

TOWARDS HOPE, NORMALITY AND
ACHIEVEMENT: HOW PARENTS COPE WITH
CHILDHOOD CANCER

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Declaration:

In accordance with the Regulations, I certify that this thesis is
a) composed by me and
b) the work is entirely my own.

Jean M. Smith

In memory of my parents

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ABSTRACT

This is a qualitative case study on how parents cope when their child has cancer, which is still a life-threatening illness despite the considerable medical advances made in recent years. 19 parents were interviewed in depth during the course of their child's treatment. Their perceptions of their experiences are reported in detail and analysed in terms of themes, which illustrate the activities, the stresses and the conflicts that coping involves.

The findings indicate that coping involves parents in redefining a normality in their lives, remaining hopeful throughout the illness, negotiating social support for themselves and meeting their care responsibilities to the child.

These findings support many observations from practice and research, confirming that the child's illness has a traumatic and disruptive effect on the whole family. Support for the findings also came from a survey of the views of 120 oncology social workers in the UK and USA about coping, which was conducted separately.

The findings are examined in relation to different theoretical perspectives, notably Lazarus and Folkman's model of "coping theory", which envisages coping as an interactional process. Their model, together with psychoanalytically based theory, was used to understand the personal changes that parents reported as having experienced during their child's illness. Some characteristics of coping are discussed, and the implications for policy, practice and for the direction of future research are proposed.

CHAPTER 1

INTRODUCTION

Cancer as a childhood illness

The treatment of childhood cancer has changed fundamentally in recent years. Thirty years ago, a diagnosis of leukaemia and most other forms of cancer meant a rapid and painful death in a family. The span of life that could be expected for many children with leukaemia was about three to six months from the onset of the illness, and a similar short time applied to children having many other cancer illnesses. The child was regarded by everyone as being "terminally ill" from the time of diagnosis, with the consequence that the family began to prepare for the loss of the child. Research studies conducted in the 1960s and 1970s which examined psycho social aspects of families' experiences of having a child with cancer focused substantially on such issues as grief reactions following the child's death or on how the family members prepared themselves to face the death of the child (Chodoff 1964, Futterman and Hoffman, 1973).

Medical treatment has made enormous advances since then: In 1993 there was a celebration for the first person in the UK who had a bone marrow transplant reaching twenty years post treatment, at the age of twenty seven. New developments in chemotherapy, radiotherapy and improvements in surgery have resulted in greatly improved prognoses for the child. The general prognosis for children with leukaemia is now a 60% to 70% chance of survival (UKCCSG, 1996) and for all forms of cancer, about 50% (D'Angio et al, 1992).

Despite the many new developments in the medical treatment in recent times, cancer in children remains a serious and life threatening illness. It is an illness which strikes apparently indiscriminately and without warning. Although there are thought to be a variety of causes of cancer including some genetic or familial ones, it cannot be discovered by genetic testing; usually the cause of a particular form of a cancer illness is never known.

Cancer is characterised by its silent approach. The way the illness develops in the body is such that the illness may be quite well established and the disease process well underway before apparently minor symptoms alert the child or his or her parents that something is wrong.

Although childhood cancer gets considerable attention in the media periodically, with the focus often on the treatment of an individual child, there is widespread ignorance in the public at large about the aetiology of the illness. It is a relatively rare illness occurring in 1 child in 600 in the population in Britain. Cancer is not one discrete illness but a range of illnesses, all of which may be diagnosed at different stages in the development of the disease, and each carrying a different prognosis. The most common childhood cancer illness is acute lymphoblastic leukaemia which is identified by abnormally developing white cells in the blood and in the bone marrow. There are also a wide variety of solid tumours, in which abnormal cells develop together to form a solid mass. These can occur in different parts of the body, brain tumours being the most common form in children.

Medical developments in the treatment of cancer

The development of new drugs in particular, and the increased knowledge of different ways of combining them, has enabled strides to be made towards providing curative treatment. A variety of drugs is usually given to have a maximum impact in killing cancer cells while reducing to a minimum the toxic side effects of the drugs on other cells in the body. This "cocktail" of drugs is what is referred to as "chemotherapy" and is usually given in repeated pulses to allow the body's healthy cells to recover in between and to regain strength for the next pulse. The course of treatment for many children is therefore an arduous one which may last for many months, or in the case of leukaemia, two years, the most intensive treatment taking place during the first six months.

Chemotherapy is not the only form of treatment. Some forms of cancer, such as solid tumours, may be treated by surgery or by radiotherapy, sometimes in conjunction with chemotherapy. The exact requirements of treatment for particular forms of cancer are usually determined by national "protocols" which have been developed from clinical trials of treatments and represent the most up to date view on the best form of treatment (UKCCSG, 1996). Child cancer treatment centres throughout the UK use these protocols to ensure consistency in treatment and to enable continuing developments in the treatment of child cancer to be made.

Once treatment is underway and there is no evidence to be found through medical tests of cancer cells remaining in the body, the child is said to be "in remission". The course of treatment continues however, in compliance with the treatment protocol, in order to have the best chance of ridding the body of hidden cancer cells. When

treatment is finished, the child continues to be monitored closely at the hospital treatment centre; scans and blood tests are administered to check that the child's body remains free of cancer cells. More treatment may be available if a child relapses, but the prognosis for cure is usually much reduced.

The longer a child remains well after treatment is ended, the greater the chance of cure. Most definitions of having "survived" cancer refer to a child having been well for five years after the conclusion of the treatment. For some children who have relapsed, cancer becomes more of a chronic illness, with repeated periods of treatment to achieve periods of remission.

Surviving, however, is not without costs to the child. As more and more children survive (and by the year 2000 one in every 1000 young adults will be survivors of childhood cancer in the UK) it is becoming increasingly evident that a minority of children are left with physical and psychological problems of varying degrees of severity. Many of these problems stem from the long term effects of the treatments which the children received.

The stress on parents

Parents of children with cancer today do not face the inevitability of their child's death. Instead, they have to live through a long period of uncertainty with the death, or permanent damage, of their child remaining an ever present possibility (Koocher and O'Malley, 1981). Yet despite the strides which have been made in recent years in knowledge about the aetiology of the disease and medical treatment, there is little detailed research knowledge available about how the illness affects the family as a whole and how individual members respond (Kazac and Nachman, 1991, Peace et al, 1992). The knowledge that is available both from clinical practice and research, indicates that the illness has a severe immediate and long term impact on all members of the family (Koocher and O'Malley, 1981, Chesler and Barbarin, 1987, Kupst and Schulman, 1988, Ross, 1993).

Many clinicians and psycho social researchers refer to the way that parents behave during their child's cancer illness as "coping." In doing so they recognise the stress that they are under and the efforts that the parents are often required to make. The dictionary definition of the word, as "to contend with, face, encounter (danger, difficulties, etc.)....often implying successful encounter" (The Oxford Standard English Dictionary, 1994), conveys well what parents appear to experience during the illness. The term "coping" however, does not give any indication of the specific

demands that the illness makes of the parents. Nevertheless, as a general term, it accords well with my own experience as a social worker in paediatric oncology, which is that the illness, and treatment, is a cause of severe strain on all parents.

This study is an attempt to understand in more detail what coping with the child's illness of cancer involves for the parents in terms of the practical and emotional difficulties that they experience. The findings which I present in this thesis will show that the experience is a traumatic one from the outset and remains stressful throughout its duration. Parents are actively involved all the time. My findings will suggest that coping with the illness is a dynamic process which involves parents in a range of complex tasks, many of which contain formidable challenges to their strengths.

What coping involves will be described in relation to various themes, each of which is concerned with a different aspect of parents' lives. I will suggest that coping with their child's illness of cancer requires parents to rediscover a sense of normality in their lives, while being fully involved in all aspects of the treatment and while accepting help and support from other people. It requires them also to combat their fears for their child sufficiently to maintain the hope that the child will recover. Coping also involves parents in experiencing personal change either through the acquisition of new knowledge and skills or, more substantially, in changes in their system of values.

Developments in patient care in paediatrics

Medical treatment involves the child's parents and the changes which have taken place in the medical treatment have many implications for them. Changes in the efficacy of treatment have altered childhood cancer from being an illness from which the child was likely to die to one for which treatment has the potential for a complete cure, or for keeping the illness at bay for long periods (thus giving the illness many of the characteristics of a chronic illness). This improved treatment picture, however, while reducing parents' fears and giving hope, cannot take away the very real threat to the child's life which still remains. The outlook is a more hopeful, but also more complex .

In the period from the end of the second world war there have been steady improvements in patient care in paediatric medical services. First, provision was made for parents to remain with their children during hospitalisation. This arrangement took account of the responsibility of parents to support their child in

an illness and the particular contribution they could make to help the child to adapt to the abrupt and frightening experience of being in a hospital. Since this development, there has been, particularly in the past decade, an increasing emphasis on involving parents of a sick child in administering some of the treatments when the child is hospitalised. The expectation is that the parent has more authority with the child than the medical staff have to ensure that the child conforms to the prescribed patient programme.

Parents are now also involved frequently in decision making. When doctors are contemplating a major change in treatment, parents are always consulted and the risks to life as well as the side effects are fully explained. Their involvement in decision making is in line with the current emphasis on user involvement and is an integral part of the "Patient Charter" which has been adopted throughout the NHS in the UK.

Another relevant development is the emphasis on reducing the period of inpatient treatment to a minimum. Increasingly, more of the medical treatment is administered in the child's own home. The period of the initial inpatient hospitalisation may now be relatively short—possibly two or three weeks in length. At the end of this period the child usually returns to live at home, and although there may be many visits to the hospital, including occasions when the child will be required to be an inpatient, much of the treatment which is not major is given on an outpatient basis. Nursing staff from the hospital unit will usually liaise with the family at home on treatment matters.

There has been a widespread recognition among medical practitioners that most families are under considerable stress during their child's illness and require support. In the UK the establishment of multi-disciplinary health teams for treating different types of illness including paediatric haematology and oncology, gives recognition to the fact that a child's illness and treatment often have to be seen in the context of the family as a whole.

A key member of the health team is the social worker whose responsibility it is to support the family throughout the illness. A particular feature of the way this type of social work is provided in the UK is that many of the social work posts in the child cancer treatment centres are funded by Sargent Cancer Care for Children (formerly called Malcolm Sargent Cancer Fund for Children). This development began in 1976 when the first specialist social worker was appointed at Alder Hey

Hospital in Liverpool (Peck, 1979). Since then specialist social workers have been appointed to every regional treatment centre, with the result that there is now a total group of about 80 paediatric oncology social work posts, some of which were initially funded, and many of which are still funded, by Sargent Cancer Care.

These social workers have the primary task in the multi disciplinary team to help family members manage the stress that they face and cope with the illness (Donnelly-Wood, 1988, Stovall, 1993). In doing so they have access to the financial resources of Sargent Cancer Care for a variety of purposes. They also have an opportunity to participate in a programme of specialist professional development through seminars and conferences.

Developing the study's focus

Since becoming a senior social worker in a regional treatment centre in 1984, I have taken an interest in the stress that families experience and the different ways that family members cope with the illness. In the course of my work I have met with parents from a wide range of social and economic backgrounds, many of whom were well supported by relatives and friends. One of the observations I have made from meeting parents around the time of the onset of the illness and following the child's illness is that it is difficult to predict how parents are going to cope as the illness progresses. Some parents, whom medical and nursing and social work staff anticipated as not going to be able to manage well, surprised practitioners by their ability to do so. The converse was also true. Some parents had severe difficulties in coping when they had been expected to do well, while others seemed to have great difficulties at one stage of the illness, but coped better at other times. These observations encouraged me to become more knowledgeable about the ways in which family members cope with the illness.

My interest in the matter was increased following a short study I undertook a few years ago when I interviewed a small number of parents of children with cancer about their views on the social work support they had received (Smith, 1995). One interesting finding was that many of the parents said that they had emotional problems which they had not been able to discuss with other people and that help was more readily available for practical matters. This led me to conclude that more detailed research was required on how parents coped with all the tensions which the illness had for the child, the parents themselves and families in general.

My initial intention when beginning to plan the study was to try to identify the most effective ways in which parents coped with their child's illness. My belief was that identifying criteria of effectiveness in coping would help to inform social work practice. As I began to study the recent research literature, however, it became clear that while there was a range of studies involving the parents of children with cancer, very few were based substantially on parents' accounts of their experiences and what they felt coping involved. This observation, together with other criticisms of the present research knowledge which I discuss in more detail in Chapter 2, led me to conclude that the concept of coping, in the context of families of children with cancer, was ambiguous and that more attention needed to be paid to identifying what was involved in terms of the problems that the illness posed for parents and how they responded to them.

My study is therefore concerned with what coping involves. It is based substantially on detailed interviews I conducted with 19 parents during the course of the child's illness. Much of the present research knowledge is based on retrospective studies with the parents' observations obtained by interview or questionnaire, at a stage when the outcome for the child (in terms of whether he or she survives this life threatening illness, or dies) is usually known. My wish was to talk to the parents at an earlier stage when treatment was ongoing and the outcome of the illness was still far from certain. I appreciated that such research would have to be planned sensitively, but felt that the timing of the interviews would have the advantage that it would be based on current experiences and perceptions of the parents and give a more detailed picture of what is involved.

I believe that my findings make an original contribution to the research literature. It is certainly not the first study which is based on obtaining detailed views of parents, but, as Chesler and Barbarin observe, very few studies allow parents "to speak for themselves" (Chesler and Barbarin, 1987, p. 286). I have also focused on parents as individuals, interviewing them separately and not with their partners, nor with their children. I did so as much of the research focuses on the mother, regarding her as the main carer of the child during the illness. By interviewing parents separately, I was able to hear about and discuss many of the personal and private aspects which parents experience in coping which often are very different from that of their partner.

My thesis sets out many of the activities that parents have to undertake during their child's illness, the problems they face, the stresses involved and the way that they

deal with them. From the parents' accounts of what coping involves and the views of professional oncology social workers which I obtained in a preliminary study (and which is reported in Chapter 4), I have drawn some conclusions on what coping involves in both practical and theoretical terms. I suggest a framework which will enable coping processes to be better understood, both by researchers and by social workers and others in relation to their professional practice. It is my hope that in describing what coping involves, in terms of the perceptions of parents of children with cancer, I can add a further dimension to the literature on how parents of children with cancer cope with the illness.

CHAPTER 2

CHILDHOOD CANCER: REVIEW OF THE LITERATURE

Introduction

The range of diseases which are called "cancer" have been the subject of major attention of medical research over the last fifty years. The majority of research studies have been concerned with the disease process, the aetiology, the efficacy of treatment and long term medical effects of the illness. In popular terms, researchers are seen to be "looking for a cure" for the basis of the disease. In studies which concentrate on childhood cancer, the position is similar. The majority concentrate on the medical aspects. Currently most major national studies focus on the effectiveness of different forms of treatment. Most children being treated in hospitals in the UK are the subject of medical research in the form of "drug trials" which are now standard practice.

The medical research studies far outweigh those which concentrate on the psycho social aspects of childhood cancer. Nevertheless, over the years, there have been a steady output of localised studies conducted in hospitals in North America and Europe. Within the spread of studies there is a group which have examined the impact of the illness both on the child and on the whole family. Some of these studies have covered medical aspects with a small psycho social dimension (e.g. Eden, 1993), while other have been conducted by social scientists and have been totally concerned with the social and psychological aspects of the illness. Chesler and Barbarin's study (Chesler and Barbarin, 1987) which I shall be considering in this review is one major example in the latter category.

In this review I will be considering first of all the studies of the main research teams, that is the ones which have been widely reported in books or articles and which have arguably had the most influence on mainstream practice in Europe and North America. I will then consider a range of smaller studies, which have been undertaken by single researchers or small groups of researchers and have focused on more specific research issues. Many of these have produced results which have helped an understanding of the stresses of the parents and families endure when their child has cancer (Bluebond-Langner, 1978).

Another section will deal with studies which address the way that individuals cope in any stressful situation. Many of these have been conducted by psychologists in laboratory conditions and tend to concentrate more on observing and reporting on an individual's reactions during experiments in which stress is simulated. Much of this work has been informative for psycho social research, in particular that of Lazarus and Folkman (1984, 1991) whose detailed research on coping has become increasingly influential in the past ten years and proved to be relevant in this study. I describe their theories in more detail in Chapter 9, together with an analysis of some of the literature on crisis theory and bereavement studies which have also been helpful to my understanding of what coping involves.

Other sections in the review are concerned with the some of the contributions made by both social workers and parents of children with cancer to the research and practice literature. This range of literature is not extensive. It can be said that the social workers' contribution to research is limited and does not reflect the important practice contribution that social workers make in helping the parents of children with cancer to cope. The literature from parents often are presented as a tribute to their child who has died from cancer and tend to concentrate on the child's bravery during a fight for life. Many of the tributes appear to be written as part of the parent's mourning process and convey the powerful influence that the child's illness has had on the parents.

Trends in research

The changes in treatment methods and improved chances of a child surviving the illness have been reflected in the way that the focus of the research has changed. The earlier psycho social studies of childhood cancer were based on a premise that the child was likely to die. An assumption was therefore made that parents were having to prepare for their child's death (Binger, et al, 1969, Chodoff, Friedman and Hamburg, 1964, Futterman and Hoffman, 1973).

An important focus of research was in examining ideas such as the way in which parents began to grieve for their child in anticipation of his or her death. This process, which has been termed "anticipatory mourning", was not confined to studies of childhood cancer, but associated with most illnesses in which there was a high likelihood of death. It was an important dimension in several studies including Koocher and O'Malley's 1981 study discussed below (Kemler, in Koocher and O'Malley, 1981). This was symptomatic of a research focus on psycho pathological

reactions of parents or other relatives of anyone who was ill or disabled. As a review undertaken in 1991 observed, there was an overemphasis on the troubles that individuals and families were experiencing at the expense of any personal benefits or achievements which might also have been present (Singer and Irvine, 1991).

The research approach adopted by Burton in her 1975 study, which I will discuss below, was influential. There was a gradual move away from viewing children and families as being at high risk of psychological problems as result of the illness (Kellerman, 1980, Spinetta, 1977), to viewing them as facing normative, but stressful, situations. As I will show in this review, subsequent research has focused more on the cognitive and emotional responses to an illness. This has been a feature of current research on many forms of chronic childhood illness. (Kupst, 1994, Kazac and Meadows, 1989).

The studies of the main research teams

One reason for singling out the work of some of the main research teams is the degree of influence that some appear to have had on the focus of other research studies and in the way they have influenced practitioners in the way they provide patient care. In general these studies have been conducted by established research teams, based in university medical units, funded specifically to conduct research on the psycho social aspects of the illness.

A major research team was led by *Koocher and O'Malley*, psychologists based in the Boston Children's Hospital Medical Centre and associated with the Sydney Farber Cancer Institute in Boston. They have researched extensively in childhood cancer and in 1981 they reported on a wide ranging study which they had undertaken of the way in which children who had survived cancer and their families had adjusted (Koocher and O'Malley, 1981). This report is now a major reference.

The focus of Koocher and O'Malley's study was on assessing the psychological consequences of cancer for the long term adaptation of children who had made a recovery from cancer and of their families. Their interest stemmed from the improving medical situation for children with cancer. They have argued that as the possibility of children making a successful physical recovery from the illness increases, there is a need for more attention to the ways in which the illness affects the psychological health of children.

Their sample group of 117 "survivors" were children and young people who were well and had completed their cancer treatment more than five years previously. The child or young person, one or both parents and the other children in the family were assessed using a variety of psychological measures, standardised psychiatric interviews and other structured interviews. The researchers found that many of the "survivors" had made a good physical recovery from the illness, but were continuing to experience a great number of medical problems as a result of either the illness itself or the treatment regime. Similarly the majority of children and young people had made a good recovery in terms of their psychological health, but a substantial minority had mental health problems and some of these were of a major nature, for example, they had depressive illnesses, had difficulties in making close relationships and problems with their employment.

The researchers noted the profound effect which the illness of the child had on all members of the family, especially the parents, in terms of family adjustment. The diagnosis was traumatic. Despite the fact that parents who took part in the study were doing so many years after their child had first been diagnosed, all of them were able to recall vividly their shock at being told that their child had cancer. The study found, however, that the majority of families adjusted well following the illness. Despite a continuing concern about the child who was ill and an acute awareness that the illness could still return, families could set these fears aside and carry out all the activities of their normal lives. There was no evidence that stability of marriages were at greater risk than in the population at large.

The researchers also examined factors which had assisted parents during the course of the illness. The attitudes of medical staff were found important, especially when warm and caring feelings were communicated to the parents. Open communication between medical staff and the parents, and between family members as a whole were also important factors in the ways the parents reacted to the illness. The researchers concluded that if parents maintained a positive attitude that their child would recover and had confidence in their medical practitioners, they were likely to deal more effectively with their child's illness.

This was an important study in that it was carried out by a multi disciplinary team of researchers and specialist professionals combining the disciplines of research and clinical expertise. The influence of this report is due to the way it highlighted the long term psychological difficulties which the child and parents had to face and the need for clinicians to be aware of these in providing treatment.

Another important study is that carried out by a team led by *Kupst and Schulman* in a large children's teaching hospital in Chicago. This is the most extensive longitudinal study of the family's adaptation to childhood leukaemia and has been reported at different stages between 1980 and 1992 (Kupst and Schulman, 1980, 1982, 1988, 1992). Sixty four families of children with leukaemia were followed from diagnosis of the illness through treatment and after its completion to six years after the diagnosis of the illness. The ways in which parents coped was measured by the administration of psychometric tests and supplemented by clinical interviews.

The main focus of the research was to assess how families cope with childhood leukaemia. Another was to evaluate a "psycho social intervention programme" which was provided as part of the research project. The purpose of this programme was to help families to understand the implications of the illness and to manage their feelings of distress, as well as use resources which could support them, including some services organised on a mutual help basis.

The study's main findings were that while parents did not suffer from any major psycho social difficulties as a result of their child's illness, anxiety and depression and other expressions of sadness, were commonly experienced. Parents were considerably anxious about their sick child. The researchers had expected the parents to react with anger, physical symptoms or guilt on the basis of previous research (Mattson, 1972). It was observed however that a large proportion of the group of parents were reported by medical and nursing staff as being "cheerful" for at least half of the time when the child was in hospital. The researchers considered one explanation for such behaviour was that parents experienced a sense of hope once their child was established on a treatment programme. Another explanation was a need felt by some parents to keep up a cheerful exterior appearance while in the hospital as an encouragement for their child.

Some parents, although a minority, who had experienced difficulties in marital or other family relationships prior to the illness continued to face these difficulties when their child became ill, thus making it harder for them to cope. On the other hand, most of the parents who had previously functioned well as individuals and in their family continued to cope well. While the researchers found a mixed range of emotional reactions by parents to their child's illness, such as anxiety, distress and grief at bad news, they regarded these as being appropriate to the situation (Kupst, 1995).

The third main reference is the research of *Chesler and Barbarin*. This research team is led by a sociologist and a psychologist based at the University of Michigan. They have conducted several linked studies on a cohort of children, including a sample of 55 children which they reported in detail in 1987 in a major text book (Chesler and Barbarin, 1987). Their particular research interest is how families respond to the challenges posed by the illness. This study was based extensively on interviews with parents and psychometric testing of their emotional attitudes.

Their findings emphasise the amount of stress that they found both in the child and all the members of the family. They observed that stress had some disabling aspects but had also been involved in the psychological growth of both parents and child as a result of the experience of the illness.

The particular value of Chesler and Barbarin's research is that it relied extensively on parents own descriptions of their experiences. Their findings highlight both the wide range of problems that parents faced and the variety of solutions that they found. The following extract illustrates a typical divergent picture that they observed:

"Some parents deny or avoid discussion of the illness, whereas others attend to every detail and take every opportunity for conversation. Some reach out to friends and neighbours for help, others manage very privately. Some complain and cry out in pain or anger, others passively or stoically endure. Every person experiencing or observing families of children with cancer has his/her own preferences regarding what coping strategies work best." (p. 268)

The particular value of their approach is that they incorporate the wide range of factors which influence adjustment. They are cautious about giving simple explanations of behaviour being aware that what is seen as a solution by one individual might not be similarly regarded by another. Nevertheless they concluded that there were three specific factors which were helpful to parents in the way they coped with their child's illness and which stood out from the others. These were that parents were active in their approach to the child's treatment, parents adopted an "open" style of communication between family members and parents had a system of beliefs or religious faith.

They also identified a number of "patterns of coping" which were employed by parents to deal with the problems arising from the illness. These included:

"seeking normalcy": parents try to maintain their family life-style in its pre-illness form or adjust their lives to the new situation.

"Taking one day at a time": most parents avoid planning too far in advance.

"Relying on others": most parents reach out for help. "No parent manages to deal with this illness alone."

"Becoming a partner in health care": most parents seek to become partners with the professional staff in the process of medical or psychological care (p. 269).

These diverse methods of coping were based on a determination that many parents showed to combat a sense of pessimism, and in some cases "a sense of doom", that many of them felt (p.115). Chesler and Barbarin judged that the strategies that parents adopt reflect their individual styles of preventing any stressful event from having a destructive psychological impact on themselves. They argued that in childhood cancer it was impossible to alter the facts of the disease process but it was possible to reduce the psychological difficulties and stresses that arise as a result. They followed Lazarus (1981) and others in distinguishing between those measures aimed directly at the whole stressful situation and other measures aimed at "buffering", in the sense of alleviating, some of the effects of the stress. The importance of "buffering" as an aid to coping, which can include activities which offer respite or a degree of comfort, is one which is integral to social work practice, being often part of the social worker's way of helping a family in difficulty.

When one considers the European teams of researchers a special mention should be made of the work of *Burton* who studied chronically ill children, not all of whom had cancer, in the 1970s and 1980s, and whose writings had an undoubted influence on the direction of much subsequent research. Based at the Queens University in Belfast in the Department of Child Health, one of her studies involved interviewing the families of 58 children with cystic fibrosis, including both mothers and fathers, about their experiences of dealing with the illness (Burton, 1975). Amongst her findings were that many parents sought to find a meaning in their child's illness in order to come to terms with it. Her most important contribution, however, was her observation that despite the range and severity of the problems that many of the parents face, they nevertheless managed to pursue their lives effectively. She observed that parents, perhaps surprisingly, were able to set aside "feelings of resentment, depression, isolation and discouragement" (p. 227) and not allow them to dominate their lives.

Prior to Burton, research on the psycho social aspects of childhood cancer had been heavily weighted towards examining the psycho pathology of families. In

demonstrating that stresses were not necessarily disabling but also had some positive aspects, she was in the vanguard of directing researchers to become more interested in the processes of adjustment that patients and their families used.

A current research team is led by *Eiser*, a psychologist based at the University of Exeter. Several interrelated studies of children with different chronic illnesses (Eiser, 1987, 1992, 1994) have examined aspects of parents' experiences and their ways of coping. A significant point which Eiser has established is that the perceived difficulties the parents of children with cancer were experiencing were greater than those reported by parents of children with other forms of chronic illness. In this study (Eiser, 1986), parents of 196 children with five different chronic illnesses (diabetes, asthma, cardiac conditions, epilepsy and leukaemia) participated by completing detailed questionnaires. Both the parents of the children were assessed separately.

Within the cancer group, the researchers also found a number of differences between the ways that mothers and fathers coped with their child's illness. Among their findings which were supported by a later study (Eiser and Havermans, 1992) were that mothers tended to make more use of social support, including help from other parents of ill children, and actively sought information about the illness. Fathers on the other hand kept to themselves and dealt with their feelings alone. The researchers referred to the fathers' approach as being one which they termed "autonomy", based on a measurement scale adopted from McCubbin and others. This scale is discussed in more detail below. Eiser's findings support the findings of an earlier study (Affleck et al, 1990) that the responses of fathers and mothers to a major illness in their child are very different, both in the perception of the illness and in the ways in which they cope.

Another major European study has been conducted by *van Veldhuizen and Last*, both psychologists, in the University Hospital of Amsterdam (van Veldhuizen and Last, 1991). They studied 82 children between the ages of four and sixteen years, with a particular focus on communication issues, defining communication broadly to include the exchange of information and the emotional reactions shown by both children and parents. This approach involved the use of psychometric tests and highly structured interviews. The findings lend strong support for those of other studies, notably that parents of children with cancer do not show more psychological stress symptoms than an average Dutch population (cf. Kupst, 1992 op cit.) and that many parents feel that the family has become closer as a result of

the experience (cf. Koocher and O'Malley, 1981 op cit.). Their conclusions on the way parents and children communicate during the illness, which they develop in a subsequent paper (Last, 1992), are that much of it is of a self-protective nature aimed at controlling unpleasant emotions. Parents, they argue, try to maintain an illusion that the child will recover, while the child's communication indicates that he or she needs the parents to be strong. This finding carries implications for the practice of support programmes for children and their parents that professional services provide.

Other studies

There are a wide range of studies which have been more specifically focused on an aspect of the family's way of dealing with the illness. Many of these have been helpful in identifying the different emotional pressures. Some of these have addressed the impact of the illness on the family and these I consider next. I will then discuss others have been concerned with the support systems which are available.

Impact of illness

The impact of the diagnosis has been described as precipitating a "crisis" for the child and the family (Stovall, 1993, Ross, 1993). It is widely acknowledged in the literature as being one of the most stressful times in the course of the child's illness (Johnson et al, 1979, Koocher and O'Malley, 1981, Rolsky, 1992, Ross, 1993). Parents describe the diagnosis of cancer as a major shock. Some aspects of information given about the illness are recalled clearly, but it is difficult for them to recall other information, such as the details of the planned treatment and possible difficulties with or effects of the treatment (Eden, 1993, Eiser et al, 1994).

Parents' feelings of shock have also been described as having an impact on the ways in which they wish to be offered professional help with the emotional impact of the illness. In a small study which I conducted a few years ago, parents reported that it took several days for the implications of the illness to be understood, and the likely need for outside help to be appreciated (Smith, 1995). In the same study parents indicated that their emotional difficulties were far greater than their practical difficulties resulting from the illness.

Another study has found that the appreciation of the reality of the situation is a gradual process and was only fully appreciated by the parents four to six weeks

after their child was diagnosed as having cancer (Fife, 1984). The impact of the illness on the whole extended family has also been studied with the observation that some members were often "excluded" from receiving help from any sources (Faulkner, 1995). The constant stress in the whole family throughout the treatment has also received attention. Desmond, in an observational study on two families, noted the complexity of family interactions at a time of great stress. She observed that the psychological defences which individual parents employed, such as denial or displacement, could have negative effects on the way in which they responded to the needs of all the family members, while assisting them to cope with the pressures they experienced (Desmond, 1980).

Social support

Another main focus has been on measuring the value of social support which is provided to the family. Support is described by a number of writers as being multi-dimensional, and it is described and categorised in many different ways (Chesler and Barbarin, op cit., Affleck et al, 1991, Williams, 1992, Krahn, 1993). Despite these differences, it is generally recognised to be of great importance for coping in parents who have a child with a major illness or disability. Morrow's study on this subject found that a parent's effectiveness in coping was significantly correlated with the perceived support he or she receives from other persons, such as the spouse, friends and medical personnel (Morrow, 1981).

One study has concluded that there is the particular need to direct support services at the mother of a child with cancer, as the burden of the care of the child mostly falls on her (Faulkner, 1995). Others have drawn attention to the fact that many families and individuals have problems which are not due to the illness, such as employment and marital difficulties, and have argued that these have to be addressed as well by professional helpers in offering support services (Kalnins et al, 1980).

The nature of support and the way in which people develop and use their support networks is very complex. Support is only found to be supportive if it matches the need for assistance (Krahn, 1993). One study has found, for example, that the client's satisfaction with support was unrelated to the amount of support being offered (Affleck, 1991).

Sometimes the grandparents and other members of the extended family are persons to whom parents turn when a child has a serious illness. Yet the illness has been

shown to have had a significant effect on these other family members, to such an extent that they may not be able to offer support, and in some cases parents may find themselves offering support rather than receiving it (Bloom, 1982).

The value of good social support is highlighted in a number of studies. One study shows that if a family has a supportive network prior to an illness with family, friends and others, the support usually continues and is helpful to the way that individuals cope (Fife, 1987). This finding is supported by Brown's study from a psychiatric perspective which takes the view that many families grow emotionally and become more cohesive as a result of the illness (Brown et al, 1992). These two studies also demonstrate the reverse situation in which families, either having poor social contacts or difficulties in their social functioning prior to the illness, continue to deteriorate throughout the illness. Support services are effective only when they are provided in a way that takes account of the underlying difficulties.

Support services also need to take account of the views of the parents about what is helpful to them. A recent small study found that the perceptions of parents of children with cancer about what was helpful to them differed widely from the perceptions of medical and nursing staff. The parents placed a higher value on emotional support than on practical support. They also commented that support from other parents of children with cancer was "essential", something to which professional staff had not given any particular significance (Williams, 1992).

The widespread endorsement that research studies give to the importance of social support in coping should, however, be treated with caution. As Krahn observes in a review of the research on how social support helps the families of children with special needs, there is a wide interpretation of the meaning of the term "social support." She argues that more attention should be given by researchers to agreeing a standard definition of the general term and clarifying what are the different kinds of support services which should be included within its meaning (Krahn, 1993).

Psychological research on coping behaviour

Researchers in psychology have long been interested in examining the ways individuals deal with stressful and unpleasant experiences, and their studies regard the individual's behaviour in such circumstances as "coping". In the 1960s and 70s there were a variety of studies, conducted by research psychologists, which involved them in observing an individual's physical and psychological reactions when a stressful event was simulated. Many of these studies produced a better

appreciation of the physiological symptoms that individuals experienced and also their psychological reactions. There were many limitations however in translating the findings into practical results. An extensive review of "coping" literature has concluded that "generalisability of results are impaired by fundamental differences between stressors in the laboratory and most aversive life events". (Silver and Wortman, 1980). A subsequent review undertaken by the same authors in 1992 reached similar conclusions. They argue that there is insufficient empirical evidence that the theoretical models which have been developed show that individuals both respond to crises in specific and predictable ways or adapt over time (Silver and Wortman, 1992). These reviewers are among a group who argue that other important variables need to be taken into account in research (Venters, 1981). Examples often cited are the social support that people receive, the opportunity for ventilation of feelings and the ability to find meaning in any crisis that is experienced.

Lazarus and Folkman are researchers whose background is in psychological research. They have studied coping behaviour extensively both in laboratory studies and in real-life situations, particularly health care. Their interest is in the way that stress factors affect illness and recovery. Their extensive work on coping is frequently referred to in health care research.

Lazarus and Folkman have for many years been developing a definition of coping to encompass all its complexities. The latest version of their definition is that coping is "cognitive and behavioural efforts to manage specific external and/or internal demands (and conflicts between them) that are appraised as taxing or exceeding the resources of the person." (Lazarus and Folkman, 1991 p.144). Their definition is one which is now widely followed by researchers who are concerned with the way in which parents cope with their child's illness (Eiser, 1987, Kupst, 1982, Chesler and Barbarin, 1987). Their approach is different from that of other researchers in a number of respects, notably, in that they emphasise that coping behaviour should not be linked to an objective measurement of stress, but to the way that an individual appraises a situation that is being faced (Lazarus and Folkman, 1984).

This different approach allows for a number of environmental factors and other aspects to be included in any focus on coping. Many of these were beyond the scope of other definitions, particularly those which were adopted for laboratory experiments. Lazarus and Folkman envisage coping as being an evolving process,

based on a series of complex interactions, such as that between cognition and emotional behaviour. The ideas of Lazarus and Folkman and the model of coping which they have proposed as a basis for future research has been very helpful for this study, and for this reason a more extensive description of their approach is given in Chapter 9.

Some psychological research studies have addressed the question of effectiveness, examining coping behaviour to see if certain approaches that individuals adopt are better than others. The findings of these studies have had negative results. Cohen and Lazarus (1979, 1983), for example, examined various strategies which individuals adopted in the face of many stressful employment situations and concluded that it was impossible to determine if any one strategy was better than others. The particular kind of stress, the duration and the context in which it occurs were all important influences on effectiveness. Some strategies which were found to be helpful in one aspect of a particular situation were not helpful in another situation, even for the same individual (Cohen et al 1986). Another study found that coping strategies may adjust and change during the course of a stressful situation (Folkman and Lazarus, 1991), thus making it difficult for researchers to identify what approach is being followed.

Eiser, whose work has been referred to above, has also tried to examine effectiveness in the ways that parents of children with cancer cope and concluded that it was difficult to do so. She has warned about the limitations of seeing any one strategy in isolation. She points to the dimensions of the stress arising, the inter-relationship of the disease and treatment processes, the personality of the parents, their understanding of the illness and their perceptions of the stress caused as all being important influences on coping (Eiser, 1993).

Assessing the family perspective

Some of the difficulties experienced by researchers and clinicians in identifying what coping involves for individuals also apply to attempts to identify in research the effects of a child's illness on a family as a whole. Various approaches have been adopted to attempt to give an objective appraisal of how a family functions as a basis for measuring the psycho social effects that an illness brings.

Psychometric measurement scales have been frequently used, particularly in the USA where they have been popular among many medical clinicians. Many of the scales were originally devised to measure coping in the context of an adult patient's

recovery from illness. Measurements scales are useful to medical clinicians in that they offer a means of analysing the relationship between social and emotional factors and illness outcome, and are often used in conjunction with other research tests. But a persistent problem is that there is a lack of consensus on the best measurement techniques (Cohen, 1987). The widespread use of the approach has in part led to a development of such scales for use in studies of childhood cancer. Popular measurement instruments used in studies concerned with childhood cancer are the Family Environment Scale (Moos, 1979 and 1981) and the Coping Health Inventory for Parents (McCubbin, 1989). Each of these concentrate on a number of factors associated with social functioning, and their authors have attempted to standardise their scales in the light of their experience. Nevertheless, substantial criticisms remain. As Grotevant observes, any measurement scale is limited by the absence of normative data of what constitutes "normal" or "acceptable" levels of stress in any individual or family in which a child has cancer (Grotevant et al, 1989). He observed that considerably more knowledge from research is required before they can be considered to be effective.

Some researchers and most clinicians rely on the interview method which also has some limitations in measuring a family perspective. The information gained is often heavily dependent on an individual's ability to recall specific information as well as an ability to judge what is relevant material in respect of the purpose of the interview. Cohen has shown in studying coping some of the difficulties there are in interviewing individuals about the social support which they have been offered. Everyday activities which can be supportive are often overlooked (Cohen, 1987). Nevertheless the importance of interview based research and qualitative research generally in understanding parents of children with cancer has been strongly supported by Chesler, writing about himself personally. As well as being a leading researcher in the field of psycho social aspects of childhood cancer into the way that families react to childhood cancer, he has indicated a personal involvement in being the father of a child with cancer. It is in his capacity as a father he argues the case for adopting a qualitative approach to bring out the many variables involved coping, and that the interview method is the best way of ensuring this (Hasenfeld and Chesler, 1989).

Many of the studies have relied on the views of one parent only (Peace et al, 1992). In most cases this parent has been the mother. Very little attempt has been made to ascertain if there was a difference between the views or coping behaviour of both of the parents of the sick child. Eiser has argued that there is a difference, and her

later studies have placed more importance on ensuring that the views of fathers are included (Eiser, 1993).

Social Work Literature

Research studies carried out by social workers in the field of paediatric oncology are limited and do not reflect the considerable degree of involvement that the social work profession has in helping parents and families to cope with the child's illness. Some of the main research teams have included social workers (Stein and Riessman, 1980, Koocher and O'Malley, 1981, Johnson, Rudolf and Hartman, 1979) who have carried the responsibility for interviewing parents and have been involved in writing the report (Foster, in Koocher and O'Malley, 1981, Kazak and Meadows, 1989). The main literature attributed more specifically to social workers is based on social workers' observations of families and making use of their casework experience. Some literature has been written in conjunction with parents groups (Rolsky, 1992) while others are text books based on the experience of specialists (Adams and Deveau, 1984, 1995, Ross, 1995, Donnelly-Wood, 1988).

Our understanding of how parents cope with their child's illness has also been helped by social work writing from other specialist areas. There are numerous examples. The relevance of helping parents of children with different chronic illness or disability (Glendinning, 1983, McCubbin et al, 1983, Singer et al, 1991) has already been mentioned. Other social work literature has looked at generic issues, for example, how support is provided (Stovall, 1993), how crisis situations are managed (O'Hagan, 1986) etc. Therefore it would be wrong to conclude that social work literature has not contributed to our understanding of what coping involves.

Amongst social workers who have contributed, Ross, a social worker based in Cleveland Ohio, has produced a number of papers about social work practice with children with cancer and their parents. She is interested in a variety of aspects of the parents' experience and has written extensively on the role of the social worker (Ross, 1982, 1995). One observation she notes is the tendency for families to grow closer together as a response to the illness, and, while this has many benefits, she cautions that and as the child or young person grows older these ties may need to be loosened to allow more independence.

She also expresses a concern about potential role conflict for social workers in paediatric oncology settings in being simultaneously a family counsellor, an advocate, a colleague, a non-medical staff member, as well as making assessments

of families' functioning and interpreting medical information sensitively to the family members while also providing information about the family to members of the staff team. These diverse roles can lead to role confusion if not conflict.

Other social work writing has stressed the important role of social workers in the multi-disciplinary team as being the one with the major responsibility for the psycho social care of the family of the child with cancer (Donnelly-Wood, 1988). The many facets include meeting with parents soon after their child's diagnosis, listening to their expression of feelings about the illness; assessing their needs and ability to cope; assisting the multi-disciplinary team in understanding the family; giving advice to the family and assisting with a variety of practical help; liaising on parents' behalf with schools, employers and other agencies. It is disappointing therefore that little research attention so far has been paid specifically to the contribution that social work help plays in enabling a parent or family to cope with the demands of the illness.

Kupst's study goes some way to limit this deficiency by examining the importance of social work interventions as part of the special "intervention programme" devised as part of her longitudinal study (Kupst, op cit. 1982). Amongst the findings were that early contacts between the social worker and parents were considered by parents to be helpful and supportive. Parents were helped by social workers to gain confidence and a sense of mastery of their situation. Constructive methods included discussing stressful events in advance, helping parents to get full information, strengthening the resources which were available to help the family, and helping parents with the return to school. The special intervention programme also demonstrated that helping parents to appreciate that their perceptions were shared by others in a similar situation was an effective way of reassuring them.

Writings by parents of children with cancer

There is now a growing amount of books and articles which have been written by parents of children with cancer about their experiences (for example Cooper and Harpin, 1991, TCF, 1995). Most of these have been written by parents of children with cancer who have died, often as a tribute to the child. What becomes clear in many of the accounts is the parents' high admiration for the endurance the child has shown and the struggle which they been through. One can infer that the courage the child has shown has been a vital part of the parents' coping with the experience, or, perhaps, a response to the parent's courage.

Literature written by parents of children who have survived or are in the course of receiving treatment for cancer is slight by comparison. A useful reference source however is television documentaries which from time to time portray parents' experiences. One interesting example was a programme in which two parents whose children were receiving treatment for cancer at Great Ormond Street Hospital in London talked about their different ways of coping with the stress of the illness (BBC, 1993).

The American parents' self-help organisation "Candlelighters" as part of a range of services, circulates a newsletter which provides an opportunity for parents to write and share their experiences with one another.

Hornby in a recent review of the writings of eight fathers of children of children with different disabilities, has pointed out that the parents' perspective brings a particular value to understanding the problems they face (Hornby, 1992). These views of parents and others (McQuown, 1981) may not be typical or representative of parents, but give a valuable insight into their perceptions which is helpful in developing a wider understanding of ways in which parents cope with their child's illness.

Cultural aspects

A general observation often made by researchers themselves is that there is a lack of attention paid to addressing cultural issues in the way that families cope with the illness. The fact that this is so reflects the current state of research knowledge on the subject and the comparative lack of attention which has been paid to environmental and social influences on coping. Some studies have included measurements of the parents educational attainment (Kupst, 1982). But overall little attention has been paid to, for example, cultural values, cultural role-definition and similar issues. Morrow appears to be atypical in recognising the problem and cautions against any generalisations based on the findings of his study (Morrow, 1981). He acknowledged that his sample group of Caucasian middle class parents were possibly more able to show better social adjustment than would be shown by other parent groups. He went on to suggest that his study should be replicated with different sample groups of parents. Kazac and Nachman make a similar point that there needs to be more replication with different cultural groups, pointing in particular to the diversity among Spanish speaking groups in the United States (Kazac and Nachman, 1991).

As my own study will show, there is a methodological challenge to the researcher in trying to separate out cultural influences from more general influences in determining what constitutes coping behaviour. The importance, however, of continuing to try ways in which this can be done is appreciated by researchers and practitioners.

Conclusion

In this chapter I have tried to show that there is a wide range of professional literature and research as well as some writings by parents about their experiences, which have contributed to the general understanding of how parents of children with cancer cope.

The work of the leading research teams which have concentrated over the last fifteen years on studying the psycho social effects of childhood cancer have been described in detail as many of the results have had a strong influence on clinical practice. As a result of their work, practitioners are much better informed about the severity and types of stress that parents experience and the importance that the family is supported throughout the child's medical treatment. The collective findings of the major studies show that the diagnosis is traumatic for most parents, and that parents suffer from stress and other emotional disorders, although not usually to the extent that they require medical treatment. They also show that the child's illness requires parents to make major adjustments in their lives. Parents are helped to cope by remaining hopeful and in some cases by finding a meaning in the illness. The findings of this study will give strong support for the relevance of some of these observations.

The strong consensus of view amongst researchers on some issues, although valuable, also helps to clarify what some of the limitations are. There is no common view in the studies on a definition of coping, its dimensions in terms of psychological considerations and the types of outcomes that are achieved (Kupst, 1995). The studies are mostly planned and conducted on an individual basis with no attempt so far on the collation of approach at either a national or international level. Kupst notes that only seven studies of childhood cancer qualified for inclusion in a meta-analysis of research on adjustment to severe chronic paediatric illness. As she and others have observed, empirical research on how parents and families cope in relation to the social and cultural environment is still at a very early stage (Kazac and Nachman, 1991, Peace et al, 1991, Eiser, 1992, Kupst, 1995).

As a term, however, "coping" has been the direct focus of very little research attention other than by a few experimental research psychologists whose field of interest is in human behaviour in times of stress. Their research work has been conducted under strictly controlled conditions for the purpose of focused research. The result has been a steady growth in knowledge about the intellectual and emotional processes that the individual uses to face stressful situations.

Lazarus and Folkman are researchers who have studied coping in its clinical form and their work is increasingly influencing researchers and clinicians interested in the area of how parents of children with cancer cope. Their work (discussed more fully in Chapter 9), makes it clear, however, that the research knowledge of how parents cope is still at an early stage of development. Although the psychological processes that are involved can be more easily identified, the relevance of the context in which stress is experienced and factors, such as the perceptions of the individual and their capacities to learn by experience, are increasingly being recognised. Chesler and Barbarin's work demonstrates clearly that the parents' perspective of what coping involves so far has had little attention in research. Their argument that more account should be taken of their views gives strong support for the particular focus of my study, which will involve in-depth individual interviews with both mothers and fathers of children with cancer.

Reference has been made in this review, to the comparative lack of research studies undertaken by social workers. The problem that social workers have comparatively little interest in research is one that the profession as a whole and social work agencies should face, as a recent government report has recommended (HMSO, 1995). Social workers have however made some contribution to the research literature in childhood cancer, mainly by being part of research teams engaged in the major studies. A criticism can be made that no research study in which social workers have made a substantial contribution has addressed directly the question of how parents cope with the illness. This observation has a particular relevance in that how an individual copes with many forms of stressful experiences forms a key part of the psycho social assessment which a social worker prepares on taking responsibility for a case. Assessment is the basis for any casework planning on how to help an individual (Middleton, 1997). In addressing the core question of what coping means in terms of parents' perceptions in this study I hope to contribute to filling an important gap in social research literature.

CHAPTER 3

METHODOLOGY

General Approach

As the central intention of the study was to understand what "coping" with the child's illness meant for the parents themselves, the first task was to select an approach which would give the best insight into the full range of parents' perceptions of their experiences of their child's cancer illness. Of particular interest was the onset of the illness, their reactions on hearing the diagnosis, how they were involved in the treatment and the care of the child and the changes the illness had brought to their lives.

Many previous studies have made extensive use of quantitative or experimental methods, sometimes including control groups. These had several advantages in terms of method but would have required a larger sample and more research resources than was feasible for this particular study. A quantitative approach could have been appropriate had the intention been to measure concepts which had been previously developed. However as the clear intention in my study was to develop ideas of what coping involves for the parents based on their own accounts of their experiences, I decided that it would not be appropriate to adopt a quantitative approach.

A qualitative approach on the other hand seemed to fit much better with the overall aims of the study. It offered more flexibility in terms of accommodating detailed research interviews with parents which I judged to be essential. A qualitative approach is often used where the main concern of the researcher is to explore a particular situation, to get a greater understanding of a particular group of persons and the meanings they attach to events or to learn about their situation "through their own eyes" (Bryman, 1988). I wanted an approach which would enable me to capture as full an understanding as possible of parents' perceptions of their experiences and their reflections on the importance they attached to these experiences.

One form of the qualitative research approach is the ethnographic study where the researcher gets closely involved with the study population. This is commonly used in ground breaking areas of research where the primary intention is to throw light on

issues about which little is known (Hammersley and Atkinson, 1983, Okely, 1994). Although this was not a typical ethnographic study, in the sense that it was exploring an area in which little research had been done, some of the characteristics of ethnographic research methods have proved to be very helpful. I considered it to be important to take full account of the parents' own perceptions of their experiences including the emotions that were involved. The ethnographic approach emphasises the importance of both observing and listening to the population under study, without imposing a pre-conceived approach which obscures the researcher's understanding of what can be learned.

Case study research is a form of research often associated with a qualitative approach, although it can be used as part of other approaches as well. Its particular usefulness is in helping to unravel the complexity of factors in an individual case. Both the "uniqueness" of the individual case and its "commonality" with the characteristics of others are of interest to the researcher (Stake, 1995, p.1).

In adopting a qualitative case study approach I was using a method which would provide detailed and extensive data from a small number of subjects and would give as full as possible an understanding of parents' own perceptions of what was involved in coping with their child's illness. Having been a specialist social worker for a number of years, I had reasonable confidence that parents would be able to engage in a discussion about their experiences, as they would have "a story to tell". As I had also undertaken a previous research study in which interviews with parents were the principal research tool (Smith, 1995, 1996), I had a reasonably firm basis to consider that this approach would be feasible.

My sample group, which was not intended to be a representative sample, was a group of parents whose children were being treated for cancer at a regional medical treatment centre where I worked. Further details of the hospital setting and the parents are given below.

Preparation for the study

As part of the preliminary stages of the study, the professional and research literature was reviewed. The review is presented in Chapter 2. In conjunction with the review, an opportunity was taken to survey a large group of specialist social workers about their extensive experience of helping the parents of children with cancer. This survey is reported in detail in Chapter 4.

The social workers were surveyed by means of a postal questionnaire about their views on what coping involved for parents. A central part of this study was the preparation of a document of 35 statements, derived from the review of the literature, which had been associated with parents' coping effectively. This document is presented in Appendix 1. Social workers were asked to rate these 35 statements in terms of their importance for parents' coping as well as contributing their own views on what they thought coping involved.

The review of the literature and the social workers' survey were drawn on substantially in deciding the format of interviews which were to be conducted with the parents. It was recognised from both sources that there could be difficulties in getting the parents to discuss constructively an abstract concept such as coping, at a time when their minds were mainly focused on their sick child and the other responsibilities they had to face and when many of them would be giving little thought to their own feelings on the matter.

Moreover, as Chesler and Barbarin had observed, superficial questioning of parents often produced a bland response which disguised the stress they were facing (Chesler and Barbarin, 1987). Therefore considerable care was given in the preparation of the interview schedule, the details of which are discussed below, to have regard to a focus on issues identified from the professional and research literature, from the information from social workers as well as from my own professional experience, as being relevant to coping.

Another important issue which had to be considered as part of the preparation was the ethics of interviewing parents in the course of their child's illness. Not only did this require to be planned sensitively, with permission being sought from a number of sources, but it had to be the basis of a specific application to the Ethics Committee of the Hospital Trust. Some of the issues and practicalities involved are discussed later in this chapter.

Obtaining a sample

The setting for obtaining a sample was a regional treatment centre for the treatment of childhood cancer. This was based in one of the leading UK academic teaching hospitals and was one of the most established centres in the UK. The children are referred to the hospital by GPs and other local hospitals in the area. The catchment area is the whole of the Southeast of Scotland. In a typical year about 40 new cases of childhood cancer are diagnosed. My sample group were the parents of children

seen at the centre over a four month period, from August to November 1993. The advantages of taking a cohort consecutively was that it provided a typical range of patients as they came to the centre.

Access to the parents was negotiated with the Consultants in the Haematology/Oncology unit. The fact that I had worked in the unit as a social worker (but was on leave of absence for the period of the study) and was well known to the doctors facilitated this process. As I had no clinical involvement in the unit for the period of the study, I was therefore not known to any of the parents in the sample group. This helped to reduce the risk that my knowledge of the children's circumstances from hospital sources would prevent an open exploration with the parents.

The parent sample

The sample consisted of nineteen parents. Where the children had two parents, both the parents were included, with the exception of two children for whom only one parent was included as the other parent did not agree to participate. There were eight couples, nine fathers and ten mothers. One parent was a step parent to the child; all the other parents were natural parents of the child with cancer. There were no adopted children. One couple were separated. One mother was a single parent.

The response by parents was largely a positive one. Only one parent specifically declined to take part. This parent, a mother, said that she felt she had got over a very difficult part of her son's treatment and that discussion about it would make her feel anxious and depressed at a time when she was beginning to feel much better. She did not wish to risk this and preferred not to be interviewed. Another parent, while not actually refusing to be interviewed, proved so difficult to contact that I assumed from this behaviour that he did not wish to participate and therefore did not pursue my efforts to contact him.

The nineteen parents were white European, by ethnic origin, and Scottish by birth. They were resident in Scotland within the catchment area of the regional cancer treatment centre. The age range was from 21 years to the 43 years with an average age of about 30. This was therefore not a particularly young group of parents. No attempt was made to classify parents by the Registrar General's classification, nor were parents asked to indicate their income level nor level of education. From the information they gave during the interview, however, it was possible to get an

indication of their occupation. None of the parents had any substantial further education, and in general the main occupation groups were in business, including self-employment, in clerical work and in manual work. (Figure 3.1 gives details of the parents in the sample group.)

Figure 3.1

Sample group: Details of parents

case number	Case number of partner	gender	marital status	employment group	number of children at home
1	2	F	m	skilled clerical (unemployed)	2
2	1	M	m	skilled tradesman (self-employed)	2
3	4	M	m	driving instructor (self-employed)	2
4	3	F	m	unskilled clerical (unemployed)	2
5	6	F	sep	part time shop assistant (unemployed)	2
6	5	M	sep	factory manager	2
7	12	F	m	skilled clerical (unemployed)	1
8	13	F	m	skilled clerical (unemployed)	1
9	10	F	m	skilled clerical (unemployed)	1
10	9	M	m	senior manager in small firm	1
11	-	F	s	social care assistant (unemployed)	1
12	7	M	m	taxi driver	1
13	8	M	m	office middle manager	1
14	18	F	m	cleaner	6
15	16	M	m	insurance salesman (self-employed)	2
16	15	F	m	skilled clerical (unemployed)	2
17	-	M	m	insurance salesman (unemployed)	2
18	14	M	m	unskilled manual worker	6
19	-	F	m	unskilled clerical (unemployed)	3

Considerations in selecting the sample:

Children with cancer are a heterogeneous group in many respects. It was important therefore to select for certain characteristics in respect of the children which could have had an impact on the experience of their parents. This related mainly to the diagnosis and to the age of the child. The timing of the interviews also had a bearing

on the composition of the sample. The issues involved in these different aspects are considered fully below.

Timing of interview in relation to date of diagnosis

An important decision had to be made on which stage in the course of treatment parents should be interviewed. The choices were between interviewing parents at an early stage, possibly near the time of the diagnosis, or at a later point, perhaps when the treatment had ended. An alternative approach may have been to interview different parents at different stages of the illness. I decided to interview each parent six to nine months after the initial diagnosis. The reason for this decision was that at this stage all the children would be well into their chemotherapy treatment, and all would have completed a period of intensive inpatient treatment. The experience of the early part of the illness would still be fresh in the parents' minds and not be viewed as being part of the distant past. Parents would be in a position to convey what coping had involved already and also the issues they were currently facing. Following the experience of the pilot study which confirmed my view that this point of time for interviewing had several advantages, I decided that there was value in choosing a time when the treatment pattern for the child would have been established and all of those in the sample would be describing and reflecting on a comparable period in the treatment process.

Some children were intentionally excluded by this arrangement. For example those children whose treatment programme was a very short one, or who had been treated with surgery or radiotherapy, but without chemotherapy, would be excluded by this time scale. These exclusions were consistent with primary requirements of the study which intended a focus on parents' current views of treatment together with their reflections back over the period from their child's diagnosis. Quite a long period of chemotherapy treatment was therefore needed for this to be possible.

The timing of the interviews in relation to the diagnosis enabled me to obtain both current and retrospective data. My intention was that for each case I would be able to get a picture of what the parent's current experiences were and also an indication of the developments which had taken place in the parent's recent experience since their child became ill. One advantage of the approach is that it gave a perspective for examining any changes which might have taken place during the period of the illness.

Child's diagnosis

A judgement had to be made about the relevance of the precise nature of the illness of the children whose parents were to be included in the sample group. I decided to include children whose treatment extended over more than six months from the time of the diagnosis and all of whom were receiving chemotherapy as the principal form of treatment. These criteria meant that the majority of cases attending the treatment centre were included. One reason for having these criteria was to ensure that my study focused on the families of children who were expected to be undergoing an extensive period of treatment.

My criteria excluded therefore children whose treatment had been concluded within six months. In practice, this meant that I excluded children who had an illness so severe that they died within a brief period, or who had a condition, such as a brain tumour or other tumour, which was treated surgically or with radiotherapy or with a short period of chemotherapy. There are sound medical reasons for adopting the approach I took. Even within one form of cancer, for example leukaemia, there is a wide diversity in specific medical diagnoses which can be made. Furthermore, even in cases of children with exactly the same diagnosis, the experience of the illness can differ in a number of ways, with a variation in the onset period, the actual symptoms and how the patient responds.

Most of the previous research in psycho social aspects of childhood cancer does not differentiate between children with different forms of cancer. While Kupst's major study is of children with good prognosis leukaemia (Kupst, 1988) and Fife's smaller study which also selected children with leukaemia (Fife, 1986), the great majority of research has not differentiated in this way (for example, Koocher and O'Malley, 1980, Chesler and Barbarin, 1986, Faulkner et al, 1995). This may be because of sampling difficulties as numbers are very small, but also may be because other researchers have taken the view that the overriding consideration is that of a cancer diagnosis and that differential diagnoses are of far less relevance.

Ages of the children

A consequence of selecting a sample of children sequentially as they came to the hospital was that it did not take account of the ages of the children. Thus the children spanned a wide age range. My survey of social workers in paediatric oncology had indicated that no particular significance was attributable to age of child in relation to the way parents coped with the illness. In addition, most

previous research had not paid any particular regard to the ages of children within the research studies, while some had indicated that the age of the child was not significantly related to the ways in which parents coped (Kupst et al, 1988). Although I recognised that the illness affects children differently at different stages of their development, I did not attempt to make a selection. One of the characteristics of the ages of the children in the sample was that there was a predominance of very young children, a number of whom had no siblings. I had no reason to believe, however, that the range of ages of the children selected was different from a typical selection of children from the treatment centre.

Description of the child sample

The children ranged in age from eighteen months to fourteen years, with six of the children being under school age. There were three girls and eight boys. (Figure 3.2 gives details of the children in the sample.) The children had been diagnosed as having a range of childhood cancers; six had the commonest form of leukaemia (acute lymphoblastic leukaemia), one had a rarer form of leukaemia (acute myeloid leukaemia), one had another form of haematological malignancy (non Hodgkin's lymphoma) and two had a solid tumours of the abdomen.

Figure 3.2

Sample group: Description of children (n = 11)

Child	Gender	Age	Type of cancer illness	Number of parents	Number of parents interviewed	Number of siblings at home
a	M	0.75 yrs.	solid tumour	2	2	1
b	M	14 yrs.	leukaemia	2	2	1
c	M	3 yrs.	leukaemia	2 (separated)	2	1
d	M	7 yrs.	leukaemia	2	2	0
e	F	3 yrs.	leukaemia	2	2	0
f	M	2 yrs.	leukaemia	2	2	0
g	M	2 yrs.	leukaemia	1	1	0
h	F	12 yrs.	non-Hodgkin's lymphoma	2 (1 step-parent)	2	5
i	F	1.5 yrs.	solid tumour	2	2	1
j	M	7 yrs.	solid tumour	2	1	1
k	M	3 yrs.	leukaemia	2	1	2
totals	M = 8			21	19	12
	F = 3					

The prognoses for recovery from the disease varied. Most of the children having a good or very good prognosis, which means that they had 60% to 80% chance of survival. Two of the children had a poor prognosis, that is a less than 50% chance of surviving the disease (UKCCSG, 1996). Although I have made no attempt to follow the medical progress of any of the children since the time of the interviews with the parents, I have been informed that at least one of the children has died and another child has relapsed. I have been careful to separate details of the children

from those of their parents for reasons of maintaining confidentiality. The specific diagnoses of any paediatric cancer illness, coupled with the identification of the hospital unit, as well as any reference to death, can help to identify any particular child. This is an ethical consideration which is discussed below.

The range of cancer illnesses which the children had reflect the frequency of occurrence of these illnesses in the population generally, with the exception of the absence of any children with brain tumours. (Figure 3.3 shows rates of occurrence of childhood cancers in the UK.) Children with brain tumours were at least partially excluded from the study because the majority of them are treated with surgery and radiotherapy rather than with chemotherapy, and because treatments are of a short duration.

Ethical considerations

Research conducted with patients in hospital or their relatives must always meet the medical institution's ethical criteria for research. Most acute hospitals in the UK have established Ethical Committees which consider in detail every request to undertake research in any aspect of patient care.

The process of gaining approval for the study necessitated application being made to the Ethical Committee which reinforced these principles. The Ethical Committee required detailed information about every aspect of the research (see Appendix 2). A full report, including the purpose, methods of the study and a copy of interview schedule were prepared and sent to them and approval was given.

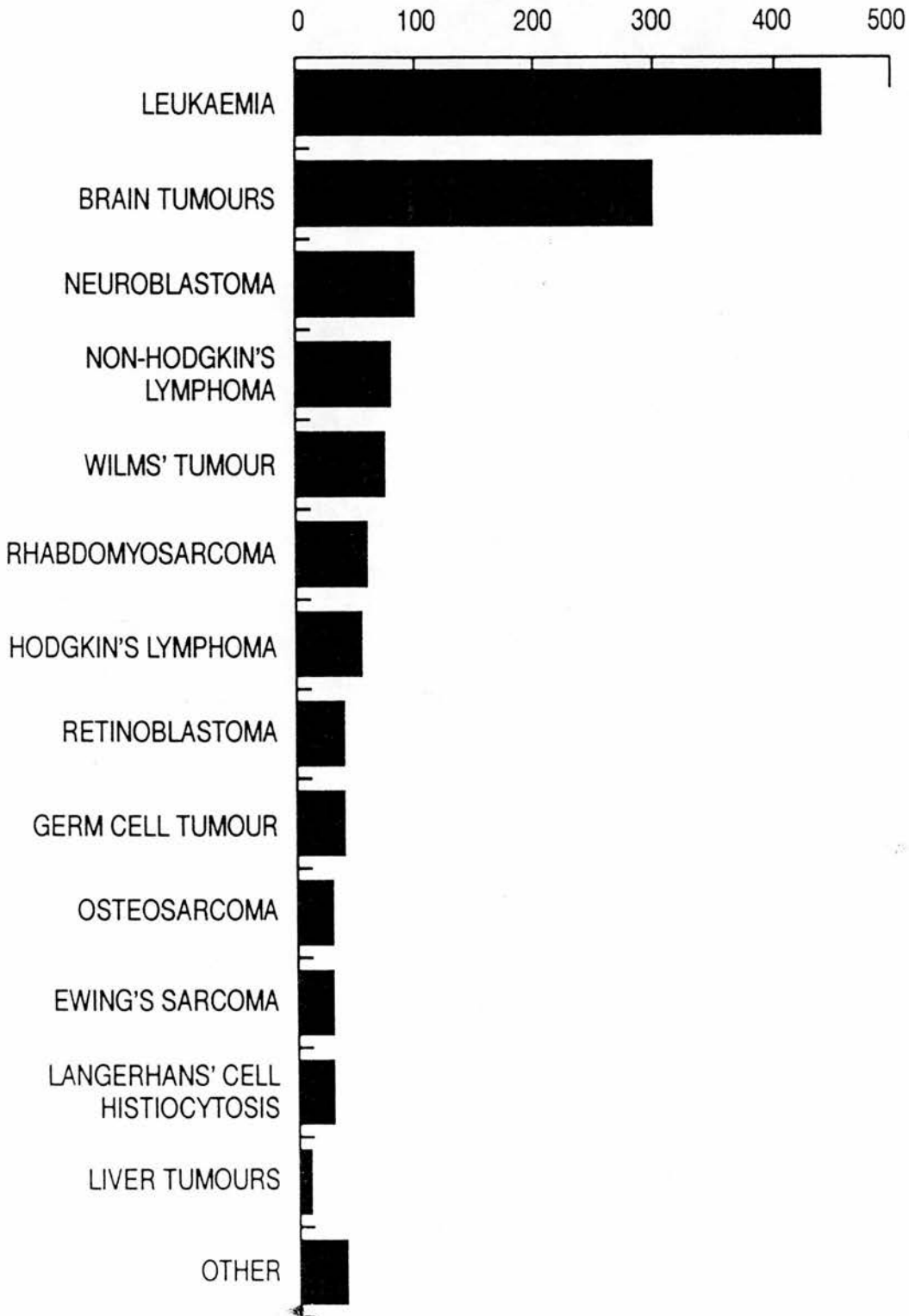
An important requirement which the committee made in granting their permission was that there should be an arrangement to ensure that parents were not coerced in any way to take part and that they could withdraw at any time. This was embodied in the letter asking parents to take part, and an additional safeguard, the parents were given the name of a social work manager, who was independent of the researcher, with whom they could discuss any concerns. One parent availed herself of this opportunity before deciding that she would participate in the study.

Other requirements to which the Ethical Committee attached importance concerned anonymity and confidentiality. They stipulated that any reports arising from the research should be strictly anonymised in terms of individual patients so that

Figure 3.3

(UKCCSG, 1996)

Numbers of children with each type of cancer presenting each year in the UK



information about any individual or child should not be able to be traced back to them. It is likely that this requirement, as mentioned above, stems from the fact that patients and families are easily identifiable because of the rarity of the occurrence of childhood cancer.

Apart from the requirements imposed by the Ethical Committee, I was also concerned that my approach was an entirely sensitive one. From my own previous experience over many years of working in regular contact with parents of children with cancer, and from other research (for example, Faulkner et al, 1995), I was acutely aware of the stress that parents experienced. I was determined to find a research approach which minimised intrusiveness, had regard to the vulnerability of parents, respected their privacy and which did not cause them any additional distress.

The interview as a research tool

Qualitative research covers a wide spectrum of methodologies. The research interview is a widely recognised instrument in qualitative research. Its advantage as a method of enquiry is that it can provide insight into the world of the individual, enable the researcher to gain information about the content and pattern of daily life and give a opportunity to see and experience the world of the respondent (McCracken, 1988). As the interview was to be the key instrument of my research it was important therefore to prepare carefully the format to enable it to be the main data collection instrument.

I gave serious consideration to the question of whether a focus of the interview with parents should address the question of effectiveness of coping, but concluded that it should not. Some of the research literature makes reference to coping in terms of effectiveness, for example by examining strategies which appear to help the individual (for example Fife et al, 1987). In my preliminary survey of social workers I also placed an emphasis on asking about indicators of effectiveness. After reconsidering the matter in the light of my review of the literature, I concluded that it was premature to be focusing on effective strategies when there was little detailed knowledge of what coping involved for the parents. The focus of my interview was intended to understand the parents' perspective. It was not my intention to obtain external measurements of how the parents in my sample were coping. Even had an external opinion of a parent's coping been obtained, from a doctor or a relative for example, this would not have reflected the parent's own view of their situation. It

might possibly be based a superficial appraisal rather than the detailed insights that I was expecting to find from my interviews with parents.

That said, in my findings I make some observations about effectiveness in coping. It should be emphasised that these observations are not part of my main findings and are mainly professional impressions which draw on my experience as a social worker. They are presented in the context on trying to develop an understanding of what coping appears to involve.

The interview schedule

An interview schedule was drawn up informed by the findings in the research literature, supplemented by discussions with selected parents and specific research which I conducted with experienced oncology social workers (reported in Chapter 4). The purpose of this preparation was to identify areas of experience to be covered in the interviews. The interview schedule was reviewed in the course of preparation, including piloting, and the final version included a number of main questions with additional "prompt" questions for each main question, which could be used if required. (See Appendix 3.)

The interview schedule was drawn up with a semi-structured approach. Main questions were designed to elicit information in the main areas being examined. These questions were put to all the parents. In addition a number of prompt questions were planned. The purpose was to create a broadly similar format for all the interviews, with prompting where necessary to cover a similar ground for all parents. At the same time there was flexibility within the schedule. This flexibility enabled a degree of similarity to be achieved between interviews by ensuring that parents were asked about key areas set in advance of the interview while still maintaining the overriding purpose of seeking parents' own opinions without too much influence from the researcher's preconceived ideas. A balance was sought between covering specific areas in all the interviews and allowing parents to pursue their own most important concerns which they wanted to be recorded. In practice the interviews were more characteristic of focussed rather than semi-structured interviews. The parents needed little prompting to elicit their observations. Most were prepared to tell their "story" in their own way, requiring only slight direction to maintain focus on the three main areas.

These areas were: First, a section which sought information and parents' views on their life at the present time; second, asking parents to look back to the time of their

child's diagnosis of cancer and third, a section which had a broader purpose of seeking reflections from parents about their experiences, their views about the illness and treatment and its effect on themselves and the family.

I had reason to believe, from previous research and from my survey of social workers' views of the ways in which parents coped, that these topics would provide information relevant to gaining an understanding of coping. The three areas are linked to theoretical concepts of coping because they examined current processes, the period of crisis and provided an opportunity to examine parents' reflections and perceptions of change over time. It was considered that these areas would reveal what was happening for parents in terms of their coping.

The structure of the interviews was influenced by professional writings about the course of the treatments and the way in which different stages are experienced by parents (Ross, 1993) and by my own clinical experience. The sequence of main questions was intended to provide a route into discussion, beginning with areas of lower emotional content which might enable parents to feel relaxed and moving on to more difficult areas. (The interview schedule is in Appendix 3.)

The setting in which the interviews took place

It was decided that the preferred option for the setting of the interviews was the parents' own homes. This had the benefit of being a place where the parent, rather than the researcher, was more familiar. An added advantage was that it reinforced a focus on the present time, as well as at the previous stages of the illness, when the child was largely at home. It also allowed them to reflect on their hospital experiences from a point of security. There were also possibly fewer distractions at the parents' own home. Parents might well have associated an interview held in the hospital with the anxieties which surrounded the hospital clinic visits which most were attending regularly for treatment purposes. One set of parents were not happy for a home visit to be made, so an arrangement was made to meet in an alternative, but non-hospital, location.

Piloting

The interview approach was piloted with three parents. As a result of these interviews, some general changes were made as it was evident that there were some difficulties for the interviewees with a much more open and unstructured discussion. While the interview worked well in general, there were a few questions

which might not be readily understood and that these were some which required more clarity or a different type of prompt. The piloting also indicated that there was a benefit in some indirect approaches to obtain some aspects of parents' views. (For example "What would you advise other parents in this situation?")

Number of interviews with each parent

It was decided to interview each parent only once. A number of considerations informed this decision. The first was that the children were still experiencing intense medical treatment and intrusion through research might have been disruptive and not in keeping with the aim of a sensitive approach. Secondly, it was felt that any series of interviews with individual parents would give additional data mainly on "progress" in the parents' attitudes rather than reveal substantial new knowledge. While this would have been helpful for studying the process of change, it would have yielded minimal additional information on the parents' attitudes.

Recording the interviews

All the interviews were tape recorded. All the parents agreed to this. The parents were consulted by me about the arrangement on the telephone when the appointment was being made. The consent which each gave was confirmed at the beginning of the interview when parents were given another opportunity to object.

Recording enabled a full concentration on the interview itself without the need to take notes. Notes were taken immediately after the interview of matters which would not have been recorded on the tape and could be relevant for understanding the context in which parents made their observations. These included the physical circumstances of the home, the mood and appearance of the parents and any information they gave about current developments which might have had a bearing on the course or content of the interview.

Conducting the interviews

Parents were contacted initially by letter giving an explanation of the purpose of the research, the nature of the interview which was planned and requesting their participation. (A copy is included in Appendix 4) Parents were then telephoned to discuss whether they were prepared to be interviewed and discuss practical arrangements for an interview at home. The response was a positive one by most of the parents.

Careful thought was also given to the style and manner in which the interview would be conducted. In keeping with my social work training, I attached importance to establishing a rapport with each of the parents, seeing it as important to create an atmosphere of trust to enable them to talk freely about difficult and possibly painful areas.

The plan which was followed was to try to establish the full co-operation of each of the parents through the introductory letter and the follow up telephone call to clarify the arrangements. This plan seems to have been successful in that all the parents appeared pleased to greet me on arrival and spoke reasonably freely in the interviews. A further indication of the parents' willingness to participate is that many were willing to give more time to the interview than I had requested in the introductory letter (3/4 hour to 1 hour). Most of the interviews extended to an hour and a quarter or an hour and a half. Two were 2 hours in length.

It was important that the parents were interviewed with careful attention and sensitivity to their particular circumstances on the day of the interview and to aspects of the content of the interview which might be particularly upsetting to them. It was also necessary to bring the interview to a constructive conclusion so that parents would not be left in any distress afterwards. To achieve this I concluded with some questions of a factual nature which were less likely to involve the parents in discussing matters which could be distressing to them. In general I attempted to lighten the tone of the interview. A letter of appreciation was later sent to all the parents (See Appendix 5).

Analysis of the data

General Approach

The transcripts of the interviews were read and the recordings were listened to extensively. The purpose of this examination was to make sense of the all interview material as data and to find structure and meaning. In qualitative research there are two main ways in which this can be done. The first is to impose categories on the data and to then test the data to look for evidence which supports the categories. The other approach, which I preferred, was to try and identify categories arising solely from within the data. This second approach is the one associated with the exponents of "grounded theory" who argue its advantages for the researcher interested in building theory inductively and not relying on preconceived ideas (Strauss and Corbin, 1987, p. 7) .

Initially I studied the data, without any firm preconceptions, to try and find groupings of ideas which could be placed in various categories. This process has been described as seeking categories which “emerge” from the data, but as Jones has pointed out, categories do not “emerge” as though they are there waiting to be discovered (Jones, 1985). They have to be interpreted and follow careful selection. The selection is a carefully refined, staged process, which was aided by the technique of “mapping” which is described below. Having grouped comments from parents together, a second level of meaning was then drawn from them. Care was taken that the concepts of this second level of abstraction were closely linked to the particular stated ideas and concepts of the parents.

Stage 1: Mapping

This technique was a valuable first step in organising the data from each interview and subsequently in drawing out more abstract concepts from each interview. The “map” brings together linked ideas about the main issues or concepts in each interview. Other ideas which relate are connected with a line and different issues are grouped. This provided a non-linear means of bringing together the important elements in each interview from a large mass of data and provided a way of examining what appeared at first sight to be random and apparently unrelated aspects of the interview. The important elements of the interview and the relationship between them were displayed on one large sheet of paper.

This technique has been used by several researchers, most recently by Faulkner who studied the impact of childhood cancer on families (Faulkner et al 1995). This technique was developed by Buzan as a “mind mapping” process (Buzan, 1974) and also developed by Jones who saw the importance of what she calls “cognitive mapping” for research purposes (Jones, 1985). It was an important tool in the analysis.

Each of the interviews was “mapped” in this way and this resulted in an extensive network of concepts, behaviours, emotions and processes relevant to each case in terms of the parents’ own perceptions. An example is given in Figure 3.4 which shows a simplified version of the ideas from one interview. The ideas were refined and numbers of categories reduced so that a more limited number of themes were developed which linked together. An example of this is given in Figure 3.5 which shows the concepts from the same parent interview interpreted through a further tier of analysis.

Figure 3.4
Example of a simplified "map" of one case

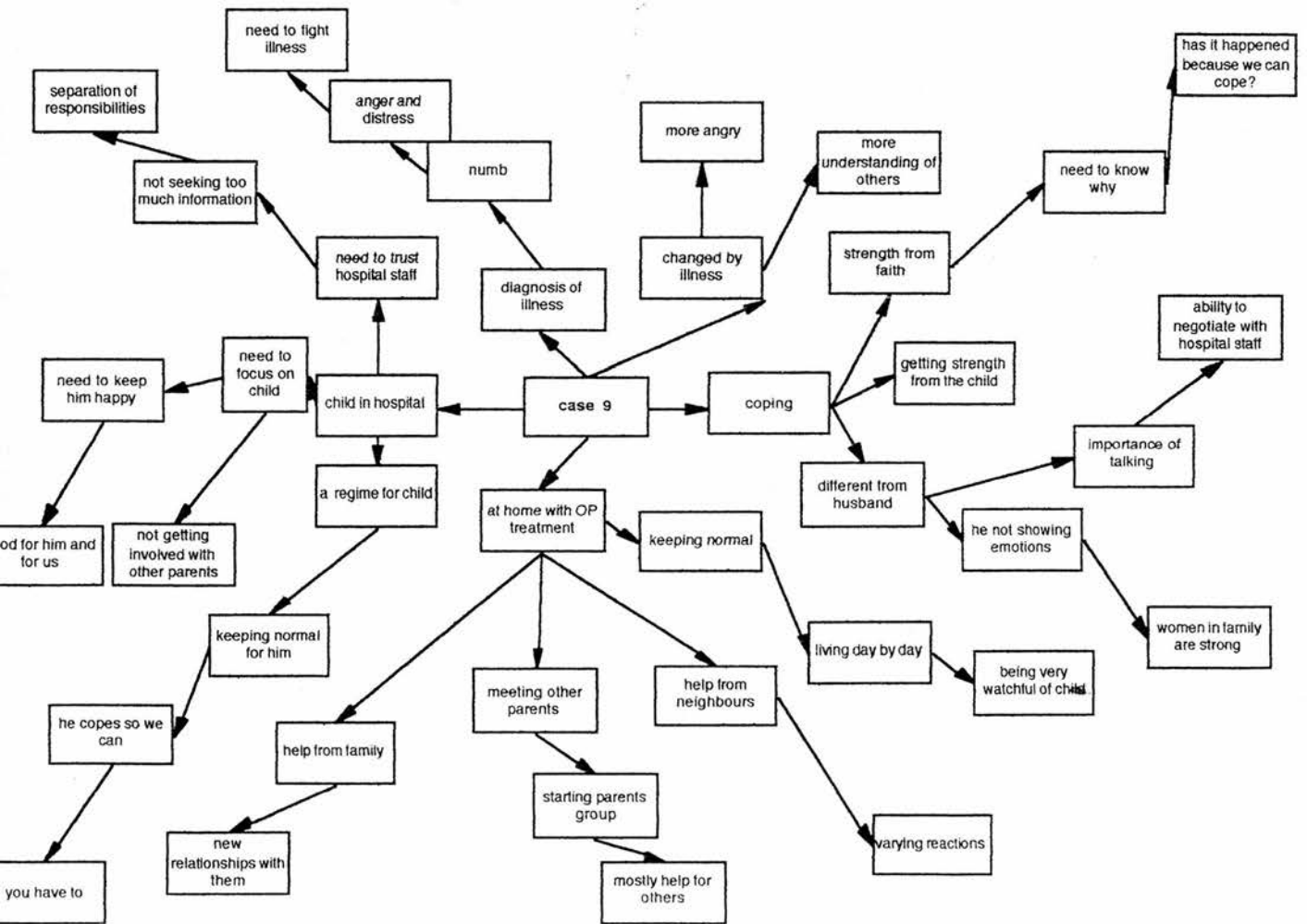
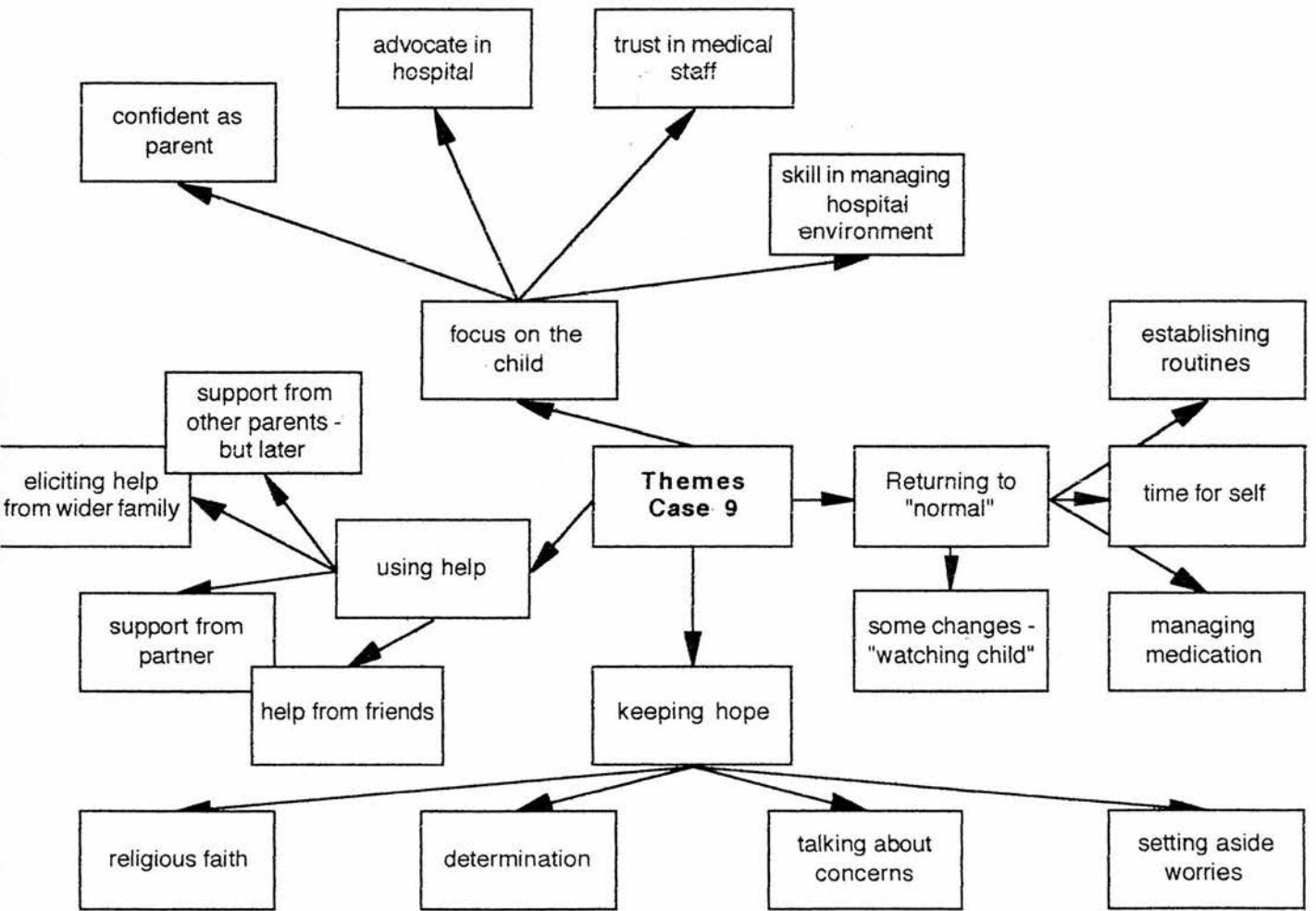


Figure 3.5
Example of a "map" of one case showing development of themes



One clear advantage that the mapping process had was that it brought together in one document a summary of the components of an interview shown in association with each other.

Stage 2: Identification of themes

I examined the mapped material for recurring ideas and concepts which could be grouped together. The material was then re-ordered cross-sectionally by placing individual data into a number of categories. A further stage involved collapsing the categories. This process involved much reflection and discussion with supervisors, resulted in a final selection of *four major themes*, all of which were “grounded” in the nineteen interviews held with parents. The identification of these four major themes is a principal outcome of the study and are reported in detail in Chapters 5 to 9.

Stage 3: Identification of sub themes

There was a further stage in the analysis of the material. First there was a more detailed examination of the material relevant to each theme for the purpose of identifying areas of the content where parents had disclosed difficulties they were or had been experiencing. This exercise resulted in eliciting tensions or dilemmas which many of the parents had and, for the purpose of analysis, these have been collated and some common tensions within each theme identified. One reason for identifying areas of tension was the assumption that understanding these areas would have a bearing on how parents coped.

Stage 4: Identification of link between themes

A final stage of the analysis was an examination of the themes and sub themes to identify material which gave more insight into explaining the data. This resulted a more detailed analysis of the data for the purpose of understanding the change which the parents experienced during the course of the illness.

Although the interview schedule had not been prepared with the intention of examining the process of change in any detail, the structure of the interview, with its focus on the recent past as well as the present and the over all comments parents made, had produced material which helped to explain the process of change in which parents were engaged. A fifth additional section in the findings was therefore developed.

The Findings

The findings are presented in narrative and analytical form and follow the structure of analysis outlined above. Within the constraints of report writing it was not possible to give every example pertaining to each theme. Findings are therefore an analysis of parents' perceptions and described experiences, illustrated by case examples from and references to individual cases. The main themes are given, with the key issues and tensions in each.

Findings are presented over five chapters, structured as follows:

1. Redefining normality
2. Maintaining hope
3. Negotiating social support
4. Caring for the child
5. Coping with childhood cancer: How parents change

The final part of my thesis involves an extensive discussion of both the theoretical aspects of what coping with childhood cancer involves for the parents and the application of my findings for the work of social workers and other professionals engaged in health care. In addition there is a brief concluding section in which I give additional observations, including some pertaining to my experiences of undertaking this study.

CHAPTER 4

COPING WITH CHILDHOOD CANCER: THE VIEWS OF SOCIAL WORKERS

Introduction

As I have indicated in the review of the literature, the total size of the social work contribution to research knowledge is disappointing. Taking account of this fact I considered that my intention of obtaining an understanding of the parents' perceptions of their experiences could be helped if I conducted a preliminary study to hear social workers' views, based on their knowledge of helping parents. An invitation was extended to a specialist group of social workers in the UK to participate in the study, and they were most willing to co-operate. Subsequently a corresponding group of specialist paediatric oncology social workers in the USA also agreed to help. The consultation, which involved undertaking a survey with about 200 social workers, proved to be a more major exercise than had been originally intended and may be viewed in some respects as being a separate research exercise. In this chapter I give a short account of the approach which was adopted to obtain social workers' views and summarise and discuss their observations.

"Coping" as a social work term

"Coping" is a familiar term in the social work and everyday professional vocabulary. It is a factor often associated with both casework assessment and goal formulation, and yet it has rarely been conceptualised or studied in the context of social work. The word, in social work professional literature, was formerly associated initially with the writings of Perlman in the 1950s, who viewed social work assessment as a process of discovery of how a problem affected a clients' ability to cope (Mailick, 1991). She argued that the social workers' task was to engage with the client in a problem solving process in which the client is enabled to develop capabilities in a context in which stress is modified and opportunities enhanced (Perlman, 1957).

The term "coping" forms part of the main psychological and sociological ideas which had a strong influence on social work practice in the UK and in the USA in



the past thirty years. Psychoanalytic theory is a good example of an influential theory, especially those aspects focused on understanding the functions of the "ego" as an adaptive mechanism and its "defence mechanisms" against anxiety and traumas (Freud, 1966). "Coping" also fits readily with other models of social work practice based on various underlying theories, for example learning theory, which has been another strong influence on social work development. The learning theory approach, which emphasises how people learn in social situations by observing and modelling behaviour, acknowledges a more conscious approach that an individual adopts in meeting adverse situations and the value in making use of cognitive processes (Payne, 1991).

Coping in relation to paediatric oncology social work

The way that parents cope or can be helped to cope with their child's illness is a matter of particular interest to paediatric oncology social workers who help parents at the time of the diagnosis, treatment and care of their child. There is now a network of paediatric oncology social workers in the UK. Since the first social worker was appointed to Alder Hey Hospital in 1976 with funds from the Malcolm Sargent Cancer Fund (Peck, 1979), about forty social workers are now in post in most of the regional treatment centres for childhood cancer. This group of social workers with its specific identity has formed the basis of a wider group of social workers who have a particular interest in childhood cancer. These social workers meet regularly at training seminars and conferences to share their experiences and learn from one another. Among matters discussed are working with parents' groups, ethnic and cultural issues, methods of working with young children and adolescents with cancer, work with bereaved families and many others.

Despite being the member of the multi disciplinary clinical team most involved with the parents of the child with cancer, or having a primary responsibility for the needs of parents and families of the sick child (Ross, 1995, Donnelly-Wood, 1988), social workers have seldom expressed a collective professional view on the effects that this illness has on family members. The intention was to use the information to assist me in the planning of the focus of the interviews with parents and also to have a consensus of their views for comparison subsequently with the views of parents.

Arrangements for the study

When the purpose of my study was explained to the office bearers of the UK paediatric oncology social work group (and shown to its equivalent in the USA) the response was a clear endorsement for the study's focus and an expressed willingness to become involved. After some discussion it was agreed to proceed on the basis of a survey in which members would participate.

Social workers views were obtained by means of a detailed questionnaire which was sent by post to all 80 members of the paediatric oncology social workers group in the UK. A similar questionnaire was subsequently issued to all attendees at a major conference in the USA for paediatric oncology social workers. An explanatory letter about the study was given with the questionnaire.

Methodology

The questionnaire sought social workers views about what they considered to be important factors for a parent's coping with their child's cancer illness and also ascertaining their views on how they conceptualised "coping" in their practice.

Part 1 of the questionnaire contained a list of 35 statements which I had drawn up based on a comprehensive consideration of the major research studies. Each of these statements had been based on a specific research finding (or aggregate findings) or on specific assertions contained in the professional literature. Every statement had been associated in at least one of these ways with a parent's way of "effective coping" with cancer in their child. Social workers were asked to consider each of these statements and rate them on a four point scale in order of importance. The categories were "very important," "important," "fairly important" or "not important".

Part 2 of the questionnaire asked for written responses to general questions about social workers' understanding of what was meant by the term "coping" in the context of parents who had a child with cancer and about their use of assessment of parents' coping in their work. The responses were analysed by transcribing the comments and grouping similar responses into several categories. This enabled me to develop themes within the factors associated with coping which the social workers identified.

Analysis of the results

I received 57 responses from the UK group, a return rate of 66%. The questionnaire was included in the conference packs of attendees at the annual conference for paediatric oncology social workers in the USA which was attended by approximately 120 persons most of whom were social workers. There were 66 returned. While it is not possible to give an exact return rate, it can be said that for both groups the return rate was high. The results are based on 120 questionnaires returned.

The responses to this quantitative data were analysed by means of a computer analysis using the statistical processing package "Statview" which enabled me to rank the statements according to the ascribed "importance" given to them by the social workers, using frequency distributions of the ratings of the individual statements. The rankings of the statements were examined both in terms of the importance ascribed to particular statements and also to groups of statements taken together to look at the factors which were associated with coping.

Characteristics of effective forms of coping

The pattern of responses of both the groups of social workers from the UK and USA were broadly similar. I have therefore chosen to examine in detail composite responses based on both groups rather than concentrate on the differences which exist. Doing so takes advantage of the total sample of 120 returns, a figure which is about 35-40% of all the specialist social workers in the UK and USA. This therefore gives a very sound basis for making observations on how social workers view parental coping.

First the 35 statements were ranked in order of their importance. The statements had been rated by respondents on a four point scale, selected intentionally, to require respondents to choose whether they judged any individual factor to be associated with a "high" or a "low" significance in relation to effective coping. By merging the categories "very important" and "important" to form a new category of "high" significance and similarly the "fairly important" and "not important" became "low" significance, I was able to determine a "measurement of importance" figure for each statement. The ranked list of statements shown in order of importance as rated by the social workers is shown in Figure 4.1.

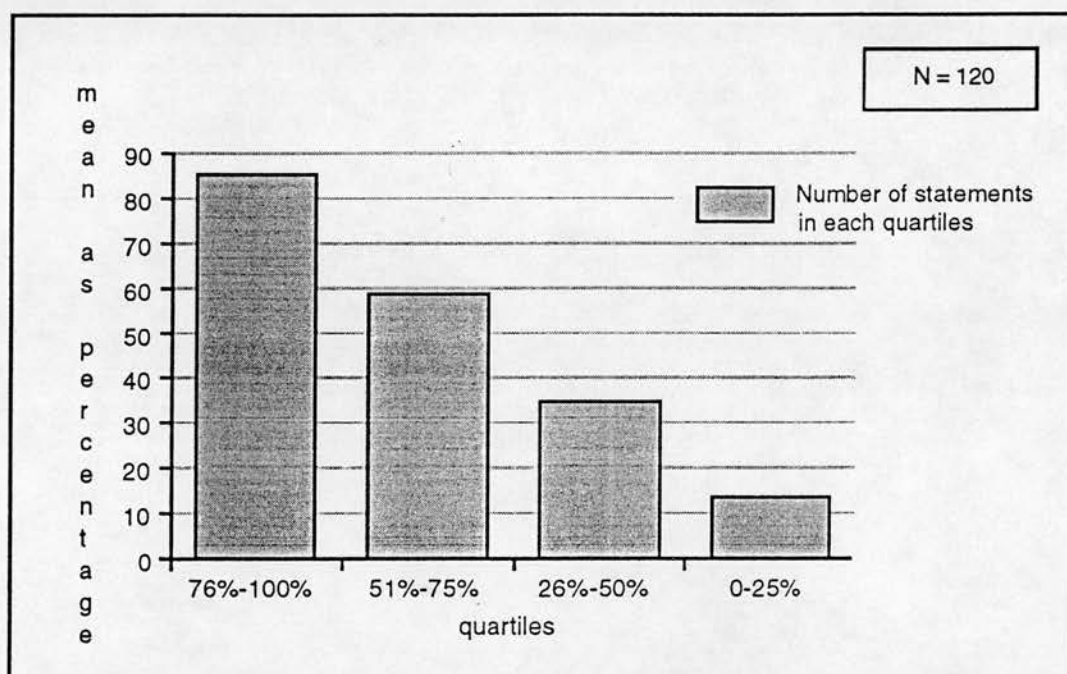
Figure 4.1: Statements ranked in order of importance

Statement reference number	Statement given in questionnaire	Measurement of importance per cent
20	Parents make trusting relationships with hospital staff	95.8
8	Parents can discuss illness together	90.0
32	Parents are flexible about day to day crises	89.2
33	Parents can ask for help and support	89.2
13	Child adapts well to the demands of the illness	88.3
14	Parents are willing to discuss the illness with their child	88.3
34	Parents try to achieve a normal quality of life	88.3
29	There was a positive previous relationship between parents and child	88.2
25	Parents can set limits on their child's behaviour	87.5
10	Parents have good physical health	86.7
1	Positive support networks exist for the family in the community	86.7
2	Parents have support from friends	84.0
15	Parents can seek information	82.3
17	Parents discuss the illness with their other children	81.7
9	Parents talk about feelings	80.0
19	Parents are able to learn about the practical management of the illness	79.2
28	Child returns quickly to some of his/her normal activities	78.3
31	Parents can accept that illness has happened	77.5
4	One parent has a sympathetic employer	70.8
7	There is a stable marriage/ partnership	65.7
24	Parents have warm family relationships	59.7
21	Parents make contact with others in the same situation	59.2
22	Parents use social workers to discuss feelings about illness	58.3
12	There is a known prognosis for the child's illness	57.6
27	Diagnosis of the child's illness was made without delay	55.0
23	Parents develop new skills in caring for their child	50.4
35	Sick child understands the severity of the illness	46.2
26	The hospital is easily accessible from home	38.2
6	There are no pre-existing financial problems which child is diagnosed	36.7
5	Parents find religious beliefs to be a support	33.6
3	Both of child's parents live with the child	28.6
11	Parents have experienced a previous crisis	26.0
16	Treatment protocol is of a short duration	20.0
30	There are other children in the family	15.0
18	Child with cancer is under 8 years of age	5.9
N = 120		

The distribution of the ranked scores was from 95.8% to 5.9%. The higher figure was the score for the statement "Parents make trusting relationships with hospital staff," while the lower pertained to the statement "Child with cancer is under 8

years of age" as being of importance to effective coping. The range of rankings in general was high (mean = 63.9%) as the majority of them were deemed to be of high importance. This finding was not surprising in view of the fact that all the statements were selected as being associated in research with having an importance for parents' coping. As can be seen in Figure 4.2, seventeen, almost half, fell into the top quartile of those for which over 75% of respondents had marked them as being of high importance. Very few fell into the lowest quartile of those for which receiving less than 25% responses of importance.

Figure 4.2: Ranked statements showing number in each quartile



The statements as a measure of coping

The next stage of the analysis involved examining the results in more detail to ascertain what factors had influenced to social workers in making their judgements. This was done by developing categories of factors which were often associated with coping, and selecting from the 35 statements those which were considered to be the best indicators of each category.

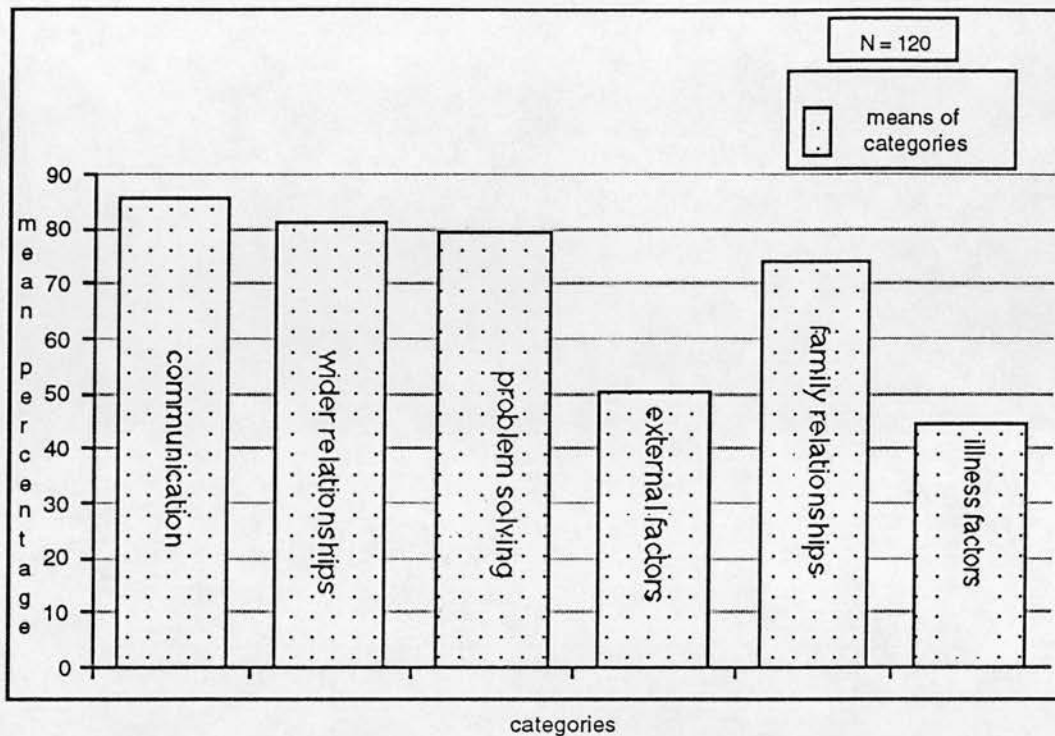
The 6 categories for analysis in this way were :

- family relationships
- social relationships
- problem solving abilities
- communication
- external factors (unrelated to the illness)
- external factors (related to the illness)

I chose four statements to represent each (and only three for the last) so that no undue weight would be given to any particular individual statement and any ambiguities would be avoided. (The statements included in each of these categories are in Appendix 6). I then calculated the mean score of each of the categories. The results of this analysis is shown in Figure 4.3.

The results indicate that social workers attach the greatest importance to the ability of parents to communicate with each other, their children and other people (this group of factors having a mean score of 85.8%). The relationships which parents have with people in their community and within the new situation of the hospital are seen as closely following in importance (with a score of 81.4%). Parents ability to address problems they encounter actively is ranked as next in importance (with a score of 79.4%). Family relationships are also important and are ranked fourth (at 74.0%). Of much less importance were deemed to be what I have referred to as "external factors" unrelated to the illness (scored at 50.4%). This group contained four very different items, of which two, concerning the parents' own health and their employment, were rated much more highly than the other two, about the parents' financial situation and the distance of the hospital from the home. Last in importance was the group of three items concerning the nature of the child's illness, (which was given a mean score of 44.2%).

Figure 4.3: Categories of factors associated with coping



In looking at these grouping, parents interpersonal skills, relationships and ability to address problems actively were therefore seen to be the most important, while situational factors of all kinds were deemed to be less important. When examining the top “quartile”, that is all those statements which received a rating of importance of more than 75% of the social workers, a similar response is seen. Social workers placed importance on parents’ abilities to relate to others outside the family and to communicate with people and approach problems in an active way as important. These themes were reflected in the responses to the second part of the questionnaire.

Factors associated with “coping” in parents of children with cancer

The social workers offered a range of illustrations of “coping” in response to questions about the way they understood “coping” and the way the concept was used in their work. Most of the comments recognised the complex range of pressures which parents faced during their child’s illness and the different challenges which they had to meet. The following extracts from a few of the responses indicate the variety of illustrations of “coping” that were given. (Figure 4.4)

Figure 4.4: Examples of comments made by social workers to illustrate "coping":

"being able to still find some peace and joy in each day."
"to get some normalcy in their lives despite the cancer."
"being able to meet the child's needs."
"being able to continue a life-style which is safe and productive and to seek help and make decisions for the child and the family's welfare."
"to grasp the implications quickly even without detailed information or in-depth understanding and then to quickly mobilise to attend to the child's needs."
"coping.... is when a clear family pattern is still recognisable,"
"family life is not totally bounded by the treatment."
"coping.....is when parents continue to tolerably manage the different areas of their lives while responding to events appropriately."
"getting by day by day, week by week, month by month; enjoying the good days and understanding the bad days."
"those parents who are able to maintain some kind of balanced perspective are those who cope."

These comments are a short selection of extracts from the definitions of coping given by 120 respondents. The selection is based on their typicality and are presented to give an indication of descriptions given.

Two distinct patterns emerged in their definitions and illustrations. One group of descriptions focused more on the maintenance of family life with terms like "keeping going" and "maintaining normality" frequently used. A slight majority of the responses came into this category.

The other group focused more on the way that parents supported the sick child during the illness. Phrases like "meeting the child's needs", "supporting the child's medical and emotional needs" were common in this group. It should be noted also that, as the extracts show, many of the responses combined the tasks, focusing

both on family life and/or meeting the child's needs. Many stressed the importance of being able to maintain a balance in their approach to the illness, meaning that parents should not neglect their continuing responsibilities to their other children or to their partner. In other words, if a parents became too focused on any particular task at the expense of others, this would be viewed by many of the social workers as an illustration of "not being able to cope."

One particular finding in relation to the questionnaire as a whole was that there were no significant differences in the pattern of responses between the British and the American groups of social workers. It was interesting that despite considerable difference in lifestyle and culture and even treatment regimes, there was a high congruence in response. There were one or two discrepancies, for example, the American group gave a higher rating to the importance of parents religious beliefs than the British group, which perhaps indicates a difference in culture. They also rated accessibility to the hospital more highly which could reflect the significantly greater differences in travelling which American families have to face in reaching their nearest specialist hospital treatment centre.

Statements not associated with effective coping

By way of contrast, some statements were seen as not being significant for parental coping. (see Figure 4.5) This table is a composite ranking based on the responses of both group. As all of the statements on the list had been included on the basis that they had been adjudged in the professional and research literature to be relevant to the way parents coped, the low scoring shows that these characteristics are regarded as being the least significant on the list. There is a consensus of view among social workers on this matter.

Figure 4.5: Statements ranked least important

Ranking of statement	Statement reference number	Statement given in questionnaire	Measure - ment of importance %
35	18.	Child with cancer is aged under 8 years of age	5.8
34	30.	There are other children in the family	14.9
33	16.	Treatment protocol is of short duration	19.9
32	11.	Parents have experienced a previous crisis	25.9
31	3.	Both of child's parents live with the child	28.5
N = 120			

Discussion

This was a small study undertaken as part of a more comprehensive examination of how parents perceived their own ways of coping with their child's cancer. The principal purpose was to use the expert knowledge of experienced social workers in focusing constructively the interviews which were to be undertaken with the parents.

An encouraging feature of the study is the large number who participated and therefore shared their experience. The total of 120 responses is in itself a creditable sample; this in fact 67% of the total paediatric oncology group of social workers in the UK and approximately 20% of those in the USA. These figures offer good support that the responses are a good representation of the specialist social workers as a whole.

The consensus of view amongst social workers in the US and UK on what coping involves was noticeable. This applies to both the factors associated with coping and in the way some of the characteristics were rated. This suggests a strong similarity in the professional attitudes, knowledge and skills within the groups of social workers in both countries. It was clear that both groups attached significance to the importance of family relationships, adaptational skills and communication skills. These factors proved to be very helpful when I came to analyse in my main study what parents said that coping involved. In Chapter 11, in which I discuss

inter alia how effective coping might be identified, I draw particularly on what social workers said were the skills parents might require.

The wider value of this preliminary study is in what it indicates about the relevance of groups of factors, rather than what it indicates about any particular statement in the list of thirty five which were presented to respondents. Two particular types of statements were constantly rated highly. These were those which were linked with *relationships* or with *communication*. If parents show a capacity to be able to form good social relationships, either prior to the illness or in the course of it, they are more likely, in the view of social workers, to be able to cope effectively.

Similarly, communication abilities were deemed to be an asset. If parents communicate well both within the family, including with the sick child, and externally, this was considered to be indicative of their ability to cope effectively with the illness. A particular manifestation of the parents' communication ability lies in the relationships they form with the hospital staff, in particular with medical personnel. Social workers clearly rated this the most important factor in determining effective coping.

The findings in relation to the factors which were adjudged not to be indicative of effective coping were also interesting. In general, the social workers' specific ratings on this matter have to be interpreted cautiously because the main focus may have been on identifying "important" factors rather than "not important" ones. Nevertheless, "external factors" of any sort were rated as being "low" in terms of being indicative of effective coping. This finding, however, helps to emphasise that social workers tend to view intra personal factors as being more important than external influences in determining an individual's behaviour.

A final observation pertains to a small point of difference between the responses of the UK and USA groups of social workers. The USA group gave a considerably higher rating to the statement "Parents find religious beliefs to be a support" than the UK group. This is interesting in itself in that this figures very little in the literature on coping, although Chesler and Barbarin found religious beliefs to be important to a significant number of the parents in their sample group (Chesler and Barbarin, 1987). The difference in view may suggest some differences in cultural values.

The USA group also attached a higher significance to the accessibility of the treatment centre to the child's home, whereas the UK group did not see this aspect

as being important. This difference could be mainly a result of the geographical distances in the United States or reflect a more centralised way in which medical treatment is provided.

A final consideration was to examine the data to see if anything new emerged in the way in which social workers judged coping which was different from the views of researchers which I discussed in the literature review. One clear impression was that social workers take much more account than psychologists or physicians do of social and environmental factors. The social networks, for example, in which parents were engaged and the types of relationship that they formed were seen as being indicative of their way of coping. The psychological research is more inclined to emphasise the importance of psychological processes, taking account especially of the cognitive skills which parents employed in problem solving as well as the emotional pressures that they experienced as a result of stress. As my findings will show, both of these perspectives are important for obtaining a clear understanding of what coping involves.

The social workers' study, more than the research literature, has helped to emphasise the complexity of the tasks that parents face. Their comments have brought out the particular problems that parents face in having to meet many of their responsibilities simultaneously. Some social workers were quite clear in their views that the way that a parent can balance and control the pressure on him or herself is an essential element of how he or she copes with the child's cancer illness.

CHAPTER 5

REDEFINING NORMALITY

Prelude

The findings presented in this chapter and the four that follow are based on my interviews with nineteen parents (nine fathers and ten mothers) of children with cancer. The interviews were conducted in depth and focused on the experiences that each parent had undergone since the onset of his or her child's illness.

As explained in Chapter 3 the parents' accounts are presented in terms of four themes, all of which emerged from the interview data. Each of these themes is concerned with a different aspect of a parent's life and in total they encapsulate the way parents in the study coped with the illness. For each of the themes I describe, I have tried to show what was involved for the parents in terms of the tasks they had to undertake and the stresses and dilemmas which they experienced.

In the final findings chapter (Chapter 9) I examine some of the changes in the behaviour and attitudes of the parents as the illness and treatment progressed, and discuss these in relation to some recognised theoretical concepts.

Introduction

The treatment requirements of the child's illness had an immediate impact on the life-style and daily routines of most family members. This first theme is primarily concerned with the day to day activities of the whole family and each parent's efforts to adjust to a way of living as a consequence of the illness. Most parents wanted to retain many of the aspects of the life-style they experienced prior to the illness while trying to incorporate new activities arising from the demands of the illness and the treatment. The task for the parents was therefore to find a new "normality" for themselves and their family in day to day living. For some this task became a major struggle.

Each parent was asked in the interview about what coping involved in everyday life as they attended to the child's illness and the treatment arrangements and met their other responsibilities. Each was given an opportunity to describe and assess the importance of any adjustment they had to make. It was noticeable, however, that many parents in fact introduced the notion of normality at an early stage of the

interviews, before I introduced this particular focus, thus showing that it was an issue of importance to them in their day to day lives. A picture which emerged clearly from most of the interviews was that parents had a concern to find a pattern of routines in their daily life which they could regard as being "normal".

The child's diagnosis of cancer was regarded retrospectively by every one of the parents as marking the end of a life pattern which had become established for them. By the time the research interviews were held, life was felt by many parents to be "returning to normal". It was clear however that for all, substantial changes had taken place and some were in process of further development.

In this chapter I will be considering both the changes in life-style which the parents indicated that they had made and the routine activities which had resumed. In doing so I will be discussing some of the problems that parents faced as they tried to meet all of these demands.

The new regime

The earlier part of the illness, from the time of the diagnosis to the early stages of treatment, was for all parents extremely hectic. Family life, in terms of day to day activities, had changed dramatically from what it had been before. The child's initial admission was often followed by further admissions and throughout the treatment there was frequent attendance at the hospital on an outpatient basis.

The frenetic activity required of parents was at its height in the early stages of the illness and involved a diverse range of physical and emotional effort, such as managing their work and domestic responsibilities, arranging care for their other children while at the same time keeping family and friends and many others informed about progress and spending as much time as possible with the sick child. Although much of the activity decreased over time, it seemed clear that throughout the whole period of the illness up to the time of my interviews with them, every parent maintained a high level of physical activity which required thought and planning.

The interviews had been planned to take place when the child was well established in a treatment regime. Parents had already been through a period of distress when the illness was diagnosed. They had all experienced their child being admitted to hospital during which medical treatment commenced. They were now at a point when much of the treatment for the child was being given either at home all the time

or occasionally on an in-patient basis in the hospital. Some of the most difficult aspects of the treatment had finished, or at least had done so for the time being.

All the children of the parents in the study were said to be responding well to treatment and were "in remission". Being in remission indicates that there is no evidence of cancer from medical tests or on physical examination, with the implication is that chemotherapy or other forms of treatment were proving to be successful. It does not mean that the illness is cured, as the cancer can return, but it suggests that while chemotherapy treatment is underway the cancer is much less likely to recur. All the parents by the time of the interview had developed some understanding of their child's illness and treatment and some parents demonstrated a good deal of expertise. They were familiar with the medical terminology, the treatment plans and the drug regimes.

The demands of the treatment

Treatment for most of the children presented a demanding daily schedule as well as frequent contacts with the hospital. It included for most families a hospital visit on at least a weekly basis to the out-patient department, as well as treatment procedures at home. The latter often involved parents in persuading their children to take a variety of drugs in tablet or liquid form and special mouth care to prevent infection. Parents were required to take additional care such as being alert to the various ways in which the suppression of the child's immune system could affect the child.

Parents had become familiar with the periods in which their children were at most risk of infection. They generally knew which symptoms they needed to be watching out for and which ones would require them to make contact with the hospital with the possibility that the child might have to be re admitted to the hospital. Most parents had also become familiar with the changes in their child's eating habits, including the child's new likes and dislikes. The need to encourage the child to eat or, conversely, to resist an excessive appetite for food created by certain drug regimes. The changes in the child's levels of energy, mood, and inability to undertake physical activities was all part of the daily life of the family. The main responsibility for these additional child care tasks fell largely to mothers. One father's comments about his son's difficulties in maintaining an appetite indicated his concern and that of his wife, about feeding. He said:

The chemotherapy affects his sense of taste, so what he liked today he might not like tomorrow, but he might like it again in a couple of days. He would be picking at food and you would try anything. For a while we had every food and drink known to man in that kitchen and nothing would take his fancy. It was very distressing, especially to my wife, because she couldn't get him to eat and drink. (Case 17)

Parents had learned about treatment regimes that were required when the child was living at home. Most of these practical tasks were carried out by the mothers of the children. In general mothers seemed accepting of this arrangement. One mother discussing her responsibility for her child's medical care said that she would not wish for any one else to do these tasks for her. She said:

I never trusted anyone else to do it for me. I feel if I do it myself then it's done right. Even a simple thing like cleaning his teeth and making sure his gums are clean, I just don't trust anyone else to do it. They might be able to, but you have peace of mind if you do it yourself. (Case 19)

Treatment responsibilities for the children were quite burdensome. Sometimes the task for an individual parent became very onerous and the parent felt that he or she was coping alone. One mother, for example, discussed a feeling of resentment that she had to bear all the responsibility for the child's treatment. She had felt that the child's illness had created a division between herself and her partner. She said:

I felt I was doing everything and doing all the worrying and thinking for the two of us, so I had a lot of resentment for a while. (Case 7)

Another mother spoke of a similar irritation that it was always she who had to listen to what the doctors said, explaining that even at times when her husband was present, he seemed unable to take in the details that were given. She said:

I'm the one who's got to listen to everything the doctor's saying. I'm the one who has to understand it and relay it back to him. In the beginning, I got quite upset and would say, 'Well, you're there same as me, you listen.' If you were to ask him what medicine she takes on a Monday or Tuesday, he wouldn't be able to tell you.....

On the other hand, she indicated that her partner had other strengths. She said:

But unlike some dads he always took his turn in the hospital. He's really quite good. He always phones from work on a Wednesday when we get home from the clinic, to see what her counts are like. (Case 8)

This last example illustrates a common pattern, in that in a family the parents often had complementary strengths and many were able to find effective ways of sharing the responsibilities that they had to manage. The irritation that some parents

expressed about their partner could be due to some gender differences in assigning roles within the family. But the irritation could also be due to the general distress that a parent was experiencing as a result of the illness, and the "projection" on to the partner of some of the stress that was being experienced.

Difficulties experienced in taking on new treatment tasks

For a minority of parents the "new" regime which the illness had brought to their lives was quite different from the "old" and many aspects of their own former life style seemed very remote. There were four mothers, for example, who were quite clear that everything in life had changed for them. Nothing from the past had been retained. A larger number of parents recognised some familiarity in the past but there was still a considerable struggle about settling into new routines.

Where the child's treatment regime required repeated hospitalisations it was much more difficult for parents to get any sense of normal life being re-established and so this struggle was a greater one. One mother said:

It's very difficult trying to get back to normality because we've been so long not knowing what a normal life is like. At the moment we're trying to treat him like a normal child, but he's not a normal child and he still has a life threatening illness, so everything revolves round him. (Case 7)

Some of the treatments for children who had solid tumours often required a period of hospitalisation for chemotherapy treatment every three weeks. The potential for disruption for the parents and families of these children was very great.

Treatment for leukaemia with its several months of intermittently intensive treatment in hospital, followed by usually 18 months of out-patient "maintenance" treatment was less difficult for some parents to manage, despite its length. However this was not true for all parents. One parent of a child with leukaemia, for example, felt that the giving of medication and the longer term worry of the illness would always preclude a sense of normality. She said:

My life would only be normal if I didn't have to give him tablets and everything all the time.... After the two years maybe we'll get back to normality but I don't think so because then I'd be living to see if there's going to be a relapse and to me that's the worst. (Case 19)

Resuming some aspects of pre-illness life-style

Parents referred with clear satisfaction about some of the activities which their child had undertaken before the illness and which he or she had been able to resume.

Children had been engaged in a variety of activities, such as nursery or school, all of which had completely stopped when the child became ill. At the time of the interviews, with treatment underway, many of the activities had resumed or were beginning to do so. In these situations the return was viewed by parents to be an important step towards normality not only for the child but for themselves and family as a whole.

There were however exceptions to this. Two children in the sample group (the two oldest children) had not returned to school, and in both of these situations parents acknowledged that this was partly a result of their own protectiveness and an unwillingness to push the children who were not happy about returning to school.

Participating in activities was also seen as very important to "normal" life. A father of a 7 year old boy described his son's participation in the school sports day. The boy had taken part in some of the races despite being still quite weak as a result of the treatment he had received. This was regarded by his father as a great achievement for his son and a source of pride and satisfaction for himself. Other parents spoke of their children's return to playing with their friends and for children of all ages this was seen by parents as being an important part of "normal" life. It gave their child an opportunity to escape from the preoccupation with treatment, to think about other things and to have some enjoyment and pleasure.

All the children had lost their hair as a result of the chemotherapy treatment. This was, for most parents, an upsetting consequence of the treatment and a significant one on occasions when a child had not appeared to be very ill at the time of the diagnosis. It provided a clear external sign of the seriousness of the illness. By the time of the interviews, the hair most of the children was beginning to grow again and this outward sign of normality was very important to parents as well as to the child.

Some of the children had been very ill when first diagnosed and were now free of the symptoms of the illness. In fact many of the children in the sample had spent quite long periods while they were on treatment, being relatively symptom free. This

helped considerably in producing a feeling of normality. One parent pointed out that his son “looked well” and indicated that this apparent good health, was very helpful to him. Another also referred to way the appearance of her child made life seem normal, although she also could acknowledge the deceptive nature of her child’s appearance. She said:

It’s hard to believe sometimes that there is anything wrong with him..... He looks and acts that normal, it’s easier just to pretend that there is nothing wrong. (Case 5)

For the very youngest children, resuming routines was of less relevance than keeping to a “normal” developmental timetable. The child’s growth and development changes very rapidly when children are very young, so change would have occurred if the child had been well. One parent, a father, commented about his little boy:

He’s just a normal growing child....Some of the things he knows about the hospital ...and procedures....are really astonishing. But apart from that you couldn’t say there are changes because of the illness. (Case 10)

Changes over the period of the treatment were difficult to assess. Both of the parents of a two year old boy pointed out that their son would have changed in any event over the time since his illness was diagnosed and they said it was difficult to know what the cause of changes had been. They both stressed that their son had made strides in his development during treatment, especially in his speech. They attributed this to the extra personal attention he got from themselves and other family members, and from his many contacts with other adults in the hospital. In contrast to this response, however, another parent (Case 1) took the view that the time of her baby’s illness was a time that was lost to her and she resented his absence from home for much of his first year of life which should, she felt have been spent “normally” at home with her.

Reaching a new state of normality

The diagnosis had brought “normal life” to an end for all the parents, either for a short or a longer period of time. Ordinary day to day activities had been halted as attention had become focused. While there was there was a wide variation in the way that parents defined “normal”, trying to fit day to day activities into a framework which had a semblance of familiarity with their former life was important for all.

Life seemed far from normal for some

Some parents were trying to achieve a resumption of the life they had enjoyed prior to the illness and were regretting the changes which had become necessary. A mother of an older boy, for example, who was upset that the family's life had changed so drastically, said that her daily life was not normal at all. She contrasted her situation with the way things had been before and to reinforce this, she described in some detail a particular weekend a few weeks previously which had brought home to her the extent of the change. She described the activities of her sick son and his brother who were playing outside with some other children; her own activities, doing some jobs about the house and her sudden awareness that this was the way life used to be. This had been the only occasion in many months when she had this feeling of normality, and she spoke with great sadness about the change that had taken place. She said, of the weekend she had described:

I felt a sense of relief. I felt that's what should be happening now.
(Case 4)

In a similar way, a father of a very young child, described the lack of what he called "normality" in his life. This he thought resulted mainly from the problems of his ill baby's risk of getting infections. The family had a few days holiday away in the Lake District and had enjoyed this but this had not felt "normal" to him because of the extent of the preparations required to go and the need for constant alertness about the baby's day to day health when they were away. He said, "Nothing in life is normal"(Case 2).

His wife echoed this view and said she had not had the opportunity of having a normal life with her baby because of his illness. She had not been able to have sole charge of his care or to undertake ordinary mothering tasks. Accepting the demands of the medical treatment regime was difficult. She resented it and felt keenly the loss of what she had envisaged as "normal" life for herself with her baby.

Moving towards integrating old and new life-styles to reach a new "normality"

In contrast, in the cases of other parents, a new form of daily life had become well established and was described as being "normal". This often involved the incorporation of new routines for dealing with a child's daily medication, procedures for examining mouth care, attendance at hospital clinics and similar activities which had become sufficiently regular as to be accepted as being routine.

For example, one mother said that her daily life felt more normal at the time of the interview because her child had completed his final planned period of in-patient intensive treatment. Although he was still facing more than a year of out-patient treatment, the fact that the child would be at home and could pick up some of his pre-illness activities provided for her a satisfactory sense of normality. She could accommodate the new aspects of the situation, such as weekly trips to the out patient clinic of the hospital and the administration of medical treatment at home without too much difficulty.

For about half the sample a sense of a new normality in relation to their sick child was beginning to be established. For example, one mother of a young boy with leukaemia reported that she and her husband had tried to run their lives in a similar way both before and since the onset of the illness and she saw this as an important objective. She showed, however that this "normal" life now included an acceptance of some of the new routines. She said:

Just now it's fine, we're attending clinic, getting C. to eat, drink and sleep and take his tablets and live as normally as possible. All the way through we have tried to live as normally as possible and I think that's what's kept us going. (Case 9)

She went on to describe differences in the child and her handling of him. She spoke of the additional care needed when he was outside playing, of her worries about infections from other people and of her change in disciplining him. She continued:

Playing is a different matter. I'm watching him constantly. When his counts are low you worry is he going to fall and is he going to bleed. Otherwise everything is normal for him.When I'm in the street there's people coughing and I move the pram, veering away from them. I wouldn't think there's anything else I would do differently. People spoil him a bit and we let him get away with things more, which we shouldn't really. (Case 9)

This mother indicated that some of the demands of the child's treatment have become routinised and are incorporated with activities from before the illness to become "normal" for life for herself and her child by the time of the interview. On the other hand she is very aware of aspects of life which cannot be described as "normal", that is, her increased watchfulness for her child and her protection of him from new dangers and risks to his health.

Other children in the family

At the time when I interviewed the parents, the other children in the family were beginning to resume some of their previous routines after an enforced break caused by the illness. While it was not the aim of my study to attempt to assess the impact of the illness on other children, it was obvious from the parents' observations that those children who were old enough shared some of the impact of the illness. The lives of younger children had also been affected by the disruption.

There had been a variety of methods used for the child care for the siblings of the sick child while the parents had to spend periods away from home in the hospital. A twelve year old boy, for example, had often been cared for by friends and relatives. He had enjoyed some of these arrangements but had complained about others. A sister of a little boy with leukaemia who was under a year old at the time of his diagnosis spent many weeks with grandparents, separated completely from her parents. Her family lived at a distance from the hospital and her parents had stayed in the hospital. In another situation a mother of a boy diagnosed as having leukaemia had been pregnant at the time of diagnosis. When the baby was born he was cared for by the mother's sister. In a large family with several children the mother spent the most time with the sick child while the father took over all the responsibilities of the care of the other children.

Seven of the parents, i.e. four families, had only one child. Concerns about other children in the family were not relevant for them. The other parents all made some comments about the effects that the disruption and worries that they had were having on their other children. One parent was very angry that her son's illness had she felt "changed the nature" of her daughter. Her little girl had been a placid eighteen month old, who after a long period of separation from her and care by relatives, had become a troublesome little girl who did not sleep. Her mother said, of R., her daughter,

E.'s illness has changed R. as well. She was one and a half when E. was diagnosed and she was a really placid, happy and laid back sort of baby, you know. But with E. being so long in the hospital she was passed about from person to person. Now she's a horror. She has turned out quite timid as well, and gets up every night and comes into bed with me.
(Case 5)

Another parent felt guilty that she had not been able to give much time or thought to her older boy who was only three at the time her baby became ill. She was beginning to be worried by what she referred to as her "neglect" of him and the effect that this

might have on him in the future. In reflecting back over the period of her baby's (R's) illness, she was concerned that having initially been totally absorbed in the baby's needs, this might have later negative consequences for the other child (S.). She said,

Another bad thing was having to leave S. I don't think he's over that. I still worry about that for the future. I'm still so pre-occupied with things that happen to R. and I'm only just beginning to think, "what has S. gone through?" (Case 1)

At the time of the interview, most of the temporary arrangements made for other children had been terminated. They were resuming all of their activities and families were living together as a unit again.

Work and child care

The way in which both employment and domestic responsibilities were managed by individual parents received a high degree of attention during the period of the child's treatment. Parents usually made decisions on, for example, whether to resume work, after discussion with their partner. In general, in this sample, the tendency was for the male parent to resume his employment either as quickly as possible, or some time later after the initial crisis was past, and for the female parent to remain at home. Only four of the mothers in the study had been in paid employment at the time their child became ill. Three of them gave up work entirely, or took extended leave of absence as soon as their child became ill. Only one mother, therefore, had returned to work at the time of the interviews.

Eight of the fathers were in employment. All were employed in the private sector, at the time when their child became ill. None gave up their employment as a result of the illness, although most took time off work, the amount of absence from work varied from a few days to, at most, three or four weeks.

Four men were self-employed; they returned to work within a short time. They all said that their businesses would have been jeopardised by any prolonged absence. Of the four fathers who were employed by others, three were able to take an extended absence from work at the time the child was first ill and diagnosed. All fathers had seen themselves as having a primary duty to return to work as soon as was reasonable, although they acknowledged that the burden of care for the sick child fell to their partners.

Only one of the fathers in the sample was unemployed. He had been made redundant one month prior to the diagnosis of his son's illness, from a firm for

whom he had work for many years. He did not actively seek work. He attributed this inactivity to his child's illness. This was partly because of his changed views of the importance of work and partly because of the demands of the treatment. He spent time with his son in hospital and often took him to out patient clinics as this involved a very long drive. He was not, however, much involved in the daily care of the child and had developed many commitments for voluntary work which took him away from home during the day, almost as a substitute for employment.

Attitudes of fathers

Most of the men in the sample saw their work life as having changed. One father saw work as being just the same as before, although he pointed out that he had many more domestic responsibilities in addition to those he had previously. A father whose work demanded very long hours, was resentful of some of the time which he was prevented from being with his child. Similarly, another father who made similar comments, said that there was a tension between the conflicting responsibilities of providing an income for the family and in providing direct care for his son. Three fathers spoke of spending less hours at work by various means in order to spend more time with their child and the family. Most of the men in the sample acknowledged that being at work provided an escape, or at least a respite, from some of the constant anxieties about their child's illness, allowing them to set aside their worries for a time. However, fears could not be wholly set aside and one father, in particular, noted that driving a taxi did not prevent him from having a great deal of time in which to think and reflect on the illness. He said,

Anything that takes your mind away from it is a help. But the type of job I have, it's quite easy for your mind to wander. (Case 12)

The "normality" of the return to work was tempered by the change men experienced in their feelings about their work, by a wish to spend time at home with the sick child and by pressures they experienced from the additional tasks related to the illness. In addition some fathers were very aware of the pressures placed on their wives who had the constant daily care, especially when a child was at home all the time. One or two fathers tried to assist by taking over when they came home from work in order to give their partner a break. One father who felt that "95%" of the burden of care fell on his wife, commented,

It's been an ill-divided responsibility, me having only a very small percentage of the day to day involvement. The burden being carried by my wife. P. and me have a day out on a Sunday.....or his Mum goes out herself and comes back looking refreshed. (Case 12)

He reflected that he would have found it "very difficult to handle" if the treatment tasks had fallen to him.

Attitudes of mothers

The picture for mothers of the children was a very different one. Their lives were much changed from before the illness. Six of the ten mothers were not in paid employment when their child became ill. Some of the attitudes to work were perhaps culturally determined: There had been an expectation that they would give up work when they had children and their expectations about an eventual return to work seemed to be towards different employment or a change in working hours or conditions which would enable them to continue to be the main carer for the child. These mothers were still at home with their children, as they had been prior to the illness. However the child care responsibilities were greatly changed. One or two of the mothers in the sample felt very burdened by their child's constant need for care and were quite critical of their partner's inability to give more time because of involvement in work. Two of the mothers in particular said they felt quite trapped by the situation and one spoke of the resentment she felt that her partner was "always working", rather than giving her support. She saw this as an indication that he did not care enough about her or the children.

The two mothers who had given up responsible and full time jobs to care for their child, said that they missed their work and kept in touch with former colleagues. They saw themselves, however, as having no choice in the matter, and indeed did not express any regret about their decisions. The fact that strong feelings about the loss of work were not expressed was perhaps surprising, but it might be that the full implication of the loss of the job were not fully realised at the time of the interviews. The well being of the child was of paramount importance. A mother who had taken a year's leave of absence from her job was reluctant to return to it, and, much in advance of the return date was planning to extend her absence further. The one mother who had returned to work did so for financial reasons but also saw her work as being important in itself. She saw it as being a great help to her both because the normality of it was reassuring, it provided an escape from her anxiety and because it provided an important degree of social support.

Major changes had therefore taken place for all parents in terms of their employment and their child care tasks. The purposes of work had been challenged and management of daily child care with its new treatment tasks was dominant in

their lives, especially of the mothers. The greater change occurred for mothers who had given up employment to care for their child when ill, which reinforced an already existing pattern, in this sample, that the mothers had given up or modified their work when they had children.

Parents' other activities

There was little opportunity for parents to maintain their leisure activities as work, home and hospital took most of their time. Some parents had clearly felt they had no time to consider such a matter. But others tried to continue some of the activities which had been part of their lives before their child's illness. The benefits of such activities were cited by several parents, especially in terms of the opportunities they gave to "escape" and to assist them to overcome feelings of stress by activity. These kinds of activities were taken up particularly by the mothers of the children. It was mothers who had most of the day to day care of the sick child. They had few opportunities to get away from the demands of the child and family.

Recommencing social activities was not without problems. One mother identified the concerns she had about going out socially to a pub; she worried about what others would think of her if she went out to enjoy herself while she had a child at home who was sick. Other mothers were more confident, however and several had begun to meet with friends once again outside of the home. One mother identified the great benefit to her of joining in a social group where others were not asking about her child and she could "just be myself". Another mother went to an exercise class, which demanded effort and concentration. This need to relinquish responsibility for the child from time to time was identified as important. It was seen as being helpful in dealing with intense stress which was being experienced and as a reassuring part of the activities of a "normal" life.

Some mothers took advantage of the frequent contact with the hospital to develop new social contacts with other parents they met there and with the exception of two or three, they had all made new friends. One mother spoke very positively about the benefits to be gained from her weekly trips to the hospital. Part of her new normal life included new social contacts with other parents whom she met in the out-patient clinic. These new friendships were clearly a major benefit to her. She said:

I like going to the clinic because you get to meet all the people you were in the ward with. ...I've got some of their phone numbers and that. S.

likes it because he's made all these friends in the hospital and he likes to go and play with all the other kids. (Case 19)

Turning attention to other problems

Another illustration of the way in which parents' lives were resuming an element of "normality" was the way in which problems which had been put on "hold" at the time of the diagnosis of the child's illness were now having to be faced. In the interviews several parents indicated that a range of difficulties had been set aside for consideration because of the problems of the illness, but now that the treatment was well underway some of these previous problems were beginning to be taken up again. Two parents, for example, who had quite serious financial difficulties were having to take these on board again, and deal with their creditors. Another parent who had been facing custody problems prior to the illness was now addressing this matter again. Another parent, a father, who had become unemployed, after many years of employment with the same company, had set this crisis aside during the illness and had not looked for new employment. At the time of my interview with him, he was now beginning to address the problem by making applications for other jobs.

In a few cases marital difficulties, which had existed prior to the illness, had also been set aside. Several parents either referred directly to the fact that there had been problems of this sort in the past, or more commonly they made comments which implied some difficulties. These issues were not discussed in any detail in the interview. I noted, however, that on occasions only one of the partners made any reference to the matter. On the other hand a couple who were living separately, both acknowledged these difficulties in the interview.

Tensions and dilemmas in redefining "normality"

A striking impression from many of the interviews (one which has been referred to above) was the importance that most parents attached to trying to achieve a sense of "normality" in their own lives, the life of the sick child and that of the family as a whole. For some, "normality" was still seen mainly in a pre-illness manifestation. Others seemed to have accepted more easily the new reality which they were facing. In some of these cases the adjustments required were possibly not so difficult as they were for others.

In reviewing the data presented in this chapter it was clear that the parents' search for "normality" contained a number of tensions. The parents did not say so directly, but their descriptions of the difficulties they were each facing can be understood in this way. The tensions included, for example, meeting the needs of the sick child and those of others in the family and balancing the individual parents' own needs for him or herself with that of meeting the needs of the child. In the following section, I discuss my interpretation of these tensions and others which the parents experienced.

Awareness of the contrast between the "old" and the "new" circumstances

Every parent in the sample held a number of contrasting pictures of their sick child; one was the appearance of the child before he or she was ill and the new appearance; the child's personality; the way he or she related to the parent before the onset of the illness and the way he or she was now; the activities enjoyed before the illness and now. Many of the children looked well and had resumed some of their day to day activities at the time of the interview. The pre-illness personality of the child had not been substantially changed. But life for the child was surrounded by the trappings of the illness—medication, hospital appointments and admissions, medical tests and a concentration, by adults around the child, on symptoms.

This experience of contrast was in itself upsetting for many parents, although some of them were possibly not aware of the distress it had caused them. An example, reported above, of a mother who contrasted her day to day life with that she described as a "glimpse" on one particular weekend of what life had been like before, is indicative of the way that several parents expressed their pain about the change in the child.

A particular dimension of the tension caused by the contrast between that of the previous life and the present one, is the contrast between the way parents presented themselves to other people and the private feelings they were experiencing. The majority of parents in the sample had managed to integrate new routines into their previous life style sufficiently to give the appearance of having achieved a new form of "normality" and one which was described by one parent as "feeling pretty normal". However, at the same time, it was clear that for all the parents much of life felt very different. Another example is that of a parent making the point by indicating that he lived in "two different worlds". He described life as

being "normal", in that he had resumed many of his former routines, but at the same time went on to comment that he had worries which were "constantly at the back of my mind", brought on by the reality he was living with that his child might never recover from the illness.

Making choices between competing priorities.

Many of the parents in the interviews indicated that there had been uncertainty about many of the decisions they were obliged to make. For example, whether and how to continue at work was an vital area of concern. Those who had made the decision to give up work, either permanently or temporarily, often regretted doing so, at least to some extent. Work had given them companionship and had brought satisfaction and all of this was now lost. Conversely, other parents who had returned to work also had regrets. One said, "Somebody's got to work. I just wish it was not me". (Case 12). It was not the same as it had been before for them. For some it seemed an irrelevant activity. Their heart was not in it. Some felt guilty that it kept them away from their children who required more of their time.

Within families, some allocation of responsibilities had changed, particularly when one parent, usually the mother, gave up most of her time to the sick child. In the main this did not present great tensions for the either partner. Some came to like the new activities that they had taken on. One father was surprised to find that he enjoyed the time he spent with his children. Another father was proud of being able to do all the cooking for the family. While some of the mothers, who undertook most of the treatment responsibilities for their child, felt very burdened by the work involved, they generally accepted this as being their responsibility in the family.

Living on a day to day basis

The adjustment that many parents had made to live their lives on a "day to day" basis and making little attempt to plan further ahead than, for example, a week at a time enabled many to retain a sense of having a degree of control over their lives. On the other hand, while this approach, was constructive in allowing them to deal with the "here and now", it brought other tensions. First, for those parents who adopted this approach and felt that it helped them, the "space" they gave themselves was in a sense unreal.

It was probably inaccurate of them to claim that they were living solely on a day to day basis. In reality it was essential for them to have a wider time perspective in

order to appreciate what was required in the child's treatment. In claiming to live on a day to day basis they were describing their wish to avoid considering the future. This helped them to contain their fears related to the outcome of the treatment and the future health of the child. There is, on the other hand, much reality in concentrating on day to day activities because there is so much work to do in participating in the care and treatment of the child and meeting other responsibilities. The daily round of activities therefore prevents the parent looking ahead. Despite a mechanism to achieve avoidance, the tensions of the situation remain.

The tensions involved in living on a day to day basis are also discussed in Chapter 9 when I consider the whole process of change.

Conclusion

My findings suggest that many of the activities in which the parents were involved were attempting to establish or to re-establish a normal pattern to their lives. I have called the general task that they appeared to be engaged "redefining normality" as many parents seemed to direct their behaviour at a norm which they themselves called "normality". This was a word which many parents used frequently in the interviews to try to explain some of their experiences. Seeking to find a degree of normality for themselves in their day to day routines seemed for many to be a very important dimension in the way that they coped with the illness.

At times "normality" was referred to in terms of being a goal towards which a parent might try to direct consciously much of their efforts. At other times, the words "normal" and "normality" were used as a way of describing the child's progress in treatment. Whatever way in which the term was used by the parent it was usually associated with reassurance and a sign that the personal upheaval that the parents and the whole family had experienced as a result of the child's illness was abating. The parent seemed to perceive the restoration of normality as being an indication that the child was going to recover.

"Normality" referred often to the parent's or family's life prior to the illness. When a parent used the word in the interviews to suggest that he or she, or the family, was now able to function, socially, closer to the way in which it had done prior to the illness, and that doing so brought much satisfaction, the clear impression was that the parent had sought to bring these circumstances about, and that in achieving it, the parent felt that he or she was being in control of events. This gave the parent

the sense of doing something positive in contrast to the relative powerlessness felt combating the symptoms of the illness.

This sense of achievement was felt positively also by those parents whose efforts were directed more at defining a "new normality" for themselves and one that was appropriate for the present circumstances. Instead of focusing so much on pre-illness habits and activities some parents appeared to be more willing and able to integrate some family routines, many of which had been temporarily set aside during the sudden onset of the illness, with new ones which took account the requirements of the present circumstances.

My finding that much of parent behaviour in coping with the child's illness is directed at, or clearly associated, with "redefining normality" for themselves and their families is one which has not been emphasised in many previous research studies. It is an aspect which is not addressed substantially in any of the coping measurement scales which some of the major studies have used. Chesler and Barbarin however found that the parents in their study (Chesler and Barbarin, 1987) attached importance to re-establishing family routines. They distinguished between two patterns, parents who actively tried to re-establish routines formed prior to the illness and parents who were able to integrate the requirements of the illness into what they call "a state of normalcy" (Chesler and Barbarin, 1987, p.226). The majority of families in their study followed the second pattern

My findings are very similar to theirs in terms of the different patterns that they found in the behaviour, but my data also show that parents have a notion of "normality" which they use also as a measure of progress for the child and, as I shall discuss later, for themselves in evaluating how effectively they are coping. My data also the strong sense of purpose that many parents had in pursuing the restoration of a set of circumstances with which they felt familiar.

Faulkner also emphasised the important part that a sense of normality restored to parents' lives but in contrast with Chesler and Barbarin's findings found that most parents in her study wanted "life to be normal" in its pre-illness sense. She found that the parents, especially mothers, reacted negatively when this was not achieved (Faulkner et al, 1995).

As I interviewed parents at a much earlier stage of the illness than either Faulkner or Chesler and Barbarin, possibly at a time when parents were still trying to work out for themselves how they should organise many of their responsibilities it was not

possible to say whether most would adopt a course of trying to retain previous routines or one which integrated the new aspects which the illness required. It was possible to conclude however is that "redefining normality" was a task which was a clear and current preoccupation for every parent. As such, whether it was as a goal or a measure, it was an important dimension of coping.

CHAPTER 6

MAINTAINING HOPE

Introduction

Despite the medical improvements of recent years, childhood cancer is still a major life threatening illness. Although the reality is that the majority of children make either a full or substantial recovery, both the risk of death or relapse in the course of the prolonged treatment weighs heavily on the parents. A key element in the parents' accounts was the importance that many of them attached to the need for themselves to maintain an attitude of confidence that their child would make a full recovery from the illness. A few of the parents were probably hopeful as a result of their personal disposition, but for the majority, however, the need to maintain a "hope" was associated with controlling fears that their child would die or at least be seriously damaged by the illness. A constant challenge for some of the parents was to try to maintain an equilibrium between sustaining "hope" and containing their worst fears.

"Hope" is one of the basic "rudiments of virtue" which is developed in early childhood (Erikson, 1964). In psychoanalytic theory it is associated with the quality of "trust" which a child acquires in its relationship with its first carer, usually the mother. Hope, however, is a quality which has a strong influence on "trust" but remains independent of it. "Trust" relies also on verification factors and is not so all-encompassing as hope. Erikson sees hope as being "the enduring belief in the attainability of fervent wishes in spite of dark urges and rages...". (pp. 118). He argues that hope is the most basic but the most lasting of all the individual virtues and in the mature adult it finds expression in a person having a strong faith or belief or in a person's determination, either in exercising strong will over others or in maintaining self-control. Erikson's theories have been very helpful in understanding the observations of parents which indicate the degree of hope that they were carrying.

In this chapter I will be describing some of the ways in which parents showed evidence of remaining hopeful and determined that their child would recover, and discussing the ways in which they associated "hope" with being "positive" about the illness and treatment. I will also discuss the pressures and problems they

experienced in doing so. It will be seen that the task of "maintaining hope" starts very soon after time that the diagnosis of cancer is made. This will be followed by an analysis of the dilemmas that the parents appeared to be experiencing.

Facing the medical reality of the child's illness

When the diagnosis was made, many parents had an immediate fear that their child would die. As I have indicated earlier, the medical reality is that while the illness of childhood cancer remains a life threatening one for most children, overall the majority of those who become ill are successfully treated. Some of those who do so may have long term physiological or psychological damage either from the illness itself or from the side effects of the treatment.

Everyone in my study reported that initially their main fear was that their child was going to die. The diagnosis was a major blow to all of them and for some it was catastrophic. They described their feelings vividly, using words like "shock", "outrage", "anger", "despair", "sadness", "helplessness", "hopelessness" and many others in a similar vein. In doing so they showed that their reactions were very similar to that reported in other studies of childhood cancer (for example, Chesler and Barbarin, 1987). The diagnosis in fact precipitated a major crisis in the lives of the parents and of the wider family. There were many illustrations of the severity of the impact of the diagnosis on the parents themselves.

One of the parents described himself as feeling violent after learning of his son's diagnosis. He explained that he had returned from the hospital when he heard the diagnosis and had punched his garage wall with his bare fist so hard that he produced a hole, because he was so angry and felt so helpless. He recalled also disturbed sleep patterns that he had around that time. On one occasion he had got up very early and walked out in the street. He was only aware of what he was doing when he realised that the sun was very warm on his back. It was summer, the dawn came very early and he realised that it was 3.30 in the morning. He was walking in the street in his pyjamas. He used the story to try to explain the "destruction" to his and his family's life which he felt his son's illness had brought. Other parents also expressed the devastation they felt in equally strong terms. Some examples of what they said were:

I went to pieces...it was the frustration, the helplessness. There was nothing I could do as an individual to put it right. It was just an invisible monster consuming him. (Case 12)

It was a nightmare. I don't have words to describe it. I was absolutely gutted. (Case 10)

I just broke down. I just couldn't accept that my wee girl who had been so healthy, might not make it....I couldn't accept it. I shut myself off. (Case 16)

Several parents referred to the shock and sense of unreality they felt initially, and in the first hours or days after they were told the diagnosis. One of the mothers said:

I think I was in a state of shock. When the Consultant told us, it was like she was speaking to somebody else. They're talking to you, but it's not about your wee girl. (Case 8)

The unexpectedness of the diagnosis was highlighted by a number of parents. One parent captured this feeling when she said:

It was far too quick. On the Monday he had a small rash...on the Wednesday it was leukaemia. It was that quick, I think we were just numb. Just zombies. I thought, "This can't be happening". (Case 9)

The fears of parents that the child would die, continued during the early hospitalisation stage and in some cases right up to the time of the interview. Other fears followed, such as whether other children in the family, or the parents themselves, would also be susceptible to the illness of cancer.

Parents were made aware by the doctors of the risks to the children that were posed by the various medical treatments. Medical staff had explained to them what was involved and the possible side effects and risks to the child's survival. One common danger which many of them had clearly recognised from medical staff was the high risks arising from chemotherapy treatment, that the child's immune system would be impaired. This would make the child more susceptible to both major and minor infections. Some of the more serious infections can be overwhelming and fatal. While the information had been helpful in many respects, it had also given a focal point for much of the parents' anxiety.

The purpose of adopting a hopeful attitude to illness.

The fact that "hope" can play a part in the way that a patient confronts the effects of an illness and can help recovery, is widely accepted by the medical profession. In my study most of the parents seemed to be in accordance with this viewpoint, inasmuch as there was evidence that they pursued maintaining their hopes in a

conscious way. Many of them said so. They differed mainly only in the time which elapsed before a more hopeful, positive approach was developed. Some parents began almost as soon as the diagnosis was made to engage in hopeful thoughts. For example, one of the fathers explained that his immediate response was to be positive that his daughter would recover:

When I was told she had cancer I knew she was going to make it. As soon as they said it, I was just firing questions. Tell me what we're going to do? What are her chances? (Case 15)

Another response, more typical of most of the parents indicated that it took them a short time to take in the news, but that after the shock, accompanied by pessimistic feelings, a rapid change was made to adopt a positive approach. The time scale of this varied considerably. One mother who had spoken of her initial numbness, said that she then became very angry and upset that her son should have the illness, and that this feeling gave way to a feeling of determination that he would get better. She said:

I was very angry. I thought, "This shouldn't happen". I cried and screamed and thumped the walls. Then I felt, "Right, you can't let this get you down. You have to fight it". (Case 9)

The parents gave several reasons for choosing to take a positive approach to their child's illness. These are discussed below.

"Being strong" for the child

One reason that many parents gave was that they required to have or to show that they were strong, because to do otherwise would have a dispiriting effect on their child. A large number of parents took the view that it was important for their child that they themselves remained calm and optimistic about the illness.

For a few parents this meant that although they privately feared the worst outcome, they had outwardly to give an appearance of optimism for sake of the child and other children in the family and often adult relatives. For example, one mother said:

You can't give in to it. This is for C., it isn't for us. You can't sit back and get depressed. We saw other parents doing that and you know the children get the vibes off their parents. I thought, "If we stay happy, C. will be happy". (Case 9)

Another parent commented:

We were quite positive. It's rubbed off on her. She's really quite good. If she had been in floods of tears all the time I don't think I would have coped as well. (Case 8)

There are a number of ways that this type of behaviour in parents could be interpreted. A hypothesis which I refer to in Chapter 1, that the parents' positive attitude is connected with the reaction he or she wishes to see in the child and which they can then interpret for themselves as a form of reassurance has been put forward recently (van Veldhuizen and Last, 1991). Although such an explanation remains somewhat speculative, many parents attached an importance for themselves and their child of either adopting or presenting a positive attitude that the child's treatment will be successful.

A few parents spoke of the importance of "staying strong" for others in the family, such as grandparents and other children in the family. One of the fathers commented on the importance for him of taking a calm approach for the benefit of his ill son, his daughter and his ex-wife. He said:

There were no tears. I felt I had to be strong for E.'s sake and for R. and J.'s sake. I tried not to show any feelings in the hospital. (Case 6)

Some of these parents in fact were concerned constantly about the effect that any deterioration in the child's health could have on relatives, particularly their own parents. They often selected the information they gave them, concealing some of the treatment dangers that the doctors had told them. Their reason for doing so was their belief that their relatives would become very upset.

Parents attempt to keep their own fears at bay

Some attributed the maintenance of hope for their child's future as having a purpose in itself in that it helped to keep their fears in check. One mother described her approach vividly making the point that she regularly reappraised the situation to remind herself of the positive features about the treatment of her very sick child. She was conscious of the fact that her main intention was to give herself reassurance. She explained that negative thoughts were unproductive as far as she was concerned. She spoke of the process she went through in developing a more positive way of looking at the prognosis for her son:

When I'm with P. I remain quite cheerful and with a lot of people I do as well. You've just got to be, you've just got to get on with it.....

I usually keep cheerful, but I have my moments...for example, a week ago, I was forever in tears and really depressed. Well, I would say "down" because I never see myself as being depressed....I'll say, "don't be so stupid, you mustn't have these negative thoughts". But you can't help it sometimes when your child has been so ill and you've been told the prognosis is only 50/50. Then I pull myself together and think, "well, 50% is better than 40% or 30%" and that keeps me going. (Case 7)

This example was fairly typical as other parents gave similar accounts of how they fought off their fears.

Ways of maintaining hope

The parents kept their optimistic and hopeful approach in a number of different ways. No one way was exclusive to any parent. For those parents who had a hopeful and optimistic approach to life, the process was clearly easier and they used a variety of sources to support their view. Where parents struggled to keep their fears at bay, reliance on support for their hopeful attitudes was very important and seemed to derive from a similar variety of sources used more extensively. Four ways which the parents used to maintain their hopes and keep fears at bay are now discussed.

Developing trust in medical staff

Their relationships with the hospital staff were seen as being vitally important by all parents. They appreciated that their child needed specialised treatment but the nature of the illness and what the treatment involved was difficult to comprehend. Even those parents who had some prior knowledge of medical matters found that the complexity of cancer treatment was not easily understood. A great deal of information about the illness, the treatment procedures and about the progress of their own child through the treatment had therefore to be taken on trust. Most parents commented positively about the treatment they had received from various hospital staffs, but a number of parents referred to particular incidents which had occurred while their child was in the hospital ward which had annoyed them or shaken their confidence in the treatment their child received. An overall confidence in the hospital as an institution was very important.

Many parents commented on the crucial importance of having good relationships with medical staff. Parents who were able to place their confidence in medical staff and particularly in senior medical staff, were able to take full account of any

reassuring news that they were given and this gave them encouragement. One father, for example, spoke of his reliance on the statistical chance of recovery which had been given to him by the consultant. He said:

It was just dead shocking, being told. I couldn't handle it at the start. The Consultant reassured us quite well that C. had a good chance because circumstances were in her favourand her chances were 90/95%. I just held on to it, I still do have to hold on to that 90/95% chance because that made me feel 100 times better.....I think that's nine out of ten, so that's only one out ten (who don't make it) and that's God saying "it's not going to be her". (Case 13)

Sometimes the parent's trust focused on a particular member of the medical team, usually a doctor they had met in the early stages, and for whom they had developed respect. A father, who had a strong faith in the doctor responsible for his child's care said:

I was pretty confident because, like he (the Consultant surgeon) says, he didn't tell us there was a 100% chance of recovery, but you could tell by the way he spoke to you that R. had a good chance. (Case 2)

Another parent placed high confidence, and almost blind faith, in the good outcome of a surgical procedure because a particular junior doctor was present in the operating room with her baby. She said:

I knew he was going to come through it OK because Dr. A. was in there with him. I trusted the surgeon implicitly but the fact that she was there too....I thought "I know she won't let them do anything really horrible to R. and she'll be there if anything happens". That's just faith in people you've got to have I think. (Case 1)

A mother who placed all her hope and faith in the Consultant Paediatrician, recognised that this was quite a burden for the doctor concerned. She said that she believed everything the doctor said and therefore took comfort from all the positive aspects of information given to her which she found to be a great source of support. She said about her reliance on this doctor:

To have somebody putting all their faith in you... that's a lot to have on your shoulders. But she never tries to fob you off with anything or tell you lies. (Case 11)

One of the parents in the sample, in describing the way in which she "shared" responsibility for her child's care with the doctor in charge of his treatment, perceived herself as being responsible for the child's care and the doctor as being responsible for his treatment. She therefore did not get involved in acquiring a

detailed knowledge of the illness and treatment, but relied on the doctor for this matter. This particular parent did in fact seem to have a reasonable knowledge of medical details, but had also appreciated that at certain points in the illness it was more constructive for her to conserve her energy and direct it towards the constant care her child needed, leaving treatment concerns to the doctor.

Not all the parents placed their trust in the medical treatment team. Some parents had difficulty in developing trusting relationships. One mother, who was depressed at the time of the interview, seemed to have little hope about her daughter's condition although the prognosis was a good one. She described the difficulty she had in believing what was said to her which would have been interpreted as being "good news" by some other parents. Another parent, a father, said he had no confidence in doctors. His daughter had been ill for some months, and although she had medical treatment including surgery, a diagnosis of cancer was not made quickly. This father's lack of trust had been confirmed by the delay in his daughter's diagnosis and he continued to distrust the new medical team treating her.

The child's response to treatment.

A very important element which reinforced a parent's optimistic attitude to the illness was the response of the child. There were two elements in the child's response, one emotional, the other physical. One was the way in which the child him or herself approached the illness and treatment procedures. Parents took pride in their child's achievements and some felt that where the child was being brave, they would respond by taking a positive and hopeful approach. One mother, for example, reported that her daughter had been physically quite well and had taken easily to life in hospital ward, including engaging the nursing staff in playing games. She said:

There was another wee boy who was sick everywhere. C. was never sick with any of the treatment, which helped. And C. was exceptional - they all said so - in the way she coped with it. She's a real chatterbox...would sit in the nurses office and pretend to write up the notes..... (Case 8)

Secondly, the child's physical response to the treatment was a crucial factor in the hope that many parents maintained. A mother, who had been clinically depressed at the outset and even at the time of the interview presented as still having many features of depression, and whose daughter had a poor prognosis, was nevertheless

able to take satisfaction from the hope provided by small improvements in her little girl's health. She explained:

We have little things that will give us a lot of hope, like we only realised yesterday that A (my daughter) has grown 6 cm. in two months. That gives you a tremendous lift. And her feet have grown. She's up to the next size in shoes. That gives you hope. (Case 16)

However the difficulty in being positive about the outcome of the treatment and the ever present danger of being overwhelmed by fears are illustrated by a comment by the same mother who talked about her worries when times for medical tests drew near. She said:

When the time for the scan is coming up I get very very worried. The fear that the tumour may be reacting and worrying what is going to happen. In some ways you're looking forward to it because you want to know that nothing is going on, but you've always got in the back of your mind that she could relapse. (Case 16)

For some parents, their hope was derived from a faith in the efficacy of the treatment. A father (6) had read extensively about the illness and treatment, and had persistently asked questions until his good working knowledge of the illness which he had acquired helped him to become convinced that there was a hopeful prognosis for his son. Another father who also placed a high importance on good information about the illness and its likely progress, said about his daughter's leukaemia:

We've had so many talks with staff in the hospital and now we know its curable. I would advise other parents not to be scared of it....You see other parents coming in and out (of the ward) and you try to reassure them a bit, because we're further down the line and we know more about it. (Case 13)

Similarly, a father whose little boy's diagnosis of leukaemia had been made at an early stage felt that this was very optimistic for the future. He said:

So in a way C. is really lucky. We reckon they caught it as quick as they possibly could...I mean it's still a major illness, but it's curable. (Case 10)

Attitude parents adopted towards the illness

A few parents saw a task of channelling their efforts into a fight against the illness. They took a forceful approach. One mother described her reaction as follows:

I'm a very practical person. I got over the initial shock and then just got down to practicalities and said, "Right lets get on with this. We're going to fight this together and we're going to beat this together". (Case 7)

Many other parents were less assertive but regarded this positive view of their child's future as being something to aspire to for the benefit of their child and themselves. A parent, for example, discussed his determination to take a positive approach to his daughter's illness. He rejected the idea that she might die, saying:

I'm not blotting it out. It's happened. But I have to think positively. I can't think negatively that it's going to happen to her. If I had to do that I'd be totally away. (Case 13)

Similarly, other parents expressed very positive attitudes which they adopted towards their child's illness, for example, one mother described the way she and her husband persuaded themselves into thinking positively . She reported:

We said to each other, "This illness can't get us down. It can be treated. Don't get depressed about it". (Case 9)

She developed this further in reporting how she and her husband had approached a difficult time when their child had been admitted to the hospital. She said:

I wouldn't say we get low or depressed about it. When C. was in the hospital with a high temperature, we just carried on and thought "this is a hard time", but we knew there were bad weeks so we thought "well this is it happening now, next week we'll be fine. We've got a bad week this week, next week we'll have a good week". (Case 9)

Finding ways of setting aside fears was a task which several parents commented on. One parent, for example, described clearly the way in which she did this. Her son had a poor prognosis and the future was very uncertain for him. He had taken severe adverse reactions to the several of the chemotherapy treatments, so there had been many periods of sudden acute illness:

I just think to myself, "He's going to be OK tomorrow". I do, I live with a sort of positive thinking. I tend to treat it like a cold that's not going to go away for a while and I don't let the seriousness get to me too much. I just sort of think, "Well you know your cold isn't going to go away if you don't take your medication" and I just cope with it like that. I don't think about the seriousness. I know about it but I don't think about it. I just take every day as it comes and think (when he's really ill and lying in the hospital), "Well, another day and he's going to get better" and nine times out of ten that's what happens. (Case 4)

Similarly another parent set aside his fears for his child, who had a very poor prognosis, but did so in a quite different way. He explained that he knew his daughter's prognosis was poor and that a thirty per cent chance of her survival had been given by her doctor, but he refused to contemplate the possibility of the failure of the treatment to cure her. He said:

I just believed she would be one of the thirty. You know, it's like the Pools, somebody's got to win. (Case 15)

He pointed out that when the situation clarified and her prognosis subsequently improved, the positive approach which he had adopted for himself was strengthened. This father also reported that he had thought frequently about the fact that his child might die and he had considered all the details of her funeral. He was well aware of the problems she faced, but set aside fears and chose to concentrate on the positive aspects.

A few parents spoke of the way in which they avoided situations which they had discovered could shake their hopeful attitudes and which might reinforce their fears. One parent, for example, indicated that she tended to avoid the company of other parents, because hearing about their situations was distressing to her and diverted her from the positive approach she had adopted. She talked to other parents in the hospital ward on occasion, but she clearly had reservations on the matter. She said:

People say it helps to talk to people in the same position, but I don't know if it helps or hinders. I think it can upset you more....I tend to be kind of different. Others like to talk. I say "I don't want to hear" and I walk away. Then I think, "Am I being too unfriendly?" They're wanting to tell somebody but I'm not the person you should be telling. (Case 4)

Another mother took a similar approach to contacts with other parents in the hospital ward. She found it unhelpful to be diverted from her son's own illness and contrasted her approach with some of the other parents. She said:

Other parents who were in the ward were getting all involved with the nurses and chatting away and we just walked off. We just concentrated 100% on C. and ourselves..... You could sit and talk to other parents and you could get quite depressed. You could say "Oh we've had a bad day" and get deeper and deeper into depression. (Case 9)

Some of the attitudes of parents can be better described as being characterised more by "acceptance" than either hope or denial of the illness. They took the view that what was necessary was to "get on with it" and not question too much or give too

much thought to the outcome. A young mother who had expressed many fears about her son, spoke of a positive outcome of the illness. She said:

For me, the most positive thing has been analysing how short life is and there's not point in sitting back and thinking that this might happen or that might happen.....The bottom line is you have to get on with it and do it and you will. As simple as that. No matter how much you don't want to or how scared or upset you are, you just will do it, if you have to.
(Case 5)

In a similar way, a father of a 12 year old girl who reported that, having been devastated by the news of her illness, on the next day he decided:

.....that most important thing was to get her in (to the hospital), to get her treated, to get her better and it's working so far. (Case 18)

In their different ways all the parents saw the maintaining of hope as being a very important way of handling their child's illness. A few adopted this approach readily and maintained the balance between their hope and their fears with little apparent difficulty. A degree of denial may exist for these parents. At the other end of the range of responses there were two or three parents who were not hopeful about the outcome of the illness and depressed, but these parents too saw maintenance of hope as being a desirable objective. For most parents a struggle to maintain a balance was evident and this involved a number of dilemmas for them.

Religious faith

Few parents made any comments in the interviews about their religious faith, irrespective of whether they had any religious beliefs or whether the illness had affected these beliefs. Two parents however discussed the negative impact which their child's illness had on the beliefs which they had held. One said that she would not now return to church attendance and another, angrily denounced "any god" which would allow such an illness to happen. In contrast, a mother said she had begun to attend spiritualist meetings with one of her family members and had found that this helped her to feel calm and optimistic about her child's future. Parents' views were not specifically sought and others made no comment at all about this issue. It would be wrong therefore to draw any major conclusions.

Dilemmas for parents in maintaining a balance between hopes and fears

Any task which has a large balancing element involves tension. As I have discussed above, maintaining a positive and hopeful approach by the parents was often accompanied by a desire to keep personal fears at bay. The fact that many of the parents had some awareness that they were adopting a positive and hopeful attitude, either from their own natural disposition or to inspire confidence in their child, gave them a sense of purpose. One parent, for example, described an incident in which he could not sleep for worry. He sought reassurance in the middle of the night by re-reading information about the illness which supported the idea that the child's chances of recovery were good. Other parents had other ways of keeping hope alive. The parents did not express directly a recognition that maintaining their hope for their child created dilemmas for them, but the data strongly indicates that this was the case. I have drawn from parents' comments some of the tensions and dilemmas involved and which are discussed below.

Keeping an accurate grasp of reality

A dilemma for parents throughout the illness was in maintaining a balance between a sense of hope and accepting the knowledge and dangers of the illness and the treatment. If their strong sense of hope concealed the dangers they would not be able to make an effective contribution to the treatment which often required them to be alert to changes in symptoms and to be able to respond quickly. This problem was particularly acute when the child was at home and when the parent was the main monitor of the treatment. One parent mentioned an incident when she had been criticised by medical staff for delaying bringing the child into the hospital when he had developed an infection. Her desire to minimise the implications of the symptoms had conflicted with the clear instructions that she had been given by the hospital.

On the other hand, other parents were more pessimistic. One mother, who was depressed at the time of the interview, seemed to have little hope about her daughter's condition even though the prognosis was a good one. She said:

They're (doctors) saying "your daughter is not going to die". But they can't guarantee to cure her, although they say the tumour is away, they also say on the other hand, with Hodgkin's disease, she's growing and lymph glands are growing as well. I think it could come back you know.

While the information that the tumour was shrinking could be interpreted as being "good news", in describing the situation in this way this parent showed the difficulty she had in believing the information which had been given to her or in deriving any hope from it.

Keeping hope against constant pressures

An approach which many parents exhibited, sometimes consciously, was always to be positive and at times "cheerful" in the presence of the sick child. Several parents said so, some indicating that this was their way of showing the child that they were "strong" and had no fears about the illness. This type of behaviour has been observed by other researchers (Kupst and Schulman, 1982). Whether this was done consciously or not, it reflects the pressure the parent feels to behave in particular ways in front of their child, either presenting a different image or more commonly concealing their real fears.

Meeting the expectations of others

The problem parents faced was compounded by the social context in which they had to maintain the equilibrium. Many of their neighbours, friends and relatives gave them messages of reassurance and in turn wanted to be reassured by the parents. In responding to them the parent was informed by the information about the treatment and progress which had been given to them by the medical staff. Despite the new knowledge of the illness and treatment which the parents had gained, it was not easy for them to explain to others the complexities of the situation they were dealing with. It was a situation beyond the experience of their families and friends. This made for difficulties in other people having a full understanding and gave rise to some unhelpful comments being made. For example, the parents indicated that they found "over positive" views by others, and also "over negative" views, as both being unhelpful to them, and yet they were obliged to respond.

In addition the feelings of distress that the wider family and friends experienced in relation to the child's illness led to their giving an emotional response which brought difficulties to some of the parents. They felt that they themselves had to "counsel" relatives who were upset by the child's illness.

A few parents were overwhelmed by their fears

When fears gained too much of a hold and blocked out optimism the parent became incapacitated and could not operate effectively. One parent, a mother, had in effect taken herself out of some important aspects of the treatment process and left this to her husband. She was unable to take her daughter for some treatment procedures and felt distressed that she could not do this. She felt she was failing her child.

Another mother (11) described the struggle to be hopeful about her son:

I can't imagine life without him. I've tried to but it doesn't bear thinking about. I just can't lose him. He *has* to live. I know that I see it like that and I wouldn't have any say in the matter if anything happened, but I have to believe he's going to live. (Case 11)

The struggle to keep fears about their child's illness at bay was a difficult one. One father who was frightened by his son's illness described the way in which he felt differently from day to day and how he behaved when feeling really worried. He said:

It's always on your mind, always there, niggling away at you. Some days are great and it doesn't bother you, but other days you think "Thank God he still here at the moment but for how long?".....If I'm feeling bad about it I find that I'll go upstairs and lie on my bed and close my mind and hope to fall asleep and that's the only way I can cope. (Case 6)

All parents had experienced some times when their fears were hard to keep at bay and could threaten the equilibrium which they were striving to achieve.

Conclusion

As Erikson has shown, a parent's ability to hope is associated with personality characteristics that are formed at an early stage in life. In the mature adult, hope is an emotion often associated with high self-esteem and confidence, and sometimes with the psychological defence of "denial", an unconscious mechanism which an individual uses to avoid unpleasant emotions. For many parents, the feeling of hope which they maintained, seemed clearly to be associated in some way with their fear that their child would die as a result of the illness. Despite the medical reality which parents learned early in the illness that a large majority of the children now survive, every parent carries the fear, that whatever the prognosis, their child will be one of the exceptions.

Almost all the parents in the study were positive and optimistic in their general approach to the illness and everyone maintained the hope that their child would survive. Even at times when there was little progress to be seen in the child or at times when there was some deterioration, most parents wanted to be "strong". Many wanted to do so for the sake of their child, believing that by doing so they could transmit in some way a strength to the child to fight back at the illness. Many parents indicated also that they would advise other parents in a similar situation that it was important to be determined to be optimistic throughout the course of the illness and never to give up.

It was not easy to differentiate between expressions of wishing to be genuinely "strong" and those which meant "appearing to be strong". As my data showed, the cheerful or bland expressions which some parents showed to the outside world belied their true feelings and the pain that many experienced.

I have called this theme "maintaining hope" to reflect the importance that all the parents attached to being positive about the illness and the eventual outcome. I have concluded on the basis of my data that "maintaining hope" is a principal dimension of coping for a parent of a child with cancer. It is an attitude of mind which reflects the parents strong wishes, and is an emotion which parents in my study clearly perceived as being associated with their motivation to help the child to fight the illness. The impression I formed, that many parents thought it was important to be optimistic, is one which Chesler and Barbarin share. They found that "optimism" was as one of the coping strategies which many parents adopt (Chesler and Barbarin, 1987, p. 94). My finding also fits well with van Veldhuizen and Last's interesting hypothesis that parents and child mutually reinforce each others' hope and optimism in order to defend each other from pain (van Veldhuizen and Last, 1991).

"Maintaining hope" also helped parents to contain much of the anxiety that they experienced frequently throughout the child's illness. It enabled them to mobilise their personal resources and "prepare for fight" (Greenacre, 1953, p. 35). It also helped them to endure the periods in which their mood was depressed. Two parents were clinically depressed for part of the illness, but the more common pattern was that a parent experienced feelings of depression periodically, and sometimes these occurred out of the blue. At these times, their sense of optimism had gone into abeyance temporarily, but later returned to give them a renewed determination to cope with the illness. These changes of feeling which most parents

experienced contributed to the variable picture which the process of coping involved and which will be explored in more detail in Chapter 11.

CHAPTER 7

NEGOTIATING SOCIAL SUPPORT

Introduction

One factor commonly believed to be associated with an individual's capacity to cope with adversity is the social support received from family, friends and others and professional helpers. As my literature review shows, the research studies on how social support helps parents to cope with the illness confirms the argument that social support is of considerable benefit, but the variation in the way the term is defined and measured has limited an understanding of what processes are involved. It was important in this study therefore to examine each parent's perceptions of the help they received and their views of the effectiveness of such help, with a view to determining the relevance of social support to coping.

It has already been noted that the child's diagnosis of cancer brought the family up against a traumatic situation which was well outside their previous experience. Most of them did not initially have much understanding of the implications of the illness and what treatment would involve. The illness itself brought the parents into contact with a "new world", which included specialist professional staff in oncology and haematology as well as the parents of other children with cancer and an environment in which "illness", as opposed to "health", was dominant. Members of the professional staff, such as social workers, had specific responsibilities for helping parents and the family as a whole and, where required, for arranging practical and personal help to be provided for them.

In addition to formal provision of help there were a host of family, neighbours, friends and colleagues, many of whom came forward to express their concern and sometimes to offer practical help.

This chapter will be concerned with how parents seek and use social support during their child's illness. I will be examining the different sources of help that they mentioned in the interviews and the tensions and difficulties they associated with them. The timing, source or type of support will be seen to be critical to the way they were able to cope.

For the purpose of this study, I will categorise the types of help they received as being either "practical" or "emotional". The advantage is that these are separate

categories, although closely interrelated in a number of respects in terms of delivery. Some research studies have adopted a more complex categorisation of the different forms of social support (for example, Chesler and Barbarin, 1985 and Affleck et al, 1991). Such distinctions are not relevant for this study and in any event can be artificial, as many forms of help, in my view, do not divide into succinct categories. The advantage of adopting a broad distinction between the two dimensions "emotional" and "practical" support is that it should help to focus on the value that parents attach to the different forms of support they received.

Types of support

The parents interviewed showed that a wide range of support was provided by family, friends, obliging employers, and neighbours as well as services being provided to the families from the hospital and community. An impression was given that they were in general a well supported group. That the majority of parents were in two parent families was in itself important – a point which will be discussed later. More than half the sample had extended family who were able to provide help and only a few of the parents were isolated people with limited social contacts.

The parents had contact with a wide range of services, some from the hospital and some from community sources, such as family doctors and community nurses. While the services given primarily focused on the child who was ill, it was clear that the way in which services were delivered was also directed towards the parents, a point which was readily acknowledged by many parents.

Practical help

The sudden onset of the illness and the seriousness of it, in themselves caused many practical problems for the parents. An immediate problem for many was the need to take time away from work. Virtually all the mothers in this study were either at home with children or gave up their employment when the illness was diagnosed. At the time of the interviews, only one mother had returned to employment. All the fathers except one, were in employment at the time of diagnosis and returned to work after varying periods of time. Most employers seemed to be sympathetic and to allow quite long periods of absence. The practical support that employers gave was by being sympathetic to the situation and showing flexibility in allowing parents to take time away from work. Fathers who were self employed had greater

difficulties. The contribution made by employers was indicated by many parents as being a positive factor in their situation.

While the child with cancer was in the hospital, some parents, mostly mothers, lived with their children in the hospital for this period. The care of other children had to be provided by others and these arrangements continued to pose a problem for a number of parents with the frequent visits to the hospital for out patient treatment. Care of other children was for most parents provided by extended family and friends.

Many of the parents reported having help with the transport for the repeated journeys to and from the hospital. Again, support with this was acknowledged by most parents as being important. All the children had a periods of treatment in the hospital and frequent visits to the hospital. This put an immediate strain on parents who divided their time between home and hospital. Many parents travelled daily from home to the hospital for several weeks. Distance of their home from the hospital was therefore a major issue for some families, as was availability of a car. Assistance with these arrangements was given by family and friends, and help with the costs incurred was, for some parents, provided by charitable sources.

The additional costs of having a child in hospital became a problem for a few parents within a short time. They needed financial help. Few parents commented about financial help they had received. A decision had been taken prior to the interviews that direct questions about financial help would not be asked in case this was seen by parents as being too intrusive. It was known that parents had access to financial help from the Malcolm Sargent Cancer Fund for Children and some may have made application to this and other charitable funds. Few parents raised finance as being a major problem, but a minority of parents indicated that their financial concerns were an important problem which they had to face.

Another form of practical help which a few parents reported, was being able to take a short holiday which enabled them to relax and spend some time together as a family. It provided an opportunity to "forget" some of the worries, a chance for parents to talk to and support one another and for tensions to be reduced.

In general, parents spoke positively about the value of practical help. One parent, a mother spoke of the ways in which she felt people could best help. She emphasised the importance of day to day practical activities which were difficult to continue while her child had been repeatedly travelling to and from the hospital. She said:

You need physical help. Someone coming and sitting and saying, 'That's a shame,' that's no good. You need someone to say, "Where's the washing, let me do the ironing, or I've got a meal ready for you".(Case 16)

Emotional support

Inasmuch as emotional support can be separated from practical support, it can be understood as being sympathy or empathy shown in a constructive way, either with or without a practical service accompanying it.

An important way in which parents reported that this was experienced was in sharing feelings and concerns with others who had similar experiences. In the first instance this was, for about half the sample, the individual parent's own partner. Some parents found that this sharing of concerns was achieved by talking with the parents of other children with cancer.

Another way in which parents felt supported emotionally was by talking with someone who was concerned and would listen. Several parents spoke to their partners about their feelings and in a few situations this was reciprocated. For many parents, however, the people they chose to talk to about their feelings were other family members, friends and in some instances professional staff. More than half the parents found talking to someone was of great value to them. One parent said:

I suppose what helps is being able to talk about it. I think if you bottle it up, that's when you actually....have problems. I talk to the social worker, to my friends and, eventually, I talked to my husband.
(Case 7)

One father spoke of his wish that he could talk to someone in this way. He contrasted his situation with that of his wife, seeing his lack of anyone to talk to as being a consequence of being a father. He said:

(My wife) can go out and speak to her pals. I could no more do that with my friends than fly a kite, you know, which is a shame. That's the difference with men. You're not expected to break down. (Case 17)

Not everyone found talking a helpful way of dealing with their feelings. On the contrary, several parents said it was unhelpful for them. Two parents in particular referred to keeping their feelings "bottled up". One of them, said that he thought that it was "better to keep things bottled up". (Case 2). He described this as being

his preferred way of coping. He was quite clear that bringing out feelings into the open merely made matters worse for him. Another parent also spoke of keeping feelings bottled up, but recognised that while talking about feelings might be helpful, it was difficult for her. In referring to her tendency to keep her feelings to herself, she said:

I'm not very good about speaking to people about how I feel, so I tend to keep it bottled up inside me. (Case 8)

In working with parents, professionals clearly need to be sensitive to such ways of coping and allow parents to maintain their preferred coping style where it is effective for them, even when this seems to go against commonly held professional views that open discussion is best.

Many parents found it very helpful when people were showing concern for their child and the family as a whole. Parents who had many people telephoning them to enquire about their child's progress found that, although this could be hard work to answer the calls, on balance it was helpful to them. For example a mother commented about the interest and concern of her wider family:

My aunties, they've always been phoning and everyone's so good about him. And it's always nice to know they've been asking about him. (Case 9)

A number of parents obtained support from knowing that particular relatives and friends, could be relied upon to be available to them whenever needed. Sometimes this need was for practical help, for example to give them a lift to the hospital or to look after a child, and sometimes the need was for someone to talk to. The fact that the person was always "there" when needed was crucial. One of the parents emphasised this in describing the ready availability of her parents said:

They're the only ones we could really rely on and be sure of help. My Dad works and he needs his job, but he says "If you need me I'll be there". (Case 4)

Link between practical help and emotional support

As has already been indicated, it is not easy in practice to separate the different kinds of help which parents received; parents themselves did not distinguish between different kinds of help and support. There was considerable overlapping in the purpose of the support and the perceived usefulness of it. For example, support whose primary purpose was the provision of a practical service to meet a particular

problem, might also have had the effect of providing emotional help. Thus a neighbour who gave a parent a lift to the hospital also demonstrated concern and a willingness to listen. The interrelationship between different forms of social support was complex.

The manner of delivery of support could be of great importance. Practical help given with a demonstration of concern and care had an additional value. Practical support often provided an opportunity to give emotional support and also made it easier to accept. This will be discussed further later in the chapter.

A parent for whom a charitable organisation gave a holiday saw the holiday in terms of the opportunity it gave to himself and his wife to talk to one another and to resolve some of the strains which they had been having in their marriage. He said,

It was a great relaxation. It took the edge off everything and allowed us to be people again. (Case 10)

Another parent commented about a similar holiday:

We went on holiday to the house in Prestwick (Malcolm Sargent holiday house) and spending a week together as a family meant we started talking and got a whole lot of things sorted out. (Case 7)

Similarly a mother whose husband's elderly relatives occasionally stayed with her ill child overnight was helped by the break which enabled her and her husband to have some time together. Another parent described the positive effects of a similar arrangement which gave the couple an opportunity to spend time together without their child. She said:

I have a friend who has P. for me occasionally to stay overnight, so my husband and I can go out or just be the two of us, so that's been good. (Case 7)

The provision of financial help could also be emotionally supportive. One parent commented on the way in which a club he belonged to had assisted him by giving him money. He saw this as a caring gesture. he said:

The club have been good...When I was there he quietly passed over a cheque....it's not the first... they've been superb. That's where I get my support basically. (My wife) has had her family and some friends but men are not supposed to cry into their beer and open up emotionally to other men, because I think they can't handle it. Even close friends, they just say, "How's C.?" And that's all they want to know. (Case 17)

Main sources of support

Most parents had a network of family and social contacts, all of whom were affected by the diagnosis of cancer in the particular child. These included the siblings of the ill child, grandparents and other family members, friends of the family, neighbours, school, work colleagues and so on.

In addition parents made many new contacts in the hospital. These included professional staff who provided assistance in various ways beyond the immediate care and treatment of the child. Parents also met parents of other children who were ill, including the parents of other children with cancer. The hospital provided a wide network of new contacts, both professional and social.

Family support

Family members provided a wide variety of help and were of major importance as a source of support for most of the parents. Immediate family was their first port of call when they needed help. The diagnosis of cancer in the child had a major impact on the whole family, including grandparents of the child and other relatives. The shock of the diagnosis affected the way in which help was offered. In some situations it resulted in a great deal of help being offered immediately to the parents of the child. In some families, pre-existing relationships were changed by the illness.

The kind of help given by family members was very varied and included care of other children in the family, visits to child and parents in the hospital, transport to the hospital, holidays and, importantly, a great deal of emotional support.

The majority of parents in the sample reported that their own parents, brother and sisters immediately offered help when they learned of the illness. One parent described the way in which she arranged visitors to the hospital who assisted in keeping her little boy occupied and distracted from the treatment. She had a rota of relatives organised which relieved her of some of the pressure to be with him constantly. She said:

My Mum and Dad helped. J.'s Mum and Dad helped. Everybody got together emotionally, I think.He had attention from J.'s mother in the morning, I went in at lunch time, my Mum came in the afternoon. He had attention 12 hours a day in the cot in the room because he couldn't come out of it. He needed the constant attention.
(Case 9)

A mother who was expecting a baby when her son was diagnosed reported she received much help from her own mother and sisters. After the new baby was born, one of her sisters took over the care of the baby so that the mother could be with her son in hospital when he had treatment. She said:

My family were really good. My sister... took G. (another son) My other sister took C. (new baby) when he was two weeks old, right through for the first couple of months. And H's (husband) mum she was good like. When my other sister had to go back to work, they took it in turns between them to watch the middle one. (Case 19)

The interrelationship between practical help provided and the emotional support given was very important. One parent spoke of the practical help given by her parents and the importance of this to her on an emotional as well as a practical way. She said:

It's my Mum and Dad who do most of the running about for us. It's got to the stage where if they're doing anything socially, they'll phone up and say, "We're going such and such a place, is it OK?" They've been brilliant...They're the ones we really rely on. (Case 4)

There were some parents in the sample whose own parents and other relatives lived at a distance and who could not offer any day to day help. Several parents reported that contact with close relatives by telephone could be helpful when direct contact was not available to them. One parent commented on her contacts with her sister by telephone, which were important to her in the absence of any other family. She said:

My sister phones regular. She stays up in (the north of Scotland). My other sister...I seldom see her. But yes, she phones and if I need someone to talk to I can phone. Other than that there's no family. (Case 11)

The relationships within the families in the sample were very varied. It was clear that for some parents, the pre-existing relationships with their family members were changed by the diagnosis of their child's illness. For some parents, relationships were brought closer than they had been before the illness. In two situations in particular, rifts which had existed were healed by the new situation. One couple who had been estranged from the father's own mother for several years found that the shock of the diagnosis caused her to set aside the feelings which had caused the rift and make contact in a helpful way. This was seen very positively by the parents, one of whom said:

We hadn't spoken to J's Mum for five years, and she came round to see us on hearing the news. So that was nice. She's been really great. (Case 9)

Many parents valued family help even when only a little could be offered. One parent commented on the support he felt from help given by relatives who provided transport for parents from their home to the hospital:

We don't have a lot of family. My wife's family are in the south of England. I've only a brother who I see only occasionally. Two aunts have been very supportive with a car....Having them there is just a wee emotional buffer. (Case 12)

The importance of the emotional support which family members gave was emphasised by some parents. The form which this support took was sometimes rather intangible. For example one parents expressed the feelings which were apparent in the responses of a number of parents that they could be relied upon in just "being there" was of enormous importance.

In contrast a few parents were disappointed that their families were not able to help. One parent reported with some bitterness that he had brother, who lived a "few minutes away". He said that the brother "could have lived hours away, for all the practical help he has given". (Case 3) One father reflected on the help he felt he needed but had not received from his mother and sister, contrasting this rather sadly with the amount of help he saw others in the hospital receiving from their relatives. He said:

If we'd had somewhere to put him (other son)...like if my sister or my mum had just taken him when R. was in the hospital. That would have helped. You see a lot of grandparents looking after other kids in the hospital.... (Case 2)

The support from close family, in particular, was quite often not unconditional. In many case parents had to develop a counselling role for members of their own family, especially their own parents, when they conveyed to them details of the child's medical progress. For many this was a major tension which is described later.

Support from friends

Most parents valued the help and support they had received from their friends. There was more varied experience among parents because some had a wide circle of

friends to turn to, some had very close friendships which became very important while other parents were rather isolated people who had few friends.

Many of the parents valued the support they received from friends as providing an opportunity to talk about the concerns they had. On the other hand, many parents saw their friends as providing an opportunity to get away from the preoccupation with the illness. So friends played a role in two different ways. One parent spoke of the contacts which she had with friends which were very important to her as a means of keeping in touch with previous activities and setting aside thoughts of the illness. She said:

There's a couple of friends from work. They keep me in touch with what's going on. We talk about things that are nothing to do with the hospital or the illness and that's great. It takes my mind off it. It's what I call my "sanity afternoon" once a week. (Case 7)

A number of parents felt that their friendships were tested out by the situation which the illness had created. A few parents were disappointed by the response of their friends especially when they realised that their friends had difficulty in understanding the illness and its implications. One of these parents said:

People don't realise it's just as serious now he's home (as it was when he was in the hospital). Nothing's changed. People are not jumping (to help) now. They think he's home so there's not the same importance. (Case 4)

Some parents thought that the illness made people unwilling to have too close a contact with them, and they were surprised, resentful or hurt by this. One parent said:

I've had a lot of friends that have helped and I've certainly found through this who are true friends. Some have stayed in touch with us. There's others (friends) that have just not bothered. They've dropped away completely.....You get the comment reported to you "I don't like to phone because it might upset them". (Case 7)

Hurt and disappointment was also felt when help was not offered by people who parents felt might have been expected to offer help. This situation was experienced by several parents. As one father poignantly put it, in relation to two examples of friends who had avoided him:

I think that somehow people think you're unapproachable and that you can't talk about anything but that (the child's illness), or they're scared if they bring it up you're going to burst into tears or have some adverse reaction. (Case 17)

The way in which contacts were made could be important. This same father said he found it helpful for friends to *offer* him the chance of participating in a social event rather than *assuming* that what they were offering would be helpful. He said:

One or two have taken this patronising sort of attitude, "Well you know it will get you out of the house andtake your mind off things".(Case 17)

Support from partners

Partners were considered by most parents who had them to be important. In fact some said that this was the most important helpful factor in the situation. Several of the parents said that the experience of their child's illness had brought them closer together emotionally. They felt they were "going through it together" and found this a great support. One of the parents who took this view said:

I think it's got us a wee bit closer you know. We always fight.....well like bickering, you know, but things seem so irrelevant now so you don't tend to bicker so much about them. (Case 4)

In contrast, the one parent in the sample who was a lone parent said that she thought that being on her own made the situation much harder for her. Some parents indicated that there was a strong sense of sharing of feelings without talking. One parent commented that sharing the experience with her partner was a great strength to her. She said:

I mean if he hadn't been there I don't think I would have got through it. He was obviously just as upset as me, but he was that much stronger.....I think it's just that we've both been down the same road and he's battered and abused (by the experience) the same as I am. (Case 5)

Most parents said that they talked together about the illness and treatment. It was clear, however, that the talking, while it brought a sense of shared concern, did not necessarily include talking about their feelings about the situation. The subject matter actually discussed was more frequently concerned with day to day events and problems.

One or two parents emphasised that talking to their partner about their *feelings* about the child's illness was important to them. On the other hand, one parent indicated that talking about feelings could bring its own problems. In sharing feelings of sadness and depression there was the risk of infecting the partner with these feelings in a detrimental way. This parents commented:

We don't really talk about it, like. He just goes to his work. At first, if I was greetin' he was strong for me and vice versa. But sometimes it didn't work like that. If I was greetin' H. would get upset too, and if he was upset, I'd get upset. So we just sort of split and he deals with it his way and I, my way. (Case 19)

In contrast to this view, two parents in particular said that they felt they depended on their partner's support. In one of these partnerships, both parents interviewed spoke of the way in which each partner reacted at different times and thus was able to support the other.

Individual parents reacted in various ways and had different ways of handling their emotional response. This difference in the kind of response to particular events and timing of particular emotional reactions was a problem for one or two couples. Their feelings were demonstrated in individual ways which did not reflect their partner's feelings. There were therefore strains experienced by some couples, which impeded their supporting one another.

One parent expressed this in terms of her overwhelming fears about the child and her need to focus entirely on him. This prevented her from accepting the support which her husband was offering. She said:

We're getting back together now, but at the beginning I couldn't be bothered with him. I wouldn't even let him put an arm round me or nothing. I said, "I'm not interested in you, you're nothing compared to my bairn". I shut him out. We didn't fall out - we just weren't the same people..... But you've got to get your life back... we were a happy couple, so we can't let it destroy that. (Case 19)

Another parent also indicated the anger she experienced when she believed that her husband, who did not show his concerns in an overt way, was not as worried as she was herself. She said:

The illness of a child either brings you together or pulls you apart. I think we were very much apart for a while. I felt I was doing all the worrying for two of us and he couldn't care less. But that wasn't so...he's just not good at expressing his feelings. (Case 7)

There were a number of examples in the study which indicated a difference between one partner and the other's reaction to the child's illness, the degree to which each was affected and their individual needs for support.

Support from other parents of children with cancer

Cancer in children is a relatively uncommon illness. Every parent in the study found that being a parent of a child with cancer was in itself an isolating experience, and one they felt that parents of other children without the illness could not appreciate. It was not easily shared with others "without a great deal of explanation". A number of parents expressed the view that "you can't understand what it's like unless you've experienced it".

This feeling of isolation was, for some, mitigated by sharing of experiences and developing a common bond with other parents of children with cancer. The majority of parents found the feeling of shared understanding with other parents to be helpful. They found it was a relief that they did not have to explain the complexities of the treatment procedures, the implications of the illness, the fears about the future. One parent expressed a view of many parents:

The biggest help I got from anybody was just actually being at the hospital with the other parents. We just talked about the behaviour, you know, just knowing that they felt the same. It's just feeling that you're not the only one and that somebody else is feeling it too. (Case 5)

While almost all parents recognised that other parents in a similar position had similar experiences, some did not want support from other parents, or pointed out the problems involved for them in seeking or receiving it. One parent spoke of her distress when a child whom she had got to know in the hospital, later died. She found it difficult to respond to the child's mother. She said:

It's quite nice to sit and talk to someone that's in the same sort of position. I'm not really one for talking, but I've got to know some of the families that have been there.....two or three of the children aren't there anymore and that really upsets me.It really upset me, that wee boy that died, because I shared a room with his mother in the parents' unit. She's written to me but I don't know what to say. I'd love to write back, but I don't know what to write. It's quite a strain on me...I'm frightened I'm going to put something that going to upset her more. (Case 4)

This comment expresses a dilemma which many parents had. They benefited from the identification with other parents and the mutuality of interest, but felt that they did not have the capacity to reach out and respond to concerns, and especially bereavements, of other parents. One parent, for example, felt an obligation to attend the funeral of a child and did so, but then felt overwhelmed by fears for her

own child. She decided that she could not attend a funeral again while her own child was on treatment for cancer.

On the other hand some parents clearly benefited from reaching out to others and getting involved in their issues. One parent, a father, took it on himself to speak to new parents as they arrived in the hospital ward to offer information based on his experience. Another example of reaching out to others was that of the support group which was set up by several parents. One of these parents saw it as having a benefit for other parents rather than herself. She also spoke of the value of the telephone contacts members of the group had in times of stress, but emphasised that she did not envisage using this arrangement herself.

Mutual support was valued by many parents, but was problematic. It carried with it an emotional "price tag" which for some parents was too high a price to pay. These emotional costs brought risks of raising parents' fears to unacceptably high levels. Some parents limited their contacts with other parents or restricted them in terms of numbers and timing of their contacts.

Support from professionals

Support from professional staff was of a different nature from sources described above. Professionals who came into contact with parents provided a very specific service which was mostly directed at the child's illness. But in describing sources of help many parents in the study referred specifically to the support professionals gave. There were several aspects to this which were nearly all highlighted as being key components which facilitated their coping. Professionals provided information about the illness, showed a detailed knowledge about the illness and about the ways in which the child and the family might be affected.

In particular, specialist staff were singled out, in some cases in comparison with the less helpful contacts with, for example, the family doctor or local hospital staff. The impression was given that many parents regarded the definite diagnosis of their child's illness, while traumatic, as nevertheless better than uncertainty. The full understanding of the diagnosis and of the consequences for the child and the family was helpful to all the parents.

Many parents developed close relationships with some of the professional staff in the hospital. Parents were not asked specifically about their contacts with individual professionals but it was clear that they nearly all had a clear

appreciation of the different roles of professional staff. They also indicated which staff members were supportive to them and in what way. The availability of support from professional personnel was referred to by one mother as being important—it would be there if required:

It was very clear from the start that they were all there if we needed them. (Case 8)

The relationships which were built up with medical staff were especially important. Doctors provided information about the illness from which many parents derived hope about their child's future. Having the doctor readily available was seen as important, as was the building up of a good relationship with the principal doctors treating the child. One father commented:

You could always ask Doctor.....(Senior Registrar). He was always there. He would always see you if you asked. It was important to have the doctor available and to have a nice person as well, a person that you liked. (Case 2)

Nursing staff were seen by many parents as being understanding of their worries. Some talked to nursing staff about their worries. One mother reported the way in which she had felt supported by time taken by two of the nurses to help her to sort out the major problem of getting her small son to take his tablets. She said:

The biggest problem was getting him to take the tablets....But a couple of nurses helped one weekend. They actually took time, took all day, just to get his tablets into him. They tried different ways I'd never thought of. (Case 5)

She had felt this practical help, undertaken in a very caring way, giving her the time she needed, to be very emotionally supportive to her.

One or two of the parents had been supported by professionals in their local community who had shown concern and understanding about their fears and anxieties. A few were critical and disappointed by the contacts they had with other professionals outside the hospital. One commented:

The GP admits himself he doesn't know....His way of dealing with it is to say "Some days you've just got to grit your teeth and grin and bear it". I don't think that's a lot of help to anybody. (Case 8)

There were several parents who had found the contact they had made in the hospital with the social workers to be especially helpful to them. A few of the parents referred to their initial reservations about social workers and the help they

might provide. It came as a surprise to parents who discussed the matter that social workers might provide help to them because of their child's illness. For example, one of the parents who later found the social worker helpful, described her initial reaction to the idea of seeing the social worker as being very negative. She said:

I wasn't really interested in a social worker, ken. I thought, "I don't need a social worker". I didn't see the point of it to be truthful.....but later I got on well with her. It just took me time to accept her, being a social worker. I thought, maybe they think "O my God...". It just frightens you. (Case 19)

Her reaction shows that social workers need to be very aware of such first reactions and careful of the way in which they present themselves to parents.

Comments were particularly made about the emotional support that parents received from their contacts with the social worker. A father who said he had been "devastated" by his son's diagnosis of cancer, described the social worker as "propping him up" and "keeping him sane" during the early stages of the illness. Several parents made similar comments about the importance to them of the contact with their social worker.

Parents comments were generally positive about the supportive help from all the professionals they had contact with in the hospital. The principal sources of support, at the stage at which the interviews took place, were for most parents, their own families and partners. Despite the relative unimportance of professional support, where this was sought or used, it was valued.

Importance of social support for coping

The majority of the parents valued some form of social support as an important contributor to their coping with the illness and treatment of their child. While for many parents the link was an implicit one, a few parents commented specifically on this. One parent reflected on the way in which she would have liked to be supported. She had few family members, was estranged from her father and her mother had died a few years before. She felt that some of the arrangements she had to make for her well child were made much more difficult by lack of close family members. She said:

If we had somebody that we could leave S. with, that would have been so much of a help. Having to take him home (from visits to the hospital) and get him washed and dressed.... If I had somebody that could have helped me with that it would have been wonderful.....to

have someone you can turn to like a mother, a big sister or a big brother. (Case 1)

Another parents spoke of the importance to her of support in being able to cope with her child's illness. She said first that clarifying her knowledge of the treatment was important. She then went on to reflect on the value of being able to talk about her feelings about the illness and especially about her fears for her child. She said that her coping was greatly helped by this support. She said:

It was important to talk to people in the hospital. Not only to the other parents. You need a lot of explaining from doctors and nurses. Going over even the silly questions you think of when you're driving home that are nothing to them but can become a big mountain..... (Case 8)

Talking is important. I couldn't have coped any other way. You have to let what you feel, out, because you can't build it up. You can put a front on, but I think you have to express your worries. Well I have, I've had to express my worries and my fears, to R (husband). (Case 16)

Problems and tensions in getting help or in using help and support

As has been shown at different points above, the availability of a range of support is not in itself a solution for the parents. There were a range of tensions and problems which many people experienced. Some of these difficulties were obviously concerned with an individual's capacity to use help in the form in which it was offered. While others were due to an individual's unrealistic expectations or, perhaps, even a wish that the illness would be cured or the problem disappear.

In the following section I will discuss some of the main difficulties which the parents discussed and also my interpretation of the tensions they were experiencing as a result of these difficulties. Many of the tensions related in part to problems experienced in asking for and using help.

Difficulty in asking for help

Asking for help for themselves was something which almost all parents said presented them with a degree of difficulty. Most of the parents were accustomed to managing their lives and dealing with any problems which were presented to them. The diagnosis of cancer in their child was of a different order, but for many this difference did not ease the difficulty of finding themselves obliged to seek help with

a range of problems. In particular, it presented a new experience of dealing with not only practical problems, but overwhelming feelings of anxiety. Emphasising the difficulty in asking for help, one parent said:

If I'd felt stronger, I'd have phoned the hospital to ask for help. But again, you're embarrassed, you don't want to say, "Help". (Case 16)

A majority of parents emphasised that this was the reason why they turned in the first instance, where possible, to their immediate family rather than to others outside the family. Their family, parents thought, could be expected to provide unconditional help.

Parents sometimes did not find it easy to ask for help even when it was offered freely. For example a mother described the willing help given by friends, in coming to the house and being with the family and, particularly, in caring for the brother of their child who was ill. She said:

It can be very hard to ask for help. My Mum and Dad are the ones you don't mind asking so much, but the others, well we have a couple of close friends and they've been really terrific, here all the time and often they're helping out by taking (our other son). You know they don't mind, but you don't sort of want to play on it. (Case 4)

Asking for help or advice from hospital staff was not easy for some parents, even in situations when they had been advised to telephone to consult about their child's health at any time. One parent expressed this attitude when she commented on her reluctance to telephone the hospital ward. She said:

I'm one of these people, I don't like bothering people too much. (The hospital) say phone, but I can't... I didn't like to bother them. (Case 7)

When parents received what they felt to be a negative response, the reluctance to ask for help was reinforced. One mother described a situation in which she had asked a friend to look after her well son while she went to the hospital with the sick child. The friend had said she was busy. The mother reported that she felt hurt by this response, feeling that if the situation was reversed, she would not have reacted in that way. She said:

It does hurt me because I am the type of person who would say "No problem" no matter what. But I just said "That's fine, it doesn't matter". and I just tried to arrange something else and thought "I'll not phone again", you know. (Case 4)

One of the parents spoke of the effort it took for him to ask for financial help. He said:

We've needed help from a lot of the charities. ...The first six weeks we virtually emptied our bank balance with all the travelling back and forward to Edinburgh. We had our car written off, no money in the bank...we had to get help. You don't want to ask but there comes a point when you've no option. (Case 6)

One parent expressed the view that the stage of the child's treatment affected the way in which offers of help might be received. He reflected on the way he had responded to offers of help at an early stage in his child's treatment. He had at first wished to manage alone as much as possible and had perceived help, particularly of an emotional kind, as very intrusive. He concluded that the timing of offers of help was very important. As an example, he said that a man who worked in the same firm as himself had come to him to express concern about the sick child and had made it known that he himself had cancer. The father had found this contact helpful to him at the time but said:

If people had done that to me in the initial two or three weeks (after his son's cancer was diagnosed) I would have felt they were prying where they weren't wanted. So it's getting the timing right. (Case 6)

In a few cases, it seemed that parents were quite overwhelmed by their problems and experiencing feelings of depression. This made it difficult for them to establish contacts with other people. These parents did not have the energy or motivation to renew or initiate social contacts or to ask for help.

Identifying appropriate help

Some parents were not clear about what might be helpful to them. One parent pointed out problems of identifying one's own needs at a times of stress. He said that when someone was in the middle of a difficult situation it was hard to think of ways of improving or to find solutions. He thought it was the responsibility of professional staffs to "push" parents by offering help in a proactive way, rather than waiting to be asked.

A few parents said they felt they had not received much help. It is important to note that the reality of the help available to parents was quite varied, so that some parents, a minority, lacked some practical and emotional support. In one or two cases this perception of receiving little help was in contrast to the help parents had described receiving in other parts of the interview. There could be a number of

reasons for this. It seemed to suggest that the assistance which they had received was not defined by them as "help".

In a few cases it appeared that parents felt that some of their needs for help of various kinds were clearly not met. The sense of need seemed an unspecified one. They could not suggest what might have been helpful or suggested something unobtainable. (For example a mother whose own mother was dead, felt it was she who was really needed.)

Ambivalence about receiving help

The illness of their child created a changed social situation for parents. For some parents it was clear that there was a tension between a wish to be in control and independent of others and a need to have help.

One of the parents, for example, who was very reluctant to depend on others or to be "beholden" to others said that she "just *couldn't* ask for help" from a neighbour for a small practical service.

There were a number of parents whose comments about help they received seemed to indicate a degree of ambivalence. This was accentuated when their perception was that there was little help available to them. A father who had felt that friends were unhelpful, went on to express mixed feelings about receiving help. He said:

There's not been any great rallying call and everybody charging around fighting to help you. I've never looked for it anyway. (Case 12)

He indicated how hard it was for him to be "beholden" to people. His attitude may well have discouraged offers of help. When asked what kind of assistance or support would have been helpful he went on to say that he was reluctant to have too many people involved in his arrangements:

I don't know what would help. I think it could get a bit crowded - people getting in the way, you know. (Case 12)

One or two parents referred to having, at times, a need to cut themselves off from other people. One said:

No. I didn't want to see anybody. I just cut them off. (Case 5)

Another parent said he wanted to be alone with child.

I just wished they (visitors) would go away. (Case 6)

One or two of the parents spoke of the way in which they at times cut themselves off from other people, specifically keeping their feelings to themselves. Three parents referred to times when they "shut off" from others. One parent did not physically go away on her own, but described a process of isolating herself even when others were present. She said:

I'm a loner. I just think about it myself. I just shut off, not so much go somewhere private. The house could be full and I just blank out and shut off from them. (Case 4)

Another aspect of wishing to be alone was expressed by one or two parents who perceived expressions of concern (or enquiries about the child) from neighbours as being intrusive or "nosy" and an invasion of their privacy. One mother, for example, commented:

Initially people were falling over themselves to say how sorry they were, especially people who never spoke to you before. I found that pretty infuriating...Sometimes people are bloody nosy, but I just tend to smile and say he's fine. They were just asking so they could say to someone else (how the boy with leukaemia is getting on). And some people look at him as though he's got two heads and that's quite annoying as well. (Case 5)

One parent interpreted possible help from the social worker as being intrusive, and therefore unhelpful. He said:

You get someone like your social worker coming to your door and they maybe see too much! Some of these agencies can be very nosy. They were never trusted when I was a kid and once you get a social worker you never get rid of them. It's no way to get through life with a social worker coming to your door every day! (Case 18)

These references to help which was perceived as being meddling or misguided were rare in the study.

Adequacy of help

While some parents wished to be alone, at least some of the time, and a number of parents preferred to manage independently and were ambivalent about receiving help, many parents indicated that they felt "alone" in facing the problems which the illness created.

Few parents *volunteered* information that they had received help which they valued. When asked about the help they had received, the majority of parents clearly had a good deal of assistance of various kinds and most parents valued the help. However other parents, who it seemed had received a variety of help, still felt it was not enough. An impression was given that there were many individual parents who had a feeling of coping on their own, despite some evidence of a good level of support. Help was given but these parents felt unsupported. The help that was given could not relieve the burden of the problem they faced. Where parents felt that their situation was not well understood by others, this difficulty was increased.

Difficulties in adjusting to new social networks

All parents found that their social relationships were changed from before illness. They were placed in a situation of having to ask for assistance from other people. Some parents found this particularly difficult. Where parents felt they had been rejected by friends, this created strains and a distancing from people with whom there had been a close relationship previously.

The help provided by family members also brought its own tensions. Some parents felt responsible for the impact of the bad news of the illness on their own parents and others. and a wish to protect them. For example, one parent who lived with her elderly mother, said that she always presented news about her son's illness in the most positive light and she could never share any of her anxieties with her mother. Another parent described to impact of the illness on her parents. She saw them as being upset both for their children and the grandchild who was ill. She said:

Our parents are I think frightened like the rest of us. They feel it doubly. They feel for their own child and for their grandchild and sometimes I think they get forgotten about. It's presumed they'll stand by....but they're upset and they're feeling it twice over. (Case 16)

A difficulty experienced by many parents was that some of the extended family members could not accept the anxiety and uncertainty of the illness. They were overly reassuring to the parents that the child would recover. One parent said:

My Mum is the kind that thinks "H. will be OK". They don't want to think that there's a chance that she'll relapse.... They're being false to themselves. If she relapses it will hit them harder. (Case 16)

A denial by the grandparent of what appeared to be the reality of the situation was felt to be unhelpful by this parent.

Some tension for some parents in using help from other parents

The sharing of concerns with other parents of children with cancer was found to be a source of support by most of the parents in the sample. However there were some tensions involved in this process. A few parents were reluctant, especially at first, to align themselves with others in the same situation. These parents resisted being part of this new social grouping.

As new relationships and friendships developed between parents, these were found to be helpful for about half the sample. Some contacts brought new worries when the children of other parents relapsed or died and parents' fears were reinforced. One of the parents who distanced herself from too much contact with other parents also recognised that there was a two way process in contacts with other parents which brought a responsibility to respond to the needs of others. She said:

I wouldn't want to keep in touch, but I'm like that, that's my way of coping. But everybody's different aren't they and you're sort of trying to help them too, aren't you? (Case 4)

It can be seen that most of the categories are associated with difficulties within the individual, with little attention being given to the adequacy of the services being offered. This leaves unanswered the question of whether, had services been presented in a different way, parents' experiences could have been mitigated. When invited to comment on professional services, few parents took up the opportunity to do so. One parent commented that he thought professionals should be more proactive in offering help and less tentative in their approach; this was a view that others might have supported.

Conclusion

The value of social support to coping is a factor which has been emphasised in a number of research studies, with the clear consensus of view that it is vital for parents to receive such help. As Chesler and Barbarin put it, "No parent manages to deal with this chronic and serious illness without help" (Chesler and Barbarin, 1986, p 269). My findings support this general argument but show also that the

issues involved in asking for help and receiving it are complex ones and the relevance of social support to coping is far from clear.

Every parent found it difficult to ask for help, even those who seemed to be able to accept it easily. In those cases where help was sought and accepted from someone whom they knew prior to the illness, asking was less difficult because of the strength of the previous relationship with the other person. The illness brought also a new network of helpers, including other parents of children with cancer and professional staff in the medical care centre.

Most parents showed clear ambivalence about receiving help. They showed this in a number of ways, including appearing to understate the extent of the help they had actually received. The result was that while parents on the whole appeared to be well supported from friends and relatives and others including social workers, there seemed to be a disparity between the services they had received and their general perception of feeling unsupported. As I have reported, most parents felt that they were dealing with the illness alone. This feeling of "aloneness" and isolation which many experience, and which is not resolved to any large extent by having close partners or by meeting the parents of other children, is one which many parents may have to retain throughout the illness. It may always be a factor which limits the effectiveness of the support services which can be provided.

My observations of the difficulties that individuals experience in seeking or receiving help are not new. As long ago as 1949, Annette Garrett, an early writer on social work theory pointed out that the helping process creates a dependency situation for the individual receiving help, and the experience reactivates infantile fears. Anyone in a dependency situation for any length of time sees the helper as having a power over his or her destiny and this will involve a negative response (Garrett, 1949). Being in a position of needing to be helped of course does not fit well with the parents' need for "normality", which for many included privacy and independence, an issue which I have addressed previously. An apparent wish for retaining privacy and independence may be paradoxical in view of the feeling of coping alone with the child's illness which most parents expressed.

It is clear that social support makes an important contribution to the way that parents cope with the illness. This was supported by the virtually unanimous observations of parents themselves. However, the ambivalence that parents felt about receiving help which their comments also showed, have made it difficult to

identify the particular contribution that various types of social support they received made to the way they coped.

The other three themes I have identified can all be seen as being connected in various ways to the parents' drive and motivation in coping. For some parents the social support they received, for example from their relatives, friends or doctors, sustained them and might well have contributed to their motivation. But even these parents did not give any clear indication in their responses of the extent to which the social support they received was of importance to them. No parent was able to give any clear indication of the form of support that they felt they needed in order to be able to cope.

In my review of the literature I observed that at least one researcher is critical of the lack of a standard definition for research of what constitutes social support, and also suggests that more emphasis should be placed on the contribution the different types of service can make (Krahn, 1993). In this study it was not appropriate to focus too specifically on different aspects of support as my overall intention was to hear what parents meant by the term. My findings show that there was no clear type of support that was particularly valuable, and both practical and emotional forms, whether they are provided separately or together, are very important. Further research is necessary to establish more precisely the particular contribution that social support services make to the way that parents cope.

CHAPTER 8

CARING FOR THE CHILD

Introduction

In developing the themes of my study, I have suggested that the sick child becomes a focal point of attention for many people, especially his or her parents, throughout the illness. Not only is the child the main subject of the parents' fears and anxieties but the *raison d'être* for their having to cope with the illness. Some of the issues arising from these matters are examined in this chapter in which I describe the fourth theme which is concerned with the ways in which parents meet their responsibilities of care for their child, and the tensions that they experience, particularly those that are directly related to the medical treatment that the child is receiving. Some of the previous ways of acting as a parent were called into question both by themselves and by others. New ways of handling situations, even ones which were relatively familiar, were required and many new responsibilities also came to them with the child's illness. It was how the parents dealt with many of their responsibilities of care for their child, or how they learned to do so in the course of the illness, which played a major part in how they were able to cope.

The way the parents saw their responsibilities for their sick child was mentioned frequently in the interviews. Parents made many references to what their role as a parent meant for themselves generally and what this meant for them in relation to the illness. In this chapter I will discuss the ways they described the types of responsibility they carried as parents, and the changes which were made in response to the child's illness and the demands of treatment.

Presently in the UK, parents are more involved than ever before in many aspects of the child's medical treatment. The responsibilities that they carry are quite formidable ones. The parents are often consulted by medical staff and are closely involved in critical decision making. Occasionally parents may feel the need to question or challenge decisions of doctors and other personnel. Sometimes this type of action requires parents to pursue a challenge in the courts of law. It would be wrong however to see parents' involvement in treatment or decision-making as being a scenario which envisages confrontation. The modern ethos of medical care is to involve and work with parents. The policy of hospitals now is to expect parents to take a major part in the day to day administering of the child's treatment.

The context in which the parents had to discharge their responsibilities to their sick child is stressful. The hospital itself has an established bureaucracy, procedures and protocols. There is a requirement to comply with a set treatment programme, both during the in-patient hospitalisation periods and the times when the child is at home. Some parents can be torn between trying to meet their responsibilities of providing care to their child either in hospital or at home, while at the same time meeting the expectations of doctors that they are the person to help the child to accept the required treatment. Finding ways of using their authority to persuade the child to undertake unpleasant and painful treatments while continuing to protect the child is a challenge for many. It can result in feelings of powerlessness in not having a control over their lives or the illness, its treatment and the care of the child, as all of these matters could be dependent on the work of the medical personnel.

What were the new demands on parents as parents

Context of the treatment

As explained in previous chapters, the diagnosis of the child's illness had come unexpectedly and in some cases was made at a time when the child appeared to be only mildly unwell. The immediate transfer of the child from home or from another hospital to the regional treatment centre came as a shock for many parents who had never experienced a serious illness before. Some had no experience personally of ever having been a hospital patient. For others who had, it brought back painful childhood memories. Despite the shock of the diagnosis, which some parents described as leaving them "devastated" and "numb", they were required to become involved immediately in discussions with medical staff and to participate in decisions about the beginning of medical treatment for the disease. For some children this meant surgery and, for all of the children in the study, an aggressive chemotherapy treatment commenced either immediately or after an initial surgical operation. The chemotherapy treatment involved giving the child, intravenously, a "cocktail" of drugs, which themselves caused, in varying degrees, a range of unpleasant side-effects.

While the regional children's hospital which the children attended was not a large one by national standards, it was, like any hospital, perceived by the parents as being a powerful institution. The particular unit to which parents and their children were admitted was a specialist one with a range of medical, nursing and other specialist staff. The busy hospital ward was often full of children at various stages

of treatment, many of whom appeared ill, and were attached to drip stands as they received their drug treatment. Many of the children who had been receiving treatment when the child had been admitted had lost their hair as a result of treatment. Some of the parents found the hospital experience difficult to deal with in itself, and recalled what they felt vividly. One parent expressed this as follows:

Hospitals give me the shivers.....If I go into any hospital, I'll sit there for maybe half an hour and then I'll go. If I'm in with K. for maybe six hours, I've got to go every twenty minutes outside and have a cigarette and a coffee and come in again. I just can't sit. (Case 18)

A few of the parents, mostly fathers, found the hospital caused them to feel overwhelmed. One or two fathers made similar comments. One said:

I don't like hospitals at the best of times very much. I have an unusual sort of phobia about it. (Case 10)

Mothers of the children did not seem to be quite so affected by this general fear. However, one or two mothers expressed other kinds of negative reactions to being in hospital. One in particular spoke about the way in which the experience of being in the hospital made her depressed. She said:

When he's in the ward I'm a totally different person. It makes me depressed.... People talk to me and I just answer their questions...I don't, like, keep the conversation going. Oh, it's just horrible being the hospital, just horrible.....You get to meet different people... you hear about children who have had relapses..... you were feart to ask them in case they had the same type (of illness) that S. had. (I kept) hearing things I didn't want to hear...(Case 19)

Most parents indicated that they became quite familiar with the hospital over time, but for some parents, their initial feelings remained. Every time their child was hospitalised, they had to overcome their own adverse reactions to the hospital.

These parents who had the most difficulties in their dealings with the hospital, also seemed to have more difficulties in helping their own child through the treatment. This suggested that their confidence in dealing with their sick child was undermined, at least initially, by the hospital experience.

Learning about the illness

The group of parents in the study had, overall, a high degree of confidence in the medical services. It can be said therefore that they were meeting some of their

principal responsibilities to their child by playing a part in getting the child good medical care and playing any role assigned to them by the medical staff.

The medical staff involved the parents closely in decisions being taken about their child's care and treatment. The parents in the study seemed in general to take the view that they had been consulted and most felt closely involved in the decision making process. Most of the parents also felt that they had received quite a full explanation of the illness and of the proposed treatment. Almost everyone accepted the proposed treatment, because they saw the doctors as being experts in the field. In addition some of the parents had become aware that their children's treatment was taking place within nationally established protocols for treatment of the specific medical conditions and what this meant. This helped them to have a confidence in the treatment.

For some of the parents, getting a high level of information about the illness and treatment was an essential component of taking part in discussions with doctors. Some needed immediate information. One of the parents described his need for information; he said:

I sought information. I wanted statistics. I wanted to see the x-rays. I wanted to see the scans. I wanted to cram up the information. (Knowing what they were doing) was the one thing that could help me handle it. I never had any reasonable request refused, you know. They wouldn't let me into the operating theatre but they certainly took me down and showed me the x-rays and scans. (Case 15)

Developing good working relationships with doctors, especially relationships that were based on trust, was important for many of the parents. It helped them to accept the requirements of the treatment and to carry these out with their child.

Some parents felt that as a result of their previous experiences, they had a head start in developing working relationships with the doctors and the wide range of other staff in the hospital. One had worked in a hospital, while another had been seriously ill herself and understood the workings of hospitals. Another parent had been an insurance salesman and said that he was very used to dealing with a variety of people and that this helped him to relate to doctors and those in authority in the hospital. He also pointed out that he was familiar with hospitals because of previous experience, and, he thought, "being a man", also helped him to get a better response from hospital staff when he chose to be assertive. He commented:

I lost a grandparent to cancer, so I've sat for a lot of hours in a lot of hospitals. Plus I think if you're a man – this sounds terribly sexist – you may be a bit more....you get a bit more attention.....I've sort of been a wee bit nastier than my wife, who will just sit and fume quietly. I get a bit more verbal. (Case 17)

On the other hand, some of the parents found interacting with doctors and other hospital staff presented major problems for them. One mother reported that she had always had difficulty when people were in authority and that doctors came into this category.

They couldn't have been more friendly, but I needed more time. I wasn't very at ease with doctors. If they could have had time to have sat down, just spent five minutes playing with the child so that I felt more relaxed, I feel I could have approached them more. (Case 5)

She had also regarded them as "infallible" and had to change her thinking when it was clear that a doctor could not automatically cure her child. It had taken her some months to find a way to relate to the doctors and she was still, at the time of the interview, not wholly comfortable in talking with them, especially when her child was in the hospital. She said:

I used to look up to doctors and put them on a pedestal. I saw them as being like God. If there's a problem, the doctor will fix it. But after about six months I realised that they're just human after all and medicine is just their job. They were really nice, most of them, but they still make me feel uneasy. (Case 5)

Another parent also felt found doctors hard to relate to initially. She commented:

I was feart to talk to the doctors in the beginning...(Case 19)

Another parent complained that she was not given enough information and that she felt "patronised" by staff in the hospital. In particular she thought she was kept waiting in the clinic for appointments, while other people who, she thought, were regarded by the staff as being more important, were given preference. She said:

I don't get all dressed up. I go in there after my night shift in my track suit and leggings. Sometimes we've sat from 9.0 till 11.0 before being taken. And these people come in their suits and they're taken straight up the stair. And you really feel it.....You think, "Why am I sitting here?" (Case 14)

This same mother had looked at her child's medical notes on one occasion and was incensed to see herself reported as "Mum was worried". She pointed out that this implied there was nothing to worry about. She felt her concerns were not being heard. She said:

I took a wee look, you know, (at the medical record). It said "Mum was worried". They made me feel as though they were patronising me. Later I said there is definitely something wrong, she's not any better and they found it (a tumour) elsewhere..... (Case 14)

One parent specifically separated her parental responsibility from that of medical responsibility. She took the view that while she was responsible for her child's care, she left the burden of the medical decisions to the doctor. She included her husband in this approach. She said:

We didn't delve into everything...I could have done because I worked as a medical secretary. But they were doing their job and we were doing our job, that's how we saw it. We saw that as our job. Our task was with C. (Case 9)

While there were some parents for whom their confidence in being a parent was clearly undermined by the illness and by the hospital regime, many parents were quite assured in handling their own child. For example the mother of a child with Down's Syndrome was quite confident in her knowledge of her own child. She said she was prepared to do what was required as far as her son's leukaemia was concerned, but she took her own decisions about his care in general. She had strong views about his management. She developed a trusting relationship with her child's medical consultant, of whom she said, "She's always been very straight. She never tries to fob you off with anything". Her comment on the care of her son on the hospital ward was that her own way of handling him was best. She said:

They wanted me to leave him lying quietly for a couple of weeks and just let him be. That's no good. I got him sitting up in his cot or had him on the floor. As soon as he is dressed he is in his buggy. I don't believe in all this "leaving them lying about". (Case 11)

Learning about their child's illness and communicating with hospital staff, particularly the doctors, was recognised by most of the parents as being essential to the task of caring for their sick child.

A common strategy used by many parents for dealing with the hospital processes was by dividing elements of their responsibilities with their partners. Some parents found there were aspects of what was required of them which were easier to deal with than others. They tried to avoid those because of the fears and anxieties which were caused by them. Some parents, for example, who found communication easier than their partner took on the principal role in discussing matters with the medical staff, or in negotiating arrangements with nursing staff about relevant aspects of the child's care.

My clear impression from the study is that many parents did not find an involvement in medical decisions a comfortable task. It seemed that those parents who had the most difficulties in this matter also had greater difficulties in supporting their child. These observations are examined in more detail later in this chapter.

Participating in treatment procedures

Understanding a major life-threatening illness like cancer, especially one in which the symptoms are not readily identified in the child's appearance, requires many parents to take a huge leap in their understanding of what the illness process involves and, more generally, of the way the human body functions. A major illness such as cancer is of a different order from the other childhood illnesses with which many parents are familiar. A parent needs to find some ways of interpreting the information that is given to them as this can become crucial in the future. The understanding, for example, of the seriousness of a particular symptom illustrates this point. Sometimes a symptom which is alarming to a parent is one which could be considered by a doctor as being "something to be expected". Conversely, an apparently minor symptom as the parent might interpret something in the light of previous experience could be very significant in a child whose immune system is suppressed.

Taking an active part in the administration of treatment procedures was taken for granted by parents by the time of the interviews. This participation involved a range of activities which had been quite foreign initially to most parents. In the hospital, parents usually remained with their child when, for example, injections were administered and this often involved holding their child who was crying or screaming. Even "thumb pricks" to get a blood sample, a frequent event, continued to be upsetting for many of the children.

Participation in treatment activities at home included giving a variety of medications several times a day. Other duties which required the parent's attention often were as result of the child's immune system being suppressed. This could involve them in administering mouth care routines several times a day to avoid the child getting painful fungal infections and mouth ulcers, paying attention to the child's temperature and constantly watching for rashes and bruises. Parents also had to assess the importance of symptoms in their child, such as tiredness, aches

and pains, tummy upsets and changed eating patterns, either eating too little or eating too much.

The main responsibility for this day to day care was taken by mothers in this study. As has been noted in previous chapters, it was they who, in general, arranged to be at home and assumed the main day to day care of the sick child. There were indications from some parents, however, that where a particular task was difficult for one parent it was taken on by the other. The one parent who was a single parent in the study pointed out the special difficulties of having to manage all the tasks alone. The two parents who were separated from one another, co-operated closely together. The mother in this situation acknowledged the important role of her son's father. She said:

We were separated, but we got back together while he was on treatment, simply because I couldn't have coped on my own. I was all right on the day to day caring for him.....But when he goes for jags and injections and things like that, I mean he's hysterical when I take him, but when his Dad takes him he's much more relaxed. I think he just feels my nerves.
(Case 5)

Once the child's treatment was well underway and parents became familiar with the routines, it was clear that in most situations, parents took on specific tasks with their child. These were determined either by parents' other responsibilities, in particular employment demands, or in some cases by one parent taking over a task that they found easier or one that was difficult for their partner.

For example, in one family where the mother was depressed, the father of the child took most of the responsibility for taking his daughter to the hospital for treatment procedures and for clinic appointments. At the time of the interview the mother of the child was hoping to be able to go alone to the hospital for the first time.

There were a number of examples of particular incidents in which one parent had taken over when the other was distressed. One such example is of a mother who described being upset by an incident in which an intravenous line came out of her son's arm and had to be re-inserted. This meant a painful search with a needle for a new vein. The child's mother felt she could not tolerate the procedure any more and left her husband to take over. She said:

P. was screaming at me "I hate you, I hate you", and his Daddy was there and I couldn't take it and ran out of the treatment room and his Dad had to stay with him....(Case 7)

The fact that fathers had returned to their employment at the time of the interviews meant that many were not so much involved in the daily care of the child. Nor were fathers as involved in accompanying the child on the hospital visits which was, in most cases, a weekly event at the time of the interviews. Many of the fathers however involved with the child's illness in other ways.

On the whole it was mothers who spent more of the time in the hospital and learned about treatment and nursing tasks. They also administered treatment at home. A number of parents, especially mothers commented on the difficulty of making the transfer from hospital to home, after an extended stay in the hospital. Despite the strains of being in the hospital, and the contrasting relief that was often felt by parents by being at home, returning home when the in-patient period had ended brought other difficulties. Several parents conveyed the isolation that they felt when the child was discharged from in-patient treatment. One parent explained:

In the hospital there's always somebody there. Someone you can speak to. We come home and it's like we've been abandoned. You're sent home and you have all this medication to give. Not that I'm frightened of giving her medicine, but it's just you are cut off. When you are in the hospital there's always somebody there so that if you're worried about something you can ask. But you come home and you've still got the illness. It's quite frightening. (Case 8)

This sense of isolation often increased as the child spent time at home. Many parents became aware of new problems. Parents began to appreciate that they were wholly responsible for administering the medical treatment which was required to be given at home. This presented many difficulties for some. An added problem was sometimes the child's behaviour. As the child resumed life in the family home and began to recognise normal surroundings, some changes in behaviour often occurred or became more apparent to the parents. Some children were described as being more anxious and clinging while others were described as being more difficult and demanding. Parents had to address some of these changes in behaviour and many did not find this easy. Some of the behaviour that the children showed following their return home could of course be a reaction to the anxiety of the parents, particularly the anxiety associated with the isolation which many of them were feeling.

Supporting child in the treatment

The dramatic events of the child's diagnosis and the beginnings of a treatment regime were recognised by all the parents as presenting them with a mammoth task as they tried to support and help their children. It is arguable that the task of supporting children in treatment is one of the most challenging tasks that any parent of a sick child had to face. Parents found a wide variety of ways in which to approach this task, which presented more problems for some parents than for others. A few parents felt overwhelmed by feelings of guilt and distress which they experienced as treatment got underway. The feelings of guilt were often associated with participation in the decisions about the course of treatment to be proceeded with. One parent expressed this thus:

I feel I'm betraying her because during her initial treatment I kept saying 'the doctors are going to help you', and I think if she was older she would be saying 'that's not right, that's not the truth.' (Case 16)

Some parents spoke of the distress they felt when treatment procedures upset their child. Some almost regarded the treatment as an assault on the child. One parent spoke of her experience in the early days of her child's treatment. She was very upset by the frequent need for son to have tablets and injections. She said:

I just remember there were people coming in the whole time and getting him tablets and sticking needles in him and wanting to scream at them to leave him alone. Looking back, they obviously had to start treating him, but it seemed cruel at the time. (Case 5)

Later, when her son was at home for much of the time, this parent continued to have difficulties in getting her son to take tablets and this continued to distress her. She said:

The biggest problem is getting him to take these tablets. He's just resisting all the time. Sometimes I have it hard, pinning him down to get the tablets down, which is traumatic for him and traumatic for me – horrible. It was like you were being forced to hit your child, forced to upset him, but at the end he knew he had to take them. (Case 5)

One or two parents spoke about the guilt they felt at putting their child through such difficult procedures. One parent said she felt she had "lied" to her child because she had been too reassuring that procedures would not hurt. This was not true, but she had been unable to find any other way. She described how her daughter had to have a needle inserted into a vein in her foot. She pointed out that while the doctors were working on her child she was "the one that's sitting there".

She said that no-one took account of her feelings while the procedure was taking place. She described her feelings about the needle being inserted. She said:

It was really horrible, because your trying to say to her, "It'll not be for long". or "This'll not hurt". But it's me that's telling a lie. The time she got it in her foot was terrible. They said to her "We'll have to give it to you". and I says to K. "Right it's not going to hurt". and she screamed and screamed, "I'm not wanting it, I'm not wanting it". and it ended up her shouting at me, "You're a liar". I mean they don't understand how it makes you feel. (Case 14)

Another parent who felt distressed at putting her child through the treatment regime, described "making up" with her child after obliging him to take his medicine. She said:

We would make up afterwards. He knows I wasn't doing it to be horrible....He knows he has to take it. I said, "I'm sorry, but I had to do it". (Case 5)

These parents who took a "soft" approach to making their child go through treatment procedures found it difficult to force the child to have unpleasant treatments done to them. The parents' approach was generally one of muddling through, meeting each demand as best they could, having mixed feelings about the treatment. which upset them as well as their child.

In contrast other parents took an authoritative approach to the treatment. They began by accepting the need for the treatment and its procedures, however unpleasant, and developed an approach which was firm with their child, while also being supportive. None of them indicated that this was easy for them, but a clear sense of purpose was communicated to the child. One parent emphasised the "positive" approach as including being clear that treatment needed to go ahead and being firm with her child. She described a typical incident as an example of what she meant. She said:

We tell her "This is going to happen". If we go to clinic on a Wednesday and she's to get her gripper in, (involving an injection through the skin), I tell her she's to get it in. She'll say, "Oh, I don't want to get it in today". And I'll say, "Well, it's either that or getting a needle in the back of your hand". Which she hates. That's one thing, I must admit, she hated was trying to get blood out of the back of her hand. So she'll say, "Well, I'll get my gripper". The thing is, when she's getting it she never says a word. They say to us that because we're positive it's rubbed off on to her. (Case 8)

Another parent described the importance of being cheerful with her young child and playing with him. She said:

We thought "Well if we stay happy, C. will stay happy." And it totally worked. We entertained him....focused totally on him.... he sat and played. He was connected up to drugs and he was sitting giggling and to see him like that made us better and everybody felt better. So giving that to him, he gave it back to us.

The importance of the attitude they adopted to the treatment was clearly regarded by many parents as being of crucial importance.

An important element in this more authoritative approach was giving children appropriate explanations about what was going to happen to them. This was emphasised by many parents. One parent described the ways in which he explained to his son what was going to happen next as part of the treatment. He, like a majority of parents in the study, regarded it as important that his child was involved in what was happening to him and had appropriate explanations about everything. He thought it was important that his son should have an explanation about the operation he was to have. He said:

We did explain it to him, because he's bright, you know. "Look they're going to put you to sleep, you'll not feel a thing, they're going to make a wee cut, there, and they're going to take out your bad kidney". He took it quite matter of factly. (Case 17)

Later, the consultant had given explanations to the child about the illness and, rather than using a euphemism, had used the word "cancer". This parent followed the consultant's lead in using the term and said:

I thought, "Right" so we took the lead off him. Cancer to adults – the word itself has a terrible fear. But C. is quite happy about speaking about it and will say to people, "You know I had a cancer in my kidney and they took it away". (Case 17)

This same parent regarded the use of humour as an important way of helping his son. He described the way in which he encouraged his six year old son's sense of humour in dealing with the loss of his hair, which both parents found upsetting. The hair came out quickly, over a week, and especially on his pillow at night, on his "Thomas the Tank Engine" pillowcases. In reporting his son's reaction, the father said:

C. had a good sense of humour about it. He went to bed one night and he says, "You know when I rub my head on the pillow, Percy (the engine) will have a moustache in the morning!" But it came out in handfuls and my wife and I did find it distressing. (Case 17)

Some parents were critical of how other parents of children with cancer handled their children. One parent, a mother, who indicated that she had strict views on discipline, felt that parents should not show any latitude in normal behaviour and that parents who had done so had more problems with getting their child to take medication (Case 8).

In general, the parents in this study used a variety of approaches in supporting their child, and this is to be expected, given the variations in the severity of the illnesses, the ages of the children and the particular types of courses of treatment being carried out. Invariably, whether or not the approach seemed to be effective, the parents were distressed by their part in supporting their child in treatment. Some tried to check their distress by convincing themselves of the necessity of the treatment and sticking to routines. Others allowed more time to deal with their child's distress. Those who became overwhelmed with the distress in their child were less able to assist with the child's feelings of fear. Those who could stand back a little and focus on seeking a way to best help their child got a response from the child which in its turn helped the parent to go forward.

The way that the parent and child interact in the treatment depends substantially on their previous relationship. There is good evidence from this study that the parents' involvement with the illness and treatment relies heavily on the strength of this relationship. The way that the relationship responds to the pressures on both parent and child may have potential for long term effects on both the parent and child.

Exercising authority and discipline over the child

Parents had to exercise their authority and discipline on matters which were clearly linked to the illness and treatment, and on other matters which appeared to be only marginally related. Both situations caused difficulties for many parents. A common one was when the child refused to comply with the treatment requirements. It was clear that all parents attached a high emphasis on the child complying with what the treatment required. In contrast they showed a latitude in terms of the child's other behaviour. One parent expressed a view which was shared by several other parents, when she commented on an incident where her child had attacked her. Rather than feel angry with the child, she felt a degree of guilt. She said:

She can scratch me and hit me and I know that it's not really her doing it, it's just a reaction to the anaesthetic. But I do get very tired of her if she wants Mummy an awful lot, and eventually I have to say, "Have Dad,

Mummy's tired of you". And yet you feel bad because you know it's not her fault. (Case 16)

When the child's behaviour became difficult at times, some parents tried different ways to get them to co operate with the treatment. Some felt that they had become more tolerant, like the mother who was trying to get her child to eat the food she was giving him. She said:

I think I react differently. Before I would just fly off the handle and say, "Oh bugger this, I'm not going to bother". I think it makes you persevere. It probably makes you a better parent. (Case 9)

Most parents indicated that they had relaxed the standards of discipline they had set for their children – all of their children – prior to the illness. At the time of the interviews, they were trying to reintroduce some of their previous rules of behaviour within the family, but in doing so were fully aware of the change that had taken place in the sick child. Their attempt to do so was proving difficult; as illustrated by a father's description of a period of disobedient behaviour his three year old daughter was showing:

We need to put our foot down now and again, which is always hard. You say to yourself, "I shouldn't have said or done that".I've had to look away a couple of times because she's been crying and I've skelped her bum and given her a real "upstairs and sit down in your room till you learn" sort of thing. And you're walking about choking a bit, but you have to do it.(Case 13)

His self-criticism was typical of several parents who did not like to be firm with their child. Another father put the dilemma he faced in exercising discipline quite succinctly:

When you get angry, you regret it right away, because you were forgetting. (Case 12)

It would seem that as the treatment progressed, most parents used their understanding of the effects of the illness on the child in order to support their wish to show tolerance. One mother put it this way:

C. is a bit hyper at the moment. Whether it's a combination of her age and the drugs, but she's not taking a telling, and is very weepy when she gets told off. She wants somebody to be there the whole time. She's very insecure. (Case 8)

But parents also recognised that the child had in the illness an opportunity for "secondary gain", that is, when the child learns to use the illness to get special

consideration in a number of ways. One parent spoke about the fact that her son's behaviour was difficult to control because "he has got used to getting what he wants". This particular parent however took a measured approach to the need for discipline for her seven year old son. At home she was re-introducing rules of discipline which had been relaxed during the hospitalisation, but doing so with the knowledge that the steroid tablets which the child had to take could affect his behaviour:

The only allowance I make now is his steroid week and the week after. His emotions are then very mercurial and he shouts at me a lot! (Case 7)

Where there were other children in the family, there were other disciplinary difficulties for the parents. As reported elsewhere in the study, the parents were fully aware that the needs of their other children were often neglected during the early stages of the illness. Most parents felt guilty about this and seemed to be aware that their emotions interfered with the ways in which they disciplined their other children. Although only a few parents in the study indicated that their other children posed difficulties for them, a few noted signs of jealousy and changes in the personality of their other children. One mother put it this way, showing that the tolerance she showed to the sick child's behaviour extended to her other child:

It's quite changed her. She used to be a placid, laid back sort of baby, you know. She has turned out to be quite timid and gets up every night and comes in with me. (Case 5)

In general it was clear that most parents had experienced some difficulties in setting limits for their sick child and, to some extent, their other children. The most common reaction was to accept a degree of misbehaviour in their children provided the child met the main treatment requirements. The fact that most children did so was due, of course, to the fact that the medical and nursing staff were also re-enforcing these treatment requirements.

The tolerance shown to the child's changes of mood and disobedience was supported by a number of factors and sustained in large measure by the fact that any misbehaviour in the child would be of a temporary nature. There were some indications, however, that the guilt that many parents felt in imposing discipline would become more marked as the child's illness progressed.

Advocacy for the child

Advocacy means speaking out on the child's behalf. As noted in the introduction to this chapter, some parents, on occasions, do so in dramatic ways, often at times when a major change in the treatment approach is being considered. In this study there were no occasions when this form of advocacy had been required. Most parents, however, indicated that there were occasions on which they had stood up for their child. Quite commonly, this was directed at the nursing staff – not the doctors – and might have been associated with a degree of rivalry some parents felt to the nurses who were playing a major part in caring for the young child.

One mother described a situation where she felt that a nurse had “overfed” her baby who had become sick as a result. She said:

I didn't really like anyone else feeding him, although I didn't have any control over that. I came in once and a young nurse who didn't have any experience of babieswas feeding him. R. would be sick if you tried to give him too much. She'd tried to overfeed him...and he had been sick...she had him sitting out, away from her, on her knee and he was howling. I went in and scooped him up, all wires and sick and everything and cuddled him in and he stopped screaming. (Case 1)

But other parents were aware of their sense of powerlessness in the hospital setting and made a point of standing up for their rights. One mother who clearly attached importance to having a good relationship with medical staff, nevertheless made a point of being involved in every aspect of her child's treatment. She had some advice for others, saying:

I would say, to someone else in my position, don't be frightened to ask anything and get to know who is dealing with your child.You've got to “gel” with them. It's not easy.....Don't be frightened to read the notes either....When anyone came in and they were talking about R. – like students and doctors – I would say, “You won't say anything without me being there”. I just wanted to be treated like an intelligent human being, not like, “Well, this is R's mum” sort of thing. (Case 1)

All the parents were advocates in the sense that they carefully monitored everything that was done to their child in the hospital and were not afraid to speak out when mistakes, usually minor ones, happened.

Some criticisms were silent ones, not made to personnel in the hospital at the time, but reported in the interview. One parents for example criticised the standard of cleanliness in the hospital, saying that she was so concerned that her son, who was very vulnerable to infections, would catch an infection, that she regularly

disinfected the cubicle in which they were placed. Another parents also commented on the physical conditions in the hospital ward. One parent said:

It's a brilliant hospital, don't get me wrong, but it's antiquated, Victorian.....it was a shock when I went in. Sometimes we were fortunate and got a cubicle, but if not we just had a fold down bed on the floor. And if she was out in the ward.....you just wanted a room to yourself. It was all far too busy. The nursing staffwere really busy....run off their feet. Every one was worried about their kids. If something (medication, medical checks) didn't happen at a set time you worried that they had missed it.
(Case 13)

At least one of each child's parents was closely involved in the treatment procedures. These parents developed a growing knowledge base from which to make informed judgements about standards of medical and nursing care and the procedures their child was undergoing. Their knowledge and the monitoring of their child's progress provided important ingredients which helped them to develop better advocacy skills.

Despite the difficulties involved for some in being an advocate for their child, most of the parents were able to do so. One parent commented that while she had difficulty in standing up for herself, she was able to do so on behalf of her child. Others endorsed this view which was expressed by one parent thus: "He's our child; it's our responsibility, and we're the right ones (to speak for him)". (Case 4)

A view that several parents expressed was that in being a parent they had "no choice" but to act on their child's behalf. Similarly, they had "no choice" other than to ensure that their child, as well as themselves, complied with the treatment that was presented. The parents' sense of obligation in both respects appeared to be a powerful drive and an influential factor in the way they coped with the illness. In this study there was no evidence of any major disparity between the two drives. But the impression was given that should the parents lose confidence that the treatment programme was an effective one, with a resulting loss of confidence in the doctors' judgements, this could release powerful psychological drives which would sustain a strong advocacy role for them on their child's behalf. This could also be a foundation for taking up a challenging position either against clinical judgements or policy decisions on health matters.

Tensions and dilemmas in caring for the child

The evidence from this study is that there are a number of tensions and dilemmas which were experienced by parents in the process of meeting many of their responsibilities as a parent to their sick child. The parents did not describe the process in which they were engaged in terms of struggling to resolve tensions and dilemmas, but the data provides strong evidence for this interpretation. There were four areas in which this struggle could be observed.

Meeting several responsibilities simultaneously

Being the parent of a sick child means meeting a number of responsibilities and performing multiple roles. These roles and responsibilities were varied. That included being at times the "manager" of the medical treatment. At other times it meant standing up for the child. At times it meant being with the child and holding or comforting him or her. The combination of roles added to the parents' perceptions that at times there was a conflict between what they were required to do and what they felt they wanted to do. This was the cause of emotional stress for many parents. One parent expressed the problem succinctly by saying that she wanted to pick up her child and run away. Her fantasy that this would resolve everything was easily checked by her rational self.

An important element in the tensions which the parents experienced was the conflicting nature of the roles being undertaken. The role of parent as carer of the child was a familiar one, although some parents found the increased dependence and new behaviours shown by their child in response to the treatment placed an additional strain on them. The role of parent as one who imposed discipline was also familiar but stresses were created by the feelings, especially of guilt, which the parents experienced when setting any limits or restrictions on the behaviour of their child. These feelings arose partly because the child was ill and partly because the parents recognised that they were already making many demands on their child to comply with the treatment requirements. Many of them said they felt guilty. The new role of "nurse" to their child which many parents had assumed, also created tensions. These points are discussed in more detail below.

Sharing responsibility with medical staff

The tension described above was linked closely with the feelings that parents experienced as they became involved by the medical staff in the child's treatment.

A major dilemma for many, which was the cause of emotional conflict, was that they were often having to satisfy the wishes of professionals, such as doctors, and the expressed wishes of their child, which were at variance. Many parents felt that they were caught in a bind, and one which was not made easier by the fact that, as parents, they were informed and consulted about all the stages of the treatment and were active alongside the professionals in administering many of the procedures.

Although parents were carrying out activities of a nursing nature which were related to the treatment, such as monitoring equipment or giving medication, their relationship to their child was of course a very different one from that of the nursing staff. The parents had a close, intimate relationship not an impartial one with a clear professional role. This close relationship made apparently easy tasks difficult to carry out and created significant tensions for the parents.

In discharging their responsibilities in these ways, parents were also preparing themselves to be acting on the side of the child, trying to protect him or her from acts of professional staff which seemed unnecessary or harsh. Decisions on intervention were taken with much difficulty: Some parents found it hard to overcome their feelings of anger that the illness had occurred. Their failure to do so was the cause, for many of them, of ambivalent feelings about the treatment. Those parents who were more able to keep to the fore their awareness of the necessity of the treatment, seemed to find it easier to find a balance between giving treatment and giving supportive care to their child.

None of the parents in this study had to make an intervention on a major scale. The disagreements which they voiced were mostly about hospital rules and procedures, and about delays, changes in appointments or minor mistakes in treatment procedures. Occasionally exception was taken to the attitude of a member of staff, usually to a member of the nursing staff. Some of the parents' criticism, which was not directed towards the medical staff, could be seen as in part a reaction to the tension they felt about the whole illness. When problems in administration occurred they also became the focus for the parents' tension.

Tensions caused by disciplining their child

The second main tension which affects the parents' responsibility to their children concerns the nature of the illness. When the diagnosis takes place, the parents' feelings about that child are intensified, and these feelings are not reduced during the treatment. Fears that their child may die serve to remind the parent of their responsibility to take all the measures they can to protect their child in every way.

In addition, the diagnosis usually marks a change in the child, who also reacts to the illness and treatment. This involves fears and anxiety; some of this is manifested in the child's behaviour and affect. A major tension for parents therefore is managing the adjustment they are required to make to satisfy their own feelings and meet the changes in their child. At some times the child appears to be "sick"; at others "their old self". Many parents in this study indicated that this task was a major challenge that they faced. Apart from the support of their partners this tension had to be managed alone. Some parents indicated that this tension was exacerbated by the fact that the illness itself had brought, for the first time, their role as parents under some external scrutiny. They felt that professionals, parents of other children and often friends and neighbours were for the first time observing them in the way they met their responsibilities.

Balancing the needs of the sick child with others

The third tension which was experienced by many of the parents in this study was to meet their parental responsibilities towards their other children. This is a source of tension which has been discussed earlier when considering the way that parents used different forms of support. For many, getting adequate care for their other children was a way of meeting their responsibilities in this regard. Nevertheless, many felt a sense of guilt towards their other children which created a tension, particularly when the other children began to show signs of jealousy or difficult behaviour. Often at these times the support of the partner was crucial, as was the ability of the partner to take on new parental tasks, as many of them did.

Positives in the experience

Despite the difficulties and tensions which parents had experienced, there was clear evidence from their observations, that the ordeal of the illness had some positive aspects. Some parents made this point directly as they reflected on their

experiences. In the case of others, it could be inferred from some of their comments. Having a "sense of achievement", the development of control over circumstances and becoming more self-confident all contributed in bringing a sense of satisfaction. There were several dimensions to these positive experiences.

A new confidence in parenting

For many the sense of identity as a parent was accentuated by the child's illness. Most parents took their responsibility both conscientiously and energetically. Most of the parents gave the impression that they derived confidence in themselves as parents as they realised that they were, mostly, managing to cope with their child's illness. The surprise with which some of the parents expressed this was indicative that they had surpassed their expectations of themselves. For example, one parent, with a sense of humour, understated his achievement:

I've been a wee bit surprised to have been able to cope with it myself. (Case 13)

Another parent commented on the sense of achievement in dealing with his son's illness up to the time of the interview. He felt this had given him confidence in other areas of his life, especially his work. He said:

I don't think I could have coped with the way I work now...job promotion and everything....., and with the pressures thrown at me, if I hadn't been through what I have been through. (Case 6)

The sense of achievement brought new confidence which itself allowed parents to move forward.

Sustaining the effort throughout the illness

Earlier in this chapter I have indicated that being the parent of a sick child brought a responsibility to ensure that the best treatment was provided for their child. This was in itself a motivating factor in coping and taking the child forward through the course of treatment. Parents said they had no choice. "You have to", was a comment which reflected the views of many. This sense of duty was expressed by one parent who pointed out that she was given no choice, she applied herself to the task. She said:

You have to do it. It's as simple as that. The bottom line is you have to get on with it and do it. No matter how much you don't want to, or how scared or upset you are, you just will do it if you have to.... I cope because I have to cope. (Case 5)

Although several points were cited by parents as reasons for sustaining their efforts, it was clear that an important one was the bond the parent had with the child. In all cases, the relationship between parent and child was closer than it had been before the illness. Some children had become more clinging and dependent on their parents during the course of treatment. The child's step by step progress became a reference point for the parent's day to day life; a good result was felt as an achievement and was encouraging, while a poor one was a disappointment but demanded new effort. Both provided a motivation for keeping going. The whole process of interaction between parent and child is an important dimension in the process of coping, which will be discussed further in the next chapter in which the process of change is examined.

A sense of achievement in new learning

A third positive element for parents was the sense of self esteem which they achieved as a result of acquiring new learning.

Several parents, more than half the group, clearly felt a confidence in their knowledge about the illness and about treatment procedures. Many had new skills, including managing many complicated nursing tasks. They had developed an expert knowledge of the hospital systems and processes. It would be wrong to attach too much importance to this. It has to be said that no matter how much new knowledge parents had, it could only be sparse and disjointed. Nevertheless, in this study, parents had gained some sense of achievement.

Conclusion

The modern medical practice of involving parents fully in the child's treatment is a creditable one. It enables them to be closer to their child and can give them the reassurance that the treatment is being administered with care. On the other hand, it places parents of a very ill child in a position which causes many of them severe anxieties as they experience the tension in trying to meet what they could see as being conflicting responsibilities. The obligation for parents, for example, to participate in some of the more intrusive treatments such as helping to administer a series of injections which could be painful to the child. For many parents the tension that they experienced was that while they willingly participated, often by restraining their child physically, because they recognised the medical importance, they also had a strong feeling that the treatment was in some ways a physical

assault on the child. The cumulation of a large number of experiences of being involved in treatments of this kind was a cause of severe distress for many of them.

Similarly, the parents' involvement in medical decision making is both constructive and a cause of stress. Nearly all the parents had very little understanding of cancer prior to the illness and some had not expected to be involved as fully as they were in the clinical decisions that had to be made about treatment. The relationship which parents formed with the medical staff was, from their accounts, highly important in determining the ease with which they participated in what were sometimes complex decisions. The trust that parents were able to develop with the doctors became an important factor which sustained them through the illness and helped them to maintain the hope that the child would eventually recover.

The main evidence from my study is that despite the anxiety that the parents were experiencing, their direct involvement in treatment is an important part in the way they coped with the illness. Being involved was for all parents a positive experience. It enhanced, for some, their sense of identity as a parent. Some of them, particularly younger parents, had not given any thought prior to the illness about what their responsibilities would be. Many acquired new knowledge and skills, many of a personal nature, which helped them to overcome inhibitions and enabled them, when necessary, to act as an advocate for their child.

It is my clear impression that parent's awareness of his or her duty to the child, enhanced by their close involvement in medical treatment and fortified by their relationship with the child which invariably intensified in the course of the illness, became a strong motivating factor in how they coped with the illness. As the illness progressed all these factors appeared to come together and helped to re-enforce the parents' sense of what the responsibilities of being a parent were. Many were able to become more assertive in their dealings with medical and nursing staff and if necessary able to question medical decisions on a better informed basis.

In the research literature I reviewed for this study, no study had focused on how the parents' involvement in treatment had contributed to the way that they coped with the illness. It is possible that the particularly intensive involvement of the parents in treatment in the hospital setting in which the study was conducted was atypical of the more usual participation that parents have in medical care, although I doubt if this is the case. It is more likely that the "partnership" relationship between parents and medical staff which is still comparatively new, has not been subject to any

detailed research. This could account for the fact that the importance I attach to the parents involvement in treatment and to their sense of responsibility as a parent, has not so far been seen as being important to the way they cope with the illness. This involvement in treatment is important also in that it gives them opportunities to learn and "grow" in the psychological sense in the course of the illness. This is a matter I will consider further in the next chapter.

The same issue plays an important part in some of the matters I will discuss in the next chapter about how parents change.

CHAPTER 9

COPING WITH CANCER IN CHILDREN: HOW PARENTS CHANGE

Introduction

In preceding chapters I have described some of the numerous activities which required the parents' attention, and I have discussed the stresses and tensions which were often associated with them. Another common thread in many of the parents' accounts of their experiences was their perception that they had changed psychologically during the course of the illness. In this chapter I will be considering some of the changes which parents discussed with me and analysing them in the context of some theoretical ideas which have been developed in professional and research literature.

My clear impression was that when I was interviewing them, many were still engaged in a process of change, not only psychologically but in the way they organised their lives. The transitional nature of the process they were experiencing was reflected in their responses in their lives.

My intention in this chapter is to study what the parents' accounts about change indicate about the way they were coping. The fact, however, that I interviewed the parents only once in the study means that the data cannot give a clear chronological account of the development of change that an individual parent experienced. Nevertheless, the parents' perspective on what change involved is relevant for understanding the process of coping.

The main patterns of change

My study showed three distinct patterns in the way change was felt by almost all the parents. These are the following:

1. Increased closeness with the child.
2. A fundamental reorientation of attitude to life
3. Living with the great uncertainty and anxiety of the diagnosis.

Of these patterns the first received more focus in the interviews because it was more directly related to the child's illness. Information about the other categories was not specifically sought, but emerged from later analysis of comments made by the parents throughout the interviews.

Increased closeness with the child

A major change for the entire group of parents was the place in their lives of the child who had become ill. The overwhelming nature of the illness made the child a focus of the parents thoughts, feelings and actions over a sustained period. For some parents this caused them to have unexpected feelings. A typical example was one mother who was quite young and who had not given "much thought" to her two children, who had just "come along", who found herself surprised by her strength of feeling for her son when he developed leukaemia. She was devastated by the diagnosis, which she at first thought was a death sentence, and said that she thought he would die and that if he died, she would die too. The child became the most important aspect of her life, initially to the exclusion of the other child. She went on to reflect:

Life changes when you have a child. I don't think anything prepares you for how much you're going to love them and how important they are going to be. But when something like this comes along, it makes you really realise how precious they are. (Case 5)

Several other parents made comments similar to these. Even when, as in the majority of cases, the child was already important and a major focus of family life, the illness had a huge impact in underlining this. For three of the families in different circumstances, the sick child was the only child.

Increased closeness between the parents and their children were expressed in various ways which are grouped into four categories. These were very close, almost "symbiotic" relationships; closeness which enabled parents to draw "strength" from the child; the development of increased feelings of affection for the child and the effect of closer relationships with the sick child on relationships with other children in the family.

Getting "strength" from the child

An important aspect of the closeness of the parent to the child, for at least half the sample group, was described by a number of parents as gaining "strength" from the child. For some parents including for example the father of a teenage boy who had been severely ill, and the mothers of two little boys with leukaemia, this was because the children themselves had coped so well with the treatment. Parents felt the children were very brave and had tolerated very unpleasant procedures without complaint. They felt that if the child could do that, so could they themselves. For example one mother said:

In the hospital, he sat and played. He was connected up to the drip for his drugs and he would be sitting and giggling. To see him like that made us better and everybody felt better. (Case 9)

Another parent reported proudly that his six year old son:

....took part in the sports day, in spite of the treatment. He was able to go in for almost all the events and tried so hard. (Case 17)

He was also proud of his son's efforts in keeping up with the school work:

He's kept up really well with the school work. He's got a glowing report. He likes to do the work here if he can't get to school. I've seen me being sent along to the school on a Thursday after he's had chemo on a Wednesday, "get me some work, Dad", he'll say. (Case 17)

Closeness was also explained as a source of strength for the parent of a six year old with leukaemia. He described the closeness as an "emotional joining together" which had not existed before the child's illness and which now carried him through. Another father gained strength from the child's progress with the treatment - each step forward with the treatment was another success for the child and for himself. This father commented:

The biggest help is to see him without pain anymore and running about and playing just like any normal child. (Case 13)

Similarly, but with less emphasis on the positive nature of the closeness to the child bringing strength, some parents described the closeness with their child being a spur to them to continue on with what was required of them. Two mothers, who were people in quite different social circumstances, reacted in the same way, and emphasised that their relationship with their children was very important in motivating them. They both said "You just have to go on". The needs that their child had for the parents to be strong, was a driving force for the parent to keep going and to continue to undertake all the necessary tasks. It provided them with the necessary strength to continue. They did not differentiate between their own needs and those of the child. In a similar way, another mother commented:

My children keep me going. When I feel, "What's the point.... where's the light at the end of the tunnel?" it's them that pick me up. If they are away at their Dad's for the whole weekend I get really depressed, real clinical depression and it's just because they're not there, but the minute I see them I'm fine. (Case 5)

New feelings of affection

Some very positive aspects of new closeness with the child were described by several of the parents. A father of two teenage boys described a new relationship which had developed with both of them. He realised that his strong feelings of affection for them should be expressed, not assumed as previously, and he took care to tell them he loved

them. He spent more time with them enjoying their company. He also found he was able to discuss with his ill son some of the son's worries about death.

Fathers in particular all described changed relationships with their children. The hurt which fathers had experienced when the illness was diagnosed was graphically described. They spoke in terms of the devastation, anger and helplessness they experienced. Alongside these feelings was the need, for a number of fathers, to keep their feelings concealed and give an appearance of calmness and strength.

It seemed that there was a greater shift at least in overt behaviour and relationships than for mothers whose caring role was already more strongly established. Fathers all seemed to be giving emphasis to spending more time with their children, either by giving less priority to work or to leisure and social activities. One father reported that he had never played games with his children before and was now getting a lot of enjoyment out of this himself. Enjoying the children was important in the new relationship with them. He said:

As a father I've never been one of these people who go out and plays a lot with their children or take them swimming and things like that. But now I'm totally changed. That's surprised me because now I spend so much time with the kids and I was never one for them before. (Case 6)

Another father described the time set aside for his son which was a new arrangement since the boy's illness. They would go out together on a Sunday. This time spent together "just the two of us", was very important new development.

"Symbiotic relationships"

For some parents, this closeness with the child was almost symbiotic. In contrast to gaining "strength" from the child's progress and achievements, there were some parents for whom the child's every change in health and even every change in mood had a parallel impact upon them. Parents, especially some of the mothers, described watching their child constantly. There was a need to some extent to keep a careful eye on the child for signs of infection which would need prompt action, but the quality of the watching and the evident need of the parent to be close to the child was much more than this. One mother said of this close relationship between her son's health and well being and her own: "If he's fine, I'm fine", and elaborated:

If S. is not well, I'm not well, but if he's good, I'm good. When he was first really ill, I just sat on the bed and gret because the minute S. is in pain I'm in pain and when S. is all right I'm all right. I wish I could just take all this on myself, rather than him have it. (Case 19)

The corollary of this was that she did not manage well the times when he was ill, even when this illness was not of major significance from a medical point of view. One or two other mothers made similar comments; two spoke of the comfort and reassurance they obtained by watching their child sleeping. For example one mother described the importance of the times alone with her baby (R) when he was asleep:

The most important times were when we were on our own. At night when he would wake up for a feed and his brother was sleeping and my husband was sleeping, I would get up. It would be dark and quiet and R. would be fed and changed and we would have a wee sort of talk and he would fall asleep in my arms. Quite honestly I could have sat all night with him because nobody was there and it was just us. (Case 1)

Attitudes towards other children in the family

Parents' awareness of their closeness to their sick children had implications for the way they saw their other children. Some parents saw the illness as a reason for getting close to their other children as well. For example two of the fathers now spent time with enjoyment with their other children. One father had to bear a great deal of responsibility for his three year old son since the sick child, a baby, was in the hospital and his wife remained there for as long as possible, returning only in the late evening each day. The father had very little time because of the financial necessity of pursuing his business responsibilities, but saw the time taken in caring for his son as one of the very few positive aspects of the illness.

However, a few parents expressed great concern about the possible negative impact of the illness on other children but felt it could not be prevented. One or two parents expressed guilt they felt about the effects on other children. One mother said she had 'abandoned' her year old daughter to the care of relatives and felt guilty about the lack of thought she had given to her. Another mother was constantly worried about her three year old son and felt torn between him and the sick baby. She had to leave her baby in the hospital at night in order to return home to care for her older son, and often felt resentful that he needed her care too. She felt guilty at having these feelings of resentment.

One mother described the difficulties she had with trying to be fair to all the children, especially as her sick child was given a great deal of attention. She tried to make up to the other children by giving gifts of various sorts. She reported:

I mean I do seem to mollycoddle her. I don't mean to do it, but it does seem she gets all the attention. The others have had a hard time. But we've scrimped and saved to send the eldest to Malta and the others

are wanting various trips. Money wise it's difficult, and you're trying not to let them think she's the only one. (Case 16)

The impression I got from the ways in which parents described aspects of their closeness with the children was that the illness itself had helped to create closer relationships in the families as a whole. It is not possible to know the extent to which this closeness would be sustained. It was strongly in evidence at the time of the interviews. It is often said that at a time of crisis families are often brought closer together for a period as they try to deal with the problem presented. In this situation many other important issues particular to the families had been put on one side in the face of the diagnosis of the illness and were still in abeyance as the treatment progressed. At a later time some of these issues would have to be dealt with and some strains might come to the fore as a consequence.

A fundamental reorientation in attitude to life

The purpose of the interviews was not to explore parents' values in detail, but several of the questions in the interview had asked them to reflect briefly on the impact of the illness on themselves and their family. It is interesting to note that many of the parents made important statements from which it can be construed that their child's illness was an event of major importance which had affected their lives in a fundamental way. It was clear that all of the parents in the study had spent some time reflecting on the illness, so that when I raised my questions, they were giving observations which had already occurred to them. One or two of the parents referred to some fundamental questions which had occurred to them. One young mother, who had quite a poor level of education, said that the illness had caused her to think much more about life in general and its purpose. Another mother asked similar questions of herself, but more focus was placed on what was happening to her as an individual. "Why is this happening to me?" was the question that was bothering her. Sometimes she shut herself away to dwell on this.

These responses were in some ways atypical in that they were addressing unanswerable questions. On a different level, it seemed, many of the other parents had progressed from such questions to dealing with issues to which there *were* answers. They had made decisions based on values which had been adjusted to meet the crisis.

Adjustments in parents' values systems were shown in various ways which have been grouped into three main areas: the change in the priorities assigned to aspects of life

which had importance, the change in the way parents managed their social relationships and the change in their concept of time.

A change in priorities

Matters which had seemed to be important prior to the illness were put into a new perspective by the illness itself. In some cases decisions on family matters such as moving house were postponed. A clear general trend was that material and financial matters of all kinds became regarded as having little importance. Several parents said so categorically. One mother said it thus:

I've realised that if my children are healthy nothing else matters. We were going to be selling the house and moving. We were living here just until we could get something better... but that is irrelevant now. I just want a place to bring up my boys where they can be happy. And if they're happy, I'm happy. (Case 16)

Business and employment matters also became of secondary importance. One father for example gave scant attention to his own business, a driving school, because he felt that teaching people to drive was unimportant and purposeless for him. He was considering giving up the business, he said. Another father who had been made redundant shortly before his son's illness was diagnosed, admitted that he had been very uncommitted to seeking another job. This was partly because of the demands of the treatment, necessitating trips to the hospital at a distance from his home, but largely because work seemed irrelevant. He added:

I was chasing jobs half heartedly and I think that showed and maybe that's why I've not got one. But I'd quite happily not work again if I knew he was going to be all right. (Case 17)

Another father who was very conscious of the risks for his son, spoke of his changed feelings about employment and the importance of the relationship with his son on a day to day basis. he said:

If something happened to him now, I'd just give up my work right away - I would be off like a shot. It's always at the back of your mind that you could lose him, so you just try to make every day as good as you can for him. (Case 6)

Others echoed these views. Men in particular, whose life had been less child centred, changed their perspective on work significantly. The importance of valuing their family, was clearly expressed in the interviews.

Even given the comparatively early stage in the process there was some evidence that the experience had been a positive learning experience for some of the parents. For example one parent said that his ability in his work had been increased by the experience of finding ways of dealing with his son's illness. He said:

I got a new job six months ago as a production manager for a company. I've been there from the beginning of the installation of a new factory. It's been hard but I can cope with that now, whereas I don't think, in fact I know, I couldn't have before. There's nothing anyone could throw at me which I couldn't handle. (Case 6)

Later in the interview, when asked if he had changed in the way he had coped during the course of the illness, he said:

I did change. I had to learn to be strong. I'd always been one for shutting myself away and dealing with things on my own. But then I had to be there for everyone else. I changed in that way. I just stayed and helped everybody else. (Case 6)

This parent was quite overt in his comments about personal development during the course of his child's illness. There was evidence of some personal learning and changes in values in other interviews. Other parents seemed to have had similar experiences.

Time perspectives

The child's illness had affected the time perspective of many of the parents in the sense that planning of all kinds was done on a short term basis only. The focus was on day to day activity. Nearly all the parents said that they could "not look too far ahead". Some connected this point with the uncertainty of the outcome of the child's illness and the consequences which they did not want to face. One father put it this way:

You can't plan and you daren't let yourself forget that. We had a good week with C. the then he was ill and we had to get the GP out three times at the weekend.We would like to plan a short holiday but which week is he going to be all right? I mean, I can't plan what I'm doing tomorrow, just in case. (Case 2)

For some parents this was a greater change than for others. One of the mothers, who had serious illness herself, said that she always lived in the present and never looked forward to any events in the future. She said:

I don't think about it. I just take every day as it come and think, "Well another day and he'll be a bit better".....The future is tomorrow. I don't look any further ahead. (Case 4)

Another mother actively tried not to look ahead because of the anxiety this created for her. She said:

I actually try not to think about the future. He's always talking about the future - "when I'm nine I'm going to do this and when I'm twelve I'm going to do this" and every time he says that, I say, "Please God, please let him. Please let him be that age, let him be an adult". (Case 5)

For several parents the change to looking at life on a short term basis was a significant one which had not come easily. One or two parents who had described themselves as being "planners" in their general approach to their management of their lives, had made a major change with great effort. Some of these parents were people who prior to the illness had well organised and highly structured lives. They spoke of their conscious awareness that they should try not to look ahead too far.

Attitudes to others

The change in attitude to what was really important in life had some positive consequences for one or two parents. For example, one mother who had no contact with her mother in law since her marriage some years before, described how this rift had been healed. However, the emphasis on giving attention to things which were really important had some negative consequences also. For example, one or two parents found that they could not engage with social relationships as they had previously. They found that the things their friends and acquaintances worried about were unimportant, given their new perspective. They knew that these were the kinds of things they used to worry about themselves in better days before their child's illness. The trivial interests and concerns of other people were therefore an irritant to them.

One father said that he had stopped going to the local pub for a drink in the evening. He was so easily aroused to anger by the comments of people who were unintentionally annoying to him, he was afraid that if he did so he would not be able to control his temper. Another father said that he also found he was much more short tempered than previously and upset by little things. He commented:

I use to think I'd got a long fuse for a temper but now I can't be bothered with things and little things annoy me. (Case 3)

It must be said that there is no way of knowing if these shifts in parents approach to life would be a long term one. What was clear was that the adults in the family evaluated their values and in doing so, their priorities changed, in some cases quite drastically. The impression I had was that irrespective of whether the child would

survive the illness, and irrespective of any disability the child might sustain in the long term, everyone's value system had been affected substantially .

Living with uncertainty and anxiety

The third dimension of change relates to the way that parents require to find ways of living with a period of uncertainty which will possibly be affecting many aspects of their lives on a medium to long term basis. The uncertainty about the outcome of the illness is a cause of high anxiety for the individual and the family as a whole.

The nature of the illness of cancer with the connotations that a human being is being destroyed by an unstoppable disease is for many people a cause of great distress. Many of the parents shared this perspective. One mother said that "the word 'cancer' is like a swear word". For at least one mother in the study the trauma caused by the illness was linked to previous traumatic events in the family. Two of her previous children had in fact died of illnesses not related to cancer. Her anxiety was linked to her earlier losses and heightened her current anxiety about the outcome for her child.

It is possible to examine parents' anxieties in three categories: Anxiety relating to the illness itself; anxiety relating to the effects of the treatment and anxiety about the effects of both the illness and the treatment on the child. These are not clear cut or separate categories. They relate closely to one another and as the analysis shows, the anxiety about the illness as a whole is connected with the anxiety about the individual symptoms.

The illness itself

The survival of their child was of paramount importance but was set aside by many of the parents for much of the time. It was always on their minds, however, and was brought into focus by particular events. For example, visits to the hospital for tests created anxiety and for a few, even the regular routine hospital outpatient visits could bring a focus of worry, as one mother expressed thus:

I often feel ...when I'm going over to the clinic on a Wednesday, "is this the day they're going to give me bad news?" (Case 16)

A distressing event which triggered a great deal of anxiety for parents was the death of a child who had become known to them in the hospital. A number of the parents in the sample had this experience and spoke of their distress as they were concerned for the other parents but also found their own fears rekindled. One or two parents went to the funerals of children, although one mother commented on the way in which this was

unhelpful to her. She had been so upset by the funeral, that when a second child died she decided not to attend the funeral. She felt she had to concentrate all her emotional resources on her own child's care:

At the funeral I just saw that wee white coffin sitting there and I thought "that could be me and my child". When another wee boy that was in the hospital with us died I knew I couldn't go to the funeral. I have to concentrate on C. (daughter). I have to think she is going to get through this. If I thought for a moment that I was going to end up like them I couldn't get out of bed in the morning or get through the day. (Case 8)

In a similar way, when parents learned about children in the hospital who had relapsed, and the illness had returned, they found their fears for their own child were heightened.

For many parents the child's illness had been diagnosed on the basis of some apparently minor symptoms such as tiredness, a slight cold or a sore leg. When the diagnosis had been made it had come out of the blue. This experience, for many parents, had implications for the way in which they interpreted any small symptoms in their child. They faced the fear of the illness returning.

The development of symptoms were a cause for anxiety to be triggered. The vagueness of the initial symptoms which the children had shown prior to or even at the diagnosis, accentuated the perception of minor problems as a cause of worry. A number of comments illustrated this point:

Every time he says he has a headache I panic. (Case 19)

It's always at the back of your mind. You're constantly in fear if she so much as takes a cold or anything. (Case 8)

If S. (her son) took a temperature when he wasn't supposed to be taking one, I thought "is it coming back?" Your mind starts running riot to be honest. Every time he gets a bruise, I keep saying "Is it a normal bruise or a right purple bruise?" (Case 5)

Speaking more generally about the worry the illness caused, one father said:

It's always on your mind, always there, always niggling away at you. Some days are great, it doesn't bother you too much, but other days, especially if I'm feeling down in myself, then you think "Thank God he's still here at the moment, but for how long?" (Case 13)

Their worries ranged over a variety of aspects of the situation the illness created. Major and minor worries were mixed together so that for some parents there was an added difficulty of being unable to differentiate clearly where anxiety should be placed. The

effect of this was to cause unnecessarily severe anxiety about minor and, from a medical point of view, unimportant details.

The medical treatment

The treatment process involved many medical tests on a frequent basis. The results of blood tests, usually at least a weekly occurrence, and other tests were important for all parents. These indicated the extent to which the child's system was tolerating the chemotherapy treatment and determined the amount of drugs which could be given. Parents were worried if a lower dosage of drugs was given because this might make the treatment less effective in counteracting the cancer. Too high a dosage might place the child under a threat from the drugs themselves. The blood levels also determined the proneness of the child to infection and this had an immediate effect on life in the forthcoming week - whether the child could mix freely with others and whether they were at risk of being readmitted to the hospital with an infection. Waiting for the results of medical tests was a problem for some parents, although conversely, positive test results were acknowledged to be helpful.

The treatment was itself an uncertain process with day to day changes. For example, parents and child might prepare themselves for a planned admission to hospital for several days' chemotherapy treatment, only to be told on arrival at the hospital that the child's blood count was at a level which could not allow treatment to be administered. So child and family would go home again for another week and would also have to go through the process of preparing themselves for admission once again on the following week.

Some particular aspects of the treatment process presented difficulties. For example, two mothers saw their main problems as stemming from those times when their children were inpatients in the hospital. Just being there was a major "threat". Anxiety was created by being in the hospital ward away from their familiar surroundings, while seeing their child undergoing treatment procedures. One mother who found the hospital particularly difficult said:

When he's in the ward I'm a totally different person. It makes me depressed. Oh, it's just horrible being the hospital, just horrible. You get to meet different parents and some of their children have relapsed. You were feart to ask them about their child in case they had the same type (of illness) that S. had.I was always hearing things I didn't want to hear... (Case 19)

In contrast, two or three parents spoke of the sense of isolation which they experienced when they were away from the hospital. For these parents, loss of the immediate reassurance of nursing staff and of the presence of full medical care, was the main issue. One mother spoke of the contrast between hospital and home:

When we were in the hospital I felt she was safe. It seemed like we had stopped being a family in..... and become a family in the hospital. We didn't expect to get her home as quick as we did. Then we felt really dropped by people because they seemed to think that because we were home so we were OK. Everything is then in your own lap to do and it can be a tremendous strain. (Case 5)

For those parents whose children were nearer to completion of the treatment, there was the realisation that once treatment had finished, there would be a new form of raised anxiety. Parents could have reasonable confidence that while treatment was in progress, the disease would not reappear. They were all aware that with the end of treatment they would be worried about relapse. Parents knew that in general children are deemed to be "survivors" of the illness when they are five years off treatment. This long time scale seemed unattainable to many parents. As one mother commented, about her daughter, then three years old:

She's going to be nearly ten before we get the all clear. I think it is the span of things which is so hard. (Case 8)

The long term nature of the treatment itself created its own difficulties in that high levels of anxiety continued to be experienced. Parents all expressed the fact that the treatment itself went "on and on" in a seemingly endless way.

Other anxieties were centred in a less immediate way on the longer term impacts of the treatment on the child. These long term effects can include loss of stature, kidney and heart damage, sterility, loss of intellectual ability, and secondary tumours. A few parents worried about these matters, although many set these less immediate worries aside.

Impact of the illness on the child

Parents reported that changes in a child's character and behaviour resulted from the child being ill, being in hospital and from the side effects of particular drugs. They worried about whether their child would ever return to being the same again. At the time of interviews, although many of the children, if not all, were seen by their parents as being courageous, brave, communicating better with adults, more outgoing, making developmental progress etc., many of the changes in the children were also negative

ones such as tantrums, awkwardness, clinging and demanding behaviour, food fads, sleeplessness, bedwetting, problems in going to bed etc. They were concerned therefore that the child was changed and that this change might be a permanent one. The perceived loss of the child they had known before the illness was a major change.

Increased anxieties were felt by all the parents. Some appeared to be about major matters while others were about seemingly minor worries. The anxieties arose from a wide variety of sources, changed very frequently creating constant uncertainty. Parents were conscious of the extent of the worries which they had. In Chapter 11, where parents own views on the ways they coped with the illness are reported, they gave indicators of the ways they harness some of this anxiety in order to manage on a day to day basis.

Understanding change: Some theoretical perspectives

In the physical sciences the results of a change process can often be predicted, but in the social sciences this is rarely the case. Change seldom moves at an even pace when the human psyche is involved. It can be spasmodic, full of stops and starts and reverses. The process is variable and fluid. This applies to any change as a social experience. It did not come as any surprise, therefore, for me to observe that there was a wide variation in the ways that families and individuals changed, given the stressful circumstances of a child having cancer and the uncertainty of the outcome of the treatment.

In order to understand the complexity it was important to root my observations in some theoretical perspectives relevant to the subject matter of the study.

Crisis Theory

“Crisis theory” refers to a body of knowledge which originated in the 1960s and has developed as a major influence in social work and psychiatric practice in both the USA and the UK. The most prominent exponent of “crisis theory” in the 1960s and 1970s was Caplan whose principal interest was in mental health services (Parad and Caplan, 1966). With colleagues in his own field of interest and many practitioners in related specialisms, research was concentrated on studying an individual's reactive behaviour in the face of any hazardous situation. One of the main purposes was to find the best basis for planning health or social work interventions and the sources of help required by individuals and groups in situations in which they were unable to find solutions for

themselves. Crisis theory therefore was popular with practitioners as it had a real practical application.

Much of the appeal that "crisis theory" had for doctors and social workers was its ability to integrate sociological theory with the psychological insights which had hitherto dominated many aspects of the psychotherapeutic approach (Rapoport, 1965). New developments in sociological thinking at that time such as understanding social roles that individuals perform and the networks in which they function were helping practitioners to develop new methods of approach in their work.

Central to the approach was the identification of the "crisis" which was being experienced. From studies conducted by Caplan and many others, research focused on individual or group behaviour when facing any type of "crisis" situation in their lives, such as coping with a death, or a mental illness or, say, a child being admitted to hospital or to a children's home. From the range of studies, a theoretical model of crisis behaviour was constructed showing the different stages of any "crisis", defined as being a situation in which the "habitual problem solving activities are inadequate to enable the individual or group to achieve a degree of equilibrium" (Rapoport, 1965, p 24). This definition allows for the fact that the perception of what constitutes a crisis is essentially subjective. Individuals will react differently to the same hazardous event.

Figure 9.1 shows in simple terms the main stages of what came to be regarded as the basic theoretical path followed by an individual involved in a crisis.

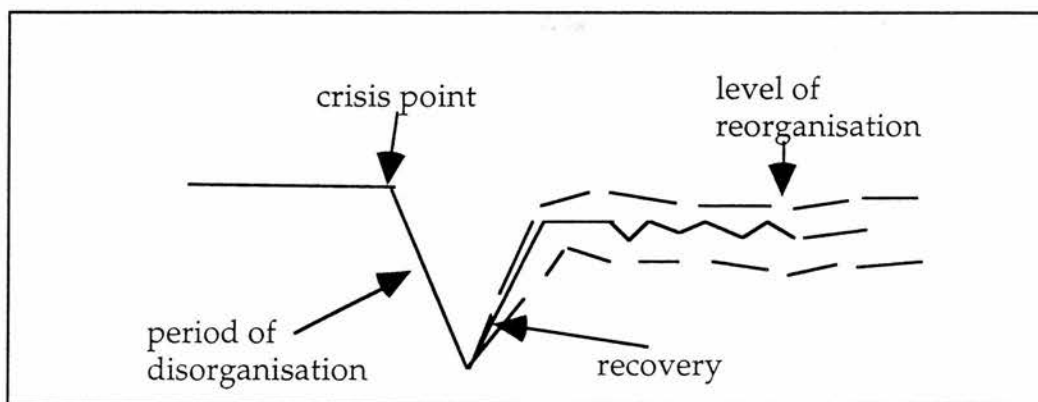


Figure 9.1: Profile of adjustment to crisis (after Hill, in Parad, 1965)

It will be noted that the diagram concentrates on the period following the crisis. One reason why I have selected this particular illustration is that it focuses on the period immediately following the precipitating event, that is the situation which has become the crisis, and for this reason it is the period most relevant for my study. As the

diagram shows, the crisis is followed by a period of "disorganisation", leading to a "recovery" phase followed by a comparatively steady period of adjustment called the "reorganisation" stage. The last stage allows for a new level of adjustment which can be achieved, depending on the ways that an individual (or group) changes as a result of the crisis. Practitioners who followed the crisis theory approach see the opportunity in any crisis for an individual or group to achieve, often with help, personal growth or new learning, and through this, acquire knowledge and skills to deal with similar crises in the future.

Within this framework it can be said that the parents in my study were probably at some point in the "recovery" / "reorganisation" stages of their crisis when I interviewed them. They were picking up the threads of their home life while developing a new pattern of life, the duration of which was uncertain. It was this uncertainty itself (which was often to be reinforced by further crises, such as a set back in the progress of treatment) which presented most of the parents with a continuing challenge.

"Crisis theory" and many of the ideas which it brought to psychological medicine and social work have been overtaken by other developments. Nevertheless, the importance of a "crisis" as a period of adjustment and its various stages continue to be acknowledged by practitioners. Some of the ideas which originated in the period in which "crisis theory" prevailed developed a research interest of their own. Some of these pertained to the study of bereavement and other types of loss. This body of research and theory is also relevant for understanding change.

Studies of bereavement and loss

The research of Lindemann about fifty years ago on the grief reactions he found in persons who had been bereaved, inspired a range of studies on reactions to death of a close relative which is a normative crisis that most individuals face at some time in their lives. He identified what he considered to be the course of "normal" grief reactions which was essentially a time limited mourning process, and those he termed "morbid reactions" which were a sign of psychological disturbance requiring professional help (Lindemann, 1944). His early work inspired many others, notably Parkes, whose extensive work has highlighted the elements of the loss that a bereaved person suffers, and the defences that are deployed to reduce the anxiety that is actually felt or to help the person recover, in some ways, the lost object (Parkes, 1986).

Studies of grief reactions have also addressed other forms of loss, Bowlby (1951) and Robertson (1952), for example, described grief reactions in young children who were

separated from their mothers. Grief reactions have also been studied as "anticipatory behaviour" where it has been seen to have features similar to those in the mourning process. Futterman and Hoffman identified clear signs of "anticipatory grief" in the parents of children with leukaemia (Futterman and Hoffman, 1973, quoted by Kemler, in Koocher and O'Malley, 1981, p.130). One characteristic which they observed was that when the child is known, or believed, to be approaching death, the family's emotional attachment to the child "loosens" in most cases, while some other parents react in the opposite way.

The particular relevance of the research on bereavement and loss for my study pertains to the life-threatening nature of the illness. The findings of the different studies relate to both the fears that were constantly in the parents' minds and the loss of the "expectations" which the parents had of the child prior to the illness. Sourkes, who has studied the reactions of families to a life threatening illness in one of its members, sees the post diagnosis situation as being "an irreversibly altered reality" (Sourkes, 1982, p. 45).

Coping theory

In the literature review I have referred to some of the psychological research into the ways that people cope with stressful situations including adverse life events. Some of these studies are rooted in psychoanalytic ideas, while some of the more recent studies have adopted a wider approach and incorporated aspects of learning theory. Arguably the most influential writers on coping in recent years are the psychologists Lazarus and Folkman who have developed a theoretical model to explain coping behaviour (Lazarus and Folkman, 1984). Their definition of coping is one which is now widely accepted by researchers who are looking at psycho social aspects of childhood cancer and other childhood illnesses. It is the Lazarus and Folkman model which can be said to be constituting the basis of what is now regarded as *coping theory*.

The study of "coping" as a behavioural response is of much more recent origin than crisis theory and is associated with the late 1970s and 1980s onwards. Coping theory, however, shares a similar theoretical background in that it had many of its origins in psychoanalytic ego psychology, which views it as being cognitive processes (such as ego defence mechanisms of denial, suppression and intellectualisation, as identified by Anna Freud (Freud, 1937)) as well as a form of problem-solving behaviour which is invoked to reduce anxiety and other forms of distress (Folkman and Lazarus, 1991). Coping theory also draws on knowledge gained from studies conducted on animals to examine their behaviour in life-threatening situations. Many of these have shown the

intensity of an animal's drive for survival seen in its efforts to protect itself or to defeat an enemy. While the studies on animals have emphasised the influences that fear and anger have on emotion, much of the research on coping has recognised that an individual's emotions are the key to coping behaviour (Lazarus and Folkman, 1991).

While accepting much of the research evidence on coping, Lazarus in 1966 began to recognise the "incompleteness" of the coping theories which were then in vogue. Subsequently with his colleague Folkman he began to suggest that coping was more than a reactive response to emotion or tension. He began to identify the other factors which are involved. A principal element is the way that a person "appraises" the significance of what he or she is experiencing to his or her well-being. This appraisal incorporates both cognitive and emotional elements which determine the behavioural response. A major criticism which they had of the current approaches to studying coping is that undue emphasis was placed on how an individual's personality and emotions influenced their way of coping. They argued that coping was a reciprocal process and that insufficient attention had been paid to the effect that coping behaviour itself had on a person's emotions. This was particularly apposite in situations in which coping was taking place over an extended period of time, as it allowed for learning and development in the individual to take place.

Lazarus and Folkman have developed a model of coping behaviour based on it being an interactional process between a person and the "environment", (that is the overall context in which coping behaviour is required) and which is influenced by other factors. Coping is seen as consisting of "cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person". (Lazarus and Folkman, 1991, p. 210). The "efforts" that the person makes in coping with any stressful event are, in their view, not predisposed by individual personality nor do they reflect a particular style of coping. A person's "efforts" are based on how the individual "appraises" the situation. Appraisals are seen as being both a cognitive and an emotional exercise which can be affected, over time, by changes the individual experiences as a result of, for example, any feedback that an individual acquires through learning about what has happened before, or from any changes in the "environment" which may have taken place separately.

The model envisages two types of coping behaviour. One is "problem-focused" i.e. activity directed at altering the situation which is causing distress. The other is "emotion-focused" which is activity aimed at modifying the level of distress.

Figure 9.2 gives in a simplified form the main elements of Lazarus and Folkman's model. I should emphasise that this figure is one which I have created based on more detailed models which the authors present, as my intention is to give only the main elements of their well-developed theory. My illustration in Fig. 9.2 shows the main processes which take place starting at the first "encounter", which is the time when the individual confronts the initial stressful situation. The authors recognise that every encounter, even simple ones, are multi-faceted and often have more than one emotion (and sometimes contradictory ones). They also acknowledge the "temporal and unfolding" qualities of the coping process (p. 226). By this they appear to acknowledge elements derived from crisis theory. Each encounter comprises different stages which they define as "anticipatory", "confrontational" and "post-confrontational" (p. 226). Coping in an anticipatory context offers a different opportunity from that which is attempted after confrontation. Emotions constantly shift throughout the whole process, adjusting to changes in the environment and within the person.

In summary, it can be said that Lazarus and Folkman attached a higher degree of emphasis on the concurrent developments and context for explaining coping than previous theory had done. Their model recognises the complexity of the range of interactions and influences. It is a model which is increasingly influential on current researchers including those whose study psycho social aspects of childhood cancer.

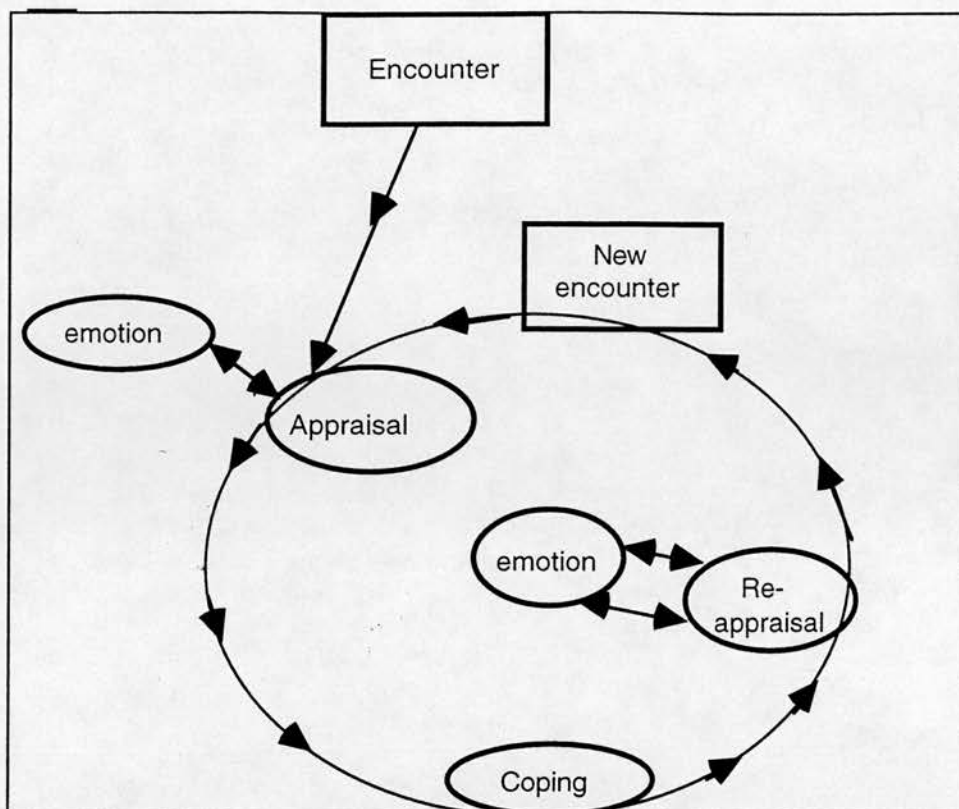


Figure 9.2: Coping and Emotion based on Folkman and Lazarus "Coping as a mediator of Emotion" (Folkman and Lazarus , 1991, p 214)

These different theoretical perspectives, crisis theory, theories of bereavement and loss and coping theory, are linked in some ways. They have collectively been the mainspring for many developments in practice in social work and medicine over the past twenty years. For the purposes of this study they will be the background for much of the analysis of coping and for the implications for policy and practice in the following chapter.

Applying theory to practice: understanding the changes in parents

"Crisis theory" gives a basic framework for examining the overall adjustment that parents had to make in coping with the illness. Although knowledge of human behaviour has developed substantially since this approach was pioneered, the main stages and elements of a "crisis" are still generally accepted. The period around the point of diagnosis of the child's illness was traumatic for everyone and constituted a "crisis" in the sense that the existing ways of coping with stressful events appeared to be insufficient. Invariably the early stage of the treatment was a period of confusion

and fear, concealed to some extent by the high level of activity that was required, much of which was of a practical nature.

As treatment gets underway and begins to have some impact on the process of the illness, a "reorganisation" phase begins. Many of the changes that the parents had experienced by the time I interviewed them, between 6 and 9 months later, were part of a process of adjustment. This is seen particularly in the way that home life was beginning to resume some of the characteristics it had prior to the illness. My findings on the "new normality" that many parents were trying to achieve for themselves and their family (which I discuss in Chapter 5) convey some of the changes that were being experienced.

Bereavement and loss . The short description I have given of the general thesis of studies concerned with bereavement and loss helps to explain some of the emotional aspects of the changes which the parents discussed with me. The emotional elements could be seen in particular in the new closeness between parent and child which many parents felt had developed during the illness and in the shift in values and priorities which had also occurred. Emotional factors were also an integral element in the parents' tension between remaining hopeful that the child will recover and facing the fact that the child might die.

Studies of bereavement and loss can explain the many expressions of sadness that many parents have shown clearly in their descriptions of events and in the affect they showed when discussing these matters in the interviews. When the parents began to appreciate the implications of the illness, they were in a sense experiencing a "loss" in that the "healthy child" that they knew had been "replaced" by a child who was ill. My study was not designed to look at feelings of "loss" in any detailed way, and for this reason it would not be appropriate for me to form a definite view on what it was that parents felt they had lost. The research data however was sufficient to say that one of the ways that many parents had changed was that they had experienced a sense of loss. One parent put it this way, "You are always living in fear.....you are never going to be sure he is going to grow up".

Signs of "anticipatory loss" being experienced have been observed in some studies of parents of children with cancer (Koocher and O'Malley, 1981). These signs were often associated with either the strengthening or loosening of relationships. My study showed only those in the first category, i.e. stronger relationships of the parents with the sick child and closer relationships also with the other children in the family. The strengthening of relationships was in keeping with the stage of the illness the child was

at. It was at a point when treatment was having an impact and when the parents were determined and hopeful that their child would recover. Nevertheless, the parents' determination did not conceal totally some ambivalence on the matter. Their ambivalence was caused by their constant fears about the child's future. These fears account also for the ways in which their view of life had changed, both in terms of priorities and changes in philosophy.

Coping theory. The hypothesis of Lazarus and Folkman has been described in some detail, because the model of coping which they have devised from their research is very relevant for identifying the range of processes involved in coping. Their model has also been useful for analysing the ways that parents felt they had changed in the illness. In viewing coping as being a dynamic and interactive process in which the individual is engaged, deploying both cognitive and emotional behaviour, they see "change", achieved by learning and psychological development, as being an integral part of an individual's coping process.

White's theories on adaptive behaviour, which precede Lazarus and Folkman's work but take into account some of the same variables, also stress the importance of change. In explaining the "temporal dimension in adaptive behaviour" (White, 1974, p. 58), White contends that an individual's characteristic way of dealing with a problem will not necessarily be the way he or she deals with it on future occasions. One reason for this is what he refers to as the individual's "autonomy" (p. 57), which requires the maintenance of a freedom of action.

In Figure 9.4, I have shown some examples of "change" as reported by three parents in the study, against the corresponding emotional and cognitive aspects that appeared to be associated with the particular change shown. Some of the aspects are manifestations of changes while others are possible influences upon it.

There is insufficient data from my study to enable a clear association to be made between cognitive and emotional factors and the specific changes that parents reported. The present state of knowledge on "coping theory" also discourages speculation on the matter. The ways that "emotions" and "cognitions" interact is not sufficiently understood. This is a matter I will be discussing in more detail in the next chapter.

Figure 9.4 : Examples of change in three parents showing examples of emotion and cognition

Example of change	Emotion	Cognition
A parent develops closer relationships with the sick child.	Feelings of loss (devastation) and anger. Sense of "helplessness".	Realising need to show affection. Finds time to be with children. Discussing with child difficult issues e.g. possible death
A parent changes priorities, sees health as being the most important	Present experiences valued highly and made "happy" ones. Close relationships are enjoyed.	Decision to move house is postponed. Commitment to work is reduced. Finds time to concentrate on the treatment.
A parent becomes accustomed to uncertainty about child's life expectancy.	Irrational fears about prognosis. Feelings of impending catastrophe.	Parent learns about progress of illness by observing other children with cancer. Parent starts to understand the meaning of symptoms.

Conclusion

In this chapter I have reviewed some of the changes which the parents felt they had experienced during the course of their child's illness and treatment. I have described the principal changes in three separate categories:

- parents achieving more closeness with their child
- changes in values and attitudes to life
- living with a high level of anxiety

Examples of change in each of the above categories have been described from the interview data.

I have also identified a body of theoretical and research knowledge, some of which has been extensively used by the helping professions in enabling people to face stressful situations. Three theoretical perspectives have been outlined. These were: *crisis theory* which envisages an individual's need to develop new patterns of behaviour for dealing with stressful situations when the normal behaviour proves to be inadequate; *bereavement theory* which has its origins in studies of mourning and grief reactions and explains the way individuals react to any form of loss; *coping theory* which is of more recent origin than the other two and conceptualises coping behaviour as being a dynamic process involving a range of influences and both cognitive and emotional behaviours.

These three theoretical perspectives have helped me to examine both those changes which I observed in the parents and those which they explained to me as ones they were experiencing. Crisis theory and studies of loss and bereavement appear to be particularly relevant to the early stages of the illness as parents heard about their child's new diagnosis and began to react to the implications of the illness. Coping theory has been particularly useful in identifying some of the complex process which all changes in behaviour involve. Most relevant to change is the way the individual appraises the situation which he or she needs to encounter and the way that the appraisal is affected by both cognitive and emotional influences. These processes or changes are inherent in coping.

In this study it has not been possible to chart the progress of change that the parents went through on an individual basis. Nevertheless, the study's focus on both current developments in the parents' lives and on retrospective events, enabled the view to be formed that many of them had changed during the course of the illness. Some of the implications that this observation has for understanding coping is discussed further in Chapter 10.

CHAPTER 10

A REVIEW OF THE MAIN FINDINGS

In this short chapter I will review some of the main findings of the study in preparation for the conclusions which I have drawn about what coping for a child with cancer involves for the parents.

The principal themes

As I have indicated in Chapter 3, different themes were drawn from the interview data as a result of detailed analysis. The themes as a whole have a presentational value in illustrating many of the activities and stresses that parents face during their child's illness.

The themes also serve another purpose in that each of the four main themes is concerned with a separate aspect of human behaviour. Each is linked to a dimension of coping and provides part of a picture of what is involved for parents in coping with their child's illness.

The theme which I have entitled "*Redefining Normality*" is essentially concerned with many of the day to day activities which parents experience in their social functioning routines, in particular their roles as family members. The task of finding a new normality for themselves was an important one. For some parents it was a goal and provided a degree of control over their situation and a sense of purpose. For others it gave a measure of progress and a sense of achievement.

"*Maintaining Hope*" concerns a more personal and private aspect of human behaviour, in particular the way that the parent experiences the realisation that the child may die as a result of the illness. It draws substantially on interview data from the parents on the emotional issues which they experience. Parents were, in general, optimistic and hopeful in their approach to the illness. They tried to be strong for the sake of their child and as a way of containing their own fears and anxieties.

The theme "*Negotiating Social Support*" is concerned more than the other themes with individuals, groups or systems that are external to the parents and the family. It is the theme which addresses most directly the parent's relationship with others. The support parents received was important to them and some parents were

sustained by this help. In view of the ambivalence which parents had about receiving help and the cost involved for them in accepting help from some sources, the way in which receiving of help is connected to parents' coping is not clear.

The fourth theme which I have called "*Caring for the Child*" is concerned with the responsibilities of care that parents have and the complexity of the task which the parent faces in both caring and supporting the child during the illness, while participating in the medical process and administering some of the treatment. The new demands on parents clarified and reinforced their identity as a parent and this, together with the strengthened relationship with their child, was a powerful motivating force for coping.

It is my contention that these four themes are principal dimensions of coping and that each deals with sets of tasks which parents of children with cancer experience in coping with the illness and treatment. My argument is supported by the findings of other research studies which I have reported in Chapter 2 and in the concluding sections of each of the chapters in which the themes have been described. My argument also gets some support from the social workers' survey which I conducted. While my methodology does not allow a direct comparison of the of the social workers' views with those of parents (see Chapter 3), the criteria of effectiveness in coping that the social workers identify fit well with the themes of the study and the skills that are required in parents to be able to meet some of the key tasks.

Another proposition I am making, is that three of the themes ("*Redefining Normality*," "*Maintaining Hope*" and "*Caring for the Child*") help to explain the strong sense of determination and motivation which I found in many of the parents. These three themes all contain elements of purpose and achievement which are in keeping with the dictionary definition of the word "coping" (see page 3).

"*Negotiating Social Support*", however, is a theme in which the relationship of the activity to coping is less clear. Although many research studies have shown that social support plays an important part in helping parents to cope with the illness (as this study has also done) the direct relationship between the help that the parent receives from others and the way that the parent copes with the illness is ambiguous. The issue is clouded by factors such as the variability in the resources that are available to help any individual parent, the parent's choice in the matter and the strong ambivalence that many individuals feel about asking for and

receiving help. It is my view is that more detailed research is required to explain the relationship between social support and coping.

The relevance of change

My findings have also shown the relevance of change to the process of coping. I have described many of the changes that parents experience, some of which were substantial, and I have discussed these in relation to some major theoretical perspectives. One perspective was crisis theory which views a person's behaviour in a stressful event in terms of adapting to a trauma and gradually readjusting. This approach helps to explain some of the experiences of parents particularly in the early part of the illness.

Another perspective was given by coping theory, which is of more recent origin, which deals with human behaviour in stressful situations over a longer period of time. I paid special attention to the work of Folkman and Lazarus whose interactional model of the factors that influence human behaviour have challenged many earlier ideas. Their approach, which I discussed in detail in Chapter 9, views coping as a process, with a series of progressive stages, each of which is influenced by emotional and cognitive factors which in turn take account of the learning that the individual acquires as experience is gained in the process.

The parents views on the matter, taken together with the theory, in particular coping theory, help to demonstrate some of the characteristics of the coping process and enable me to conclude that it is both an evolving and developing one, and not one that is fixed or static or determined only by the parent's personality traits as some early research had viewed it to be the case (for examples see Kupst, in Bearison and Mulhearn, 1994).

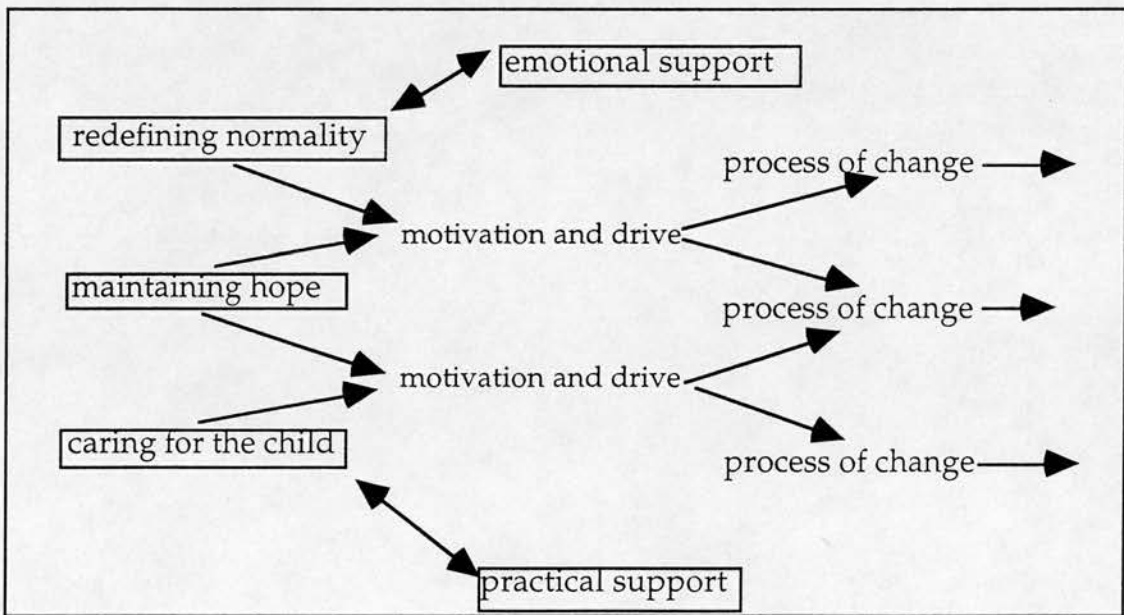
My interview data on the process of change has been very helpful in establishing some of the characteristics of coping which I discuss in the next chapter.

I attempt to summarise the findings in illustrative form in Figure 10.1. The figure is very much simplified and its main value is in showing the connections between the dimensions of coping. In the next chapter in which I give conclusions to the thesis, I define a number of important factors of what coping involves, including those which help to explain its variable and spasmodic nature, and discuss other influences such as the importance of cultural factors. None of these are shown in this particular diagram. It might be helpful to consider Figure 10.1 in conjunction

with Figure 9.2, which depicts a model of coping based on that proposed by Lazarus and Folkman, which illustrates the spiralling nature of coping processes and reappraisal which occur dynamically .

In Figure 10.1, the boxed categories are the themes (the ranges of tasks) outlined in Chapter 5—8. Three of these are presented centrally, as opposed to the fourth theme (“Negotiating social support”) which is of a different nature from the others and is split, in this figure, in terms of its elements of practical and emotional support. The central three themes are the dimensions of coping which create the motivation and drive which carries forward the process of change. The parent’s motivation and drive and personal characteristics, including the way they change during the course of the illness, are also determinants in the process of coping.

*Figure 10.1 Dimensions of coping for parents of children with cancer
(Based on themes in Chapters 5-9)*



CHAPTER 11

CONCLUSION

My study has shown that coping is a behavioural process which starts from the moment that the parent learns that his or her child has a cancer illness. The initial period is a traumatic one for every parent but as each gets to know the medical and nursing staff and becomes involved in the treatment, confusion is gradually replaced by an appreciation of the implications of the illness and an awareness of the changes that will be required, for an indeterminate period, in their own and their family's lives. From the accounts of the experiences that parents discussed with me in the interviews, it can be said that coping with the child's illness is a complex challenge for every parent.

Identifying and analysing what coping involves for parents whose children have cancer have been at the heart of this study. My findings have been presented in this thesis around a structure of themes drawn from the parents' detailed accounts of their experiences. The four principal themes, together with my analysis of the process of change which parents experience during the course of the illness, give a comprehensive account of what coping involves for parents of children with cancer.

Effective and non effective ways of coping

In my introduction to the thesis, I indicated that the study would not try to identify effective forms of coping, and that the study would concentrate on trying to understand what coping involved in general for the parents of children with cancer. It had become clear to me that it was premature to put any emphasis on defining effectiveness when the present state of research knowledge about what coping consists of for these parents is very limited.

I did, however, include a brief focus in the interviews on effectiveness when I asked the parents in the study to estimate how well they were coping and give the reasons for their opinions. Their responses on the matter, together with my other findings about the dimensions of coping, enable me to make some observations on what might constitute "effective" ways of coping and conversely, to suggest what "not coping" means in the case of parents of a child with cancer. For many practical purposes in health care, including the social worker's assessment of the support services a parent might require, the question of estimating the effectiveness or non

effectiveness of a parent's coping is highly relevant. It is interesting therefore to review the self assessments on the matter which the study shows.

Most of the parents in the study (14) saw themselves as doing "well" or "very well". Figure 11.1 summarises the responses they gave and gives the basis on which they had made their judgement. Several parents claimed that they had surprised themselves by how well they were coping. A typical comment made by parents in both the "very well" and "well" groups was that they felt a sense of achievement about what they had done. It is important to recall that their observations on themselves were made by parents at a comparatively early stage of the illness, that is about nine months after the diagnosis, and the treatment outcome for most was still very uncertain.

The figure shows that many of the parents were included in the "coping very well" and "coping well" groups, and gives example of the reasons for their opinion, showing, for some parents, the sense of achievement which they felt. Even among those parents who did not evaluate their coping highly, some satisfaction with their performance was evident. It is interesting to look at this explanation against the theories of Erikson and White.

Erikson's writings have focused extensively on an individual's identity formation, seeing it principally as a maturational process, which is shaped also by cultural and social influences and experiences (Erikson, 1963, 1964). The parents in the study had subsumed a new "identity" as the parent of a child with cancer, in the sense that Erikson uses the term, as being a way an individual identifies him or herself in relation to the outside world. They were associating with other parents of children with cancer and were clearly becoming accustomed to their new role, taking on the many responsibilities which it brought for them.

This identification was clearly important to the parents. Many showed it, for example, in the way that they acknowledged the parents support group. In rating themselves, some parents took the ways of coping that they observed in other parents as a reference point. Identification with other parents was a source of satisfaction in many but not all cases, and, as a result, many acquired a sense of self-esteem. White, a psychoanalyst with an extensive research interest in the subject of ego development, attaches importance to self-esteem as a means of coping. He links the acquisition of self-esteem also to feelings of efficacy and

competence that a person has (White, 1992). These feelings can be generated within the individual but often have to be reinforced by the judgements of others.

Figure 11.1: How parents evaluate their own coping

Category of self evaluation	Number of cases	Examples of behaviours
"Coping very well"	6 cases	Parents have a sense of achievement. They have confidence in their own skills. Strength is gained from the sick child and other children in the family.
"Coping well"	8 cases	Parents "keep strong" for child and family. Parents set limited objectives and take "a day at a time." There is satisfaction from managing well. "Just getting on with it."
"Not coping very well"	3 cases	Coping in some areas e.g. when the child is well. Does not find talking helpful. Takes time out or withdraws from other people.
"Don't know"	2 cases	Parents are fearful of future. Determined to get child through. Sometimes overwhelmed by uncertainty.
N=19		

In keeping with White's theory, it can be said that the satisfaction a parent feels with his or her own achievements strengthens their efforts to continue to face up to the many demands that the illness brings. Many of the parents made this point, particularly those who had regarded themselves as coping "well" or "very well". Also, one parent of the "don't know" group felt that she was "growing in confidence" and developing an expertise in how her own child was responding to the treatment. Her "don't know" self-evaluation conceals both the determination

she showed and the learning which she was putting to good use. A more objective assessment was that she was coping well and her hesitation about acknowledging the fact related to her fears of the future.

In assessing whether or not an individual is or is not coping effectively, it is important not to rely only on his or her self evaluation unless it can be supported by sound evidence. Chesler and Barbarin have made the observation that when the parents of children with cancer are asked to evaluate their performance in coping their answers are usually monosyllabic and usually positive (Chesler and Barbarin, 1987). The high satisfaction rate that I received from the parents is consistent with their observations, although my clear impression of the parents in my study is that most were coping relatively well and some of the reasons that they gave were supported by other information which they had given elsewhere in the interview.

The parents' self-assessments, together with some of the findings of the preliminary study of social workers which I conducted, can help to further the understanding of what the phrase "coping effectively" might mean. There was a clear correlation in the interview data between those parents who rated themselves as "coping very well" or "coping well" with many of their observations suggesting satisfaction with their performance in key tasks in two of the four themes, "redefining normality" and "caring for the child." Some parents had a clear sense of achievement in managing the wider challenge of having to care for the child and at the same time deal with many other responsibilities.

When asked to identify criteria of coping effectiveness, social workers, in the survey, rated parents' adaptational, communication and problem-solving skills as being important (Chapter 4, Fig. 4.3). It would seem from the survey data that the social workers were able to identify these skills mainly in the family and social relationships which the parents made. This context, of a person's relationships, is a part of parent behaviour which social workers are able to observe directly or get evidence about from their discussions with the parents, or that they hear about in other ways.

I would like to suggest that when one takes the skills of parents that the social workers regard as being elements of effective coping, and links them with the parents comments about what gave them a sense of achievement, which in itself is a mark of effectiveness, there is a basis for a framework for judging how well a parent is coping with their child's illness. This idea is proffered tentatively at this stage in

the light of the fact, a point I have emphasised previously, that detailed research knowledge of what coping involves is very limited. My framework, however tentative, has the advantage, however, of being an approach which combines data both from parents' own perceptions of what is involved in coping and the professional understanding, based on the knowledge of a large sample of experienced oncology social workers, of what skills are required by the parents.

The same framework might also offer a basis for considering what "not coping" with the illness means. "Not coping" is not having the necessary adaptation, communication, and problem-solving skills, or not being able to apply these skills in the context of the different themes I have discussed in this thesis. The combination of the context and skills, or the absence of such, might be indicative of whether a parent is not able to cope with the illness. As the sample of parents I interviewed for this study all appeared to be coping reasonably well, it is perhaps not a good basis for developing ideas on what "not coping" could mean. A counter argument however is that my findings have shown what some of the principal tasks which a parent has to deal with in coping with the illness are, and it may well be that if a parent "opts out" of any of these tasks by excluding him or herself from what is required, this might be a clue that he or she may be "not coping" with the child's illness.

But care must be exercised in making any judgement that a person is not coping. When, for example, a father works long hours in order to increase the family income, this does not in itself imply "not coping," if it is done in full agreement with his partner and based on the total reality of the circumstances. Similarly, as I will discuss further below, the process of coping is not a steady course for the parent throughout the child's illness. During a child's illness a parent may be "coping" at times and "not coping" at others. Both physicians and social workers require to be able to recognise these periods when a parent is not coping and may need to offer additional support. The question of what effectiveness in coping means is relevant for many aspects of practice, and in examining the issue I have been alluding to some general characteristics of the whole coping process. These are discussed further below.

Characteristics of coping

In the last chapter, I have discussed some of the ways in which parents felt they had changed during the course of the illness. This change that is experienced

confirms that the process of coping with the illness is neither a steady one nor one which is determined at the outset of the illness by the parents' personality. As I will discuss below, coping can be understood more fully in terms of its being a course of behaviour which involves a variety of interactions rather than a concept viewed only in terms of what the behaviour achieves. As Lazarus and Folkman have shown, coping is better understood as a process rather than an outcome.

On the basis of my data I have identified some characteristics of what coping appears to involve for the parents of children with cancer. These characteristics do not appear to fit neatly into a single framework, other than in being observations which seem to apply across the themes which I developed for presenting my data, and reflect the temporal dimension of the process which allows for the individual to change. In presenting the following characteristics, I have tried to show the strength of the data which supports the observation. A particular difficulty in focusing my observations was that I was dealing with physical, intellectual and emotional factors in combination, and also trying to identify characteristics which were partly visible and partly concealed. Many of the latter were drawn from some of the evaluations that parents made in the interviews about some of their private concerns which they had not shared with others.

Coping involves effort

My findings illustrate the considerable efforts that most parents make to meet the multiple demands on them. I have described (in Chapter 5) the different ways in which they were fully involved in the treatment, how they familiarised themselves with the medical world and learned its special vocabulary, acquired new skills, often of a nursing nature, and found ways to deal with problems which could not be faced alone. Some were very determined to fight the illness. The impression I formed was that parents had to become very active both physically, intellectually and emotionally from the moment the diagnosis was made.

The capacity parents demonstrated for integrating most of their new tasks and responsibilities with their everyday lives was remarkable. There was a substantial physical burden in caring for a more dependent child—at whatever stage of development—whose health could change rapidly and who was at the same time responding both physically and emotionally to the effects of the illness. There was also a burden on parents in giving their child medication regularly, carrying out numerous health checks, and attending out patient appointments for review or

treatment. Most parents were managing all of this within the context of one of them returning to paid employment, and both meeting the needs of other children and undertaking ordinary household and family tasks. The cumulative range of responsibilities the parents had to deal with left many physically exhausted, particularly in the early stages of the illness.

The efforts that parents made included many intellectual ones, particularly in understanding the nature of the illness, the treatment regime, and the dangers involved, both in terms of the illness and the side-effects of the treatments.

The knowledge which parents acquired involved a huge leap for them in their understanding of both simple and complex medical ideas. Parents had all acquired, to a varying degree, a knowledge of treatment protocols, medication, implications of the various symptoms the child might have and of the results of medical tests. Much effort had been invested in this learning.

Apart from the illness itself, the changed circumstances of the family required their attention in order to manage their lives. In seeking solutions to particular problems that they faced, the parents worked hard to consider ways of how they could use the help of others most productively.

The emotional element of effortful behaviour by parents is shown in the emotional activity in which parents engaged as they faced the demands of the changing relationships that were taking place within the family. It was clear that the relationship of most parents with their sick child had become much closer than before the illness and a new importance was attached to having close relationships with all their children. Parents indicated that they had problems disciplining their sick child and in being "fair" to other children, as they recognised that they too had been much affected by the illness. There were also changes in relationships within the wider family, from whom most parents had sought help and support. While the child's illness had drawn some families closer, in others there were additional strains. Similarly some of the parents' relationships with their friends were changed in nature. Adjusting to relationship changes made enormous emotional demands on them.

Other efforts were required for balancing the conflicting emotions involved in maintaining the hope that the child will recover and containing the fear that the child will die. For some parents the need to remain optimistic in the face of a poor prognosis was seen as being an important driving and sustaining force in their

capacity to cope. Remaining hopeful in spite of many fears and anxieties, and in the context of constant changes in the state of their child and the treatment process, placed considerable demands on the emotional energy of all the parents.

Coping involves learning

From the moment they are told the diagnosis, parents are involved in learning, both about the illness itself and about a wide range of other matters. In Chapter 5, in which I examined the way in which illness affected the every day life of the parents, I have described the variety of ways they had become very involved in administering some of the treatments. This experience had required them to learn a medical vocabulary and a variety of new skills often of a nursing nature.

Learning also involved other aspects. A variety of new practical skills were acquired by many. One father learned to cook, which he had not done before, and felt some satisfaction that he had acquired a new skill which others appreciated. A mother, who was at the outset of the illness a very unconfident car driver, quickly improved as her journeys to the hospital required this of her. These acquisitions of practical skills were in some cases a necessity, possibly a way of displacing anxiety, and in many cases a tangible way that individual parents played their part in supporting their partner and other members of the family.

The new knowledge which parents acquired was, for some, substantial and included understanding complex medical ideas. Getting an understanding of medical procedures, such as protocols, drug treatments and their side effects, and the significance of symptoms, might not have come easily to many of them, but the knowledge they showed as they discussed them with me in the interviews was impressive.

Learning was not confined to practical skills. Parents also learned about their own child and developed new parenting skills. Chesler and Barbarin have observed that doctors need to recognise the expertise that parents bring in this respect to the management of the illness (Barbarin and Chesler, 1986). This expertise can be enhanced as they learn how the child reacts to the various treatments. As I have shown in the findings, observing and learning about their child was characteristic of many parents.

Coping is personal and private

In my study all the parents perceived their experience as being a personal matter and one which was not fully shared with anyone else. This finding seemed to be true of all the cases including those in which a parent had a close relationship with his or her partner. While marital partnerships in general were an important form of mutual support and offered parents an effective means of sharing the many commitments that they had to meet, these advantages did not remove the sense of isolation that everyone felt at times.

The above observation is one which does not seem to have been emphasised in other research studies. As I indicated when I reviewed the literature, many studies which have examined aspects of parental coping are inclined to view parents as a couple rather than as individuals. In addition, the research methods of some studies which have relied principally on psychometric testing or on taking the views of only one parent, usually the mother, have not enabled a parent's personal perspective to be examined in any depth.

That said, it has to be acknowledged that many parents are reluctant to reveal their private feelings to anyone. From the detailed accounts they gave me, it was clear that many of them felt that the image which they presented to the outside world was in fact a facade and not a true representation of their feelings. The real self was one of turmoil and fear. Two of the parents interestingly used the same metaphor to explain their experience, saying that they were "screaming inside," while they felt that outwardly they would appear to be calm. The fact that parents can reveal such information in a research interview demonstrates the importance for practitioners of being aware of the isolated nature of the process in which parents are involved and sensitive to the part of parents' feelings which may be concealed.

Coping offers parents an opportunity for personal development

The many emotional demands which the child's illness makes on the parents have been described throughout my findings. It has been difficult, however, to specify what particular characteristic these multiple challenges represent. I have concluded that the most I can say is that, from their descriptions of how they faced up to their responsibilities and took on tasks for which they had never been prepared or expected to have to undertake, how they readjusted their lives and used their cognitive abilities to control many emotional responses in their interaction with their child or others, was that the experience had given them an opportunity to "grow"

psychologically. My clear impression was that some change, particularly in the young parents, had been maturational, although the research approach adopted for the study did not enable me to make any assessment of this. It is on this basis that I regard the whole period of the illness as an opportunity for growth and that many of the parents had taken advantage of it.

Coping is variable

The process of coping is uneven. Almost every parent acknowledged this point in the interviews. Although many felt they had changed and had become "stronger" emotionally as the illness progressed, they also indicated that there were many fluctuations in the way they coped. For some this started at the diagnosis. While most parents had immediate strong reactions, some felt they had, or showed, no reaction at the time but several days later they became anxious and depressed as they began to appreciate the full implications, both in terms of the aggressive treatment which was involved and the possibility that ~~their child~~ might die. "Delayed shock" was the description that some parents gave to this behaviour.

This way of dissociating an emotional reaction from the actual time of the event was common in the way they described other incidents particularly matters in which they dealt effectively at the time, for example with a medical emergency, and subsequently felt very distressed. Sometimes their anxiety about the illness was displaced on to a comparatively trivial matter. On occasion, panic attacks seemed to come out of the blue, such as in an incident in which a parent had to rush out of a treatment room although she had previously been able to remain with her child.

The impression I had was that the parents' ability to cope was variable, often depending on outside influences and events, but depending also on the prevailing mood which at times had many depressive features. Even those 12 parents who in the study adjudged themselves to be coping "very well" and "well" (see Figure 11.1) indicated that at times they found it difficult to manage. The outside influences were many, such as the health of the other members of the family, progress in treatment and, above all, the influence the sick child had on the parents. This last seemed in fact to be of considerable importance and I discuss it below as a separate characteristic.

Coping is influenced by the parent's interaction with their child

My study was not designed to study the parent-child interaction, but the importance that parents attached to their relationship with the child was quite evident in the interviews. The responses of a substantial number of the parents showed that the relationship with their child was a source of strength for themselves throughout the illness. As I indicated in the last chapter, there were a number of patterns to the types of relationships that the parents seemed to have with their children, and each one had an important impact on the parent's coping.

Many of the parents clearly attributed their own capacity to sustain coping principally to their relationship with their child. One parent who had a very close involvement, told me that "if S. is not well, I'm not well, but if he's good, I'm good..." Most others were less involved than this, but from the way they spoke about how they watched their child continuously and played with and took courage to themselves from his or her efforts, I concluded that the relationship had a strong influence on parents.

The hypothesis which van Veldhuizen and Last (1992) have developed in their study of communication in families of children with cancer, to which reference has already been made (in Chapter 2), strengthens my impression that the parents' relationship with the child is an important characteristic of coping. The hypothesis that much of the communication between parents and child during the illness is of a non-verbal and unconscious nature must be considered speculative at this stage. Van Veldhuizen and Last argue that the behaviour of both parents and child are connected and motivated in part by a form of mutual support to protect each other from the stress caused by the illness. This is an area which requires considerably more research and could be fruitful in terms of getting a more detailed understanding of what coping involves.

What coping is not

The identification of the main characteristics of coping also enable clarification of aspects which my findings do not support. Some of these are the converse of the characteristics I have identified in coping.

First, coping, in being an individual matter, is not a family or group process. Most of the parents in the study were married or in partnerships with the result that two parents were generally involved in coping with the illness of the one child. These

parents shared many of the same feelings and provided mutual support. Some worked well as a "team," dividing up the work and each complementing the strengths of the other. In situations where parents had a close relationship, they were often able to recognise that they each responded differently to their child's illness and said so clearly in the interviews.

Coping does not appear to represent a fixed trait in an individual. My findings show a range of influences on the parent which have a bearing on their coping, and that they are all capable of change throughout the progress of the illness. The idea that individuals have a fixed way of coping are associated mainly with earlier theories of psychological development, including the psycho dynamic perspective (Lazarus and Folkman, 1984). The more common modern view is to accept that there is some pre-disposing factors in an individual's personality which has a bearing on their style of coping, but that the contribution is minimal (van Veldhuizen and Last, 1991). Lazarus and Folkman's work has been highly influential in this respect. To label an individual as being a "repressor" or "denier" in terms of coping as some researchers have done (for example, Moos, 1974), seems to be inappropriate in the light of new knowledge.

Another way in which coping is often viewed is as a "strategy" which an individual or group uses. Strategy in this sense is a pattern of behaviour, some of which is used on a conscious basis. The focus on strategy is usually associated with researchers who make use of psychometric measurement scales to assess social functioning, which I discuss in the review of the literature. My findings have caused me to question whether it is helpful to view coping as being a strategy. Not only are there a wide range of influences on the individual, but the interactive processes between cognitive and emotional factors, indicate a much more detailed picture than the term "strategy" implies. Lazarus and Folkman also appear to question the validity of viewing coping as a strategy. They argue that some researchers confuse "processes" with "outcomes" in studying coping. They suggest that an individual's "strategy" can only be seen in terms of what it achieves or produces, i.e. outcome. Any definition of coping, they argue, "must include the *efforts* to manage stressful demands regardless of outcome." (Lazarus and Folkman, 1991, p 201). My own view gets further support from the views of Eiser. She indicates that present knowledge suggests that while a particular strategy will work for one individual it will not work for others (Eiser, 1995). This concurs with my findings on the individual nature of coping which I have described previously and which is an important characteristic.

The relevance of drive and determination to coping

The characteristics of coping with a child with cancer can be summarised as being that it is a private and personal matter which involves the parents in learning and possibly in psychological development, often of a maturational nature. Coping also involves determination and drive. This was evident from the high level of physical and emotional energy that parents appeared to expend throughout the illness. This drive accounted for the way efforts were sustained over time and, at times when parents spirits were low or they were depressed, helped them to "pick themselves up."

It was interesting to look at the findings to try to identify the sources of parents' drives. There seemed to be three main sources:

Post-traumatic anger

The first stemmed from an initial reaction experienced by some parents to "hit out" at the illness. The initial reactions of "shock" and "devastation" were internalised reactions. Soon they were replaced by expressions of anger which was often undirected initially. Gradually, as parents began to ally themselves with what was seen as a route towards the child regaining health, their anger was transformed and became part of the medical effort to tackle the illness. This was evident in the good and trusting relationships which many parents were able to develop with the medical staff who were treating their child.

Sense of responsibility to child

Secondly, parents' determination was due in large measure to a sense of responsibility to protect their child. As I have discussed in my findings, some parents discovered in the illness what it means to be a parent in terms of decision making about the treatment which was involved, their advocacy for their child when it became necessary to take a stand on their behalf, and providing care and nurturing for their child on a daily basis. Their identity as a parent to the sick child and acceptance of the role was an important influence on all the efforts they made.

Strength gained from the child

The sick child provided a third source of energy for the parents. This seemed to take one of two distinct forms. The first was the parents' clear recognition of the

needs of the child which they recognised and reacted to. In some respects this type of energy was not too distinct from that discussed above. The second form was the parents' responsiveness to the changing behaviour of the child, seen as the child's expressed wish for love and attention or in the child's reactions to treatment. It was immaterial whether the child was responding positively or negatively to the treatment. The parent seemed often to interpret the child's behaviour in a way that helped to refuel their own energy for coping with the illness.

These three sources of energy help to explain the high level of drive that parents seemed to show through their descriptions of coping. The coping model of Lazarus and Folkman does not address any of the drives which sustain coping, but it explains how the drives are directed and modified from the time of the parents' first encounter with the illness and the stress generated by the diagnosis. The way in which the parent "appraises" and subsequently "re-appraises", in Lazarus and Folkman's terminology, the stresses they face is an important element in their course of coping. My findings however, raise some questions about the completeness of the model. This pertains in particular to the interplay between cognitive and emotional factors, and the lack of clarity about how their combined interaction influences the processes of coping, including the appraisals. I would argue that in understanding coping one must recognise that many emotional influences on the parent are likely never to be fully identified or understood. Therefore, in drawing any conclusion of what coping involves one must guard against offering too facile an explanation based on the more observable aspects.

Cultural issues

The parents in my study were all white European and indigenous to the south east of Scotland, many having some members of their extended family living nearby. My approach did not enable me to separate out from the other data the part which gender or cultural factors played in the coping process, but I wanted to take some account of aspects which had been omitted from other studies. This point is particularly relevant in relation to fathers' views of coping which have often not been taken into account except by subsuming the father's perspective within a more general family focus, or by the researcher relying on accounts given by the mother. For these reasons, I was keen to ensure that the fathers' individual views were included in my study.

I found that fathers took less responsibility for the day to day treatment procedures which their child required than mothers did. The overt reason was that most of the fathers in the study had returned to their employment, and therefore had less time available to be with the child. But most of the fathers seemed to acknowledge that their partner had the principal role in administering the treatments and for keeping track of what was required. They also admitted that they themselves would have had a difficulty in carrying out the treatments in the same way that many of the mothers did. A few fathers, on the other hand, were much involved in their child's treatment, even after their return to employment. Even in these few cases, the mother played a more active role in the day to day care of the child.

As I have discussed previously (Chapter 6) all the parents described vividly the very strong emotional reaction they had experienced when they discovered that their child had cancer. There were noticeable differences between the mothers' and fathers' reactions. The fathers were inclined to be more vehement than the mothers in the way they expressed, in the interviews, the outrage, anger and frustration they had felt about the diagnosis. The way they described their feelings gave the impression that their self image as a "protector" of the family unit had been shaken considerably. This impression got some support from the way that the fathers discussed with me the changes which the illness had brought for them. Most of the fathers spoke with feeling of the greater amounts of time they now spent with their children and they reflected on the degree of enjoyment which they derived from this. Their employment was seen as being much less important, although a necessary part of their lives. Material matters became less significant in their value system.

Faulkner observed in her 1995 study in the north of England, that when she interviewed fathers (Faulkner et al, 1995), she found that their "philosophy of life" had changed as a result of the illness; they had changed many of their ways of living and placed a strong emphasis on "living in the present" and not planning ahead. My study supports her view that the fathers had changed but suggests (in Chapter 5) that these changes may have been of a more fundamental nature in terms of the new values which the fathers had acquired. Whether these changes would be maintained in the long term is difficult to assess.

Another distinction between mothers and fathers was that the fathers in my study found it harder than the mothers to use the support that was available to them from the hospital. One explanation could be that their contact with the hospital as their child's treatment progressed became less frequent than the mothers'. Another

was that the fathers seemed to be particularly uncomfortable about being present in a hospital. Three in fact had used the word "phobic" to describe their feelings of what it was like for them.

Some of them also said that they were inclined to resist help which involved "talking." In general, they appeared not to be accustomed to talking about their concerns nor expressing their feelings. Some told me specifically that they did not find talking to be helpful, a point which is supported by other research which shows that women attach more importance to help which involves "sharing feelings" than men do (Belle, 1987). But my impression nevertheless was that fathers' emotions are affected as much as mothers' by the child's illness and it is important that practitioners offering support services should not steer away from finding ways to help them with their emotional concerns. More generally, hospitals and social service agencies need to be more sensitive to the difficulties fathers may have in accepting help so that they can engage them more effectively in getting support.

Although I have been concentrating on identifying some of the differences which appeared to distinguish the mothers and fathers ways of coping, I should emphasise that there was no homogeneous pattern in my sample of either mothers or fathers. Within each gender group there was a range of approaches. Within each marital partnership there also variation in the way each coped and consequently the way that each partner's role complemented that of the other. Both men and women, however, were under some pressure to conform to cultural norms, although this was more clearly defined in matters concerning employment than in any other area. The father's role as the family's bread winner, reinforced by the fact that his earning potential from employment were considerably more than the mother's in all cases, was an important consideration which was taken for granted.

My findings give support for the view that research studies should concentrate more on assessing the part that cultural factors play in coping. Cultural values and traditions have a bearing on how many individual issues present themselves to parents and the degree to which the parent is affected. My study, for example, showed parents to have a determination to fight the illness and maintain the hope that their child would recover. A similarly focused study in a culture in which there is a short life expectancy for children or in a society in which children were not valued so highly, might well have quite different findings. Cross cultural research

studies have therefore an important part to play in helping to understand what coping involves.

The importance of the social worker

The important part that a social worker plays in supporting parents and other members of the family and in helping them to deal with problems that they face has already been emphasised. The findings of my study have implications for the work of social workers, particularly in terms of the way they assess the needs of the individual parent for the support services that can be provided and the way that support services are provided.

Assessment of coping

There are four points which are particularly relevant to social work assessment.

First, the image that many parents present to the outside world conceals, or attempts to conceal, the internal struggles and tensions which they are experiencing. The majority of parents in my study indicated that the image they felt that they presented was a false one. Sometimes the picture of calmness which they showed was a response to their perceptions of what the cultural expectations were and sometimes it was fear of upsetting their child or other members of the family, including their other children or their own parents. The "calmness" which they presented was a mask behind which they concealed their own pain.

Second, parents are individuals as well as being members of a family unit. Their reactions to the illness can be different from that of their partner, even when as a couple they have a close mutually supportive relationship.

Third, parents change in the way that they respond and in the way they cope as the course of the illness and treatment progresses.

Fourth, the initial reactions of parents to the illness are not indicative of any of their ways of coping, nor is a coping "style" set at the outset of the illness. Coping is an evolving process and parents can learn new skills and develop new values as the illness progresses.

These four points may not come as a surprise to many social workers. My preliminary survey of social workers' views showed that many of the specialist social workers who gave me their observations were well aware of the problems

that parents experienced, and the individual nature of what was involved in coping. This is shown in their specific comments about the range of differences which exist between parents in their ways of coping. It was clear that many social workers recognised the complexity of the task, particularly the need for the parent to balance a number of tasks including meeting their responsibilities to the sick child and to the other children in the family, and containing the emotional atmosphere within the family unit; and in doing so, enabling the family to take advantage of times when things were going well and not be constantly overwhelmed by worries about what the future holds. Nevertheless my findings, especially those which show the personal and variable nature of coping, point up the importance of the social workers taking the time to do a careful assessment of parents' needs on an *individual* basis both at the outset and as treatment continues.

At the present time in many health care units, social workers spend a reduced time on assessment. One reason for this is the shortage of staff resources. Another is the pressure on the social worker to take steps to mobilise the provision of support services, often to enable the family to manage during a period of hospitalisation, or to enable the child to be discharged more quickly. A social work assessment requires, in my view, each parent to give a comprehensive account of what is involved for him or herself and a self assessment of how the family is managing. My findings show the range of issues which parents face and the themes of my study could be a framework for the areas which could be explored in assessment interviews.

The social worker is well placed to identify any problems that appear to be arising in the parents' relationships with doctors, or with any member of the clinical team. In view of the relevance these relationships could have to coping, it might be on occasion necessary for the social workers to intervene if necessary in an intermediary role if difficulties arise. In most cases it would probably be sufficient to alert colleagues to the difficulties which the parents may be experiencing.

The value that the parents in my study placed on the importance of having good relationships with medical staff reflect a view which the social workers also expressed in the survey. Similarly, the importance that parents' attached to the relationship with their own child, also concurs with a viewpoint that social workers expressed. The convergence of view between parents and social workers on this matter suggests that relationships are a focal point for social workers' assessments.

Organising support services

The parents received a wide range of support from many individuals and groups (see Chapter 8). This support was very important to them. The family network was particularly important. Family members were often viewed as being "reliable" and able to be called upon at any time and for any purpose. Friends were also important (and more so for parents who had few family members to call upon) but some disappointed them by not offering any form of help. Despite the high levels of support and contact with other parents in similar circumstances, most parents felt alone at times, and all were learning to live with high levels of anxiety and stress. I noticed that no parent gave any indication of their being helped specifically to deal with the stresses they faced. I would suggest that support of the individual parent can be more effective in terms of helping them to cope if it is directed specifically at the way they deal with stress.

Two specific practical approaches are worth considering in this respect. One concerns involving other parents of children with cancer. Chesler and Barbarin (Barbarin and Chesler, 1986) have made a suggestion that some parents whose child has recovered from the illness could be trained specifically to act as "educators" for parents of children currently undergoing treatment, to teach them how to cope with the illness. While this idea is not without considerable hazards, and would have to be organised carefully, it has positive merits including the advantage that it introduces the parent to a helper who has had a personal experience of what is involved.

Parents' groups have long been recognised to be of value as a support for parents. About 85% of treatment centres in the USA have such groups. There is a wide variation however on how these are organised, and some are more effective for support purposes than others (Barbarin and Chesler, 1986). Two of the parents in my study were founder members of a local group, but these parents also indicated that they would not look to members of the group for help with their emotional concerns as they were worried that their concerns would upset other parents. This highlights a general difficulty for parents groups as a helping resource. Chesler and Barbarin's proposal would avoid this difficulty.

Another approach for alleviating the stress of parents was suggested by Kupst. As part of her substantive longitudinal study she developed a model "intervention programme," whose effectiveness she also researched in the Coping Project (Kupst

et al, 1982). Two "intervenors" were employed by the Project, one being a social worker and the other a trained counsellor. Both had extensive experience in paediatric oncology. The purpose of the scheme was to provide an additional and proactive service of support to a sample of parents of children with leukaemia. The parents were allocated to one of three different groups each of which was given a different level of support: A "high contact" group received a more proactive approach and a greater amount of help; a second group received a "moderate" amount and the third no support other than the standard help of the treatment centre. The findings of this research are illuminating.

The "intervention" was effective when it was established early in the treatment and concentrated on giving parents a degree of confidence and to some extent a "mastery" of the situation. Methods which seemed to be particularly helpful included giving them information and enabling them to anticipate stressful events, and helping them practically with specific advice on, for example, how they should deal with the child's return to school. Parents were also helped by being reassured that their reactions to the illness were "normal" in the context of an illness which was "abnormal" to them.

The findings of Kupst's "Coping Project" together with the views expressed by social workers in my study (Chapter 4) show that combating stress is a key aim of the help that social workers provide as well as one that can be effective if organised well. It is possible however to think in terms of including in the social work team parents as trained volunteers, with a role similar to the one that Chesler and Barbarin suggest. The combination of the social workers and trained parents, using the format of a small dedicated team to focus on providing a service which could alleviate a parent's stress could make a valuable contribution in the future. My suggestion would essentially be a combination of both schemes which have been described with the social worker using the skills of the others as required.

The importance of the doctor

For some parents the trust that they placed in the doctor was an important factor in the way they maintained their optimism that the child will survive. Trust seemed to be associated with particular facets of the doctors behaviour including the following:

- the doctor's reliability and ability to give clear information to parents;
- the doctor's genuine concern for the individual child;

the doctor being seen by parents as being a "real" person with emotions and feelings;
the doctor being honest and open in discussion, especially about medical dilemmas.

It is interesting to look at these observations in the light of the significant finding of the social workers' survey that 95% of the social workers both in the UK and USA regarded the doctor-parent relationship as being a crucial factor in determining the way parents coped. The crucial element which social workers identified was the trust which parents placed in the doctor. Trust is important also for effective communication.

Much of the modern clinical approach adopted by the regional cancer treatment centres aspires to a good practice model based on "open communication," in which doctors give as much information and explanation to the parents about the illness and the treatments as they can. It was clear in my study that parents appreciated the way they had been treated by doctors and welcomed the "honesty" they had been shown. The parents had a high trust in hospital doctors who they considered as having an absolute commitment to the child.

The new "openness" between doctor and patient and between doctor and parents can also be a cause of anxiety and add to the stress that many parents feel about taking part in decision making. For many parents, their involvement in decisions came as a surprise, and when the "openness" in communication was extended to the child, when the child was old enough for this, they were unsure about how to react. Most parents welcomed, or at least were willing to accept, that their child should have a full knowledge of all the details of their condition. They generally accepted advice that this would be helpful to their child. They referred to "taking the lead" from the doctor about the way to talk to their child about the illness.

Parents gradually began to acquire the confidence to participate fully in the decision making process. The occasions on which they were involved in decisions about, for example, a change in the course of treatment, however, brought an upsurge in anxiety for them. One mother told me that her involvement in making a decision on the child's possible involvement in a clinical drug trial caused her as much stress as hearing the initial diagnosis had done. Her discussion with the consultant had raised doubts in her mind about whether the medical team was offering her the best course of treatment and whether aspects of the diagnosis were being concealed from her. The implication is that doctors need to be aware of the unfamiliarity that many

parents have in making medical decisions, of the anxiety that can be caused and of the need for them to adopt a sensitive approach.

Policy implications for the health services

Many of the parents clearly felt intimidated by different aspects of the health service, focusing their discontent on the hospital as a bureaucratic "institution" with complex and numerous rules. Being involved in treatment from the very beginning of their child's illness and sharing much of the nursing responsibility for their child, parents soon acquired a new role which gave them some satisfaction in that they were involved in the treatment, but also caused considerable stress. They were learning to understand what the treatment procedures involved and to implement them while at the same time dealing with their child's behaviour which was at times uncooperative and "difficult." Attempting this very demanding task under what they saw as being the "scrutiny" of professionals (i.e. medical and nursing staff) and doing so in the public arena of a hospital ward was daunting to nearly all of them. Those parents who were more confident quickly adapted, but others who were less sure of their skills as a parent found great difficulties, despite the friendliness of all the staff which they reported.

The way in which parents are involved in the ward routines has changed considerably in recent years. Parents are welcomed into the ward as carers who are closely involved in the treatment process which their child is undergoing. There is now an expectation that they will participate in nursing tasks and that one parent will be present with their child for most of the time. Current nursing levels in many hospitals are such that the parents' participation is usually essential for the running of a ward. Whatever the reasons are for involving the parents, most of the parents welcomed being closely involved and recognised the benefit which their child derived from the arrangement.

The contrast between the active and responsible role which the Health Service expected the parents to play and the variety of frustrations that seemed to be presented to them needs to be addressed. Some of the difficulties that parents had were admittedly due to a shortage of resources, but the vast majority appeared to be due to the "system" being unable to be flexible enough to respond to individual needs. In the modern hospital there should be no need to wait, as one parent did, for five hours after the child had been discharged from the hospital to have drugs delivered from the pharmacy unit. Nor should staff unfamiliar with the needs of a

particular child ignore helpful suggestions made by the parents on the way that medication can be given. Some hospitals now assign key nurses to have a liaison responsibility. This liaison role is particularly useful when the child returns to live at home and parents need to be in regular contact with the hospital. My findings suggest that there are a variety of matters which require the attention of "liaison" personnel and that any improvement would be of assistance in helping parents to cope.

Summary

In this chapter I have reviewed my findings in relation to previous research and to coping theory. I have offered an explanation of what coping appears to involve for parents of a child with cancer. Some of the practical implications have been discussed.

Coping is presented as being both a complex and evolving process in which the parent is engaged from the moment he or she hears initially about the child's diagnosis. Some of the characteristics of coping have been considered and an attempt has been made to attribute the parents' energy and drives to their anger about the illness and their need to protect their child as well as respond to his or her needs. The way in which gender and cultural issues affect parents' coping have also been considered.

The findings have implications for the work of social workers and doctors and more generally for the policy and administration of the Health Service in the UK. It is argued that the increased responsibilities which parents now bear through their detailed involvement in the care and medical treatment of their child have to be more clearly recognised in the ways that health care is organised and some ways are proposed for developing services to focus more directly on the anxieties and stress which parents experience. In general more sensitivity needs to be shown by Health Service personnel to the process in which parents are engaged in coping with their child's illness.

CHAPTER 12

AFTERWORD

My approach to the study

Cancer is the most common form of life threatening illness to children in the UK. Despite the changes in medical treatment in the past twenty years or so which have improved considerably a child's chances of recovering from the illness, there is still a high risk of death or permanent damage resulting from either the illness itself or from the aggressive drug treatments which are increasingly deployed.

Modern approaches in paediatric health care involve the parents extensively. When a child has cancer, parents participate in medical decision making and are expected to assist in the administering of many of the treatments. Throughout the illness they are required to be able to counsel and support their child constantly while meeting their other domestic and employment responsibilities. Being able to do all of this effectively is generally deemed to be "coping" with the child's illness.

One of my reasons for undertaking this study was that despite the numbers of children involved and the accumulated experience that health care professionals had acquired through supporting parents and children, comparatively little was known about what coping with the illness involves. My study has sought to obtain an understanding of what coping means for a parent of a child with cancer.

I brought to the study a perspective of having been a social work practitioner specialising in supporting parents of children with cancer for more than twelve years and a longer background in helping the parents of children who had emotional and learning difficulties. During this time I have helped parents from different occupational, economic and social groups. Some have been able to manage very independently making little by way of demands in terms of professional support, while other parents have become very dependent either on me or on family and friends. I have observed a range of attitudes that parents show towards the child who is ill. Often parents cannot bear to be away from their child for any period of time no matter how short. Occasionally there are parents who find it difficult to be with the child, particularly during the hospitalisation period. All of this experience gave me an opportunity to form a view of what coping involves.

In undertaking this study, I have had an opportunity to examine coping from a different and wider perspective. Firstly, I have been able to explore the research literature and the theoretical basis of the psychological processes in coping. Secondly I have been able to survey a large group of experienced social workers in both the UK and the USA on how they make use of the concept of coping in their practice. Thirdly, and most importantly, I have interviewed 19 parents in depth during the course of their child's illness, at a point when the outcome of the illness was uncertain, and I have discussed with them their experiences of coping with the illness. It is on the basis of these different perspectives I have presented my thesis.

Practitioner research

The transition from social work practice to research in the same subject area has advantages and disadvantages. An initial advantage is that a practitioner can bring to the task a body of knowledge arising from her experience; she does not have to familiarise herself with a new area of interest. Her knowledge can pertain both to the clientele and to the setting. The practitioner who conducts research may have a ready awareness of where to get relevant data and other information and may sometimes have an easier task in negotiating access than someone unfamiliar with the area of work may have. Another advantage is the transferable skills that the practitioner can bring, such as interviewing and analytical skills, both of which are very relevant for undertaking any type of research.

A disadvantage which I found in transferring to research (and which I had to check) was a tendency to rely on my former ways of looking at issues based on my training and practice as a social worker. In practice my focus was primarily on an individual case, seeing each one in its own right. My analytical skills had to be engaged in understanding the circumstances and dynamics of each person I was helping. As a researcher, on the other hand, I was required to see a wider perspective and identify patterns across a range of cases. To do so I needed to distance myself from some of the "conceptual and linguistic apparatus" that I had acquired as a practitioner (Fuller and Petch, 1995, p9) in order to be able to recognise issues with which I had not previously been familiar.

Making the adjustment from practitioner to researcher was not an easy one. I wished to transfer without abandoning much of what I already knew, while acquiring a new range of observational skills. The type of study I wished to undertake made it important that I maintained the skills required for relating to

individuals under stress and being aware of the difficulties they face. I believed that if I could make the transition which enabled me to combine practice and research skills, the quality of the study could be enhanced.

"Practitioner research" in the field of social work is becoming increasingly popular. Social work students who are now undertaking their professional training are more likely than their predecessors to be given an understanding of research methodology and opportunities to participate in conducting studies. There is also an emphasis on research in post graduate and post qualification training. A recent programme which has been developed at Stirling University is now dedicated to Practitioner Research and helps practitioners to begin the process of conducting evaluative research associated with their own practice (Cheetham, 1995).

Cheetham argues the case for developing practitioner-research studies. She sees their main value in their analysis of the impact that different forms of social work services have on the individuals or groups they are meant to help. By undertaking these studies, social workers can comment with more authority on the effects of their interventions. The cumulation of the results of small scale studies can make an important contribution to the process of social policy formation (Cheetham, 1992).

Practitioner research also helps the professional development of the practitioner. In my own case, I believe that my observational and analytical skills have improved and the knowledge base of a subject area with which I was previously familiar, has increased substantially. The fact that I placed particular emphasis on obtaining comprehensive accounts from parents and analysing them in detail was in itself a learning experience. Some aspects of what coping involves came as a new insight to me. The sense of isolation that many parents felt during the illness was a case in point.

My study also shows the value of those which concentrate on the "user perspective." The value of obtaining the views of the recipients of social work services has been acknowledged amongst social workers since the pioneering work in the 1960s (Mayer and Timms, 1970). As my study has shown, clients, when given the opportunity, can indicate both directly and indirectly through their responses the types of help that are needed. The results of such research can make a persuasive contribution to the way that services are planned and developed.

Suggestions for future research

My approach to this study drew on many of the ideas associated with ethnographic research. One of the claims that the exponents of this type of research make is that the method is best suited for providing a clear picture of the *detail* of people's lives (Hammersley and Atkinson, 1983). Other approaches it is said, can miss many of the nuances. My findings have given a detailed account of how a small sample of parents cope during their child's cancer illness. As such it makes a contribution to the growing body of knowledge on the subject. My findings have, however, to be seen in the context of the sample size and culture. There is a need for more studies which concentrate on obtaining the views of parents and which are conducted across different population groups.

My study has concentrated on the parents' experience of coping at a comparatively early stage of the child's illness. The Healthcare Trust's Ethics Committee, which considered my application to conduct the study, were quite rightly concerned to ensure that intervention in the families' lives for research purposes was conducted with full sensitivity as the children were very ill. (At least one of the children to my knowledge, subsequently died and another had a relapse.) I hope however, that the fact that my study showed that important information on coping can be obtained at this stage, when parents are actively engaged in trying to understand and adapt to the implications of the illness, will encourage the conduct of similar studies. It is through replication that the knowledge base is extended.

My study's focus was on a parent's general experience. There is a value, however, in having more focused studies which examine some factors in more detail. One aspect which could be considered is whether the severity of the child's illness affects the way they cope. The consensus of research opinion at this stage (Eiser, 1992, van Veldhuizen and Last, 1991) is that there is not a correlation. No major study has been conducted which examines this closely in relation to parents' perceptions. A related research focus could be on the length of the treatment as a factor in the parents' coping. As my study has indicated, treatment can be protracted, with the child's future uncertain for extended periods, during which the process of coping an uneven one for many parents. There is a case for establishing the relationship, if any, between the objective degree of medical risk and the way in which a parent reacts. A detailed study on this matter could give important information on coping.

Coping with the child's illness is not the prerogative only of the parents. The way that the sick child deals with the illness has been the focus of many studies (for example, Bluebond-Langner, 1978, Judd, 1989, Rait et al, 1992), but little attention has been given to the impact of the illness on the other children in the family and other relatives, such as grandparents (Faulkner et al, 1995). My study has shown that the impact of the illness has a traumatic effect on the whole family and that the extended family is a very important source of support for the parents. More research is required, in my view, on the way the family copes. A particular dimension to this is the way that the individual coping of the two parents combine. While my findings have emphasised that coping is a personal, individual matter, parents in a two parent family can combine their strengths to enable them to function effectively as a family unit. A study on this matter can be useful in investigating how family systems operate and, on a practical basis, how support services can best be provided.

The model of coping devised by Lazarus and Folkman (Lazarus and Folkman, 1991) has been referred to frequently in this thesis. Their interactional model of the processes involved is essentially a theoretical one at this stage, although the authors and others are engaged in research. There are two dimensions to the model which my findings suggest are areas in which further study is required. One is in relation to social research. The model allows for the fact that coping has to be understood in terms of the "environment" or context in which it takes place. My study has shown some element of the context, in particular the trauma which is experienced following the diagnosis. But there are many other dimensions to the illness, and a number of social and economic contexts to be considered. Social workers can make a valuable contribution to this area of study

Another area for study relates to the psychological processes which are involved. In my thesis I have relied extensively on the professional views and research of clinical and research psychologists who have taken a close interest in the micro processes which are involved. Central to the more detailed understanding which is now required on coping is the way in which cognitive and emotional influences combine to inform and determine judgements and, possibly, decision making. In my view, only a concurrent study in which a parent is followed closely through the process of experiencing the child's illness will reveal a thorough understanding on this matter. Such a study may never be possible for practical and ethical reasons. But understanding the relationship between cognition and emotion is arguably crucial for our understanding of coping in a substantial way.

A final suggestion for further study is the parent-child relationship during the course of the illness, and the effect the behaviour of each has on the other. This proposal is put forward with diffidence because it is based on the findings of van Veldhuizen and Last's study rather than my own study (van Veldhuizen and Last, 1991). It rests on an area of interest lying predominantly in psychology. But my findings suggest that the child's behaviour in the illness has a very important bearing on coping. The constraints of my study enable me to make only a general observation that parent-child interaction appears to be important. Van Veldhuizen and Last emphasise the importance of communication that takes place both a conscious and unconscious basis. In the light of my own findings I would venture to support their observation and hope that it will be followed up.

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UNIVERSITY OF EDINBURGH RESEARCH STUDY

CHILDREN WITH CANCER: PARENTS' CAPACITY TO COPE

1/ Coping

'Coping' is a term in common usage. The research is attempting to establish what it involves when applied to parents or carers of children who have cancer or leukaemia. Perceptions of parents are to be sought, about their capacities to cope and action they take to try and cope. This questionnaire (which will be supplemented by meetings with social workers to study case material) seeks to identify the professional views of social workers about what coping involves for parents, and what work is undertaken to enhance parents' coping abilities.

- 1) Below is a list of statements. Most of them are based on research findings and are presented randomly. Please rate on a scale of 1-4 how important each is as a feature of parents who cope well with their child's illness and treatment.

1 = very important, ie fundamental, cannot cope without it

2 = important, ie usually present when parents cope well

3 = fairly important, ie may be a feature of coping

4 = not important, ie not very relevant to coping

	1	2	3	4
1. Positive support networks exist for the family in the community.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Parent(s) have support from friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Both of child's parents live with the child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. At least one parent has a sympathetic employer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Parent(s) find religious beliefs to be a support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. There are no pre-existing financial problems when child is diagnosed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. There is a stable marriage/partnership.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Parent(s)/partners support each other emotionally	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Parent(s) have the capacity to talk about feelings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Parent(s) have good physical health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Parent(s) have experienced a previous crisis in their lives.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- | | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| 12. There is a known prognosis for the child's illness. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Child adapts well to the demands of the treatment. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Parent(s) are willing to discuss the illness with their child. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Parents are able to seek information about the illness. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. Treatment protocol is of a <u>short</u> duration. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. Parent(s) discuss the illness with their other children. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. Child with cancer is under 8 years of age. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 19. Parent(s) are able to learn about the practical management of the illness. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 20. Parent(s) make trusting relationships with hospital staff. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 21. Parent(s) make contact with others in the same situation. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 22. Parent(s) use social worker to discuss feelings about illness. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 23. Parent(s) develop new patterns of caring for their child. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 24. The family does things together as a unit. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 25. Parent(s) can set limits on their child's behaviour. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 26. The hospital is easily accessible from home. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 27. Diagnosis of the child's illness was made without undue delay. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 28. Child returns quickly to some of his/her normal activities. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 29. Prior to the illness there was a positive relationship between parents and child. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 30. There are other children in the family. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| 31. Parent(s) have the capacity to accept the implications of the illness. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 32. Parent(s) are flexible about day to day crises. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 33. Parent(s) can <u>ask</u> for help and support. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 34. Parent(s) try to achieve a normal quality of life. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 35. Sick child understands severity of his/her illness. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

2) Please state any 'very important' statements of your own which are not listed.

3) Looking at this list of statements, and at others you have named as being very important, which do you regard as the most important single elements in judging how parents cope?

Please rank in order of importance:

- 1.
- 2.
- 3.

4) Any further comments you wish to make?

7. What methods, if any, do you use to help parents to cope?

8. Do you assess each parent's capacity to cope, individually?

Thank you very much for completing this questionnaire. Please return it, before 10 December 1993 to:

Jean Smith
22 House O'Hill Crescent
Edinburgh
EH4 5DH

This questionnaire should give you an idea of the focus of the research. If you have further comments you wish to make, please do so:-

Name: -----

Address: -----

(This is optional but helps my administration)

APPLICATION TO ETHICS COMMITTEE

Children with cancer: capacity of parents to cope with the illness and treatment

Aims:

The study seeks to understand and explain the nature and extent of the difficulties felt by parents of a child with cancer during the treatment process.

The concept of 'coping' is fundamental to social work rhetoric and practice and yet remains relatively unexplored as it affects clients and their families. The primary focus of this study will therefore be on 'coping', a definition of which will be developed from analysing the accounts of parents of their perceptions of their coping with their child's illness and the treatment he or she is receiving.

The study is neither an evaluation study nor a comparative study, but will adopt an ethnographic approach, exploring with parents the effect of the illness on themselves and on the family as a whole, what changes have taken place in their lives and the strategies used to manage the problems posed.

It is anticipated that the research will make a contribution to crisis theory (an important and commonly used theory underlying social work practice in this area of work), to social work practice in the field of chronic and life threatening illness, to the growing body of knowledge of psycho social aspects of cancer and to research methodology in assessing how an ethnographic approach may yield qualitatively different data from much current psychological research.

Rationale

The experience of child cancer has changed in fundamental ways over the last two or three decades. Even twenty years ago, a diagnosis of cancer meant an early death, but now there is a changed picture with greatly improved prognoses. The new treatments which bring a hope of cure for many children also bring great uncertainty and thus, ironically, bring some unanticipated consequences for families. Parents in particular can find that meeting their parental responsibilities poses an emotional challenge.

Ways in which people cope with the demands and conflicts of adverse life events is a widely researched area of psychological research. How parents and children cope

Appendix 2

with the stresses of cancer and its treatment has been described as a 'core issue' in the literature on child cancer. Much of the research in this area (which is largely from the USA) has sought to evaluate the behaviour and functioning of parents of children with cancer and to identify effective coping strategies. Although the design of some of these studies has given importance to qualitative information obtained from interviews with parents, one aspect largely absent has been an analysis of parents own perceptions of their experiences and their attempts to cope with them.

An attempt to obtain the perceptions of the users of services both in social service and medical settings is increasingly viewed as being important. Another largely unexplored area has been the views of fathers.

Methodology

The principal tool for the collection of data will be in-depth, focused interviews with parents or carers of children with cancer, separately, in their own homes.

A cohort of parents of children with cancer or leukaemia will be sought from those whose children have been diagnosed at RHSC and are currently receiving treatment. The children will have been diagnosed at least four months prior to the arrangement of interview in order that the treatment will be past the initial stage. It is not intended to select for particular diagnoses of cancer except to exclude those whose treatment does not include any inpatient treatment.

Parents will be contacted by letter to request their participation in the study, and this will be followed by a telephone call to make specific arrangements, (at which time it will also be possible for people to refuse to take part). Parents will be seen individually, partly to ensure that fathers are adequately represented in the study and partly to take account of individual differences.

The interviews will allow parents to develop the themes which are important to them and although not highly structured, have been carefully planned. They will have two main aspects: practical issues and emotional issues. In the former category areas such as finance, hospital access, household and child care arrangements, social contacts, employment will be covered. The 'emotional' issues are more complex to investigate and a selection of foci will be used. All of these areas have been developed from previous research studies, from the professional literature, from a prior study eliciting information about parents' coping from social workers and from the researcher's professional experience.

Coping with Childhood Cancer

Introduction

As I explained on the telephone, I am interviewing a number of parents whose children are currently receiving treatment for cancer at RHSC, to get an understanding about how parents cope with their child's illness and the treatment. I have been a Malcolm Sargent social worker in the hospital for the past seven years and have taken a leave of absence to conduct this research in the Department of Social Work in the University of Edinburgh.

The main purpose is to learn more about parents' feelings and thoughts about how the illness affects them, so that the professionals in the hospital can better understand parent's situation.

I would like to emphasise the point I made in my letter, that everything you say will be treated in confidence. I will be preparing a report, but no individual parent will be identified. If you are agreeable, I would like to tape record this interview, so that I have an accurate record of what you say. Are you agreeable to this?

The discussion will cover several different areas so it may be helpful for you to know what these are and in what order I hope to cover them. There are three main parts: First, I would like to discuss how home life is at present, for you and the family; second, I would like to hear about the time when the illness was first diagnosed; and finally, I have some general questions to ask about your thoughts and feelings about the illness and the way you cope with it.

Appendix 3

A. Interview information sheet

Interview No.:

Date

Time

Subject's name:

Sex:

Age:

Address:

Residence since:

Marital status:

Employment:

Names of children:

Name of child on treatment:

Nature of illness:

Treatment regime:

Comments:

Appendix 3

B. Life now, at home

I would like to ask you about what life is like for you at present.

1. Can you give me an idea of some of the main things you have to do with _____?
What are the main activities for you?
Please describe (eg main events in this week)
2. What are the most difficult things to cope with at present?
3. How do you cope with these difficulties?
4. Do you find you need help with coping with things that have happened as result of _____'s illness?
5. Are there ways in which people have been helpful to you?
If so, who?
6. Has day to day life changed from before the illness? If so, how?
7. Are you able to do some of the 'normal' things that you did before the illness?
8. How have the changes affected you?

C. Diagnosis

I would like to ask you to think back to the time when _____ was first diagnosed as having cancer.

1. When did you first think that the diagnosis was going to be cancer?
2. How did feel when you heard the diagnosis? how did it affect you ?
3. How did _____ react to all this?
4. Can you give an indication of how you handled this?

D. First period in the hospital

1. What was the most difficult thing for you to cope with in the hospital?
2. Did your other child/ children react to _____ being in the hospital?

Appendix 3

3. How did other family members and friends react?
4. How helpful did you feel staff in the hospital were / are?
5. Who has been most important to you?
6. Have you had contact with other parents of children with cancer?
7. In general, how did you cope with that time in the hospital?
8. _____ has been in the hospital more recently / has had a number of times in the hospital. Have these more recent admissions been different from the first time?
9. How do you feel now about the illness?

E. General questions about coping

Finally, I would like to ask you one or two general questions about how you cope and how you think others might cope.

1. In general, what are the main ways in which you have managed to cope over this period since the illness was first diagnosed?

2. How well do you think you are coping?

I am interested in whether people cope differently when they have to deal with something difficult over a long period of time

3. Do you think you have changed in the way you cope with things now, compared to the time when you first knew _____ was ill?

3. Sometimes husband and wives/ partners react differently to situations. Would you say you and you husband/ wife/ partner have reacted differently? If so:

4. Has _____'s illness changed the way you get along together?

5. As a result of the experiences you have had, is there any advice you would like offer other parents in this situation?

6. From your contacts with a lot of professional people in the hospital and at home, do you have any views about the way professional people can be trained to better understand parent's situations?

7. Are there any other points you would like to make which we haven't covered?

Thank you very much for answering my questions.

Appendix 4

Name

Address

3rd May 1994

Dear Mr. and Mrs. ,

Research study at Royal Hospital for Sick Children

A research study of parents of children with cancer or leukaemia is being undertaken at the hospital in co-operation with Dr. Angela Thomas and Dr. Hamish Wallace, and I am writing to ask for your help.

The aim of the study is to record parents' own accounts of their experiences of caring for a child during the period of diagnosis and treatment and to identify different ways in which people cope.

We would like to interview parents on an individual basis, in your own home (or elsewhere, if you prefer), each interview lasting about 3/4 hour to an hour, arranged at a time convenient for you. Your responses would be confidential to the research team.

Participation in the research is entirely voluntary. If you prefer not to take part, this will not affect any treatment or services that you or your child receive at the hospital. Should you wish to discuss your participation with someone independent of the study, you may contact Mr. John McBride, Practice Team Manager, Social Work Dept., Royal Hospital for Sick Children (668-2251) who would be pleased to speak with you.

As I am the principal researcher involved and will be conducting the interviews, I very much hope you will be willing to take part. Unless I hear from you to the contrary, I will contact you by telephone in the next couple of weeks to arrange a time to meet with you. If you do not wish to be involved, please telephone me or write to me at the above address, or, if more convenient, feel free to contact me at home at 031-312-8619.

Thank you very much for your help.

Yours sincerely

Jean M. Smith
Researcher

Appendix 5

Letter of thanks to parents

Name
Address

31st May 1994

Dear Mr. and Mrs. ,

Research study at Royal Hospital for Sick Children

Thank you very much indeed for allowing me to come and interview you both last week. It was good of you give your time to talk to me and the interviews were most useful for my research.

When I come to read the transcript of the interview, I might find that there are one or two questions I hadn't asked you. Perhaps I could telephone you fill any gaps?

I am very grateful to you for your help. I hope that R 's treatment continues well.

Yours sincerely,

Jean M. Smith
Researcher

Appendix 6

Six categories developed from the 35 statements (showing which statements selected to represent the category)

Family relationships:

- | | |
|-----|--|
| 7. | There is a stable marriage/partnership |
| 17. | Parents discuss illness with their other children |
| 24. | Parents have warm family relationships |
| 29. | There was a positive previous relationship between parents and child |

Social relationships:

- | | |
|-----|---|
| 1. | Positive support networks exist for the family in the community |
| 2. | Parents have support from friends |
| 20. | Parents make trusting relationships with hospital staff |
| 21. | Parents make contact with others in the same situation |

Communication:

- | | |
|-----|---|
| 8. | Parents can discuss illness together |
| 9. | Parent/s talk about feelings |
| 17. | Parents discuss illness with other children |
| 33. | Parents can ask for help and support |

Problem solving:

- | | |
|-----|---|
| 15. | Parents can seek information |
| 19. | Parents are able to learn about the practical management of the illness |
| 20. | Parents make trusting relationships with hospital staff |
| 33. | Parents can ask for help and support |

External factors unrelated to child's illness

- | | |
|-----|--|
| 4. | One parents has a sympathetic employer: |
| 6. | There are no pre-existing financial problems when child is diagnosed |
| 10. | Parent/s have good physical health |
| 26. | The hospital is easily accessible from home |

External factors related to child's illness:

- | | |
|-----|---|
| 12. | There is a known prognosis for the child's illness |
| 16. | Treatment protocol is of short duration |
| 27. | Diagnosis of the child's illness was made without delay |