acknowledge that the ill child regardless of age understands that procedures have to be undertaken, but do require an age appropriate explanation of why certain procedures are carried out. From the findings, the many losses that the families experience throughout the illness, especially the long-term illnesses, can be overlooked, or not recognised, and when they are, the health and social professionals make assumptions regarding what would be 'best' for the families and often refer on to inappropriate services such as psychologists with whom the families find it difficult to relate. More consideration should be given to resources that are external to the hospital staff and based within the community where the family are aware there are no NHS connections.

The primary recommendations for practice may be summarised as follows::

- a) The major finding of this study is the insight that 'normal' family life is dramatically affected by diagnosis and treatment of both categories of illness, but in very different ways. Therefore a major recommendation would be that health professionals should be provided with understandings of the range of adjustment processes through which families have to go to manage these changes successfully.
- b) If this is to be implemented, there is also a need for NHS managers to identify policies and procedures that take account of the serial and life-long obstacles facing families of children with life-shortening illnesses, and the dramatic ups and downs of treatment regimes for life-threatening illnesses, especially the toll that it can take on marital and 'normal' family relationships..
- c) Following from this, specific general paediatric training for *all* health professionals on the difficulties for the individual family of life-threatening and life-shortening conditions would be of enormous benefit - that includes district nurses, health visitors, GPs, nurses on the ward, registrars and consultants. More thought also needs

to be given to the fact that these children are now surviving well into adulthood and those who believe it to be a paediatric issue only, will eventually be working alongside the family and ill person as an adult.

- d) The findings of this study suggest that education and training specifically in relation to family social systems and communication issues, together with enhanced skills in working with families should be provided for ward staff, registrars, and consultants within maternity, paediatrics, and social work.
- e) The findings also suggest that health professionals and out-patient staff who are in contact with children would benefit from specific communication skills training with children and young people. In particular, sensitivity to the sibling relationship and how the illness and treatment impacts upon it could alert support staff to potential problems and strengths within the wider family, reducing the current focus on ill children and their mothers.

Other more general recommendations include:

- f) Greater awareness regarding the transition from paediatrics to adult services, with the transfer not just linked to the fact that the patient has reached either 16 or 17 years of age, would enhance continuity of care. Ongoing discussion with the family and the paediatric consultant alongside the adult provider is required to ensure that the appropriate information regarding the medical management of the condition is available, how it will be maintained, followed by a meeting with the 'new' consultant. Primary Care Trusts should consider continuing the practice of providing free items such as disposal gloves and syringes, which when the transfer occurs the family have to provide themselves.
- g) Whilst there are numerous leaflets for parents on the particular condition that the child has, for example, hospital rules and regulations, community services, and benefits, it would be useful if leaflets were similarly available for health professionals giving advice and information on the basic problems that the families of life-threatening and life-shortening conditions endure and how they may help.
- h) One of the greatest frustrations parents have noted when attending out-patient appointments, is that often no-one appears to have taken the time to read the child's file. This implies that more time should be given by health professionals to offer confirmation that they are familiar with their patients' condition and their families' needs.

- i) There appears to be a need for more effective communication between the various agencies involved with these families, including liaison between the local and specialist hospitals, and between the hospitals and other community services.
- j) Whilst few parents with chronically ill children are involved with their local health centre, there are occasions when in an emergency they do attempt to see their GP. This can create problems where receptionists do not understand the situation even after an explanation. Many GPs have little experience of paediatrics and even fewer have experience of paediatric chronic illnesses. Therefore, all GPs should undergo updating in paediatric chronic illness, which could reduce the delay in the diagnosis of childhood cancer, and help reassure parents of children with chronic life-shortening illnesses, and ensure that they are directed to appropriate specialist services.

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GLOSSARY OF TERMS

ACT	Association for Children with Life-threatening or Terminal Conditions and their Families
ALL	Acute Lymphoblastic Leukaemia
AML	Acute Myeloid Leukaemia
BACP	British Association Counselling and Psychotherapy
BPS	British Psychological Society
BSA	British Sociological Association
'C'	Cannula
CCSS	Childhood Cancer Survivor Study
CEO	Chief Executive Officer
CF	Cystic Fibrosis
CFNS	Cystic Fibrosis Nurse Specialist
DOH	Department of Health
GP	General Practitioner
NHL	non-Hodgkin Lymphomas
NSF	National Service Framework
ONS	Office of National Statistics
PNET	Primitive Neuroectodermal Tumour
PWS	Prader-Willi Syndrome
RCPCH	Royal College of Paediatrics and Child Health
SJS	Stevens - Johnson Syndrome

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APPENDIX ONE

SAMPLE DETAILS

Family Number	Interviewee	Ill Child	Illness	Family Members	Location of Interviews	Number of interviews	Observation
1	Mother	Son - Richard	Leukaemia	Father - Mark Son - Matt	Office	2 - April 2006 [1 interview re well sibling]	Hospital/ Community group/home Over a ten year period
2	Mother	Daughter - Annie	Leukaemia	Father - Sean Son - Sam	Office	2 - April 2006 [1 interview re well sibling] June 2005	Hospital/ Informal group over a two year period
3	Mother	Son - Steven	Aperts Syndrome	Father - Lewis Son	Office	1 - June 2006	Informal community group over a three year period -on going
4	Mother	Daughters x 2 Eldest daughter - Natalie Youngest daughter - Alice	Chiari - Malformatio Born with one kidney with limited function - recent kidney transplant [2007] and a number of other internal abnormalitie	Father	Home	2 - January 2004 October 2006	Home/ Hospital/ Professional meetings over a eight year period -on going
5	Mother	Son	Spina Bifida	Father 2 Daughters	Home	1 - September 2006	Home over a two year period - on going
6	Mother	Daughter	Aperts Syndrome	Father Son & Daughter	Home	1 - April 2006	Home/ Community group over a two year period
7	Sibling (adult) mid 40s youngest daughter - Molly	Deceased brother in childhood - Philip prior to Molly's birth	Brain Tumour	Elderly father Older sister -Kate Molly's own family Husband Son and Daughter	Office	1 - April 2005	None

Sample Details Continued

8	Well sibling – Simon mid 20s eldest son of four children	Sister – 3 rd child – Vickie Brother – youngest sibling - Jimmy	Severely disabled including Holoprosencephaly Prader Willi Syndrome	Mother Father Two ill siblings – one well sibling - Theo	Home	1 – September 2005	Home/ charity events over a eight year period – On going
9	Ill Child Harriet	Eldest Child	Steven – Johnson Syndrome	Mother Father 2 Brothers 1 Sister	Office	1 – November 2009	Office – mother and youngest sibling over a five year period
4	Ill Child Natalie	Eldest daughter	Chiari Malformation	Mother Father Youngest sister Alice	Home	1 – November 2009	Home/School over a eight year period – on going
4	Ill Child Alice	Youngest Daughter	Born with one kidney – recent kidney transplant and a number of internal abnormalities	Mother Father Older sister Natalie	Home	1 – November 2009	Home/school/hospital over a eight year period – on going
Social Worker					Office	1 – January 2007	None
CEO of Children and Family Project					Office	February 2007	None
Paediatric Oncology Nurse Specialist					Office	1 – May 2007	None
Paediatric Cystic Fibrosis Nurse Specialist					Office	1 – June 2007	None

APPENDIX TWO

4. Risk Assessment of proposed PGR Investigations

Identify the main risk element regarding your health and safety and assess the potential risk. Risks may be categorised as tolerable, moderate, substantial or severe. Indicate the actions that you have taken to reduce the risk and then indicate the residual risk. Tolerable risk is acceptable. Moderate risk must be managed carefully. Substantial or severe risks which are serious and likely to happen are not acceptable and you would not be allowed to proceed.

Risk Element	Potential Risk	Existing controls to reduce likelihood	Residual risk rating
Emotional risk to parents, children and families (Payne & Lloyd-Williams 2005, Randall & Downie 2005, France 2007, Crang & Cook 2007).	The research is being undertaken at a potentially emotionally stressful time for the families and individuals. There is potential that the research process could exacerbate these emotions.	No research will be undertaken without parental consent. The consent will be requested in collaboration with the Project staff and the potential risks made explicit. Further counselling support will be available throughout the research to provide support for the families and their children.	Tolerable.
Political risk and adverse publicity.	There is the potential that this research could be perceived as public interference into private lives at an emotional and stressful period.	The researcher is cognisant of the needs of the children and their families and is aware that the primary role is to ensure non-maleficence. Research would suggest that parents who are experiencing the illness of a child will not be adversely affected by talking about and being consciously aware of the situation (Payne & Lloyd-Williams 2005).	Tolerable.
Emotional risk to the researcher (Lee 1993, Rolls & Relf 2006).	Research into potentially terminal childhood illness is sensitive and there is a risk that the emotional well-being of the researcher will be compromised.	The researcher is an experienced practitioner, who has supported vulnerable children and families emotionally for many years. Consequently the need for supervision and support is recognised and acknowledged (Rolls & Relf 2006).	Tolerable.
Physical risk to the researcher (Lee-Treweek & Linkogle 2000).	Potentially visiting participants in their home or other venues other than the hospital setting.	The researcher has many years experience of working with vulnerable families and undertaking the necessary risk assessments. Strategies will be in place when	Tolerable.

Any additional comments/issues:

The researcher is aware of the potentially perceived risk of working with children and young people. The researcher has many years experience of working with vulnerable families, has an enhanced Criminal Records Bureau (CRB) check and is registered with the General Social Care Council (GSCC). Furthermore, the researcher has a thorough understanding of child protection and safeguarding procedures.

5. Research Ethics

Ethical Approval

Does the proposed study entail ethical considerations? Yes No

If 'yes', please indicate how you intend to address each of the points, as appropriate. If no, you may proceed to the next section.

<p>Consent Parental consent will be sought and gained prior to all family members being approached (Children and Young Persons Act 1993). Although under Common Law parental permission is not a requirement for children who have 'sufficient understanding' to participate in research, (Masson 2007), the parents' views will be respected. The purpose and process of the research will be explained to all participants, both verbally and in the written form and their consent obtained (Neill 2005). Prior to each interview session, the researcher will confirm with the participants their wish to continue. In addition they will be informed that non participation will not affect any care or support they are currently or are likely to receive from the project in the future.</p>	<p>Interview research Semi and unstructured/informal interviews will be the primary data collection method. Where appropriate these will be tape-recorded, but all participants will have the option of talking off-tape. Assurances will be given in writing that this data will be kept securely and tapes destroyed at the end of the research. Participants will also be made aware that they may withdraw all or parts of any information provided in the research at any time, or withdraw themselves from the project at any time.</p> <p>Observation research Participant observation will be the supplementary data collection method. All the participants will be made aware of the researcher's role and its distinction from her role as counsellor. This information will be included in the consent forms and participants will be verbally reminded at the beginning of each data session in which data might be produced. Permission to use such data will be requested at the end of each session.</p>
<p>Deception The perceptions of families where a child has a life-threatening/life shortening illness are central to this research, and therefore, the researcher recognises that she has a moral obligation to record as accurately as possible the participants' accounts of events and feelings.</p>	<p>Giving advice The role of the researcher will be explained to the participants prior to the interviews commencing. Within the role of participant observer, the researcher will not give advice to the participants and will need to be aware of 'boundary crossing' (Rolls & Relf 2006) from researcher to practitioner. However within the collaborative approach the researcher will inevitably be seen as a familiar supporter of the family and thus will become involved in the children's biographies. The services of a counsellor will be utilised to offer support to the participants over and above that of the researcher as practitioner.</p>
<p>Debriefing Feedback on research insights will be offered to participants in an ongoing way during the research. They will be given the opportunity to ask questions and express feelings. A counsellor will be available to provide post-interview support if required.</p>	<p>Research undertaken in public places Not Applicable.</p>
<p>Withdrawal from the investigation Prior to each interview, the researcher will confirm</p>	<p>Academic integrity The researcher will be working to the University of</p>

<p>with the their continued involvement. The consent form will be explicit that they are free to withdraw from the research at any time and that this will not affect any future treatment/support from the host establishment.</p>	<p>Derby's Research Ethics: Code of Practice. In addition the researcher will adhere to the British Sociological Association's Ethical Guidelines.</p>
<p>Confidentiality and data protection All names and other identifying information will be anonymised and stored securely. Confidentiality will be explained and discussed with all the participants (Masson 2007) and this will be included in the consent form. During the initial introduction of the research goals, explanations will be given which include individual, family and setting confidentiality. The researcher has a duty of care to all children involved in this research and if there are any safeguarding concerns these will be dealt with following DoH guidelines (2003). Following transcription, all tapes will be destroyed.</p>	<p>Animal rights Not applicable.</p>
<p>Protection of participants The needs of all the participants will be placed before the research. The provision of emotional support has been built in to the design of the research (Neill 2005) to facilitate the needs of families and children. Guidelines for Research, The National Children's Bureau (2003) will be followed.</p>	<p>Contractual responsibilities Not Applicable.</p>

Do you intend to request clearance from any other body/organisation (eg local education authority)?

Yes ✓ No

If 'yes', who? Community Project supporting families with children with severe life-shortening/life-threatening medical conditions.

Does any other Code/s of Practice of Professional Bodies apply?

Yes No ✓

If 'yes', which? (eg British Psychological Society).....

Is NHS Ethical Approval required? (see <http://www.corec.org.uk>) No ✓

If the answer is 'yes' then you and your supervisor must prepare an appropriate application and have it approved by an MREC or LREC committee. This can be a difficult process and it can take considerable time. Advice can be gained form your School's representative on the University Ethics Committee.

NOTE: In submitting this section you are confirming that you have read and understood the University of Derby's Code of Practice on Research Ethics. You are also confirming that, if approved, this research will be conducted in full accordance with the code.

APPENDIX THREE

Dear Parent

Following our recent conversation you are aware that I am presently in the middle of a research PhD investigating how well families adapt and cope when a child has been diagnosed with a life threatening/shortening illness with special reference to the well sibling(s).

I would like to stress at this point that although you know me as a counsellor the research is not counselling based, but sociological. The research will, therefore, follow the British Sociological Association Ethical Guidelines.

It is hoped that from the findings of the research that more awareness is raised particularly within the medical and social work settings for better communication/information with and for families. That sibling(s) are supported throughout the illness and following a death, and will no longer be in a position of being voiceless and somewhat invisible both within the family and certainly from the professionals involved. How the illness effects the sibling relationship (or not) and the long term effects into adult life. That families are considered as a unit with individuals, to perhaps being viewed from a professional perspective of one parent and an ill child.

I would like to stress again that you may withdraw and/or remove your contribution from my research at any time and that anonymity and confidentiality will be maintained throughout the research

I would, therefore, ask if you would consider being part of the research process, which consists of semi-structured interviews. I have enclosed a consent form for signature that can be returned in the sae, or if you wish to discuss this further please do not hesitate to telephone me on 01689-898979.

With best wishes

Pam Dawson

APPENDIX FOUR

RESEARCH CONSENT FORM

I am willing to participate in the research being undertaken by Pam Dawson, who has clearly explained the reasoning for the research and that the interview will be used as part of her PhD.

Name.....
.....

Telephone
Number.....

Pam Dawson has also informed me that my consent can be withdrawn at any time during her research and that any interview material will be destroyed.

I also understand that all interview material will be used in complete confidence and all names changed.

Signed.....

Date

APPENDIX FIVE

Dear

Following our recent conversation you are aware that our original discussion regarding my PhD investigating how well families adapt and cope when a child has been diagnosed with a life threatening/shortening illness with special reference to siblings has changed slightly. Although there is still an emphasis on the well sibling, they are part of the family unit. Therefore, the research will be looking at the impact the illness has on the family system as a whole, and the changed [if any] relationships within the family.

It is still hoped that from the findings of the research that more awareness is raised particularly within the medical and social work settings for better communication and information for and with the family as a whole, along with the actual needs of the sibling(s), instead of their assumed needs. Also, that the family is viewed as a unit with individuals instead of one parent, usually the primary carer and the ill child.

I would like to stress again that you can withdraw and/or remove your contribution from the research at any time and that anonymity and confidentiality will be maintained throughout the research.

I ask if you would again consider being part of the research process and have enclosed a consent form for signature that can be returned in the sae.

With best wishes

Pam Dawson

APPENDIX SIX

Dear

Following our discussion regarding and Taking part in the research, I am happy that although is not willing to answer direct questions but will agree to do drawings. I would be grateful if you would sign the enclosed consent form and send back to me at the office in the sac.

With best wishes

Pam Dawson

APPENDIX SEVEN

PARENTAL AND YOUNG PERSONS RESEARCH

CONSENT FORM

I am willing for to participate in the research being undertaken by Pam Dawson who has clearly explained the reasoning for the research and that the interview will be part of her PhD.

Parent.....Please print

Child/Young Person.....

Telephone number.....

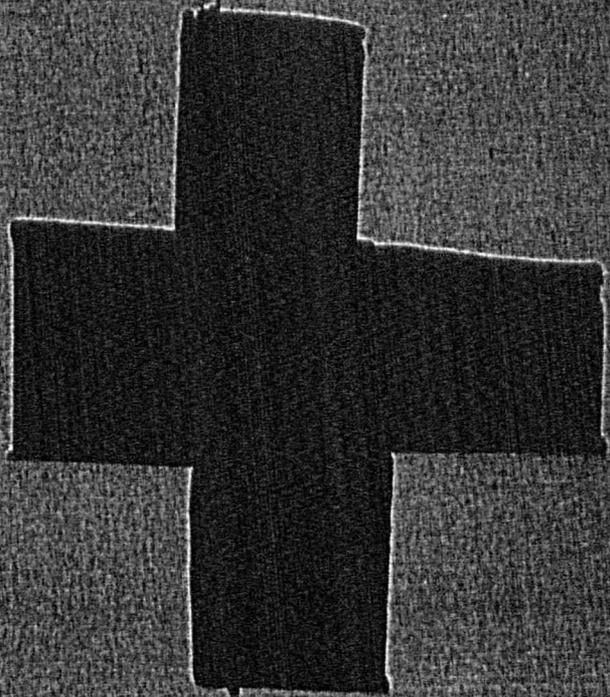
I have also been informed by Pam Dawson that my consent can be withdrawn at any time and that all interview material will be destroyed, and that all interviews will be used in complete confidence with all names changed.

Signed.....Pa
rent

Date

The research follows the British Sociological Association Ethical Guidelines

Things I Dislike
About the Hospital

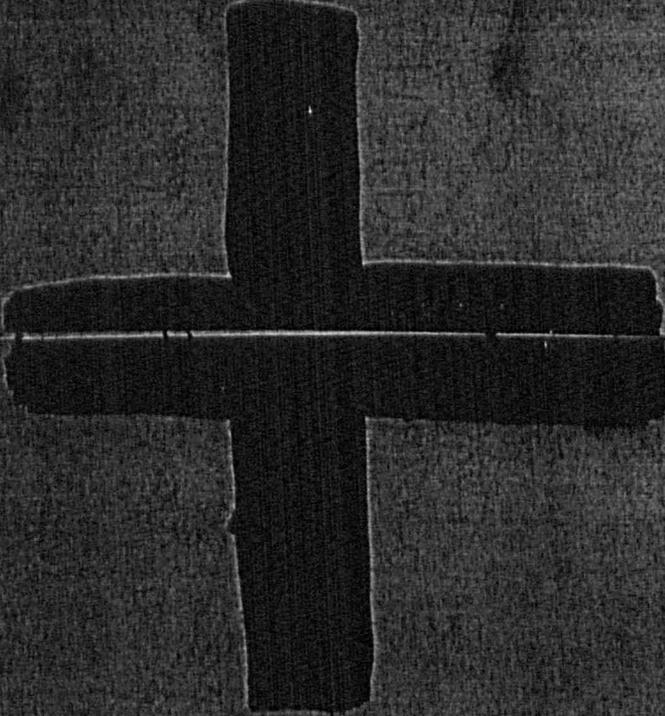


I don't like it when you have
an X-ray and after you see a doctor they even
spend all they're time on the computer

2. I also don't like it when the
nurse asks you what ~~is~~ hand do you
write with and she puts the needle
in the wrong hand!

APPENDIX NINE

Every one has
I'm a



Chubbins

chordons

to

Consider

I'm a

• Please doctor ask out to the children
out well as the adults

• Please doctors learn how to do
the C word before putting it on
a child

• Please be kind and honest to the
children if they find things scary

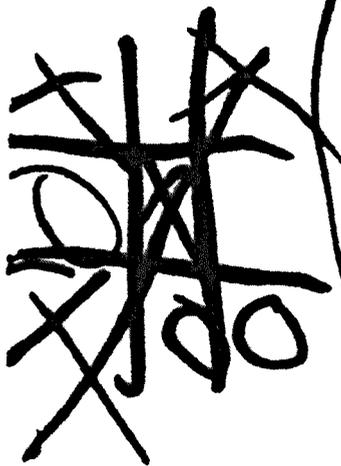
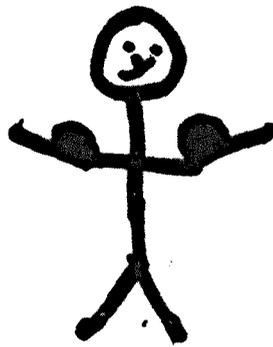
• US CHILDREN HAVE
FEELINGS AS WELL!

Doctors

Thank you!
for
Lusans



Every one knows
I'm a
Hero

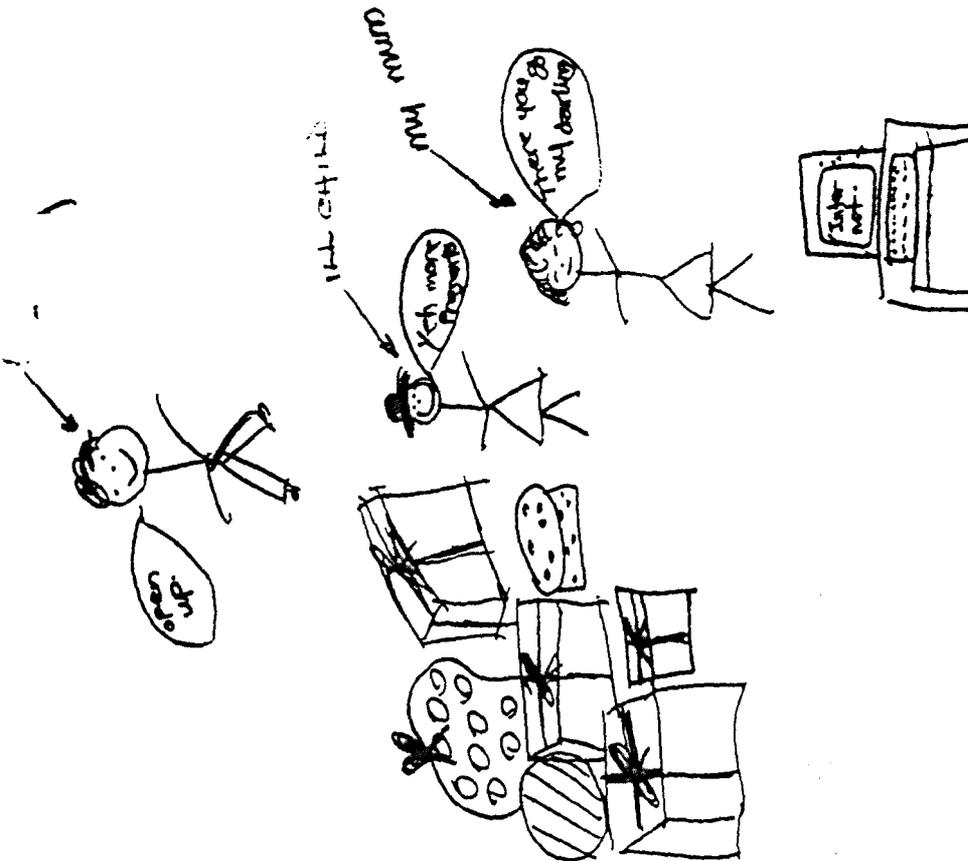
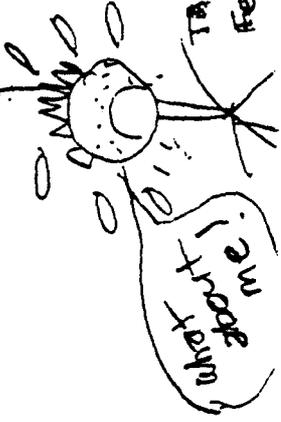


But I'm not
treated like one
I'm treated as
if I'm a
loser

MALE SIBLING - BONE
MARROW DONOR FOR HIS
ELDER BROTHER

APPENDIX ELEVEN

THE 12 YEAR OLD
FEMALE SIBLING WITH
A 9 YEAR OLD SISTER
WITH CANCER



APPENDIX 12

Well my name is Susan and its September 18th 2006. I have a husband, a son who is 13, and Annie who is 12, and indeed in my family it is Annie who was diagnosed with ALL. It was in March 2003 after fracturing her spine in February of the same year, which is how they diagnosed the leukaemia. So quite a traumatic start and of course following through the treatment plan, the actual fracture to the spine was, and lots of people have said to me since that it had actually been a god send as it were because it did actually, that slip down the stairs literally and the impact of the break fractured a vertebrae in the spine and she got sent to the hospital. So literally flat on her back for 2 weeks until somebody decided that they were going to be able to do something to support the fracture. There were regular blood tests and 3 weeks on from the fracture that's how the leukaemia was diagnosed. So actually it was there manifesting but the fracture to the spine brought it all a bit sooner so we started treatment quite promptly. She had her diagnosis on a Wednesday at ... and they were able to start treatment on the Thursday [PD wow]. Yes very quick and indeed people who we have met since whose children are poorly for months and months and months and are of a higher category and much more severe treatment. So we thanked everybody for that at the time because she was graded as a very low risk group even though your whole world fell apart, we went through two and a half years of treatment. She is now in remission but at the time the fracture to the spine was bad enough because nobody knew when that was diagnosed the damage and spinal injury from that so that was a bit of a shock. And then the 3 weeks on of course her becoming, to look at her looking more and more unwell, paler and then on the Friday I had to take her back for a out-patients blood appointment through the hospital and she was wearing her back brace and everything and it was really quite traumatic for her and she had been at school doing some morning school and she was exhausted and I remember taking her in to the hospital and saying to the nurse can you check her for anaemia, she was ashen she was, not just grey. She looked awful and the nurse touched my arm and said don't worry dear we check her for everything, I didn't, you know in my little world [both laughing] that was it, and that was on the Friday and on the Monday I had kept her off school because she wasn't well, and I had a phone call to say Friday's blood test was suspicious. We are not saying what we don't know at this time, could you bring her back in, could you be here within the hour, could you pack a back be prepared for over night, but don't worry [both laughing] you know that really was, don't worry, so we were in, we arrived and they did the blood test quite promptly and within the hour the hospital said it was leukaemia. They were more and more sure, they were 90% sure it was leukaemia because the leukaemia blood cells were showing blue on the Monday under the microscope and they were not doing that on Friday, so it was literally Friday-Monday that change in her blood was such that they were more than sure, then on the Wednesday we were at ... and on the Thursday she started treatment. So it was like one hell of a ride.

PD Did you get chance to draw breath

S. No, on the Monday when they said they were 90% sure my world did fall apart, I had been with her every day, every night, every waking hour when it was just the fracture to the spine because she was doing everything flat on her back and there was a lot of time and energy going into her care, and then on the Monday I had to come home, Sean stayed with her on oncology and I came home to my parents and we just

sat up and cried it was awful I can remember it like it was yesterday, and then on the Tuesday they took me back up early on the Tuesday morning not knowing what I was going to walk into, and then we had a talk with our oncology nurse specialist, and until it happens to you it doesn't happen in your world and suddenly there is all this information, drip-fed. I have to say a great big booklet, leaflets, and then she sat down with Annie and said this is what it means and probably one of the side-effects you will loose your hair. And she was only eight and a half at the time and I remember she sat on the bed and our oncology nurse specialist said some times the hair comes back a different colour and Annie just said but I don't want blue hair [both laughing] out of all the colours, it wasn't blonde, or brown it was blue. It sought of lightened the moment, that was obviously how she perceived the change of colour. Then we had 14 ambulance rides backwards and forwards to different hospitals for MRI's CT scans and up to ... for her back, and it was all just, just to much really, and you just muddle on, you really do just muddle on in your own little world but it meant that I wasn't at home, so my sudden absence from home was difficult, especially on Sam who was 10 and a half at the time and carrying on at primary school. Last year at primary school was not a good time for him at all, not that there is ever a good time, but his peers really played on that, he had such the last 6 months at primary school was an awful time for him and we were in countlessly, not me to start with because I was away from it all, but my husband and my parents were having to go into the school to talk to his teacher about what had gone on the day before with other kids in his class and the Head Teacher actually said in the end, I think Sam is just his sensitivity, as if that's the answer. You know he's being over sensitive, well sorry but his sister has just been, she is in hospital plus mum's away as well and people just have no idea, even though you sit down and obviously we had kept the school informed of Annie's illness because she was away from school and they still just sort of, but I will never forget him saying that it's just his sensitivity, but my door is always open. He was trying to say the right things but never followed them through, he never looked for Sam in the classroom, you know, do you want to come and have a chat, just to offer that, no it was difficult, it was a really difficult time. Sam stayed at my parents house and thought it was fantastic staying at nannies and granddads it was like staying at a hotel you know, he'd get up in the morning and his cereal bowl is full, I'd say its in the cupboard help yourself lov, but nannie waited on him so staying away was not an issue it was normality changing, which he found difficult because Sean had to carry on working at the time, he was rushing up every night after work, by the time he got to us in the hospital the maximum he was with us was a couple of hours and then it was time for him to go. That was awful I just remembered the nights, so long and lonely in hospital it was awful, then once her treatment had started we were back, well she should have been at home but she look quite unwell quite early on, so we were at the local hospital in and out of our shared care for weeks, weeks in, weeks out, days home then back in again with another infection and that is what they expect in the first year of ALL because the treatment is so intense and you just have to go with that really.

PD Do you think there will be in the future or has there been a knock-on effect

S. I don't know if its all to do with that but he has issues and I just put it down to his disposition because he is so easy going and tolerates an awful lot and he is a red head so he has had all the jibbing in the world to the point where he will then blow so whether he has just leant to be tolerant and then he gets to a point where he thinks I

am not going to let you talk to me that way, he's not physical, not punchy but he can wind people up and he winds his sister up and sometimes they have a bit of a go and I just shut the door whereas before I would say what is going on after what we have been through.

PD Did the fracture to her spine make it more difficult for the treatment?

S. Not to regards to having the treatment they had her in a body brace and the people who made the body brace for her actually made a little hole in it for her Hickman line, for her central line so she was very, very restricted with her movement and her every waking upright hour she had to be supported so in the end she didn't want to get up because she clicked that as soon to go to the toilet we had to strap her into this thing. So it was easier for her to stay in bed and I never appreciated, it never dawned on me that I would have a depressed eight and a half year old to deal with, let alone my own. But there she was, she had everything worked out, if she didn't move, she didn't have to have this thing on, and that was a saga because when she was diagnosed they said they could do the back brace which they did but when she was diagnosed with leukaemia ...condemned the back brace that the other hospital had made and said it was totally inadequate for the fracture as there was no support at all, it was just like a bullet proof vest that was made initially it was very rigid, it was like a shell, a tortoise shell but it didn't support her neck or anything and the weight of her head with gravity brought pressure on to the fracture of the spine and everybody's alarm bells started ringing again. In week 3 when she had been wearing this thing for a week at school for those few mornings and then bum, we were at the specialist hospital with them saying you are not to wear that, and they made her a proper one, proper one, they made her a better one, in their opinion, then she wore right through for eight months, so that was a bit, and everyone at the time said are you going to pursue that, because that's really awful that could have been detrimental to, but you haven't got the energy, you just haven't got the time or energy, you just hope it doesn't happen to anyone else. That's the thing, yes, yes it was a bit of a game and one hell of a roller-coaster ride, you can't imagine lots of my friends now say I don't know how you got through it, but you do day-to-day and you just cope with everything that is thrown at you in your own little fashion, then Sam had started secondary school and not many of his peers went to the chosen secondary school so we hoped it would be a fresh start and he wasn't starting with the knowledge that he had a sister who was ill. However, we did tell the form teacher and everything just in case there was anything that was said or showed up it was probably the explanation for it, the issues that he had, and he did have some bless him, mixing with the new lot. Clashes like we all get, so that was a bit demanding of everybody as well but not directly because of the situation. Then time went on and 8 months the hospital were happy that the fracture was mended as best as it could, and she could stop wearing the brace and that was a big improvement for her and just made life a lot easier and was closely monitored in regards to the back let alone the leukaemia treatment that we were still enduring, so yea, it was just continual really and everything then went fairly smoothly. Apart from the fact that we found out that she was metabolising very slowly so she didn't need anywhere near as much chemo as the norm, which unfortunately in the first year they can't do anything about because the doses are set and that's it, and that's why she was extremely poorly. Then in the 2nd year maintenance they were able to tailor it a bit better and I have just heard now its improved even more, things that they been able to get personal to the individual so their life improved a bit more and her hair began to grow back things

like that [very loud] not blue. No not blue, certainly darker than she was she was a real strawberry blonde, and her school work didn't suffer, fortunately for her she is, like she is, studious, through her treatment she wasn't mentally ready, and that's a real big thing as well when they diagnose the children there is a lot of pressure is put on the parent to get them to school, keep normality going, when actually your normality has gone out of the window, and you don't need to be putting a child who is ... suppressed into a class room whatever time of year let alone winter time with all the children coughing and spluttering all over each other. It was just a bit of a battle and we kept her off for most of her, certainly for the first year, but we had a home tutor, we had 5 hours a week and that kept her ticking over, she wasn't always really mentally, some mornings she would wake up and I would think not today, and that I also think somebody should sit back and realize that.

PD What does normal mean?

S. Absolutely [spoken slowly and drawn out]

PD Its not only ignoring things like the diagnosis of the ALL, it was also the fracture of the spine so like you said normality had gone out of the window and you are at the beginning of a new normal.

S. Yes, whatever that normal is, and people would say to me, oh get back to normal now then, and I just felt like smacking them in the mouth really because no, my life as I know it had gone, I have another life now.

PD And you will never get that life back

S. No, no, not at all, and I resent it for that, you know she was eight and a half when she was diagnosed and nearly 11 when she finished and that gap she grew up so quickly because of what she had to endure, so really a lot, a lot of misgivings, no its not nice and the whole thing, the way it comes together, well the help that is there that they all say, here I am at the end of the phone and things like that and actually the oncology nurse specialist we had was very good at the time, then we had a bit of a change and now I don't think we have seen or heard from our [new] oncology nurse, I know we are in remission but we go and have our check ups regularly, don't see her, don't see her at all, and then you have, if your consultant is off for whatever reason you have someone else standing in for them and they don't actually know, they might not even specialise, so quite often we do go 3 monthly now, so in that time something might have happened, the blood count might be a little bit, and I like answers and when you sit at a table and they say remind me, then what are we dealing with here, no actually, you have her notes in front of you, you are seeing us today, you should have done a little bit of home-work before you come into the room.

PD I think the other side of the coin is in actual fact you are now the 'expert' parent in front of the expert

S. Yes, they have the knowledge [big emphasis] and of course you know your own child they, they [eyes raised] medical people. Professional people, in general try to treat everybody the same, where you do – they say mother's instinct, its only because you live with that person and you know how they tick, and you know I mean I know

when she has got out of bed on the wrong side and you know to tread carefully, and sometimes they [medics] do talk to you as if you are neurotic or paranoid and there has been a good few times when we have persisted over some thing and its turned out right, whether its medicine dosage, or you are double checking and re-checking and you are double checking all the time and that's exhausting.

PD I think that's what is scary for a number of parents, I have heard other parents have actually said or instilled into their child, don't let a nurse do anything unless I am there because of possible mistakes re dosage.

S. There was a spell where Annie was having transfusions every week whether it was a week or 10 days she was having either platelets and blood either or and she was having so many she actually built up an allergic reaction. So she had this allergic reaction one day, so it was oh dear, and alarm bells started ringing, we will give her some anti-histamine to correct it, right on the front of her notes, big red letters must have cover before transfusion. So a nurse went off and I had seen it, on the front of her book in red in big capital letters, next time she had a transfusion, didn't give her the cover, and had it not been for me they were just about to put the bag up and I said she hasn't had her ante-histamine, oh right, yea, yea that's right I didn't read that, well why haven't you done it when its there in front of them. I know they are busy but actually when they walk into our room to deal with my child that's what they should be concentrating on

PD I'm busy is no excuse

S. No, not at all, especially when you are on a ward such as our shared care, you've got oncology, a couple of rooms that are purely for oncology but its ... and I know they are going from treating children ... general problems, it's a specialised which brings its own problems, like too much chemo we were half way through the treatment and they changed the suppliers for one of the chemotherapy drugs and what was being supplied was actually in the bottle which was the same bottle that we were used to seeing, the actual strength of it was stronger so you had to give less and time and time again I would be checking this with them, because I remembered being told it, but then you see other people who dispense it to you, and so that's right then is it, so I've just got to give, well no, and they would tell me the double they would tell me the other version, well no, because we've got this new, oh yes, that's right, and actually when all our changes happened in the medicine it was nearing the end for us, the end of her treatment and our change of oncology staff, but for those just starting or your, my mum always said your good to be on top of it all, what about the people who aren't but that shouldn't be my worry, I am only concentrating on my own, and it doesn't concern me unless somebody realizes.

PD So all this is happening to your family

S. Yes, a big network, my sister and her family my husband who was working solidly through that time, ...so he was trolling along to work missing us not being at home, and I always ended up doing the weekly shop, which was my omen in the end because I would do the weekly shop and the fridge would be stocked then she would spike a temperature and we would end up in our shared care, and Sean not that way, I mean he can fry a egg but that's is about it, so he was round my mother's house for

dinner and things which was fine and that worked to, but if I didn't have the support on the doorstep, we are a very close family fortunately, again for those that don't have that it must be a bit of a problem. Then daddy would arrive and shun or deny issues that were happening, get quite stroppy with things that, things that we have said checking and double checking he would go in with his stroppy head on rather than trying to be diplomatic about it, and a couple of times quite near the end of treatment he did offer to stay with her at the hospital because the majority of times it was me and one of the nurses said to me the following morning your husband is not coping is he, not coping very well and I said I don't know what you compare it with, and she said it's the dad's all the dad's are the same they all go into denial especially when its there little girl, and he didn't sort of want to talk to anyone about it, he just sort it out in his own head. I suppose some do and some do it successfully, but I imagine some don't.

PD Do you think Sean accepts now?

S [a long emmmmmmmmm]

PD I am sure some dad's just blank it out

S. I don't think he blanks it out, if anything he's not kid gloves, he does treat her, he doesn't treat her like oh god we nearly lost her, we could have lost her, its changed my whole concept, he will still tell her off when she needs to be told off and things like that, but it has made him like the other day she had a nose bleed and it both rung alarm bells for us so it takes you right back to the very beginning when like things happen, and only yesterday he said to me, I meant to ask you has Annie had any more nose bleeds, and I said no, not at all, it was like those 2 in a week and then nothing at all, and he said oh good, but whether he had been thinking it through in his own mind at that time, and like, oh I forgot to ask you, so he is very aware and the fact that we have lived through it all and she is here, although she has said recently if she became ill again she wouldn't have the treatment, and I told him, and he said silly of course she would, yea, but that's quite a big issue, I don't know where that came from recently

PD How did that make you feel

S. Awful at the time, awful, she said it about 3-4 weeks ago, and it was actually after we had been to our shared care and our normal Registrar wasn't there and the doctor we saw started saying oh her count is down, her platlets had gone down or something for the month, and has she been well, and I said yes, no bruising, no nose bleeds, no this and that, and I said oh this is like it was in the beginning, we were asked all these questions and Annie was there, lets check it out, and I suppose for her, she is now 12 and there is also a record they are playing on the car at the moment, its quite, the words to it are about losing someone it's a rap, Puff Daddy song and I am driving to school the other morning and she said she would like this song played at her funeral. Well, I don't know how I didn't crash the car, and I went Annie, and what I should have said was, this will be long out of the charts you will be old and grey love, but I didn't straight away, I said [sharply] because it was awful, she, she but she is quite deep, she leaves notes and things for me, you do know I love you and I find it on my pillow, so it has obviously had a big [very long pause]

PD I think children of 12 are far more astute in the world around them and about their own lives and that they can say anything from what colour my bedroom needs to be, to, I am not going to have treatment anymore, which is good on one hand but for the parents

S. And actually I did say, well you would because we would get through it together but I don't know where that's come from, I hope she is not dwelling on it I hope its not a bedtime thing when she goes, when you lie there, as you do and every thing looks so much bigger you lay there but without probing to much, without bringing back into the fore front, I just hope its sitting there at the back and she is not worried about it to much. You actually in your own little world life is a bitch, and you are dealing with that then the way they minimalise everything I hospitals does make you think its not as big an issue, which isn't right.

PD some parents who may minimalise it then what would be the consequences

S. Definitely

PD I suppose one of the consequences as you were saying earlier is when people say as a family we are keeping everything normal which I assume is not really possible

S. Yes, yes what we know and what we are told fairly early on is that commonly, quite often you do not loose them to leukaemia, its secondary infection and that was our reasoning for not putting her into an environment where everybody was coughing and splutting or had chicken pox or measles. You know as soon as you got a sniff of it in the class yes you pull her out of school but what if somebody unfortunately like we were saying earlier society today don't care a dam, if mum works they will send little Johnny to school with a few spots and that could be to my daughters detriment, on the day he starts cropping spots we are paying the consequences. So I really do feel that if anything comes of it [Ph.D] the issue of education within an age group of children going through treatment has to be addressed, it really has its such, such a big, big issue. The schools are still quite good with sickness and diahorra that kind of problem, our school has a 48 hour ruling but actually you know you can prove it, prove that you shouldn't be there its very hard and I am sure there are cases where they get sent in as well and shouldn't really be there. But they should'n keep saying send her to school because we know and the medical profession know it as well because the treatment you are depleting the immune system of which it does. So why would you send anybody into that kind of environment. I know some of the medicines have been tailored even more since Annie had hers and there was one that gave us big issues of which we had to get involved and that was an injection into her thigh. Now they give it in one injection but that was a big hurdle, you can't numb it, it was a big injection that had to be done every other day for 9 days, so by the time one leg was recovering they were here the day after for the next leg and she screamed, boy did she scream and kicked the nurses, it was awful. Things are improving but the things that are not improving is being aware, but to me its just common sense, and I sit back and think am I the only person to think like that.

PD I am aware some parents are highly critical and state this should have been done, and I have said why didn't you say anything, and the general reply has been but it's my child that is being treated.

S. Yes, yes I suppose there is that, but they should surely think these are professionals and putting all aside, professionalism should take over

PD It's almost as if there should be an advocate, someone in the middle

S. Yes, yes, another division

I mean I know there are medics who actually think support for families going through treatment is inferior and not top of their agenda

PD I am aware of nurses who believe they are the right people to give emotional support to families

S. No you have got to specialise in it, you can't just turn your hand to it, it's almost like choosing to be counsellor, you have got to really

PD So it's raising the educational awareness both in schools in what is happening because the education includes teachers and pupils.

S. Well our oncology nurse specialist came into school talked about the care of her Hickman line and everything else and the teacher was horrified, we sat round this table and I felt for her because you know poor woman she is a teacher she doesn't have to, you know there was a train of thought, I actually thought she Annie shouldn't be there with these issues, she shouldn't be at school, if the line gets snipped accidentally by a child doing crafts with a pair of scissors she could bleed to death [laughing] unless you pick it up quickly, and her face [teachers] and there are plugs some plastic plugs and you and you with some gauge, and I could see her saying I don't want to do this, why should I

PD I have been on one of the school visits where a teacher actually passed out

S> I can imagine, it's almost, you need somebody like you with all the special needs that we have in our main stream schools today because that's what it is, a special requirement, and if they are going to pursue and really the issue of normality [in inverted] having these children in school then they have to put something aside, when we phoned the school to bring them up to speed how Annie was, the receptionist said, and I think she had worked at the school for 15-18 years something like that, she said they had never had a child with leukaemia in the school before. So that to me was like wow, we might have some issues here, but I think she stayed as well as she did and that was quite poorly, but she stayed as well as she did because we didn't send her every day, not that, that was the detriment to her she really did well, she sat her stats in hospital, and one of the hospital teachers sat with her and her home tutor came in to observe the actual doing of it and I had to leave the room, so it was all done properly, yea it just needs a bit of thought, a bit of time and a bit of energy but I suppose people haven't got that.

PD What about the training and educational needs of hospital staff

S For schoolteachers within

PD No the medics themselves, about families about parents about the ill child and siblings and how illness changes everything and everybody

S. Nurses used to say well I'm not really I don't specialise or I'm not really familiar with all this so I will have to go and get someone else, so yes, it is quite different but if you are working on that kind of a ward anyway and our play-specialist we had wasn't really [big sign] at our shared-care she was difficult to say the least, Annie used to grimace when she came in the room just because of her way and that wasn't helpful because actually that the play-specialist is a bit of time out but I could never leave Annie when she was coming because it was just awful, Annie would shut down, completely shut down.

PD But that's the whole object of a play-specialist is that children open up

S. But the play-specialist at the specialist hospital were great and the early diagnosis play was brilliant because they did all the blood cells and Annie remembers that now, so that had much more impact then when we were back at our shared care and again it falls down to the same thing its such a varied ward, their needs are so different and they are not capable of tailoring it

PD How do you think the ward at the specialist hospital and the shared care cope with parents for whatever reason go [don't know how to write the noise but an explosion]

S. erm at the specialist hospital I went [same noise] on the she started her treatment on the Thursday but we couldn't get a vein till Friday because she was anxious and all her veins were just popping every time they got a needle in and on the Friday afternoon they started at 2 o'clock to try and get a vein and at 7.30 they got me a priest in for me who walked me out the room because I couldn't cope anymore I could see them almost strapping her down on the bed just to try and get a canular in and literary as we walked he took me to a room and he didn't talk about what they were doing to her we just had a cup of tea and sat, then Sean walked passed the door cause he's just arrived so he went in with Annie and then within 15 minutes he was back in the room saying they had got one in her ankle and obviously they were going for her arms, her hand, her wrists, but at 7.30 that night they got one in her foot but it was the most traumatic afternoon of my life. So now she is needle phobic which is only to be expected but that is getting better. I sought help from a friend who is a homeopath and she gives me these little sugar things that she dissolves on her tongue so when we know we are having bloods done and things like that this is what we do, and it does, it might be a placebo but it doesn't matter its 3 times its helped so we will continue to do that, but big issues, the very first night at our shared care when we went in for the fractured spine they wanted to do bloods, because it was February all the nurses are new, all the doctors are new in February and I didn't know this at the time, so never become ill in February and I didn't know this at the time so never become ill in February and

August/September cause you get new Regi's and we got up on to the children's ward and this doctor came in, he didn't speak a lot of English and the lovely nurse who was quite mature in years and she had been there donkeys and she was sitting on the bed and Annie was very anxious and they were trying magic cream on her of her hand and they put this canular in, and blood just went everywhere and the nurse went ok, ok that's fine you have got it in can you leave it now, that's fine could you leave it now. And there was blood all over her hand and the nurse in such a discrete way. I had picked up on it said leave this child alone now its really late it was getting on for the early hours of the morning by the time we had come out of A&E with her back, and they just strapped it up, she secured the canular it up the following morning daylight hours they came in to check her and said cor who ever did this and it was covered, her hands was covered in dried blood all over the palm of her hand, all threw her fingers that was it then, every time anyone came near her with a needle there after so, she was eight and a half then. Some people have since then who actually specialise it's a knack that some people have and surely if you are coming to canulate a child of that age then send a specialist don't send somebody who is a bit some times, I am all right some times I am not. So that was not helpful and it just went on there really.

PD Amidst all this was your son

S. Yes, well he came out of school mum had him straight away we were in hospital on the Wednesday for the diagnosis and mum remembers him running out of school to her at the gate saying what does she look like, is she all white, what does she look like because he thought straight away she would be bald, you know from whatever they have done to her today she is different so his whole concept at 10 was that and she is going to die, but we were given some quite good books that was Jo's story, I have still got them actually and it was spot on, the little had a Hickman line and things like that, but apart from that nobody spoke to him, he came in to visit her in the shared care but it was, is this your brother, and brother goes home to nanny.

PD Do they talk about the future

S. Not really, but you don't know how their little minds work, and it's the long term for me, I am sure she doesn't think like that but 20 years down the line, I don't know what how she is going to be, the medicines she had, the repercussions of that, reading now its about the side-effects of, but of course what I am reading now is people 15-20 years ago and I have asked when we go for our check-ups but they said its good to read them but just remember that what you are reading that period of time ago and how we are treating the children now has changed a lot, but people still don't know, nobody can foresee and having it doesn't make you more vulnerable to other things later on in life, and I suppose we are all time bombs anyway when you have had it, when you have been touched by something like this its more.

PD Did they mention anything about fertility

S. No, that was never mentioned and she actually said yesterday, I think I am a late developer and I said what makes you say that, and she said well have you seen the size of the girls and I said don't worry about that its good to be a late developer love.

PD Do you think it has changed relationships within your own family and extended family

S. Definitely my extended family, we were always close anyway but if it was ever possible to be closer and everybody even now, my mum can see someone on the High Street and they will ask after her granddaughter and mum will say so and so was asking after Annie the other day, but Sean still [pause] certainly through her treatment we, not rows we don't row and we have been married 15 years last week [congratulations] yes, you would get less for murder [both laughing] but we are not a couple to row but we do have our periods where perhaps where perhaps he hasn't picked up on something I will send him to Coventry for it rather than have it out and a big discussion and clear the air and suddenly he will say I have missed something, something I haven't done or, like last week for instance it was our anniversary and he came home and said what's for dinner [oh dear] you just don't do that do you really, and Annie was saying oh its mummy and daddy's anniversary are you going out to dinner and I am saying oh I wonder and we were chuckling along to our selves then he came home and its just a normal day, but we did go out Saturday night so that was nice and made up for it, but certainly things through her treatment I was a bit, if only he would not help more but be more sensitive to things and that probably all it was really more sensitive, but I don't think he was brought up like that.

PD Its quite an isolating place to be, mum in hospital away from home with an ill child

S. You become institutionalised when you come out its wow, its like its not been happening everything comes to a grinding halt when you are in a place like that but it actually doesn't when you come home you have to pick up the pieces. Fortunately my mum was doing the washing and ironing and things like that but again if she hadn't been there he could have put the washing machine on but he certainly wouldn't have ironed anything and everytime you come home you think what am I going home to [long pause] I suppose you would have to work it out between you, but its another avenue when at the time you have enough to deal with, I suppose ironing clothes isn't that important, but to some people it would be

PD And I suppose at some point marriage becomes secondary

S. Yes, definitely, he hated me not being there hated completely but what can you do

PD Do you think that is why some parents separate

S. Yes, he jokes, well I think he jokes about the pecking order in our house and of course everything changes over night, so some people might not deal with

that and would find that a struggle and even though he jokes and jests about it even now, we've got a dog now and he's lower down the pecking order than the dog now and he's lower down the pecking order than the dogs now, and that's what he laughs about, but he's not really, but no he obviously at the time his status quo had changed like all of us had but and you feel like saying well its not just you, and his mum, his dad passed away years before anyway and his mum is not really the sort of mother-in-law, mum, nannie figure she used to say well you know where I am, but actually no, no that's fine and that's what makes me think he wasn't brought up like that to be not a coper, because people cope in their own way but to be close to parents and be there for each other , my sister has just moved away which has been really hard because we have always lived round the corner from one another all our days really and she is down in Hampshire now and it is only one and half hours away but even that and her and I had a few big blows through when Annie was ill, real big issues which we had but obviously going through, it was hurtful at the time really, really big issues silly as it sounds one of them sticks in my mind, we are all doggy people and the doggy walkers we all used to walk with had invited us out because they knew I had been in and out of hospital with Annie and said you deserve a night out, doesn't she to my sister, yes she does, lets all go down to the Indian or something down the road, nothing more was said to my sister about it like when, where, and what time, I went didn't think it was 2 weeks on, didn't think that her husband was working away so I I went on the night out and she phoned up my home and Sean said oh no she has gone out with the doggy walkers, and as he said it he thought I shouldn't have said that, and it was oh has she, and I got the most awful text from her thanks for ruining my evening I hope you choke on it, really hurtful stuff it was awful and I just think it probably wasn't about the evening as such, it was just a bit of a attention for somebody but not in the right direction she felt or but that was a big issue, oh it was dreadful, I have never rowed with her like that before but through Annie's illness we did

PD Some parents say remission is worse than the actual illness

S. Because you have all that structure 2 years for girls and 3 years for boys but because of the delay we incurred it was two and a half years and literary you go from week to week and this and that and the other and that gets less frequently but you are still going and you have all that structure in your life then suddenly on a given day somebody says its all finished. They don't do blood tests now, they did when she was first diagnosed and we were led to believe that it would happen because of the way she was diagnosed, it was just her injury and a round of blood tests that picked it up, she wasn't unwell so they say now you will know if she becomes unwell again, you will know, but for us we wouldn't want to go that far because of how different it was when she was diagnosed, so we fought our corner and we do have blood tests just prior to her check-up but it wasn't easy and generally speaking people don't, I have a friend whose little girl its almost like she has been forgotten at the hospital to have her check-ups, so unless they are on the phone asking in the specialist hospital they are assuming that she is under the other department but its just not good enough really

PD Not with anything as serious as this

S. But it actually makes you think its not serious, now I go to the hospital and I look around and feel very humble because there is always someone worse off than you

PD Is there anything that you would like to add

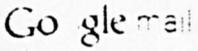
S. Rules, I my world rules are rules and certainly at our shared care, when you are in an oncology room a lot of money was spent for the facility of a barrier lobby where you barrier nurse, the amount of times that nurses would come in specially on the ward round they would bowl in the door and they would realize where they had walked into and you would think well you could have jeopardized my child's health there and with MRSA rife as it is I know in some hospitals worse than others, during Annie's care I used to smell bleach, the cleaners used to come in and do the floors and about 4 months into her care she was still an intensive patient the smell went and I asked one of the cleaners why, she said well there's proof from health and safety there is evidence that washing down with bleach makes no difference so now were supposed to just wet wipe everything, in the specialist hospital they were coming in and wet wiping they couldn't understand you anyway, but they were wet wiping everything down with like a fluffy cloth thing, rinsing it out in a bucket that wasn't clean water I don't know where they had been, they could have come from all sorts of rooms before. We said to people half way through her treatment what we say to people is exhausting not just dealing with the whole hospital business its just exhausting and just to have somebody a bit more responsive a bit more respective to help you through to know its not just what you do to take the pressure off, you are just watching points all the time and you don't want to leave them because of it, because you are worried that they are going to come in and do something detrimental, give them something they shouldn't, have got the wrong notes, not read something that is written up, so if anything I would say education and I would also so just for people to be more switched on generally, in the caring profession that we have just to bit a bit more sensitive just to be what I expect from people who work in the so called caring profession

PD And the last thing is you say that you are happy to keep your own name

S. Yes I am happy to keep my own name, definitely, I would like to think some good would come of all of this, as indeed when we signed for the Guthrie card, you know when they have a heel prick when they are a baby

PD Thank you very much indeed for agreeing to be interviewed.

APPENDIX THIRTEEN



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Dear Pam

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We do not hold that information here but would suggest you contact the CCRG who hold statistics

PPE weekend

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Mr Charles Stiller
Childhood Cancer Research Group
Richards Building
University of Oxford
Headington
OX3 7LG

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charles.stiller@ccrg.ox.ac.uk

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Regards

Danen McNally

-----Original Message-----

From: pam dawson [mailto:pam.bereavementcentre@googlemail.com]
Sent: 15 June 2010 09:56
To: info@cdg.org.uk
Subject: Contact from the CCLG website

Below is the result of your feedback form. It was submitted by pam dawson (pam.bereavementcentre@googlemail.com) on Tuesday, June 15, 2010 at 09:56:16

Comment: I am a Ph D student and wondered if you have any statistical information re childhood cancer that are more up to date than 2002 which are on the Cancer Research UK web site. thank you

KT_Update1 Contact us

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pam dawson to charles.stiller show details 15 Jun Reply

Hello Charles your email address has been passed on to me by info@ccig.org.uk who I contacted regarding statistics. I am a Ph D student and looking for more recent statistics on childhood cancers than 2002 which are available on the Cancer Research UK web site. could you point me in the right direction. Thank you for your help best wishes Pam Dawson

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