Services for children with cancer: The views of parents, professionals and relevant charities'.

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A submission presented in partial fulfilment of the requirements of the University of Glamorgan/Prifysgol Morgannwg for the degree of Doctor of Philosophy

December 2002
DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed ............................................................(Candidate)
Date .................................................................

Statement 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references.

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Date .................................................................

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ABSTRACT

In adopting a tabula rasa approach, this study sought to determine those elements of care that should be prioritised in the service provision for families with children who have cancer. An innovative approach was adopted, as opposed to a conventional thesis structure, in which the literature in this study was used both as a means of informing the research rationale and design as well as being a data source in its own right and precluded providing a conventional literature review. Conventionally a thesis contains an introduction, chapters that review the literature, describe the methods, present results and ends with a discussion and conclusions. However, because there are many different elements to this thesis it is intended to structure it differently. Given that each form of data requires a different form of analysis, each data source has its own chapter. The reader will therefore find chapters headed The Professional Literature, The Charity Leaflets, and The Delphi Study. Furthermore, within each chapter methodological considerations, and the reasons for the methodological decisions taken are discussed. These are made in the appropriate places. Three sources of data were investigated including the professional and relevant charity leaflets literature and a Delphi study was undertaken to obtain the views of both professionals (n=31) and families (n=15). A content analysis was conducted for the first two sources of data and the first round of the Delphi study. All sources were essential in compiling a comprehensive list of desirable elements of care.

The salient elements of care from the three sources of data were synthesised in order to identify elements that were common to all data sources. The elements of care were grouped under six headings as categories with relevant subcategories. The main categories were ‘Communication and Cooperation’, ‘Maintaining Normality’, ‘Professional Issues’, ‘Research’, ‘Resources and ‘Treatment Issues’ for the professional literature and charity leaflets literature and a Delphi study was undertaken to obtain the views of both professionals (n=31) and families (n=15). A content analysis was conducted for the first two sources of data and the first round of the Delphi study. All sources were essential in compiling a comprehensive list of desirable elements of care.

‘Partnership in Care’ was the analytical framework devised from the government directives of involving patients and their carers more in the healthcare process. The framework adopted was based on the families’ participation as informed, decision-making and empowered families. The framework was then used as a means by which the data for all three sources could be summarised, compared and contrasted. This then enabled a comparison between the service provision advocated for children with cancer and what the Delphi study of the families’ opinions had highlighted.

Given the rhetoric of policy directives in involving the family more in participation of care, the findings have shown that there is a disparity between the perspectives of the families and professionals. In line with policy directives, the professionals had prioritised the involvement of families as partners. However, their commitment to the partnership is questionable, as they did not regard more training in understanding the impact of the disease on the family as important. The main emphasis was on clinical service provision in terms of dedicated adolescent units in regional centres and emergency contact provision. The families placed an emphasis on communication in terms of their contact with the GP in avoiding late diagnosis, having a key worker,
providing continuity between hospital and home, and training courses for the professionals to better understand the impact of the disease in the family. By contrast the professionals placed an emphasis on clinical provision namely age appropriate environment for care and 24 hour emergency contact and input from regional units.

The findings suggest that in reality, families cannot always be equal partners with the professionals, nor do they necessarily wish to be. From the families' perspective a partnership in care has been defined as mutual respect, advocacy, encouragement, and having continuity of care between hospital and home, given by practitioners who have the expertise and who understand the impact of the disease on the family.
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ABBREVIATIONS

ALL Acute lymphoblastic leukaemia
BMJ British Medical Journal
CACI Children's Adjustment to Cancer Index
CASP Critical Appraisal Skills Programme
CAT Computerized Axial Tomography
CCSI Childhood Cancer Stressors Inventory
CCRG Childhood Cancer Research Group
CF Cystic fibrosis
CNS Central Nervous System
DGHs District General Hospitals
DNA Deoxyribonucleic acid
DoH Department of Health
DHSS Department of Health and Social Security
DSS The Department of Social Security
GP General Practitioner
GVHD Graft versus host disease
FPM Family Panel Members
MCTR Manchester Children's Tumour Registry
MRC Medical Research Council
MRI Magnetic Resonance Imaging
MRS Magnitude Ratio Scale
NRCT National Registry of Childhood Tumours
PCAs Patient Controlled Analgesia pump
POONs Paediatric Oncology Outreach Nurses
PPM Professional Panel Member
PNB Positive Negative Balance
OPCS Office of Population Censuses and Surveys
RCT Randomised Control Trial
RUs Regional Units
SPSS Statistical Package for Social Science
SD semantic differential
UKCCSG United Kingdom Childhood Cancer Study Group
UI Unique identity number
ACKNOWLEDGEMENTS

This thesis is dedicated to my family, particularly my husband, Dennis whose constant enablement and encouragement provided me with the strength and determination to complete the project. I would like to include in this dedication Tony and Jack whose family, particularly Freda and David Gibbs-Morris who showed me what family-centred care really means.

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List of conference presentations

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International Nursing Research Conference (RCN Research Society). Symposium
Topic: Understanding the needs of children and their families in community settings:
‘Childhood cancer: a content analysis of charity information leaflets.’
Led by Professor S. Procter. Professor of Nursing Research.

Bangor October 1999

North Wales Paediatric Forum
Chair: Ms Sue Burr
‘Elements of care for families with a child suffering with cancer: Examination of the
contents of childhood cancer charity leaflets.’

Sheffield April 2000

University of Sheffield. RCN Conference April 2000
Poster presentation accepted. ‘Key elements of care of families in which a child has
cancer: Three sources of data explored.’
Had to withdraw for serious family health reasons.
INTRODUCTION

This study was partially funded by a children’s cancer charity. As users of childhood cancer services throughout the UK, the charity was convinced of the merits in improving and organising the service delivery. In accepting the commission, it was agreed that the study would not be conducted to evaluate a preferred way. The intention was rather to start with a *tabula rasa*, that is, no prior assumptions about knowledge, experience, or the literature.

The objective of this study was to determine which elements of care should be given priority in a service for families in which a child has cancer. The term ‘element of care’ was selected after considering the definitions of the key words found in the Concise Oxford Dictionary (1982) in which an element is described as a ‘component part’ (page 334) and care was described as to ‘feel a concern or interest’ (page 149). Therefore, almost any nursing activity, intervention, treatment, procedure or care given related to helping families in which a child has cancer could be included in this term. At first sight, the term may appear too general to be useful, possibly this term could be thought to be vague and ill thought out. However, there was always a possibility that families and professionals would have a different focus. If more tightly defined words had been used, issues that were salient to families and professionals would have not been spontaneously mentioned. The term was consciously selected and deliberately not defined in the questionnaire used in Round One of the Delphi study; consequently, the elements of care would be operationally suggested. The term was intended as a stimulus to enable respondents to indicate what sort of items they would include as ‘elements of care’. In addition, it was considered necessary to have a common term that could be applied throughout the data source when synthesising the three data sources. Thus, the term did not occur by chance; it was consciously used to stimulate the respondents and as a core factor for synthesis throughout the data sets. Analysis of data has demonstrated that the approach was successful and an example of a statement containing an element of care from this study is as follows:

"A named key-worker who would be responsible for the co-ordination of the whole treatment."
Once those elements of care were identified, the next stage was for the families and professionals to prioritise them so that they could compare these with current and future provision in their own areas. It should be noted that in this thesis there was no attempt to provide an in-depth review of the pathophysiology, treatment regimes of specific cancers or family system theories.

In trying to establish what such elements of care might be, several sources of data were available. These included the professional and relevant charities literature. In addition, it was possible to obtain the views of a sample of professionals and families by undertaking a three round Delphi study. All sources were essential in compiling a comprehensive list of desirable elements. The data sources therefore were as follows:

- The professional literature. That is, studies and previous work conducted by health care professionals. This was based on the assumption that the health care professionals would be implementing and reporting on what they perceived to be good practice (regardless of particular preferences they might hold in terms of the best way of organising services);

- A range of leaflets produced by childhood cancer charities (and other charities involved with life-threatening illnesses). This was based on the assumption that the charities would be aware of disparities in the services because they are in regular contact with families and would wish to offer such services to families as a means of providing support.

- The opinions of a selected group of experts, ('experts' that is in the Delphi sense of the word). Such experts would be professionals involved in caregiving and the families as experts by virtue of their experience. From these experts it would be possible to try and identify, in a formalised way (a Delphi study), the elements of care on which there would be a consensus opinion about:
  - How many families would benefit from a particular element of care;
  - To what extent each of these elements was of a high or low importance.
Design of the study

It was decided that the nature of the design should be exploratory. It was not a conventional quantitative hypothesis-testing study, neither was it an unstructured qualitative hypothesis-generating study. This study attempted to achieve a combination of both. There was respondent defined data but with a structured analysis. Theoretical and empirical attributes from all three sources were amalgamated to form a list of elements of care. The combination of data sources, both human and from the literature, the choice of both professionals and family members as respondents, and the use of both qualitative and quantitative methods, would ensure that the study was an in-depth comprehensive investigation.

In considering the methodological approaches to the study, a conventional literature review and a survey of opinions about existing ways of giving care would reinforce current views and not elicit new views that were unencumbered by existing preferences. A trial was found not to be appropriate, as this would merely test existing models as an independent variable and thus exclude the generation of new variables. At this stage, there was a chance that by identifying the essential elements of care, they would resemble the components of current ways of organising care and obviate the need for a trial. A systematic review could, in theory, be a suitable approach. However, there was not sufficient evidence of the right type to justify this method. There were, however, some characteristics that a study of this kind should exhibit. Clearly, it was necessary to consult researchers in the field, perhaps by examining the research literature (even if not in the form of a systematic review).

It would be possible to use the literature as a source for discovering these key elements and, in so doing, would enable a far wider survey (albeit by proxy) than would be possible with a conventional survey. It is not unusual to have literature as a data source; this can be seen, for example, in meta-analyses of systematic reviews. What is unusual is the use of the literature as a method of data collection and this is discussed at the conclusion of Chapter Three. The cancer charities literature was also a source of data that would need to be consulted. Those two sources on their own might, however, have presented a rather incomplete and arid picture of the field.
It was thought therefore, that a desirable addition would be to consult currently practising professionals, even if they were not writing in the research literature. Finally, in the current climate of a patient and professional partnership within the NHS (See Chapter Two), this study would probably have not been regarded as comprehensive if it had not sought the views of the families of children suffering from cancer. Therefore it would also be necessary to ask both the professionals (in a variety of care settings) and the family members (caring for a child with cancer) what they thought the essential elements of care were. By using a Delphi approach (described in Chapters Six), it would also be possible to obtain a consensus view about the importance (or otherwise) of the elements of care identified from both the literature and the survey of families and professionals. Furthermore, in using three sources of data, a form of triangulation was made possible. Such triangulation would result in a measure of comprehensiveness and consistency.

In reconciling all the approaches used in answering the research question, the final design used three data sources and was in four stages (See page 5). The fourth stage was needed in the event that some of the elements of care, which had ranked highly in stage three, may have been impossible to implement and beyond current resources. Ideally, a policy should be not only desirable but also achievable. The final outcome would be a prioritised list of essential elements of care that would serve for policy implementation against which providers and users of health care are able to compare current and proposed future provision in their own areas.

A flow diagram of the study is shown in the next figure (1.1).
Common core elements come at the overlap of the three circles (Venn diagram)

Figure 1.1. Flow diagram of the study
Finally, the approach adopted in the research design provided a way of gathering data that:

- Respected the fatigue level for families caring for sick children;
- Recognised the limited time available to professionals;
- Provided data from both the statutory and voluntary agencies;
- Would remain within the financial limitations of the sponsors.
- Could be replicated, with appropriate quantifiable data;
- Would not compromise the academic integrity of the project;
- Could be sustained for the life-span of the project;
- Conformed to ethical proprieties.

Overview of thesis

This thesis consists of nine chapters. The introduction dealt with the objective of the study, the definition of an element of care and justification for the methodological approach adopted for a study considered to be exploratory in nature. Chapter One provides the background to the study of childhood cancer. Chapter Two discusses how the role of the patient has evolved throughout the history of the NHS and presents the analytical framework of 'Partnership in Care' based on the concepts of information, decision-making and empowerment. The question is raised whether, in reality, the framework is effective for families of children with cancer, or whether it remains government rhetoric. Chapter Three presents the methodological considerations for analysing the first two data sources of professional literature and charity leaflets. A content analysis approach was adopted and is discussed. In Chapters Four and Five, the results and discussion of the professional literature and charity leaflets are presented respectively using a six category framework of 'Communication and Cooperation', 'Maintaining Normality', 'Professional Issues', 'Research', 'Resources', and 'Treatment Issues'. Chapter Six deals with the methodological considerations in conducting a Delphi study by obtaining the views of professionals and families on elements of care. In Chapter Seven the results and discussion of the Delphi study, the third data source, are presented. Chapter Eight is a synthesis of the results of the Delphi data source supported by the other data sources of the professional literature and the charities leaflets in forming a common-core of prioritised elements of care.
The common-core is then compared against the three concepts of the analytical framework in determining the efficacy of the government directives embodied in a ‘Partnership in Care’ between the families and the professionals. Finally, Chapter Nine presents the conclusions, recommendations and limitations of the study.
CHAPTER ONE
BACKGROUND

Caring for a child with a life-threatening disease is possibly one of the most distressing events a family has to face. The diagnosis often means adapting to a whole range of invasive, traumatic treatment regimes and disrupted family life. The impact of the diagnosis of childhood cancer has a major effect on the lives of all the family (Faulkner et al. 1995). Until families have adjusted to their circumstances, they need help (While et al. 1996a). This study was initiated to establish active measures to help families during the course of a childhood cancer. In order to achieve this, it sought to identify the elements of care that are needed as families progress through the experience.

Childhood cancer

Childhood cancer is a significantly life-threatening and life-limiting condition and for the purposes of this thesis, the term childhood cancer encompasses both solid tumours and blood dyscrasias. The expression 'childhood cancer' is an umbrella term that covers a range of different cancers in children. A cancer is a malignant tumour that arises from a new and abnormal cell growth. Cells undergo changes in the deoxyribonucleic acid (DNA) leading to transmission of faulty information for cellular development. The malignant tumours are progressive growths in which there is loss of the distinctive nature of the cells. Subsequently there is uncontrolled growth with loss of normal cellular function. Consequently, the cells are no longer able to perform their original function (Waskerwitz & Heyn, 1989). This leads to loss of functions with worsening of the condition often leading to death.

Each year approximately 1,200 children in the UK are newly diagnosed with a cancer. Although childhood cancer in the past has been associated with death, advances in the treatment of childhood cancers in the past twenty years have meant that the diagnosis of childhood cancer is not necessarily a death sentence. Currently, it is anticipated that nearly two thirds of children with a childhood cancer will survive five years beyond the diagnosis (Stiller 1988; Stiller & Bunch 1990; Stiller 1994; Stiller et al. 1995).
Coleman et al. (1999), for example, reported an increase in the five-year survival rate from 68% to 94% for malignant testicular germ-cell tumours during the period 1971 to 1990. Survival rates for children with tumours of the brain or spinal cord rose by 16% during this period whilst the survival for children diagnosed with acute lymphoid leukaemia was 76%. Although the prognosis of certain cancers is reasonably predictable, nevertheless, there is no guarantee of who will survive and who will be in the one third who do not.

Frequently, the public may be tempted to equate childhood cancers with adult cancers. However, cancers in childhood are different from adult cancers in several ways. Firstly, cancers in children tend to develop in different tissues from those of adults. Many childhood cancers involve connective tissue, whereas adult cancers tend to involve epithelial tissue. Secondly, childhood cancers respond more readily to treatment than adult cancers and the cure rates for children are higher than those for many adult cancers (UKCCSG 1995). This means that children are less likely than adults to die from their cancer, whereas cancers are one of the three main causes of death for adults in both developed and developing countries (Stjernward & Teoh 1991; MORI 1992). Thirdly, cancers in children are rare. One child in six hundred under the age of fifteen in the U.K. will develop a childhood cancer (Botting & Crawley 1995; UKCCSG 1995); whereas it is estimated that four people in ten (over the age of sixteen) will develop a cancer at some stage in their life (Health Statistics 1999).

Childhood cancer treatment

Increasing attention has been paid to childhood cancers from the early 1960s with, for example, the Manchester Children's Tumour Registry (Birch et al. 1988) and the National Registry of Childhood Tumours (NRCT). The latter, for example, contains population-based data on childhood cancers diagnosed in the UK from 1962 onwards. Stiller et al. (1995) described the registration and classification of childhood cancers used by the Registry from 1978-1987. The calculation of rates were estimated on the incidence per million of the child population from birth to fourteen years of age, thus giving an indication of the risk of developing childhood cancer in the first fifteen years of life.
In 1975, the Childhood Cancer Research Group (CCRG) was set up. This followed the recommendations of a working party (the Ministry of Health Standing Advisory Committee Sub-Committee on Cancer) on childhood tumour registration. The main aim was to create a register of childhood cancers occurring under the age of 15 years.

A network of population-based regional registries carries out registration in England and Wales. This is co-ordinated nationally by the Office of Population Censuses and Surveys (OPCS). Since its inception in 1977, the United Kingdom Childhood Cancer Study Group (UKCCSG) keeps its own register and provides data for national use. Nationally, these bodies are able to provide more information and better diagnostic data than would be available in general cancer registers. Thus, there is an overall picture of the incidences, trends in survival (incorporating an analysis of treatment regimes), the genetics of childhood cancer and the health of long-term survivors and their offspring (Stiller et al. 1995).

Many of the advances in treatment and improvements in survival are thought to be the result of the effective co-ordination of treatment regimes and their evaluation. In 1977, fourteen representatives from seven paediatric oncology units met to form the UKCCSG. Representatives from six other paediatric oncology units joined them later. From its early beginnings, the UKCCSG has had a multidisciplinary approach to childhood cancer. Multidisciplinary in this context meant the participation of paediatric oncologists, haematologists, surgeons, radiotherapists and pathologists. The original group has increased its size and there are currently 22 centres in the UK. Their aims in setting up the group were to improve the results of treatment, extend their knowledge of the disease, and establish co-operative trials. The group would collect epidemiological data, encourage members to specialise and provide expertise for the subject (Stiller 1995; Mott et al. 1997). The exceptions to this were clinical trials for leukaemia which would be co-ordinated by the Medical Research Council (Stiller et al. 1995).

Current childhood cancer treatment

Whilst the prognosis is encouraging, childhood cancer is, nevertheless, a serious life-threatening illness for children from their first year of life through to their late teens.
Almost all affected children will receive some form of treatment, be it curative or palliative. Childhood cancer is treated with several different treatment modalities, which can include chemotherapy, radiotherapy, surgery and bone marrow transplant. The treatment will vary according to the type of cancer and the treatment modalities may be used singly or in a combined regime. For example, few malignant tumours in children will be treated with surgical incision alone: a combination of chemotherapy, radiotherapy as well as surgery may be needed. Consequently, the treatment for most childhood cancers will require a range of health care professionals. These can include Bone Marrow Transplant coordinators, nurses, oncologists, radiotherapists, social workers and surgeons (Nemes & Donahue 1994; Bennett-Rees & Soanes 1999).

It is likely that a child will be treated at a specialist treatment centre, often referred to as a regional unit (Mann 1997). In the initial acute stage and in the event of relapse of the disease, it is more likely that a child will be treated at the specialist treatment unit. These are mainly located in the 22 regional units throughout the UK (Calman & Hine 1994). The route to the specialist treatment centre can vary. For example, some children may be referred directly by their General Practitioners; others may be referred by their General Practitioners to a local District General Hospital for further investigations, and then from there to the Regional unit. As the treatment progresses, facets of care can be managed in the community or in a ‘Shared Care’ setting at a District General Hospital nearer to the child’s home. This might happen, for example, during the continuation of treatment. At the end stages of the illness, where treatment has not been successful, care can be given by the family and community services at the child’s home.

Prior to 1977, children with cancer were not necessarily referred to the specialist centres. Some hospitals tried to provide facilities for children with cancer, but these were poorly resourced. Treatment protocols were mainly ‘in house’ and limited cohorts of children meant that studies were inadequately assessed. Although some centres took part in the Medical Research Council trials for leukaemia, Wilms’ tumour and osteosarcoma, there was no national focus for improving the treatment of childhood cancers and research was limited. The prognoses were poor and less than 50% of children with cancer survived (Mann 1997).
For example, Stiller & Bunch (1990) note that between 1971-73, the five-year survival rate for acute lymphoblastic leukaemia was 37%. However, as the coordination of treatments in specialist centres improved, so too did the prognoses (Stiller 1994). This was seen in the data provided for the period 1983-85 for the same diagnostic group which showed the five-year survival rate as 70%. Improvements in survival rates for several diagnostic groups, such as the various leukaemias, lymphomas, central nervous system (CNS) neoplasms and sympathetic nervous system tumours were also seen. These improvements have been attributed to an increasing number of children being treated at specialist centres who were participating in national and international clinical trials (Stiller & Bunch 1990).

**The need for a study**

The prognosis for childhood cancer has improved in the last 20 years, nevertheless, the outcome is still unpredictable and cancer remains a significant life threatening condition. Clearly, childhood cancer is not a single condition, neither is it a single experience, for it varies from family to family. However, there is an overall general structure to the experience. That is, the illness begins with the pre-diagnostic stage, at which point there are usually no dramatic clues that something is seriously wrong with the child. It continues through the diagnostic and treatment stages and has an outcome. This may be remission, leading to a cure, or repeated relapses, leading to death. The period of time therefore that a child and the family are in contact with NHS is long and can be stressful. Although different families need different considerations at different times, there are common core requirements in terms of how the service is delivered and the impact on the family. It is imperative that the service provides the best possible care from suspicion of the illness through to the cure or even death. This raises the question “Do families get ‘good /best/proficient’ care?

There is a great deal of literature about caring for a family in which a child has cancer, however, much of it has been written from the perspective of the professionals (Bignold *et al.* 1994; Hunt 1995; While *et al.* 1996a/b; Eaton 2002). Indeed very little literature could be found that was written by a parent of a child with cancer (Arango 1990). It was not possible, for example, to locate trials of different models of care, as would be the case in the meta-analysis of randomised control trials.
Studies that involved the evaluation of existing ways of organising care were located, however most of these studies begin by contemplating existing models of service delivery but the evaluations were not conducted under trial circumstances. For example, Hunt (1995) and Bignold et al. (1994) examined the role of Paediatric Oncology Outreach Nurse Specialists, whilst Tatman et al. (1992) described the first two years of a paediatric home care service.

The published studies mainly represent the perspective and prerequisites of the professionals, acknowledging families' participation, but their perspective is not directly included. A recent study by Northway et al. (2001) successfully redressed this problem in a study called 'For Us' in which the users of the service with learning disabilities were also involved in the design of the study as well as being asked directly what service provisions they would like to see implemented. Occasionally, a large charity may commission a study, but not as often as the professionals as research is a fundamental part of their evidence-based practice. Self help groups, for example, do not design or execute studies and publish their results in professional journals.

It is reasonable to conclude that there is little to be gained (in terms of planning the most desirable service) from the results of the studies that were located. The results are equivocal and biased. For example, a funding body in favour of an 'In Reach' model would want research findings to support that model. Likewise a charitable organisation in favour of an outreach model would also want evidence to support their perspective. Given that this study was partially funded by a charity, caution was needed to avoid any such bias.

It became clear that previous studies had not answered the question "What are the essential elements of care for families in which a child has cancer?" This has also been verified in the findings of the Audit Commission report (Children First: A Study of Hospital Services 1993), discussed below.

Reports published by the Audit Commission are meant to highlight national issues and provide the material for investigating local issues following their publication. In that report, the Audit Commission noted problems with paediatric services.
In essence, the Audit Commission Report (1993) showed that clinicians, managers and other hospital staff did not give sufficient attention to the needs of the children and their families. Under the heading 'The Problems', section 19 notes that,

"The root problem identified in the Audit Commission study is that clinicians, managers and other hospital staff did not give sufficient attention to the needs of the children and their families. It is manifest in a lack of written policies, management focus, and poor communication between staff and parents."

(page 10 Audit Commission 1993)

The report emphasised that children have different health care needs from adults. It also identified the importance of a well-developed community health care service for children. Had there been clear evidence on the implementation of the principles included in the Audit Commission report since its publication, there would have been no need for this study to be undertaken. However there were anecdotal observations that the degree of implementation of these principles varied. There was also published evidence suggesting the existence of some gaps. For example, While et al. (1996a) noted that,

"A family-centred approach to care was emphasised but involvement was reported to be dependent upon the abilities of the families to voice their views to professionals, the readiness of families to accept help, the ability of the family to make care decisions and the willingness of professionals to involve parents." (p 236)

These observations therefore raise the question, of whether families and professionals share a consensus on what services should be provided as well as concuring on the prioritisation of those services for the family in which a child has cancer.

However, as providers of healthcare, professionals are required to carry through a concept of partnership in care within a framework in which policy documents aim to put patients first, to offer information, choice and sharing in the decision-making (White Paper Working for Patients DoH 1989a; NHS Plan National Assembly 2000). This may be for perfectly altruistic reasons, however, if patients (or parents) are involved in the decision making process does this reduce the risk of litigation for the professionals had they made the decisions alone? In theory, participation and shared decision-making is laudable, however, it is questionable whether this is feasible in reality.
For example, there can be no shared participation and decision making until the unequal balance of power between the professionals and the patient has been addressed. It should be pointed out that the use of the term 'power' is not being used here in a pejorative sense. It is rather, recognition that the knowledge possessed by professionals places them in a position of power at a time when parents are asked to make objective decisions from a subjective perspective when they are weak and vulnerable? How can families make rational decisions when they are weak and vulnerable? Is this what families say they want or is it perhaps the case that they respect the professional expertise and are confident in relinquishing their decision-making to the professionals'. That is, after all, a form of decision-making, and as such should be respected.

This study was needed because, at the time, there was an unresolved question about the best method of providing the service. The Calman-Hine Report (1995) and Cancer Services Expert Group (Cameron 1996) had outlined the importance of the regional services in the place of successful cancer management. That position is not challenged, either by the researcher or in the literature. The unresolved issues revolve around the best way of providing a service. This involves incorporating the expertise based in regional referral centres together with the input from District General Hospitals and primary based services, all of which are also important contributors to care. Clearly, the essential elements of care for families in which a child has cancer still needs to be addressed.

In Chapter Two consideration is given to the choice of analytical frameworks and the selected framework of 'Partnership in Care' is presented.
CHAPTER TWO
ANALYTICAL FRAMEWORK

Introduction

The information obtained from the three data sources of professional literature, charity leaflets and that of the Delphi study are not of a type that can be part of a conventional modelling procedure, for example the entry of variables into a mathematical calculation. By contrast the outcomes are statements of prioritisation of both families and professionals. For the families, the statements which have been prioritised are influenced by their experiences and emotions, whilst for the professionals, their priorities have been influenced by their education and knowledge, all of which are essential components of the outcomes. However, as the ultimate aim of this study is to establish ways of improving the care given for families and their children, a framework in which the outcomes can be summarised and expressed was needed. The method by which this can be established, is in the use of a framework called ‘Partnership in Care’ whereby participating as partners embrace concepts of information, decision-making and empowerment.

There is no doubt that the diagnosis of a childhood cancer is traumatic, and families need information in order to make decisions and to cooperate with the professionals providing the ensuing treatment regime. Almost all affected children will receive some form of treatment for the ultimate goal of the treatment regime is to accomplish a remission of the disease leading to a cure, with a good quality of life taken into consideration. Palliation and quality of life issues are the overriding aims of the treatment regime in children for whom a cure cannot be obtained. The ability to achieve such goals depends on a number of factors. They include type of cancer, the stage of the disease, the extent of its spread, and the different treatment options.

However, before any treatment regime can be implemented, it is necessary for several events to take place. Admission to a specialist centre is necessary, so that accurate diagnoses can be made so that the child can receive optimum treatment. It is also necessary to determine the extent of the disease and the investigations required.
These investigations can include invasive procedures, such as blood tests, tissue biopsies, bone marrow aspirations and lumbar punctures. They may also include less invasive, but nonetheless frightening, investigations such as Magnetic Resonance Imaging (MRI), Computerized Axial Tomography (CAT) and bone scans. Such activity will:

- Involve the child and family in contact with a range of health care professionals including nurses, oncologists, radiotherapists, social workers and surgeons (Waskerwitz & Heyn 1989; Nemes & Donahue 1994);
- Require parental consent at a time when they are distressed;
- Raise questions and concerns for families, and their involvement in decisions and participation to varying degrees in their child’s care. (Bennett-Rees & Soanes 1999).

Changes in the provision of health care services

The nature of the relationship between the health care professional and the patient has continued to evolve since the inception of the NHS with developments happening more quickly in recent years. One such early development is the role of the family in the care of the sick child. As early as the 1950s, Bowlby (1953) and Robertson (1970) raised the profile of the role of the family in the care of the child. The publishing of the Platt Report (1959) also contributed to the development of the place of the family or family-centred care. More recently, there was recognition that children were different from adults and therefore had different health and associated service requirements. The document Health of Children in Wales (1997) for example, drew together guidelines based on this recognition of health and associated services. The document acknowledged children’s rights and relevant legal requirements, and was intended to be a practical guide for Health Authorities to help them in developing local health strategies. With particular reference to childhood cancers, the document recommended:

- Adoption of national trial guidelines such as those produced by the Medical Research Council and the United Kingdom Children’s Cancer study Group;
- ‘Seamless’ ongoing care;
- Expert management of nutritional support;
- Maximisation of possible cure with minimal morbidity;
- Focus on facilities for the well-being for the whole family;
- Palliative care facilities.
Simultaneously with this development has been the rise in the concept of consumerism over the last three to four decades. The rise of the concept of consumerism has meant that the purchaser or user has expectations of:

- Receiving information;
- Access to a facility;
- Choice;
- Redress;
- Representation through law (McIver & Skelcher 1997).

Such expectations can now be seen for example in information in handbooks on electrical white goods, access to public buildings, consumer magazines such as 'Which', and organizations representing the interests of the consumers.

Not surprisingly, Callery and Smith (1991) have suggested that the expectation of parents in the care of their child has changed considerably over the past 30 years. Whereas parents were previously expected to stand back so that the professionals could fulfill their role, currently it is expected that parents stay with their child and become involved in their care. The combination of the rise in consumerism, the focus on the family in the care of sick children, and acknowledgment of childhood needs to have implications for the delivery of care for families in which a child has cancer.

**Potential for differing perspectives on health care**

Essentially, the data from this study would be from both the professional and families involved in the care of children with cancer, however, because of their different experiences, there was the possibility that the professionals and families would have differing views on what was necessary in the provision of care. It therefore appeared appropriate to first examine the rhetoric in the literature and then investigate discrepancies and similarities in the professional and lay thinking. In other words, does the rhetoric, advocated by government policies, match the reality as experienced by the family/user of the service? It is important to ask this question. This study was motivated by a lack of constructive and unified methods of service provision.
This was referred to earlier in the Introduction (page 14) where for example, the conclusions of the Audit Commission Report (1993) showed that clinicians, managers and other hospital staff did not give sufficient attention to the needs of the children and their families. Clearly, if problems associated with the provision of care did not exist, then this study would not have been necessary.

**Consideration of other potential frameworks**

'Partnership in Care' with participation as an over arching factor in the provision of health care was pursued as a viable framework within which active and efficient strategies were stated and justified in the care of families with childhood cancer. The framework also reflected and included all the main prioritised elements of care raised within the current government directives. However, consideration was also given to three other potential frameworks.

The recommendations of the Audit Report (1993) were one such framework. This consisted of six principles that needed to be accepted and implemented by national organisations involved in child health care services. These were:

- Child and family-centred care;
- Skilled staff from all health care disciplines;
- Separate facilities for children;
- Effective treatments;
- Appropriate hospitalisation (where there is a therapeutic advantage over home care);
- Strategic commissioning.

This framework appeared appropriate on first consideration. However 'effective treatments' was a major theme of the framework but was not within the remit of this study. Furthermore, it was important to be open to any potential policy suggestions involving a strong emphasis on care in the community for example. For these reasons, the recommendations of the Audit Committee, whilst having many appropriate themes, was not used as an analytical framework.

Hymovich’s (1990) model for research into paediatric oncology was a second potential framework and was initially favoured by the researcher.
This model has six main categories labelled ‘Family Systems’, ‘Mediating Variables’, ‘Time’, ‘Adaption Variables’, ‘Level of Functioning’ and ‘Interventions’. At first sight, the Hymovich model appeared to be appropriate. However, the framework contained more than 20 subthemes. For example, the category labelled Family Systems contained subcategories including:

- The child with cancer;
- The family; including the parents, siblings and extended family members;
- The community; school and local health care professionals;
- Society; local, national and international government provision legislation.

Although Hymovich’s (1990) work is grounded in a family system theory, it contains many elements of care which would need to be incorporated into a list of priorities. Nevertheless it was not considered to be appropriate for this study for three reasons; First, the work contained valuable elements of care that could be used as data and this precluded it from being used as a theoretical framework. Second, it was based on a systems theory and although there are merits in considering a family systems approach, for example, in understanding why families behave in different ways, it was not the intention to be confined at the outset by any particular theoretical framework. Finally, with the use of three different data sources in this current study, there was a danger that the framework would be suitable for one but not all three data sources.

Careful consideration was given to a third framework using the trajectory of the illness. It was considered appropriate to focus on the stages of the illness beginning with the pre-diagnostic stage. At this point there are no dramatic clues that something is seriously wrong with the child. Later, there are niggling doubts that all is not well. There is movement along a trajectory, through the diagnostic and treatment stages and finally an outcome. This may be remission, leading to a cure, or repeated relapses leading to death.

Exploration of the professional literature and to some extent the charities leaflets, suggested that following the trajectory of the illness, using ten trajectory stages of the illness would be an apt way to proceed. Namely,
• Prediagnosis;
• Diagnosis;
• Treatment induction;
• Treatment maintenance;
• Treatment completion;
• Survivorship;
• Relapse;
• Palliation;
• Terminal care;
• Bereavement.

There were several attractions in following this route. First, there were strong inferences in the professional literature (and to some extent the charity leaflets) that using the illness trajectory as a framework would be an appropriate way of presenting the results of this study. These indications were explicit, for example in the Faulkner et al. (1995) study and through studies that focused on a single stage of the trajectory such as Cohen's (1995) examination of the prediagnostic stage. Second, it would be possible to categorise statements to distinct stages of the illness. Third, all stages of the illness would be served and finally, the findings would be readily identifiable in the clinical field.

However, problems became apparent with the completion of the Delphi study. This was because, with the exception of one statement in the Delphi study referring to the prediagnostic stage, this framework would not be appropriate. Attempts to resolve this were made and the ten stages were reduced to four:

• Leading up to and including the diagnosis;
• Concerned with treatment;
• Concerned with successful outcome of treatment;
• Concerned with unsuccessful outcome of the treatment.

It was clear from the above discussion that it would not be possible to synthesise the three data sources if this framework was used. Even after collapsing the stages into four, there remained a great deal of overlap between the stages and this would make the placing of statements into categories difficult. For example, wanting a skilled professional would be relevant for several of the stages. It therefore seemed appropriate to consider participation as an over arching factor in the provision of health care within a framework ‘Partnership in Care’.
In view of the recent government legislation and the involvement of the patient as an active participant in health care, a 'top-down' approach was adopted so that a comparison could be made between what the government directives were and the extent to which these directives had been effective from the families' perspective.

It therefore seemed appropriate to consider participation as an over arching factor in the provision of health care within a framework 'Partnership in Care' involving the following concepts (see Figure 2.1):

- Information;
- Decision making;
- Empowerment of patients;

Figure 2.1 Analytical Framework of 'Partnership in Care'
Figure 2.1

Partnership in Care

Government Policies

Participation

Information

Decision-making

Empowerment

Family

Professionals

Voluntary Agencies
Consumerism

The Concise Oxford Dictionary (1990) defines consumerism as,

"the protection or promotion of consumers interests in relation to the producer." (p. 247)

The rise of the concept of consumerism has meant that patients (or in the case of minors, parents acting on their behalf) have expectations of the provisions identified above. Pittman (1992) went a step further and suggested that childhood and early adolescence are the most advantageous times to introduce roles and responsibilities to health consumers before the influence of the traditional submissive patient role becomes established.

When the concept of consumerism is applied to health care, the patient, in theory, has a number of benefits. These include access to information that enables choices to be made, representation through the offices of the Community Health Councils for example, and the right of redress through the law, for example, The Patient’s Charter (1992). However, in addition to the benefits, is the expectation by the government that the population takes responsibility for their own health matters?

Yet the concept, when applied to health care, may not be as clear-cut as the definition implies and there are perhaps differing perspectives. It might, for example, be argued that there is a democratic, rights-based approach to user influence, which emphasises equity and fairness in provision (Winkler 1987). It could also be claimed that consumerism should be individual choice within the health care market place (Green 1990).

In the UK and within the National Health Service specifically, a rise in consumerism had been noted and attributed by Dimond (1993) to the Griffiths Report (DHSS 1983). Prior to the Griffiths Report, the medical profession was able to exercise a considerable degree of autonomy.
For example clinical autonomy meant that the medical judgement of doctors was unscrutinized, consequently poor clinical practice was difficult to challenge. The medical profession also held the responsibility for individual patient care. Advances in medical and surgical care meant that costs were escalating out of control. The expenditure on the NHS therefore was unpredictable and inconsistent. Understandably, this created a tension between the government and the medical profession.

The Griffiths Report identified the need for managers to be more sensitive to consumer satisfaction. Following the Griffiths Report, the shift of power moved from the previous dominance of the medical profession towards that of the managers of the NHS. Accountability for both clinical practice and resources came into being. As a result, there was a change from that of a powerless administration to one where there was room for innovation, aims and targets to be met.

Certainly, for over a decade, the rhetoric of consumerism has featured in many health policy documents and directives that place an emphasis on the sovereignty of the consumer in determining, shaping, and evaluating health services (Poulton 1999). This was seen for example in:

- The 1989 NHS reforms continued to strengthen the influence of management. The white paper ‘Working for Patients’ (1989a) expanded the responsibilities of management. The compositions of Health Authorities changed to resemble company boards and were accountable for their actions to the Secretary of State, while consultants were held accountable for medical audit and consultants’ contracts;
- The government White Paper ‘Caring for People’, (DoH 1989b) focused on responsiveness to the needs of individual patients and their carers, allowing them a choice of care and care provider and fostering independence in the community;
- This legislation was subsumed into the NHS and Community Care Act (DoH 1989c) which created a purchaser-provider split, placing a responsibility on health authorities and boards to purchase care based on the needs of the populations they serve;
- The White Paper ‘Working for Patients’ (1989d) was premised on the importance of promoting patient choice and the provision of services based on the ‘expressed wishes of patients’;
• In addition, GPs were given responsibility to evaluate services at user level and practices were required to provide information to patients indicating for example, the services available, how to change their GP and how to seek a second opinion (Health Department of Great Britain 1989);
• Furthermore, The Charter for Patient’s and Clients (DoH 1992) provided users with rights and expectations (Poulton 1999).

Such activity has not been confined to the UK. Almond (2001) has noted that similar policies were produced by Australia, Canada and the USA, although there were some variations that were specific to existing health service structures in the relevant countries.

The Griffiths report brought to the forefront the need for reforms within the NHS. Clearly, changes in one section of society do not happen in isolation, and the move to consumerism in the health service was a mirror image of what was happening in commerce and industry. Consumerism within the British NHS therefore required:

• A change in attitude about the role of the patient in health care services. The process by which this change took place was for example, via consumer satisfaction surveys and complaints procedures (Almond 2001);
• An expectation that people will change from the passive role (embedded in paternalism) to take responsibility for their own health and to a more active role than previously had been the case (Avis 1995).

Over the last two decades language associated with healthcare policies and practice has changed to reflect a move towards financial efficiency, and an acknowledgement of the healthcare recipient as a consumer of healthcare services.

Healthcare initiatives emphasised value for money, the provision of good quality care and co-operation between healthcare providers and those who require the services. The high cost of health care and its demands on the public purse have led to calls for healthcare facilities to be more accountable to the public.
This was seen for example in the public inquiry of the performance of paediatric cardiac surgeons involved at the Bristol Royal Infirmary between 1984 and 1995 which made 198 recommendations on how to prevent failures in the future (Bristol Royal Infirmary Inquiry 2001; Coulter 2002). The lessons learnt in the inquiry were clearly stated in the report. The changes demanded were well founded and achievable. The changing terminology reflected in the literature moved from patient, to client, to consumer. It implied participation and the 'buying' of a service with the expectation of certain standards. The question therefore arises, can consumerism be effectively implemented within the NHS when it is clearly not a market place and choices are limited? Given the limitations of the consumerist model of healthcare, a framework of 'Partnership in care' has been developed for this study taking into consideration the government directives on involving patients more in health care. The 'Partnership in Care' concepts of information, decision-making and empowerment are now discussed.

Participation in care

The Concise Oxford Dictionary (1982) defines participation as "taking part, having a share in something" (p.746) and by implication there are elements of reciprocity in that sharing process.

The issue of the detrimental effects of hospitalisation upon children was raised some 50 years ago by the Platt Report (1959) and it has been emphasised in paediatric nursing since then. The passive accepting role adopted by patients in previous years is replaced by a more active, questioning approach, reflecting the social change and greater awareness of health issues (McQueen 2000).

Throughout that time, five government reports have reiterated the importance of involving parents in the care of their sick child (Ministry of Health 1959; Department of Health and Social Security 1976; Department of Health 1989; Department of Health 1991; Audit Commission 1993). The Children Act (Department of Health 1989d) explicitly stressed the importance of developing a partnership with the child's parents and promoting the role of the families in the care of their children.
It is therefore now widely accepted that parent participation is a key concept in the provision of high quality nursing care for children and their families. However, in a review of the literature on parent participation, Coyne (1994) points out that although there is a great deal written on the topic, it would appear that there is no clear consensus on what constitutes ‘parental participation’. This is because a number of terms have been used to describe the concept of parental participation. Terms such as, ‘mutual participation’, ‘family-centred care’ and ‘partners in care’ are used loosely and clearly need defining. As a result there is no clear common understanding of the concept, and any consistency in its practical application is questionable. It is then easy for misinterpretations to occur. Consequently if there is no consensus on the definition of a concept, its use is greatly limited (Rogers 1989; Jewell 1994; Callery 1997).

Are parents equal partners in the participation of care?

Whilst having parents caring for a sick child in hospital is the ‘norm’, it is not an easy option for families who are out of their normal setting. There are many individual stressors that families have to cope with and frequently they experience more than one stressor concurrently (Tiedeman 1997). For example, emotional stressors were the most significant stressors reported by families in the Horn et al. (1995) study. All parents in the sample mentioned their emotional state with feelings of guilt, of being a “bad parent” (because their child was sick) (Horn et al. 1995 p. 114), fear for the child and frustration at losing control being recorded. Anxiety was the main emotion reported by the parents in the Strachan (1993) study and Chesler & Barbarin (1987) and Enskar et al. (1997) also reported parents feeling emotionally distressed. The helplessness they experienced watching their child suffer was cited as an important stressor. The feelings expressed by the parents in the Clarke-Steffen (1997) study were identified as worry, uncertainty, vulnerability and helplessness as stressors.

Similarly, well siblings feel the impact of their sick siblings illness and hospitalisations on family life (Wang & Martinson 1996). The fatigue of carers is a very real issue. The emotional stressors noted above were compounded by the difficulty in finding rest, 88% of the parents in the Wells et al. (1990) sample reported that fatigue interfered with their normal activities.
Forty-three per cent of parents reported trouble getting to sleep, whilst 35% found difficulty relaxing and 31% reported that sleeping was troublesome. In addition, 42% reported that they did not feel rested on waking. Ninety-four percent of mothers in the Stewart et al. (1995) study complained of fatigue, and 79% of parents felt worn out in the Horn et al. (1995) study.

In spite of the stresses involved in caring for a sick child in hospital, parents generally want a role in the care of their child. This is based on their belief that ultimately the care of their child is their responsibility (Gravelle 1997). It has also been seen that the health care professionals have invited greater participation (Cleary et al. 1986; Sainsbury et al. 1986; Callery & Smith 1991). Romaniuk & Kristjanson (1995) found that parents appreciated a good working relationship with nurses and wanted to be involved in caring for their child. They suggested that there were two important elements to this relationship. One was that parental participation was fostered, for example through encouragement and acceptance.

A second important element was that of a willingness to provide Family-Centred Care. Simons et al. (2001) studied the involvement of parents in their hospitalised children’s pain care (n=20 parents and nurses n=20). They found that there were shared perceptions of participation in that 13 of the 20 parents involved in the study said they felt involved and 14 nurses felt parents were involved. At first this degree of accord between parents and professionals appeared encouraging. However, although there appears to be agreement between professionals and families, the content of the interviews indicated that their involvement was that of a passive nature. This was because parents interpreted involvement as understanding of what was happening, but did not expect involvement at the level of partnership. This expectation has been supported by a recent study in which expectant mothers expressed the wish to be informed but did not want to be involved in the decision making process. For these women ‘information’ and ‘choice’ were clearly two separate concepts and professionals were using them as though they were one. It was obvious in this study that because of this the women and professionals sometimes had a different agenda. (Mead & Moseley 2001b).
Families demonstrated that they were not always prepared to accept a passive role and they learned to challenge health care professionals if, in the opinion of the families, the health care professionals were not acting in the child’s best interest. The parents in the Heaman (1995) study said they fought for what they felt was needed in the care of the child. However, this was not always the case. Simons et al. (2001) found that whilst there were the shared perceptions referred to above, they also reported differing views and communication difficulties.

Such discrepancies in views of parents and nurses were evident from the interviews. Parents described a passive role in relation to their children’s pain control care and conveyed feelings of frustration and only a minority of parents expressed satisfaction with their children’s pain control care (3/20), yet almost all the nurses perceived that there was adequate involvement of parents in their children’s control pain care. Eight of the 20 parents commented on the need for more information in relation to pain control, but all nurses stated they were satisfied with the children’s pain control care. One nurse acknowledged that it was not easy for parents to be with a child in pain but did not identify any actions to help, and another one disagreed with a parent that the child was in pain. Only two of the 20 nurses commented that parental involvement in their child’s pain care could be of benefit to the child. This seemed to suggest that the importance of parents being well informed, and that parental involvement might be needed to ensure that the child receives optimum pain management.

Much of the stress in the Hayes & Knox (1984) study was attributed to the ‘gap’ between the health care professionals understanding of the parents’ experience and that of the parents’ own comprehension. Kawik (1996) noted that parental participation appeared to occur on an ad hoc basis rather than as result of planned negotiations. It appeared that there was little indication to suggest that parents were equal partners. Casey (1995) conducted a study that aimed to discover the extent to which families were involved in the care of children in hospital. It was noted that although there was explicit commitment to family involvement, it was not apparent. It seemed that parents and staff were not always working together to meet the needs of the child and family.
Previous work by Bowlby (1953), Robertson (1970), the publishing of the Platt Report (1959) and subsequent government white papers have contributed to raising the profile of the care of the sick child and role of the family in their care. Furthermore, since that time, there is evidence to suggest that parents are encouraged to take an active part in their hospitalised child's care (Cleary et al. 1986; Sainsbury et al. 1986; Casey 1995). Therefore, thirty years following the publication of the Platt Report, the expectation of parents in the care of their child has changed considerably during those years (Chesler & Barbarin 1987; Callery & Smith 1991).

It was noted that parental participation appeared to occur on an ad hoc basis rather than as result of planned negotiations. There did not appear to be any recognition on the part of the nurses in the Simons et al. (2001) study for example that the onus was on them to anticipate and address the worries of parents. It would appear that the current role of parental participation is unclear, and that a philosophy of family-centred care needs a degree of clarification and negotiation (Coyne 1994). Parents in the Simons et al. (2001) study valued the nurses' opinions and made an effort to deny any negative emotions they had in order to maintain a working relationship with them. The nurses did not invite parents to be actively involved or discuss the ways in which they could be involved or negotiate the terms of involvement and parents accepted this situation unquestioningly. The relationship appeared to work on the basis of parents accepting that the nurses knew best and not challenging their practice even if they were unhappy with it. For those parents who did challenge nursing staff, they were labelled as 'demanding'.

Stressful situations can arise when parents participate in care. Yet in spite of the stressors identified above, parents generally want a greater role in the care of their child. However, for parental participation to be successful, there is a need for a communication of common goals, adjustment with a degree of negotiation and compromise by both parent and professionals (Shelton & Stepanek 1994). Furthermore, these will be incomplete unless there is commitment and flexibility in a non-judgmental atmosphere (Shelton & Stepanek 1994; Casey 1995; Simons et al. 2001).
Information

Information involves communicating news or knowledge to a second party. It is an important part of health care, and is especially important in child health where parents more often than not make decisions on behalf of the child. There is a need to assimilate new information in order to understand the child’s diagnosis and the management of the illness, from diagnosis to either a cure or the death of the child. There is a sense in which families are inundated with information about treatment regimes, dosages, side effects and other related matters.

This event is particularly intense at the beginning of the treatment phase of the illness. In addition, information receiving is not limited to clinical details. Families have to learn to negotiate hospital premises and the role of the many professionals with whom they have contact. Therefore managing information can be an important method for coping (Aranda 1992).

Without question, informed consent is an important factor within this concept. At the beginning of the illness, the parents will be asked to give their consent not only for the investigative procedures mentioned above, but as the clinical diagnosis is confirmed and treatment starts, they may be asked to make decisions about their child entering clinical trials. For the parents of children with cancer, the subject of consent is difficult and many factors complicate the informed consent process for paediatric research. The dilemma facing parents is clearly highlighted by Kodish et al. (1998) who note that children who participate in clinical trials are patients in need of complex medical care and at the same time human beings requiring the protection of the risks involved in research. For both these reasons Kodish et al. (1998) remind health care professionals that informed consent is essential for the ethical conduct of paediatric research. Correspondence about the difficulties involved in giving consent and decision-making was noted in the medical journals. In the BMJ (1994), a paediatric oncologist, who although committed to the concept of entering patients into randomised trials, often found it difficult to obtain truly informed consent from parents.

"Frequently, requests for consent are met with blank stares, anger, or even the comment, "You do whatever you think is right; we can't make a decision."
(Eden, 1994, p 272)
The sharing of information needs to be both sensitive and effective at times of great stress. Sending out the information does not mean that it is also received. A balance needs to be drawn between giving sufficient information, yet not overloading families with more than they can cope (Bennett-Rees & Soanes 1999). Clearly, choosing the right time, place and method is crucial to effective communication (Aranda 1992; Eden et al. 1994; Soutter et al. 1994; Faulkner et al. 1995; Sloper 1996; While et al. 1996a; Turner 1998).

The presentation of information by the professional, and the assimilation by the family, can present a considerable challenge to all concerned, especially when the news is deeply distressing. There may well be differences in perceptions when providing and receiving information. Some families will find the communication of information insensitive, others will be satisfied with the level of sensitivity. Achieving the right balance clearly requires considerable skill.

Decision making

In an ideal decision-making process, people are maximally informed, positive and negative features of the situation are weighed and a decision is made. Similarly in health care, patients are maximally informed, the positive and negative values of that situation are weighed before decisions can be made.

With the development of consumerism, the traditional paternalistic pattern of patient care has been increasingly challenged in recent years, and in its place is a shared decision model in which more often than not patients work in collaboration with their clinician (Auerbach 2000). However, as Montgomery & Fahey (2001) have noted, agreement may be difficult to achieve if views are polarised. Medical decisions involving children raise particular issues for physicians and other members of the health care team who must work with the child's family. Although parents and physicians have traditionally made most medical decisions on behalf of children, the developing autonomy of children is increasingly being recognised in medical decision-making (Harrison et al. 1997).
The research on decision-making presents the informed consent process, the variation in patient's preference in decision-making, and factors that influence decisions. Unlike the current study, not many papers were able to contrast, within the same study, the comparative views of patients and professionals. However the few exceptions to this are discussed below.

Parents of children or adolescents with cancer and their health care providers face difficult treatment-related decisions. They have to deal with a range of decisions during the course of treatment, be it curative or palliative. Such decisions vary in size, nature, impact and these crucial decisions are made at critical times and health care professionals try to involve families in the decision process and where possible, the child/adolescent is similarly involved. However, the families and professionals will consider the factors involved from different perspectives. Understanding the different factors and emphases therefore helps to promote a better understanding of the approaches adopted by those involved (Hind et al. 1997).

When it came to considering adult patient preferences, there was considerable variation in the way patients preferred an active role (in which they alone decided on treatment) and the passive role (in which the physician decided for them) or some form of shared decision making. Active decision making for the patients in the Strull et al. (1984) study was only 3% compared with 20% in the Bruera et al. (2001) study. There was a marked variation in passive decision making, ranging from 17% (Bruera et al. 2001), 47% (Strull et al. 1984) to 69% (Arora & McHorney 2000); and some form of shared decision making varied between just under half 49% (Strull et al. 1984) to 63% (Bruera et al. 2001). Interestingly the clinicians in the Bruera et al. (2001) study were not so wide ranging in their opinions, with 29% thinking patients would want an active role, 39% a shared role and 32% selecting the passive role.

Not only are there differences between families and professionals but there were differences amongst the professionals. Shemmings (2000) for example, noted a difference between social workers and non-social workers involved in the care of young people at risk.
Social workers were inclined to take each situation on an individual basis, whereas non-social workers believed that young people who could not make decisions for themselves should not be involved in conferences.

There are occasions during the course of treatment when the parents and health care professionals have to make decisions about the continuation of treatment when it is clear a cure cannot be affected and the palliative stages are reached. Parents in the Hind et al. (1997) study, identified 65 factors that influenced their decisions. For the parents, the recommendations they receive from health care professionals and what their child had said about continuing or not continuing treatment figured most frequently, and were the most important factors in their decision making. ‘Feeling supported by and trusting of the staff’ and ‘making decisions with my child’ followed this. For the health care professionals, discussions with the patient’s family and certainty that the patient will not get better, figured most importantly in their decision-making. Similarly the parents in the Kodish et al. (1998) study also found the discussion with staff helpful, more so than the accompanying written information they were offered.

In deciding whether to participate in experimental treatments, adult patients appear to weigh up prospectively the potential risks and demands involved against their hope of success or benefit (Moore 2001). In retrospect, patients appear to reflect positively for despite the lack of clinical benefit, at least they had tried. Other authors, such as Stretz (1993) and Cox (1999) mirror findings in the Moore (2001) study. Patients in the Moore (2001) study seemed to be actively engaged in what was described as survival work because of the desire to survive, a need to do something, and a feeling of having no other choice. While patients in the Cox (1999) study appeared to be actively engaging in what is called ‘therapeutic alliance’ with the experts where they felt everybody is working on the same side and actively doing something in the fight against their disease. Strull et al. (1984) found that the more highly educated patients with greater levels on morbidity were more likely to prefer greater discussion.

The trauma of decision making at the beginning of the illness is traumatic yet equally the case is the trauma in deciding to end active treatment (Hind 1997). Dimond (1996) noted that,
"There are very few laws relating to the procedure by which consent should be obtained." (p. 63)

This statement refers mainly to specific Acts such as the Mental Health Act 1983. However as Dimond wisely points out, although consent can be given by 'word of mouth' or non-verbal communication, nevertheless, written evidence of consent is clearly helpful should a dispute occur.

In addition to the new information to be absorbed about their child and the illness, there is a new language to learn, that is, the language of childhood cancer (Aranda 1992; Bignold et al. 1994). All this takes place whilst they are emotionally devastated from the knowledge that their child has a life threatening illness. Ruccione et al. (1991) (n=28) noted the problems in obtaining informed consent from parents of children newly diagnosed with acute lymphoblastic leukaemia. The results of the study confirmed previous clinical judgement, which suspected that parents were given intricate information, and asked to make difficult decisions about their child’s life whilst in an intensely emotional state. The extent of participation in decision-making will depend on both their individual preferences for being involved and the clinical decisions they have to face. (Montgomery & Fahey 2001).

Discussion with staff is a factor that influenced their decisions for the parents in both the Hind et al. (1997) and Kodish et al. (1998) studies. Awareness of patient and family needs and emotions seems to be a fairly consistent working style of physicians. Shared decision making (SDM) on the other hand is more variable and decision-making can be influenced by clinical problems and patient characteristics (Strull et al. 1984; Bruera 2001; Wensing et al. 2002). Bruera (2001) found that even when the physician had good communication skills, they were not necessarily good at predicting the decision making process of patients (Bruera 2001). Patients and indeed parents will often choose to ignore their doctor’s advice and do something that their doctors regard as odd. A prominent example in the UK is Measles Mumps and Rubella (MMR) vaccination (Smith 2002). Although 69% of the patients (Arora & McHorney 2000) (n= 2197) preferred to delegate decision making to the physicians, preferences varied by patient characteristics. For example, preferring an active role increased with education but decreased with age.
Younger patients (between the ages of 35-44) were seven times more likely to be involved in decision-making. College educated patients were three and a half times more likely to prefer active roles.

In concluding this section, it seems that there are patients who want shared decision-making and want to work with their clinicians, as well there are those who want to be the sole deciders and those do not want to be involved in decisions about their own care. When patients are provided with unbiased, evidenced based information about treatment options, likely outcomes and self-care, rational choices are usually made and are often more conservative and involve less risk than their doctors would choose (O’Connor et al. 1999).

Empowerment

The 1986 Concise Oxford dictionary defined empowerment as ‘to make able’. Three years later the concept was described much more elaborately and describes empowerment as “to invest legally or formally with power or authority, to impart or bestow power to an end or for a purpose, to enable, to permit, to gain or assume power over” (Oxford Dictionary 1989, page 339). The implication of this second definition is that power is being passed from one entity to another for the purpose of enablement.

Empowerment as such is a difficult concept to define (Ellis-Stoll, & Popkess-Vawter 1998; Nordgren 2001), for it is used by different disciplines such as psychologists, educationalists and social workers and therefore has different meanings in different disciplines. However, in common with Nordgren (2001), for the purpose of this study, empowerment was considered to be the patients’ perceptions of self-determination as expressed within the context of health care.

The traditional ‘paternalistic model’ of patient care has been challenged in recent years (Ellis-Stoll & Popkess-Vawter 1998) and as changes do not happen in a vacuum, the increased interest in the concept of empowerment should perhaps be seen in conjunction with changes, the rise in consumerism referred to above is a case in point.
Such changes are then reflected for example in the European common policy that has been introduced to protect patients' rights (WHO 1994 ‘Declaration on the promotion of patients rights’). In the United Kingdom, the Department of Health paper ‘Shifting the balance of power within the NHS’ (DoH 2002) suggested that health care professionals accept and respect patient’s choices. Indeed, Smith (2002) writing in the BMJ suggested that, “medical authorities will have to learn to live with “irrational” decisions by the public” (p 497).

Leino-Kilpi’s (1999) observation that empowering patients within the context of care is complex, nevertheless the study identified several adult studies that enabled the recognition of seven components of empowerment. These are presented in Table 2.1.

Table 2.1. Dimensions of empowerment

<table>
<thead>
<tr>
<th>Dimensions of empowerment</th>
<th>Manifestation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biophysiological</td>
<td>Knowing one’s own body, and its biological changes and symptoms.</td>
</tr>
<tr>
<td>Cognitive</td>
<td>The level and complexity of one’s knowledge when referring to health.</td>
</tr>
<tr>
<td>Economic</td>
<td>One’s ability to afford technical aids and other supports.</td>
</tr>
<tr>
<td>Ethical</td>
<td>The feeling of being valued and respected as an individual human being.</td>
</tr>
<tr>
<td>Experiential</td>
<td>One’s earlier experiences and self-esteem.</td>
</tr>
<tr>
<td>Functional</td>
<td>Knowing the function of ones own body and mind.</td>
</tr>
<tr>
<td>Social or communal</td>
<td>The social interactions and human networking.</td>
</tr>
</tbody>
</table>

Leino-Kilpi’s (1999) noted from such observations identified (table 2.1) that patients have expectations from empowerment and require the following areas of provision (see table 2.2.)
Table 2.2. Patients’ expectations of empowerment

<table>
<thead>
<tr>
<th>Area of provision</th>
<th>Patients Expectation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care provision</td>
<td>Flexible access</td>
</tr>
<tr>
<td>Competent practitioners</td>
<td>Adequately trained and accountable for their actions.</td>
</tr>
<tr>
<td>Information and education</td>
<td>Patients want information about their diagnoses and alternative therapies so they can make informed choices.</td>
</tr>
<tr>
<td>Responsiveness and sensitivity to needs</td>
<td>Respect, advocacy and encouragement.</td>
</tr>
<tr>
<td>Individualised care</td>
<td>Patients want nurses prepared to listen and are available when needed.</td>
</tr>
<tr>
<td>Continuity</td>
<td>Patients expect their care to continue systematically and that documentation and information are reliable.</td>
</tr>
</tbody>
</table>

Empowerment therefore can be seen as an opportunity in the adaptive process within the nurse-patient/client dyad for active learning. The purpose of this is particularly relevant to changing poor health behaviours. Ellis-Stoll (1998) suggested that the desired consequence of the empowerment process is establishing independent health promoting behaviours. Clearly motivation is critical, changes require mutual participation, listening and gaining new knowledge in the health professional-client dyad.

It is noticeable that health care professionals do make attempts to meet the needs of patients. In a recent survey by Van Maanen (1998) of nursing research and postgraduate education in Europe, 24 out of the 35 countries contacted had responded to a questionnaire. It showed that in 18 countries, the most frequently researched topics were quality of nursing care, the nursing process, patient education, personal power planning and continuity of care. The World Health Organisation (WHO 1996) also considered the quality of care in Europe. Overall satisfaction with the quality of care, (a marrying of expectations and satisfaction), appeared to be high with an average of 71% of respondents in the European Union who consider the quality of their care to be ‘good’.
The countries in northern Europe frequently expressed levels of satisfaction in the order of 90%. Leino-Kilpi's (1999) for example found surgical patients in Finland rated their level of satisfaction between 70-80%.

As recently as 1996, The WHO report on the rights of patients in Europe found that the role of the patient remains passive, their voice is weak and they are not listened to by the professionals (Leino-Kilpi 1999). Whilst the European study (WHO, Number 17) found that there was a high level of satisfaction and that patients in the north were clearly satisfied with the level of care, there where 21% of respondents who thought their care was “bad”. There was a clear north-south divide between the Mediterranean countries such as Greece, Italy and Spain expressing greater levels of dissatisfaction. European countries outside the European Union were also dissatisfied with their level of care. In Bulgaria for example, just under two thirds (64%) thought their health care situation was bad. The main causes of their grievances were shortages of medication (66%), nepotism (66%) and bureaucracy (60%). Yet satisfaction as a concept is a confusing term with no consensus of definition (Stanisweska & Ahmed 1999). For example, recent studies have shown that patients in severe pain continued to rate satisfaction with their care as either 'good' or 'very good' (Bostrom et al. 1997: Beauregard et al. 1998; Hulme et al. 1999).

Even more recently, Nordgren (2001) found that that although patients expressed confidence and trust in the care provided, nevertheless they felt powerless because of not being part of the decision-making process concerning their care. They felt that they were not well informed and that they would have made different decisions if provided with information. Patients noticed that the staff were busy, so that they felt their views on their condition were not listened to and they were not respected.

The professionals are perceived to have power over patients; patients are viewed as those without power (Nordgren 2001). Lack of information and knowledge about medical and nursing interventions were factors that contributed to feelings of powerlessness. The responsiveness and sensitivity to needs, respect, advocacy and encouragement, referred to by Leinio- Kilpi (1999) was seen in a small study (Inman 1991).
From the child’s perspective, the visits to the oncology clinics were more acceptable if they felt the staff gave them personal attention, adequate explanations and treated them sensitively. However, there will always be patients who do not want to be fully involved in their care (Nordgren 2001). This too is surely exercising choice and expressing their decisions. By contrast, patients can have confidence in the health care professionals and unconditionally accept the care and treatment they receive. It is not until parents feel they have a grasp on understanding the illness and treatment regimes that they can see the role that they play in their child’s care (Hayes and Knox 1984; Aranda 1992; Bignold et al 1994). A precondition for empowerment is that there is communication between the two parties.

**Conclusion**

With changes in government policy (Putting Patients First 1989a; The Patients Charter 1992) and the rise of the concept of consumerism, the nature of the relationship between the health care professional and the patient has evolved. With the provision of health care for a family in which a child has cancer, a conceptual framework of ‘Partnership in care’ assuming participation as partners based on concepts of information, decision-making and empowerment is presented. In order that the families’ needs are addressed and effectively integrated into the provision of health care, the framework would be based on the basic tenets that health care professionals would:

- Encourage a greater participation of the family by communication and negotiation of common goals.
- Give information to the family in a sensitive and effective way that the family can understand;
- Engage in a shared decision model in which the autonomy of the family is recognised and a collaboration formed;
- Accept and respect the family’s choices and an effective two-way communication network established;

In Chapter Eight (Synthesis) the findings from the current study will be used to demonstrate the extent to which these tenets have been supported.
The extent to which there is a disparity in the way professionals and families think, whether their views on the provision of care are compatible, and whether health care professionals genuinely want to share knowledge (and by implication) shed a degree of power will be discussed.

In summary therefore, a greater participation in the care of the child with cancer by the parent can only be achieved as a result of effective information giving and receiving, shared decision making, and empowerment to participate confidently in that care. The question of to what extent have the 'Partnership in Care' concepts been realised within the field of childhood cancer is now posed. In Chapters 4, 5, 7, 8 the results, discussion and synthesis for the three data sources will provide valuable evidence of whether the rhetoric of 'Partnership in Care' has been achieved in reality.

Choosing a theoretical framework is always something of a judgement call. There are some criteria that can be applied to assist in establishing whether or not an appropriate one has been used. An appropriate analytical framework would emphasise the meaningfulness of the findings. Sandeloweski (1986) argues that the criteria of confirmability, auditability, creditability and fittingness should be applied to test the rigor of qualitative research. As a result of using this framework it will be demonstrated (Chapter Eight page 245) that there was evidence of each of these criteria.
CHAPTER THREE
METHODOLOGY 1: CONTENT ANALYSIS

In this study, three sources of data were subjected to a content analysis. The first two sources consisted of statements obtained from the professional literature and the charities leaflets. The third source of data was the first round of the Delphi study in which statements were generated by the families and professionals.

Content Analysis can be defined as the process of clustering and categorization of data for the purpose of the formation of categories, summarization and tabulation (Fox 1982). At one extreme, it is a largely statistical approach and at the other extreme, it is an approach associated with the narrative tradition of qualitative research, whereby the researcher broods on the data until it ‘makes sense’ or ‘feels right’ (Plummer 1983). In this study, both approaches were used. Essentially an analysis of the content of textual material involves creating categories within the data (for example themes) and developing rules for coding them into these subject areas. It entails the rigorous examination of communicated information.

The versatility of this method means that an analysis of the content of the textual material can be used in a variety of situations. For example, it is frequently applied to such materials as journal publications, books, diaries and letters. For this study it was used to categorize elements of care for children with cancer that were obtained from two literature sources and an open-ended question from the Delphi study (Round One).

Burnard (1995b) noted that:

"Nursing research – like many other forms of social science research-often makes use of interviews, transcriptions and textual analysis as qualitative research methods." (page 55)

Burnard (1995b) also noted that once data have been transcribed, various textual data-material analysis methods are possible. One of which is a content analysis, at which point enumeration is possible (see paragraph two this page).
Such popularity was noted in the extensive use of content analysis in the articles used as data collection material for this study. For example, 33% (n=61) publications used in the data collection for this study employed content analysis of structured, semi-structured or open interviews. These are represented by Barbarin & Chesler (1985); Aranda (1992); Clark-Steffen (1997).

Authors other than those used for the data collection of this study, have also demonstrated the versatility of content analysis. Davis et al (1997), for example, considered the use of QSR. NUD.IST computer program to identify the way in which clinical midwife mentors view their work. In a report of a descriptive study Burnard (1995a), examined nurse educators’ perceptions of reflective practice, whilst Odling et al (2002) undertook a study that described nurses’ opinions of the need for care and support for women with breast cancer. An interesting feature noted in that study was the discrepancy between professional and families’ perspectives of care noted in this current study (see page 261, Figure 8.1).

The following comments can be made about content analysis:

- It is a method for studying the content of communication in an equitable, qualitative and systematic way (Holsti 1969; Weber 1985; Nieswiadomy 1993);
- The use of content analysis enables themes contained in the data to be identified from which theories and hypotheses can be generated;
- This may be undertaken deductively or inductively.

Top down deductive reasoning moves from a general explanation (theory), to specific scenarios in the real world (with empirical data). One of the methods in validating the proposed theory can be through a ‘What if’ approach. That is, what results could be expected if the theory was valid. (Polgar & Thomas 1988; Nieswiadomy 1993). An example of deductive reasoning was seen in a study by Hockenberry-Eaton et al. (1997). It was hypothesised that childhood cancer stressors (such as changes in physical appearances) have an influence on the child’s adaption during treatment. Hockenberry-Eaton et al. (1997) developed and tested two questionnaires that examined stress and adjustment in children with cancer. These questionnaires were identified as the Childhood Cancer Stressors Inventory (CCSI) and the Children’s Adjustment to Cancer Index, (CACI).
From their findings, Hockenberry-Eaton et al. (1997) indicated that it was possible to measure the child’s perception of the cancer experience. It was seen that changes in their physical appearance were the most frequently noted stressors. Hair loss, for example, gave 72% of children the greatest stress. This was followed by 70% needing to take medication and 68% experienced weight changes. On a four point scale (from ‘not at all’ to ‘a lot’) more than 25% said the physical changes bothered them ‘quite a bit’ to ‘a lot’. Results from the Children’s Adjustment to Cancer Index, (CACI) indicated that children with low adjustment ratings had fewer friends \( (p=0.001) \). The relevance of the study to childhood cancer was that the instruments would be important tools when assessing the impact of cancer on the child.

Bottom up inductive reasoning, by contrast, is a process whereby data are collected from real-life situations and used in the development of theory. This involves discovering general patterns in explaining specific events or behaviours (Polgar & Thomas 1988; Nieswiadomy 1993). Following the data collection, generalisations are made and propositional statements are used to form a theory. An example of inductive reasoning was seen in Hymovich’s (1990) study (‘A Theory for Pediatric Oncology Nursing Practice and Research’). Tape-recorded semi-structured interviews were conducted with ill children \( (n=20) \), family members \( (n=78 \text{ parents and well siblings } n=11) \) and health care professionals \( (n=21) \). The interviews provided the data from which empirical generalisations were made and a theoretical framework was developed.

It is recalled that one of the approaches used in this study was to assume, as far as possible, a *tabula rasa*, that is, no assumptions from knowledge and experience. Having decided that the selected sources would provide rich data, the analysis of the content of textual material was used inductively. This meant that themes were identified as they emerged from the data and eventually formed the list of elements of care to be prioritised and recommended as policies.

It is important to note that the nature of the content analysis undertaken could only offer a means of organising data into groups (called variously clusters, themes or categories) and a means of helping to identify patterns within the data.
The method has no explanatory power and its use cannot be an end in itself. After a content analysis has been carried out, the task was to offer explanations of the findings. It is important to link the findings back to the particular context from which they came and to provide their explanation within a theoretical framework. In this study the framework of 'Partnership in Care' has been used to help explain the different conclusions reached from the data sources.

As with any research tool, using content analysis has drawbacks, one of which is the researcher's bias. This could lead to difficulty in maintaining objectivity and inaccuracies in the summarising of the data. Miles (1979) noted that the most serious and central difficulty in the use of qualitative data is that methods of analysis are not well formulated. For quantitative data, there are clear conventions the researcher can use but the analysts faced with a bank of qualitative data has few guidelines for protection against self delusion – let alone the presentation of unreliable or invalid conclusions to strategic or policy making organisations. It is argued that the methods used in this research have produced valid and reliable conclusions. This position is supported because of the following.

The measures of inter rater reliability have been described and demonstrate that levels were obtained. Validity is an equally important measure and for the reasons stated above difficult to achieve when analysing qualitative data. According to Sandelowski (1993) (see page 42) rigor has been demonstrated and in addition the following is offered as evidence. Minimally, the codes should have face validity in that the categories should bear an overt relationship to the purpose for which they have been created. Sandowleski would call this "fittingness" It is believed that this has been achieved. However the data are coded, that is, from an imposed framework or via an emerging one, the researcher should be able to argue that there is a rationale for what is in the categorisation and what is not. In addition, the researcher should be able to demonstrate that there is some rationale to the way in which the different levels of code (sub themes) have been organised. With any set of data, many coding frameworks can be developed.
For the code to be valid Fox (1982) argues that it must be organised upon a logical and rational perception of the data and the research purpose. It is argued that this has been demonstrated in this study.

The potential problems of researcher bias and lack of objectivity when conducting a content analysis were addressed by submitting the results of the analysis to a member of the academic department for independent coding using the first researcher's categories. Agreement was high for the professional literature and the charity leaflets (page 55).

**Alternative data collection methods**

In addition to the data collection methods, self-reporting methods (e.g. diaries) could also be considered (Polit & Hungler 1999). Participants could recount significant events from their history. It could be argued that if an event was important enough, it would be readily recalled. However, they were not used as they may have missed important matters that had taken place prior to the study, for example, a disagreement with the GP during the prediagnostic stage.

Consideration was given to conducting interviews (Meredith & Wood 1996). This approach could have a number of advantages. For example, interviews produce a wide range of subject matter and respondents are more likely to participate having been asked as opposed to receiving a postal questionnaire. They can be structured, semi-structured or completely unstructured. These could take place face-to-face, or over the telephone. In semi-structured or unstructured interviews, interesting trends or thoughts can be followed and explored. This means that the interview situation provides a considerable level of flexibility (depending, of course, on the design of the study). The interviewee may feel that they can respond more easily in an interview than in writing as they can always seek clarification if they have not fully understood the question. Similarly, so can the interviewer if they have not fully understood the reply. This is particularly the case in the presence of regional or cultural differences.
There were also several disadvantages associated with interviewing (May 1989). An important consideration is that the interviewer can bias the replies of the interviewee, albeit unwittingly, by giving non-verbal clues, such as frowning. The interviewee may then feel inhibited and not elaborate or mention the topic again. Also, the interviewee may take a dislike to the interviewer. On the other hand, there is always the possibility that the interviewee may reply in the way they think they ought to be replying. This may be to please the interviewer, commonly known as Hawthorne effect (Polit and Hungler 1999).

In the current study, the questionnaires were distributed personally by the researcher to the families so that any ethical problems arising could be dealt with immediately. For example, a parent becoming distressed when completing the questionnaire. However, by adopting high ethical standards, a problem with Hawthorne effect could have occurred. In an attempt to avoid this problem, the researcher tried to maintain a disciplined approach with minimal conversation until the questionnaire had been completed. It was only once this task had been accomplished that a more relaxed approach was adopted. In addition, there may be difficulties in recording the information from the interview and the analysis and coding of the information may be complex. Other disadvantages associated with interviews are that they are not anonymous and time-consuming for both the interviewer and respondent.

Questionnaires and focus groups were also considered. Questionnaires have the advantage of being given to many people at the same time, for example in a large mail distribution. They can be answered anonymously so respondents are likely to be honest in their replies. Therefore, the potential for coding and analysis is reasonably straightforward. Focus group members have the opportunity to exchange and express their views, in addition they have the advantage of moving beyond the 'tick box' (Bulmer 1998). They can be conducted with several people at the same time, for example a parents support group or patient group (Beyea 2000). A focus group can also bring together in one session a range of experts.

The use of focus groups was not pursued. There were several reasons for this decision.
Childhood cancer is a highly specialised area of paediatric care and it was thought that an anonymous range of professional respondents throughout the UK would better serve the study. The size of the panel and the widespread geographical location of such respondents would mean focus groups would be time consuming and expensive and therefore impractical (MacLeod Clark 1996). In addition, focus groups would not be able to offer anonymity to respondents. This was an important consideration in a highly specialised community for, frequently group dynamics means that a powerful member of that group can take over. Consequently, members of a focus group may feel inhibited in presenting their opinions especially when they are uncertain of their reception. This is particularly so if members of a focus group are colleagues. In addition, having made a decision and stated it publicly, people may not feel able to abandon that position. Furthermore, people are frequently unwilling to make decisions until the facts of the situation are known. Whilst a good facilitator may be able to overcome many of the problems, the advantages were not convincing enough to use focus groups as an appropriate source of data for this study. (Bennett & Mansell 1999; Beye 2000).

A questionnaire was developed through the use of a Delphi study. The way in which it was performed overcame many of the problems associated with questionnaire design. For example as with interviews, respondents may give the replies they think they ought to be giving or be casual in their approach to the questionnaire. Respondents may not be able to express their opinions and seek clarification. Similarly, the researcher cannot ask the respondent for clarification. They may be expensive to reproduce and some people simply do not like filling in forms. All these problems were overcome as can be seen in Chapter Six (page 185). Questionnaires can be time consuming in their preparation; they also need time in order to test for reliability and validity. However, preparation of the questionnaire used in the Delphi study also proved to be time consuming but this was time well spent.

The data collection

The literature search was undertaken electronically using CINHAL, Medline, Cancerlit and EMbase databases. Library journals were also manually searched.
In addition, a search was made of ‘the grey literature’. This included newspaper and magazine articles. The search was confined to publications written in the English language. Should a relevant article be located, that was not written in English, preparation was made for translation facilities to be made available. However, this did not arise and all the publications used in this study were published in English.

The search was restricted to a time frame that covered the period 1980 to 2000. The year 1980 was selected for the professional literature in order to incorporate the pioneering work, as well as the current work in the field of childhood cancer. The first search was deliberately broad and key words were used that incorporated chronic life-threatening and life-limiting illnesses. Key words used on that occasion were: cancer, childhood cancer, paediatrics, paediatric oncology, family, family-centred care cystic fibrosis, renal failure, congenital heart disease and metabolic diseases, cancer services/provision, government policies.

There were potentially several thousand publications available during the initial searches. The term ‘publications’ was used to refer to research studies, reviews of literature, textbooks reports and opinions expressed. However, because the early searches of the professional literature were deliberately broad, using the key words cancer, childhood cancer, paediatrics, paediatric oncology, paediatric neoplasms, family, and family-centred care, subsequent searches were more refined.

Family centred-care was combined with childhood cancer but only seven publications were located. These were of limited benefit for this study because three out of the seven publications failed the Critical Appraisal Skills Programme (CASP) grade I-III.

In order to determine an understanding about the type of publications referred to in this thesis, and to assess the strengths and weaknesses of individual papers, each paper was critiqued using a proforma to maintain consistency (CASP 1996). (Appendix 1 CASP Proforma). The paper was then allocated a grade using the CASP categorisation (Appendix 2 CASP categorisation). In using CASP for grading, the literature included: anecdotal material, opinions, reports, studies conducted by reputable academic establishments and academic course work.
CASP was considered to be a beneficial tool in selecting studies as data for this study. The aim of CASP is to enable health and social care professionals and users of the NHS to be judicious when evaluating evidence to support decisions. It involves disseminating and cascading knowledge and skills in an area of evidence based practice. It is an attempt to make learning more accessible—by critically appraising evidence—thereby improving the quality of health and social care service.

In this study, CASP was used to provide evidence on the quality of the studies cited. This was a three-stage process that initially involved finding relevant literature to answer the need of the enquiry. Secondly, it was necessary to assess the evidence in order to assess:

- What those results were;
- How valid the results were;
- How relevant the results were to this study.

Third, it was necessary to act on the evidence. Papers now graded according to CASP Proforma (Appendix 1), meant that when the final list of prioritised elements of care was established by this study and recommendations presented to policy makers, one could be confident that:

- The papers were relevant to the research problem;
- The evidence in the studies were supported;
- There was a report of what those results showed;
- The studies were relevant to the problem addressed;
- The results within the studies were relevant.

It should be noted that a different proforma was used for the analysis of the charity leaflets as, unlike the professional literature, CASP was not an appropriate method of assessing given that it was the content rather than the quality of the leaflet that was important.

Once the papers had been graded using the inclusion criteria, the next stage was to identify the elements of care as described earlier (see page 1). In order for a statement containing the element of care to be included, the following criteria had to be met:
• Statements were from appropriate studies;
• The statement was taken from the conclusion of a study or report;
• It was possible to prefix the statement with the following (Appendix 3).

"An attribute (or barrier) of family-centered care.

For example:

An attribute of family centred care is...

"A need to recognise the special concerns of parents who live long distances from the tertiary treatment centre."

A barrier to family centred care is...

"A gap between services currently available for parents and what is purported in the literature as necessary to promote optimal long-term outcomes."

Although content analysis can be conducted at various levels (e.g. at the level of individual words or phrases), it is probably the case that most nursing researchers will want to identify key themes (Berelson 1952, Carney 1982). A difficulty arises when statements contain more than one idea, as was the case in this study.

One way of handling this is to reduce the statement into its component themes, these are then coded and placed into one of the existing categories (unless it is a new theme in which case it becomes the first idea in a new category). Unless the sentence is reduced as described, then matching becomes very difficult. However, what is gained in terms of having only one theme to deal with can lead to losses in that if a theme is taken out of its context (i.e. the complete statement from which it originated) then the original meaning can be lost and errors in coding occur. As stated in Mead (1993), a text out of context is a pretext. In retrospect, the use of a qualitative analysis software package such as NUDIST/NVivo would have avoided this problem had it been available to this researcher at the time of the beginning of the study.
In order to overcome the need to have one variable to deal with and to be able to see each variable as part of the sentence in which it was originally placed, the following action was taken. The statements were then examined for themes and where two or more themes were present, these themes were identified within the context of the whole statement. This can be seen in the examples immediately below. When this process was completed, the new sentences were referred to as a statement and given new unique identity numbers. This process can be seen in the sample statements below.

Original statement

"Oncology staff with appropriate experience and in sufficient numbers."

(L 123)

New statements

"Oncology staff with appropriate experience and in sufficient numbers."

(L 456)

and

"Oncology staff with appropriate experience and in sufficient number."

(L 789)

These two new statements were given unique identity numbers and the initial statement in its original form was removed from the analysis, but kept in the database so that the phrase could be seen in context as necessary.

Appropriate studies were placed in a database referred to as ‘References used as data’ (See page 272). These publications were available to be cited as evidence in this study. Conclusions from papers that could not be prefixed with the statement “An attribute (or barrier) of family-centered care is ...”, were removed from the analysis and placed in a database labelled ‘Rejected Material’. These publications were not to be used as part of the body of evidence. Within the context of this study ‘Rejected Material’ meant studies unsuitable for this study because:
• An attribute or barrier of family centered care could not be clearly identified;
• The CASP grade was IV.

Ultimately, 178 publications were thought to be potentially appropriate for this study. These were subjected to a rigorous screening process described below.

Coding and agreement

Each statement was coded using a conventional content analysis method. The researcher conducted this independently. A coding framework emerged based on six categories developed from the professional literature and then adopted for the charity leaflets and the first round of the Delphi study. It was felt that the category framework would fit comfortably for all three data sources. This would also be beneficial in ensuring a consistency in the analysis and presentation of findings. However, it should be noted that subsequent subcategories were developed in accounting for the differences in the three data sources. For example, within the category of ‘Communication and Cooperation’, a subcategory of ‘Glossaries’ was unique to the charity leaflets given that they focused on defining and explaining medical terms used for the families. By contrast, the use of glossaries would not be found in the professional literature given that, in this data source, professionals are communicating with professionals. Inter-rater reliability was established by a second researcher coding the statements (no statements were placed in a miscellaneous category). This researcher was unaware of the codes given by the first; however, the same coding framework of six categories was used. Coding of the professional literature took approximately six weeks to complete. The task of coding the professional literature and the professionals panel members responses from the first round of the Delphi study, took this length of time because the statements were very esoteric and dense. The researchers involved in the inter-rater reliability are two health professionals themselves and both gained different interpretations in coding the literature. Although the inter-rater reliability score was high by conventional social science standards, the disagreements were considered carefully. It was discovered that the source of the disagreement was not the coding per se but the different interpretations placed on statements, which were very difficult to understand because of the language used.
When agreement about the meaning of statements was achieved then coding was a straightforward process with high agreement. By contrast, the coding of the charity leaflets was a much easier task and took approximately two days to complete as the statements were more straightforward given that they were directed at families and assumed no prior knowledge or experience of childhood cancer. It is of no surprise therefore to report a much higher agreement for the charities leaflets (Kappa = 0.958, p< 0.001) indicating the reliability of the coding, compared with the extent of the agreement for the professional literature (Kappa = 0.677, p< 0.001). Further details on the extent of agreement for both charity leaflets and the professional literature can be found in Appendix 4.

Data management

A Lotus Approach database was prepared for the management of the data. There were nine fields which included: unique identity of the paper, the author, title, journal details, CASP grade, country of origin and the element of care. Papers were allocated an identity number for quick identification of a paper once it was in the database, and as an attempt to avoid confusion in the case of locating a range of papers by the same author. The country of origin of publications was noted in the database so that awareness of a variety of cultural or ethnic backgrounds could be demonstrated. It was anticipated that this facet of care might not be present when recruiting panel members for the Delphi study (Appendix 5).

The Use of Quantitative Methods in Content Analysis

There is a debate about whether or not numeracy can strengthen the findings of content analysis. Miles & Huberman (1984) advocate the use of numeracy arguing that it can establish whether a particular theme or pattern happens a number of times or if it happens in a particular way. Against this is the argument that a single statement or response may be as significant as a cluster with many responses. Sommer & Sommer (1991) suggest that one of the aims of content analysis is quantification.
There is no doubt that numeracy enables the verification of findings e.g. the extent to which a category is occurring and the potential meaning of the frequency. For example, Tesch (1990) suggested that content analysis is, in any event, largely numerical not in a statistical sense but from a substantive perspective. By the use of numeracy, a cluster can be discussed in terms of the number of responses, thus giving a substantive perspective in terms of volume. Once the data are categorised, it is possible to count the frequency with which particular themes or headings occur (Moseley & Mead 1993). Such counting can be analysed at three levels. That is:

- How many people (respondents) mention a given theme;
- How frequently that theme occurs;
- How many statements are contained in that theme.

It is necessary to involve this level of detail because there is a difference with the following scenarios.

**Scenario A**
The theme ‘Key worker’ occurs 20 times and is mentioned by one respondent.

**Scenario B**
The theme ‘Key worker’ occurs 20 times but is mentioned by 20 respondents. Scenario B would carry a different weight from Scenario A, for it might be that the single respondent in Scenario A had greater levels of verbosity or felt so strongly that they repeated the same idea many times than the 20 respondents in scenario B.

In a third scenario (C), the following could also be the case, and account is taken of the two topics in the sentence.

**Scenario C**
The theme ‘Key worker’ is mentioned by one, two, three, four or more respondents but in conjunction with another theme. For example,

"A key worker is present at the diagnosis, stays with the family throughout the illness, and minimizes confusion between staff."
"A key worker who provides continuity during the illness and co-ordinates information within the team."

If the data are analysed in this way, that is, numerically by the number of responses and number of respondents, the researcher is trying to understand the respondents and give meaning to their world. Enumeration is therefore thought to be an important part of content analysis and that qualitative data can be strengthened by attaching numbers (Miles & Huberman 1984; Ely et al. 1991). In the case of this study, the data were analysed by the number of authors and the number of statements.

Although quantification of responses is supported by authors such as Field & Morse (1985), nevertheless, they also caution not to lose the meaning of the data. However, it could also be argued that rather than lose the meaning in the data, quantification clarifies it and leaves it open to inspection. Quantification therefore should be seen as strengthening the process of summarisation rather than as a departure from the qualitative tradition.

Quantification for this study was used in the following way. The use of a Lotus Approach database for the management of the data enabled a nominal level of measurement to be adopted. That is, the statements could be labelled, placed into categories and counted. The number of subthemes within each category could also be identified and quantified and it was possible to count the number of responses and respondents.

The same method was applied to the charities leaflets and this gave the added advantage of being able to compare the data from the professional literature with the data from the charities leaflets.

**Conclusion**

It is not unusual to have literature as a data source. This can be seen for example, in the meta-analysis of systematic reviews. What is unusual is to use the literature as data and then to undertake a content analysis of that literature. Within the literature search, it was not possible to locate randomised-control trials.
Undertaking a content analysis of the literature enabled the data to be ordered as described by Abbott and Sapsford (1992). This has enabled interpretation to be made using the analytical framework. This meant that it was possible to make judgments in a formal way from the textual material. Analysis of the content of the professional and charities literature provided an opportunity for summarization of the data, which is shown in the use of tables and thereby achieve the objective of the study. The results then become defensible and transparent, that is, an audit trail of all the judgments taken of the data is possible.

Introduction to the charity leaflets

There were several reasons for studying the charity leaflets, the second data source. It was thought that an examination of the leaflets might give an insight into the world of the charitable agencies that supported families in which a child has cancer (or other life threatening illnesses). Moreover, there was uncertainty about the function that such leaflets play in supporting families. At this stage it was unclear as to wherever the charity leaflets were providing the same services, new services or complementing existing services provided by the NHS. Given that two thirds of the charities included were founded by people who had personal experiences of childhood cancer, a fourth consideration was that of whether these people felt they had to do something to help others going through the same experience.

When leaflets are distributed, an assumption is made that they are a form of communication and information giving and families can access the knowledge base of the professionals. This was seen in the glossaries and lists of publications found in the leaflets, but on their own, these are of limited effectiveness in empowering families. Aranda (1992) noticed that parents felt that if they learnt the language of cancer care, they would "be accepted as intelligent" (page 112). If the leaflets are one of the means by which the parents learn this language, then it could be argued that they are an important component of care. Secondly, as with the literature, this was an analysis of the content of the charities leaflets. As experts in their own field, it was assumed that they would focus on a range of situations met in childhood cancer. Thirdly, there was uncertainty about the function that such leaflets play in supporting families.
This examination of the leaflets would give an insight into the world of the charitable agencies that support families with a child who has cancer (or other life threatening illnesses).

The possibility of interviewing a sample of senior executives of the different charities was considered. However, this was dismissed for the following reasons:

- There was a danger that the views would not have been fully representative of the organization or indeed of charities;
- The large geographical spread would have proved expensive and beyond the budget allocated for the study;
- The information was already available through the printed leaflets.

As experts in their own field, it was assumed that the content of the charities leaflets would focus on a range of situations met in childhood cancer. Furthermore, the material was already available thus negating the need for interviewing senior executives of the different charities.

**Data collection and management**

Ninety four charitable organizations were contacted from a list compiled by the British Association of Cancer United Patients (BACKUP) in 'Children with Cancer: A Guide to help Families,' and 'A National Directory of Childhood Cancer Support Groups' (1994). Although the entries in the directories were listed as cancer charities, there were also charities for families of children with other life-limiting illnesses. The charities were contacted by letter explaining the nature of this study and requesting relevant information. Relevant information in this context included appropriate leaflets, audit reports, standards of care, protocols, general publications and research based activities. Stamped addressed envelopes were included for the convenience of the respondent and to maximize the response rate. However, the response rate from the charitable organizations contacted was low at 30% and it is not possible to give precise reasons for this. Wray & Gates (1996) maintain that there are three barriers to recruitment of participants for nursing research. First, problems are encountered in accessing a hidden population.
Second, professionals take it upon themselves to act as 'gate-keepers' to their client group. For example, access to potential family members was denied for the Delphi study as it was considered, by the charity, that their members were too vulnerable to be approached. Third, there is a lack of interest in the study.

Whilst it is not possible to give reasons for the low response rate in this study, one reply from a charity indicated that it was not their policy to provide the information requested as they were 'overwhelmed' with the volume of requests from researchers. Providing information to researchers can be demanding on their time and budget, when their focus of care should be directed at the families. In addition, two charities were no longer functioning at the time of data collection and two envelopes were returned 'not known at this address' which may indicate that they also were no longer functioning or had re-located.

The responding charities were coded chronologically as responses were received. The term 'leaflet' was applied to all the received material. This included single sheet A4 leaflets, double and triple-fold leaflets, booklets and newsletter/magazines. In terms of confidentiality, the charities were treated with the same respect as panel members. This was because it was considered appropriate to treat all data sources in the same way. For this reason, a numerical identity code prefixed with the letter 'A' was given to each responding charity. For example, 'A1' and 'A12'. Identifying features such as names and locations of charities were altered and referred to as 'this charity' or Charity 'X'.

The leaflets were scanned and the image converted into a text file. Consequently, no typing had to be undertaken. A Lotus Approach database was prepared for the management of the data and were placed into five fields. They included:

- The code number for the charity;
- Unique identity of the statement (a statement in this context referred to the sentence that became a measurable unit);
- The statement;
- The category;
- Additional comments.
One of the advantages of using a database to manage the data is its capacity to quickly compute the size of each category. For example, it was possible to find the number of statements contained in a category and the number of leaflets that contributed to each category. Identifying the number of leaflets contributing to each category was important because two leaflets devoted themselves entirely to one topic. A failure to identify single topic leaflets could potentially result in a distorted data set. Possible subjectivity in the analysis by the author was addressed by submitting the analysis of data to a second assessor (see page 55).

Consistency was needed when examining the leaflets. Therefore an interview schedule was developed. Each leaflet was examined and the following questions formed the basis of a semi-structured interview schedule. The schedule was as follows:

- Why did this charity start?;
- What does this charity do?;
- How does this charity organise itself?;
- Who is target group?;
- What were the intentions in producing such a leaflet?;
- How does this charity maintain its momentum?;
- Finally, is there anything else?

The same process of content analysis for the professional literature was also used for the charity leaflets. As stated earlier (page 54) the same coding framework was adopted for categorizing the statements. An example of a statement from the charities literature is given below.

"The main focus of our work therefore, is to help parents overcome their feelings of loneliness and reduce their stress." (A1 #123)

This became,

*The main focus of our work therefore, is to help parents overcome their feelings of loneliness and reduce their stress.* (A1 #456)

Also,
"The main focus of our work therefore, is to help parents overcome their feelings of loneliness and reduce their stress." (Al #789)

The charities’ financial details such as balance sheets, names of personalities in photographs, travel directions and logos were excluded from the scanning process. The categories and leaflets are shown in Table 5.2 (Chapter Five page 100).

In this chapter the data sources were identified and methodological considerations made known. Potential threats to a study when using content analysis were addressed, and other methods of data collection were considered. In the next chapter, the results and discussion of using the professional literature as a data source are presented and then discussed. Elements of care were identified and it was possible to categorize the elements of care by placing them into six main categories. These categories, in turn, can be successfully synthesized with the concepts of the ‘Partnership in Care’ framework discussed in more detail in Chapter Eight.
CHAPTER FOUR
RESULTS AND DISCUSSION
THE PROFESSIONAL LITERATURE

Introduction

The use of the professional literature as a data source, which aimed to capture the elements of care, is presented in this chapter. An initial perception that information about best practice would be found in the professional literature became apparent from its analysis. The following provided supporting evidence for the reported findings:

- It was possible to identify elements of care;
- More detailed examination of the professional literature showed that it was possible to identify elements of care that were replicated in the charities leaflets and in the Delphi study thereby enriching the process of triangulation;
- The emergence of six main categories that could be effectively linked with the concepts of the 'Partnership in Care' framework;
- International and cross-cultural perspectives were obtained. In the design of this study, it was acknowledged that within the panel of experts for the Delphi study, there was a deficiency of panel members from an ethnic background. Attempts were made to overcome this situation by including studies from non-European or North American cultures. For example, a study by Martinson et al. (1995) provided a perspective from an Asian culture. In that study, Martinson et al. (1995) showed that Korean mothers bear a great deal of the responsibility for the treatment and care and demonstrated that the readjustments in family life were not limited to families living in the Western Hemisphere.

Presentation of results and discussion

As mentioned earlier (see Chapter Three page 54), each statement was coded using conventional content analysis methods. The findings discussed below have attempted to set out the emergent categories and subcategories from the content analysis of the professional literature used as the first data source; this discussion therefore will focus on these categories. However, at this point, it will be useful to show what the categories and category descriptions were (see tables 4.1) and the ratio of publications to the statements (see table 4.2).
Table 4.1. **Categories and category descriptions**

<table>
<thead>
<tr>
<th>Categories</th>
<th>Category descriptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication and Cooperation</td>
<td>Issues concerned with imparting information between professionals and with the family, continuity of care from clinical setting to community/home.</td>
</tr>
<tr>
<td>Maintaining Normality</td>
<td>Issues related to the needs, values, perceptions, coping and quality of life of family members in order to maintain their usual life style.</td>
</tr>
<tr>
<td>Professional Issues</td>
<td>Scope of clinical practice, knowledge base, accountability, response and sensitivity to family needs.</td>
</tr>
<tr>
<td>Resources</td>
<td>Issues related to the means of supplying that which is needed in order to enhance caring for a sick child.</td>
</tr>
<tr>
<td>Research Projects</td>
<td>Issues related to the acquisition of new knowledge and/or the collation of established knowledge.</td>
</tr>
<tr>
<td>Treatment Issues</td>
<td>Regimes, short and long term side effects and symptom control.</td>
</tr>
</tbody>
</table>

The six categories above (table 4.1) emerged from 435 statements collected from 183 publications (see table 4.2.). The ratio of statements to publications indicated that most publications provided 1.6 statements, although this ranged from 1.00 to 1.83. It is important to note that this factor gives a clear indication that no single publication monopolised the data set. Thus publication bias of the data set, for this reason, was minimal.

Table 4.2. **Categorised statements to publications ratio**

<table>
<thead>
<tr>
<th>Category</th>
<th>Statements</th>
<th>Publications</th>
<th>Ratio of Statements to Publication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional Issues</td>
<td>152 (35%)</td>
<td>83 (29%)</td>
<td>1.83</td>
</tr>
<tr>
<td>Maintain Normality</td>
<td>89 (21%)</td>
<td>68 (24%)</td>
<td>1.31</td>
</tr>
<tr>
<td>Communication and Co-operation</td>
<td>67 (15%)</td>
<td>58 (20%)</td>
<td>1.56</td>
</tr>
<tr>
<td>Resources</td>
<td>66 (15%)</td>
<td>40 (14%)</td>
<td>1.65</td>
</tr>
<tr>
<td>Treatment Issues</td>
<td>52 (12%)</td>
<td>29 (10%)</td>
<td>1.79</td>
</tr>
<tr>
<td>Research</td>
<td>9 (2%)</td>
<td>9 (3%)</td>
<td>1.00</td>
</tr>
<tr>
<td>Total</td>
<td>435 (100%)</td>
<td>287 (100%)</td>
<td>-</td>
</tr>
</tbody>
</table>
It is interesting to note the spread of statements across categories. It is clear that no category monopolised the majority of the statements. It was seen that the largest category labelled 'Professional issues' contained 35% of the total number of statements referred to whereas 'Research' was the category with the smallest number of statements (2%) and the least number of authors (3%). Subcategories, their frequency of occurrences and examples of statements within each subcategory are given and discussed below.

**Professional Issues**

**Table 4.3. Distribution of subcategories**

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>No. of statements</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional input</td>
<td>67</td>
<td>44</td>
</tr>
<tr>
<td>Knowledge and skills</td>
<td>35</td>
<td>23</td>
</tr>
<tr>
<td>Interdisciplinary approach</td>
<td>26</td>
<td>17</td>
</tr>
<tr>
<td>Purchaser/provider issues</td>
<td>24</td>
<td>16</td>
</tr>
<tr>
<td>Total</td>
<td>152</td>
<td>100</td>
</tr>
</tbody>
</table>

In table 4.3, it was seen that the largest subcategory, containing 44% of the statements were related to 'Professional input', with the smallest number of statements (16%) based on 'Purchaser/provider issues'. Eighty-three authors (29%) contributed to this category.

**Professional input**

The responsibility of designing and implementing programmes of treatment, which took account of the dynamic, multi-faceted context in which care was given, was seen to be the responsibility of health care professionals:

"Healthcare providers have a responsibility to understand the plight of families in order to direct efforts towards helping them cope with childhood cancer." (L 18)
It was found important for the professionals to pay close attention to changes that might be stressful, and be sensitive to the coping strategies of families:

"Child care professionals should not assume that each member of the family will cope with the illness in the same way." (L 342)

The input from some professionals was successful in that situation:

"Macmillan paediatric nurses are able to facilitate continuity of care and improve quality of life for children with cancer." (L 325)

Management principles therefore needed to be flexible and adapted to suit individual needs when working in a partnership:

"A simple flexible model that appears to represent paediatric nursing in any setting". (L 7)

However this was not always the case and there was evidence to suggest that a service did not adapt to meet the needs of the family:

"Parents could be involved if it did not interfere with professional care." (L 312)

Neither were the health care professionals necessarily prepared to work with families.

"Nurses were reluctant to share with parents." (L 307)

Nurses were in a position to facilitate support and to provide care that was relevant to the needs of the child and family:

"There is support from the community and school nurses." (L 11)

However, providing such support required innovation in order to move forward with developments in practice:

"There is a potential expanded, complementary role for nurses that enhances and adds a new dimension to care." (L 41)
Innovation was not limited to nurses, but could involve other professionals including play and art therapists:

"Familiarity with the emotional consequences of diagnosis and treatment, sensitivity and trust allow the art therapist to be a valuable support to physically ill children." (L 19)

Knowledge and skills

Nurses needed to be skilled and possess up-to-date knowledge:

"Nurses working in the area of bone marrow transplant require research-based knowledge in order to provide care that is relevant to the needs of the child and family." (L288)

Furthermore nurses were able to provide a distinctive contribution to care:

"Discovering more about the duration and quality of life of children dying of cancer, comprehensive preparation for future bereavement care can be made." (L 84)

The role of the nurse in the spiritual dimensions of the family was not neglected:

"It is of the utmost importance that nurses enhance their awareness of and ability to provide spiritual care to this special group of clients." (L 195)

It was suggested that systematic evaluation and intervention with the family should be taken at admission and reassessed regularly during the course of the child's illness. Wherever possible, measurements obtained by the application of rating scales may be used to monitor the situation:

"To provide quality care for chronically ill children and their families, nurses must be able to systematically identify specific risk areas." (L 83)

However, competence was also needed to include an ability to deal with the complex reactions of parents to the diagnosis:
"Nurses who examine their practice as it relates to family behaviour patterns and responses." (L 185)

**Interdisciplinary approach**

It was noted that the care should be integrated and coordinated with collaboration between health care professionals:

"Coordinated care ensures that each family receives appropriate intervention at times of greatest vulnerability." (L 122)

This included key workers and specialist paediatric oncology nurses, social workers and school staff:

"Children in all clinical settings are cared for by appropriately educated staff and the staffing levels and skill mix reflect their needs." (L 311)

"Nominating a key worker from the Primary Health Care Team who would liaise with the specialist team from diagnosis and could co-ordinate care." (L 122)

However it was also suggested that:

"Every district needs a senior co-coordinator to establish expertise, oversee the supervision and monitor the case-load of key workers." (L 220)

Families who had access to Paediatric Oncology Outreach Nurses (POONs) demonstrate the value of the many facets of this work:

"They teach parents to coach their children during stressful medical procedures." (L 16)

An acknowledgement of the collective expertise of the professionals located in regional specialist paediatric oncology units was also identified:

"A network of centres providing services in paediatric oncology" (L 112)

"Improvements in survival took place when children were being treated in specialist centres participating in clinical trials." (L 142)
Purchaser and provider issues

It was accepted that commissioners should have the responsibility to plan strategies to ensure that the relevant services were purchased, standards set within the NHS agreements and the implementations monitored by providers:

"Commissioners and providers should be aware of best practice" (L 218)

Furthermore, such strategies should continue with the planning of services under constant review to ensure the Audit Commission findings are addressed:

"All commissioning authorities should have an action plan in place to improve services which is regularly reviewed." (L 337)

Joint planning and funding between health, social and education services was required:

"Co-ordination between different providers." (L 279)

Discussion

The fact that the largest category related to ‘Professional Issues’ and focused predominantly on the topics encountered during the contribution to care by the professionals was not surprising, for in effect, the professionals were talking to professionals about professional practice published in professionals’ journals. As stated earlier in the design of the study (see Introduction page 4), when selecting panel members for the Delphi study, the professionals were assumed to have considerable experience when caring for families in which a child has cancer and within the context of a Delphi study they are referred to as ‘experts’ (see Chapter Six, page 181). Thus, evidence of good practice was seen and there was refreshing honesty where inadequate or inferior professional practices were identified. Whilst it is beneficial that good practice is identified, recognition of the barriers to good care provides an objective lesson in ‘how not to do’ and presents opportunities in addressing substandard practice.
The challenge for the input of care for the health care professionals was to address the realities of economic and social pressures and establish clear goals for intervention in families of sick children. Therefore, when striving towards best practice and planning services, health care professionals expressed an interest in creating the conditions for a collaborative, flexible, co-ordinated and integrated approach to care. This was seen, for example, in the subcategory called 'Professional input’ and the way in which help was given to parents at the time of the diagnosis. For most families identified in the data source, the process of receiving the diagnosis was the first time they had serious contact with health care professionals. Such an event left lasting impressions on most of the families. Eden et al. (1994), Soutter et al. (1994) and Faulkner et al. (1995) found that where families were given diagnosis by a consultant paediatric oncologist in a regional centre, they were satisfied with the delivery and amount of information. The use of a quiet room in the specialist centres where parents received the diagnosis together was noted (Eden et al. 1994; Faulkner et al. 1995). Faulkner et al. (1995) also noted the beneficial presence of a specialist nurse or social worker at these interviews. Kindness and sensitivity emerged as factors that helped parents (Faulkner et al. 1995; Sloper 1996; While et al. 1996a; While et al. 1996b). However, it was noticed that when parents received the diagnosis from ‘non-specialist’ professionals in a District General Hospital or local hospital, there were problems associated with abruptness and lack of privacy (Soutter et al. 1994; Faulkner et al. 1995; Sloper 1996; While et al. 1996b).

Awareness by the health care professionals of the needs of all family members was noted. Consequently, the professionals helped families to find ways in using the health care system to their greatest advantage, thus they were able to support and guide families with the strategies the families selected in order to manage their concerns. This also involved nurses in the development and maintenance of their assessment skills. In assessing parental anxiety, nurses directed their attention to strategies for supporting a family with unique and innovative care giving approaches (Council 1993). Families therefore derived practical and emotional benefits from participation in well-designed supportive programmes. The support of nurses in the community was seen as valuable in that link when, for example, other families in similar situations could be of assistance (Chen 1994).
In delivering care into what is an extremely intricate and multifaceted scenario, it was crucial that knowledgeable and skilled practitioners provided that care. It was emphasised that their knowledge should be current, with up-to-date information about relevant aspects of childhood malignancy (Bennett-Reese & Soanes 1999; RCN 2000). It was seen that a named nurse provided an ideal opportunity for nurses to develop their relationship with child and family. It was also seen as critical that the approach to care was interdisciplinary in order to enhance comfort and quality of life for the child and family. Two factors were important in this context. One was that there should be a person with the responsibility to act as a key worker (Pearce et al. 1994). Such a person, it was suggested, would be in a position to ensure not only a high standard of care in the relevant settings but also a high level of integration and team working between those care settings. However, the reality did not necessarily match the rhetoric (While et al. 1996b). Second, input was unique to the professional disciplines. For example, whereas the role of the GP was seen as valuable in the treatment stage of the disease, the skilled input from nurses was seen as valuable during the end stages of the disease. Families who had access to the paediatric oncology clinical nurse specialist demonstrate the profound value of the many facets of this work (Bignold et al. 1994; Eaton 2002). Such was the extent of their esteem that it was seen that they should work with other health care professionals within a wider interdisciplinary team particularly in the community and share 'on-call' provision in rotation with other colleagues (Hunt 1995). An acknowledgement of the collective expertise of the professionals located in regional specialist paediatric oncology units was also identified. The many benefits gained when children are referred to specialist centres were noted and the maintenance of this network was seen as a priority (Calman & Hine 1994). It was recognised that purchasers needed to build on progress already made, particularly in the regional units. Fundamental to the provision of care was the understanding that it was the responsibility of commissioners to plan a strategy to ensure that the relevant services were commissioned. This also included standards set within the NHS agreements and monitoring the implementation by providers.
Summary

Although it is clear that a disparity of standards of care given exists between specialist and non-specialist professionals, the specialist professionals rose to the challenge of providing skilled professional support that helped to cushion the impact, sustain and nurture family members through the crises that arose in paediatric cancers. It was seen that strengthening and empowering families could assist them through the illness. By contrast, there were areas of care that also needed to be addressed. Negative attitudes of the health care professionals would be transferred to the family and have a detrimental effect.

Maintaining Normality

Table 4.4. Distribution of subcategories

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>No. of statements</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supportive interventions</td>
<td>43</td>
<td>48</td>
</tr>
<tr>
<td>Adaption and coping</td>
<td>22</td>
<td>25</td>
</tr>
<tr>
<td>Focus on the family</td>
<td>13</td>
<td>15</td>
</tr>
<tr>
<td>Cultural issues</td>
<td>11</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>89</td>
<td>100</td>
</tr>
</tbody>
</table>

'Supportive interventions' was identified as the largest subcategory containing 43% of the statements whereas 'Cultural issues' (11%) contained the smallest number of statements (see table 4.4.). Sixty-eight authors (24%) contributed to this category.

Supportive interventions

It was suggested that practical help appeared to play an important role in the well-being of parents during the process of paediatric cancer treatment:

"Actions that minimise the difficulties of helping, may assist parents, informal helpers and professionals improve the delivery of social support to parents of children with cancer." (L 246)
Failure to provide such care was detrimental:

"In response to failing support systems, the father is forced into the male stereotype of self-reliance and emotional bankruptcy." (L 228)

There was a need for continued intervention for children who have undergone the trauma of childhood cancer:

"Adolescent care that addresses present as well as future needs." (L 159)

The importance of contact with family members and peers was facilitated and encouraged:

"The importance of school is recognised." (L 211)

Furthermore, intervention at school and home was needed at an early stage to try to forestall continuing problems. Opportunities provided for regaining control such as the 'normality' of school, fantasy play through art and story telling were suggested:

"To play out anxiety and reach a level of mastery, children gain control over emotionally painful situations." (L 102)

The interventions by health care professionals were valued particularly when parents showed evidence of fatigue or felt a sense of lack of control over the illness:

"Paediatric Oncology nurses are cognizant of the need to provide social support interventions to meet the psychological needs of siblings of children with cancer." (L 333)

In preparing teachers to be better able to manage the individual needs of their pupils, it was suggested that they must be made aware of their potential physical, academic, psychological and behaviour problems:

"It is important to acknowledge that healthy siblings may be vulnerable to difficulty and that their internalising behaviours occurred frequently because of the increased stress." (L 276)
It was suggested that the sibling facing or experiencing the death of a brother or sister would benefit from emotional support provided by more than just parents. Contact with other children who are facing similar experiences was helpful:

"There is provision of a support and counselling service for a minority of siblings who are likely to be seriously affected possibly could help to avoid longer-term effects." (L 2)

Higher self-esteem was seen to be more likely in bereaved siblings if they participated and felt involved in the care of the sick sibling and had an opportunity to say 'good-bye':

"Higher self-esteem is more likely in bereaved siblings if attend the funeral." (L 250)

It was seen that the professionals intervened in order to offer training for the care of children with life-threatening illnesses. This included offering support, providing stimulation and paying close attention to changes that might be adaptive or stressful:

"The health care professionals continued to pose the questions which allow parents to identify their own self-concept and dependence needs." (L 136)

Focus on the family

Health care professionals had knowledge of theories related to the family and the processes that influenced family functioning:

"Marital functioning is mediated by family processes such as the congruence of parental coping." (L 17)

However, this was not always the case:

"Does not recognise that caring for a sick child has a great impact on the mental health of the mother." (L 131)
Clearly the additional expenses incurred by families at this time did not help and accentuated the experience of not being ‘normal’. However, the longer the child survived post diagnosis, the more the quality of life for the family improved.

Adaption and coping

Health care professionals acknowledged the challenge that the ordinary props of family life may well prove insufficient when facing such a challenge:

“Help with strengthening the adaptive capabilities and coping styles specific to each family member.” (L 219)

Where practical support was missing, anger and bitterness intruded:

“Mothers who had not assumed their role out of choice but rather from lack of viable alternatives became frustrated and resentful.” (L 96)

It was noted that health care professionals needed to acknowledge that the parents’ concept of their role and the stress associated with it may be different from their own and may result in friction:

“Resistance to family presence was wide spread among nurses elsewhere too.” (L 264)

Previously prescribed roles may change when the sick child is not living with both his or her birth parents. Attention to the complicated family dynamics that occur when parents are divorced and stepfamilies are involved with caring for a profoundly ill child were noted:

“Attends to the issues which arise for step-families in caring for a profoundly ill child.” (L31)
Cultural issues

The need for awareness of the cultural background of the family when planning health care was identified so that the familiar patterns and life-styles could continue as closely as possible:

"Cultural systems of families are taken into account when planning health care." (L327)

Where relevant, health care professionals were encouraged to be alert to the cultural dimensions of the patient and family's religious affiliations that contribute to the well-being of the family:

"If the spiritual needs of the child and family are not met, spiritual distress can ensue resulting in further debilitation for the child and family." (L 194)

Discussion

It was noted that at a time of serious illness, the ordinary props of family life may well prove insufficient (McKay & Hensey 1990; Mott 1990). Emphasis therefore was placed on supportive interventions to meet the needs of different family members in order to restore some degree of equilibrium and maximise normality. This was seen in several aspects of care identified in the data.

First, there were considerations given to the child with cancer, with particular reference to survivors of childhood cancer. Improvements in treatment regimes means that survivors of childhood cancer are no longer unusual, attention therefore needed to be paid to the significant number of children who survive paediatric cancer. In view of this, it was not surprising that the needs of adolescents were seen as important (Viner & Keane 1998). Consideration of their care was needed both in terms of their care setting and future needs of survivors who experience residual physical and psychosocial sequelae. Adolescence is a time of change; it is a time of physical, emotional and social growth. However, for the adolescent with cancer, it is also a time of psychological distress, conflict and anxiety.
In addition to coping with the changes they would normally experience, the adolescent with cancer also has changes associated with a life-threatening disease process. They are old enough to understand the disease, yet not old enough to have the life experiences adults often have to help them cope. It is a time when they want their independence, but may feel a burden to their parents as they care for them through the various phases of the illness (Reid 1997). They see that their independence is within their grasp, yet may have to depend on others, and they lack control over many facets of their life (Kazak & Meadows 1989; Neville 1996). The development of cancer therefore is a barrier to the type of life they wish to lead. It makes them different and isolates them from their peers (Noll 1991; Whyte & Smith 1997). The spiritual aspects of an adolescent's life too may be overlooked when planning care; spiritual needs are difficult to address in children particularly adolescents. However, spiritual care in this context involved activities that help a person find meaning and purpose to life, to continue relationships and go beyond the boundary of self (Fulton & Moore 1995). All these factors had implications for the environment in which adolescents receive their treatment so that appropriate accommodation should be provided (Burr 1993).

Second, the position of the well sibling, particularly the younger one, was noted to be difficult, for they are faced with the possibility that their sick sibling might die. Understandably they would want life to be as it was before the diagnosis was made (Murray 1995). The difficulties faced by siblings were recognised in terms of their school life and opportunities to express their feelings. Certainly both parents and professionals were aware of the increased risk to siblings from the greater disruption of family life and benefits were seen when the well sibling felt included.

Third, the tasks for parents meant dealing with the lifestyle implications of the illness and treatment. A thorough assessment of family factors including coping resources, past coping mechanisms and concurrent stresses as essential in order to gain a full understanding of families whose child had been admitted to hospital with a life-threatening disease (Wills 1999). Within the literature it was seen that for some families in the studies, there was a reliance on previously ascribed roles thus preventing reallocation of roles. For others, reallocation of roles helped families adapt successfully.
Consequently, previous and subsequent roles played by family members were central to their well-being. It would be foolishly presumptive to assume that a family returns to normality following the death of their child, however, it was thought that the health care professional was in a position to support and ease families in the mourning of their child.

Summary

In social terms, normalisation is subjective entailing selective attention to some aspects of family life and inattention to others. It was suggested that health care professionals who make an effort to be culturally sensitive and competent, avoided stereotyping and treated each family individually, discovered the family’s values, beliefs and traditions. Attention to the subculture of adolescents noted the need for an appropriate environment of care.

Communication and Cooperation

Table 4.5. Distribution of subcategories

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>No. of statements</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interactions</td>
<td>30</td>
<td>46</td>
</tr>
<tr>
<td>Partnership</td>
<td>13</td>
<td>19</td>
</tr>
<tr>
<td>Information</td>
<td>9</td>
<td>13</td>
</tr>
<tr>
<td>Education</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td>Counselling</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>100</td>
</tr>
</tbody>
</table>

It is not surprising to find that ‘Interactions’ was found to be the largest subcategory with 46% of the statements with the smallest number of statements (10%) relating to ‘Counselling’ (see table 4.5.). Fifty-eight (20 %) of authors contributed to this category.
Interactions

The benefits of contacts with others were noted:

"Provision of peer support for parents who are struggling with the emotional crisis, was therefore seen to be a vital component of care." (L 236)

There was communication between professionals:

"Liaison between the hospital, Primary Health Care Team and family support nurse are important." (L 9)

"Information packs available to the Primary Health Care Teams following diagnosis." (L 285)

with documentation of specific aspects of care:

"Documentation of specific aspects of liaison, information and support to families." (L 82)

The need for communication between health care professionals and parents was noted:

"There is a need for open lines of communication between parents and professionals." (L349)

It is difficult to communicate during times of heightened emotions, and these are the times when communications could go wrong:

"Doctors are willing to explain and are willing to give honest answers to parents questions." (L 167)

Within the relationships between family and health care professionals, parents described a greater need for respect, empathy and compassion from the professionals for all family members:

"Good parent-nurse relationship is an important component in care of the hospitalised child with cancer." (L 130)
By understanding the unspoken fears of parents', comprehensive preparation for future bereavement care was made:

"Parents wanted someone to be intimately involved with them as they experienced their child dying." (L 238)

Barriers to effective communication occurred when professionals were not consistently available to offer information and answer their questions, and health care professionals' perception of parental informational needs were often different from the actual parents' requests. By contrast, it will be shown that the charity leaflets have been effective in communicating effectively with the families and meeting their informational needs (see Chapter Five):

"Ineffective communication between health care professionals, the child and parents." (L 100)

It was suggested that a contributing factor to ineffective communication also occurred where there were problems associated with a perceived late diagnosis:

"Quality of care is jeopardised when families have not resolved ambiguous feelings towards the GP." (L 33)

Overall continued emphasis on specific and routine aspects of interactions was needed:

"Regular communication with the family by domiciliary visit or telephone calls as needed." (L 8)

**Partnership**

Collaborative working that recognised the importance of parent/professional relationships was noted in the statements:

"Paediatric nursing today needs to strive towards defining "principles" for partnership which can be adapted at a local level to meet the needs of defined populations or families." (L 267)
Efforts were needed if the concept of partnership was going to be successful as families became an integral part of the team:

"Concern for good relationships between patients and physicians as they become part of the long term situation." (L 232)

Any changes therefore should be negotiated:

"Proposing significant changes are done in consultation." (L282)

Through working collaboratively with families, nurses were able to support parents' decisions and convey respect and regard for their efforts in decision-making:

"Enhancement of parental coping is the essence of parent and professional collaboration." (L 233)

Knowledge of concurrent stressors faced by families was important and by giving parents clear messages about what they are supposed to do, for example, during the medical procedures, parental anxiety was decreased:

"There is a need for open lines of communication between the nurse and parents to avoid the nurse presuming the appropriate level of parental participation." (L 349)

Information

It was also thought that increased teaching on pain for parents and nurses would prove helpful in creating awareness of surrounding issues and clarification of the parental role:

"Parents would be told what they needed to know." (L 312)

It was also suggested that health care professionals needed to focus on analysing the effectiveness of communication skills in relation to the information currently provided:
"Nurses can assist parents in obtaining the information and recommendations they require to feel certain of their decision and they can assist themselves as well as other health care professionals in providing the information." (L 328)

A range of informational opportunities were identified and included, for example, contacts for sibling stress and support groups:

"Information booklets specifically designed for particular client groups." (L 287)

In addition, it was noted that where there is a change in the course of illness/treatment, information should be provided to the child and family.

**Education**

It was suggested the family's individual coping should be incorporated into the care plan:

"Provision of appropriate drugs for (symptom relief) and education in their use so parents have confidence they can control symptoms." (L 8)

Similarly it was also noted that an important element of care is one that prepares children and their families for the long awaited day when treatment is completed:

"Prepares children for both the positive and negative aspects of completing treatments." (L 54)

**Counselling**

Health care professionals working in the field of paediatric oncology needed to be aware of the needs of all family members to deal with their anxieties:

"There is counselling for parents, patients and for siblings." (L 98)
The inference in the professional literature was that whilst personal one to one counselling has a role, there is a place for counselling within the family as a whole.

Discussion

This category focused on the interaction by the stakeholders, and three different types of interactions were noted. One was seen in the interaction within families in which open and honest communication was encouraged. The stresses and strains of caring for a sick child were well documented. The rigorous and unrelenting pattern of treatments meant parents experienced fatigue, with mothers particularly lacking time for themselves, and it was seen that families experienced a range of different emotional stressors because of the illness. (Chesler & Barbarin 1987; Wang & Martinson 1999; Enskar et al. 1997; Clarke-Steffen 1997). Frequently families reported experiencing more than one emotional stressor concurrently (Tiedeman 1997). The emotional stressors were compounded by fatigue. Ninety-four percent of mothers in the Stewart et al. (1995) study complained of feeling fatigued, with 79% of parents who ‘felt worn out’ in the Horn et al. (1995) study. This exacerbated the potential for ill health (Stein et al. 1989; Quine & Pahl 1989; Cornman 1993; Tomlinson et al. 1995; While et al. 1996a). While et al. (1996a) observed that 72% of mothers reported that they considered the child’s disorder had affected their health and 51% felt that their child’s disorder had affected the health of the father. The development of childhood cancer was also seen to pose a risk for depression in the parents. Roman-Clarkson et al. (1986) and Manne et al. (1996) observed that parents who reported moderate to severe depression just after the diagnosis were likely to continue with their symptoms six months later. However, as they rightly noted, the possibility that depression pre-existed the diagnosis needed to be considered.

The potential for fatigue and ill health of parents have important implications. First, for participation in care when parents may feel overwhelmed and wish to withdraw to some degree but feel guilty in so doing, or feel pressurised from the professionals for not participating in care. Second, it is also quite reasonable to see why families would feel inhibited in sharing with their spouse, for fear of overburdening the other. It could also be the case that the other partner was over burdened and could not respond.
It was thought that for those who may not be able to articulate their fears and concerns with family and friends, participating in support groups provided opportunities of seeing and talking with others who were able to give support.

A second type of interaction was noted in which there was communication within professionals, with the coordination between agencies and professionals regarded as a necessary part of the service. Within the professionals' interactions, liaison and clear documentation were key features. Part of the liaison also included providing specialist information for health care professionals in the community. It was also suggested that documentation on specific aspects of care would enhance liaison between the different care settings. Parent-held records were thought to make a valuable contribution to simplifying a means of improving communication.

The third interaction noted was between families and professionals. Traditionally, the professionals have dominated the parent–professional relationship and working with parents can be challenging for the professional in what is a highly skilled and complex care setting. Previous work by Bowlby (1953), Robertson (1970), the publishing of the Platt Report (1959) of the expectation of parents in caring for their child (Chesler & Barbarin 1987; Callery & Smith 1991), have been discussed earlier (Chapter Two page 17). However, providing care for sick children focusing on the needs of all family members has been a central principle of paediatric care for some considerable time (Evans 1994). It was recognised that there was an assumption that children benefited from the continuous presence of their parents. Therefore, one of the tasks parents had to embark on was learning to interact with health professionals and similarly the professionals had to learn to share with families.

Most families are the one constant presence in the child's life, and it is they who have the responsibility of responding to the child's physical, emotional, social developmental and routine health care needs seven days a week until they reach their late teen years. It is therefore reasonable to suppose the people the child knows best are his/her parents. Nevertheless, the very diagnosis and unpredictable nature of the disease brings families into contact with the health care professionals.
The families are reluctant consumers of those health care services, yet are required to share or relinquish some of their parenting roles to professional caregivers at different times of the illness and at a time when the child looks to their parent for security (Rushton 1990). Consequently, the delineation of roles and responsibilities in caring for the child with cancer also need to take into account the unique contribution made by both the parents and professionals.

Summary

In most cases health care professionals were able to provide families with appropriate information, cooperate with parents' wishes in terms of participation in care, and support parents' decisions with respect, empathy and compassion. Suggestions were made to address the areas where communication and cooperation had been unsuccessful.

Resources

Table 4.6. Distribution of subcategories

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>No. of statements</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supportive intervention</td>
<td>30</td>
<td>44</td>
</tr>
<tr>
<td>Family centred facilities</td>
<td>15</td>
<td>23</td>
</tr>
<tr>
<td>People as resources</td>
<td>14</td>
<td>22</td>
</tr>
<tr>
<td>Purchaser/provider issues</td>
<td>7</td>
<td>11</td>
</tr>
<tr>
<td>Totals</td>
<td>66</td>
<td>100</td>
</tr>
</tbody>
</table>

It is natural to find that 'Supportive Intervention' was the largest subcategory of statements (44%) of the statements. However, within the resources category, 'Purchaser/provider issues' was the smallest subcategory (11%). Forty publications (14%) contributed to this category.

Supportive interventions

Support groups were seen to provide services particularly at vulnerable times:
“Develop social support networks to assist vulnerable parents such as those with a recently diagnosed child.” (L233)

Vulnerable times were also identified such as during periods of hospitalisation, if the child was in pain, and during the palliative stages of the illness:

“In palliative care the needs for support are recognised.” (L 283)

The approach to care by children's hospices was in the provision of flexible, supportive care for the whole family. This was particularly noticeable following the death of a child:

“Children's hospices that provide continued bereavement support.” (L 139)

The problems associated with the provision of appropriate aids to daily living requirements were noted:

“Difficulties in obtaining items of special equipment even though they were not expensive or sophisticated.” (L 84)

There was also a single yet nevertheless important reference to the financial state of families when a child develops a life threatening illness:

“If National Insurance contributions could include insurance against being unable to work due to the illness of the insured children.” (L 5)

Family centred facilities

It was seen that a children's community service to care of all family members should be readily available:

“All children should have access to a community Children's Nursing Service.”

(L 217)
There were specific suggestions for interventions for the well siblings of the sick child and for grandparents:

"Effective interventions with siblings of children with cancer should be included in the family centred approach to care." (L 333)

Overall it was noted that the services for adolescents should be given greater focus and priority:

"Adolescent units are needed." (L 293)

When, despite best efforts, a cure was not possible, it was suggested that the focus of care needed was helping the child or adolescent approach their death:

"Art therapy can assist with an understanding of a dying child's experience."

(L 2)

People as resources

It was suggested that there was access to advice from a knowledgeable and skilled professional as and when the need arose:

"The service should be available 24 hours a day, seven days a week." (L 217)

This applied throughout the illness but was seen particularly when the child was in the palliative stages of the illness:

"It is important to have one person dedicated to children's palliative care in the district." (L 220)

The contributions made by Paediatric Oncology Outreach Nurses (POONs) were noted:

"POONs nurses who disseminate their skills to a wide range of families." (L 64)
Purchaser/provider issues

Suggestions were made that purchasers and providers regularly review their provision of care:

"Trusts should review their domiciliary physiotherapy support." (L 177)

Discussion

It was revealed in the professional literature that quality of life is affected if adequate support is not also available to carers. The mention of a comprehensive directory of social support would therefore be a useful tool when searching for appropriate support for families. It was suggested that if support services were in place, families would feel less pressure from serious situations. This was particularly the case for families who lived long distances from the tertiary treatment centre and were involved in periods of time away from home. A family oriented facility such as home-from-home accommodation is an essential support service. For the child making regular visits to clinics, it was thought that a welcoming environment in the clinic is beneficial and could be instrumental in reducing children's distress pain and anxiety. Where appropriate, it was suggested that respite care and hospice at home facilities aimed to maintain a degree of normality and reduce stress. There was also a single yet nevertheless important reference to the need for financial support for families when a child develops a life threatening illness.

Conversely, it was also seen that where there was limited support for families, those parents experienced frustration. However, it was also noted that finite resources involved the limitation of community care. This was seen in problems associated with the provision of appropriate aids to daily living requirements and a disparity was noted between the services currently available for parents and what is purported in the literature as necessary to promote optimal long-term beneficial outcomes (While et al. 1996b).
People as a resource were also noted. This was seen for example in the establishment of senior management focus for children's services. Such a person would be in a position to stimulate support, and offer training in the care of children with life-threatening illnesses. However, this would require a level of co-ordination. It was likely that the suggestion for a local care key-worker, available on a 24-hour basis for families, would meet this need.

Summary

The needs of family members were considered individually and collectively. Thus, the provision of continuity of individualised care in an appropriate environment was the main thrust of this category.

Treatment Issues

Table 4.7. Distribution of subcategories

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>No. of statements</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain &amp; Symptom control</td>
<td>24</td>
<td>45</td>
</tr>
<tr>
<td>Psychosocial aspects of treatment</td>
<td>16</td>
<td>31</td>
</tr>
<tr>
<td>Side effect of treatment</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Survivor issues</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Totals</td>
<td>52</td>
<td>100</td>
</tr>
</tbody>
</table>

As demonstrated in table 4.7, ‘Pain and symptom control’ was the largest subcategory and contained 45% of the statements. The smallest subcategories related to ‘Side effect of treatment’ (12%), and ‘Survivor issues’ (12%). Twenty-nine publications (10%) contributed to this category.
Pain and symptom control

The combination of improved nutritional and pharmaceutical support was seen to reduce overall mortality during aggressive chemotherapy regimes in the paediatric cancer patient:

“Parental nutrition can successfully maintain the body weight of patients who are unable to receive enteral nutrition while receiving antineoplastic treatment.” (L 308)

Acknowledging and treating pain was noted:

“Increased attention should be given to the possibility of pain in children.” (L 335)

The contribution made by children’s hospices in providing help with symptom control was also noted.

Psychosocial aspects of treatment

It was noted that the needs of children are different from those of adults:

“Children have the same right as any other citizen that is, easy access and designed to meet their needs.” (L 216)

The use of evaluation tools and careful history-taking including consideration of contributory and alleviating factors of current situations, were seen to enable staff to develop appropriate interventions for both individuals and family members:

“These two instruments may provide important measures that will assist the professionals in evaluating the impact of childhood cancer.” (L 224)

Similarly, it was suggested that an approach to measuring health-related quality of life offered an advantage during the treatment process, and particularly when returning to school:
"The development of cognitive and behavioural treatment interventions designed to enhance the quality of life of at risk children with cancer in the transition period through school and reintegration." (L 340)

**Side effects**

An awareness of the vulnerability of children with visible and serious effects of treatment was needed:

"Knowledge of the actual and potential side effects of treatment ensures that the nurses are able to assess, manage and evaluate care." (L 301)

**Survivor issues**

Enhancing coping abilities was the goal of meeting the psychosocial needs of survivors and their families when planning care:

"When planning and teaching new coping strategies, to keep in mind that motor and emotional strategies are extremely useful for children who have poorly developed cognitive coping abilities." (L 318)

**Discussion**

This subcategory considered the effects of the treatment regimes on children and their families, for almost all children will receive some form of treatment and it is likely that a child will be treated at a specialist paediatric oncology hospital often referred to as a Regional Unit. There were two main reasons for this. First, in order that the child can receive optimum treatment, an accurate diagnosis has to be made and this expertise is usually found in regional units. Second, the co-ordination of treatments in specialist centres has improved as well as the prognoses (Stiller 1994). It was seen that the specific difficulties encountered in fulfilling the demands of treatment was recognised and addressed by health care professionals. However, ultimately, the whole family system will be affected by a life threatening disease, for the cancer diagnosis constitutes a potential crisis for the whole family (Mott 1990; Loebig 1990). Siblings, particularly, feel left out.
The families need to readjust to their change in circumstances. Martinson et al. (1995) noted that such changes are not limited to families living in the Western Hemisphere.

The four main methods of treatment used were noted to be chemotherapy, radiotherapy, surgery and bone marrow transplantation with combinations of chemotherapy, radiotherapy and surgery. The treatment protocols for the different cancers are highly individualised and have evolved from empirical studies of childhood cancers. Therefore, different early short-term common side effects of treatments and the more long-term side effects were noted. There was a need for the effects of treatment to be addressed. The short-term side effects could be eased with good symptom control. However, an awareness of the vulnerability of children from the long-term visible and serious effects of treatment was needed. The anticipation and control of symptoms by the professionals was seen to play a crucial part in symptom control, and the acknowledging and controlling of pain as a key component of paediatric care. The development of policies for pain control was an important part of that care and the use of evaluation tools and careful history-taking enabled staff to develop appropriate interventions.

Multimodal therapy and the improvements in symptom control have improved the survival rates for children (Stiller 1994). Nevertheless, awareness of the vulnerability of children with serious effects of treatment required continued monitoring of survivors of childhood cancer. This was to enhance coping abilities of survivors and their families and also forestall latent long-term serious side effects that might emerge.

Summary

Relocation from home to a regional unit so that the child receives the best possible opportunities is disruptive to family life. The long and short-term effects of the treatment protocols required sensitive responses from skilled and knowledgeable professionals.
Research

Table 4.8. Distribution of subcategories

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>No. of statements</th>
<th>%</th>
<th>No. of publications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific studies</td>
<td>5</td>
<td>56</td>
<td>5</td>
</tr>
<tr>
<td>Consumer issues</td>
<td>2</td>
<td>22</td>
<td>2</td>
</tr>
<tr>
<td>Purchaser/provider issues</td>
<td>2</td>
<td>22</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
<td>100</td>
<td>9</td>
</tr>
</tbody>
</table>

'Specific studies' had the largest frequency containing 56% of the statements. Other subcategories were much smaller, with 22% of statements relating to 'Consumer issues' and 22% 'Purchaser/provider issues'.

It is of interest to note that although this category was by far the smallest of the six, particularly when research is fundamental in advancing knowledge in this field, the findings are not indicative of a lack of support for the importance of research. Elements of research, directly or indirectly, are integrated in all other categories and subcategories by the nature of the investigation and the sources that the data have been collected from. This is elaborated more in the discussion below. Nine publications (3%) of contributed to this category.

There were seven statements that referred to specific studies:

"Long-term follow-up studies are continued to identify late effects of treatment." (L 143)

Two statements were placed into the subcategory 'Consumer issues':

"Monitor families views of the services." (L 279)

Two statements were placed into the subcategory 'Purchaser/provider issues':

93
Discussion

Although this was the smallest category, nevertheless it contained two important issues. The first was concerned with the establishment of reliable databases. This made the registration of childhood cancers possible. The registration of childhood cancers made possible the monitoring of the epidemiology of childhood cancers. The specific studies were wide ranging and varied from forecasting potential incidence and needs, to quality of life issues. Some studies had identified guidance for new treatment interventions; others, were of necessity, continuous such as the registration of childhood cancers or areas of paediatric oncology nursing that needed additional research. In addition, commissioning authorities could also calculate a robust estimate of life-threatening disease (While et al. 1996a).

Second, consumer issues were identified in two statements in which it was suggested that the opinions of parents and children were sought regarding the provision of services, thus enabling the planning for future provision of care. This was exemplified in an observation that indicated an evaluation of children’s community nursing should be undertaken (Welsh Office 1997). A study undertaking such an evaluation was completed two years ago (2000) (Eaton 2002). In that study it was seen that the provision of children’s nursing services was erratic throughout the principality. The introduction of an effective children’s community nursing, highlighted in that study, would provide considerable relief for mothers who generally carry the burden of care.

Summary

The establishment of reliable databases made it possible to monitor current trends in childhood cancers and plans for future provision. In addition, the provision of care considered consumer issues.
Summary of Professional Literature

The category of 'Communication and Cooperation', showed that the health care professionals were able to provide families with appropriate information, cooperate with parents' wishes in terms of participation in care, support parents' decisions with respect and convey a sense of empathy and compassion. It was seen that sustaining and enabling families could assist them through the illness. There was a balanced attempt to acknowledge the weaknesses of situations, and recognition that there were areas of care that also needed to be addressed, specifically in confronting attitudes. Enehaug (2000) contended that by creating an atmosphere for change, practitioners could examine their own behaviour and attitudes and empathise more with the patient. This was translated into reality, in which a patient/relative and health care professional forum gained valuable insight to improve the care given. Within the 'Maintaining normality' category, enhancement of family coping was the essence of parent-professional collaboration in empowering families. Concepts that integrated a balanced view of family-centred care and recognised parental individuality were components for empowerment.

The knowledge and skills of the professionals assisted families with decision-making with regards to role allocation by enhancing their coping abilities and thereby minimising the impact of the condition on all family members. Thus families could be assisted through the illness. However, it would appear that the current role of parental participation is unclear, and that a philosophy of family-centered care needs a degree of clarification and negotiation.

In a review of the literature, Coyne (1996) traced parental participation in their hospitalised child's care back to the Curtis Report (Ministry of Health 1946) and noted the evolutionary process whereby care has moved from care in the home by the family, to care by professionals in hospital, to the current situation where there is care at home and in hospital by family and professionals. It was perhaps not surprising that in the opinion of Glasper (1990), parents need to be 'emancipated' from paternalistic approaches to care, and that families are seen by health care professionals to be effective carers.
However it was also noted that there was an effort to move towards families to involve them more in the care of their child. There was a need for open lines of communication between nurse and parent so that they both share the same perceptions of the illness in striving towards a unified approach to care.

The needs of family members were considered collectively and individually in the category called ‘Resources’. Responsiveness and sensitivity to needs were noted, ensuring that there was access to advice from knowledgeable and skilled professionals as and when the need arose. This would provide continuity of individualised care in an appropriate environment. The effects of the treatment regimes on children and their families were highlighted in the ‘Treatment Issues’ category. Again, responsiveness and sensitivity to needs ensured that there was access to age appropriate environments for care. Knowledgeable and skilled professionals provided this. This was particularly so in the regional units where the anticipation of immediate side effects and the long term side effects of treatment ultimately had implications for the quality of life of child and family. Although the ‘Research’ category was the smallest in terms of statements, nevertheless it contained two important issues, concerned with consumer issues and the future provision of care.

It was seen that there was a marked attempt to provide services based on an analysis of the strengths and weaknesses of situations, according to the needs of users, and the effectiveness of the service according to current best practice. Thus there was an attempt, to take serious account of the families as consumers of a service.

However there were areas of care that also needed to be addressed. These were mainly in the sphere of professional issues and were concerned with confronting attitudes that were outdated and furthermore failed to reflect on the sensitivities of families’ feelings at times of heightened emotional states. It is ironic that resources in terms of staff and equipment are not always available in the community where the families live and would need to access (Eaton 2002). This meant that there was a short fall between that which was needed and the reality experienced by those using the services.
In the next chapter, the results and discussion for the second data source, the charity leaflets, are presented.
CHAPTER FIVE
RESULTS AND DISCUSSION
THE CHARITIES LEAFLETS

Introduction

The charities leaflets were the second and essential source of data as their activities presented their publications provided a major source of information. They also provided a different perspective to the subject area, as they were representing the perspective of families. In doing so, the charities would provide an insight into the service provision as experienced by these families.

Presentation of results and discussion

As previously stated (see Chapter Three page 59), directories of charitable organizations were consulted and 94 were targeted nationally. Of those, 28 leaflets were collected on which a content analysis was performed. It is worthy of note that using the same coding strategy of the six categories was feasible for this data source as well as the professional literature thus providing a consistency in the analysis and presentation of results. The categories labelled 'Communication and Cooperation', 'Treatment Issues' and 'Maintaining Normality' were rich enough to present their subcategories as well as providing an overall summary for the category. In addition, using the same taxonomy for the charities as the professional literature meant that obtaining a fit was not problematic. There was no 'shoe-horning' of the statements into the categories that had emerged out of the professional literature. Fittingness is one of the criteria for robustness as argued by Sandeloweski (1993). In order to gain a greater insight into the categories, examples of statements from the charity leaflets are also provided. The results are followed by a discussion and a summary of each category.

Responding charities

Twenty-eight leaflets covering different topics were available for examination. (see table 5.1).
In Table 5.1 it was seen that of the 28 leaflets, 16 leaflets were related specifically to childhood cancers. Out of the 16 leaflets, two had sections that were intended for teachers to help the schoolchild with cancer, two were intended for teenagers and the remainder were specifically related to the needs of parents. One could be classed as 'technical'; that is, it was produced by an organisation that was not strictly a charity. However, their material was included because it was identified in the charities directories. It was also included as it would be made available to families from diagnosis onwards. Nine of the leaflets made available were concerned with life-threatening illness in children. One charity provided material that was relevant to both the child and adult with cancer within the same leaflet. Finally, one leaflet was concerned solely with the care of family members following bereavement. Most of the leaflets were from the 'professional' larger national charities (86%). The remainder (14%) were local charities or charities serving larger regions such as 'the north east' or 'the south west'.

There were three differentiating characteristics of the charity leaflets. First, it was found that they had a considerable emphasis placed on fund-raising activities and the encouragement of supporters (table 5.2.). Second, the quality of the leaflets produced by the smaller more 'home grown' charities were of a poorer quality when compared with larger national charities that produced professional, coloured glossy magazine type publications. The leaflets from the smaller charities were often on single sheet A4 leaflets on friable paper, the font was small and the text appeared cramped. This suggests that the charities had limited resources and placed their priorities in directions other than expensive published material.
Third, the families and friends (often of a child who had died) founded two thirds of the charities that replied. This requires commitment and prudent planning. If this is not conducted carefully, the charity is in danger of disbanding. This may have been the situation in the four charities in which the returned mail stated that they were ‘no longer functioning’. The distribution of statements is shown in Table 5.2 below.

Table 5.2 Distribution of statements

<table>
<thead>
<tr>
<th>Distribution of statements</th>
<th>No. of statements</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>External working of the charity relevant to families</td>
<td>3730</td>
<td>62</td>
</tr>
<tr>
<td>Issues relevant to the internal working of the charity</td>
<td>2245</td>
<td>38</td>
</tr>
<tr>
<td>Total</td>
<td>5975</td>
<td>100</td>
</tr>
</tbody>
</table>

From Table 5.2 it can be seen that 38% of the analysed material was concerned with the internal working of the charity (e.g. administration), and 62% was related to the needs of the families. The statements categorized ‘Issues relevant to the internal working of the charity’ were disregarded. They included topics such as ‘Administration’, ‘Aims’, ‘Achievements’, ‘Fund-raising activities’, ‘Origins’ and ‘Volunteers/supporters’. The statements categorized ‘External working of the charity relevant to families’ (e.g. counselling) are explored in further depth.

As stated earlier (see Chapter Three page 54), the researcher adopted the same coding framework of six categories as was used for the professional literature and did this independently. No statements were placed in a miscellaneous category. A second researcher then coded all the statements. This researcher was blind to the codes given by the first researcher. Following discussion with second researcher disagreements were annulled.
Table 5.3. Categories and number of leaflets relating to the external working of the charities

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of statements</th>
<th>Number of leaflets contributed to this category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication and Co-operation</td>
<td>1537 (41%)</td>
<td>28 (100%)</td>
</tr>
<tr>
<td>Treatment Issues</td>
<td>785 (22%)</td>
<td>14 (50%)</td>
</tr>
<tr>
<td>Maintain Normality</td>
<td>753 (19%)</td>
<td>28 (100%)</td>
</tr>
<tr>
<td>Resources</td>
<td>327 (9%)</td>
<td>25 (89%)</td>
</tr>
<tr>
<td>Professional Issues</td>
<td>247 (7%)</td>
<td>18 (64%)</td>
</tr>
<tr>
<td>Research Projects</td>
<td>81 (2%)</td>
<td>14 (50%)</td>
</tr>
<tr>
<td>Total number of statements</td>
<td>3730 (100%)</td>
<td>-</td>
</tr>
</tbody>
</table>

In total, 3730 statements were coded from 28 leaflets (table 5.3.). It is worth noting that all the leaflets contributed to the largest category labelled 'Communication and Co-operation' which contained 41% of the total number of statements. The importance of the leaflets as a means of communication with families is noted in the subcategories discussed in the following section. By contrast, at 2%, 'Research' was the category with the smallest number of statements from the least number of leaflets. This category was also the smallest in the professional literature. It was seen that all the leaflets contributed to two categories with the lowest contribution from 14 leaflets. It was not appropriate to examine the ratio of statements per leaflets because of the variation in the size of each leaflet, however the number of leaflets contributing to each category has been included.
Communication and Co-operation

Table 5.4. Distribution of subcategories

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>Number of statements</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information about the disease</td>
<td>523</td>
<td>34</td>
</tr>
<tr>
<td>Glossaries</td>
<td>228</td>
<td>15</td>
</tr>
<tr>
<td>Empathy: diagnosis</td>
<td>199</td>
<td>13</td>
</tr>
<tr>
<td>Empathy: bereavement</td>
<td>129</td>
<td>8</td>
</tr>
<tr>
<td>Communication with others</td>
<td>152</td>
<td>10</td>
</tr>
<tr>
<td>Working with others</td>
<td>30</td>
<td>2</td>
</tr>
<tr>
<td>Befriending &amp; counselling</td>
<td>22</td>
<td>1</td>
</tr>
<tr>
<td>Education</td>
<td>166</td>
<td>11</td>
</tr>
<tr>
<td>Eligibility &amp; contact points</td>
<td>88</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>1537</td>
<td>100</td>
</tr>
</tbody>
</table>

In table 5.4. it was seen that the largest subcategory, containing 34% of the statements was labelled ‘Information about the disease’ which is unsurprising given that all the charity leaflets were providing some element of information. The smallest number of statements (6%) was labelled ‘Eligibility and contact points’ relating to who would be able to access the service and where that service would be. Twenty-eight (100%) responding charities contributed to this category.

Information about the disease

It was made clear that children’s cancers were rare:

“Over 2,000 children throughout the country each year are newly diagnosed with cancer or leukaemia.”(A 2460)

“On average every 14 days a child in this area is diagnosed with cancer.”(A2511)

A description of the normal cell function was contrasted with aberrant cells activity:

“The bone marrow is the blood making factory of the body producing hundreds of millions of red and white blood cells each and every day of our lives.” (A 6420)
"If one of these bone marrow cells becomes cancerous it starts to grow and divide aggressively out of all control and pushes out all the normal blood making cells from the bone marrow." (A 6421)

Some known causes of cancer were mentioned such as viruses and known carcinogens:

"It is clear that certain chemicals including petroleum products and pesticides can cause cancer". (A 6449)

"In Japan a virus has been identified as causing one certain type of human leukaemia found only in Japan." (A 6451)

In reality, it was suggested that there are probably several causes of cancer:

"This is the multihit hypothesis and would account for why it is that not all of us develop cancer or leukaemia because of the necessity of being exposed to two (or more) agents simultaneously." (A 6455)

"Equally it may be that some leukaemias have no outside cause but may arise entirely within the individual due to genetic or other factors." (A 6457)

For example, if neuroblastoma is used as an illustration, it was seen quite clearly in the leaflets that the cause was unknown:

"Doctors are as certain as they can be that it is not an inherited condition, i.e., it did not come from one or other side of the family." (A 3959)

Families were also reminded that whilst some forms of adult cancer were undoubtedly linked with environmental causes, such as smoking, this did not seem to be the cause of neuroblastoma:

"It may help you to remember that all forms of adult cancer are very different from neuroblastoma." (A 3961)

There was no evidence to suggest that any event during the mother's pregnancy was linked with the neuroblastoma:

"This means that nothing that you did or did not do as a parent had any effect on the disease." (A 3957)
However, the diagnosis of bilateral Retinoblastoma did have genetic implications:

"Children with bilateral disease (both eyes) have a genetic or hereditary form and the tumours tend to develop during the first year of life." (A 5224)

Sporadic incidences of sometimes two or three children developing cancer in the same school or village, were addressed in the leaflets:

"These cases are carefully investigated but at present they do seem to arise by chance." (A 4810)

A range of different childhood cancers and characteristics were identified alphabetically throughout the leaflets. It was explained that there were different names for the tumour depending on where it originated. Again, using neuroblastoma, as an example, the tumour was described as arising from particular nerve cells:

"These nerve cells run in a chain-like fashion up the back of the child's abdomen and chest and into the skull following the line of the spinal cord (neuro = nerve, blastoma = collection of tumour cells)." (A 3273)

It was emphasised that in order for treatment to be most effective, a definitive diagnosis was needed, and that this was a crucially important stage in the illness:

"It may take several days for the tests to be completed." (A 3338)

"The results obtained can affect the type and duration of treatment that will be given to your child." (A 3342)

Factors that could affect the child's prognosis were noted to be their age and the type of tumour and the degree of spread:

"Sadly, more malignant tumours, especially in very young children, have a very low chance of cure." (A 5060)

"The success of treatment depends on where the tumour was and the type of tumour, with many kinds of tumour about 50% of children are cured, while some have a cure rate as high as 80%." (A 5059)

However, it was recognised that despite the improved prognoses, some children die.
Glossaries

The glossaries gave clear and detailed explanations of the medical and technical terms used in childhood cancer. The format followed the convention for a glossary and medical terms were arranged in alphabetical order. This was followed by an explanation of the term in clear short phrase or sentence:

“ANOREXIA, lack of appetite.” (A 469)

“BENIGN, not cancerous, a lump made of benign cells which do not spread to other parts of the body.” (A 471)

“CATHETER, a thin, flexible tube used pass fluid into the body to drain fluid from the body.” (A 480)

Complex words and technical terms introduced the families to the language of childhood cancers:

“Ganglioneuroblastoma, a special type of neuroblastoma made up of less 'aggressive' tumour cells.” (A 4193)

“mIBG scan - mIBG stands for 'metaiodobenzylguanidine'.” (A 3313)

In addition, the full impact of disease would be reinforced as exemplified in the statement below:

“METASTASES, tumours that have come from a first (primary) tumour in another part of the body, known as secondary tumours. (A 500)

It was anticipated that with seven leaflets contributing to this narrow topic contained in this subcategory, there would be some degree of repetition. Detailed examination of the data set showed this was the case. The way in which repetition took place is exemplified as follows. In the leaflet identified as Number 4, the following explanation of alopecia was given.
"ALOPECIA, lack of hair". (A 463)

In the leaflets identified as Numbers 8 the following repetition was noted.

"ALOPECIA, hair loss" (A 1042)

Yet another repetition was seen in the leaflets identified as Numbers 10.

"Alopecia is loss of hair." (A 4751)

The extent of the repetition is summarised in Table 5.5.

Table 5.5. Frequency of repetitions

<table>
<thead>
<tr>
<th>No. of repetitions of a statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>Total number of occasions repetitions occurred</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of occasions repetitions occurred</td>
<td>20</td>
<td>14</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>28</td>
<td>6</td>
<td>4</td>
<td>0</td>
<td>6</td>
<td>64</td>
</tr>
</tbody>
</table>

In table 5.5, it was seen that single occurrences was the largest number of repeat statements. This was attributed to the leaflets identified as Numbers 4 and 8 in which it was noticed that repetition occurred on 14 different occasions out of the 20.

Discussion

It is worth noting that when combined, the two largest subcategories ('Information about the disease' and 'Glossaries') contained 20% of all the identified statements. The glossaries gave clear and detailed explanations of the medical and technical terms used in childhood cancer. It appeared that an assumption was made that families had no prior knowledge. Complicated words and technical terms were introducing the families to the language of childhood cancers referred to by Aranda (1992) and Bignold et al. (1994). In addition, the full disease impact was reinforced in the necessary use of language as seen with the word 'metastases'.

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The leaflets that provided the glossaries were intended for the newly diagnosed to keep as a form of handbook for the duration of the treatment. The provision of specialist knowledge meant that there was a degree of respect for families who valued them, for in providing the information there was an oblique invitation to participate in the unfolding events. Thus a substantial amount of information about the disease was provided for the families. This information fulfilled three important functions.

First, it provided clear and simple information about the biophysical nature of healthy and aberrant cell function. Contrasting normal cell function with that of aberrant cells, served to illustrate the way normal function was lost and provided an insight into the range of presenting symptoms. It was explained that different kinds of cancer are found in different parts of the body, and a range of different childhood cancers were identified alphabetically throughout the leaflets. These included, for example, Acute Lymphoblastic Leukaemia (ALL), Hepatoblastoma, through to Wilms' Tumour. It was also explained that the tumours have different treatments and cure rates. The fact that the prognosis had improved dramatically in thirty years offered encouragement to families. However, other factors that could affect the child's prognosis such as their age and the degree of tumour spread were noted. There was also a note of stark realism recognising that despite recent advances in medical treatment, many children suffer the consequences of the disease and some die. This volume of information meant that families were provided with a basic understanding and knowledge of biophysical changes and functions, for example, when discussing and making decisions about treatment regimes.

Second, it was made clear that children's cancers were rare, that many adult types of cancer were rare in children and many children's cancers were rare in adults. The statistics of incidence were presented nationally and locally, identifying the incidence in a geographical area known to the readership of the leaflets. This highlighted the considerable number of families who faced the trauma of the diagnosis of childhood cancer. Making known the rarity of the illness served to reassure parents neither they, nor their doctor, should have noticed anything untoward sooner. Furthermore, parents were reminded that it was possible that many of the symptoms their child presented with were similar to those of the more common, non-serious childhood illnesses.
The rarity of the disease also meant that there are only 22 hospitals (often referred to as regional units) in the U.K. who regularly treat children with cancers. A child might therefore be transferred from the hospital where a cancer was first suspected to one of these centres for diagnosis and treatment. The stress families experienced when undergoing the different tests and waiting for results was acknowledged to be an anxious and exhausting time. Nevertheless, this was emphasized as a crucially important phase in the illness for a definitive diagnosis was needed in order for treatment to be most effective. The process of staging was needed in order to assess the extent of the disease. These were important factors when considering the phenomenon of perceived delayed diagnosis (See Chapter Eight page 244).

Third, it served to quell fears of the common occurrence that families might have harboured the thought they were a 'cancer family' or had in some way been singled out for this illness. It was explained that the causes of childhood cancers were not fully understood and families were reassured that they could dismiss such fears and were informed that even if another member of their wider family had, or currently has a cancer, there was no known association with childhood cancers. Families were reassured that there was no evidence to suggest that any event during the mother's pregnancy was linked with the development of a childhood cancer. Similarly, no particular food, habit, environment, smack, bump or previous illness could be said to have been responsible. This also served to help dispel feelings of guilt parents might have felt about previous life-styles. However, some childhood cancers did have genetic implications such as the diagnosis of Retinoblastoma. It was noted that regular monitoring of children with the genetic form of the disease was needed for they have an increased risk of developing other malignant tumours. In addition, genetic counselling was offered to all long-term survivors since the risk of retinoblastoma developing in the offspring of patients with the genetic form of disease was noted to be nearly 50%.

Leino-Kilpi (1999) referred to this input of information and its implications as manifestations of dimensions of empowerment that enabled an individual to manage, adjust and cope with their situation, particularly in matters related to health.
Summary

The provision of such a vast amount of information was presented in a matter-of-fact manner that would leave families in no doubt of what lay in front of them. Nevertheless, it was necessary information if families were to feel included in the world of childhood cancer and to be equipped to cope with their future. Such information was therefore a fundamental tool for the empowerment of families. This volume of information meant families were provided with a basic understanding and knowledge of biophysical changes and functions, for example, when discussing and making decisions about treatment regimes.

Empathy: the diagnosis

There were two points in the illness to which the empathetic response was directed. The first was at the point of diagnosis (13%) and the subsequent impact in the early days of the illness culminating at the end of treatment. The distress that surrounds the diagnosis of childhood cancer was addressed, the reactions of others, the need to talk to others, the perceived delay in diagnosis and completing treatment:

"On being told their child has cancer, initial feelings of devastation, disbelief, anger and helplessness occur to most families." (A 1241)

It was common for parents to feel that in someway they had been singled out for such devastation:

"'Why us?' is a common question, to which there is no answer'." (A 6505)

The great fear of death when cancer is mentioned was acknowledged, as well as the emotional and physical strain on families when for caring for a gravely ill child:

"The serious illness of a child is a crisis for which no family can prepare."

(A 2707)
Parents were reassured that there was no evidence to suggest that they could have been more observant or acted sooner:

"Most parents ask themselves if they could have prevented the cancer happening or if they could have done something earlier." (A 5013)

It was also noted that the emotional strain of diagnosis and treatment, could be almost unbearable:

"You may not realise the stress you are under until something 'gives' and you are surprised to find yourself reacting in a way unusual to you." (A 2725)

Practical common sense advice was offered when telling others the news:

"Try to discuss the illness in a calm and confident manner and express your absolute trust in the medical staff who are treating your child." (A 6620)

Although this quotation could be seen to contradict the empowerment of parents as partners in care, it could be argued that the message conveyed here was one of reassurance to anxious relatives rather than persuading them to relinquish all decision-making. Even though the time during treatment was difficult, including the strain and inconvenience of hospital visits, it was suggested that the drug therapy had probably provided a sort of assurance for parents:

"Many say they have a feeling that the disease has been eradicated or held firmly at bay while the drugs were being given." (A 4160)

Family members were encouraged to talk to others about their feelings of isolation, depression or exhaustion:

"It is often helpful to discuss and share your feelings with other parents in similar positions." (A 2728)

It was recommended that talking about their feelings was recommended to be a better solution than taking tranquillizers.
The difficulties associated with perceived delay in diagnosis were raised in the leaflets:

"It cannot be stressed often enough that in the present state of knowledge there is no evidence at all to suggest that there is anything parents could have done, or should not have done, to prevent a child from developing cancer."

(A 6781)

It was also noted that by the time some cancers were diagnosed, the disease had already spread:

"Unfortunately, it is probably the case that most of these tumours have already spread in the child's body by the time any symptoms are apparent."

(A 3969)

"Therefore, the treatment or the outlook would probably not be very much affected by the time of diagnosis." (A 3970)

It was recognised that in their distress at the diagnosis, families might want to blame someone for the illness:

"However, the need to blame someone or something for the tumour is very great, and all the logic in the world is hard to accept when the cause of the disease remains unknown." (A 3967)

"It may be helpful at this stage to talk over the way you feel with others in the hospital." (A 5019)

Even the completing treatment was tempered by a continuing fear of the recurrence of symptoms:

"Parents describe the 'coming off treatment' as a time when it feels that the 'safety net' has been removed." (A 4161)

"They are entering a period of great uncertainty." (A 4162)

At this time it was suggested that some parents who had maintained the ability to cope throughout treatment, found to their concern and surprise that now was the time they felt depressed.
They may describe feelings similar to one father who said "...My daughter is now perfectly well, cured it seems to me, but we have to wait five years for it to be confirmed; it is like living with a time bomb...".” (A 4164)

Reassurance was offered to parents that the uncertainty could be eased a little by the regular follow-ups that their child received:

"Clinic visits and examinations will perhaps cause you a worrying few days beforehand, but reassurance that everything is well will carry you through to the next visit." (A 4138)

Empathy: bereavement

The second point at which an empathetic input was noted was at the end stage of the illness and the time following the death of a child. Those parents who had previously lost children frequently provided the compassion and sympathy through the medium of the charity leaflets:

"Having built the Charity from personal experience, the complexity of issues involving a seriously ill child and the family are uniquely understood." (A 6301)

"It has been said that Hospice is a philosophy not a facility and certainly support for the sick and dying within the community." (A 1655)

There was concern and consideration expressed by the charities through the leaflets:

"Knowing that your child will die is devastating." (A 4450)

The charities thought that in the supportive non-judgmental atmosphere they provided for the family, understanding of their circumstances could begin to take place:

"They are emotionally drained and exhausted, it is important that we make sure that they are given all the information necessary to help them to make decisions which are right for them." (A 1643)

"We also need to protect them from making hurried decisions which they may later regret." (A 1644)

It was, however, pointed out that the pain of bereavement did not end with the funeral:
“Perhaps it only begins after that [the funeral] and we are committed to remaining alongside, 'befriending our families for several years.”’ (A 1653)

“We expect that most families will continue to use our support at home and in this charity for several years following the death of the child.” (A 1628)

Families were advised that after the death of a child they have loved, beginning to resume life took a long time:

“There is no timetable on grief.”(A 2001)

Empathy through publications

A charity had produced a catalogue of a range of book titles, audio and video tapes, concerned with bereavement were available for bereaved families and the professionals working with them:

“We have produced this leaflet in the hope that it will offer information, support and choices that will help you.” (A 144)

Some of the 700 titles available were mentioned in the leaflet and were used as examples in the leaflets, these totalled 61 and covered a range of bereavement scenarios. This range included expected and unexpected deaths, attitudes, family reactions and the legal aspects of death. These are summarised in Table 5.6, with examples of the titles below.

Attitudes to Death:
“Tracing Western Attitudes to Death.” (A 61)

The family:
“Thoughts on What it Feels Like for Different Members of a Family.” (A59)
“I Must Be Going Mad" The Fears And Worries Of Bereaved Parents.” (A 76)
“The Bereaved Parent Coping Alone.” (A 119)
“The Bereaved Adolescent.” (A 76)
"Bereaved Grandparents at Christmas and Holiday Times plus My "Daughter's Child is Dead." (A 69)

Table 5.6  Bereavement publications

<table>
<thead>
<tr>
<th>Bereavement issues</th>
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</tr>
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<tbody>
<tr>
<td>Attitudes to death</td>
<td>8</td>
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</tr>
<tr>
<td>Unexpected death</td>
<td>3</td>
</tr>
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<td>Family members</td>
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</tr>
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<td>Parents</td>
<td>15</td>
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<td>General</td>
<td>5</td>
</tr>
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<td>Loosing only or all children</td>
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</tr>
<tr>
<td>Siblings</td>
<td>6</td>
</tr>
<tr>
<td>Extended family</td>
<td>2</td>
</tr>
<tr>
<td>Legal aspects of death</td>
<td>2</td>
</tr>
<tr>
<td>Grieving process</td>
<td>10</td>
</tr>
<tr>
<td>Bereavement counselling</td>
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<tr>
<td>Gender perspectives on death</td>
<td>1</td>
</tr>
<tr>
<td>Funerals</td>
<td>1</td>
</tr>
<tr>
<td>Professional and parents after death</td>
<td>1</td>
</tr>
<tr>
<td>Helping teachers cope with death of pupil</td>
<td>1</td>
</tr>
</tbody>
</table>

Discussion

Empathetic support was provided via the leaflets at two points in the leaflets. The first was at the point of diagnosis, and the second following the death of a child. The distress, shock and disbelief that surrounds the diagnosis of childhood cancer were addressed with a combination of sensitivity and commonsense. It was noted that the emotional strain of diagnosis and subsequent treatment could be almost unbearable. The great fear of death when cancer is mentioned was acknowledged, and caring for a gravely ill child imposed an emotional and physical strain on families.

All the new and rapidly changing circumstances created a major disruption to the families' home and family-life. It was suggested that most parents would agree that life could never be quite the same again and the anxieties and practical difficulties arising from a child's serious illness put an enormous stress on family relationships. This included the reactions of others, and the need to talk to others.
There was the extra worry of how to talk to the sick child about the illness and treatment, what to say to the other children, or grandparents, other family members and close friends about what was happening to them. Practical common sense advice was offered with simple explanations at first that would be sufficient for family members. Reassurance that their child's condition was not contagious was usually sufficient to enable family, friends and neighbours to become as sympathetic and as helpful as possible.

In addition to concern about their sick child, it was recognised that families have to adapt to many new faces, learn unfamiliar, and at times frightening medical terms and procedures, all of which are connected with their child's treatment. Family members were encouraged to talk to others about their feelings of isolation, depression or exhaustion. The sharing of experience was seen as important throughout and after their child's treatment. Of particular value were those experiencing similar circumstances. It was recommended that to talk about their feelings was usually a better solution than resorting to taking tranquillizers.

It was understood that such a time of waiting was a very difficult and anxious one for all the family. Receiving a diagnosis was recognised to be a slow process as consultant paediatricians and GPs meet few childhood cancers during their entire career and would need to investigate them carefully. It was recognised that in their distress at the diagnosis, families might want to blame someone for the illness, often the doctor for not detecting the cancer earlier, whilst others blamed themselves or felt that they should have been more concerned when their child was first unwell. It was also noted that by the time some cancers were diagnosed, the disease had already spread. Families were advised that there was very little to be gained from going from one doctor to another as most doctors were using similar treatments all over the world.

Even though the time during treatment was difficult, hospital visits places a strain on families and are often inconvenient, nevertheless, it was suggested that the drug therapy probably provided a sort of assurance for parents. Months of treatment felt like a long and anxious time, however, even the eventual relief of coming off treatment was tempered by a continuing fear of the recurrence of symptoms.
At this time, it was felt that some parents who had maintained the ability to cope throughout treatment, found to their concern and surprise that now was the time they felt depressed. This would be the time when health care professionals and other family members would assume that all was now well. It would also be the time when parents had far less contact with families and would not be in a position to advise them. Reassurance was offered to parents that the uncertainty could be eased a little by the regular follow-ups that their child received.

It was recognised that for many people, this might be their first experience of death. Therefore it was considered to be important that through the pages of the leaflets parents, brothers and sisters and other members of the family were given 'permission' [sic] to do whatever they felt was appropriate to do at that stage. The essence of the statements offering empathy at the time of bereavement was one of compassion, often provided by those who too had lost children. This degree of empathy conveyed at bereavement was in keeping with the 91% of mothers from five different countries in the Davies et al. (1998) study who rated the support they received from the health care professionals as satisfactory. Acts of 'kindness' and 'just being there' enhanced the mothers' sense of satisfaction. One charity assured their readership that it appreciated the needs of families who are confronted both by the threat of the death of their child and with the grief and loss if that child eventually dies. It was made clear that when the time came for a child to die, they would do their utmost to ensure that the life-changing event happened with dignity. It was however, pointed out that the pain of bereavement did not finish with the funeral and families were advised that beginning to resume life after the death of a child took a long time.

The bereavement leaflets and publications included expected and unexpected deaths, attitudes, family reactions and the legal aspects of death. They were available to anyone who requested them. Nevertheless with individualised selection of appropriate topics, the approach used provided a form of individualised attention, so that families could feel they were not alone in their grief. However, if they wished, they were able to remain anonymous so that their privacy was respected.
Summary

The charities concern and consideration was clearly evident. They provided a form of silent supporter who had knowledge, experience, and a common sense approach to coping with the anger and frustration where there was a perception that the diagnosis had been delayed and the trauma of the diagnosis through to completion of treatment or bereavement. Furthermore, families were free to accept and reject interventions, as was appropriate for their situation. The essence of the statements contained in these two subcategories was one of compassion that respected the dignity of families in a supportive non-judgmental atmosphere.

Communicating with others

Three charities indicated that they had links with national cancer charities and social work organisations, thus providing a considerable network for relevant contacts:

“Families are kept in touch nationally through a quarterly newsletter, with contributions from children, parents and professionals.” (A2677)

One large national charity reported that as a multidisciplinary organisation it had a strong collective voice:

“We work closely with a wide range of professional workers, finding out what's going on in different parts of the country so that we can pass this information on to parents.”

It was pointed out that cancer is a word that provokes a strong emotional response in most people, consequently communication especially at the beginning of the illness can be difficult:

“It is an illness that we will all have encountered amongst our family or acquaintances and we end to view it as sinister and frightening.” (A 1013)

For this reason, parents were advised to communicate with family and friends, and if possible to make the first move in awkward situations:
"From a combination of fear and ignorance, people may be either unable or embarrassed to approach you." (A 997)

In the leaflets, it was noticed that inevitably children pick up information from other sources when they are inpatients. Similarly, it was seen as important to reassure with encouragement the child who might have sensed pessimism in adults:

"It may help to explain to your child that not everyone understands as much about cancer as he does." (A 6697)

Details need only be brief and factual, truthfulness therefore was recommended to answer questions, with help from the professionals when the answers to awkward questions were not known:

"Finally, if you do not know the answer to your child’s question you should say so, and ask your GP or hospital specialist for the answer" (A 850)

The child or adolescent with cancer was encouraged to make contact with the health care professionals in the hospital, particularly if they felt unable to talk with their parents. It was thought that close family members, like siblings and grandparents, might also find it helpful to talk with the health care team:

"It is a good idea to get to know the people at the hospital, the doctors, nurses, social workers and others."(A 886)

"Talk to them; they can help you to understand that you are not alone.”
(A 861)

Families were also advised to establish and maintain contact with health care professionals, thus making their passage through the illness easier. They were also advised to exercise a degree of patience with the health care professionals whilst waiting for test results, difficult though that may be:

"It may be that the Doctor has to wait for results of certain tests before any realistic discussion can take place."(A 3270)

Choosing the moment for contact was important:
"This is not to rebuff your urgent worry, but to provide a setting and a time when unhurried discussion can take place." (A 3269)

Families were advised to establish and maintain contact with the child’s school:

"It will be helpful if the teacher can prepare the class for hair loss or weight gain or loss if any of these have occurred." (A 6688)

If problems of interpretation and perception of the illness occurred, then contact with either the parents or health care professionals was appropriate:

"If a child's ideas about his illness seem to be at variance with what you understand, it is wise to check with the child's parents or with the treatment centre." (A 5786)

Sensitive advice for the school was offered in the event that the treatment had failed and preparation could be made:

"Children and adolescents need to be told as soon as possible about the loss of a classmate." (A 969)

Preparation also included warning teachers about the ways in which different children and children of different age groups would react to the loss of one of their contemporaries:

"Children's reactions to death can vary from apparent indifference - in younger children- to open grief." (A 791)

"Some children may need reassurance that we can be too sad to talk or cry about our dead friend." (A 974)

It was suggested that in time, the school may like to remember the child with a memorial - such as a tree or a bench.

There were 16 statements that referred to ineffective communication, and of these nine were concerned with poor pain control from the perspectives of the parent and the children in pain. The parents noted:
"It took some time before his spinal tumour was diagnosed during which he suffered a great deal of pain." (A 651)

"Once, the procedure was carried out by a doctor taking instructions on the phone from another hospital." (A 578)

The children in pain noted:

"They told me I was a fusspot." (A 652)

"'If you tell them they are hurting you they just say "nonsense" and keep on doing it'. (said a 12 year old following spinal surgery). " (A 555)

Discussion

The subcategory ‘Communication with others’ encompassed a wide range of people from the voluntary sector, the statutory agencies and family members. One large national charity reported that as a multidisciplinary organisation, it had a strong collective voice. It reported that it could affect national policies, planning and provision of services for sick children. It undertook to develop and promote a continuing dialogue with relevant agencies and individuals. It sought to improve communication and co-operation between the different statutory and voluntary agencies working in the field. This they achieved by answering professional carers' requests for information, which they in turn were able to impart to parents.

Information about parent support networks and the importance of these networks was seen. Three charities indicated that they had links with national cancer charities and social work organisations, also providing a considerable network for relevant contacts. Families were sent a quarterly newsletter with contributions from children, parents and professionals.

Advice was offered to families to carry them through, particularly in the early stages of the illness. They were advised to establish and maintain contact with the health care professionals to make the passage through the illness easier to cope with and to exercise a degree of patience with the health care professionals whilst waiting for test
results. Choosing the moment for contact was important. If a particular moment was inconvenient, it was suggested to families that at a mutually agreed time, the doctor and perhaps other members of the team could sit down with them and go over their concerns.

Communication within a family at times of trouble can be both rewarding and fraught for cancer is a word that provokes a strong emotional response in most people. For this reason, parents were advised to communicate with family and friends, and if possible to make the first move in awkward situations. The adolescent with cancer was encouraged to make contact with the health care professionals in the hospital, especially if they felt unable to talk with their parents. Help from the professionals was always available for the answers to awkward questions. It was thought that close family members, like siblings and grandparents, might also find it helpful to talk with the health care team. Parents were advised that, inevitably, children pick up information from various sources when they are inpatients; it was therefore seen as important to reassure with encouragement the child who might have sensed pessimism, particularly in adults. Only brief, factual details were needed, and truthfulness was recommended when answering questions.

Families were advised to establish and maintain contact with the child’s school. Advice was offered in preparation for the child returning to school following treatment and would enable the teacher to be of most help to the child. It was suggested that a teacher should be willing to listen, comfort, and answer questions. If problems of interpretation and perception of the illness occurred, then contact with either the parents or the health care professionals was appropriate. Sensitive advice for the school was offered in the event that the treatment had failed. For the dying child who kept in touch with school, preparation could be made for the opportunity to say ‘goodbye’ appropriately. Consideration was given to other disciplines of professionals. Teachers were prepared for the different reaction to grief their pupils might show.

There seemed to be an impression given in which parents had, on occasions, to take the initiative. This was of course beneficial in that they were taking control of their own situations. However, there was also a sense in which there were yet more tasks for parents to undertake.
Working with others

Provision was made for continuity of care:

"Also ensure that the emotional, medical, social and psychological problems associated with the child and family are met from diagnosis through to cure or, in a number of cases, death and beyond." (A 6572)

In order that all stakeholders understood the philosophy of care of their workplace, guidelines were available in print:

"These guidelines demonstrate several common themes which are fundamental to children's hospice care." (A 4329)

It was made clear that the care given was from capable members of staff and that the skills of the families were recognised:

"We have a leaflet that stresses parents share the care of their children with nurses and encourages them to use the special knowledge of their children to work with health care staff." (A 635)

However this was variable. Opportunities were given for families to speak through the leaflets. One of the issues raised was that of attempts to pass on information to the professionals which proved to be a negative experience:

"Occasionally, I tried to give advice which some doctors and nurses found hard to cope with by parents." (A 669)

Efforts were made to provide continuity from the home to the care setting:

"We always carry out care in the way that the parents do at home and we try to meet their requests in terms of support." (A 1641)

Furthermore, such adaptation was extended to decisions about the provision of care:

"They [families] should be given an opportunity to be involved in all decisions relating to care." (A 6580)
Despite the use of guidelines, nevertheless, there was also evidence that professional practice was not rigid and could adapt to special needs and circumstances:

"We are sometimes able to continue to care for children after they have reached sixteen but we cannot normally take anyone for the first time beyond this age." (A 1200)

At the point of death of a child it was noticed that essential and sensitive emotional support for all members of the family was offered:

"The family can then spend as much time with the dead child as is helpful and should be offered accommodation at this hospice during this period." (A 4305)

One charity reported that it found itself in the position of working with families and other professionals in the provision of support services:

"It is frequently consulted by parents, voluntary and statutory agencies about the establishment of parent support, counselling or service providing self-help groups." (A 2418)

It was noted that such activities needed to have a close and co-operative relationship with paediatric specialists, paediatric nurses and other health care professionals in the hospital. This process also needed to include discussions with other agencies contributing to the care of the child and family:

"Access and availability of these services will be enhanced if there are effective relations between the hospice and referring bodies." (A 4297)

Discussion

An analysis of the statements placed in this subcategory demonstrated the way the professionals worked together for the welfare of the child and family, and the role of families in that care from the point of diagnosis through to discharge or bereavement. However well-intended, the dedication and commitment to the care of children and their families was not sufficient.
In order that all stakeholders understood their role, three charities made available in print their underlying philosophies for care and guidelines for interventions. It was however emphasised that they were guidelines and there was evidence that professional practice was flexible and could adapt to special needs and circumstances of the families. The care given was from practitioners who were prepared to work with families by sharing knowledge and fostering decision-making.

One charity reported that it found itself in the position of working with families and other professionals in the provision of support services. It was noted that such activities needed to have a close and co-operative relationship with paediatric specialists, paediatric nurses and others in the hospital. This process also needed to include discussions with other agencies contributing to the care of the child and family. Thus having provided the information, there was an attempt to encourage parents to utilize the source of help likely to be most beneficial for them. It was made clear that the care given was from capable members of staff, and similarly the skills of the families were recognised. Efforts were made to provide continuity from the home to the care setting. Furthermore, such adaptation was extended to decisions about the provision of care that were made. In recognising the particular skills parents bring with them when caring for a sick child, there was the recognition of a more lateral relationship between the families and professionals.

At the point of death of a child it was noticed that essential and sensitive emotional support for all members of the family was offered. Respect for the autonomy in decision-making made by families was shown when it came to withdrawal of bereavement services.

**Befriending and counselling**

Most of the references were made for the provision of befriending. One charity described befriending as their 'Listening Ear' for anyone whose life is, or ever has been, affected in any way by a child with cancer:
“Our friendly supportive "Listening Ear" aims to provide callers with emotional support, befriending, telephone counselling and bereavement support.” (A 1571)

There were telephone help lines provided ensuring anonymity at times of distress:

“All calls will be treated with the utmost confidence and all callers have the right to remain anonymous.” (A 959)

There were trained and experienced parents acted as volunteers for parent-to-parent contacts:

“These volunteers are trained by counsellors to give the necessary support.” (A 9)

Parent support groups existed to provide the opportunity for structured but informal meetings for parents to share experiences.

Counselling, as opposed to befriending was of a more formal nature available from specialist counsellors:

“They also run specialist counselling groups.” (A 4511).

Respect for the decisions made by families was shown when it came to withdrawal of bereavement services:

“Positive support is available throughout the on-going stages of grief until the families, themselves, decide that the charity’s assistance is no longer required.” (A 6347)

Parents highlighted the benefits of such contacts formal or otherwise:

“It was a great relief to be able to share the problems, as well as both positive and negative emotions with someone who really understood.” (A 2665)
Discussion

The statements placed in this subcategory, referring to the provision of befriending and counselling, confirmed there was sensitivity and responsiveness to needs, with the provision of encouragement. The offer of informal help was there for families to help them find their way out of some of the tangle of emotions that accompanied having a child with cancer. There were telephone help lines that provided anonymity at times of distress from trained and experienced parents who acted as volunteers for parent-to-parent contacts. Parent to parent support meant that families seeking help were able to draw on those previous experiences.

One charity described their befriending as their 'Listening Ear' for anyone whose life is, or ever has been, affected in any way by a child with cancer. The existence of parent support groups provided the opportunity for structured but informal meetings for parents to share experiences. There were opportunities provided for parents who highlighted the benefits of such contacts formal or otherwise. Support and counselling was offered to families who have suffered the death of a child. There were also contacts for siblings and for grandparents whose grandchild has died.

Summary

The tenor of these three subcategories was one of speaking directly with family members. This appeared to be particularly effective when offering advice about contact with the professionals and other family members. Families were recommended to set up and continue contact with relevant professionals for it was suggested the professionals were working together for the benefit of all family members. The charities had provided the means whereby families were able to decide on their actions and who would be involved with providing the support they needed. It was noted that the larger charities were in an influential position to affect national policies and providing contacts for support and counselling with other national charities.
Education

The subcategory concentrated on matters concerned with the education of the child and with broader aspects of education related to families, the professionals and the general public. The information for teachers was aimed at mainly primary school aged children, and provided advice when a child in their class or school has cancer:

"Children with brain tumours may have problems with co-ordinating eye movement, so it is important to find the best place in the classroom for them." (A 358)

If the child was having home tuition, it was suggested that there should be liaison with the home tutor in co-ordinating the schedule of schooling and homework:

"It helps if the school teacher co-ordinates one work scheme with the home tutor or hospital teacher, rather than the child getting different sets of work from different people." (A 347)

It was also seen as important that the parents' and the child's regular school staff (and the school staff of well siblings if different from the child with cancer) were kept informed of the changes that were taking place in the sick child for example a change in their treatment regime:

"These are some of the ways you can help your pupil cope with school after treatment for cancer." (A 363)

"These problems may be related to the disease itself, or may be temporary side effects of treatment." (A 428)

The charities made funds available for health care professionals to advance their specialist knowledge:

"We provide funds for specialist oncology training at such centres of excellence at the 'X' hospitals." (A 2554)
"The workshop is open to up to a dozen participants, including social workers, nurses, GPs, hospital doctors, teachers, psychiatrists, psychotherapists, counsellors, the clergy and those whose work brings them into contact with the sick child and their family." (A 4646)

Reference was also made to the need of education of the general public for a greater awareness of the disease.

There were references in which professionals offered their services to fellow professionals:

"This charity would like to share their knowledge of good practices in the care of life limited children, with other establishments expressing interest in this area of paediatric care." (A 4276)

Facilities for some specialist courses were not available in the UK, so it was necessary for one charity to send a student to North America:

"I am looking forward to this experience and would like to thank this charity for making possible the experience I am unable to obtain elsewhere.” (A 1997)

Some charities announced that they had provided educational material for a range of disciplines over several years. Furthermore, it was seen that the charities waived copyright in order that the educational material could be spread to others:

"This paper sets out to address the educational needs of health care professionals, social workers and clergy, who are caring for patients and carers experiencing loss or facing death." (A 4643)

"This page has been designed so that you can take photocopies and pass them to other teachers at the school.” (A 4633)

The material was presented in an easily acceptable format of questions and answers addressing parents and child:

"How much does the child know about the illness?” (A 944)

"How will cancer affect my everyday life?” (A 735)
The answers dealt briefly but clearly with each topic raised:

"Most children will have been told the name of their disease." (A 339)

"Older ones will know that their illness is serious or life-threatening, and that they will need frequent hospital visits." (A 340)

The authors of the leaflets also discussed the way in which adults can cope with the sick child and their own feelings:

"This booklet is aimed at parents, it is a very readable book and focuses on the emotional and social impact, for both child and family." (A 533)

There were suggestions and information to help young people cope with their treatment and stay in hospital:

"Sometimes we have a catheter or tube [Hickman or Broviac catheter] called a 'wiggly', which allows drugs to be injected and blood samples to be taken without a needle." (A 449)

Very specific information about managing to protect the child from infectious diseases was included:

"Please may we ask for your co-operation in an important matter." (A 460)

"We have decided to produce a leaflet for families to give them information." (A 632)

Discussion

Education for families about the disease was extensive and covered the biology of various cancers in general, for example signs and symptoms of and sites of presentation of specific cancers (these are noted in the subcategory 'Information about the disease'). This subcategory concentrated on the topics concerned with educating families and friends, teachers and health care professionals in matters relevant to coping with childhood cancer.
A child with cancer is a highly emotive subject, and was realistically addressed. Frequently the material in the leaflets was presented in an easily acceptable format of questions and answers addressing parents and child in which each question appeared to address the individual. The answers dealt briefly but clearly with each topic raised. The authors of the leaflets also discussed the way in which adults can cope with the sick child and their own feelings in a manner that was direct and informative yet with sensitivity, understanding and providing opportunity for thought and decision-making. An opportunity was given to present information about returning to school. It was seen that it was important for liaison to occur between the hospital teacher and the child’s regular teaching staff as they were encouraged to discuss and hand over the schedule of work. If the child was having home tuition, it was suggested that there should be liaison with the home tutor and co-ordination of the schedule of schoolwork to be done.

The information for teachers was intended mainly, though not exclusively, for primary school aged children, and provided advice when a child in their class or school has cancer. Advice adjusted for older children and adolescents was also provided. Very specific information about managing to protect the child from infectious diseases was included. This involved a considerable amount of cooperation between the school, parents of both the sick child and well children and health care professionals. In a letter addressed to families of well children, their parents were asked to keep the school informed if their child developed an illness such as chicken pox or measles. In a similar tone, families were warned that if the child had a Hickman or Broviac catheter in situ certain general precautions were needed.

The advantages of these contacts were four fold. First, so that it would have been possible to make informed choices in terms of activities the child undertook. Second, a level of continuity in the child’s education between hospital and home was ensured. Third, behavioural problems in the sick child or well siblings could be dealt with firmly, but with sensitivity and understanding. Fourth, some of the problems likely to be encountered, such as bullying or name-calling because of alopecia, were made known to the regular teaching staff.
There were suggestions and information to help young people cope with their treatment and stay in hospital. The emotional and psychological methods that helped children cope with both acute and chronic aspects of pain were included. It also included a page for children answering questions they might have and incorporated a pain identification chart. It was interesting to note the innovative input of ‘veteran’ children providing a lateral flow of information avoiding the input of adult with their preconceived thought on what is appropriate (Stewart & Dearmun 2001).

The charities made funds available for families and a range of professionals to advance their specialist knowledge. This was undertaken broadly through providing conferences, workshops, establishing recognised courses and study days. They also provided for individuals to study specialist courses. Some charities had clearly developed areas of expertise in providing educational material for a range of disciplines over several years and this experience was offered to colleagues.

Summary

The nature of this subcategory focused on two main features. First was the provision of the necessary information that would ease the way back to school for the child, their family and teaching staff. Second, it was seen that the charities provided opportunities via conferences and similar activities for the spread of knowledge between the charities, the families and a range of professionals.

Eligibility and contact points

The focus of this subcategory was to provide readers with information about the function of the charities and as a contact point for a range of other resources for charities:

"We do not provide long-term care and would not attempt to look after those who would benefit more from treatment in an acute hospital ward." (A 1203)

That noted, it was also made clear that efforts were made in being flexible and to accommodate appropriate referrals and requests:
"... although children residing outside the area of that Authority being treated at the Children's Hospital may also benefit." (A 1946)

Whilst some geographical referral locations were confined, others were much broader:

"Referrals will be considered from anywhere in the country." (A 1680)

The location, illness of the child, and age were identified:

"Referrals are considered from eight counties." (A 1220)

"Children with a progressive illness such as Metabolic disorders or CNS degenerative disorders, inoperable cardiac disease, malignancy and other, often rare, conditions are accepted." (A 1239)

"Children from O-17 years are welcome." (A 6543)

In initiating a referral for hospice provision, it was suggested that informal visits were made before decisions were taken:

"We usually suggest that the family makes an initial visit either overnight or for part of the day, so that we can begin to get to know each other." (A 1682)

Families and professionals were eligible to use the facilities offered by the charities:

"The support offered by this charity is not just for life-limited children, but for the whole family." (A 4447)

"Children of any race or creed are welcome and inquiries can be made by GPs, hospital staff, other professionals, families and friends." (A 1683)

Eligibility and referral procedure for holiday provision was also noted.

There were 15 leaflets that provided contact point for charities or organisations other than their own. Contact points for 27 different charities were provided. The links were for national and local charities or organisations and provided for a range of services.
Discussion

The declared intentions/roles of those charities were noted within nine leaflets. This was an important inclusion for these leaflets would find their way into the domain of the professionals and an inappropriate referral might cause confusion and disappointment for those for whom their particular service would not be appropriate. Examination of the leaflets showed that eligibility was frequently limited by a geographical boundary, the illness of the child and age.

The charities made frequent attempts to include families and professionals in the provision of their services. This included a helpline that was open to any parent, relative or professional worker, with the intention of offering information and advice. Similarly, both families and professionals were eligible for the training and support offered for a wide range of topics relating to children's special needs.

Repeatedly there was a double page giving brief details of other charities, their function and particular interests. Thus the domain for increasing information was enlarged.

Summary

The provision of information about the function of the charities was four-fold. One, the criteria for eligibility was made clear. Two, it avoided distress and frustration for families and professionals seeking those services but for whom they would not be suitable. Three, frequent attempts were made to include families and professionals in the provision of their services. Four, the range of services provided by other charities were noted.

Overall summary for ‘Communication and Co-operation’

The overall effects of this large category was to demythologize the folklore associated with the disease, and place the disease process onto a scientific foundation based on knowledge and expertise.
This information enabled families to enter into the culture of childhood cancer armed with the knowledge of the malignant processes identified in the subcategory ‘Information about the Disease’. It provided families with a clear understanding of the complexities surrounding the disease process and its impact on family life. The charities played an important role in the process of imparting information so that not only could decisions be made but also families would have a level of knowledge and understanding in making those decisions. The charities, via the leaflets, acted as silent supporters offering practical advice and emotional support. Respect for the unique contributions to care parents made enabled a partnership of cooperation between the professionals and families and there was evidence of a flexible approach to care where possible. Leino-Kilpi (1999) referred to manifestations of the dimensions of empowerment. (see Chapter Two page 38). Table 5.4. shows that the first category alone met all the concepts identified in the analytical frame work (Chapter Two).

**Treatment**

Table 5.7. **Distribution of subcategories**

<table>
<thead>
<tr>
<th>Subcategory</th>
<th>Number of statements</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment modality</td>
<td>325</td>
<td>42</td>
</tr>
<tr>
<td>Side effects of treatment</td>
<td>180</td>
<td>23</td>
</tr>
<tr>
<td>Controlling symptoms</td>
<td>168</td>
<td>21</td>
</tr>
<tr>
<td>Investigations</td>
<td>88</td>
<td>11</td>
</tr>
<tr>
<td>Clinical trials explained</td>
<td>24</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>785</td>
<td>100</td>
</tr>
</tbody>
</table>

The largest subcategory, containing 42% of the statements was unsurprisingly relating to ‘Treatment modality’, and the smallest number of statements (3%) were called ‘Clinical trials’. It should be noted that clinical trials in this context is not a research issue, as it refers to explanations of the benefits of participating in clinical trials to treatment outcomes. Fourteen of the 28 (50%) responding charities contributed to this category (table 5.7).
**Treatment Modality**

In accounting for the individual variation of treatment that might occur, for example in the site and stage in the cancer, there was an avoidance of much detail about specific treatments:

"Once the diagnosis of neuroblastoma is confirmed, the site and stage of the tumour will guide the Oncologist in charge of the child's treatment as to the very best protocol (treatment regime)." (A 4725)

A multimodal approach could be used in the treatment regimes and include chemotherapy, radiotherapy, surgery and in any combination of all three if necessary:

"The three main types of cancer treatment are chemotherapy, surgery and radiotherapy, either used alone or, more commonly, in combination." (A 584)

In giving information about the treatment process, in the first instance chemotherapy was given to shrink the main tumour and any possible secondary deposits; if possible, the tumour is then removed by surgery:

"After the courses of chemotherapy your child will be reassessed and if the tumour is thought to be operable, it will be removed and then possibly more courses of chemotherapy will be given." (A 642)

The routes for administration of medication were also varied:

"Also you may have to have some injections into your muscle." (A 6590)

However, frequently the use of a Hickman catheter was noted:

"Children may have a central venous line fitted through which treatment can be given directly into the bloodstream." (A 963)

In addressing the child, directly a lighter approach was adopted:
"If the doctors think that your treatment will involve a lot of 'needles', they may decide to put a special tube into your body so that they can take blood through it (fewer blood tests!) and give you all the drugs and other treatment." (A 3357)

Generalized approaches to the administration of chemotherapy were given:

"If you and your child embark upon the treatment regime recommended, you may have to stay at the main centre for one or two cycles of treatment."

(A 3309)

Bone marrow transplant, as a treatment, was mainly used for leukaemia but has increasingly been used for other conditions. Different types of bone marrow transplant were noted and further explanations given.

"In an autologous transplant, or autograft, some of your child's own bone marrow or peripheral blood stem cells may be taken and rein/used after high dose radiotherapy and chemotherapy have been given to kill any malignant cells left." (A 308)

It was explained to the child that after having their bone marrow removed and treated, they were then reinfused with their own bone marrow:

"In the meantime you receive chemotherapy or radiotherapy to kill any cancer cells left in your body, and then you are 'rescued' by returning the bone marrow which was removed, through an intravenous infusion." (A 320)

"The new healthy bone marrow cells find their way to the bone marrow cavity in the long bones and there they start producing normal blood cells." (A 579)

Surgery was seen as the main treatment for localised solid tumours, and was an important form of treatment:

"Surgery is usually performed to remove the affected kidney but chemotherapy may be used first to shrink the tumour." (A 4946)

Radiotherapy was described as powerful x-rays used to kill cancer cells:

"Radiotherapy is treatment given by high energy x-rays that kill malignant cells which lie in their path." (A 4825)
It was noted that only after several years in remission can a child be considered to be cured of his or her cancer:

"If reoccurrence of the disease occurs, it normally does so within two years of stopping treatment but occasional late relapses occur even up to 10 years later." (A 307)

A small percentage of survivors of childhood cancer develop other tumours later on:

"There is also a small risk of developing a different cancer in later life." (A 5234)

The possibility that some children do not survive was mentioned:

"Sadly, treatment for some is not always successful." (A 4846)

Discussion

There was a focus on the different approaches to the treatment of childhood cancers. The treatments noted included chemotherapy, radiotherapy, surgery and bone marrow transplantation. Treatments were based on the rationale that chemotherapy and radiotherapy work by killing dividing cells, and since they affect normally dividing cells, malignant cells would also be destroyed. Because treatments changed as knowledge grew, it was not considered appropriate to give specific details about any procedures currently being tested. Similarly, in order to allow for the individual variation that might occur, there was an avoidance to give too much detail about specific treatments. However, it was made clear that whatever the treatment protocol was adopted, the hospital was going to become an important part of the life of the child and their family.

The approach adopted by the leaflets was that childhood cancers are, for the most part, systemic diseases and as a result a multimodal systemic approach was needed.
There were exceptions too and they usually occurred when a tumour was discovered in the early stages, had not metastasised and local resection was possible or radiotherapy was an appropriate treatment option.

A multimodal approach could include chemotherapy, radiotherapy, surgery and in any combination of all three if necessary. It was explained that both surgery and external radiotherapy are treatments that can only deal with tumours in one specific part of the body. In addition, radiotherapy and chemotherapy were given when surgery was not possible.

Chemotherapy was explained as a complex treatment of cytotoxic drugs that worked by poisoning cells that divide rapidly. It was seen as the most important treatment because of its systemic application, and it was noted that chemotherapy could be given for varying lengths of time, ranging from a few weeks to two years. It was given before and after local treatment to destroy secondary deposits and might also be given to help prevent the tumour growing again. Giving generalized approaches to the treatment regimes for chemotherapy had the advantage of avoiding confusion and families believing they were not having the ‘right’ treatment. Parents were advised that the drugs were given by a number of routes, including the oral route, injection into the muscles or veins. However, frequently the use of a Hickman catheter was noted, sited into an appropriate vein for an appropriate length of time whilst their child received their chemotherapy. Surgery was described as an important treatment method for localised solid tumours. It could also be used at a later stage of treatment, often after several courses of chemotherapy so that the tumour had shrunk to a size that it could be more easily removed by the surgeon. Radiotherapy was described as a painless treatment in which a beam of powerful x-rays outside the body penetrates deep into the body to kill cancer cells.

It was noted that a relapse of the disease was still possible even after several years following completion of treatment. Furthermore, for a small percentage of survivors of childhood cancer, other tumours may develop later on. The possibility that some children do not survive was addressed with clarity and sensitivity.
Side effects of treatment

The side effects of treatment were seen to be distressing. The consequences of this were seen in intestinal upsets, such as nausea, vomiting, and mouth ulcers:

"Chemotherapy may cause nausea (feeling sick), vomiting, hair loss and possibly a sore mouth." (A 884)

In particular, the side effects for the immunosuppressed child are potentially dangerous:

"The consequences of a childhood cancer sufferer catching any infectious disease can be dangerous, even fatal." (A 5037)

The long and short-term side effects of chemotherapy were experienced systemically:

"Some treatment may affect your child's fertility, but treatment is available to help your child develop sexually during puberty." (A 4925)

Comments were directed towards the parents and to the child:

"Chemotherapy may make your child feel sick and may directly affect the lining of his gut so that he will not want to eat and will lose weight." (A 885)

"There are changes in physical appearance." (A 5215)

The short and long-term side effects from radiotherapy were noted:

"For example, if he is having radiation, his skin will be sore as if he were sunburnt." (A 293)

If for example, the external beams had been directed at a leg, then that leg might be shorter than the other:

"Surgery and radiotherapy may stop bones growing and make muscles and tendon shorter so that other operations may be necessary for the child later in life." (A 4941)
Discussion

It was explained that in addition to killing cancer cells, powerful treatment agents also damaged normal cells in the body of the patient, side effects of which were seen to be distressing. There would be short and long-term side effects from the treatments.

It was explained that the long and short-term side effects of radiotherapy tended to be more localised (depending on the selected site and regime). Conversely, the effects of chemotherapy were experienced systemically. This was because one of the problems associated with chemotherapy regimes was that drugs used in treatment particularly affect the cells that multiply quickly. Thus several body systems can be affected to varying degrees. In the gastro intestinal tract, it was explained that drugs are not absorbed well through the stomach and they may damage the lining of the digestive tract. The consequences of this were seen in, intestinal upsets, such as nausea, vomiting, and mouth ulcers. Immunosuppression could also be problematic.

Depending on the regime of treatment being used, the side effects of chemotherapy were reported to be between moderate and severe. However, knowing what side effects to expect, it was possible to prevent some and treat others. Parents were warned that they could expect their child to be affected to some extent and to be prepared for changes in moods and physical appearance. However, it was important for them to understand that their child would not necessarily have all the side effects mentioned. Despite the list of long and short-term difficulties it was reported that most children tolerated treatment well.

Controlling symptoms

Effective pain control in children varied. One problem was that of inappropriate timing of withdrawing of pain relief:

"When he had to go out of the hospital for tests elsewhere, he was often in such pain that he had to be given drugs at the outside clinic before the tests."

(A 6702)

A second problem appeared to be the lack of understanding by the professionals of appropriate analgesia for effective pain control:
"At first, he was given mild painkillers, then a stronger one was tried - but because medical staff were afraid it would give him constipation he was given too little!" (A 780)

A third problem was that effective analgesia was available but the staff to supervise it were not:

"A child may be taken off a PCA when moved back into a general children’s ward because there is insufficient supervision to continue on the PCA."

(A 612)

The child with pain was given a voice also:

"This was my seventh operation and it has always been very painful afterwards." (A 6472)

One leaflet noted that:

"The Royal College of Surgeons and Anaesthetists’ Report Pain after Surgery (1990) disclosed that high numbers of children are in pain on the day of surgery - and many in pain the day after. It found that all the adults received pain relief but 24% of the children received nothing." (A 5165/6)

This was the experience of a 13-year patient referred to as Mary:

"It was never just offered to me." Mary 13 (A 3877)

Not all experiences were negative and it was suggested that the care team could assist in the control and prevention of pain and unpleasant symptoms that cause distress:

"Children sometimes receive very good pain relief after surgery." (A 980)

It was noted that to be effective, symptom control required assessment and frequent evaluation. Appropriate analgesia given prior to the procedure was seen to be helpful:

"I used to have a shot before they came to turn me, then I didn't get so tensed up." (A 3227)
Different ways of administering analgesia were also noted; this included topical as well as, epidural injections and the use of PCAs:

"It may be painful at the time, but we can use a cream called 'EMLA' to deaden the pain." (A 344)

"This time was brilliant, I had an epidural and there really was no pain at all. (Anna 14, after spinal surgery)." (A 6466)

The benefits of Patient Controlled Analgesia pump were noted. However, conflicting messages in one leaflet were given about the use of PCAs and are exemplified in the following two statements:

"Even very young children can use them (PCAs)." (A 2466)

However,

"PCAs have to be closely supervised by staff and many hospitals don't have them for children. (A 3212)

There were occasions when children need antibiotics directly into the bloodstream to combat infections.

Furthermore, there were also occasions when patients needed to be kept in isolation to avoid infections from other people. A professional spoke from her experience about this:

"For seven months Nicola lay in isolation and only the doctors, nurses and her parents, scrubbed and gowned, were allowed contact with her". (A 3186)

Parents were reminded in the leaflets not to allow their child to have any form of vaccinations. In upper case print, parents were reminded not to allow their child to have any form of vaccinations, and were asked to speak to their doctor if their child is in contact with childhood illness such as measles, chicken-pox or shingles:
"REMEMBER, WHILE YOUR CHILD IS ON TREATMENT, VACCINATIONS OR IMMUNIZATIONS MUST NOT BE GIVEN."
(A 4842)

"Measles and chicken pox can be particularly serious if your child is not immune. If not, and your child has been in contact, you should let your doctor or hospital specialist know immediately so that an injection can be given to prevent the infection developing." (A 3234/5)

In the event of an unacceptable weight loss, measures were taken to counteract this:

"Your child's weight will be checked regularly so that if it is falling too much s/he may be fed through a tube passed through his nose into his stomach or intravenously via the central line." (A 6747)

Should a relapse occur after a period of remission, the child and their families were encouraged that they were not alone in this situation:

"Some have finished their treatment, others are coping with relapses - they have felt like you." (A 4913)

Discussion

Pain was the dominant symptom mentioned in the leaflets followed by immunosuppression, weight loss, nausea and vomiting. There was evidence within the contributing leaflets that effective pain control in children was variable. Inappropriate timing of withdrawing pain relief was cited as one problem, whilst another problem appeared to be the lack of knowledge by the professionals of appropriate analgesia for effective pain control. A third problem was that when effective pain control was established, the health care professionals were not available to monitor the situation. It was noted that to be effective, symptom control required assessment and frequent evaluation.

There was evidence of both competent practitioners and those who were unaware of the principles of good pain control, for not all experiences were negative. The children with pain were given a voice with a balanced representation of effective and poor pain control.
Appropriate analgesia given prior to a procedure was seen to be helpful and it was suggested that the care team could assist in the control and prevention of pain and unpleasant symptoms that cause distress. Different ways of administering analgesia were also noted; this included topical as well as epidural injections and the benefits of using the Patient Controlled Analgesia pump (PCAs) pump were noted. Caution was needed to protect vulnerable children from infections.

In conclusion, it was seen that adequate and appropriate nutrition and attention to weight loss was important. It was suggested that it was important that the child ate sensible foods (not just sweets and crisps) when they were feeling well, and to make up for the days when it was hard to eat. Vomiting and the presence of mouth ulcers would aggravate poor appetite and weight loss, therefore good oral hygiene was important, as was appropriate medication. Families were advised that children in remission should be well and were unlikely to have any symptoms or complaints relating to the illness. After treatment, many families experienced anxiety for the future. In part this anxiety was justified for it was seen that there was a small risk of the child developing a different cancer in later life. Follow-up clinics were therefore essential to monitor for any of the various late side-effects of treatment (Gibson & Evans 1999). Should a relapse occur after a period of remission, families were encouraged not to despair, and that they were not alone in this situation.

**Investigations**

As stated earlier, the subcategory ‘Investigations’ presented a frank account of why some investigations were necessary:

> “If a blood test suggests that the bone marrow is affected then a bone marrow aspiration may be done.” (A 5089)

> “X-rays will then be done to see whether other bones or the lungs are affected.” (A 605)

The range of different investigations was consistently referred to as tests:
Perhaps it would now be helpful in the next section of this booklet to consider, in more detail, how you may be able to help your child through the tests and treatment to come.” (A 4740)

The names of invasive and non-invasive investigations were given. Descriptions of their purpose were given:

"Small doses of a radioactive substance can be injected into the body to make the bones show up.” (A 4899)

"Other tests are done including a chest x-ray, a bone scan and a CT or MRI scan.” (A 4733)

"A lumbar puncture is usually done under an anaesthetic and sometimes drugs are injected into the fluid at the same time.” (A 618)

Such information had also accounted for the fact that families were not familiar with the mechanics or physics of the more technical pieces of equipment used in the investigations for their child:

"Ultrasound waves are sound waves that the human ear cannot hear.” (A 6649)

"A computer integrates the pictures to reveal any tumours.”(A 245)

Discussion

The statements that referred to investigations were, of necessity, frank. For example, references were made to the need to establish whether or not metastases were present and for the small number of families with a genetic risk of the disease, exploration would be undertaken. Parents were reassured that efforts were made to reduce the trauma associated with the many different investigations. In keeping with the consistently ‘user friendly’ approach adopted throughout the entire range of leaflets, the investigations were referred to as tests. It was indicated that the investigations needed would depend on the child's symptoms or the provisional diagnosis. This enabled families, who would be new to the world of childhood cancer, to understand the type of investigation and the reason for it.
The same or similar investigations were used at different times in the stages of the illness for different reasons, for example, the taking of blood.

Summary

Considerable amounts of information about the different treatment modalities were expressed clearly. So too were the different routes for administration of drugs. Comments were directed towards the parents and to the child but when addressing the child directly, a lighter approach was adopted.

Both long and short-term side effects of treatment were acknowledged with a reassurance that child would not necessarily experience all those mentioned. It was also anticipated that reassurance was the key to reducing such side effects. The frankness in the approach was noticeable and necessary in order that parents were prepared for the future, for the treatment regime could follow a tortuous route with no guarantee of who would survive and who would not. Sharing with the family knowledge of the complexities of different investigations and the results meant that many parents were able to participate in discussions in order to understand what was happening, why it was happening and how it was happening. It also established a partnership in which the role of the parent was valued and respected.

Maintaining Normality

Table 5.8. Distribution of subcategories

<table>
<thead>
<tr>
<th>Subcategory</th>
<th>No. of statements</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on family members</td>
<td>370</td>
<td>49</td>
</tr>
<tr>
<td>School</td>
<td>151</td>
<td>20</td>
</tr>
<tr>
<td>Adaption for the family culture</td>
<td>149</td>
<td>19</td>
</tr>
<tr>
<td>Interventions</td>
<td>57</td>
<td>8</td>
</tr>
<tr>
<td>Body image</td>
<td>26</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>753</td>
<td>100</td>
</tr>
</tbody>
</table>

146
It can be seen that the largest subcategory, containing 49% of the statements were unsurprisingly relating to a 'Focus on family members', and the smallest number of statements (4%) were labelled 'Body image'. All 28 (100%) responding charities contributed to this category.

**Focus on family members**

The aim of the charities was to consider the welfare of the child and the family as a whole:

"The whole family is affected when a child has cancer." (A 4657)

It was clear from the leaflets that every effort should be made to enable the child to remain at home and keep the family united:

"The charity is committed to providing a seamless web of care and support throughout the National Health Service and into the community, ensuring that the child is treated as much as possible in its home environment." (A 1007)

An insight into the mental anguish parents faced was highlighted. This involved many parents admitting to 'rehearsing' imaginary details of their child's death:

"Some parents describe either moments of panic or periods of having morbid thoughts or dreams, and almost all parents, at some time, think about the possibility of their child's death." (A 870)

Parents were encouraged to create time and space for themselves:

"Because your child is sick, it is not wicked to think about a night out, to enjoy a film or spend an evening with friends." (A 3949)

Also, it was suggested that fatigue exacerbated feelings of inadequacy:

"No-one will make judgements about your capabilities as a parent, or label your child as having special problems or difficulties." (A 4380)
"There may be occasions when you feel so worried, depressed and tired that you wonder if you are 'breaking down' or even 'going mad.'" (A 2501)

Parents were entreated to share their feelings with their spouse or if that was not possible, with someone of their choice:

"If you can, try to talk to each other as openly as possible." (A 198)

"Fathers, however, do cry just as often as mothers when hearing about their child's disease and it is not a sign of 'cracking-up' or potential inability to cope." (A 983)

It was explained that undoubtedly, both parents will be distraught and will try to hide feelings from one another, but this will prove to be an extra strain, with the likelihood that pre-existing relationship difficulties may be exacerbated by the stress of the situation:

"Conversely, there are many husbands and wives who feel their partnership is strengthened by the need to share in the care of their sick child and the need they have of one another's support at this time." (A 4135)

If it was not possible to share intimately with a partner or friend, support at this stage from another parent who has been through a similar crisis was seen to be invaluable:

"Confidence can be increased by meeting and sharing experiences with other families in a similar situation." (A 842)

It was recognised that considerable extra expenses are incurred by families with a very sick child, and are almost impossible to budget for:

"Travelling expenses can soon mount up; you may have extra gas and electricity bills for a while when your child returns home." (A 2735)

A parent was given a voice via the leaflets and said:

"She will have to give up her job to care for our son and this will place a financial burden on the family." (A 2767)
‘Home-from-home’ accommodation was helpful for families:

“Families who stay at the house will often be staying hundreds of miles from home for long periods.” (A 4102)

Almost all the accommodation provided somewhere for parents, brothers and sisters to stay:

“We are becoming a real family once again away from the pressures of hospital and treatment.” (A 3927)

“They will be worried about you, confused, maybe frightened and wondering whether they will become ill, too.” (A 4022)

It was noted that the professionals declared that children's questions about their illness would always be answered truthfully, and parents were encouraged to take the same approach. Parents were also reminded that a school age child might have heard the word 'cancer' from unreliable sources:

“At the same time remember that the children are likely to have picked up impressions from overheard conversations or chance remarks, and/or from just being sensitive to their parents' moods and anxieties. (A 4080)

For the younger child only simple explanations were needed:

“For example, it may be possible to say something like "... The pain in your tummy is because there is a lump there which the doctors found by taking special pictures." (A 3993)

Discussion

Central to the aim of the charities, this was the recognition that the child is part of a wider circle of family and friends. Therefore, however the illness affects them will automatically affect those closest to them and goes beyond the realm of medical treatment. Similarly, professionals caring for the child at home recognized the child's home as the centre of care and the family as the experts in the care of their child.
The interventions undertaken had, in the opinion of the charities, far reaching consequences both for the child and the rest of the family. Not surprisingly therefore, the charities made it clear that in addition to professional help, they worked closely with the health services, social services and education departments to provide their services. An important focus of their work was to help parents overcome their feelings of loneliness and isolation, and reduce their stress by reinstating hope and increasing their confidence. They offered practical, emotional and spiritual support and friendship to children with life-threatening conditions and to their families in order to regain and maintain their equilibrium, providing ongoing support, if required, to both parents and children by listening to them.

Parents were encouraged to create time and space for themselves. This was because most parents felt they did not want to show their distress in front of the child but sometimes they found it hard not to do so. Similarly, time spent with each other or with friends could go some way in easing tension and recreating a sense of normality. Also, it was pointed out that feelings of inadequacy could be exacerbated by fatigue. Parents were encouraged to share their feelings with someone of their choice. Sharing did not mean not coping, and could actually be beneficial. If it was not possible to share intimately with a partner or friend, support at this stage from another parent who had been through a similar crisis was seen to be invaluable.

Treatments at regional units meant that many parents had to travel to and from the hospital. The opening of ‘home-from-home’ accommodation was a haven for parents. With a place to stay close to the hospital, unnecessary travelling was reduced thus cutting down of the fatigue of parents. In addition with every house that was set up, the charities were able to remove the financial pressures on parents of finding a hotel to stay in and of organising daily travel to visit their child. It was recognised that considerable extra expenses are incurred by families with a very sick child, and are almost impossible to budget for. It was seen that wages were lost when work is interrupted. Income therefore can be lost at the time of greatest need. Almost all the accommodation provided somewhere for families to stay.
It was noted that the professionals declared that children's questions about their illness would always be answered truthfully, and parents were encouraged to take the same approach, thus it was impossible to hide the truth about the diagnosis. The difficulties associated with 'truth telling' were recognised, particularly at a time when the parents themselves found it difficult to accept. However, it was suggested that it was better for the child to learn about their own disease, at the outset, from trusted parents rather than hearing things from others that may bewilder and worry them. Parents were advised that at any age, if their child could not rely on their parents to listen to their worries and answer questions honestly, insecurity would result.

School

In the case that the child was not able to return to school for a while because of medical unfitness after treatment, the Local Education Authority would provide a home tutor for a period of time:

"Some Local Education Authorities, also provide educational equipment, such as home computers and videos, where a child is expected to be away from school for a long time." (A 6219)

Different approaches to home tuition were noted:

"The advantage of having a home tutor to cover the period while hair regrows is considerably outweighed by the disadvantages of not returning to school and rejoining friends, nor does having a home tutor usually make eventual return difficult." (A 4974)

"Doctors are sometimes reluctant to authorize home tuition because they feel that the family may become dependent on the service, which can discourage an early return to school and normality." (A 4693)

It was seen as important that the children's lives remained as normal as possible, both in and out of school:

"If the child feels well enough, visits from school friends may be helpful, provided that they have been briefed as to what to expect in advance." (A 6667)
Advice was given to teaching staff for the smooth re-entry back into school for the child:

"Try to avoid adverse comparisons, particularly when the sick child is a pupil of the same school as his/her sibling/s." (A 3905)

"But once back at school, the child should be encouraged to achieve his or her full potential." (A 5531)

Discussion

Some references were made to maintain contact with the child in hospital. It was suggested that simple homework, letters or tapes would convey that s/he is not forgotten and is still a valued member of the school. To the child at home not yet able to return to school, invitations to special assemblies, parties or discos might be appropriate.

The statements placed in the subcategory labelled ‘School’ were predominantly about the normality of returning to school and the social contacts with their peers. Although it was possible for the Local Education Authority to provide a home tuition for a period of time, nevertheless, two quite different approaches to home tuition were noted in which the advantage over the disadvantages of home tuition were pointed out to parents.

In the experience of the charities, when the child returns to school, teachers sometimes made the mistake of holding up children with cancer as 'good examples' to the rest of the school or to his/her siblings. However, it was advised that, to a child who already feels different and isolated from their friends, such actions did not help them returning to normality. A child's successful, and early return to school was seen as a vital step in re-establishing normality and in ensuring a happy, well-adjusted and fulfilled future life. Teachers were encouraged to be flexible about work. However, the charity leaflets advised that, as a general rule, they should expect the same standards as for other pupils.
Adaption for the family culture

Leaflet readers was made aware that they have a choice over much of what happens to them and encouraged parents and children alike to exercise that choice:

"It is very important to us that the families remain in control of what they want for themselves and their children." (A 1622)

The child with cancer was also addressed directly:

"When you have been in hospital a few days and the routine is becoming a little more familiar, you may begin to think about how you are feeling.” (A 601)

They were advised to think positively:

"Looking further ahead, it is better to look on the bright side, since thinking gloomy thoughts all the time can only make you miserable and depressed.” (A 6999)

"Think about falling in love and maybe getting married.” (A 3200)

It was also suggested that as much normal family discipline should stay intact, giving the child greater security if normal discipline was applied:

"You may be tempted to spoil your child and relax your usual rules, but this can cause more unhappiness than happiness in the long run.” (A 97)

Cultural and religious norms for families other than Christians were in terms of diet and religious observance:

"We need also to be aware of cultural differences as funerals happen so quickly for our Jewish and Muslim families.” (A 160)

Discussion

The statements in the subcategory labelled ‘Adaption for the family culture’ reflected the changes and adaptations experienced by the child and family.
Through the leaflets problems were identified and where possible appropriate solutions or remedies offered that could be adapted to the family's own mores. Leaflet readers were made aware that they were in a position to decide on much of what happens to them and encouraged family members to exercise that choice. The children with cancer were also addressed directly, and were advised that having cancer would affect their life, but that it need not take over. They were encouraged to have some ambition to help pull themselves through the immediate difficult times and avoid becoming depressed by looking at all the unpleasant and frightening things that were happening. They were encouraged to think about the time when they felt stronger and fitter, when they could leave school, get a job and go out into the world. It was explained that people who are able to think positively usually did better than those who gave up hope.

**Interventions**

The interventions that were offered provided practical, emotional and spiritual support:

"Support and comfort are offered by telephone, visits to the family, one-to-one and group meetings, through social gatherings." (A 6769)

"Again, providing all members of the family with support, a voice and a link." (A 960)

During the treatment phase of the illness, while families were at regional units, often a long way from home, it was understood that they needed the support of a husband or wife or other relative or friend to providing an important contact with home and to be available to hear what the professionals were saying:

"It is a good idea to have someone with you right at the beginning to hear what the doctors have to say about your child's disease and treatment." (A 4448)
Discussion

The interventions offered provided for a range of needs for families to regain and maintain their equilibrium when caring for children with life-threatening conditions. Furthermore if required, ongoing support was available to families. Relationships with siblings were seen to alter considerably especially at the beginning of treatment. Suggestions were made that involved the sick child sharing what they knew, and by talking and listening to their brother and/or sister, the cancer and its treatment would not separate them. From experience, the charities were able to say that children who have been in hospital can often be difficult and demanding when they return home. However, parents were reassured that their children usually would settle into the home routine again when they know that their parents would not 'give in' and allow behaviour that was not acceptable before their illness.

It was suggested that indulging the child would not be reassuring to them that life has returned to normal. Rather, it was also suggested that as much normal family discipline stay intact, giving the child greater security if normal discipline was applied so that the cultural norms for families were observed.

Body image

It should be noted that the number of statements relating to body image was small, however the other subcategory of side effects and controlling symptoms would have accounted similar statements. The approach adopted in the leaflets connected with issues of body image was to 'speak' directly to the child or family member:

"If you have lost weight, look pale, your hair has come out or you look different in some way, the others will be surprised at first and may seem to be staring at you or keep asking you questions." (A 3888)

Comments were made by family members. A mother said:

"His appearance was grotesque to him... moonfaced." (A 3200)
A child said:

"I had decided to have the operation because I had to wear a very uncomfortable and hideous-looking extension prosthesis." (A 3224)

Where problems were identified, there was also reassurance:

"Fortunately, most children treated for leukaemia grow and develop normally." (A 2020)

Discussion

Comments from the child or family member personalised the input and provided a glimpse into the way in which others were experiencing the changes in body image. Alopecia was seen to be particularly distressing for teenagers and it was suggested that it was better to allow them to decide on whether or not they wish to disguise the fact and how. They were further reassured that their hair would grow again quite normally and in some cases thicker and better within a few months of stopping treatment.

Summary

There was recognition that if the care of the child with a life threatening condition was to be effective, then there was a need for a holistic approach that focused on all family members. The feelings of the families were considered with sensitivity when offering interventions, particularly in relation to economic difficulties and potential behaviour situations of both the sick child and their well siblings. In the subcategory ‘Adaption to family culture’, advice from skilled practitioners was given with respect for the very private domain of family life. Flexibility and sensitivity on the part of parents and teachers was noted to be the key to successful re-entry into school during and at completion of treatment. Two charities produced their information for teachers in a question and answer format to help with re-entry back into school. The tenor conveyed was positive and balanced.
It also suggested that most children know their own limitations and would participate as much as they felt able to do so. The personalised approach adopted in the style of the leaflets meant that the sensitive issues of appearance and body image conveyed attitudes of respect for the individual as a human being. Where problems were identified, there was also a suggested solution and reassurance. The charities made marked efforts to convey to parents that via their offered interventions, families were valued, respected, and encouraged. The uniqueness and individuality of each child and family was clearly emphasised.

Resources

Table 5.9. Distribution of subcategories

<table>
<thead>
<tr>
<th>Subcategory</th>
<th>No. of statements</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individualised attention</td>
<td>82</td>
<td>25</td>
</tr>
<tr>
<td>Information about provision of resources</td>
<td>74</td>
<td>23</td>
</tr>
<tr>
<td>Environment of care</td>
<td>72</td>
<td>22</td>
</tr>
<tr>
<td>Responsiveness to needs</td>
<td>35</td>
<td>10</td>
</tr>
<tr>
<td>Competence of staff</td>
<td>22</td>
<td>7</td>
</tr>
<tr>
<td>Flexibility in provision of resources</td>
<td>20</td>
<td>6</td>
</tr>
<tr>
<td>Technical equipment</td>
<td>16</td>
<td>5</td>
</tr>
<tr>
<td>Continuity of care</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>327</td>
<td>100</td>
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In this subcategory, 25% of the statements related to 'individualised attention'. For example in adapting the facilities to meet the needs of families. By contrast the smallest number of statements referred to 'Continuity of care' focusing on the transition of care from hospital to the community. Twenty-five of the 28 (89%) responding charities contributed to this category.

**Individualised attention**

The specialist nature of some charities made it possible to meet the needs of families not catered for by other sources:
"This charity tries to meet the needs not met by the authorities or other charities" (A 679)

This was seen for example in the following statements:

"Day-care facilities have also been set up in here to help families escape the stresses of ward life for a while; to relax in a homely environment." (A 3084)

Hospice provision was also discussed, in terms of meeting the informal needs of families:

"An informal "Drop-in" Centre where they can have a chat with our carers."

(A 1556)

Telephone contact was also highlighted with the reassurance that there would be a response even if the lines were busy when they rang:

"An answering machine is available to take your calls at all other times (or when the lines are busy)." (A 1550)

Approaches to care, noted mainly by the hospices were flexibility, adaptability and sensitivity:

"They can choose to care for their sick child or may take the opportunity of a break, perhaps a weekend away or a holiday with the rest of their family knowing their child is well cared for and is safe." (A 1221)

The therapeutic role of toys was noted:

"Welfare grants: This charity recognizes that a seriously ill child will always result in heavy expenditure for the family "Toy therapy" always expensive." (A 1407)

The library was also available to professionals and those caring for bereaved families:

"Who's Who in the Health and Allied Services." (A 1342)
"Siblings have their own sibling contact network, leaflets, and a quarterly newsletter, SIBBS (Support In Bereavement for Brothers and Sisters), is edited by siblings." (A 103)

The other was information that helped families to start a local parent's group including local campaigning and attracting and keeping new membership:

"Producing a newsletter for your group." (A 1353)

Information was provided for State benefits and was also available in audiovisual form:

"Your local social services department, Child Health Clinic, Doctors Surgery and DSS can also advise you about facilities and benefits available to you locally." (A 4236)

The help provided by the charities was able to complement those services offered by the Department of Social Security (DSS):

"If you are not eligible, or if the DSS cannot help with a particular need, 'The X Fund' may be able to give you a direct grant." (A 2710)

Regular newsletters, 'Information Bulletins' and non-medical advice, provided a social function for parents and children:

"Our very own newsletter and is now available." (A 6801)

"Written information for parents including a quarterly newsletter, 'Share an Idea' and fact sheets on subjects such as benefits, holidays, special education and sexuality. (A1289)

Information about several different types of appropriate environments for care were noted. It was important for children who have a terminal illness to have fun and this was reflected in the provisions of facilities:

"There is a large well-equipped garden and play area." (A 4386)
There was recognition that children needed different hospice provision from adults:

"It is important to emphasize that a children's hospice is different from an adult hospice." (A1354)

A new purpose built unit funded by a charity minimized the risks of infection and gave the children a better chance of survival:

"A bacteria free environment, its own treatment room to reduce the number of child visits to the operating theatre, playroom and accommodation for parents." (A 2531)

Special facilities for bereavement care in the hospice setting were also noted:

"This charity offers terminal care and has a special bedroom where families can spend time with their child after death and members of the Community Team offer bereavement support too." (A 4460)

The extent and nature of services offered by charities in serving the needs of families when caring for a sick child was also evident:

"Over the past five years an event has cared for over 2,000 children and their families." (A 5856)

"The charity responds to requests for financial assistance for wide and various reasons that always benefit the child." (A 6202)

The charities funded a range of staff appointments:

"Since last year we have provided two paediatric community nurses." (A 2584)

"We now have fifty Social Workers throughout the country, and the number continues to grow." (A2755)

Several charities highlighted their own particular area of interest:

"Our national and international networks are steadily expanding, increasing the chances of parent and group linking." (A 1275)
Flexibility in the provision of resources was noted and the way in which the charities were able to support families in a practical way:

"Night care, washing machines, a wheelchair, holidays, pagers, travelling expenses, a polo bicycle, driving lessons, play mat, clothes car seats, a mobile 'phone and many other items have recently been provided." (A 700)

Three charities noted that they purchased technical equipment:

"As ever I am grateful to this charity for providing the funds to resource the laboratory infrastructure to support this development." (A1949)

"First, our main analyser is to be upgraded to enable the differential white count." (A 1956)

Continuity of care provided support to the family at differing times during the period of ill health:

"Bereavement support; positive support is available throughout the on-going stages of grief until the families, themselves, decide that the charity's assistance is no longer needed." (A 1537)

Discussion

The charities made it clear that they were able to provide help and support in a variety of settings, with services tailored to meet the needs of each family. Continuity of care was provided to the family at differing times during the period of ill health. The extent and nature of the responsiveness of the charities to the range of needs encountered by families when they are caring for a sick child was seen. The specialist nature of some charities made it possible to meet the needs of families not catered for by other sources. This was seen for example in day-care facilities, hospice provision, through telephone contact where the approaches to care, (noted mainly by the hospices) were flexibility, adaptability and sensitivity. The needs of siblings were not forgotten and with a suggestion that particular and appropriate facilities should be provided for brothers and sisters. Two charities identified the need for toys and their therapeutic benefits.
One of these provided a toy library in which the charity either had, or could obtain, any special toys or play equipment that the family thought their child would enjoy but was too expensive or of too short-lived an interest for them to buy.

Seventeen different charities were able to provide a range of information about the resources they provided. These were two-fold in nature. One was the provision of information that gave information to families, this included publications, audiovisual material, library list and directories. The content has been referred to in the category ‘Empathy: Bereavement’, however it was interesting to note that if families wished, the librarian would advise on suitable books to meet each parent's personal experience. The library was also available to professionals and those caring for bereaved families. The second was information that provided a social function for parents and children. This was seen for example in regular newsletters, 'Information Bulletins' and non-medical advice and social activities. Advice was given about the starting a local parent's group. Information was also provided for State benefits and was also available in audiovisual form.

Appropriate environments for care were noted on several different occasions. This was particularly so with hospice provision, where each hospice appeared to have its own character yet they retained several features in common. The main one was the recognition that children needed different hospice provision from adults. To overcome some of the problems encountered during the treatment stage, to improve the quality of childhood cancer care, one charity provided treatment facilities with a dedicated children's cancer unit. The creation of the unit was seen as a major step forward. The charities funded many staff appointments such as clinical nurse specialist, play therapists, social workers and researchers and three charities also purchased technical equipment.

Family facilities varied according to the care setting. In the acute setting the overall aim in offering 'home from home' facilities was to provide a haven for families experiencing the rigours and tensions of life on the children's cancer ward. This was usually in the grounds of the hospital or in an adapted house nearby.
In the hospice setting, the aim was to provide homely accommodation and be part of the hospice family (if they so wished). Both settings provided accommodation in which the whole family could be accommodated, with well siblings. There were also special facilities for bereavement care in the hospice setting.

Summary

Flexible provision of resources to meet needs in an appropriate environment for care was evident from the data. It was found important to support families at times of crises throughout the illness. These facets of care were reflected in the provisions of facilities. The up to date technical equipment meant that the charities were extending boundaries in the provision of care thereby meeting any expectations held by families for quality services. Noticeable was that the professionals continued with care until the families, themselves, decided that the charity's assistance is no longer needed, thus respecting their autonomy.

Professional Issues

Table 5.10. Distribution of subcategories

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<thead>
<tr>
<th>Subcategory</th>
<th>No. of statements</th>
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<tr>
<td>Knowledge and skills</td>
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<td>43</td>
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<tr>
<td>Professional input</td>
<td>83</td>
<td>34</td>
</tr>
<tr>
<td>Interdisciplinary working</td>
<td>51</td>
<td>20</td>
</tr>
<tr>
<td>Purchaser/provider issues</td>
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<td>3</td>
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<tr>
<td>Total</td>
<td>247</td>
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It is of no surprise to find that 'Knowledge and skills', was the largest subcategory of 'Professional Issues' containing 43% of the statements. By contrast 'Purchaser/provider issues' was the smallest number of statements (3%) focusing on planning and management of services. Eighteen of the 28 (64%) responding charities contributed to this category.
Knowledge and skills

It was recognised that the range of health care professionals needed in the treatment regimes had skills, experience and qualifications appropriate to their field of care:

"Paediatricians are doctors trained in children's diseases and are known as paediatric oncologists if they have specialized in the treatment of children's cancers." (A 4650)

"The nursing care of sick children should at all times be under the direct supervision of a Registered Sick Children's Nurse or Registered Nurse (Child Branch)." (A 4560)

"Haematologists are doctors with a special knowledge of the blood." (A 2995)

Particular reference was made, in this context, to knowledgeable and skilled symptom control that aimed to promote comfort and enhance quality of life, especially at the end stages of the illness:

"In some cases where a child becomes terminally ill, they are here to provide a pain free and dignified death for the child and his/her family." (A 4080)

The collaborative cooperation between health care professional was noted:

"The doctors who look after these cancer centres have regular, frequent meetings to make sure that as soon as there is any evidence that one form of treatment is better than another they can consider a change to the new treatment." (A 2749)

This reassurance applied also for the parents of children with the more rare tumours.

"Paediatric Oncology, and especially the treatment of retinoblastoma, is such a small and specialised area, all the doctors involved in it tend to know one another and meet frequently." (A3099)

Provision of continuity of care from hospital to home was mentioned:

"Our Nurses are community based, forming a friendship with the child and family to ensure that all emotional, medical, social and psychological problems are met from diagnosis and throughout the various stages of the disease." (A 5866)
Prominence was given to the role of the social worker who could provide practical help with problems:

“They [social workers] work exclusively with children with cancer and their families and so know very well the sorts of problems that can arise.” (A 104)

Raising awareness among professional workers of the importance of support networks for parents was also noted:

“If no group exists we can advise parents wishing to start one.” (A 1551)

The health care professionals were there to share this knowledge with the family:

“You may like the Doctor to have a chat with your child in your presence, having decided with you first what they will say.” (A 1284)

There were elements of befriending particularly by the health care professionals:

“In particular, your Social Worker can become a friend with whom you can talk things over as well as address practical problems.” (A 1288)

It was recommended that local authorities needed to be aware of the possible implications of the changes.

“Some purchasers were well-informed, very enthusiastic about purchasing the best, not just in terms of value for money, but most of all in terms of the quality the child or adult with something like Cystic Fibrosis deserved.” (A4663)

Discussion

Not surprisingly the category of ‘Professional Issues’ was a much smaller category compared to that of the professional literature. In this data source, the range of professionals that would come into contact with the families was identified and in a way that families could understand the position they occupied in the hospital world.
This included dieticians, haematologists, physicians, pathologists, radiotherapists, social workers, specialist paediatric nurses and surgeons. It was recognised that the health care professionals needed the skills, experience and qualifications appropriate to their field of care. Knowledgeable and skilled symptom control provided the means for good practice, in order to achieve and develop a high quality service. Within this context, the role of the regional units was recognised; highlighting the fact that children's cancers are rare and the doctors working in the specialist centres are in contact with other centres both nationally and internationally. However as Eaton (2002) argues, although regional units are well equipped there is a disparity within the community sector.

Health care professionals employed by the charities were responsive and sensitive to needs, and offered a range of support, advice and help as needed. A considerable degree of flexibility was encountered in the way in which the health care professionals offered support, particularly in the provision of continuity of care from the hospital to the home, and throughout all stages of the illness. Prominence was given to the role of the social worker who could provide practical help with the problems. Raising awareness among professional workers of the importance of support networks for parents was noted.

There was a sense in which the families were encouraged to expect an element of working together with the professionals. It was noted that every member of the team had their own area of experience and expertise, and that they were there to share this knowledge with the family in order to help them in anyway they could. There was also a recognition that local government reorganisation brought with it new authorities, new names, and frequently, changes to previous existing local authority boundaries and could have implications for the provision of services.

Summary

The degree of knowledge and skills of the professionals, with respect to competent and available practitioners were highlighted.
Families were given an understanding that the professionals would be providing individualised care and that the professionals would be available as needed to listen to family members and their worries. Therefore the expectations families might have had in terms of professionals in direct contact with them were met. The input into care highlighted the ability to provide services that were individualised, responsive and sensitive to needs, with systematic continuity in care. Furthermore the professional support, help and advice, empowered families through encouragement of self-advocacy fostered in support groups.

Research

Table 5.11. Distribution of subcategories

<table>
<thead>
<tr>
<th>Subcategory</th>
<th>No. of statements</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific studies</td>
<td>37</td>
<td>46</td>
</tr>
<tr>
<td>Research in action</td>
<td>30</td>
<td>37</td>
</tr>
<tr>
<td>Available funds</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Clinical trials</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>81</td>
<td>100</td>
</tr>
</tbody>
</table>

In table 5.11, it was seen in the largest subcategory, labelled ‘Specific studies’ for example those especially commissioned contained 46% of the statements and the subcategory labelled ‘Clinical trials’ (7%) was the smallest subcategory. Fourteen of the 28 (50%) responding charities contributed to this category.

Specific projects such as the study commissioned by the Department of Health (1992) to estimate incidence, needs and provisions were identified:

"The long-awaited results of a two-year study into the needs of children with life-limiting conditions have now been published." (A 4537)

One charity noted that as a result of their studies, particularly in paediatric palliative care, they were called to give evidence to the House of Commons:
"We are extremely pleased that we have been called to give oral evidence to the House of Commons Health Select Committee which is currently enquiring into children's health." (A 4505)

There was particular reference to the ongoing work of the National Registry of Childhood Tumours:

"The majority of these tumours are now registered through the United Kingdom Childhood Cancer Study Group (UKCCSG) Office." (A 5341)

It was acknowledged that there were 24 Working Groups, including discipline groups in radiotherapy, radiology, pathology and surgery, as well as newly created Chemotherapy Standardisation and Supportive Care Groups:

"The Group operates clinical trials in almost all areas of childhood malignancy, except leukaemia, which is covered by the Medical Research Council (M.R.C.)." (A 5371)

The quest for more effective treatments was also seen:

"It is for these patients that scientists working at this Leukaemia Research Laboratory turn their attention by developing new forms of more potent and more effective treatment." (A 6481)

In addition, collaboration with other centres and participation in clinical trials meant this knowledge was disseminated to patients on a large scale:

"They are constantly in touch with one another's work and research." (A 5279)

Not only does the UKCCSG arrange national studies but found it was often necessary to collaborate with international groups in order to find the best way to treat a particularly rare tumour:

"Not only does the Group run national studies, but it is often necessary to collaborate with international groups in order to find the best way to treat a particular rare tumour." (A 5342)
Another area highlighting active research was that of pain control where one leaflet indicated that:

"Another study compared pain treatment for the first three days after heart surgery for 50 adults and 50 children (aged between two days and four years)." (A262)

However, the particular studies were not identified in the leaflets.

Attempts were made to bridge the gap between research and practice through the dissemination of information of innovative work. This was seen in a number of ways:

"To make research findings accessible to managers and practitioners through publications, summaries and other publications and papers." (A 2415)

The benefits of clinical trials were explained to families in the following way:

"As soon as there is any evidence that one form of treatment is any better than any other, then all patients benefit." (A 263)

Three charities indicated their readiness to fund research projects linked to academic establishments. They indicated that they were committed to giving grants, purchasing equipment, and employing a range of expensive, but essential staff for diagnosing and treating cancer:

"This charity’s funds are available to finance local research concerning cancer and leukaemia in children." (A 2555)

Discussion

Attempts were made to bridge the gap between research and practice through the dissemination of information with regard to innovative work. This was seen in a number of ways such as conferences, work-shops and publications. An explanation was given in the leaflets for the term clinical trial; informing parents that it simply meant that the doctors involved in their child’s treatment were trying to measure consistently and reliably, information about the effects and results of treatments.
It was made clear that new clinical trials were constantly striving to improve the treatment regimes by investigating new combinations of the same and new drugs and new schedules. The benefits of clinical trials were explained to families in the following way. Three charities indicated their readiness to fund research projects linked to academic establishments. They indicated that they were committed to giving grants, purchasing equipment and employing a range of expensive but essential staff for diagnosing and treating cancer. Thus they could claim they were in the forefront of research in action. In addition to supporting research, one charity funded education projects aimed at improving the quality of life for very ill children and their families and another provided funding that looked at the feasibility of creating easy access to drop in centres. Both these areas would provide credibility for the supporters and sponsors of these charities.

Summary

Specific projects to estimate incidence, needs and provisions were identified. An important facet in the combating against childhood cancers was the role played by the United Kingdom Childhood Cancer Study Group and its multidisciplinary input. Such dissemination of knowledge by UKCCSG was of particular benefit for children treated in the regional centres (using UKCCSG protocols). Attempts were made to bridge the gap between research and practice through the dissemination of information of innovative work.

Usefulness of analysing the charities' leaflets

An examination of the charity leaflets found that they fulfilled three important functions. First, families received an understanding of some of the potential effects they could expect from the physical and psychological impact of the illness. This was undertaken with a balance between sensitivity and pragmatics, providing the material needed to manage the ensuing years. They also provided a record of information that could be referred to at any time. Second was the detailed offer of help and support the various charities were able to provide.
This included practical every-day help, the input from skilled professionals and the emotional support in the form of advice and empathy. The charities were frequently in a position to provide those services not met by statutory provisions. This provided for the third important function, that was, to say to families ‘you are not alone; others have been in this place before you and have coped, so will you’ for help was at hand. This was particularly noticeable in the leaflets that often adopted a ‘frequently asked questions’ format.

The leaflets sent by the various charities provided material for a snap shot at that time. Some were of the more ‘technical’ variety, and clearly intended for newly diagnosed families. It appeared as if several were from a common source and had similar formats. That is, there appeared to be an assumption that families had no knowledge of childhood cancer. There were descriptions about malignant changes, the way different cells in the body developed their specific type of cancer and outlined a range of treatment modalities. Included in these were glossaries and contact points for other organisations. The information was directed at parents, the child and occasionally teachers. Others were more in the style of glossy magazines or tabloid newspapers, and would have been provided for newly diagnosed families. If families expressed an interest in that particular charity, therefore they would have a regular readership of supporters for the particular charity. It is thought that this would have had a beneficial effect for the newly diagnosed family, when reading about adjustment for returning to school and talking about long term projections. However, some of those leaflets also provided obituaries. Clearly for the bereaved parents who were supporters of the charities, it was recognition of their child’s life. Conversely however, for parents struggling to hope that their child will survive, obituaries would be a regular reminder that children can and do predecease their parents.

The leaflets presented a balance seen for example in the glossaries, which provided the vocabulary needed to cope with the initial stages of the illness, and the activities highlighted in the leaflets provided a reminder that it was possible to do normal activities such as holidays and ‘fun days’ at a later stage in the illness. It was clear that an attempt had been made to reconcile the different perspectives of the health care professionals as well as those of the families.
In Chapter Three (page 58) the usefulness of the charities leaflets as a data source was questioned. The results have clearly shown that the charities provided at the very least complementary services to those provided by professionals within the NHS as well as those services not currently provided by the professionals. An example of a complementing service provided by the charities is the provision of funding for family holidays as opposed to state benefits to sustain daily living. An example, of a service provided by a charity which is not currently provided by the professionals would include an informal ‘family-to-family support network.

**Subcategories emergence and analysis**

The possibility of adopting a unified six category coding framework developed in the professional literature and subsequently implemented for the charity leaflets was demonstrated in (Chapter Three see page 54). This provided the basis for a comparison to be made between the results obtained from the two sources of data. However, differences were observed in terms of the distribution of statements within the categories and are shown in table 5.12. For example, the professional literature category ‘Professional Issues’ (35%) was greater than that of the charities leaflets (7%). Conversely, the percentage of statements from the charities leaflets in the category ‘Communication and Cooperation’ (41%) was greater than that of the professional literature. This is referred to later when both data sources are compared (page 173).
Table 5.12. Comparison of the six categories in the two data sources

<table>
<thead>
<tr>
<th>Category</th>
<th>Professional Literature</th>
<th>Charity Leaflets</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>Ranked order</td>
</tr>
<tr>
<td>Communication and Co-operation</td>
<td>15</td>
<td>3</td>
</tr>
<tr>
<td>Maintain Normality</td>
<td>21</td>
<td>2</td>
</tr>
<tr>
<td>Professional Issues</td>
<td>35</td>
<td>1</td>
</tr>
<tr>
<td>Research</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Resources</td>
<td>15</td>
<td>4</td>
</tr>
<tr>
<td>Treatment Issues</td>
<td>12</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>100</td>
<td>-</td>
</tr>
</tbody>
</table>

It is arguable that if the six category coding framework had been successful in accounting for all the statements, in the two data sources there would have been no need to have used subcategories as was the case. However, whilst there were similarities in the statements for both data sources, there were also variations (table 5.12). Indeed the analysis of the results would have been incomplete and important variations between the data sources would have been overlooked. In the next section, a comparison is made between subcategories from both data sources of the professional literature and the charity leaflets. This comparison will be undertaken for each category where it will be seen that some categories:

- Contained the same topics and were given the same title for example, 'Education';
- Were given the similar titles and contained similar topics 'Interactions' and 'Working with others';
- Were 'source specific' appearing in one data source but not in another for example 'Glossaries'.
Communication and Cooperation

Table 5.13. Comparison of subcategories

<table>
<thead>
<tr>
<th>Professional literature</th>
<th>%</th>
<th>Charity leaflets</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interactions</td>
<td>46</td>
<td>Information about the disease</td>
<td>34</td>
</tr>
<tr>
<td>Partnership</td>
<td>19</td>
<td>Glossaries</td>
<td>15</td>
</tr>
<tr>
<td>Information</td>
<td>13</td>
<td>Empathy: diagnosis</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Communication with others</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Eligibility &amp; contact points</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Empathy: bereavement</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Working with others</td>
<td>2</td>
</tr>
<tr>
<td>Education (professionals)</td>
<td>12</td>
<td>Education (Charities)</td>
<td>11</td>
</tr>
<tr>
<td>Counselling</td>
<td>10</td>
<td>Befriending &amp; counselling</td>
<td>1</td>
</tr>
</tbody>
</table>

It is not surprising that in a category called, 'Communication and Cooperation' there was a subcategory of 'Interactions' (table 5.13) and that this was the largest subcategory (46%). Furthermore, it is worthy of note that the charities provided a considerable amount of information about the disease (34%).

Both the professionals and the charity leaflets highlighted counselling. However, it is interesting to note that the charity leaflets referred to both counselling and befriending. This is reflecting differences in perspectives of the charities and the professionals in the way they view their preferences. The term 'counselling' is used rather freely and it is important to understand that the purpose of counselling is to bring about a change in behaviour/attitude that is perceived as detrimental to the person seeking counselling. It is also a skilled discipline that requires regular contact. Therefore, it is quite likely that the professionals would be aware of the need for counselling in order that a family adapt to cope with childhood cancer. Conversely, the charity leaflets conveyed their messages to their readership entirely through the medium of the printed word and it is unlikely that they will never know the recipient of their leaflets as individual people. Consequently, any form of counselling requiring careful management would be totally inappropriate. However, befriending or supporting with kindness would be more appropriate and could be achieved through the medium of the charity leaflets. Indeed it was advised that counselling from the appropriate person may be necessary for some families.
It is worthy of note that these subcategories of both data sources highlighted the need for psychosocial support and that befriending and counselling are not mutually exclusive. However, they require different approaches and the way in which these were addressed within the two data sources was entirely appropriate.

The subcategories identified as 'Interactions', and 'Partnership' in the professional literature as well as 'Communication with Others', 'Working with Others' in the charities leaflets contained similar material in their being labelled within the 'Communication and Cooperation' category. For example, it was noted that the content of the data for the subcategory 'Communication with Others' contained statements of a similar nature to that of the subcategory 'Interactions'. However, professional literature was reporting on publications in which there had been a face-to-face contact, hence the label 'Interactions' whereas the communication for the charity leaflets was through the printed medium and the label 'Interactions' was not entirely appropriate, hence 'Communication with Others' was a more suitable subcategory.

Some categories were 'source specific', that is, they were appropriate for one source but not the other. For example, it would not have been appropriate to convey the amount of information about the disease to fellow professionals in published studies. The place for that was in specialised textbooks. However, it was entirely appropriate for the charity leaflets to convey the type and volume of information to families in the charity leaflets the subcategory 'Information disease' (34%). Similarly, the subcategories 'Eligibility and Contact Points', 'Empathy : Diagnosis' and 'Empathy : Bereavement' were 'source specific' to the charity leaflets.

'Partnership' was an interesting subcategory located on the professional literature. The fact that this subcategory was not found in the charity leaflets is interesting and worthy of further investigation. Almost equal weighting was given to the subcategory 'Education' by both sources. Whereas the charity leaflets (11%) referred to the education of the child and other professionals, the professional literature (12%) placed an emphasis on education to enable adaption and coping.
A range of communication and cooperation issues were noted in the subcategories with the subcategory 'Interactions' containing the most number of statements for the professionals and the combined subcategories of 'Information about the disease' and Glossaries' provided almost half (49%) the total number of statements for charity leaflets.

Maintaining Normality

Table 5.14. Comparison of subcategories

<table>
<thead>
<tr>
<th>Professional literature</th>
<th>%</th>
<th>Charity leaflets</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supportive interventions</td>
<td>43</td>
<td>Interventions</td>
<td>8</td>
</tr>
<tr>
<td>Adaption and coping</td>
<td>25</td>
<td>Adaption to family culture</td>
<td>19</td>
</tr>
<tr>
<td>Focus on the family</td>
<td>15</td>
<td>Focus on family members</td>
<td>49</td>
</tr>
<tr>
<td>Cultural Issues</td>
<td>12</td>
<td>School</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Body image</td>
<td>4</td>
</tr>
</tbody>
</table>

There were many similarities in the subcategories identified in table 5.14, for example 'Focus on the family', 'Focus on family members' and 'Cultural Issues' and 'Adaption to family culture'. However, it was important to retain the distinctiveness of the approaches from both data sources. Such distinctions meant that from the professional perspective, the approach was more clinical, that cultural systems were respected, and theories of family systems could be applied to maintaining normality, whereas a very different informal approach had been adopted. Had the finer analysis not taken place these distinctions in the understanding of differences in approach would have been lost.
Professional Issues

Table 5.15. Comparison of subcategories

<table>
<thead>
<tr>
<th>Professional literature</th>
<th>%</th>
<th>Charity leaflets</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional input</td>
<td>44</td>
<td>Professional input</td>
<td>34</td>
</tr>
<tr>
<td>Knowledge and skills</td>
<td>23</td>
<td>Knowledge and skills</td>
<td>43</td>
</tr>
<tr>
<td>Interdisciplinary working</td>
<td>17</td>
<td>Interdisciplinary working</td>
<td>20</td>
</tr>
<tr>
<td>Purchaser/provider issues</td>
<td>16</td>
<td>Purchaser/provider issues</td>
<td>3</td>
</tr>
</tbody>
</table>

Interestingly, professional issues was the only category in which all the subcategories received the same titles (table 5.15). It is not surprising that the subcategory ‘Professional input’ should be the largest subcategory in the professional literature for it was an opportunity for the professionals to talk to other professionals. This was a forum in which theories could be voiced, researched and applied to professional practice. In contrast, the charity leaflets focused on the nature of the role of the professionals and their input into practice. Again there was a difference in perspectives, the clinical as opposed to a more ‘user friendly’ informal approach.

Research

Table 5.16. Comparison of subcategories

<table>
<thead>
<tr>
<th>Professional literature</th>
<th>%</th>
<th>Charity leaflets</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific studies</td>
<td>56</td>
<td>Specific studies</td>
<td>46</td>
</tr>
<tr>
<td>Consumer issues</td>
<td>22</td>
<td>Research in action</td>
<td>37</td>
</tr>
<tr>
<td>Purchaser/provider issues</td>
<td>22</td>
<td>Available funds</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Clinical trials</td>
<td>7</td>
</tr>
</tbody>
</table>

This was the smallest of the six categories for both professional literature and charity leaflets with ‘Specific studies’ as the largest subcategory for both. Consideration was given to the need for a ‘Research’ category given that the professional literature is based on previous research was the result of previous, however, as can be seen from table (5.16). This was necessary as indicated by the subcategories.
With only one common subcategory for both data sources, other subcategories in the professional literature dealt with researching the opinions of the users of the NHS labelled as 'Consumer issues'.

For the charity leaflets, 'Research in action' was the second largest subcategory in which the charity leaflets identified active research, an important feature to be included in their publications that would help to reassure their ongoing research work and assist fundraising for further research.

Resources

**Table 5.17. Comparison of subcategories**

<table>
<thead>
<tr>
<th>Professional literature</th>
<th>%</th>
<th>Charity leaflets</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supportive interventions</td>
<td>43</td>
<td>Individualised attention</td>
<td>25</td>
</tr>
<tr>
<td>Family centred facilities</td>
<td>24</td>
<td>Environment of care</td>
<td>22</td>
</tr>
<tr>
<td>People as resources</td>
<td>22</td>
<td>Responsiveness to needs</td>
<td>10</td>
</tr>
<tr>
<td>Purchaser/provided issues</td>
<td>11</td>
<td>Competency of staff</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Flexibility in provision of resources</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Technical equipment</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Continuity of care</td>
<td>2</td>
</tr>
</tbody>
</table>

The main feature to be noted in this table (5.17) is the range of subcategories provided by the charity leaflets. Again there is a similarity within the content of the subcategories for example, the use of support groups. This was seen in the subcategories ‘Supportive interventions’ in the professional literature and ‘Individualised attention’ in the charity leaflets. ‘Supportive interventions’ was more large-scale and abstract with provision of statements to encourage contact with support groups. By contrast, ‘Individualised attention’ in the charity leaflets was of a more personalised informal approach.
Treatment Issues

Table 5.18. Comparison of subcategories

<table>
<thead>
<tr>
<th>Professional literature</th>
<th>%</th>
<th>Charity leaflets</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain and symptom control</td>
<td>43</td>
<td>Controlling symptoms</td>
<td>21</td>
</tr>
<tr>
<td>Side effects of treatment</td>
<td>11</td>
<td>Side effects of treatment</td>
<td>23</td>
</tr>
<tr>
<td>Survivor issues</td>
<td>11</td>
<td>Investigations</td>
<td>11</td>
</tr>
<tr>
<td>Psychosocial aspects of treatment</td>
<td>35</td>
<td>Clinical trials explained</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Treatment modality</td>
<td>42</td>
</tr>
</tbody>
</table>

Both pain and symptom control and side effects of treatment were noted in the two data sources and this was to be expected (table 6.7). The professional literature is an appropriate forum for research findings to be presented. It is of no surprise to find this is a major area of discussion in the charity leaflets given that treatment issues are a major concern for the families. Particularly the side effects and symptoms experienced. The difference in approach was identified with the clinical emphasis from the professionals and an interesting question and answer format used by the charity leaflets. Survivor issues were not dealt within the charity leaflets but comments made by children and their families were captured within the charities’ fund-raising and social activities statements located within the 'Internal working of the charities.'

Considerable attention was paid to the psychosocial aspects of treatment (35%) in the professional literature but not in the leaflets. This did not mean that this area had not been dealt with by the charity leaflets but rather the focus of attention on the statements was on maintaining normality in the light of the psychosocial aspects of treatment and were consequently categorised as ‘Maintaining Normality’. The input from the charity leaflets namely, ‘Investigations’, ‘Treatment modality’, ‘Clinical trials’ provided statements that were useful adjunct to professional input at the time of diagnosis and beginning of treatment.
Conclusion

A comparison of the two sources of data showed that although a cursory inspection might indicate that subcategories were unnecessary, an in-depth comparison of the sources provided a justification for forming subcategories as different headings.

Clearly, there were considerably more statements contributing to the data collection in the charities leaflets than the professional literature as well as a broader range of subcategories. It was appropriate, for example, that the charities leaflets contained glossaries where as this was not appropriate for the professional literature. However there were sufficient similarities in the content of both data sources to justify applying the same coding framework and allowing for a consistency of content analysis. In essence, there were common core areas between the two data sources but highlighting different perspectives.

In the next chapter the methodological approach of the Delphi study, the third data source is presented.
CHAPTER SIX
METHODOLOGY 2: THE DELPHI STUDY

The Delphi approach is an integral part of this study as individuals are given an opportunity to state which elements of care they consider important in a service for children with cancer, and later to rate the importance of each element. The rationale for this part of the study therefore were as follows:

- The literature was a static entity. The Delphi study, because of its iterative nature, was dynamic and the interaction that this engendered provided the opportunity to capture insights that may have not been offered in the literature;
- The literature is inevitably dated (it has to have a cut-off point) and the Delphi study afforded the opportunity to gain more up to date ideas;
- The Delphi element completed the triangulation that characterises this study.

Characteristics of a Delphi study

The term ‘Delphi’ originates from the oracle at Delphi where the ancient Greeks were said to be able to predict the future. A Delphi study is an efficient and effective way of combining the expertise of a group of people to obtain information for planning and predicting purposes (Parahoo 1997; Polit & Hungler 1999). It differs from other surveys and questionnaires as it involves asking a panel of experts to generate, rate and prioritise elements of care. These elements of care focus on the experts’ opinions, predictions, and judgements concerning a specific topic of interest. The Delphi approach has been used to enable long-term forecasting needs (Williams & Webb 1994; Polit & Hungler 1997) and the results from a Delphi study are useful for producing sufficient information for policy suggestions (Jillson 1974). As a research tool, its early use was documented by the Rand Corporation in which expert opinion was sought about the outcome of nuclear attack on North American cities. The Delphi approach has been used on many occasions, particularly in health care (Hinds et al. 1990; Moseley & Mead 1993; Procter & Hunt 1994; Schmidt et al. 1997; Murphy et al. 1998). It therefore represents an important methodological approach for problem solving, planning, and forecasting.
Another important feature of the Delphi approach is the anonymity of the panel members. The panel members never meet (as part of the study) and no one panel member is told about the identity of others. The process is usually carried out by correspondence. The essence of the Delphi approach is that there should be no discussion or collusion between experts. This approach helps to overcome the social-psychological problems inherent when groups meet. Such psychological problems may limit the range of options that may be generated in the first place, and also the frankness with which panel members may demonstrate in their judgements of those options. This can result in much less comprehensive coverage of the issues and the risk that the opinions of some individuals are submerged early on. These are the common problems of committee dynamics that Mead & Moseley (2001a) have described as follows (table 6.1).

Table 6.1 Problems Associated with Committee Dynamics

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Many committee members are unwilling to take a position on an</td>
</tr>
<tr>
<td></td>
<td>issue before all the facts are known.</td>
</tr>
<tr>
<td>B</td>
<td>The domineering personality or the outspoken individual takes</td>
</tr>
<tr>
<td></td>
<td>over the committee process.</td>
</tr>
<tr>
<td>C</td>
<td>It is difficult for committee members to publicly contradict</td>
</tr>
<tr>
<td></td>
<td>colleagues in higher positions.</td>
</tr>
<tr>
<td>D</td>
<td>Many committee members are unwilling to abandon a position</td>
</tr>
<tr>
<td></td>
<td>once it is publicly taken.</td>
</tr>
<tr>
<td>E</td>
<td>Committee members are inhibited from presenting their ideas</td>
</tr>
<tr>
<td></td>
<td>publicly when they are uncertain whether the idea might be</td>
</tr>
<tr>
<td></td>
<td>regarded as idiotic and result in loss of face.</td>
</tr>
</tbody>
</table>

Mead & Moseley (2001a)

A view has been expressed that anonymity can lead to irresponsible decisions being made. However, Goodman (1987) dismissed these concerns and argued that expert panels are recruited for their knowledge, expertise and willingness to participate in the study. Mead & Moseley (2001a) maintain that biases occurring in the face-to-face encounter are likely to move panel members away from their own view towards the view of the articulate, domineering members, thus giving a false illusion of consensus. This can occur even when there is skilled and sensitive facilitation of the group.
By contrast, the Delphi approach offers a way of handling the opinions of individual experts in a way which is collaborative rather than combative and which aims to arrive at consensus without eliminating minority views at an early stage.

A Delphi study can be conducted in a traditional consensus generating approach or it can be subjected to modifications. Traditionally, the Delphi approach entails gathering information, opinion, and ideas from a panel of experts. It entails using a specific sequence (table 6.2).

Table 6.2. Sequence of a traditional Delphi approach

<table>
<thead>
<tr>
<th>Stage</th>
<th>Conducted by</th>
<th>Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Select expert panel</td>
<td>Researcher</td>
<td>Initial</td>
</tr>
<tr>
<td>Formulate Question(s)</td>
<td>Researcher</td>
<td>Initial</td>
</tr>
<tr>
<td>Statement generation</td>
<td>Panel</td>
<td>Round 1</td>
</tr>
<tr>
<td>Reduction &amp; Categorisation</td>
<td>Researcher</td>
<td>Intermediate</td>
</tr>
<tr>
<td>Statement Rating</td>
<td>Panel</td>
<td>Round 2</td>
</tr>
<tr>
<td>Analysis of consensus</td>
<td>Researcher</td>
<td>Final</td>
</tr>
<tr>
<td>Iteration</td>
<td>-</td>
<td>Round 3</td>
</tr>
</tbody>
</table>

Round One serves to generate statements;
Round Two involves rating those statements generated by the panel members (experts in the Delphi sense of the word);
Round Three (and any subsequent rounds) is devised to move the panel towards a greater level of consensus with panel members usually being invited to revise their views in light of other panel members' opinions.

**A modified Delphi approach**

As a method for structuring a group communication there could be many ways in which it can be adapted according to the needs of any one study (Linstone & Turoff 1975). In a modified approach there are opportunities to follow basic ground rules yet allow for variety and originality in order to meet the needs of the topic under investigation. This was seen, for example, in a study by Hitch and Murgatroyd (1983) in which the experts were gathered together, but without compromising anonymity.
Their study, conducted at a conference, showed that it was possible to provide instant feedback in a Delphi study. Similarly, in a study to define the place of graduates in nursing, it proved possible to gather the experts together whilst preventing the adverse social dynamics described above (Mead 1993). Similarly, different forms of rating can be used, and different questions posed in different rounds.

Although generating consensus has been discussed in the literature, it appears that more recently, Delphi studies have been used for identifying consensus (Butterworth 1991). That is, no attempt is made to move the opinion of panel members towards a group consensus. It is a method that can be equally used for identifying consensus if it exists while not influencing it. In such cases, the traditional Round Three is not used to inform members of a tentative group consensus (or even the views of other panel members, consensual or not). Thus, rather than generating consensus, the objective is to identify one which may already exist.

The study is concerned with the latter type. No attempts have been made to enforce a consensus. Rather, it was left for consensus to take its natural role. Round Three was not designed to revise opinions based on feedback from the results of Round Two. Instead, different tasks were offered in Round Two and Round Three. These tasks were set in such a way as to focus the attention on different dimensions of the problem and these are discussed later on (page 198 and 204).

The Expert Panel

The first step in a Delphi process is to define and access the expert panel. The composition of the expert panel is crucial to the outcome of the whole undertaking. Experts may be defined in a number of ways. They may be a group defined by their position or status such as executive nurses, or because they share a similar experience e.g. researchers in a particular field, or patients who have undergone a particular type of treatment. They may be publicly acknowledged experts, as in people who have published or lectured widely on a topic, or they may be experts in the eyes of some group of people under study.
The groups described above would be homogenous in that they all share a similar expertise or experience. This may not be appropriate because too homogenous or likeminded a panel, could produce a skewed data set. There may be a case for having a panel of experts with varying experiences of the topic under study e.g. managers, educators, clinicians and researchers. In this study the panel was heterogeneous.

In this study, it was intended that the panel should include not only a range of professionals from different disciplines and locations, but family members too. The rationale for this decision was based on an assumption that it would be exceptional for a professional panel member to have personal experience of childhood cancer (other than what can be afforded through work). Therefore, professional panel members might not give the same weight to elements of care as would the families. In addition, by including several families, by virtue of the different diagnosis and outcome of the disease, a wide range of experiences would be brought to bear. Family members have only their own lived experiences to refer to. Important though this may be, it would mean that family panel members would be unlikely to give weight to elements of care from the broader perspective.

The combination of professional and family panel members views meant that, collectively, they were able to bring to the study a breadth of experience as well as intensely individual experience. Such an approach would enable a broad spectrum of statements and a diversity of opinions to be presented. Other advantages of having two distinct groups to make up the panel included:

- Any consensus on the topics suggested for policies would be from both family and professionals perspectives;
- The composition of the panel provided an opportunity to compare and contrast the opinions of the two groups.

The most important consideration when selecting a panel is that the criteria for inclusion should be clearly set in advance (page 184). As the criteria have set out in advance and provided details of those criteria, then the audit trail is complete. Having set and followed the inclusion criteria for the sample, it is important to note possible sources of bias.
For example as with any study a low response rate would be a source of bias. This is because the researcher may have no means of knowing whether the sample composition remains the same or that bias has occurred because one group is disproportionately represented or even missing altogether. In this study there was little attrition of panel members. Where this did occur an attempt has been made to assess the potential effect of the particular panel member's disappearance on the representativeness (in terms of the criteria for the panel not in any other conventional sense), of the sample. For such an analysis see page 216.

The literature states the arguments for and against the selection of a representative sample. Often it is difficult for researchers to draw a representative sample because they do not know anything about the total population of experts. The expert panel is more like a purposive sample where people are included because they meet certain pre-defined criteria (Polit & Hungler 1999).

Selecting experts instead of a random sample, on the premise that they will yield significantly better and substantially different responses than those from non-experts, means there is a responsibility to justify the selection procedures used Goodman (1987).

The next stage is to seek people who meet those criteria. There is no requirement to be exhaustive. In other words, it is not necessary to include everyone who meets the criteria but there is an obligation to go beyond those people who are known to the researcher (Mead & Moseley 2001a).

In Mead's (1993) study of primary nursing, each expert had to meet one of the following criteria:

- To have published papers about primary nursing;
- To have conducted research into primary nursing;
- To have presented a paper on primary nursing at a conference;
- To be regarded by peers as an expert in primary nursing (for example other nurses visit the ward or unit in which this person works in order to observe primary nursing taking place. Alternatively, the individual may have been given an award for their work in relation to primary nursing).
Sometimes exclusion criteria are also important. For example, in Mead’s (1993) survey of primary nursing, the study was based in Wales. Therefore, individuals who met the above criteria but who also worked in the Principality were excluded from the pilot study because they might well be included in the actual data collection in the main study.

Other forms of selection are possible. Bond & Bond (1982) selected a panel of nurses broadly representative of geographical area, grade, and clinical speciality.

In this way, they recruited respondents from all grades of qualified nurses from staff nurses to the chief nurse in a region. Butterworth (1991) started with nurses who were known to him personally or ‘well known’ in the popular sense of the word and then used a snowball technique asking each of them to identify three ‘important’ nurses in their country. In this way, he was able to make up quite a large panel of experts.

Family Panel Members

The inclusion criteria for family panel members were threefold:

- The parents were known to the particular charitable organisation identified as ‘Charity A’;
- The parents had a child who was diagnosed with a childhood cancer before the age of 18;
- The child was about to begin treatment, was still in treatment, or had completed treatment within the last three years.

Professional panel members

All professional panel members were selected based on the following criteria:

- They were in the paid employment of a voluntary or statutory agency;
- They had previously or were currently involved in the provision of care for children and their families in which the child has cancer.

To be invited as panel members, a potential respondent had to exhibit both characteristics. It is important when selecting a panel to ensure that potential panel members know what is expected of them.
A Delphi study involves several questionnaires and a commitment which is greater than that found in most surveys. The study can be compromised if panel members drop out before all rounds are completed.

The formulation of the question or questions to be posed in Round One is important. The questions need to be unambiguous. The reasons for this are twofold.

First, the researcher obtains data which will answer the study question. It is interesting that one of the features of the oracle at Delphi was that if the question was asked in such a way that a misleading answer could be given, an ambiguous answer was in fact given. As a consequence of Oedipus's unclear question to the oracle, this resulted in him marrying his mother and killing his father! Second, as the researcher does not at any time see the respondents face to face, there is no opportunity to explain what is really meant by the questions. The question should, therefore, be piloted on a small group, who in some way resemble the participants in the main study. This is to reassure the researcher that the data obtained will provide the data required.

The initial question was piloted with five people who resembled the expert panel members required for the main study. That is the pilot study panel members had experience of childhood cancer or life threatening illness (Appendix 10). In view of the chronic nature of some childhood cancers the use of a panel with experience of life threatening illness in the pilot study was considered to be acceptable for this stage. Each participant received a pack by post outlining the study, a consent form and a questionnaire. The demographic details of the participant in the pilot study are indicated in Appendix 10.

Participants were asked to identify five elements of care as follows;

"What are the essential elements of care for families in which a child has cancer?" (Appendix 11)
The questionnaires were returned in the stamped addressed envelope provided within two weeks of the initial postal date. All five participants replied within the required time scale and the piloted questionnaire yielded 20 statements.

Statements that identified elements of care for families in which a child has cancer clearly indicated that there was a need for practical help in the home, counselling facilities, family-centred care, financial help and continuity of care (See table 6.3).

Table 6.3. Pilot study 1: Emergent statements from piloted question

<table>
<thead>
<tr>
<th>No. of statements</th>
<th>Nature of statements</th>
<th>Statements made by family or professional</th>
<th>Example of pilot study statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Need for practical help at home</td>
<td>Both</td>
<td>&quot;That there is active support in the house, such as nursing care.&quot;</td>
</tr>
<tr>
<td>4</td>
<td>Counselling needs</td>
<td>Both</td>
<td>&quot;Counselling support so that parents and siblings can express their feelings.&quot;</td>
</tr>
<tr>
<td>4</td>
<td>Family centred care</td>
<td>Both</td>
<td>&quot;To see the child within the context of the family situation.&quot;</td>
</tr>
<tr>
<td>3</td>
<td>Need for information</td>
<td>Both</td>
<td>&quot;Good information about the disease and its treatment.&quot;</td>
</tr>
<tr>
<td>2</td>
<td>Financial help</td>
<td>Both</td>
<td>&quot;Financial help for all the extras needed when caring for a sick child.&quot;</td>
</tr>
<tr>
<td>2</td>
<td>Continuity of care</td>
<td>Both</td>
<td>&quot;Good communication to ensure smooth changes from hospital to home and home to hospital.&quot;</td>
</tr>
</tbody>
</table>

It was concluded that:
- Elements of care had been identified. The statements were relevant to the area of research and dealt with services for families in which a child has cancer. In that sense there aspects of both face and content validity were demonstrated.
- The initial question would be appropriate for the main study;
- The information about the study and instructions were appropriate.
The aims of conducting a pilot study were therefore achieved and further amendments were not required. In any event the Delphi method is such that if any of the statements were seen as inappropriate or irrelevant, then such statements would not survive in subsequent rounds. A measure of validity is obtained by the decisions that the panel makes about the ideas contained in the statements.

There was an example of this in the main study. Some family members provided statements that were essentially cathartic and provided an opportunity for frustrations to be expressed. These statements were either removed (see Chapter Seven) or reworded to become an element of care.

There is no magical number but it may be useful to give some minima and maxima. The researcher chose to set a maximum. The reasons for limiting the number of statements to five were as follows:

In limiting the amount of information allowed, respondents are channelled into focusing their responses on the issues that are really important to them:

- In allowing five statements each, a large data set might result;
- If a limit, even of five suggestions, had not been set, the resulting data set might well have been even larger;
- In addition, each of the statements has to be fed back to the panel in round two for rating. If the task becomes too onerous (because of an unmanageable number of suggestions) there would be a strong likelihood of attrition.

Practical issues associated with setting up the panel

Ethical approval was obtained from the relevant ethics committee. It was emphasized to the ethics committee that the care and welfare of professional and family members had been prioritised.

It was also shown that this study was based on principles that honoured beneficence, non-malevolence, and respected autonomy and confidentiality. This was demonstrated by the following:

- The provision for anonymity for all panel members;
• Informed written consent would be obtained from panel members who agreed to ‘opt’ into the study;
• Panel members would be free to withdraw at any time giving a reason;
• It was made clear that if any family withdrew from the study, that this would in no way affect the care that they were receiving as no one would be informed of their withdrawal;
• A database administrator would allocate the identifying codes from a list of panel members’ names. The database administrator would be responsible for addressing the free-post envelopes and attaching the relevant code. The database administrator only would retain the address list and code. Thus, the researcher who read the responses would be unaware of who had made those responses;
• The provision of a safe environment in which family panel members could express their views. This would be achieved by the author delivering the documentation to the home (or place of choice) of family panel members. The research for this study focused on sensitive areas in the lives of families and it was necessary to be aware of this. Serious consideration was given to the possibility that within this client group, families could experience distress when completing the Delphi phase of the study. It was important that family panel members felt they were in a safe environment in expressing their views. The researcher was aware that participant fatigue and/or anxiety was likely for families in which a child has cancer. For these reasons, the documentation for the Delphi phase of the study was delivered to the homes of participating families (or location of their choice). In addition, the researcher had made provision for management of distress if this had proved necessary;
• Panel members would be informed that any policy implications resulting from this study would be fed back to them;
• Panel members were aware of the possibility of professional publication and were further reassured of their anonymity;
• Personal ethical monitoring of the researcher of this study had been arranged. Professional supervision sessions with an independent counsellor were undertaken prior to visiting families. This was to ensure against any transference of the researcher’s feelings to families.

The rating

One possible route was to follow the conventional consensus generating tradition described at the beginning of this chapter, with at least two rating rounds both of which rated the same items, but with varying degrees of information provided. This approach however would only give a single judgement on the elements of care.

In the current study, it was identified that the degree of benefit that a given policy might produce could be defined in two ways.
It would be possible to judge *how many* families would benefit from the elements of care identified or *how much* they would benefit, but not both. If the topics from this study were to be used as suggestions for policies, it would be important to be able to demonstrate not only the dimension of depth (*how much*) but also the dimension of breadth (*how many*).

In Round Two a decision had to be made. The possibilities were:

- To make a decision to prioritise for breadth and depth simultaneously;
- To make a decision to prioritise for depth;
- To make a decision to prioritise for breadth.

With any study involving ratings, there is a danger of cognitive overload. The well-attested psychological principle usually called Miller’s Magical Number (Miller 1956; Baddiley 1994) comes into play. This principle suggests that humans have difficulty in holding many items in their short-term active memory simultaneously.

The limit is commonly set at $7 \pm 2$. As any comparative ratings involve the holding of items in short term memory, this was a danger posed to panel members. The researcher consciously kept the scale to seven points to avoid this danger for each individual item to be rated.
However, it is not known whether when asked to make judgements on a 7-point scale on 57 items, the respondent treats them as 57 separate judgements (as is usually assumed), or whether they look back at earlier responses to calibrate later ones, thus complicating the problem, so that it becomes one which is beyond Miller's Magical Number.

Given that rating scales are so common in research, including nursing research, one would expect that there would be a direct answer to this question in the literature. This becomes a more important judgement when one tries to rate each item on two dimensions in the same questionnaire. In the current study the two dimensions were breadth and depth, but another one that has been used is whether a policy is desirable and whether it is likely to be implemented.

Unfortunately, it was not possible to locate any study that has compared the use of the two-dimensions-in-one-round approach with an attempt to cover the two dimensions in two different rounds approach which was eventually adopted in this study. There was some difficulty in trying to frame a single question that would cover both aspects of the issue. These considerations of a possible halo effect led this researcher to a major design decision. Given the lack of guidance in the literature, it was necessary to make a judgement. To be sure that the results were less likely to be influenced by Miller's Magical Number, two definitions of benefit were split between two rating rounds (rather than one). However, a decision on how to make the split still needed to be made. Such a split had to keep a balance between breadth and depth that was ethically acceptable.

The rating round

In order to conceptualise the implications of this two-dimensional approach, a simple tabular representation was used. The numbers in the discussion refer to the cells in Table 6.4.
Table 6.4. A schema to enable prioritisation of 'breadth' versus 'depth'

<table>
<thead>
<tr>
<th></th>
<th>Many families</th>
<th>A few families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Great benefit</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Some benefit</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

It would then be possible for policies to be interpreted as follows:

- Cell 1 Great benefit to many families;
- Cell 2 Great benefit but only to a few families;
- Cell 3 Some benefit to many families;
- Cell 4 Some benefit to only a few families.

Clearly, policies in cell 1 could be recommended as meriting high priority, whilst those in cell 4 might well merit low priority (or be disregarded entirely).

Any serious decisions would focus on the relative ordering of cells 2 and 3. If cell 2 is selected as meriting recommendation, the decision is in effect going for quality or depth of benefit, even though only small numbers will benefit. By contrast, if cell 3 is selected, in effect priority is given to breadth of benefit, in that such policies will benefit many people, even if only to a slight extent.

*Breadth first or Depth first: the debate*

It was decided to measure breadth in Round Two and Depth in Round Three. This raises the question, ‘Why was the depth not measured in Round Two?’

It could, after all, be argued that having asked for the elements of care, knowing the degree of depth to which families could benefit would be considerably more helpful when suggesting policies than knowing the breadth. After all, the misery of childhood cancer is clear. This was identified earlier in Chapter One (page 8). It has also been stated that the unvoiced needs of families was the motivation for this study. For those families, although small in number, such policies could be extremely beneficial.
It could also be argued that a caring society would protect the weak and vulnerable even though they were in a minority, no matter what the cost. Ideally, with infinite resources such an approach could be adopted.

However, it could also be argued that families are citizens of a democratic country in which the needs of the majority take priority. This topic is regularly debated in the media. For example, debates take place proposing special schools for academically elite children versus a more comprehensive system in which it suggested that there are equal opportunities for all. It has been acknowledged that childhood cancer is rare. If the policies are so refined that they benefit some or very few people, who is actually going to benefit? It would in effect be a minority of a minority.

Bentham formalised the utilitarian approach in which it is suggested that actions should be judged by their consequences. A benchmark for a right action therefore is one that promoted the greatest happiness for the greatest number of people. Bentham's sixth principle of Morals and Legislation written in 1789 notes,

"An action then may be said to be conformable to the principle of utility, or, for shortness sake, to utility, (meaning with respect to the community at large) when the tendency it has to augment the happiness of the community is greater than any it has to diminish it." (Cited in Clayer, 1977, p 302)

The two dimensions of breadth and depth posed a classical dilemma worthy of a debate considering ethical approaches. However, the situations surrounding this study had to be weighed and a pragmatic judgement was required. A decision had to be made, either for policies in which a small number of people would benefit considerably, or policies that would be of benefit to a greater number of people. On balance, the judgement resulted in the utilitarian principle being adopted.

However, this decision does not preclude the minority from benefiting. Rather, their needs may well be served by other agencies, such as the various charities that have become adept at meeting the highly specialised needs of families. After careful consideration, it was decided that Round Two should aim to find a measure of breadth (that is, how many families would benefit). This meant that Round Three could then aim to find a measure of consensus on depth (that is, how much would families benefit from a particular element of care).
In practice, this meant that the decision was taken to include in Round Three only those elements of care that fell in cells 1 and 3, and exclude those in cells 2 and 4. Statements were not retained for the next round if they failed to reach sufficient consensus on the breadth dimension.

There were two main motivations behind this decision:

- Ethical – as can be seen above, this researcher was persuaded by Bentham’s principles;
- Practical – the rating in Round Two was to be made using simple Likert-type scales, whilst the ratings in Round Three would use a cognitively more complex scaling method. In using Round Two to reduce the statements to be rated to a small number, the complex method would be used on only a small number of statements.

For the rating rounds, the method adopted is seen in table 6.5.

**Table 6.5. Judgments on methods of analysis for Round Two and Three**

<table>
<thead>
<tr>
<th>Round Two</th>
<th>How many families would benefit? (Breadth)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Between rounds</strong></td>
<td>Drop items on which there was not consensus on that breadth dimension.</td>
</tr>
<tr>
<td><strong>Round Three</strong></td>
<td>How much would each family benefit? (Depth)</td>
</tr>
</tbody>
</table>

The wording of the Round Two questionnaire invited panel members to tick the appropriate box beside each statement (See Appendix 15) and the Likert type labels were:

- All families
- Most families
- Many families
- About half of families
- Some families
- Very few families
- No families
In principle, any pattern of responses could be possible. It was necessary to find a way that would permit conclusions to be drawn about whether there was consensus or not on each statement and whether that consensus would result in a policy directive benefiting a large number of families.

If there were a consensus that a given statement would benefit a large number of families, it would be included in the Round Three ratings on how much that benefit might be. However, to prevent frivolous or prejudicial judgements, it was necessary to be clear on exactly how such a judgement would be made. 'Clear' in this context refers to the ability to write rules on how to make the judgement, to follow those rules in this study, and to produce results that other researchers could reproduce.

The reproducibility criterion would have to be strict. This means that other researchers could apply the rules to their own data and, equally important, if they applied the rules to this current data, they would have to come to the same conclusions. This is dealt with in the section in 'Defining consensus' on the next page. The purpose of this exercise is to reduce the number of statements passing into Round Three, but to do so in a defensible, principled and reproducible way. This reduction is important.

After the analysis of the Round One suggestions, there were 57 items identified for submission to the Round Two rating exercise. It was difficult to envisage what health care planners could in practice do with as large a number as 57 items. The procedure of prioritising breadth over depth reduced the number to 15 items, which were rated as being useful to a large number of families. Even this would have been rather unfocused for planning purposes, thus the 15 items were submitted to a form of rating in Round Three. The outcome of Round Three rating reduced the number of items from 15 to nine. A sliding scale was then devised for implementation according to local needs and within local budgets and is discussed more fully in Chapter Seven (page 242).

**Round Two**

As stated earlier (page 196), it was decided that traditional Likert-type scale would be used in Round Two, more specifically a seven-point scale would be used.
This was intended to provide a balance between the fineness of judgement of a 9- or 11-point scale (accompanied with psychological difficulties in rating) and the crudity and other undesirable psychometric properties of a five-point scale. There were several reasons for this. The scale falls within the bounds of the number of items that can be combined and manipulated by the human memory at one time (see Miller’s Magical Number page 186). Often when a five-point scale is used, there is the problem of end aversion, and thus a tendency to rate up the middle (Streiner & Norman 1991). This effectively collapses a five-point scale into a three-point scale. With seven items there is flexibility to observe the way in which groups respond. One could use a grouping for example, 1-2; 3-5; 6-7 or 1-3, 4, 5-7 giving a positive, middle and negative value. If it was needed, a very positive response could also include grouping 1; 2-6; 7. Therefore using a seven-point scale offered a greater degree of flexibility. This gave the advantage that when one does obtain apparent consensus, it is a true consensus and not an artefact of the method. The fact that the data were numerical and ordinal meant that it was possible to consider different sets of rules for determining if consensus had been obtained.

**Defining consensus**

The first step in deciding on defining the rules for determining consensus was to consider a wide number of hypothetical and actual distributions of responses to ratings on breadth using the Likert-type scale. Shown below are examples to give an insight into the considerations and discussions that occurred. The scenarios are given together with the researcher’s own reactions, and an indication of whether each showed consensus.

Scenario 1

Fifty percent of the panel recommend that of ‘All’ families would benefit, 32% stated that only ‘Few’ families would benefit and the remaining 18% said ‘None’ would benefit. This scenario was fairly positive, but it was decided that it would indicate no consensus.
Even though half the respondents felt that all families would benefit, the high proportion thinking that only a Few or None would do so means that this could not be considered as consensual.

Scenario 2

Sixty-seven percent of the panel think that ‘All, Most or Many’ families would benefit from a topic and of the remaining 33%,'About half” would benefit. In this case, it was acceptable to call it consensus, because there is a fairly strong positive feeling that is not counterbalanced by any negative feelings.

Scenario 3

It could well be the case that 67% of the panel recommend ‘All Most and Many’ families would benefit from a topic but the remaining 33% of panel members could recommend that ‘None’ will benefit. This scenario would indicate a split panel, and clearly it would be wrong to call that consensus, despite the positive views of so many.

These are only three of the many scenarios that were considered when trying to decide on what was meant by consensus. Clearly, formalising this into a repeatable procedure was going to be no easy task but setting out a variety of potential scenarios did clarify the researcher’s thinking.

When undertaking such a task, it is common to look to the literature and the conventional practice in which the top and bottom quartiles of statements are dropped and the median is used (Linstone & Turoff 1975). This approach was considered but not pursued. It has to be acknowledged that such an action would retain the middle ground.

Nevertheless, removing the top and the bottom quartile in this way effectively excluded those people who had clear opinions about a statement. Serious consideration needed to be given to what the panel members were actually saying. A novel approach was therefore devised in order to select the elements of care in Round Two that would go forward into the next round.
Developing rules to establish consensus

From the scenarios it became clear that establishing consensus by one criterion in most cases was likely to be misleading. Therefore, a more complete consideration of consensus was given. In the current study, it was thought that consensus for recommendation of statements needed to be based on several principles. In commonsense language, consensus could be thought to be present if the principles of consensus are applied. However, the question then needed to be posed 'How do such considerations translate into formal repeatable rules?'

Several rules that can be replicated were introduced. It was decided that consensus was present when all the following rules were used. The principles and the translation into rules are seen in table 6.6. A unique method of gauging minimal opposition to the element of care, referred to as positive negative balance, is described in the next section.

Table 6.6. Achieving consensus using replicable rules

| Principle 1 | Many panel members rated an element of care positively. | Rule 1 | 66% or more of panel members said that 'All', 'Most' or 'Many' families would benefit from the policies; that is, they gave ratings at the top three points, although not necessarily at the very top point. |
| Principle 2 | Substantial numbers of panel members gave a very strong positive rating to an element of care. | Rule 2 | 50% or more of panel members said that 'All' families would benefit from the policies; that is the very top point of the scale. |
| Principle 3 | There was little opposition to the element of care. | Rule 3 | The Positive Negative Balance was 3 or more. |
Positive-Negative Balance (PNB)

The Positive-Negative Balance (PNB) was introduced as the third principle. One might have thought that Rule 1 would, on its own, be sufficient to justify a judgement of consensus. However, if 67% of respondents gave a positive rating (or even a very positive rating), one's judgement must still be conditioned by what the remaining 33% thought. If they were rather middling in their judgement, it could still be claimed that consensus had been found. If, by contrast, the remaining 33% were opposed to a given statement, then in effect a split vote (not a consensus) had been reached. Yet the extent of the split had to be considered.

If the split was 67-33, the ratio of positive to negative would be 2:1. It was thought that this was too small to permit a consensual judgement. A decision was made therefore to set the criterion at 3:1 (75-25). This means that any middling votes are effectively discounted. In the current study, this was unimportant, as the focus of attention was trying to find a consensus based on positive ratings. A consensus based on about half the families benefiting would not have been informative.

The PNB was defined as,

\[(\text{All} + \text{Most} + \text{Many}) / (\text{Some} + \text{Few} + \text{None})\]

The benefits of PNB based on the considerations above are that the method:

- Gave useful repeatable rules;
- Avoided problems arising from 'undecided' panel members who elected to take a middle path in the Likert-type scale;
- Took account of panel members with end-point aversion;
- Gave some weight to the views of all panel members.

Clearly, the rules would apply in the light of the panel and statements. If the purpose is not to recommend topics for adoption but for rejection, some of the rules would require modification.
The introduced PNB is thought to be a unique contribution to knowledge in that it avoids researcher biases and had the potential for further applicability in similar area of research.

Round Three

At the end of Round Two, the aim was to obtain a reduced list (shorter than 57 items) of suggestions (elements of care which could be implemented) and for which it could reasonably be claimed that there was a consensus in the panel on how many families would be likely to benefit. Note that this was a combined consensus of all panel members, not of professionals or family members separately. If there had been differences of emphasis of the two groups of panel members, this combination would mean that the chances of obtaining consensus were minimised. Because of this, if consensus was found, it would be more reliable.

The intention of Round Three was to find the depth (that is, how much would families benefit) of consensus amongst panellists and considerations was given to the type of scale that might be used at this stage. Another seven-point Likert-type scale was considered a possibility.

The use of a Likert-type scale is a common technique (Polit & Hungler 1997). It could provide a measurement that showed the degree to which the panel members rated the depth of the topics.

The summation property of a seven-point Likert-type scale also allows distinctions to be made amongst panel members. It has the added advantage of having been used in Round Two, so that the panel members were familiar with it. On this occasion different dimensions, such as ‘a great deal’ through to ‘not a lot’ could be used. That said, the measurement is constrained between the scale points. There is no facility for providing a measurement (either above or below) beyond the limit imposed by the scale. It also has the problem that drawing distinctions between phrases such as ‘a great deal’ and ‘quite a lot’ are difficult for the respondents to undertake and difficult for the researchers to interpret.
A great deal of work is required therefore to develop Likert-type scales properly. Although that work is rarely reported in the literature, it is nonetheless required if one is to have confidence that such scales measure anything.

A useful scaling method described as Q Sort was also considered. It is a method where the participants sort statements into a number of groups, usually between nine to 11, according to bipolar dimensions such as most benefit/least benefit. The method has advantages if studying the different roles, such as friend, parent or manager. It could also be used if asking patients to rate professional input on a continuum from most helpful to least helpful. (Nieswiadomy 1993; Polit & Hungler 1999). Q Sort can be a powerful tool and the versatility of this method was certainly worthy of consideration. It had an added attraction of being different to a pen and paper exercise. However, this method has a number of disadvantages. It can be time-consuming for a large number of people and cannot be administered effectively through the mail.

The total number of panel members for Round Three was 41, and were scattered throughout the U.K., therefore this was a serious disadvantage for using this method for this study. In addition, any sorting method in which one compares all items with all other items places a cognitive burden on the respondent, as in this study, they would have had to make 229 comparisons in Round Two and 57 comparisons in Round Three.

A third technique known as the semantic differential (SD) was considered to gather data about the depth of the likely benefit of the suggestions. This could be achieved using a series of bipolar adjectives such as “important ” through to “unimportant” on a seven-point scale (Nieswiadomy 1993; Polit & Hungler 1999). This method had the advantage of being flexible and easy to construct. However, again there is no facility for providing a measurement (either above or below) beyond the limit imposed by the scale and was therefore inappropriate for this study.

A fourth consideration was the use of a Visual Analogue Scale. It is used in clinical practice to measure subjective experiences such as pain (Ohnhaus and Adler 1975, Gudex et al. 1996, Briggs and Dean 1998).
Its advantages include that it is a quick and easy scale to complete and not demanding of respondents. The convention is that respondents place a mark on a straight line on a continuum from 0 to 100 mm long indicating, in the case of pain, the level of pain experienced. The anchors at each end of the line indicate extremes of the scale representing 'no pain' and the other end representing 'unbearable pain'. It is therefore theoretically possible to record a score between 0 through to 100. This is a reasonable contention, but again fails to take account of the limitations imposed by the researcher, that is 0 -100. Therefore this method was not used in this study.

A fifth method that used rating techniques whilst avoiding a fixed length was by using a scale that offered the aspect of the magnitude of the depth to which statements were deemed beneficial. This method is known as Magnitude Ratio Scaling (and the method finally used in this study). This would reflect the degree of depth with which statements were considered to be of benefit and establish just how important each statement is relative to the others.

The Magnitude Ratio Scale (MRS)

This was a novel approach and to the best of the researcher's knowledge, not previously been used in any research in obtaining family and professionals' views on cancer care. Previous research has dealt with the methodological considerations of using it (Schriesheim et al. 1989, 1996). In addition, Moseley & Mead (1993) documented its use in primary nursing.

Ratio scales are considered to be at the pinnacle of a hierarchy of scales that enables quantitative measurement. With the MRS method, responses are not restricted to checking values on a pre-set scale as for example, the 1-7 points in the Likert-type scale. MRS can be compared to a ruler that can be used in measuring the location of each of the statements. The points on the ruler for each statement are interpreted as scores and calculated using the geometric mean as opposed to the arithmetic mean that is explained in detail later in the discussion. Therefore, by its very nature, an MRS score is the geometric mean.
This allows for an expansion of the potential range on some items, about which panel members feel very strongly, so strongly that it cannot be accommodated in a Likert-type scale (Polit & Hungler 1997). MRS involved the panel members giving a score to every statement and calibrating it by asking them to compare each individually with a fixed point, not with each other.

(This means that they have to make only 56 comparisons for a 57-item data set, or 14 for a 15-item data set). It avoids the cognitive complexity and overload of comparing each item with every other item. This fixed point is referred to as the 'anchor point'. Such a point acts as a reference point against which other statements can be gauged.

Its use permits an unlimited value to be placed on a topic (statement or property). This method has additional properties in that the values are distinctive, and there is an ordering in the magnitude. This means that larger values really do mean more of the topic. In addition, the equal intervals on the scale are the same distance between points on the scale, and MRS also can have an absolute zero property. MRS therefore, provided an opportunity for panel members to focus in some depth on just how much help these statements would be.

Choosing an anchor point

As all other items in the scale are to be compared one by one with the anchor point, it matters therefore what the value of the anchor point is. Ideally, it should be one that is at, or rather below the midpoint of ratings. However, when devising the scale, the answers are not known and therefore it is not possible to say where the midpoint will fall. The classic study into life stressors by Holmes and Rahe (1967) also faced the same problem.

It was thought that most of the respondents in that study would have at least experienced marriage (as a husband, wife, child, grandparent, friend, etc.), and chose that as their anchor point. Following their example, they selected an item thought to be rated positively by some respondents, but which might not be rated at the top of the scale.
Most families will have some experience of communication problems with professionals and would like to see communication improved. All professionals will have experience of training courses, and some will have done so in the context of communication. Therefore, the following statement was chosen as the anchor point:

"Training courses for staff to improve their ability to communicate with patients and relatives."

This was arbitrarily allocated a score of 500, and panel members would be asked to judge the other statements relative to it. For example, Statement 13 read,

"Emergency contact number 24 hours a day, seven days a week."

If a panel member thought that this suggestion about an emergency contact number would be of less benefit to families than the training courses, Statement 13 might be given a score of 300 (or alternatively, 200 or 50 for example).

If a panel member thought that the emergency contact number would provide greater benefit than the anchor point, they should give it a score greater than 500 (for example 700, 1000 or more). If they thought that the emergency contact number was likely to bring more benefit than the anchor point, they were at liberty to give it scores such as 10,400 or even 10-15 million. The intention was to permit people to give full range to their own subjective feelings about the importance of different policy suggestions. This was an uncommon approach and a pilot study was conducted to test the method and clarity of the instructions in preparation for Round Three.

Fourteen members of the academic staff with a range of clinical experience and seven families with experience of childhood cancer or life threatening illness were approached and agreed to participate in a pilot study (See table 6.6). Each participant received a pack outlining the study, a consent form and a questionnaire. Participants were asked follow the instructions (Appendix 19) and complete the questionnaire (Appendix 20). The researcher was available to the pilot study participants to clarify potential difficulties.
No problems were encountered and all participants completed the questionnaires within 20 minutes. The range of scores is given in table 6.7. Similar scores recorded the main study were reflected the scores given by the participants in the pilot study.

Table 6.7.  
**Pilot study 2: participants and scores obtained from piloted MRS instructions**

<table>
<thead>
<tr>
<th>Participants</th>
<th>Range of scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionals $n=14$</td>
<td>500-2000</td>
</tr>
<tr>
<td>Families $N=7$</td>
<td>200-4000</td>
</tr>
</tbody>
</table>

It was concluded that the:
- The information about the study and instructions were appropriate; Panel Members gave full range to their own subjective feelings about the importance of different policy suggestions and were observed to reflect back to the anchor point;
- Relevant information had therefore been obtained from Panel Members;
- MRS would be appropriate for the main study.

The aims of conducting the pilot study were achieved, further alterations were not required, and therefore, the resulting pilot study indicated changes were not necessary.

*Summarising the resulting scores*

Once the panel have undertaken their ratings, the researcher has a large number of ratings to analyse. In the current study there were 41 ratings on each of 15 items (recall that the anchor point was fixed). To summarise the data, one rating on each of the 15 items was needed.
The purpose of the MRS is to enable panel members to express extreme views if they so wish. Each of the methods suggested for the summarising of Likert-type data is at a disadvantage because of the (deliberately encouraged) tendency of the MRS to produce some, perhaps several, very high scores. The resulting distribution is rarely normal.

Excluding the extremes excludes those respondents who have a strong and extreme view on a given item, meaning that judgements that were sought would be lost. Taking the median is similar to excluding the extremes and again loses the extreme judgments, thus nullifying the purpose of the exercise, which is to spread responses out. Taking the arithmetic mean avoids that problem, but suffers from a different problem. The mean takes all measurements into account, thus not excluding important ones, but unfortunately takes them all into account with equal weighting.

When the data are normally distributed (or are rectangular) the arithmetic mean is an efficient and useful way to summarise the ratings.

The MRS however tends not to produce such distributions. The very high ratings, often in the thousands or millions, not only influence the arithmetic mean (as one would wish), but influence it disproportionately (which one would not wish). An example may help clarify this. For the sake of simplicity, the following example is used.

\[2, 2, 3, 4, 5.\]

In this case the arithmetic mean is \((2+2+3+4+5)/5 = 16/5 = 3.2.\) That is a fair summary of the series. Given that there are two higher (but not very high) scores above the mid-point and two below it and that the higher records will contribute equally to the computation, then an average of 3.2, i.e. just above the mid point, gives a fair account of the rating behaviour of the panel.

It should be noted that this has already given slightly greater weight to the higher ratings, since on the scale presented they are of higher average value. Simple visual inspection suggests that in this case the median (3) would be an even fairer representation of the distribution overall.
However, in a similar distribution, with only one entry changed, the picture changes entirely.

2, 2, 3, 4, 5,000,000

In this case the arithmetic mean is \((2+2+3+4+5000000)/5 = 5000011/5 = 1,000,002\)

Clearly, when the distribution contains four out of five entries with a value of less than five, to say that the average is over one million does not give a meaningful description.

**Summarizing MRS data distributions**

Having considered conventional measures of location, the question was asked, "Is there a better way to summarise the unusual distributions obtained from an MRS scaling exercise?" There are available means other than that of simple arithmetic mean. The arithmetic mean is suitable for approximately rectangular or normal distributions. The adopted geometric mean provided a closer approximation and more representative exponential distribution.

Arithmetic means are calculated by adding the individual values and dividing by \(n\) while the geometric mean values are multiplied and the \(N\)th root is taken. The multiplication extends the range of the values. On its own, this would produce a ridiculously large result. Dividing by \(N\) would reduce this, but only by a small extent. Taking the \(N\)th root brings the final result back into the plausible range. One can view the two procedures pictorially in Table 6.8.

**Table 6.8. Producing a measure of location**

<table>
<thead>
<tr>
<th>Aim</th>
<th>Arithmetic Mean</th>
<th>Geometric Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Producing a total.</td>
<td>Add values</td>
</tr>
<tr>
<td>2</td>
<td>Summarising the total to produce a measure of location.</td>
<td>Divide by (N)</td>
</tr>
</tbody>
</table>
A practical implication

Clearly, the computations have to be undertaken using a computer, which have their limitation in storing numbers. Very large and very small numbers may be stored inaccurately, and such inaccuracies can occur at any intermediate stage of the computation. With arithmetic means, this is rarely a problem, as the operations needed include only additions and divisions. For the geometric means, multiplications and taking roots are used. With large numbers of values or with very large values, this can lead to integer overflow, producing inaccuracies. In the case of many values and large values, as with the geometric mean, this is a serious danger.

The computations were undertaken using the spreadsheet Excel, which has a reputation for such inaccuracies, that danger has to be taken seriously. It was therefore decided to reduce the operations required to additions and divisions.

It is natural to perform the multiplication of large numbers using logarithmic transformations converting the multiplication to addition. To do this, values had to be reduced to their logarithms. The logarithm of the geometric mean is the arithmetic mean of the log of these observations. The geometric mean is therefore obtained by taking the logarithm of the observed values, averaging them, and finally taking the antilogarithms of the result. This is well within the scope of a standard spreadsheet such as Excel. To summarise, the procedure, the computation of a geometric mean is shown in table 6.9.

Table 6.9. Procedure to compute a geometric mean

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Transform each value to its logarithm.</td>
</tr>
<tr>
<td>2</td>
<td>Add those logarithmic values together.</td>
</tr>
<tr>
<td>3</td>
<td>Divide the result of Step 2 by n.</td>
</tr>
<tr>
<td>4</td>
<td>Take the anti-logarithm of the result of Step 3.</td>
</tr>
</tbody>
</table>

One might ask why this reduces the dangers of overflow. The answer is that the logarithms of values are usually quite small.
To take the example above, which contained the value 5,000,000, if logarithms are used to the base $e$ ($e = 2.71828$) (which is the standard provided in the spreadsheet) the largest logarithm produced was only 15. If logarithms to the base 10 are used, the largest logarithm would be six. These numbers are, on their own, well within the scope of a spreadsheet.

In addition, the fact that the operation of producing a total involved the addition operator rather than the multiplication one meant that the growth in the size of the quantities involved was modest. So, accuracy was gained both in terms of the size of the values to be represented, and in the operations to be performed.

**Summary**

It was possible to achieve an ordered and size-difference differentiated list of suggested policies that could be of use to policy makers. The panel produced the initial list of 57 items. No addition was made from the literature or any of the other sources considered. In Round Two it was possible to make justifiable judgements on the items thought likely to be of use to a large number of families. As stated earlier other researchers can repeat the PNB. With the rules established for this study, 15 items were found to be both found to both of wide usefulness, and were demonstrated to be consensually agreed.

Due to the innovative use of the MRS in Round Three, it was possible to rank them in order of depth (how much benefit each would bring – it was already known that all of them would benefit large numbers of families). Thus the Delphi study was performed in a technically advanced fashion, and in a way that would permit others to repeat the work. Whatever results emerged were representative of the best judgements of the panel. It was then possible to compare the results emerging from the professional literature and from the analysis of the charity leaflets.

In the next chapter, the results of the Delphi study are presented.
CHAPTER SEVEN
RESULTS: DELPHI STUDY

In this chapter, the results and discussion are presented based on the three rounds of the Delphi study from the two panels of family and professional members.

Round One

In recruiting the panel members for the Delphi study, the intention was to gain 'expert' (in the Delphi sense of the word) opinion from two perspectives. The first was from the expertise gained from the personal experience of families \( (n=15) \) and the second from the professionals \( (n=31) \) caring for children with cancer. It was the intention to treat the panel as a heterogeneous group from which a single set of conclusions would be drawn. These conclusions would represent the views of the panel with no attempt to distinguish between the two groups. However, as some interesting and important differences emerged between the family and professional panel members, a separate analysis was performed and is presented below.

Family panel members

Table 7.1. Composition of the Family Panel Members

<table>
<thead>
<tr>
<th>No. of Parents</th>
<th>Family Group</th>
<th>Domicile</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Mother &amp; father</td>
<td>Both birth parents living in the same household.</td>
</tr>
<tr>
<td>1</td>
<td>Mother only participant</td>
<td>Both birth parents living in the same household.</td>
</tr>
<tr>
<td>1</td>
<td>Mother only participant</td>
<td>Birth parents not living in the same household.</td>
</tr>
<tr>
<td>1</td>
<td>Father only participant</td>
<td>Both birth parents living in the same household.</td>
</tr>
<tr>
<td>2</td>
<td>Father &amp; sister</td>
<td>Living in the same household.</td>
</tr>
<tr>
<td>2</td>
<td>Mother &amp; grandfather</td>
<td>Living in the same household.</td>
</tr>
<tr>
<td>2</td>
<td>Mother &amp; grandmother</td>
<td>Living in different households.</td>
</tr>
</tbody>
</table>

The composition of the family panel members group (15 in total), is presented in table 7.1. Details of other demographic features are shown in Table 7.2.
Table 7.2

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Employment Status</th>
<th>Indigenous</th>
<th>Occupations</th>
<th>Religion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents 25-70 years</td>
<td>3 fathers previously employed now unemployed Unemployment as direct result of child's illness</td>
<td>14 local to their birth place Strong support from family and friends</td>
<td>Lawyer</td>
<td>Christian</td>
</tr>
<tr>
<td>Children 3-12 years</td>
<td>1 father previously employed took early retirement working on a part-time basis Unemployment as direct result of child's illness</td>
<td>1 not local to their birth place Negligible local support</td>
<td>Light industry</td>
<td>Jewish</td>
</tr>
<tr>
<td></td>
<td>3 mothers previously employed now unemployed Unemployment as direct result of child's illness</td>
<td></td>
<td>Local store manager</td>
<td>None</td>
</tr>
<tr>
<td></td>
<td>2 single mothers previously employed now unemployed Unemployment as direct result of child's illness</td>
<td></td>
<td>Nursing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 mother has successfully sought part-time employment in order &quot;to stay sane&quot;</td>
<td></td>
<td>Taxi driver</td>
<td></td>
</tr>
</tbody>
</table>
It was not possible to locate stepfamilies (in which the step parent was caring for the child). Neither was it possible to contact families of ethnic origin. However, these factors were addressed within the final sample as there were two families in which the birth parents of the affected child had previous marriages and stepchildren from those marriages. The two single mothers were previously married but now divorced and contact with the children's fathers had ceased. In addition, one family who observed the religious practice of the Jewish faith participated in this study. Additional demographic information is provided in table 7.2.

**Professional panel members**

Thirty-one professional panel members participated in the study and their professional backgrounds are indicated in Table 7.3. Clearly, the professional component of the experts provided an array of professional disciplines from a wide range of geographical areas and settings.

**Table 7.3. Composition of the Professional Panel Members**
**Acute Perspective**

**District General Hospital**
- Commissioner of services (included a rural perspective)
- Manager of patients' services
- Member of the ward staff
- Paediatric Consultant (General)
- Dietician (included a rural perspective)

**Regional Centre**
- Commissioner of services (Regional Services)
- Manager of patients' services
- A member of the ward staff
- Paediatric Consultant (Oncology)
- Chaplaincy member
- Pharmacist
- Physiotherapist
- Social Worker

**Community Perspective**

**Rural**
- General Practitioner
- Health Visitor
- District Nurse
- Teacher (Primary school)
- Community Pharmacist

**Urban**
- General Practitioner
- Health Visitor
- Community Paediatric Nurse
- Teacher (Secondary school)
- Social Worker

**Miscellaneous**

<table>
<thead>
<tr>
<th>Educational psychologist</th>
<th>Hospice staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local clergy</td>
<td>Play therapist</td>
</tr>
<tr>
<td>Voluntary Agency (Local)</td>
<td>Voluntary Agency (National)</td>
</tr>
<tr>
<td>Policy maker</td>
<td>Paediatric Oncology Specialist Nurse</td>
</tr>
<tr>
<td></td>
<td>(serving rural and urban populations)</td>
</tr>
</tbody>
</table>

The setting and recruitment criteria were successful and the aim to create a panel of experts with a broad range of personal and professional experience was achieved. The representativeness of the selected panels ensured that their views would provide a representative current opinion.
Non-response rate of panel members

Prior to Round One, six potential professional panel members did not wish to participate. All indicated that they were committed to other studies. They were replaced with substitutes from the same professional disciplines and settings before the study started. Therefore, the panel who entered Round One had conformed to the pre-set criteria and no bias was introduced even at this early stage.

Round One

All 46 participants responded.

Round Two

Five panel members (1 family and 4 professional) were lost from the study for reasons shown in table 7.4 below.

Table 7.4. Round Two Attrition

<table>
<thead>
<tr>
<th>Potential Total from Round One</th>
<th>Family</th>
<th>Professional</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not reply</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Died</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Moved away</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Actual Total for Round Two</td>
<td>14</td>
<td>27</td>
<td>41</td>
</tr>
</tbody>
</table>

Efforts were made to follow up the panel members who did not reply but without success. As Health (1995) maintains, reasons for sample attrition can include respondents moving and the inability to trace them afterwards.

The possibility of bias at the loss of these panel members was considered. Their expertise was examined and was found to be present in the experience of other panel members. For example, one panel member who did not reply was a nurse from a regional unit. However, there was another panel member with nursing experience in a regional unit. It was considered that the loss of four professional panel members and one family panel member did not introduce any serious bias.
Round Three

All remaining 41 participants responded. However, during the analysis, it was clear that one panel member recorded unusual scores. It appeared that for this participant, the 500 anchor point was not taken into consideration and therefore that participant scores were meaningless. It was concluded that this panel member had not fully understood the instructions for the MRS. In order to ascertain their understanding of the instructions, four unsuccessful attempts were made to contact the panel member. It was decided that the risk of introducing a serious bias, by skewing any means that were to be calculated, was too great and so this panel member’s scores were not included in the analysis of Round Three. The responses of 40 panel members were therefore used for the analysis for Round Three.

As stated earlier (page 204), in order to prioritise the statements, the MRS was used which involved participants scoring statements in comparison to a pre-set anchor point. The set score value (the geometric mean) was not restricted (except they were asked not to give a negative value) and it was anticipated that panel members would produce scores in the high hundreds or thousands. The member’s scores were easily detected when this panel member consistently recorded scores between five and seven (that is, in single figures). Whilst it was true that the aim of using MRS meant that members were free to award any number they wished, clearly there was something out of the ordinary about this panel member’s responses. As expected, all other panel members reported scores in the expected direction. In addition, the scores obtained from the main study were consistent with those provided by the panel members in the pilot study.

Results: Round One

The panel was invited to make five clear statements in relation to the key elements they felt were essential in a service supporting families in which a child has cancer (See Appendix 11). In response to this question there were 229 statements. These were examined and a content analysis was performed to obtain a categorisation of the statements (See Chapter 4 page 64). Results of this categorisation are seen in Table 7.5 below.
Table 7.5. Categories and category descriptions

<table>
<thead>
<tr>
<th>Categories</th>
<th>Category descriptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication and Cooperation</td>
<td>Issues concerned with imparting information between professionals and with the family, continuity of care from clinical setting to community/home.</td>
</tr>
<tr>
<td>Information</td>
<td>Availability of information-giving, internet facilities, leaflets and showing respect.</td>
</tr>
<tr>
<td>Maintaining Normality</td>
<td>Issues related to the needs, values, perceptions, coping and quality of life of family members in order to maintain their usual lifestyle.</td>
</tr>
<tr>
<td>Practical Issues</td>
<td>Provision of facilities to reduce stressors, such as attention to pets.</td>
</tr>
<tr>
<td>Professional Issues</td>
<td>Scope of clinical practice, knowledge base, accountability, response and sensitivity to family needs.</td>
</tr>
<tr>
<td>Resources</td>
<td>Issues related to the means of supplying that which is needed in order to enhance caring for a sick child.</td>
</tr>
</tbody>
</table>

The same six category coding strategy used for the professional literature and charity leaflets was also used for the first round of the Delphi study with the exceptions of 'Research' and 'Treatment' for there were no appropriate statements. However, two additional categories emerged that were unique to the Delphi study namely that of 'Information' and 'Practical Issues'. Unlike the other two data sources, it was not necessary to explore the Delphi statements to the same extent; the aim was to reduce the statements at the end of Round Three for policy suggestions. Nevertheless it was still possible to provide a consistency to the analysis and presentation of results.

Prior to the rating, it was acknowledged that potentially the family and professional panel members (FPMs and PPMs) could suggest different items in Round One. Thus, it was necessary to recognise (even before rating) that there could be two groups with different types of suggestions.
Table 7.6. Round One: Statement categories

<table>
<thead>
<tr>
<th>Categories</th>
<th>FPMs</th>
<th>PPMs</th>
<th>All panel members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication &amp; Cooperation</td>
<td>21 (28%)</td>
<td>46 (30%)</td>
<td>67 (30%)</td>
</tr>
<tr>
<td>Professional Issues</td>
<td>25 (33%)</td>
<td>41 (27%)</td>
<td>66 (29%)</td>
</tr>
<tr>
<td>Maintaining Normality</td>
<td>16 (21%)</td>
<td>42 (28%)</td>
<td>58 (25%)</td>
</tr>
<tr>
<td>Information</td>
<td>5 (6%)</td>
<td>16 (10%)</td>
<td>21 (9%)</td>
</tr>
<tr>
<td>Practical Issues</td>
<td>9 (12%)</td>
<td>3 (2%)</td>
<td>12 (5%)</td>
</tr>
<tr>
<td>Resources</td>
<td>-</td>
<td>5 (3%)</td>
<td>5 (2%)</td>
</tr>
<tr>
<td>Total</td>
<td>76 (100%)</td>
<td>153 (100%)</td>
<td>229 (100%)</td>
</tr>
</tbody>
</table>

At this stage in the Delphi study, the largest categories for both the family and professional panel members (FPMs and PPMs) were the categories identified as 'Professionals Issues, 'Communication and Cooperation’ and Maintaining Normality’ (table 7.6).

Round One gave complete freedom to the panel members and invited volunteered responses. Therefore, the researcher could not, and did not wish to predetermine the general type of answers that were given. This meant that many of the statements had to be modified or excluded in the original form. This was because many of the statements were exact or near duplicates of each other.

"Identification of key workers in the hospital and community.” (PR 62)

"Identification of key workers in the hospital and home.” (PR 230)

"Provision of individualised seamless care between hospital and the home.” (PR 97)

"Personalised package of seamless care between the clinical and home setting.” (PR 61)

Clarification of the process, details of the removal, and retention of statements are given in Table 7.7. The table shows that 92 statements were removed on such grounds.
Table 7.7. Statements retained or rejected by all panel members

<table>
<thead>
<tr>
<th>Categories</th>
<th>Duplicate Statement</th>
<th>Vague or Unratable</th>
<th>Retained for Round Two</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication &amp; Continuity</td>
<td>27</td>
<td>29</td>
<td>11</td>
<td>67</td>
</tr>
<tr>
<td>Professional Issues</td>
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<td>Maintaining Normality</td>
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<td>12</td>
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<tr>
<td>Resources</td>
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<td>0</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Total for all panel members</td>
<td>92 (40%)</td>
<td>80 (35%)</td>
<td>57 (25%)</td>
<td>229 (100%)</td>
</tr>
</tbody>
</table>

A further 80 were unratable as they were unclear and esoteric,

"Knowledge available at cognitive levels required so targeting at all stage development." (PR 22)

or did not fit the stem of the questionnaire,

"All the staff were extremely kind and helpful, I had a small baby on the ward as well as my daughter having treatment and I had no family to help so it was a relief to get help from the staff." (FY 182)

As a result 75% of statements were removed for these reasons.

Clearly a large number of statements were not accepted, with more statements removed than were retained. However, 92 statements (23 family panel members, 69 professional panel members) were rejected because they were duplicated statements made predominantly by the professional panel members. The statements were related to home-from-home accommodation, key workers, professional working relationships, respite care, and seamless care. Repeats from different participants is an indication of the importance of those statements.
In the case of the family panel members, 30% of their statements were also removed because of their duplication. The focus of their duplication was improved early diagnosis, privacy, accommodation, finance and holidays. In addition, 38% of the statements were also removed because they were vague or unratable \((n=29)\). Some family members had good experiences whilst others did not. The family panel members appeared to use the questionnaire as an opportunity for a cathartic release of their feelings (predominantly distress), as they described their experiences. However, by describing an experience, they failed to offer an element of care that would resolve the situation (where there was a barrier to care), or to enlarge upon their good experience so that others could benefit. For example,

"Even though she (child) couldn't stand up, the GPs still refused to take any notice." (FY 81)

"My child did not feel he was in a hospital environment due to the care and attention of the play therapists, for the role they played with his care-from the clinic to the ward." (sic) (FY 44)

It was of interest to observe if there was a difference in the attribution of statements between family panel members and professional panel members. A comparison is shown in table 7.8 and 7.9 below.

### Table 7.8. Statements retained or rejected by family panel members

<table>
<thead>
<tr>
<th>Categories</th>
<th>Duplicate Statement</th>
<th>Vague or Unratable</th>
<th>Retained for Round Two</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional Issues</td>
<td>9</td>
<td>12</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td>Communication &amp; Cooperation</td>
<td>4</td>
<td>10</td>
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<td>Maintaining Normality</td>
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<td>16</td>
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<td>Practical Issues</td>
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<tr>
<td>Resources</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Total for FPMs</td>
<td>23 (30%)</td>
<td>29 (38%)</td>
<td>24 (32%)</td>
<td>76 (100%)</td>
</tr>
</tbody>
</table>
Table 7.9. Statements retained or rejected by professional panel members

<table>
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<tr>
<th>Categories</th>
<th>Duplicate Statement</th>
<th>Vague or Unratable</th>
<th>Retained for Round Two</th>
<th>Total</th>
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<td>Professional Issues</td>
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<td>41</td>
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<tr>
<td>Resources</td>
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<td>5</td>
</tr>
<tr>
<td>Total for PPMs</td>
<td>69 (45%)</td>
<td>51 (33%)</td>
<td>33 (22%)</td>
<td>153 (100%)</td>
</tr>
</tbody>
</table>

In terms of the number of retained statements, 32% were provided by the Family Panel Members as opposed to 22% of the Professional Panel Members. There was a difference of five percentage points for the unratable statements. However, the professional panel members were more likely than the Family Panel Members to include duplicates (45% professional – 30% the family panel members). This was possibly because those with similar backgrounds and learning sources are likely to hold similar views.

Although 57 statements were acceptable, in order to enable the statements to be rated, it was necessary to reword some them. For example,

"Provide a 'home-from-home' flat close to the hospital but away from the ward." (FY 193)

became,

"Provide for 'home-from-home' facilities close to the hospital."  
(Statement No 37)

and

"Contact with other families in the same situation- help by regular contact." (PR 190)

became
Once this was completed, there were 57 statements available for Round Two. To summarise therefore, Round One produced a large number and wide range of statements. These had been reduced from the 229 statements generated in Round One to 57 statements for Round Two.

Results: Round Two

In this round, panel members were asked to state *how many* families would benefit if each statement was implemented. This was achieved by the application of the *breadth* dimension of the *breadth versus depth* debate in which responses were coded by rating them in the form of a seven point Likert-type scale (See Chapter Six page 196).

All panel members’ ratings on the 57 statements are presented below. Table 7.10. indicates the distribution of responses for each statement. A decision was needed in order to identify which of the 57 statements were sufficiently higher rated and consensual before proposing them as suggestions for the development of policies in the future. The statements with an asterisk were those for which the rating criteria for Round Three were met (see page 196 for details on the criteria).

Table 7.10.  *All panel members’ ratings on the fifty seven statements*
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<th>Statement Number</th>
<th>All</th>
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<th>Many</th>
<th>About Half</th>
<th>Some</th>
<th>Very Few</th>
<th>None</th>
<th>Total</th>
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<td>43*</td>
<td>59</td>
<td>12</td>
<td>12</td>
<td>8</td>
<td>7</td>
<td>2</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>44</td>
<td>44</td>
<td>30</td>
<td>7</td>
<td>7</td>
<td>12</td>
<td>0</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>45*</td>
<td>59</td>
<td>24</td>
<td>12</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>46</td>
<td>42</td>
<td>30</td>
<td>17</td>
<td>1</td>
<td>10</td>
<td>0</td>
<td>0</td>
<td>100</td>
</tr>
</tbody>
</table>
The figures given are to the nearest whole number and represent the valid percent. That is, the number of responses for a given statement as a percentage of those who gave a rating for each statement. However, these were so few that no bias was introduced.

The following incidences took place:

- On 14 occasions panel members (1 FPM and 13 PPMs) failed to respond to 1 question;
- On 2 occasions panel members (1 FPM and 1 PPM) failed to respond to 2 questions.

In recommending those elements of care for the development of policies in the future, many criteria could have been used. For example, a criterion could have stated that only statements with an 80% or more positive rating in which 'All:Most:Many' families would benefit should be accepted. Similarly, a criterion could have stated that only statements that have an 50% or more 'All' rating in which 'All' families would benefit should be accepted. Indeed, by looking at table 7.10 one might be forgiven for thinking that a single criterion was used, that is, 50% or more on a given statement indicating 'All' families would benefit. This is a plausible interpretation since this is the case for the asterisked statements. However, had this been the only criterion for selection, this would have created problems. For example, it could well have been the case that whilst 50% of panel members said 'All' families would benefit, it could also have been the case that 50% said 'None' would benefit.
Thus a consensus opinion would not have been achieved (See Chapter Six page 200). As it was not possible to predict ratings, strong rules were needed, and the data set from this study confirmed that need. Therefore, there is confidence of the benefits of a more discriminating selection method (The three rules identified in Chapter Six table 6.5. page 200).

Table 7.11. Application of the three rules for Round Three statements *

<table>
<thead>
<tr>
<th>Statement No.</th>
<th>Positive</th>
<th>About half</th>
<th>Negative</th>
<th>50% rule</th>
<th>PNB</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>98</td>
<td>2</td>
<td>0</td>
<td>80</td>
<td>1000</td>
</tr>
<tr>
<td>39</td>
<td>97</td>
<td>3</td>
<td>0</td>
<td>78</td>
<td>1000</td>
</tr>
<tr>
<td>26</td>
<td>95</td>
<td>0</td>
<td>5</td>
<td>61</td>
<td>19.0</td>
</tr>
<tr>
<td>45</td>
<td>95</td>
<td>0</td>
<td>5</td>
<td>59</td>
<td>19.0</td>
</tr>
<tr>
<td>54</td>
<td>94</td>
<td>2</td>
<td>4</td>
<td>59</td>
<td>23.5</td>
</tr>
<tr>
<td>42</td>
<td>93</td>
<td>7</td>
<td>0</td>
<td>59</td>
<td>1000</td>
</tr>
<tr>
<td>43</td>
<td>83</td>
<td>8</td>
<td>9</td>
<td>59</td>
<td>9.2</td>
</tr>
<tr>
<td>52</td>
<td>93</td>
<td>2</td>
<td>5</td>
<td>56</td>
<td>18.6</td>
</tr>
<tr>
<td>55</td>
<td>93</td>
<td>5</td>
<td>2</td>
<td>56</td>
<td>46.5</td>
</tr>
<tr>
<td>17</td>
<td>91</td>
<td>2</td>
<td>7</td>
<td>56</td>
<td>13.0</td>
</tr>
<tr>
<td>50</td>
<td>83</td>
<td>4</td>
<td>13</td>
<td>55</td>
<td>6.4</td>
</tr>
<tr>
<td>34</td>
<td>93</td>
<td>0</td>
<td>7</td>
<td>54</td>
<td>13.3</td>
</tr>
<tr>
<td>36</td>
<td>86</td>
<td>12</td>
<td>2</td>
<td>54</td>
<td>43.0</td>
</tr>
<tr>
<td>51</td>
<td>86</td>
<td>12</td>
<td>2</td>
<td>51</td>
<td>43.0</td>
</tr>
<tr>
<td>5</td>
<td>78</td>
<td>4</td>
<td>18</td>
<td>50</td>
<td>4.3</td>
</tr>
</tbody>
</table>

*NB For this study the number 1000 represented ‘infinity’ i.e. the highest possible agreement that the statement would provide maximum benefit to the families.

Three issues will be noticed from this table. First, there was evidence of a high level of consensus and support, for example, in Statements 13 and 39 nobody was against the item, in the ‘About half’ column there was only 2% and 3% respectively, and the ‘Positive’ column had ratings in the high 90%s. Even in Statement 5 (just reaching the 50% rule), only 18% of panel members thought ‘Some: Very Few: None’ would benefit. Second, the statements were not ranked. The question could be asked, for example, why preference was not given to the positive rating? Or why was preference not given to the PNB? Clearly, that preference could not be given for either, as that was not the intention of Round Two.
The task of Round Two was to follow the rules and identify a list of statements that survived the breadth rules to go forward into Round Three for the next task. Third, the analysis was blind, i.e. the researcher deliberately avoided having the statements in their textual form during the selection process. This meant that it was not possible to retain a statement by virtue of its content. However, it was now appropriate to decode the statements and refer back to their actual wording of the statements. They are identified in Table 7.12.

Table 7.12. De-coded statements selected for Round Three

<table>
<thead>
<tr>
<th>Statement Number</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Care organised by regional, specialist oncology centres and delivered into the community by staff from the regional unit.</td>
</tr>
<tr>
<td>13</td>
<td>Emergency contact number 24 hours a day 7 days a week.</td>
</tr>
<tr>
<td>17</td>
<td>Training courses for health care professionals to increase their awareness of the impact of the child's illness on the family.</td>
</tr>
<tr>
<td>26</td>
<td>Improved communications between hospital and community services to ensure better follow-up.</td>
</tr>
<tr>
<td>34</td>
<td>A named key worker who would be responsible for the coordination of the whole treatment programme.</td>
</tr>
<tr>
<td>36</td>
<td>Improved communication between doctors and nurses and other members of the health care team.</td>
</tr>
<tr>
<td>39</td>
<td>Ensure that all take home medications have clearly written instructions prepared by the pharmacist.</td>
</tr>
<tr>
<td>42</td>
<td>An attempt to avoid the problem of late diagnosis by providing specialised training for GPs in spotting childhood cancers.</td>
</tr>
<tr>
<td>43</td>
<td>Ensure that provision for overnight parental stay is genuinely of a home-from-home nature.</td>
</tr>
<tr>
<td>45</td>
<td>Older children should be treated and cared for in an adolescent unit and younger children cared for in an environment suited to their age.</td>
</tr>
<tr>
<td>50</td>
<td>A mechanism to ensure that expert advice is available more promptly than it is at present.</td>
</tr>
<tr>
<td>51</td>
<td>The continued use of, and preferably expansion in the use of evidence based guidelines for the care and treatment of children with cancer.</td>
</tr>
<tr>
<td>52</td>
<td>A conscious effort to ensure that children with cancer remain in touch with their peer group.</td>
</tr>
<tr>
<td>54</td>
<td>Using parents as much as possible not only as partners in decision-making, but also as partners in caring.</td>
</tr>
<tr>
<td>55</td>
<td>Keeping pharmacy informed about discharge plans, so that medications are ready when needed, and can be provided without delay or undue haste.</td>
</tr>
</tbody>
</table>
The statements for Round Three that are listed in table 7.11, could be clustered under four categories as demonstrated in table 7.13.

Table 7.13. Categorisation of Round Three statements

<table>
<thead>
<tr>
<th>Category</th>
<th>Statement Number</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication &amp; Cooperation</td>
<td>26 : 34 : 36 : 54 : 55</td>
<td>5</td>
<td>33</td>
</tr>
<tr>
<td>Maintaining Normality</td>
<td>43 : 45 : 52</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>Information</td>
<td>39</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>-</td>
<td>15</td>
<td>100</td>
</tr>
</tbody>
</table>

Forty percent of the statements retained for Round Three referred to 'Professional Issues'. A third referred to issues concerned with 'Communication and Cooperation' and one fifth were concerned with 'Maintaining Normality'. The topic that referred to the least was 'Information'. Topics that related to 'Practical Issues' were lost following selection for Round Three. This exclusion was not arbitrary on the part of the researcher, it emerged from empirical rating from the panel.

Family panel members

If the family panel members only had been used, 28 statements would have met all three rules for Round Three. There were 14 statements from the list of 15 selected at the end of Round Two, and there were 14 additional statements that met all three rules for Round Three. However, the professional panel members did not support these. If the opinion of the family panel members only had been sought, the statements at the end of Round Two could have been placed in the categories labelled below (Table 7.14).
Table 7.14. Additional statements selected by Family Panel Members

<table>
<thead>
<tr>
<th>Category</th>
<th>Statement Number</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintaining Normality</td>
<td>23 : 57</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Information</td>
<td>40</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Communication &amp; cooperation</td>
<td>12</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Practical Issues</td>
<td>4</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>-</td>
<td>14</td>
<td>100</td>
</tr>
</tbody>
</table>

In this extended list of family panel members’ statements (that met the three rules), a further 14 statements would have been added. The category given the most additional statements was ‘Professional Issues’ whilst those with the least were the categories called ‘Communication & Cooperation’ and ‘Practical Issues’. These statements were decoded and referred back to the actual wording of the statements (table 7.15).

Table 7.15. De-coded additional statements selected by Family Panel Members

<table>
<thead>
<tr>
<th>Statement Number</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>When unemployment strikes a family with a child suffering from cancer, there should be specific, targeted allowances to help them.</td>
</tr>
<tr>
<td>6</td>
<td>Care organised by the locality but with referral to the regional centre when necessary.</td>
</tr>
<tr>
<td>9</td>
<td>The use of written objectives (from diagnosis, through a schedule of visits, to discharge) which are agreed with the family, and which are continually updated.</td>
</tr>
<tr>
<td>12</td>
<td>Formalised scheme for involving the school in the child’s care.</td>
</tr>
<tr>
<td>14</td>
<td>The right to by-pass local services and go straight to the Regional Centre.</td>
</tr>
<tr>
<td>25</td>
<td>Regular published audit of skills to provide the families with increased confidence in the treatment their child is receiving.</td>
</tr>
<tr>
<td>27</td>
<td>Provision to families of more accurate, and up-to-date information than is currently available.</td>
</tr>
<tr>
<td>28</td>
<td>Routine availability of counselling if family members request it.</td>
</tr>
<tr>
<td>40</td>
<td>Each family to be issued with a comprehensive and regularly updated guide to sources of financial aid (statutory and voluntary); which they could then use independently if they so wished.</td>
</tr>
</tbody>
</table>
More careful assessment to ensure that children are admitted to hospital only when the care which they need cannot be provided at home.

Offering counselling from an experienced member of staff to family members who have feelings of loss, bereavement or grief.

Developing a greater role than at present for charities in the provision of services for families of children with cancer.

Auditing care regularly to ensure that children with cancer remain in touch with their peer group.

**Professional Panel Members**

Eleven statements by the professional panel members met all three rules for Round Three. Ten were from the list of 15 selected for Round Three. Statement Number 26 was an additional statement that met all three rules by the Professional Panel Members, but was not in the additional list suggested by the Family Panel Members. If the opinion of the Professional Panel Members only had been sought, the statements at the end of Round Two could have been placed in the categories labelled below (Table 7.16).

**Table 7.16. Statements selected by professional panel members only**

<table>
<thead>
<tr>
<th>Category</th>
<th>Statement Number</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication &amp; Cooperation</td>
<td>26 : 34 : 54 : 55</td>
<td>4</td>
<td>36</td>
</tr>
<tr>
<td>Professional Issues</td>
<td>13 : 17 : 50 : 51</td>
<td>4</td>
<td>36</td>
</tr>
<tr>
<td>Information</td>
<td>29 : 39</td>
<td>2</td>
<td>19</td>
</tr>
<tr>
<td>Maintaining Normality</td>
<td>45</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>-</td>
<td>11</td>
<td>100</td>
</tr>
</tbody>
</table>

230
It is clear from table 7.16 that ‘Communication & Cooperation’ and ‘Professional Issues’ continued to be the main categories, with no statements relating to ‘Practical Issues’. An additional statement suggested by professional panel members (but not included in the additional list by family panel members) was Statement Number 26.

“Improved communication between hospital and community services to ensure better follow-up.”

Of the 15 statements that were retained for Round Three, 10 were common to both groups of panel members.

Table 7.17. Round Three statements supported by Family and Professional Panel members

<table>
<thead>
<tr>
<th>Statement Number</th>
<th>Family panel members</th>
<th>Professional panel members</th>
<th>Both groups</th>
<th>Statement selected</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>39</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>26</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>45</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>54</td>
<td>YES</td>
<td>NO</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>42</td>
<td>YES</td>
<td>NO</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>43</td>
<td>YES</td>
<td>NO</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>52</td>
<td>YES</td>
<td>NO</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>55</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>17</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>50</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>34</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>36</td>
<td>YES</td>
<td>NO</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>51</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>5</td>
<td>YES</td>
<td>NO</td>
<td>NO</td>
<td>YES</td>
</tr>
</tbody>
</table>

All 15 statements were not common to both groups of panel members. The ratings indicated by the professional panel members were Statements 42; 43; 52; 36 and 5, and Statements 51 for the family panel members failed to meet the 50% requirement rule.
The results at this stage indicated that there was some level of agreement. However, a higher rating of the positive attributes of the statements by the family panel members meant that they selected 27% more statements than professional panel members to be included in Round Three. When the ratings of both the family panel members and professional panel members were combined, there were 15 statements that met all three rules and were available for Round Three.

Results: Round Three

Round Three would examine the depth dimension, that is, how much families would benefit from the provision of care using a Magnitude Ratio scale (MRS) (See page199/200 for explanation of MRS). This method was used to estimate not only the rank order but also the amount of benefit, (to estimate the distance and the degree of distance between each statement). At the end of Round Two, statements had been selected in which the topics would provide benefit to a great number of families. Fifteen statements met the rules for selection for Round Three and were therefore available for policy suggestion.

Of the 41 panel members who responded in Round Two, all 41 replied in Round Three. The statements using MRS were placed in ranked order as seen in the table below. The statements and MRS scores for the whole panel (combined family and professional panel members) given in table 7.18 below are organized in descending order of the geometric mean.
Table 7.18. Ranked order of statements using MRS scores (Geometric means)

<table>
<thead>
<tr>
<th>Statement Number</th>
<th>Statement</th>
<th>MRS Scores (Geometric means)</th>
</tr>
</thead>
<tbody>
<tr>
<td>42</td>
<td>An attempt to avoid the problem of late diagnosis by providing GPs with training.</td>
<td>973</td>
</tr>
<tr>
<td>34</td>
<td>A named key worker responsible for co-ordination of the whole treatment programme.</td>
<td>906</td>
</tr>
<tr>
<td>54</td>
<td>Using parents as partners not just in decisions making but also in caring.</td>
<td>886</td>
</tr>
<tr>
<td>5</td>
<td>Care organised by RU and delivered into the community by Regional Unit staff.</td>
<td>855</td>
</tr>
<tr>
<td>13</td>
<td>Emergency contact number 24 hours a day 7 days a week.</td>
<td>777</td>
</tr>
<tr>
<td>45</td>
<td>Adolescents cared for in an adolescent unit, younger children in an age suitable environment.</td>
<td>775</td>
</tr>
<tr>
<td>26</td>
<td>Improved communications between hospital and community services.</td>
<td>770</td>
</tr>
<tr>
<td>50</td>
<td>A mechanism to ensure expert advice is available more promptly than it is.</td>
<td>731</td>
</tr>
<tr>
<td>36</td>
<td>Improved communications between doctors, nurses and other members of the health care team.</td>
<td>682</td>
</tr>
<tr>
<td>51</td>
<td>Continued use and preferably expansion of evidence-based guidelines for care and treatment.</td>
<td>668</td>
</tr>
<tr>
<td>43</td>
<td>Ensure provision of overnight parental stay is genuinely of a home-from-home nature.</td>
<td>650</td>
</tr>
<tr>
<td>17</td>
<td>Training courses for staff to increase their awareness of the impact of the illness on families.</td>
<td>637</td>
</tr>
<tr>
<td>55</td>
<td>Keeping pharmacy informed about discharge plans so medication is ready.</td>
<td>630</td>
</tr>
<tr>
<td>39</td>
<td>Ensure all take-home medication has clearly written instructions prepared by pharmacist.</td>
<td>592</td>
</tr>
<tr>
<td>52</td>
<td>A conscious effort to ensure that children with cancer stay in touch with their peer group.</td>
<td>517</td>
</tr>
</tbody>
</table>

Some of the main points to be noted are as follows:

Given that the anchor point was 500, it is worthy of note that none of the statements scored below this point. However, it should be recalled that in order for the statements to have survived to Round Three they had been:

- Suggested by the panel members in Round One (229 reduced by removal of duplicates and unratable statements to 57 in Round Two);
- Selected using strict rules;
Selected from Round Two having achieved a high degree of consensus and support in that many families would benefit.

It might have been even more surprising if the statements were rated lower than the arbitrary anchor point that had not gone through the rigorous process of judgement, refinement and attrition. Individuals may have rated lower than the anchor point but that was not the case for the whole panel, and was not expected.

It may also seem surprising that the attempts to achieve discrimination and to distribute the scores evenly using the MRS, the panel geometric means ranged from 517 to 973 with a ratio of less than 1:2.

This suggests that the MRS achieved its aims. The whole panel consisted of two groups, the family panel members and the professional panel members. The family panel members had a median score of 893 with a range of 324, going below the anchor point, (so that the anchor point did not serve as a barrier), and rose to a high of 1673, a ratio of 1:5.

The other group, (the professional panel members), had a median score of 672 with a range of 510-829, a ratio of 1:1.8. Clearly, the professional panel members were more conservative and limited in the range of scores given. This was reflected in a similarly conservative tendency in Round Two. By contrast, the family panel members’ scores were wider and higher than the professional panel members, possibly because the rating is reflected in their harrowing experiences (table 7.19).

Panel members’ rating

The rating of the panel was then examined for:

- Differences in the order of priority of elements of care as suggested by the family panel members and the professional panel members;
- Correlation between the scores awarded by the family panel members and the professional panel members.

Table 7.19. Comparison of rating between Family and Professional Panel members
<table>
<thead>
<tr>
<th>Statement Number</th>
<th>Statement</th>
<th>Geometric Mean</th>
<th>Rank Order</th>
</tr>
</thead>
<tbody>
<tr>
<td>42</td>
<td>An attempt to avoid the problem of late diagnosis by providing GPs with training.</td>
<td>1673 727</td>
<td>1 6</td>
</tr>
<tr>
<td>34</td>
<td>A named key worker responsible for co-ordination of the whole treatment programme.</td>
<td>1280 752</td>
<td>2 5</td>
</tr>
<tr>
<td>26</td>
<td>Improved communications between hospital and community services.</td>
<td>1058 648</td>
<td>3 10</td>
</tr>
<tr>
<td>43</td>
<td>Ensure provision of overnight parental stay is genuinely of a home-from-home nature.</td>
<td>1019 510</td>
<td>4 15</td>
</tr>
<tr>
<td>17</td>
<td>Training courses for staff to increase their awareness of the impact of the illness on families.</td>
<td>948 514</td>
<td>5 14</td>
</tr>
<tr>
<td>5</td>
<td>Care organised by RU and delivered into the community by Regional Unit staff.</td>
<td>908 828</td>
<td>6 3</td>
</tr>
<tr>
<td>55</td>
<td>Keeping pharmacy informed about discharge plans so medication is ready.</td>
<td>900 520</td>
<td>7 13</td>
</tr>
<tr>
<td>54</td>
<td>Using parents as partners not just in decisions making but also in caring.</td>
<td>893 882</td>
<td>8 2</td>
</tr>
<tr>
<td>50</td>
<td>A mechanism to ensure expert advice is available more promptly than it is.</td>
<td>856 672</td>
<td>9 8</td>
</tr>
<tr>
<td>13</td>
<td>Emergency contact number 24 hours a day 7 days a week.</td>
<td>760 786</td>
<td>10 4</td>
</tr>
<tr>
<td>51</td>
<td>Continued use and preferably expansion of evidence-based guidelines for care and treatment.</td>
<td>736 634</td>
<td>11 11</td>
</tr>
<tr>
<td>36</td>
<td>Improved communications between doctors, nurses and other members of the health care team.</td>
<td>691 677</td>
<td>12 7</td>
</tr>
<tr>
<td>39</td>
<td>Ensure all take-home medication has clearly written instructions prepared by pharmacist.</td>
<td>680 549</td>
<td>13 12</td>
</tr>
<tr>
<td>45</td>
<td>Adolescents cared for in an adolescent unit, younger children in an age suitable environment.</td>
<td>597 892</td>
<td>14 1</td>
</tr>
<tr>
<td>52</td>
<td>A conscious effort to ensure that children with cancer stay in touch with their peer group.</td>
<td>324 664</td>
<td>15 9</td>
</tr>
</tbody>
</table>
When a ranked Spearman correlation was calculated and the rating given by the level of agreement on the rating of statements was assigned at 0.639 (p<0.001). This indicates that there was a significant difference between the ratings of the two groups.

The ranked order rather than raw scores highlight several important features. First, the large difference between the family and professional panel members in the order in which they ranked the statements. Most striking is Statement 45 (Older children should be treated and cared for in an adolescent unit and younger children cared for in an environment suited to their age). This was first out of the 15 for the professionals but last but one for the family panel members. Second, the difference in the rank ordering was not an isolated event. Similar situations occurred in Statements 43 and 17. In Statement 43 (Ensure that provision for overnight parental stay is genuinely of a home-from-home nature), families rated this statement 11 places higher than the professional panel members. Family panel members rated Statement 17 (Training courses for health care professionals to increase their awareness of the impact of the child's illness on the family), nine places higher than the professional panel members.

Third, statements were scored higher by family panel members but scored lower by the professional panel members. However, this was not the case as evidenced by the Spearman correlation calculation in which it was seen that there were no relationships (either negative or positive) between the two groups; in effect they acted independently of each other. Statements 42 and 45 exemplify this. Statement 42 was the highest scored statement (1673) and the highest for the family panel members. This was also the largest difference (946) in scores between the two subgroups, 1673 for the family panel members compared with 727 for the professional panel members. Clearly an extremely important issue for family panel members but less so for the professional panel members. A similar phenomenon was seen in statement 45 in which the professionals ranked this statement as their primary ranked statement, awarding a score of 892 (their highest). It was clearly the case that the professionals felt that age appropriate environments were important.

By contrast, the family panel members ranked this statement at 14th position (their penultimate lowest priority position).
From the differences in the family and professional panel members scores, in which the family panel members gave higher and wider scores, one can conclude that the family panel members were more discriminating than the professional panel members. Thus, in view of the difference in the panel members' scores it was considered important that the selection of the final statements was an equitable interpretation of the panel's opinions, both family and professionals. Before the final selection was made, several approaches were considered and are as follows.

**Approach 1**

*Highest geometric mean*

The selection of statements from the highest geometric mean was obtained for all panel members, that is the combined scores of families and professionals members. Had this been the case, the following statements would have been selected as presented in Table 7.20.

**Table 7.20. Selection of statements using the highest seven MRS scores**

(Geometric Mean)

<table>
<thead>
<tr>
<th>Statement Number</th>
<th>Statement</th>
<th>MRS scores (Geometric Mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>42</td>
<td>An attempt to avoid the problem of late diagnosis by providing GPs with training.</td>
<td>973</td>
</tr>
<tr>
<td>34</td>
<td>A named key worker responsible for co-ordination of the whole treatment programme.</td>
<td>906</td>
</tr>
<tr>
<td>54</td>
<td>Using parents as partners in not just in decisions making but also in caring.</td>
<td>886</td>
</tr>
<tr>
<td>5</td>
<td>Care organised by Regional Unit and delivered into the community by Regional Unit staff.</td>
<td>855</td>
</tr>
<tr>
<td>13</td>
<td>Emergency contact number 24 hours a day 7 days a week.</td>
<td>777</td>
</tr>
<tr>
<td>45</td>
<td>Adolescents cared for in an adolescent unit, younger children in an age suitable environment</td>
<td>775</td>
</tr>
<tr>
<td>26</td>
<td>Improved communications between hospital and community services.</td>
<td>770</td>
</tr>
</tbody>
</table>
Approach 2

*Smallest difference in MRS scores (Geometric Mean)*

Should some attempt be made at reconciling the difference between the score given by the families and the professionals? For example, considering the least difference in geometric mean. In which case, the following statements identified in Table 7.21. (Smallest absolute difference in geometric mean of the family and professional panel members’ scores) should be selected.

<table>
<thead>
<tr>
<th>Statement No.</th>
<th>Statement</th>
<th>FPM Geo. Mean</th>
<th>PPM Geo. Mean</th>
<th>Absolute difference in Geo. Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>36</td>
<td>Improved communications between doctors, nurses and other members of the health care team.</td>
<td>691</td>
<td>677</td>
<td>14</td>
</tr>
<tr>
<td>13</td>
<td>Emergency contact number 24 hours a day 7 days a week.</td>
<td>760</td>
<td>786</td>
<td>26</td>
</tr>
<tr>
<td>5</td>
<td>Care organised by Regional Unit and delivered into the community by Regional Unit staff.</td>
<td>908</td>
<td>828</td>
<td>80</td>
</tr>
<tr>
<td>51</td>
<td>Continued use and preferably expansion of evidence-based guidelines for care and treatment.</td>
<td>736</td>
<td>634</td>
<td>102</td>
</tr>
<tr>
<td>39</td>
<td>Ensure all take-home medication has clearly written instructions prepared by pharmacist.</td>
<td>680</td>
<td>549</td>
<td>131</td>
</tr>
<tr>
<td>50</td>
<td>A mechanism to ensure expert advice is available more promptly than it is.</td>
<td>856</td>
<td>672</td>
<td>184</td>
</tr>
<tr>
<td>45</td>
<td>Adolescents cared for in an adolescent unit, younger children in an age suitable environment.</td>
<td>597</td>
<td>892</td>
<td>295</td>
</tr>
</tbody>
</table>
Approach 3

Acknowledgment of panel members’ opinions

The question was posed, ‘should the extreme scores of the two groups be acknowledged?’ It was recognised that both family and panel members had different perspectives and the differences in experience were considered to be an important contribution to the study. This could be achieved by accepting the three highest scored statements from the perspectives of both groups. If this had been the case, the statements in Table 7.22 would have been selected.

Table 7.22. Highest three MRS scores (geometric means) of family and professional panel members’ opinions

<table>
<thead>
<tr>
<th>Statement</th>
<th>Statement selected by FPMs</th>
<th>Statement selected by PPM</th>
</tr>
</thead>
<tbody>
<tr>
<td>An attempt to avoid the problem of late diagnosis by providing GPs with training.</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>A named key worker responsible for co-ordination of the whole treatment programme.</td>
<td>34</td>
<td></td>
</tr>
<tr>
<td>Improved communications between hospital and community services.</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Adolescents cared for in an adolescent unit, younger children in an age suitable environment.</td>
<td></td>
<td>45</td>
</tr>
<tr>
<td>Using parents as partners in not just in decisions making but also in caring.</td>
<td></td>
<td>54</td>
</tr>
<tr>
<td>Care organised by Regional Unit and delivered into the community by Regional Unit staff.</td>
<td></td>
<td>5</td>
</tr>
</tbody>
</table>
Approach 4

Statements supported by both family and professionals on entering Round Three

This choice is based on the selection of statements that are supported by both families and professionals on entering Round Three. It is important to note that, of the 15 statements that were retained for Round Three, nine were common to both the family panel members and professional panel members. (See Table 7.17, page 231)

A matrix (Table 7.23) was prepared based on the three approaches in order to make a judgement about which seven statements would be recommended. It was decided that an equitable course of action for selection should be based on the frequency of occurrence in the matrix.

Table 7.23. Selection of statements based on their frequency of occurrence

<table>
<thead>
<tr>
<th>Statement Number</th>
<th>Approach 1</th>
<th>Approach 2</th>
<th>Approach 3</th>
<th>Approach 4</th>
<th>No. of occasions selected</th>
<th>Final selection</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
<td>3</td>
<td>✓</td>
</tr>
<tr>
<td>13</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>3</td>
<td>✓</td>
</tr>
<tr>
<td>17</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>✓</td>
<td>1</td>
<td>x</td>
</tr>
<tr>
<td>26</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
<td>3</td>
<td>✓</td>
</tr>
<tr>
<td>34</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
<td>3</td>
<td>✓</td>
</tr>
<tr>
<td>36</td>
<td>x</td>
<td>✓</td>
<td>x</td>
<td>x</td>
<td>1</td>
<td>x</td>
</tr>
<tr>
<td>39</td>
<td>x</td>
<td>✓</td>
<td>x</td>
<td>x</td>
<td>1</td>
<td>x</td>
</tr>
<tr>
<td>42</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>x</td>
<td>2</td>
<td>✓*</td>
</tr>
<tr>
<td>43</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>0</td>
<td>x</td>
</tr>
<tr>
<td>45</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>4</td>
<td>✓</td>
</tr>
<tr>
<td>50</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
<td>2</td>
<td>x</td>
</tr>
<tr>
<td>51</td>
<td>x</td>
<td>✓</td>
<td>x</td>
<td>x</td>
<td>1</td>
<td>x</td>
</tr>
<tr>
<td>52</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>0</td>
<td>x</td>
</tr>
<tr>
<td>54</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
<td>3</td>
<td>✓</td>
</tr>
<tr>
<td>55</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>1</td>
<td>x</td>
</tr>
</tbody>
</table>

Statement 42 was selected as a case for special consideration. The rationale for this decision was based on the following:
The high rank order and geometric mean score awarded by family panel members;

This was the highest geometric mean score awarded for any statement (see table 7.22);

Furthermore, 100% of family panel members expressed the opinion ‘All:Most:Many’ families would benefit (Rule 1 see page 200);

93% family panel members considered ‘All’ families would benefit (Rule 2). Statement 42 failed to be supported by the professional panel members at the end of Round Two because the ‘All’ score (in which 50% of families would benefit, Rule 2) was 41%;

This study was initiated in order to help families during the course of a childhood cancer and there was an overwhelming opinion expressed by the family panel members;

The families are ‘users’ of the service and such a strongly expressed opinion should not be disregarded.

It is interesting to note that the final selection is mirrored by a selection based on the ranked order of the geometric means of all panel members (Approach 1).

The findings of the Delphi study were compared with the findings from the content analysis of the professional literature and the charities leaflets (See Chapter Eight).

**Approach 5**

*Use of a sliding scale*

A fifth approach for the selection of the statements for recommendation was considered and finally used. This involved the use of a sliding scale, in which it would be possible to establish a rule, whereby the sliding scale would give priority to statements from the perspectives of both the family and professional panel members.

A midway point of the 15 statements was selected. The rationale for adopting this approach was to provide a ‘balance’ between both groups of panel members.

A rule was established in which,

_A statement that has been ranked seventh or higher by the family or professional panel members is to be considered for recommendation as policy suggestions._
In table 7.19 it was seen that a comparison of rating behaviour of the family and professional panel members was made.

For example, if the purchasers/providers sought to implement policies that met the first ranked order (or choice) of both the family and professional panel members, statements 42 and 45 would be selected. If however, they wished to select more than two statements that met the second and subsequent ranked order (choices) of both the family and professional panel members, the following statements would be selected (table 7.24)

Table 7.24. Using a sliding scale as a form of selection for policy recommendations

<table>
<thead>
<tr>
<th>Ranked order by panel members</th>
<th>Level for implementation</th>
<th>Family panel members</th>
<th>Professional panel members</th>
<th>Cumulative number of statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st choice</td>
<td>1st level</td>
<td>42</td>
<td>45</td>
<td>2</td>
</tr>
<tr>
<td>2nd choice</td>
<td>2nd level</td>
<td>42:34</td>
<td>45:54</td>
<td>4</td>
</tr>
<tr>
<td>3rd choice</td>
<td>3rd level</td>
<td>42:34:26</td>
<td>45:54:5</td>
<td>6</td>
</tr>
<tr>
<td>4th choice</td>
<td>4th level</td>
<td>42:34:26:43</td>
<td>45:54:5:13</td>
<td>8</td>
</tr>
<tr>
<td>5th choice</td>
<td>5th level</td>
<td>42:34:26:43:17</td>
<td>45:54:5:13</td>
<td>9</td>
</tr>
</tbody>
</table>

At the fifth level, the symmetry of selection is lost. The reason being that whilst statement 17 was accepted as the fifth choice of the family panel members, the fifth choice for the professional panel members (statement 34) had previously been selected as the second choice of the family panel members. Therefore statement 34 had been allocated at the second level. It was therefore appropriate to stop at level five, for at the sixth and subsequent levels, statements had already been selected at previous levels.

There were several benefits in adopting this approach:

- Balance was given that reconciled the differences in perspectives of both the family and the professional panel members;
- The opinions of both the family panel members and the professional panel were respected;
• The number of statements selected by those responsible for implementing policies can be at the appropriate level according to local need and existing provision;
• A wider range of policies could be suggested (nine as opposed to the seven statements when using the other approaches);
• It can be seen as a generalisation of the various approaches discussed above as it can accommodate all the statements that could have possibly been selected under different scenarios, with the addition of statements 17 and 43;
• Adaptability and flexibility of its implementation under different circumstances.

The merits of adopting a sliding scale therefore recommend its implementation for making policy suggestions.

Conclusion

A comparison of the groups in Round One showed that panel members had prioritised the same groups of statements. Whilst it was recognised that the panel contained two groups nevertheless there was confidence that the panel could be treated as a whole. In Round Two of the study (the breadth versus depth debate), results indicated that a high level of consensus and support for the statements was achieved, thus giving confidence in the discriminating selection method using the three rules identified on page 200.

In Round Three regarding the decision on the extent to which families would benefit, (the depth dimension), there was no significant correlation between the family and professionals panel members indicating that actions were taken independently of each other (see page 236). Weak and insignificant similarities were observed. For example, in the following statement,

*The continued use of, and preferably expansion in the use of, evidenced-based guidelines for the care and treatment of children with cancer. (Statement 51)*

Both families and professionals ranked statement 51 in 11th position but awarded geometric mean scores of 736 (family panel members) and 634 (professional panel members) respectively. Yet this was the one occasion they agreed in terms of ranked order. The extent of their dissimilarity was evidenced in the following statement,
An attempt to avoid the problem of late diagnosis by providing specialised training for GPs in spotting childhood cancer. (Statements 42)

Family panel members had ranked this statement as their premier statement with a geometric score of 1673 whereas the professional panel members ranked this statement at sixth position with a geometric score of 727. Conversely, professional panel members ranked the following statement as their premier statement with a geometric mean score of 892,

*Older children should be treated and cared for in an adolescent unit and younger children cared for in an environment appropriate to their age.* (Statement 45)

However, the family panel members ranked this statement at 14th position with a geometric score of 597.

The implementation of the sliding scale meant that it was possible to reconcile these differences and provide suggestions for policies that respected the opinions and experiences of both family and professional panel members.

In the next chapter, the relationship of the statements to the professional literature, charity leaflets and the framework of ‘Partnership in Care’ will be discussed in Chapter Eight.
CHAPTER EIGHT
SYNTHESIS OF DATA SOURCES

Introduction

The anticipated outcomes of this study were policies that could promote some degree of normalisation throughout the turbulent trajectory of the illness, thereby attempting to improve the quality of life for families with a child who has cancer. Had the opinions of family members in isolation been sought, any potential policies proposed from this study would have ran the risk of rejection, justifiably citing bias by presenting the views of only one group of stakeholders concerned with cancer care in children.

In order to avoid this imbalance, data obtained from three sources (Professional literature, charity leaflets and a Delphi study) were collected incorporating three different perspectives. The use of the professional literature was based on the assumption that good practice was being reported, the charities leaflets had addressed the needs of the family and a Delphi study represented the views of the breadth of experience accrued by the professionals and the intense personal experience of the family members.

Sandeloweski (1986) argued that the criteria of confirmability, auditability, creditability and fittingness should be applied to test the rigor of qualitative research (page 42). The use of the framework ‘Partnership in Care’ demonstrated that these criteria were evident during the synthesising process of the triangulated data (See Figure 1.1). For example, the rigorous data collection methods described in Chapter Three (pages 49) enabled this researcher to undertake the synthesis efficiently and effectively. This could be seen for example in the unique identity of each statement (see page 248). In addition, another reader or researcher would be able to follow the audit trail successfully. Further evidence of meeting the criteria identified by Sandeloweski (1986) was demonstrated by the ease in which it was possible to synthesise the three data sources, for example, in the section ‘Information’ (page 254) in which it was possible to mirror and match the data.
Any resistance or attempts to force the data into an inappropriate fit would have showed, as with the previous frameworks (page 19).

**Implementation of government directives for partnership in care**

The main policies of government in supporting families with children who have cancer have been stipulated in the implementation of directives advocating partnership in care. This approach is intended to help the family by giving them a voice thereby ensuring that they are able to participate as equal partners in care. This is embodied in their participation as informed, decision-makers and empowered parents. In a document, Shifting the Balance of Power (DoH 2002, Section ‘Working Differently’) that directs changes in the NHS, it was seen that such changes required a culture that provided mutual respect across all levels that focused on the needs and concerns of the patient. These principles were made clear in the following statements.

“*Our goal is to move away from a paternalistic model of decision-making towards a model of partnership, whereby citizens have a greater connection with their local services, and have a say in how they are designed, developed and delivered.*” (Number 64)

“*More information will be made available to patients on the services offered by the Trust and patients views of them.*” (Number 67)

“*These local reviews will provide the basis for change, and further action at national and local level will promote the involvement and empowerment of patients and staff in all levels of NHS decision making.*” (Number 58)

In addition to The NHS Plan (2000), the National Assembly for Wales initiative (Improving health in Wales: a Plan for the NHS With its Partners 2001) also made it clear that,

“*The new NHS will enter into a partnership with the people of Wales so that each citizen and each community is helped to play a role, directly or through bodies representing them, in the development of health policy, the setting of aims for the NHS, the improvement of health and well being and the narrowing of health and social inequalities.*” (paragraph 1 page 31)

In addition it was noted that,
“Attention will be paid to involving patients more in decisions about their care and in providing adequate evidence to help patients make informed decisions.”
(Paragraph 4, page 31)

Furthermore, the National Assembly declared itself to be

“...determined to further improve joint working to create a health and welfare system that is truly accessible and responsive to individuals, carers and families, and which provides seamless continuity of care.”
(Paragraph 2, page 37)

The government is clearly committed to involving patients and their carers as partners in their care. However, what is not clear is the extent to which the rhetoric is actualised and in the context here, the degree to which families of children with cancer are participating as partners. It is agreed that families can participate in care at many different levels, for example, feeding and, by contrast, deciding to stop active treatment. However, families’ participation as equal partners can only be realised through the achievement of the provision of greater information, involvement in decision-making that results in families experiencing empowerment. It can be seen therefore that there is a logical progression of the concepts, in which one follows the other. For example, decisions cannot be made without the availability of relevant information to the families concerned. Equally, parents cannot be empowered until they have been informed and are able to make decisions based on that information.

Synthesis

The synthesis will be based on those links established from the three sources of data and taken specifically from three of the six categories namely ‘Communication and Cooperation’, ‘Maintaining Normality’ and ‘Professional Issues’ located in the three sources of data. In the next section, a debate on whether parents are participating as equal partners in care is presented based on the three framework concepts of information, decision-making and empowerment.
Parents as partners in care?

It is clear that the government directive proposes that parents as partners in care need to be informed, involved in decision making so that they can be empowered to actively participate (DoH 2000). Yet it seems that there is no clear consensus on what parental participation means (Coyne 1996). Participation is argued on an *ad hoc* basis rather than on planned negotiations (Evans 1994). There is no explicit commitment to family involvement, yet it is also the case that families have a limited level of expectation at the level of partnership. Subsequently, there is a gap between professional understanding of parents' experience, from their perspective. Evans (1994) has noted that negotiation to foster mutual understanding between families and healthcare professionals is fundamental to a successful outcome of parental participation. Such negotiations would take account of the emotional component of the family's experience. The question needs to be asked of how families actively participate when they are vulnerable, fatigued, worried and stressed (Koocher & O'Malley 1981; Stein *et al.* 1989; Faulkner *et al.* 1995; Clarke-Steffen 1997).

Using 'Partnership in Care' to validate family's participation as equal partners

The arguments raised above are now discussed and validated in this section using the three data sources.

*Using parents as much as possible not only in decision making, but also as partners in caring.* (Statement 54 Round Two Questionnaire, Appendix)

*An attempt to avoid the problem of late diagnosis by providing specialised training for GPs in spotting childhood cancers.* (Statement 42)

In looking more closely at the Delphi study findings of family views, it was found that the statement recognising parents as partners was prioritised as the eighth most important statement of the 15 in Round Three. By contrast, the professionals prioritised this statement as the second most important.
However, the professionals gave low priority (14th out of 15) to training courses for staff in promoting a greater awareness of the impact of the disease on the family, in marked contrast to the families who rated this statement as the fifth most important statement. It is possible that the professionals prioritised this statement as this is a policy directive they must be seen to be implementing. However, how committed they are in doing so is questionable given that they did not prioritise the importance of training in understanding more the impact of the disease from the family perspective.

In looking at the other data sources there is much discussion in both the professional literature and the charities leaflets about supporting families during the emotional turmoil and in raising awareness of family stress. Indeed the charities noted their readiness to fund events and scholarships in order to improve the knowledge base of the professionals. In the professional literature data collection there were 43 publications that identified a range of stressors, twenty-five were associated with day-to-day living such as managing the home and treatment regime, 20 referred to the emotional stressors involved with caring for a sick child, other people as stressors accounted for 15 publications and eight noted the stress involved in trying to rationalize the diagnosis.

It was evident from the charities leaflets that there was a gap in the knowledge base of the professional that they were prepared to fill. Publications within the data source provided by the professional literature showed that the professionals were aware of majors stressors, but it is not conclusive whether any attempt was made to incorporate this awareness further into the care. Clearly, the evidence of the panel members in this study represents incongruence in perceptions between the families and the professionals. Whilst the professionals prioritised parents as partners in care, for the families this was not such a high priority.

An important observation in all three sources of data was that parents are valued differently. This was exemplified in the problem of perceived delay in diagnosis. In the Delphi study, families gave high priority to avoiding a late diagnosis whereas the professionals ranked this statement as 6th out of 15.
However, there were 12 publications that referred to the angst families experience when they perceive the diagnosis has been delayed. It was suggested in the professional literature that in easing the pain of parents through the initial stages of childhood cancer, care and attention needed to be paid to the difficulties associated with perceived late diagnosis (Koocher & O'Malley 1981; Bignold et al. 1994; Eiser et al. 1995; Faulkner et al. 1995; While et al. 1996a, While et al. 1996b). It was also suggested that when the health care professionals were developing care plans, particularly at the time of diagnosis, an account of prediagnostic distress was needed. Several authors suggested that many families struggled to convince health care professionals that their concerns for their child's health were serious and merited attention (Koocher & O'Malley 1981; Bignold et al. 1994; Cohen 1995; Faulkner et al. 1995; While et al. 1996a, While et al. 1996b). Thus, the time between first presenting with concerns to the delivery of diagnosis was perceived as valuable time lost before treatment began.

Yet it is important to keep a balanced perspective. So far, a considerable proportion of the parents in the study samples in the professional literature experienced dissatisfaction during the prediagnostic stage. However, the experiences cited above represented a tendency not a certainty. This was not the experience of all the sample families in the studies mentioned. Although in the While et al. (1996a) study, it was clear that 36% of families perceived a delay of seven months or more, 33% experienced a delay between one and six months.

However, 31% did not experience a delay. That is, between the time the families suspected a serious health problem to the diagnosis, the delay was less than one month. In the report by Sloper (1996) for example, if over half the families (57%) reported a perceived delay in the diagnosis, presumably the other 43% did not. If they had experienced problems, they were possibly not important enough to mention. Similarly, Faulkner et al. (1995) noted that 53% experienced difficulties in the prediagnostic stage but again, presumably 47% did not or it was not considered sufficiently important to comment upon. As Faulkner et al. (1995) observed, not all comments about this stage were negative.
This was evidenced in parental appreciation of the doctor in that study who had been attentive and alert to the presenting problems. The vigilance of the doctor (on that occasion an Accident and Emergency doctor) resulted in a swift referral to a specialist.

The plight of GPs also needs to be given consideration. First, it is reasonable that GPs have a limited knowledge of childhood cancers. The very title ‘general practitioner’ implies that doctors working in the community are expected to have an overall knowledge of a range of illness for a broad age band of the population. The rarity of the illness means that GPs see very little (if any) childhood cancer during their careers. This is exemplified in a statement from a GP in the Faulkner et al. (1995) study, who noted that in the 25 years he had been in practice, he had only seen three children with cancer. Moreover, the vast range of common signs and symptoms associated with childhood cancer can compound the situation and can be complicated even further.

As for the current study, some of the children were not only suffering from a rare childhood illness but were diagnosed with particularly rare types of childhood cancers. It was quite reasonable therefore, that the GPs exemplified by the one cited above, do not know that the presenting symptoms were indicators of serious illness. Second, GPs are human beings and therefore subject to human fallibility. This means that they are not immune from events that the public experiences. This is not to overlook inattentiveness, but rather to recognise that GPs are subject to the fatigue, stress and strains of everyday life. Third, is the dilemma a GP faces in decision-making (Buckingham & Adams 2000).

Nationwide, the ratio of a child developing a childhood cancer is approximately 1 to 600. If almost all children develop common childhood scrapes and ailments at some time in their childhood, for every 600 children who present with symptoms resembling a childhood cancer, one will have a positive diagnosis. It is possible that the child with an underlying malignancy will be the fourth, fifth, sixth child the GP has seen during a day with a raised temperature, sore throat or poor appetite.
This may be particularly so during winter outbreaks of ‘flu’. In their decision making the GP faces four difficult scenarios. One scenario is that the GP make a provisional diagnosis of ‘flu’, but subsequent investigations confirm a childhood cancer is present. In a second scenario, it is also possible that a GP will think provisionally a child has a malignancy, but subsequent investigations show that no malignancy is present (this is usually referred to as the Type I error). Yet in a third scenario, the child may have aggressive or advanced disease and the GP will provisionally think a child has a malignancy, and subsequent investigations show that malignancy is present. Finally, in a fourth scenario, the child has symptoms present, the mother has been advised not to worry, (that there is no underlying malignant pathology), and the doctor has not been right in their judgement. This is known as the Type II error. These possible scenarios are reproduced in table 8.1.

Table 8.1. Possible scenarios facing GPs in decision-making

<table>
<thead>
<tr>
<th>GPs decision</th>
<th>Cancer</th>
<th>No cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>The child has a cancer</td>
<td>True Positive</td>
<td>False Positive</td>
</tr>
<tr>
<td></td>
<td>Diagnosis confirmed</td>
<td>Diagnosis not confirmed</td>
</tr>
<tr>
<td>The child has NO cancer</td>
<td>True Negative</td>
<td>False Negative</td>
</tr>
<tr>
<td></td>
<td>Diagnosis confirmed</td>
<td>Diagnosis not confirmed</td>
</tr>
</tbody>
</table>

Therefore if GPs are too liberal with making provisional positive diagnoses, which in turn do not result in the confirmed diagnosis of childhood cancer, they will cause unnecessary stress and anxiety to families. By contrast, GPs would not want to make true negative diagnoses.

Clearly there is an important disparity and the implications of a perceived delayed diagnosis were seen to be three fold. One was seen where parents no longer trusted their own judgements (Cohen 1995) thus reducing their confidence to participate in care.
A second was seen, for example, in the parents' emotional response to the illness, and the way parents respond when faced by the person who confirms their worst fears. Anger, mistrust of health care professionals and the fear that the delay might prevent the disease from responding to treatment were cited (McKay & Hensey 1990; Eiser et al. 1995; Faulkner et al. 1995; Sloper 1996; Eaton 2002). Eiser et al. (1995) also noted that even after two years, fathers who blamed doctors for failing to diagnose the illness also found medical staff less helpful in general. Third, there was the potential for care to be jeopardised if negative feelings towards the GP were not resolved when the family returned to the community to continue care. Eiser et al. (1995) implied that quality of care was potentially put at risk when families have negative feelings towards a health care professional, (often the family’s GP), and they suggested that regional units were suitably placed to assume some of the responsibilities for helping to resolve these negative feelings.

The experience of the health care professionals in the regional units meant that it may be possible to put into perspective misgivings about the perceived incompetence surrounding the diagnosis of such a rare condition and to deal with the complex reactions of parents to the diagnosis. However it was also acknowledged that nurses did not always develop skills to negotiate conflict situations. Therefore it is unsurprising that implications of parents not trusting their own judgements, the impact of their emotional response and their negative attitude towards their GP are not conducive in facilitating an equal partnership and the parents.

It was noted earlier (Chapter Three page 50), that the start date for the data collection would be 1980 in order to include the work from pioneers in childhood cancer. It was therefore disturbing to note that several years after Koocher & O’Malley (1981) reported that parents felt that the health care professionals had not listened to their prediagnostic concerns, which resulted in a perceived late diagnosis, more recent studies described a similar phenomenon (Soutter et al. 1994; Faulkner et al. 1995; Sloper 1996; While et al. 1996a & 1996b; Eaton 2002).
Information

Care organised by regional, specialist oncology centre and delivered into the community by staff from the regional centre. (Statement 5)

A named key worker who would be responsible for the coordination of the whole treatment programme. (Statement 34)

Improved communications between hospital and community services to ensure better follow-up. (Statement 26)

Parents must be participating as equal partners in care, need to be informed and involved in decision making so that they can be empowered to actively participate. In order for parents to be partners in the care of their child with cancer, they need to be participating as informed parents. Information should be given to families in a sensitive and effective way that the family can understand. There are several important considerations in information giving to parents with children who have cancer, or indeed any life-threatening disease as there are differences in professionals’ perceptions of parents when providing information and for those parents who receive it. Cancer is a highly emotive and sensitive area, especially when it involves children. Therefore achieving the right balance of giving appropriate information requires skill so that families are not overburdened with more than they can cope with.

In the Delphi study, within the nine most prioritised statements, both families and professionals identified a need for continuity of seamless care, involving a key worker to co-ordinate care from the regional unit. These findings are well supported in both the professional literature and the charity leaflets (Hunt 1995; Bignold et al. 1994: Leaflets A10 and 28). Yet there were differences between both perspectives.

For example, families had prioritised improved communications between hospital and community services priority (three out of 15) yet this was a low priority for the professionals (10 out of 15). It was also interesting that the professionals gave a low priority (13 out of 15) to informing the pharmacy when a child is ready for discharge as opposed to the families who placed this seventh.
This is perhaps a situation that could foster irritation if the anticipation of returning home is thwarted by having to wait for drugs to be dispensed.

For the families, it is difficult to communicate during times of heightened emotions when communications can be less effective. Decisions have to be made at critical points in the illness when parents are given complex information and asked to make decisions about their child's life whilst in a highly anxious state. Health care professionals therefore seek to involve parents and where possible, the child/adolescent, in decisions associated with their care. However, this can become problematic when all three parties view the situation differently (Hind et al. 1997).

Understanding of the disease was a major task for parents (Eden et al. 1994; While et al. 1996a; Bailey & Caldwell 1997), made easier with input from professionals in conjunction with written information (Glazer-Waldman et al. 1987; Dolgin 1990; Melville 1997). A fuller understanding of the disease was possible for parents when written information in the form of booklets was given. They were seen as a valuable adjunct to written information, but with the caveat that they should not be used as a substitute for on-going communication with the health care professionals. This was clearly supported by the volume of statements (n=1537) in the charity leaflets particularly in relation to the information about the disease and the glossaries explaining and interpreting some of the language families would have to learn.

The role of the key worker (Pearce et al. 1994) is essential in planning and coordinating care both efficiently and effectively. They are an invaluable resource within the Primary Health Care Teams (PHCT) and can be instrumental in reducing the number of visits the family have to make to the regional unit.

Frequently there were calls for a skilled and knowledgeable key worker who would be available on a 24 hours seven days a week basis (Soutter et al. 1994; Thornes 1997) and able to liaise between different agencies, coordinate service provision and become a focus for references for various concerns.
However, in a study that included four Regional Health Authorities, While (1996a) (n=99) noted that in reality of all the families in that study, less than one third has been assigned a key worker. Similarly, Thornes (1997) noted that it would seem that despite considerable endorsement for the role of a key worker, their role is inconsistent. Although it is not possible to generalise from these two examples, it would appear that the work of key workers is not being undertaken.

Decision making

* A conscious effort to ensure that children with cancer remain in touch with their peer group. (Statement 52)

* Provision to families of more accurate and up to date information than is currently available. (Statement 27)

* Emergency contact number 24 hours a days, seven days a week. (Statement 13)

* The continued use of, and preferably expansion in the use of, evidence based guidelines for the care and treatment of children with cancer. (Statement 51)

For decision-making, the benchmark to be achieved is that of a shared decision making model in which the autonomy of the family is recognised and a collaboration is formed. It therefore follows that the recommendations parents receive from the professionals as well as the child’s decision are the most important factors in their decision-making (Harrison *et al.* 1997). However, similar to the giving and receiving of information, it is acknowledged that families and professionals will consider different factors from different perspectives. For the families, there is also a new language to learn, as well as new information to absorb. They also have the emotional devastation component to contend with (Aranda 1992; Eden *et al.* 1994; Faulkner *et al.* 1995; While *et al.* 1996b).

There is also a variation in the way some parents prefer an active, passive, or some form of shared decision-making role (Arora & McHorney 2000, Bruera *et al.* 2000). Some parents want to be the sole deciders while others take a different view.
This is exemplified in a study of 1012 women with breast cancer, whereby 22% wanted to select their own treatment, 44% wanted to collaborate with their doctors in the decision and 34% wanted to delegate responsibility for decision making to their doctor (Degner et al. 1997). Clearly an individualised approach is needed when involving families in the decision making approach. For some families, feeling supported and trusted by the professionals is an important factor.

It should perhaps be remembered that the process of participating in the Delphi study was, in itself, part of a decision making process. Families had the opportunity to generate statements from topics they considered to be important in giving them a voice. Therefore, from their experiences, they were identifying important elements of care. They then decided on the breadth dimension and in Round Three made a valued judgement via the MRS scale on the priorities of those statements. They were therefore prepared to make decisions on what was important to them and what was not. This was seen in the statement that advocated for the child to remain in contact with his/her peers. In a non clinical arena, where families were in control of their personal family decisions, they made it clear that this was not a high priority in the care of their child, for it was ranked the lowest of the 15 statements in Round Three. Furthermore, it was contrary to the advice given in the charity leaflets. However, paradoxically, it was also interesting to note that statements that would involve them in the decision making process, concerned with clinical care, received low priority.

This was seen in three statements. The statement that provided for the availability of expert advice was ranked nine out of 15 by the families and the statement to provide for 24-hour emergency contact seven days a week was ranked 10th out of the 15 by the families. In contrast however, it was the fourth prioritised statement for the professionals. This again raises the issue of the influence of professional publications as a medium for raising awareness on the professional matters, for this element of care was highlighted by the UKCCSG (1997). Likewise, the families ranked the statement providing evidenced based guidelines for care, 11th out of 15. However it was also interesting to note that evidence based guidelines for care were also prioritised by the professionals at 11th out of 15.
This highlights the following scenarios:

- This was part of the family's decision process;
- Having to make too many decisions was not high on the families' list of priorities.

Subsequently, the family members in this study were prepared to abdicate some degree of their decision-making powers to the professionals as indicated in the professional literature above (Degner et al. 1997; Arora & McHorney 2000; Bruera. 2000).

Despite the influence of professional publications highlighting professional matters, the professionals placed a low priority on the provision of evidenced based guidelines for care. It is possible that they felt it was already known and the evidence based guidelines for care were functioning and that other statements not in current practice needed to be highlighted and this was an opportunity to do so.

**Empowerment**

*Training courses for health care professional to increase their awareness of the impact of the child's illness on the family. (Statement 17)*

*Ensure that provision for overnight parental stays is genuinely of a home-from-home nature. (Statement 43)*

*Older children should be treated and cared for in an adolescent unit and younger children cared for in an environment suited to their age. (Statement 45)*

*Care organised by regional, specialist oncology centered and delivered into the community by staff from the regional centre. (Statement 5)*

The aim of empowerment is to accept and respect the family's choices with the establishment of effective two-way communication. This is of particular importance for families in which a child has cancer. Advances in treating childhood cancers have helped the number of children surviving the illness to rise (Stiller & Bunch 1990).

However, the weight of responsibility for the care of these children has fallen increasingly on the parents, particularly mothers.
Although this presents families with many challenges, nevertheless, most are able to adapt and develop a sense of control over their lives, allied with the concept of empowerment. This has been described by Gibson (1995) as a personal process in which individuals developed and employed the necessary knowledge, skills and confidence to make their voices heard. The factors involved were ‘discovering reality’, fuelled by frustration that brought about ‘critical reflection’. This led to parents ‘taking charge’ of their situation as a result of the power they have gained. Participatory competence, being the ability to be heard by those in power, was the outcome of the process. Gibson (1995) made the observation that this was partially intrapersonal and interpersonal experience and that clearly, these processes of empowerment are intertwined.

Although parents have confidence in their own ability and trust in the care provided for their children, nevertheless they feel powerless if they are not part of the decision-making process (Nordgren 2001), which is a crucial step in the process of participation. Lack of information and knowledge about medical and nursing interventions, failure to discuss with parents their role in the care of their child will contribute to feelings of powerlessness thus impeding parents ability to participate (Dearmun 1992; Darbyshire 1993).

Conversely however, there are those families who do not want to be fully involved in the care and are exercising their choice. There is a need for families to receive personal attention, adequate explanations and be treated sensitively. Therefore, there is a requirement that professionals accept and respect the families’ choices (Smith 2002). This would be seen, for example, in families following the implementation of Leino-Kilpi’s (1999) dimension of empowerment (see Chapter 2 page 39) whereby the resulting expectations from empowerment require the following areas of provision:

- Flexible access to health care;
- Adequately trained and accountable practitioners;
- Information on the diagnosis so that informed choices can be made;
- Respect, advocacy and encouragement;
- Being listened to by the professionals;
- Continuity of care;
- A clean and peaceful environment.
In terms of professionals accepting and respecting the families' choices, one of the prioritised statements of the families was that of training courses for health care professionals to increase their awareness of the impact of the child's illness on the family. The family panel members ranked this statement as fifth in their order of priority, clearly an important issue to them. However, for the professionals this was their penultimate lowest ranked statement.

From the Delphi study, there were clear indications that the professionals want parents as partners as this was the second priority for the professional panel members. However, in contrast, the parents placed this statement in eighth position out of the 15, and although it held a similar value as the professionals (893 families: 882 professionals) the families geometric mean score was half that of their highest scoring statement (1673). The position adopted by the families therefore appears to be one of wanting the opportunity for partnership but not according it the level of importance given to the previous seven statements.

The wide divergence in perspectives is clearly demonstrated in the next figure (8.1) in which the differing prioritisation of statements is shown between the professionals and the families.
Differences in the ratings of the 15 statements between the professionals and families are represented in the figure above. In this, each point refers to a pair of ratings of professionals and families. For example, the professionals rated statement 42 (an attempt to avoid the problem of late diagnosis by providing GPs with training) as 6th out of 15 whereas the families rated it as the highest priority, 1. The further apart the point from the central line, the larger the disagreement on prioritisation.

In looking at these differences in more detail, is that of the statement providing for the overnight stay for families and age appropriate environment for care. The benefits of overnight accommodation or home-from-home accommodation have been highlighted in the charity leaflets but were not apparent in the professional literature.
This was mirrored in the findings of the Delphi where families ranked it fourth priority but the professionals ranked it 15th. It was noted in the statements from the charity leaflets that home-from-home type of accommodation made a considerable financial saving for families. This is even more revealing when statement one and four of Round Two were examined (see Appendix 15). These statements made provisions for financial help for families when a child develops cancer, however they failed to meet the PNB rules in Round Two, mainly because the rating by the professionals was low. Similarly intriguing was the penultimate lowest rank given by families to the provision of age appropriate environment for care.

It was apparent that the professionals had prioritised the need for age appropriate environments given that it was a policy directive (Burr 1993; Welsh Office 1997; Viner & Keane 1998). However, this was not apparent in the families rating. There are two suggestions why this should be so. Firstly, parents were unaware that they could request separate facilities for their children. Second, the children in the families involved in this study were young and had not reached their teen years. Therefore the problems of inappropriate facilities on adult wards or crying toddlers in paediatric units had not as yet proved problematic.

Conclusion

A partnership is based on the assumption that both parties are willing and able to participate. However, a partnership with parents in the care of their child is based on the understanding that all parents are willing and able to carry out the type of care needed, that professionals are willing to share their contribution to that partnership and there is congruency in the aims and perspectives for both.

The process of synthesising the three sources of data for this study has demonstrated the emergence of different perspectives of families and professionals as a clear theme. From the professionals' perspective, clinical issues i.e. adolescents cared for in an age appropriate environment and emergency contact were prioritised. However, the families' priorities were explanations and communication aspects of coordinating care, perceived late diagnosis, understanding the families' perspective, and improved communications between primary, secondary and tertiary sectors.
It is clear that the government directives are not meeting what parents are saying they need. It is difficult for parents to be partners because there is incongruence between the perceptions of the professionals and those of families. Two examples of this were demonstrated by a low priority given by the professionals to the training courses that would help them better understand the impact of the disease from the families perspective. A second example was seen by the lowest priority given by the professionals to overnight accommodation for parents.

One could argue that if parents are not on site at a time when a decision needs to be made, it is possible that they would not be involved in that decision-making, especially during an emergency situation. It is hoped therefore that the findings and recommendations derived from this study will make a significant contribution to the understanding, planning and management of the provision of care with respect for the family needs in a non-judgemental atmosphere as the focus.

In the next chapter, Chapter Nine, the conclusions and recommendations are presented.
CHAPTER NINE
CONCLUSIONS AND RECOMMENDATIONS

The diagnosis of a child with cancer is devastating and traumatic for both the child and their family. In the early days of the illness, its impact is seen in the way families have to adapt to the harrowing treatment regimes with the subsequent disruption to family life. Despite the substantial improvements in the prognosis during the last 20 years, childhood cancer remains a significant life threatening condition with an erratic course. Even if the outcome of treatment is long-term remission leading to cure, there is always the fear of its return or the development of a second primary cancer. Ultimately with the failure of the treatment regimes, the family is faced with the impending death of their loved one.

This study was initiated to identify the essential elements of care that are needed as families progress through their experiences of childhood cancer. A tabula rasa approach was adopted in answering the question ‘what are the essential elements of care for families in which a child has cancer?’. In response to this, an innovative approach was adopted using primary (a Delphi study) and secondary sources (the professional literature and charity leaflets) and a framework, of ‘Partnership in Care’ based on government directives aimed at encouraging a greater participation of the family in the health care process. The framework was used as a means for comparison between the implemented directives of the government and the realities as experienced by the families in which a child has cancer. In comparing the rhetoric and the reality, it was clear from the data sources that a greater parental participation was only possible when effective information giving and receiving, shared decision-making, and empowerment to participate confidently in that care were present.

The use of the professional literature provided evidence of good practice. However, by examining the charity leaflets, it was clear that the charities were providing services not provided by the health professionals. For example, contact with support groups. The Delphi study, the third source of data, provided the opinions of two groups of selected experts so that, in a formalized way, there would be a prioritised consensus on the elements of care contained in the statements.
Given that the same coding framework for the three sources of data, had been used, it was possible to synthesise the three sources in a consistent way. On the basis of the three sources, elements of care were identified, categorized, prioritised, synthesized and enhanced by the process of triangulation.

The emergence of six main categories and their use across the three data sources meant that they could be effectively linked with the appropriate analytical framework of ‘Partnership in Care’, based on participation as partners and using the concepts of information, decision-making and empowerment.

By synthesising the three sources of data, it was clear that a difference in the perspectives of families and professionals had emerged. This was demonstrated by the clinical and theoretical approach adopted by the professionals, compared with the need for families to have communication and cooperation from the professionals in understanding the impact of the disease from their perspective. This incongruence was demonstrated by the low priority given by the professionals to the training courses that would help them better understand the impact of the disease from the families perspective and the provision of overnight accommodation for parents.

However, numerous books, articles, research projects and key-note addresses have produced a wealth of material providing the professionals with an understanding of how families experience illness and the many interventions health care professionals utilize in their work with families. Such a vast amount of material, (as evidenced by the conduct of this study), served to confirm the dedication of health care professionals in helping families meet the challenges posed by the illness. Similarly, the charities leaflets produced much information providing families with information, empathetic responses, contact and support from others in similar circumstances and needed financial help.

Commitment, dedication, good intentions and conformity with government directives are not disputed. However, the results of the Delphi study made it possible to provide the primary source of data in establishing whether the rhetoric of the government directives had been in reality successfully achieved.
During the analysis of Round Three, it became apparent that what was intended to be a heterogeneous panel were, in reality, two groups of stakeholders with very different perspectives. Furthermore there was a considerable disparity between the perspectives of the families and those of the professionals. For example, the families had prioritised measures to avoid a perceived delayed diagnosis as opposed to the provision of age appropriate environment prioritised by the professionals.

It is therefore concluded that 'Partnership in Care' within the health care context may be the ideal framework for promoting a partnership between families and professionals. However, having presented the reality of the families experience in dealing with childhood cancer, it is clear that what is implemented as the ideal scenario is not what is needed.

**Recommendations**

**Education**

Families should not be placed in a position in which they are stereotyped and disempowered. The families in the Delphi study made it clear that a perceived delay in the diagnosis was a major factor contributing to their distress, particularly in the early prediagnostic stages of the disease. In support of this finding, the complaint of being stereotyped and of not being heard or listened to was strongly echoed in the professional literature.

The implementation of educational modules to help health care professionals improve their listening skills would be of benefit, not just to families in which a child is finally diagnosed with a cancer, but across the patient population in general. Educational departments should provide and regularly review opportunities for healthcare professionals with particular emphasis on GPs to improve their listening skills.

To help reduce parental distress and enable professionals to understand the impact of the illness on the family, the following two statements obtained from the Delphi study recommended:
An attempt to avoid the problem of late diagnosis by providing specialised training for GPs in spotting childhood cancers (Statement 42).

Training courses for health care professionals to increase their awareness of the impact of the child’s illness on the family (Statement 17).

It is important to note that although the role of the professional is demanding and at times harrowing, interestingly, the need for staff support was not identified by either of the groups. Without question, the professional support for the families can only be effective if they too are adequately supported and valued.

**Professional Input**

During the coding stage of the professional literature as the first data source, it became clear that the language used was often esoteric and open to different interpretations. This was demonstrated during the inter-rater reliability stage in which two health care professionals experienced difficulty in coding as they themselves were not sure of the meaning of the statements. By contrast, it was far easier to understand the statements from the charity leaflets. It is recommended therefore that if professionals wish to communicate more effectively with families, they need to communicate more clearly with their peers in the first instance.

It should be acknowledged that parents are authorities on their own children and that their status and views should be respected. Parents should not be in the position whereby they are unsure of their role in the care of their child. Greater participation in the care of their child with cancer is to be encouraged within the considerations of the three concepts of effective information giving and receiving, shared decision-making, and empowerment. There should be a better understanding of the relationship between professionals and families so that the ideals expounded in the rhetoric can move closer to reality.

Within this context of partnership in caring, the following statement is suggested:

*Using parents as much as possible not only in decision-making, but also as partners in caring (Statement 54).*
At the time of diagnosis, parents will need to learn as much as they can about their child’s condition. They will also be made aware of the existence of a number of professionals who work in the field of childhood cancers in regional units and who will be responsible for their child’s treatment. This enables them to work as a team in building on and sharing their expertise providing improved and consistent care. The perpetuation of the regional units and their contribution in advancing care was recognised in the request for,

*Care organised by regional, specialist oncology centre and delivered into the community by staff from the regional centre (Statement 5).*

With so many new professionals involved in caring for children, families need advocates to liaise between the hospital and their community and also encourage local healthcare professionals, to increase their expertise and maintain their skills. This is particularly relevant during times of crisis when the distance between regional units and family home could be considerable. Clearly, efficient liaison and good communications are essential elements of care as indicated in the following recommendations.

* A named key worker who would be responsible for the coordination of the whole treatment programme (Statement 34).

* Improved communications between hospital and community services to ensure better follow up (Statement 26).*

Advances in clinical practices have greatly improved the survival rates of children with cancer. Increasingly, children with cancer return home as soon as possible to continue with treatment, recover and attempt to regain their former lifestyle. Most families caring for a sick child at home need regular support. This is particularly so for the families with a very sick child. Whilst families may wish to care for their child at home, nevertheless, appropriate paediatric medical and nursing support was required and was recommended in the following statement:

*Emergency contact number 24 hours days, seven days a week (Statement 13).*
Most parents, when faced with a life threatening illness in their child, will want to nurse and care for them, often sacrificially. The provision of a home-from-home type accommodation close to the child will ensure families' participation in care yet continue some semblance of family life. This facility also means that they are able to take periods away from the wards for rest and relaxation and yet remain close at hand in times of crisis. It is therefore recommended that the following facility be provided,

*Ensure that provision for overnight parental stays is genuinely of a home-from-home nature (Statement 43).*

It was recognised that the needs of children were different to those of adults. Nevertheless, the child with cancer should be treated with the degree and respect accorded to adults. They may also need to participate in school or recreational activities. They should therefore be given the option of privacy, away from staff, other patients or their visitors in an age appropriate environment. A request for a separate adolescent unit was the highest rated by the professionals and was subsequently endorsed in the professionals’ literature. An age appropriate environment for children with cancer is therefore recommended.

*Older children should be treated and cared for in an adolescent unit and younger children cared for in an environment suited to their age (Statement 45).*

**Contributions to knowledge**

The distinctive and innovate design used in this study permitted the identification of elements of care by both families and professionals in an unbiased and comprehensive way which can be implemented for families in which a child has cancer.

Contributions of new knowledge to cancer care have included:

- A *tabula rasa* approach that produced a consensual prioritised list of elements of care that can be implemented on a sliding scale according to local needs and resources;
- Three different types of one primary and two secondary data sources have been used;
- The use of the professional literature provided a source of data;
- An extensive analysis of the service provision offered by the charities via the information leaflets provided to families;
- The Delphi study observed a disparity between the professionals and families perspectives;
- The unique method for rating the statements in round two (PNB);
- An uncommon method for ranking the statements in round three (MRS);
- The framework of ‘Partnership in Care’ was successfully adopted in linking the synthesis of results from three data sources and facilitating a comparison between the rhetoric of the government directives and the reality of the lived experiences of the family;
- The sliding scale provision for decision makers to concentrate on priority statements bases on available resources.

**Limitations**

Whilst the strengths of this study lay in the comprehensive approaches, the limited number of panel members, although sufficient in terms of a Delphi study, provided findings that are difficult to generalise. In addition, the family panel members were from one locality and received their care from one regional unit. Furthermore, with the exception of one family member, all were indigenous to their locality. A larger variation in the location of family panel members would strengthen future studies.

**Suggestions for future research**

Identifying the mercurial components of a beneficial working relationship between families and healthcare professionals is a challenging task. At times, the interaction between families and health care professionals is a source of great comfort and support, affording encouragement to families and satisfaction to the professionals. Clearly, the professionals in this study felt strongly about wanting to use parents as partners. Conversely, the relationship can be frustrating and on occasions hurtful, as evidenced in the Delphi study (Statement 42) and professional literature relating to a perceived delay in the diagnosis.
Following the overall disparity observed between the professionals and the families as evidenced by the Delphi study, a number of interesting areas could be suggested for further research. These may include:

- Subsequent investigation to examine aspects of parent care and their influences parent/professional relationships;
- Further verifications of the study results;
- Implementation of the outcomes of this work and monitoring and measuring its impact on family and professional relationships;
- Extension of the Delphi results and ensuring their generalisability through a broader participation for professionals and families with childhood cancer covering a broader geographical area as well as different levels and stages of the disease.
Professional literature as data


McKay, M., Hensey, O. (1990). From the other side: parents' views of their early


Royal College of Nursing Paediatric Oncology Nursing Forum (2000) *A framework* for developing practice in paediatric oncology, Royal College of Nursing, London.


281


Centered Nursing care of children. WB. Saunders Company, Philadelphia, PA, USA.


References


Department of Health (2002). 'Shifting the balance of power within the NHS'. HMSO. London.


289


mental handicap: A longitudinal study. Center for Health Services Research, George Allen Wing, Cornwallis Building, University of Kent at Canterbury.


Shelton, T.L., Stepanek, T. (1994) *Family-centered care for children needing specialized health and developmental services*. Association for the Care of Children's Health, Bethesda, Maryland, USA.


Stiller, C.A, (1994). Population based survival rates for childhood cancer in Britain,


Tomlinson, P.S., Harbaugh, B.L., Kotchevar, J., Swanson, L. (1995). Caregivers mental health and family health outcomes following critical hospitalization of a child,


Studies, King's College London. Department of Nursing Studies, King's College London.


Personal contact:

Hymovich, DP. (1998) Re: discussion of her framework that can be used to guide pediatric oncology nursing practice and research.

Thompson A. (2001) Re. An audit of palliative care services for children and families in which a child has cancer. A study undertaken for the UKCCSG and Paediatric Oncology Nurses Forum.
# APPENDIX 1

## CASP Proforma

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<tr>
<th>1. <strong>Was there a clear statement of the aims of the research?</strong></th>
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<td>• why was it important</td>
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<th>2. <strong>Is the qualitative method appropriate?</strong></th>
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<td>• If the research seeks to interpret or illuminate the</td>
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<td>actions and/or subjective experiences of the research</td>
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<td>participants</td>
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**Is it worth continuing with this study?**

<p>| 3. **Was the research design appropriate to address the aims  |</p>
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<td><strong>Consider</strong></td>
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<td>• If the researcher has justified the research design</td>
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<td>(e.g. have they discussed how they decided which methods</td>
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<p>| 4. **Was the recruitment strategy appropriate to the aims of  |</p>
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<td>• If they explained why they were selected, were the most</td>
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<td>• If there was any discussion around recruitment e.g. why</td>
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<td>some people chose not to take part</td>
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<p>| 5. **Were the data collected in a way that addressed the      |</p>
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<td>semi-structured interview etc.)</td>
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<td>• If the researcher has made the methods explicit</td>
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<td>(e.g. for interview method, is there an indication of</td>
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<td>how interviews were conducted, did they use a topic guide?)</td>
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<td>• If the methods were modified during the study. If so</td>
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<td>has the researcher explained how and why</td>
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<td>• If the form of data is clear (e.g. tape recordings, video</td>
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<td>material, notes etc.)</td>
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<td>• If the researcher has discussed saturation of data</td>
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| Comments |
6. Has the relationship between the researcher and participants been adequately considered?
Consider whether it is clear:
- If the researcher critically examined their own role, potential bias, and influence during:
  formulation of the research questions
data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?
Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g., issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous?
Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis of the data for presentation

9. Is there a clear statement of findings?
Consider
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g., triangulation respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research questions

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10. **How valuable is the research?**

   **Consider**
   - If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)
   - If they identify new areas where research is necessary
   - If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

   **Comments**
APPENDIX 2

CASP Categorization

Levels of Evidence

1-1  A well done systematic review of two or more Randomized Control Trials

1-2  A Randomized Control Trials

11-1 A cohort study

11-2 A case-controlled study

11-3 A dramatic uncontrolled study

111  Respected authorities, expert committees etc

IV   Anecdotal Information
### APPENDIX 3

**Content Analysis proforma**

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<th>An attribute of family-centered care in childhood cancer care is ..........e.g.</th>
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<th>Category code</th>
<th>A barrier to family-centered care in childhood cancer care is .......... e.g.</th>
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<td>02</td>
<td>II-1</td>
<td>C</td>
<td>&quot;lack of clear information&quot;</td>
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(2) Prefix before identifying barriers of family-centred care
APPENDIX 4 Professional literature

<table>
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<th>Judge 1</th>
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<td>Resources</td>
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<td>11</td>
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<td>Treatment</td>
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<td>160</td>
<td>10</td>
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<td></td>
<td>297 out of 435 = 68.3%</td>
<td></td>
<td>Blind agreement (Kappa) = 0.677</td>
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### APPENDIX 4. Charity leaflets

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Identical coding (diagonal entries) = 3616 (114) out of 3730 = 97%

Blind agreement (Kappa) = 0.958384

p < .001
APPENDIX 5

Details of the literature used as data

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CASP grades

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Country of origin

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APPENDIX 6
Letter to family panel members

Dear Mrs. Jones

Re. Elements of Care for Families in Which a Child Has Cancer

Thank you for agreeing to see me at your home on Monday, 22nd January 1999 at 4pm to complete the form for the study mentioned above. I anticipate I will be with you for approximately an hour in total. I appreciate your participation in this study that is examining the aspects of care for families in which a child has cancer. The study is supported by the Christian Lewis Trust and is being undertaken by a team at the University of Glamorgan. This study will need two or possible three visits in total. During the first visit I will invite you to complete a form in which you are asked to name five (5) important aspects of care when caring for a family in which a child has cancer. These five important aspects of care that you have identified will then be collected and placed into a second round questionnaire. In a second visit I will ask you to grade or rate these aspects of care in a questionnaire, there is a possibility that there will be a third round.

It is thought that your knowledge and experience will contribute considerably to this study and your participation would be gratefully valued. Information will be treated confidentially and the data analyst knows each participant only by a code number. A data base administrator keeps the actual names of participants separately, and those analyzing this data will have no idea which respondent completed which questionnaire. If we have to come back to you for any reason, the survey team will provide the database administrator with your code number and s/he will contact you.

A leaflet is enclosed giving you more detail about the study but if you have any queries please do not hesitate to contact me at the above address.

In order to indicate your willingness to participate I would be most grateful if you would complete the tear-off slip at the bottom of the page, enclosed is a stamped address envelope for your convenience.

Yours sincerely

Elizabeth A. Parry, RGN., M. Phil.
Ph. D. Student

Consent Slip
I wish to take part in the study project entitled Elements of Care for Families in Which a Child Has Cancer beginning in January 1998.

Signed................................................................. Date ............
Dear Colleague

Re. Elements of Care for Families in Which a Child Has Cancer

I would appreciate your participation in a study that is examining the elements of care for families in which a child has cancer. The study is supported by the Christian Lewis Trust and is being undertaken by a team at the University of Glamorgan and specific details are enclosed.

It is thought that your knowledge and experience will contribute considerably to this study and your participation would be gratefully valued. Please can you complete the white form with your comments as indicated. Information will be treated confidentially and each participant is known to the data analyst only by a code number. A data base administrator keeps the actual names of participants separately, and those analyzing this data will have no idea which respondent completed which questionnaire. If we have to come back to you for any reason, the survey team will provide the database administrator with your code number and s/he will contact you.

A leaflet is enclosed giving you details about the study and the Delphi approach but if you have any queries please do not hesitate to contact me at the above address.

In order to indicate your willingness to participate I would be most grateful if you would complete the tear-off slip at the bottom of the page, enclosed is a prepaid envelope for your convenience.

Yours sincerely

Elizabeth A. Parry
Ph. D. Student

Consent Slip
I wish to take part in the study project entitled Elements of Care for Families in Which a Child Has Cancer beginning in April 1998.

Signed....................................................................................................................................Date................................
APPENDIX 8

Information for family members

Title of the Study: Elements of Care for Families in Which a Child Has Cancer

- During the past twenty years care of children has developed in response to recognizing the importance of the family in providing care for children with cancer.

- The Audit Commission Study (Children first: a study of hospital services HMSO 1993) found that hospital staff do not give sufficient attention to the needs of children and their families. This was seen in a lack of written policies, management focus and poor communication between staff and parents. There is no reason to assume that the same is not the case for services in the home.

- This study tries to address the need to identify and assess the type of care required by families during the illness of their child.

- A team is being used for advice and guidance of this study that is designed in two parts.

- The focus of the first part is an investigation to discover the key elements of care for the family in which a child has cancer. This will be done by examining the magazines and journals of health care professionals and the leaflets of a number of childhood cancer charities. As the research develops key aspects of care in which a child has cancer should become apparent.

- In part two, the key features of care identified in the Delphi approach will be used to obtain a consensus view about the importance or otherwise of the features identified. The Delphi study is explained in a separate sheet.

- From these three sources (the professional literature, charities' leaflets and the Delphi study), it is hoped to establish key aspects of care. All the information will be collected together to form recommendations for care.

- In this study the question will asked, 'What are the key elements of care for the family in which a child has cancer?'

- This questions will be directed at:
  - parents and extended family members of children with cancer;
  - professionals involved in the care of children with cancer;
  - voluntary agencies involved in the care of children with cancer.

- The overall aim of this study therefore is to try elements of care recommended by you for the provision of care for families in which a child has cancer.
APPENDIX 9

Information for professionals

Title of study: Elements of Care for Families in Which a Child Has Cancer

- During the past twenty years a philosophy of care has developed that originated as a response to the acknowledgement of the centrality of the family in providing care for children with cancer.

- The Audit Commission Study (Children first: a study of hospital services HMSO 1993) found that hospital staff do not give sufficient attention to the needs of children and their families. This was seen in a lack of written policies, management focus and poor communication between staff and parents. There is no reason to assume that the same is not the case for services in the home.

- This research seeks to address the need to identify and assess the type of care required by families during the illness of their child as they progress through the cancer trajectory.

- A team is being used of this study that is designed in two parts. This research project is based on a team approach for advice and guidance, but using a Ph. D. studentship to investigate aspects of care for the family in which a child has cancer.

- The focus of the first part is an investigation to discover the key elements of care for the family in which a child has cancer. This will be done by examining the magazines and journals of health care professionals and the leaflets of a number of childhood cancer charities. As the research develops key aspects of care in which a child has cancer should become apparent.

- In part two, the key features of care identified in the Delphi approach will be used to obtain a consensus view about the importance or otherwise of the features identified. The Delphi study is explained in a separate sheet.

- From these three sources (the professional literature, charities' leaflets and the Delphi study), it is hoped to establish key aspects of care. All the information will be collected together to form recommendations for care.

- In this study the question will asked, 'What are the key elements of care for the family in which a child has cancer?'

- This questions will be directed at:
  - parents and extended family members of children with cancer;
  - professionals involved in the care of children with cancer;
  - voluntary agencies involved in the care of children with cancer.
• The overall aim of this study therefore is to try elements of care recommended by you for the provision of care for families in which a child has cancer.
Appendix 10  Demographic details of pilot study participants

<table>
<thead>
<tr>
<th>Age range</th>
<th>No. of panel members</th>
<th>Role</th>
<th>Eligibility</th>
<th>Employment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents 30-60 years</td>
<td>Parents n=2</td>
<td>Parent</td>
<td>Child had survived childhood cancer.</td>
<td>Parents: Part time</td>
</tr>
<tr>
<td>Sibling 18 years</td>
<td>Sibling n=1</td>
<td>Sibling</td>
<td>Sibling with a life threatening illnesses. Subsequently bereaved.</td>
<td>Sibling: Full time</td>
</tr>
<tr>
<td>Professionals 40-50 years</td>
<td>Professionals n=2</td>
<td>Teacher</td>
<td>Taught children with life threatening illnesses.</td>
<td>Professionals: Full time</td>
</tr>
<tr>
<td>Clergy</td>
<td></td>
<td></td>
<td>Hospital Chaplaincy and pastoral care of families experiencing life threatening illnesses in children</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX 11

Delphi Questionnaire Round One

You are invited to make five (5) clear statements in relation to the key elements of care you feel are essential in a service that supports families in which a child has cancer.

1.

2.

3.

4.

5.

Thank you

Please return in the addressed envelope
ABOUT THIS STUDY

STUDY AIM

To obtain an expert consensus view on the distinctive features of the care of families in which a child has cancer

HOW THE DELPHI TECHNIQUE WORKS IN THIS STUDY

- Uses questionnaires to seek the informed opinion of a panel of experts. You are considered by us to be an expert because of your experience.

- Provides the panel with feedback on overall group responses. Everyone's ideas are important so all ideas obtained will be shown to the panel, but no one will know where that idea has come from.

- Utilizes repetitive surveys (usually three rounds) to evolve a consensus view

APPENDIX 12

WHEN IS A DELPHI STUDY USEFUL?

- As a means of obtaining information on topics about which little is known.

- In defining concepts and determining priorities (Mead, 1993).

CONSTITUTION OF THE EXPERT PANEL

- Parents, grandparents, single parents, older siblings

- GPs, community nurses, teachers in urban areas

- GPs, community nurses, teachers in rural areas

- Clergy, doctors, nurses, pharmacist, physiotherapist, social worker working in a Regional Center.

- Doctors, nurses, dietitian, social worker working in a District General Hospital

- Commissioners and managers of services in Regional Center setting and District General Hospital

- Play therapist, psychologist, voluntary agencies, hospice staff

ADVANTAGES OF THE DELPHI TECHNIQUE

1. Increases respondent openness

- provides anonymity for individual responses

- decreases group dominance by individuals

- minimizes intimidation or conflict due to any different professional views
2. Conducive to individual thought
   • provides an opportunity for thoughtful reflection
   • reduces researcher and respondent bias which might stem from subjectivity, and failure to listen

3. Practical benefits
   • eliminates the time and cost constraints of a group meeting together
   • enables wide geographical representation on the panel

Contact person for either more information about the study or the Delphi approach is:-

Elizabeth Parry
University of Glamorgan
School of Nursing and Midwifery
Research Unit
GlynTaff
Pontypridd
CF37 1DL

Tel: 01443 483114
Fax: 01443 483113
Email: nursesec@glam.ac.uk

DELPHI REFERENCES


• Mead D (1993) The Development of Primary Nursing in National Health Service Care Giving Institutions in Wales.
APPENDIX 13

Letter of thanks to family panel members

Dear Mrs Jones

*Re. Elements of Care for Families in Which a Child Has Cancer*

Thank you for agreeing to take part in the above study. Most replies have now been received and the information is being analyzed. If you have not sent your first round reply yet it is still not too late.

I hope to be in contact with you in the early autumn with round two of the Delphi study.

In the meantime thank you for your help and cooperation, your continued participation will be greatly valued.

Yours sincerely

Elizabeth A. Parry
APPENDIX 14

Letter of thanks to professional panel members

Dear Colleague

Re. Elements of Care for Families in Which a Child Has Cancer

Thank you for agreeing to take part in the above study. Most replies have now been received and the information is being analyzed. If you have not sent your first round reply yet it is still not too late.

I hope to be in contact with you in the early autumn with round two of the Delphi study.

In the meantime thank you for your help and cooperation, your continued participation will be greatly valued.

Yours sincerely

Elizabeth A. Parry

Ph. D. Student
Appendix 15

Delphi Questionnaire Round 2

Elements Of Care For Families In Which A Child Has Cancer

We wish to estimate the importance of each of the statements that emerged from round one of this study. To do this we would like you to state what approximate proportion of families in which a child has cancer are, in your opinion, likely to benefit substantially from each of these statements. To enable you to do this as simply as possible, we have, beside each statement, provided a series of tick boxes.

A tick to the leftmost box would indicate that you think that literally all families of children with cancer would benefit from the policy stated to the left. If you think that most, but not all, such families would benefit tick the second box from the left. If, by contrast, you think that the statement would benefit only a few (or none) of the families, tick the boxes towards the right hand side of the scale. Each of the boxes is labelled at the top of each page.

Clearly, many of these statements will be important to substantial numbers of families, and there will be a temptation to rate them highly. However, any policy development resulting from these statements has to be selective (we have to do some items first, others later). It would be helpful if you think very carefully and use the ‘all’, or ‘most’ categories only when you are really convinced that the benefit would be widespread. We know that most of these statements will be useful to some people; what we need to know is which of them are likely to be most widely useful.
1. Financial help to parents of the children e.g. for transport, heating, fuel or for special holidays.

2. Financial help for minor expenses incurred by families.

3. Financial help to be spent at the discretion of the family.

4. When unemployment strikes a family with a child suffering from cancer, there should be a specific targeted allowance to help them.

5. Care organised by regional, specialist oncology centre and delivered into the community by staff from the regional centre.

6. Care organised by the locality but with referral to the regional centre when necessary.

7. Care organised by regional, specialist oncology centre and delivered in the main by local staff not employed by that regional centre.

8. Provision of chemotherapy at home (rather than in hospital) by local staff not employed at the regional centre.

9. The use of written objectives (from diagnosis, through a schedule of visits, to discharge) which are agreed with the family, and which are continually updated.

10. Education of health care professionals to prevent domineering attitudes.
11. Education of families to prevent unreasonable demands.

12. Formalised scheme for involving the school in the child’s care.

13. Emergency contact number 24 hours a day seven days a week.

14. The right to by-pass local services and go straight to the regional centre.

15. A ‘one-stop’ information point in the regional centre covering sources such as literature, the Internet, and advice from professionals.

16. A ‘one-stop’ information point, locally rather than in the regional centre covering sources such as literature, the Internet, and advice from professionals.

17. Training courses for health care professionals to increase their awareness of the impact of the child’s illness on the family.

18. Increase the number of units in which the initial visual impact is welcoming.

19. Provision of holidays by the charities.

20. Where there is the need for expensive treatment for the child with cancer, if necessary money is diverted from services for other patients.
21. Provision of short-term respite admissions of 1-2 weeks for parents to have time for business or social purposes.

22. Provision of a few hours respite for parents to have time for parents to have time for business or social purposes

23. Provision for specialised facilities to enable the family (including the sick child) to have a holiday together.

24. The extension of the audit of clinical staff from evaluating their clinical skills to include also evaluating their communication skills.

25. Regular published audit of clinical skills to provide families with increased confidence in the treatment their child is receiving.

26. Improved communication between hospital and community services to ensure better follow-up.

27. Provision to families of more accurate and up-to-date information than is currently available.

28. Routine availability of counselling if family members request it.

29. The routine use of formal measures of readability and comprehensibility of all printed information provided to families.

30. Routine offers of contact (which can be declined) with a spiritual leader.
31. The service provides contact with families in similar situations.

32. Provision of practical services, e.g. feeding pets while parents are in hospital.

33. A 'one-stop-shop' for the provision of specialised equipment at the regional unit.

34. A named key worker who would be responsible for the coordination of the whole treatment programme.

35. Additional arrangements for families who live in rural areas.

36. Improved communication between doctors, nurses, and other members of the health care team.

37. An increased number of hospice places specifically designed for children.

38. Provided for home-from-home facilities close to the hospital.

39. Ensure that all take home medications have clearly written instructions prepared by the pharmacist.

40. The issuing to each family of a comprehensive and regularly updated guide to sources of financial aid (statutory and voluntary); which they could then use independently if they so wished.
41. More careful assessment to ensure that children are admitted to hospital only when the care which they need cannot be provided at home.

42. An attempt to avoid the problem of late diagnosis by providing specialised training for GPS in spotting childhood cancer.

43. Ensure that provision for overnight stay is genuinely of a home-from-home nature.

44. Offering counselling from an experience member of staff to family members who have feelings of loss, bereavement or grief.

45. Older children should be treated and cared for in an adolescent unit and younger children cared for in an environment suited to their age.

46. Deliberate planning to ensure that, wherever practicable, families see the same core member of staff at every contact.

47. Ensure that families who are seen by staff who are on short-term placements, they will be seen in the same visit by a member of the core team.

48. Education to preserve parenting skills, (e.g. feeding, or bathing) for a child receiving treatment and/or suffering the effects of cancer treatment.

49. Better provision of private, quite places for the expression of feelings of anxiety, guilt or grief.
50. A mechanism to ensure that expert advice is available more promptly than it is.

51. The continued use of, and preferably expansion in the use of, evidence-based guidelines for the care and treatment of children with cancer.

52. A conscious effort to ensure that children with cancer remain in touch with their peer group.

53. Auditing care regularly to ensure that it does not remove from parents their feelings of choice and control.

54. Using parents as much as possible not only as partners in decision-making, but also as partners in caring.

55. Keeping the pharmacy informed about discharge plans, so that medications are ready when needed and can be provided without delay or undue haste.

56. Providing mechanisms for parents to remain in touch with professionals after the death of their child.

57. Developing a greater role than at present for charities in the provision of services for families of children with cancer.

If you wish to make any comments please use this space

Thank you for your co-operation
Dear Mrs Jones

*Elements of Care for Families in Which a Child Has Cancer: Round Three Delphi Study*

I am writing to you in your capacity as a member of the Delphi panel for this study. The study is now nearing completion and I would like to thank you for staying with this project throughout the last year. Throughout this project I have been aware of the imposition on the time of panel members.

Included in this mailing is a report on the study findings so far and the questionnaire for the third and final round of judgment (I promise this is the final round!). I have piloted the questionnaire for this round with a group of people with similar backgrounds to the panel and found that on average they took between ten to fifteen minutes to complete this round.

I was very grateful for the speedy reply to Round Two and would welcome a similar response for this final round. I would very much value a response by the 20th September 1999.

Enclosed are:
(a) an update on the study;
(b) instructions for the completion of Round Three;
(c) final questionnaire for Round Three;
(d) a 'Freepost' addressed reply envelope.

I will keep you informed of the overall results as soon as possible.

Yours sincerely

Elizabeth A. Parry

Ph.D. Research Student
APPENDIX 17

Round Three: Preparatory letter for professional panel members

Dear Colleague

*Elements of Care for Families in Which a Child Has Cancer: Round Three Delphi Study*

I am writing to you in your capacity as a member of the Delphi panel for this study. The study is now nearing completion and I would like to thank you for staying with this project throughout the last year. Throughout this project I have been aware of the imposition on the time of panel members.

Included in this mailing is a report on the study findings so far and the questionnaire for the third and final round of judgment (I promise this is the final round!). I have piloted the questionnaire for this round with a group of people with similar backgrounds to the panel and found that on average they took between ten to fifteen minutes to complete this round.

I was very grateful for the speedy reply to Round Two and would welcome a similar response for this final round. I would very much value a response by the 20th September 1999.

Enclosed are:
(a) an update on the study;
(b) instructions for the completion of Round Three;
(c) final questionnaire for Round Three;
(d) a 'Freepost' addressed reply envelope.

I will keep you informed of the overall results as soon as possible.

Yours sincerely

Elizabeth A. Parry
Ph.D. Research Student
APPENDIX 18

Progress report for all panel members

Round One

In Round One you and other panel members were asked to identify five elements that you considered to be essential in the care of families in which a child has cancer. Your suggestions produced 299 statements. Many of you mentioned the same elements, and there was a lot of duplication. Nevertheless, when I analyzed the results, I found that there were 57 distinct and different policies mentioned by one or more of the panel members.

Round Two

In Round Two these 57 statements were sent back to you, and you were asked to rate how many families would benefit from each of these policies.

The scoring system was:

- 7 All families would benefit
- 6 Most families would benefit
- 5 Many families would benefit
- 4 About half families would benefit
- 3 Some families would benefit
- 2 A few families would benefit
- 1 No families would benefit

There was disagreement among individual panel members about the importance of many of these policies, and for those policies we could not say there was any consensus. However, there were 15 statements on which there was strong agreement that they were likely to be beneficial to many families. This consensus included both members of the family panel and members of the professional panel. These 15 policies are listed on the attached sheet.

Round Three

I now have a clear picture of which policies you think would benefit all, most or many families. I know which policies you think would help lots of families. However, I do not know how much help you think that they would be. There might be two policies that would be of use to all families, but one might be of greater help than the other. I therefore now wish to establish just how important each policy is relative to the others, and I am asking for your help in doing this. This final round will be less time consuming than the previous two rounds. On this occasion, all I are asking you to do is write down 15 numbers.

In practical terms, this final round is important for policy making. If we were to present policy-makers with a list of 57 things that they could do, we doubt that they would be received with any enthusiasm. If, by contrast we could present just a few and say, “These are the ones which our panel members thought were really important”, your views would be more likely to have influence.
APPENDIX 19
Instructions for Round Three

Please read the following instructions carefully before completing the final stage of this study.
The way of rating these 15 statements in the third round will be different to Round Two.
This time the way of rating the statements will depend on a statement acting as an 'anchor point', with every other statement being rated either above it, below it or given the same value.
I want to know, not that a statement is more important, but how much more important it is.
To enable a reasonable comparison I have given a statement an arbitrary figure of 500
I would like you to rate each statement in comparison with that 'anchor point'.
If you think a particular statement would be of less help than the 'anchor point' statement,
give the other statement a score of less than 500. The only restriction is if you are choosing a lower score DO NOT score below 1.
On the other hand, if you think a particular statement would be more helpful you can award it a score of 500 or above. THERE IS NO UPPER LIMIT. The more important you think the statement is the bigger the score.
If you think a statement is of equal importance to the 'anchor point' then award that statement a score of 500 also.
Please make sure that you compare each statement with the 'anchor point' NOT with other statements. For example:
I have given a value of 500 points to the following statement.

Training course for staff to improve their ability to communicate with patients and relatives

If you look at the statement “Emergency contact number 24 hours a day 7 days a week”, ask yourself is the statement more important, less important or the same as the 'anchor point'

The 'anchor' statement has been provided in case you wish to keep the example in front of you while you are scoring.

Trainig course for staff to improve their ability to communicate with patients and relatives

Value Box
500
## APPENDIX 20

**Delphi Questionnaire Round Three**

<table>
<thead>
<tr>
<th>Round Three: Statements to be rated</th>
<th>Value Box</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency contact number 24 hours a day seven days a week.</td>
<td></td>
</tr>
<tr>
<td>Ensure that all take home medications have clearly written instructions prepared by the pharmacist</td>
<td></td>
</tr>
<tr>
<td>Care organised by regional, specialist oncology centre and delivered into the community by staff from the regional centre.</td>
<td></td>
</tr>
<tr>
<td>Improved communication between doctors, nurses, and other members of the health care team.</td>
<td></td>
</tr>
<tr>
<td>Older children should be treated and cared for in an adolescent unit and younger children cared for in an environment suited to their age.</td>
<td></td>
</tr>
<tr>
<td>An attempt to avoid the problem of late diagnosis by providing specialised training for GPS in spotting childhood cancer.</td>
<td></td>
</tr>
<tr>
<td>Using parents as much as possible not only as partners in decision–making, but also as partners in caring</td>
<td></td>
</tr>
<tr>
<td>A conscious effort to ensure that children with cancer remain in touch with their peer group.</td>
<td></td>
</tr>
<tr>
<td>A named key worker who would be responsible for the coordination of the whole treatment programme.</td>
<td></td>
</tr>
<tr>
<td>Training courses for health care professionals to increase their awareness of the impact of the child’s illness on the family.</td>
<td></td>
</tr>
</tbody>
</table>

**PLEASE CONTINUE OVER THE PAGE**
Improved communication between hospital and community services to ensure better follow-up.

Ensure that provision for overnight stay is genuinely of a home-from-home nature.

A mechanism to ensure that expert advice is available more promptly than it is.

Keeping the pharmacy informed about discharge plans, so that medications are ready when needed and can be provided without delay or undue haste.

The continued use of, and preferably expansion in the use of evidence-based guidelines for the care and treatment of children with cancer

THANK YOU FOR YOUR COOPERATION
Dear Mrs Jones

_Re. Elements of Care for Families in Which a Child Has Cancer_

Thank you for your reply to the previous round of this study. Most replies have now been received and the information is being analyzed. If you have not sent your first round reply yet it is still not too late.

I hope to be in contact with you early next year with final results of the Delphi study.

In the meantime thank you for your help and cooperation, your continued participation will be greatly valued.

Yours sincerely

Elizabeth A. Parry

Ph. D. Student
APPENDIX 22

Letter of thanks to professional members

Dear Colleague

*Re. Elements of Care for Families in Which a Child Has Cancer*

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I hope to be in contact with you early next year with final results of the Delphi study.

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Yours sincerely

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