
ROLE OF INFORMAL NETWORKS AND MEDICAL CARE ORGANIZATIONS
IN HELPING FAMILIES COPE WITH CHILDHOOD CANCER
PROSPECTS FOR COLLABORATION

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SHARE: FAMILIES OF CHILDREN WITH CANCER
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In this symposium report we present three research papers which address some common themes in families' experiences with childhood cancer. These themes include:

1. The impact of childhood cancer on the family, specifically the nature and extent of major stresses identified by parents.
2. The coping patterns families with children with cancer develop in order to deal with these stresses. Of the variety of possible coping patterns parents use, two are treated in this report:

The attempt to mobilize and use help and support from various sources.

The attempt to play an active role in treatment, and to create a partnership with the medical care system.

Each of the following papers further develops and explores one of these themes, as experienced and reported by parents of children with cancer. These papers represent our initial analyses of a rich and exciting data set. As a first cut, we make no effort here to be exhaustive or conclusive, but we do consider some key issues and begin the process of analyzing the experiences of families of children with cancer.

We have prepared this report to be read simultaneously by medical practitioners, parents of children with cancer, and medical and social scientists interested in these issues in health care and social stress. Since various readers may have quite different interests in the action-research study, we have adopted several conventions: tables and quantified data are presented, but detailed discussion of research methods and statistical procedures are kept to a minimum. References to related bodies of literature are introduced, for the most part, in footnotes accompanying the text. Although we do present parents' perceptions and reactions to the disease and treatment, a detailed discussion of the medical aspects of childhood cancer has been omitted. Persons wanting more details on any of these issues may consult the references or write to us directly for more information.

INTRODUCTION TO AN ACTION-RESEARCH EFFORT:
COPING PATTERNS OF FAMILIES OF CHILDREN WITH CANCER

The research reported here is a joint project of the Center for Research on Social Organization, University of Michigan, and SHARE: Families of Children with Cancer. SHARE is a self-help and education group of families of children with cancer who are served by the University of Michigan's Mott Children's Hospital. It has created a working partnership with the Pediatric Hematology-Oncology staff, and with researchers and practitioners at the University.

SHARE has been interested in improving the quality of life of families experiencing this chronic childhood disease. As part of its attempt to create and communicate new understandings to other families (and to medical personnel as well), SHARE decided to conduct an action-research study of families of children with cancer. The results of this study will be used by SHARE as part of its own internal education program, as well to stimulate its efforts to improve medical and psychosocial services. In addition, the research can and should contribute to the advance of scholarship in areas relevant to chronic childhood diseases, family reactions to childhood illness, organization of parent support groups, etc. In order to establish the context for these papers, we first describe the larger action-research effort we have been conducting.¹

The research is stimulated by improved life chances for children with cancer. What was once an almost universally fatal childhood disease is so no more. For instance, as recently as 1973, Child Psychiatrist C. M. Binger could write that (1973, p. 172):

Diagnostic tests revealed that Jimmy had a fatal disease - acute leukemia...As the hematologist proceeded to answer their questions concerning the diagnosis, anticipated course of illness, treatment, and its fatal prognosis...

By 1975, however, Wilber noted that:

many people...treat children with cancer as though they will all have a fatal outcome. Out of this has evolved a particular emphasis on helping families and children prepare for their expected death. The expectation of a frequently successful outcome with eradication of disease, and a recognition of the importance of rehabilitation, has just begun to emerge (1975, p. 809).

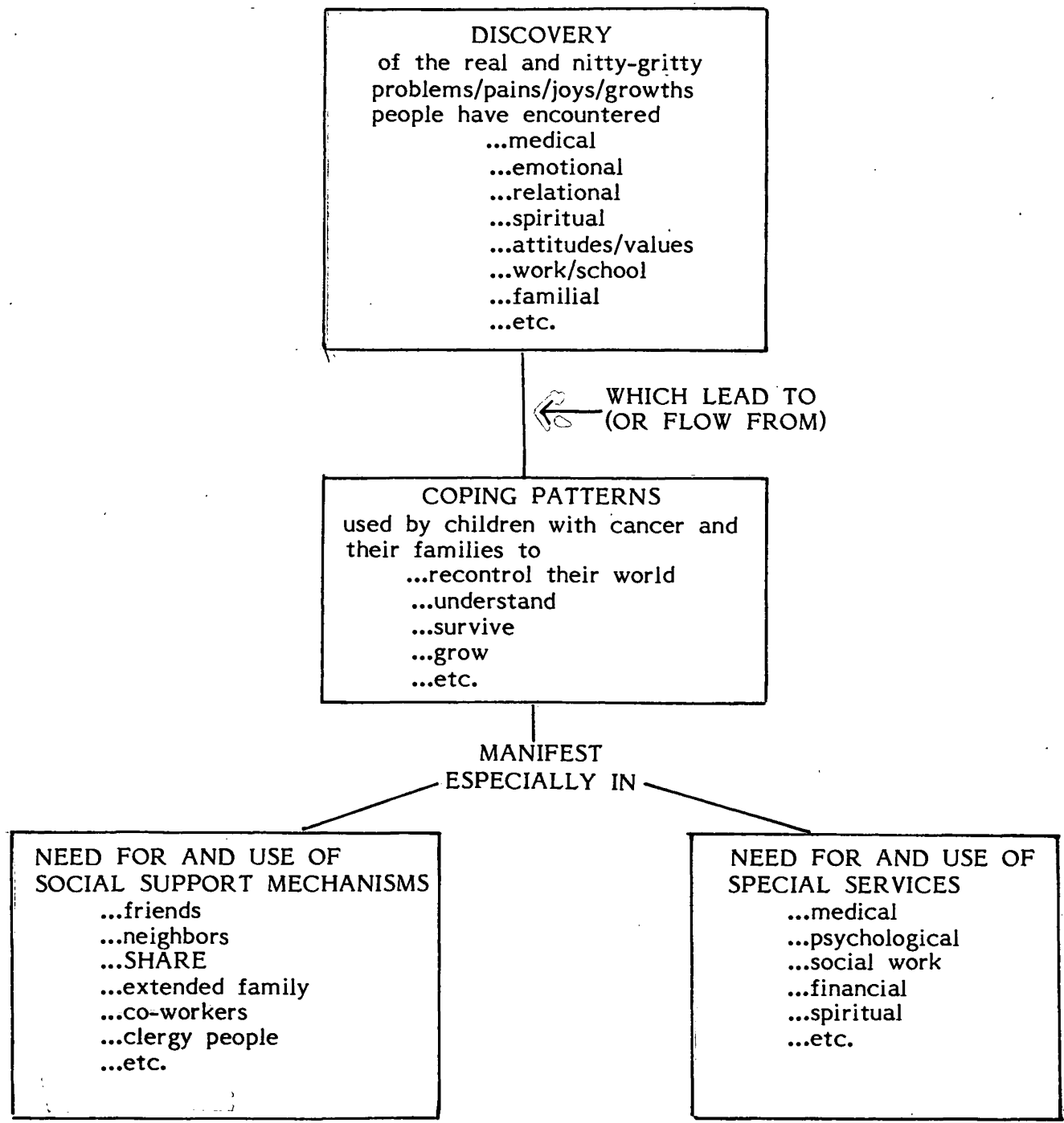
In 1979, the National Conference on the Care of the Child with Cancer projected a "cure" rate of 40-50% for children with Acute Lymphocytic Leukemia, and from 30-90% for the other most common forms of childhood cancer (D'angio, 1980).² As parents and families celebrate recent medical advances in the treatment of childhood cancer, they also encounter new psychosocial problems and issues in the care and management of the child, and in the maintenance of the family and other social relationships. With a greater chance of "life" many families now are concerned with enhancing the "quality of life" of those affected by childhood cancer. Within the medical community, more and more attention is being drawn to this issue. Wilbur argued, as early as 1975, that "without successful emotional rehabilitation, neither the successful treatment of the tumor nor the successful correction of physical problems will have great meaning" (1975, p. 811). And van Eys stated his concern for "a truly cured child", a child free of cancer and of the secondary physical, psychological and social side-effects of disease and treatment (1977). The past few years has seen increased attention to those issues, with more scholarly articles and several books being published on the psychosocial aspects of childhood cancer (Adams, 1979; Kellerman, 1980; Schulman and Kupst, 1980).

The general design of the action-research project we have undertaken can be illustrated by the conceptual map in Figure 1.

Figure 1

Pilot Study of Children with Cancer and Their Families

What is this research all about? What are we looking for? What is the conceptual map we are following/exploring?



Characteristics of the sample and research procedures

In order to generate a sample for this study, we examined the total population of childhood cancer families treated at Mott Hospital within the past 8 years. We decided to stratify this population pool by the current age (at the time of the study) and life status of the children with cancer, and found fairly accurate information for the following numbers of families in each of several categories.

Figure 2

Characteristics of the Pool of Families Treated at Mott Hospital

Child characteristics	Total Treated by Mott	Within 50 miles of Ann Arbor	Within 50 miles with current information
Living, under 6 years of age	106	42	28
Living, between 6-11 years of age	121	55	49
Living, between 11-21 years of age	295	101	64
Deceased	151	67	59
Total	673	265	200

The low level of resources allocated to carry out this pilot study led to a decision to limit the study to families living within a 50 mile radius of Ann Arbor.³

On the basis of this information, we drew a representative sample of families, as below. Within each of the age and life-status categories, we selected a sample on the basis of assignment via a table of random numbers. Then, in order to maximize other important comparisons, we made substitutions to have adequate representation within each category to include: (1) male and female patients; (2) children with markedly different kinds of cancer - blood cancers, bone cancers, lymphatic cancers, and soft tissue cancers, etc.; (3) age of child within the 6-11 and 11-21 categories (the 6-11 group was divided into children between 6-8 and 9-11, and the 11-21 group

was divided into adolescents 11-16 and 16-21). Whenever a family declined to participate in the study, or could not be located, we made substitutions to match as closely as possible the original sample. In each family we planned to talk with both parents and with children with cancer over 6 years of age. We also planned to interview some siblings.

The study was announced in the SHARE newsletter, a quarterly publication sent to over 400 families of former and current patients treated at Mott Hospital. Then, each family in the projected sample was sent a letter describing the study, including child and adult consent forms. About 2 weeks after the letter was sent, families were called and asked if they would agree to participate in the action research effort. Of the 85 families in the original pool, 15 families could not be located, and another 15 families declined to be interviewed. The final sample of 55 families includes those listed in Figure 3. Our search of prior literature in these areas suggests this is a comparatively large study of families and parents, at least with this depth of direct inquiry. There have been several larger studies of youngsters (patients), but not many of parents and/or families.

Figure 3

The Sample for this Study

<u>Child Status</u>	<u>Total Families</u>	<u>Both Parents</u>	<u>One Parent⁴</u>	<u>Child w/ Cancer</u>	<u>Sibling</u>	<u>Total Persons</u>
Living, under 6	9	7x2=14	2	0	1	17
Living, 6-11	17	13x2=26	4	16	7	53
Living, 11-21	18	12x2=24	6	12	7	49
Deceased	11	8x2=16	2	0	6	24
Total	55	40x2=80	14	28	21	143

In a meeting with the Steering Committee of SHARE, parents suggested and discussed their priority areas of inquiry. Then a pilot instrument was created, and it was tested in interviews with members of the Steering Committee. Following these pilot interviews, the Steering Committee critiqued the interview content and procedure, and made suggestions regarding new questions, deletions, interviewer approaches, etc. In addition, interviewers conducting the pilot conversations also debriefed and discussed their reactions. Throughout this stage of preparation, training and orientation, we gave full attention to various parties' inputs, to heighten the research staff's accountability to the needs, desires and experiences of SHARE members. As a study directed in part by members of the population being studied, and accountable to an organization representing this group's interests, we anticipated that this "insider" approach would lead to different design decisions, questions, analysis choices and strategies of utilization than would research conducted in the more traditional "outsider" mode.⁵

Interviews were conducted by University students with prior experience working as volunteers with seriously ill children and their families at the University Hospital. The interview format was semi-structured; it included a number of direct questions and a series of indirect probes. Interviewers were instructed to be as responsive as

possible to informants' desires to tell about their experiences in the ways they wished. The general questions in the interview with parents of living children covered topics such as:

- The nature and process of the diagnosis
- The course of illness and treatment
- Family members' responses to the illness
- Reactions of friends and neighbors
- Toughest times and problems during the illness
- Positive events or outcomes for the family or the patient
- Images of the child's future
- Changes in the family and in family members' roles
- Relations with the school and with the hospital
- Use of professional and lay help

Interviews with parents of deceased children focussed upon some additional issues, such as preparation for and experience with death and dying.

The average interview took about an hour and one-half to complete, with several lasting three hours or more. All interviews were tape-recorded, and interviewers listened to these tapes in reconstructing their conversations in written form on the interview schedule. When the interview was completed, an additional 6-page questionnaire was left with all adult (parent) informants. They were asked to complete and return it to the study director in a self-addressed, stamped envelope. This questionnaire focussed on some of the same issues raised in the interview, but now in a more structured and closed-ended format. It also asked for demographic information, and various reactions to the interview process itself. Eighty-five of the ninety-four adults interviewed returned the questionnaire (90%).

In general, parents reported very positive reactions to the study, and to the interview itself.

- a. 66% said the interviewer made them feel very comfortable and relaxed;
34% said they felt fairly comfortable;
none said they were not very comfortable at all.
- b. In response to the questions about informants' feelings after the interview:
almost all said they were glad they had done it;

most said that they were glad to have the chance to talk about the issues again.

- c. When asked how complete a picture of their feelings and experience we received:
60% said it was excellent coverage of most issues;
33% said it was fairly good coverage, with some parts missed;
7% said it was sketchy coverage of only a small part of the issues.
- d. When asked whether family members talked about their interviews with one another afterwards:
73% said yes;
everyone who responded to the question of whether talking with family members was good or bad, said it was good.

Several parents reported their participation in the interview was cathartic, indicating that at times it was painful, but also that it was a helpful avenue of release or reconceptualization. Some of their comments follow:

I think it is great that you people are gathering this information because everyone who has experienced such an illness has something to share with others. It sure should be helpful to others.

I am glad I participated in the interview because it helped to get in touch with, and express, many feeling that I had buried.

I remembered the love shared by many, and all the positive coping that was done.

It confirmed our feeling about what we had done and reinforced our confidence.

We talked about it afterwards, which we never really did talk about it very much before.

We spoke about how much we miss our son...it hurts inside our hearts.

Our oldest child revealed hidden hurts and feelings with us after the interview.

Interviewers' comments indicate that they, too, felt the interviews were an effective device; they reported that:

- a. 76% of informants had a good and clear understanding

- of most questions
23% of informants had a moderate understanding
1% of informants had little understanding of
the questions.
- b. 56% of informants appeared to be relaxed throughout
the interview
39% of informants got more relaxed as time went on
1% of informants got less relaxed as time went on
4% of informants appeared uneasy throughout the
interview.
- c. 82% of informants appeared to be friendly and eager to
talk
18% of informants were cooperative but not particularly
eager
none were indifferent or suspicious

Both interviewers and informants reported occasional episodes of tearfulness or weeping during the conversations. Clearly, some interviews were deeply emotional experiences for many informants. Our understanding of interviewers' and informants' reports is that this experience was emotionally coherent and positive in almost all cases.

In the coding and analysis of these interviews and questionnaires we took special precautions to maintain confidentiality. Interviews were assigned an identification number, and then retyped by question and identification number. Coding was performed on these retyped versions of the interviews. Since this is a study of one geographic and medical site, and since we are interested in sharing the general research results with families and professionals connected to this site, the analysis and reporting aspects of this research are as important to monitor for confidentiality as were the interviewing and coding aspects. In all these functions, the inclusion of two of the researchers as part of the informant pool should be helpful in ensuring continued sensitivity. We think that our potential tunnel vision has been more than compensated for by the safeguarding actions of other staff members, and by the extra richness the multiple perspectives provide.

Our review of prior research in this area indicates it has been limited by several ideological or methodological premises:

1. a focus on problems of death and dying
2. the utilization of a medical model assuming passive and compliant (but occasionally reactive) family interactions with benevolent and powerful health care professionals
3. a concern about pathology in family adjustment/coping, and for identifying better ways health professionals can "prevent" or manage them
4. the use of highly structured questionnaires that fail to inquire into or respond to informants' unique or divergent concerns and experiences
5. the use of clinical and projective instruments that emphasize individual reactions and that promote comparisons with pathogenic populations
6. a retrospective approach to families' experiences
7. the use of small samples

Our own effort avoids some, but not all, of these problems. For instance, we have not focussed on death and dying, nor have we utilized a traditional medical model to undergird this research, nor have we focussed on patient/family pathology as an assumption or problem. Moreover, we have tried to avoid the twin dangers of over-structured instruments or excessively clinical and anecdotal data collection devices. On the other hand, this study suffers from a retrospective rather than longitudinal approach to many of the issues and variables. Moreover, the sample size is still rather small.

Throughout the research process, we have been concerned primarily with describing, analyzing and understanding the experiences of this group of families. We have not charted this research with a formal theory and rigorous hypotheses, but with a set of concerns about what these families experienced, what the shape and meaning of these experiences was and is for them, and how they have coped with their experiences. Understanding how these issues are both common and different, for various families and individuals, should generate a set of concepts and theories about families of children with cancer. It also can lead to action designed to improve the

quality of their lives and the medical, social service, community and other resources they develop or receive.

In conducting this study, we proceeded primarily from a phenomenological and subjective base, progressing to a more objective and analytic stance. Although as scientists and educators we were familiar with some issues of family life and coping, our first step in the study was to embed ourselves in the reality of childhood cancer. Then we broadened our experience through conversations, observations, and exchanges with other families of children with cancer, and with health care practitioners. The development of instruments and gathering of data from the study sample followed. Recording and analyzing the reports of many families with childhood cancer gradually has led to a higher level understanding and conceptualization of their experiences. The last step in this process was to connect these conceptual understandings, these attempts to create meaning out of our own and others' experiences, to prior theory and scholarship in the social sciences. As the step most distant from the subjective experience of families, it is at once the most fragile and abstract link in the inquiry chain, the step most fraught with potential meaninglessness or error for the families involved. At the same time, this step has the most potential meaning for social scientific scholarship.

We emphasize that this action research effort focussed on the families of children with cancer being treated primarily by one medical care organization. Thus, generalizations to other medical systems may be difficult, at least on those dimensions of the research related to service provision. On other dimensions of the research, we think the results are quite appropriately generalizable to a wide range of locales (and perhaps to a range of other chronic childhood illnesses as well). However, the local limitation of this research, for some of our action purposes also is its greatest strength. While we are interested in the general experiences of families of children with cancer, we also are interested in the specifics of care and service at

this particular institution. The use of the research to create a more effective partnership between families and the medical system requires such institutional specification. We look forward to hearing from families, scholars and practitioners in other settings; and to comparing and contrasting evidence about these issues across a wide range of treatment facilities, services, and organized efforts at coping and reducing stress.

Finally, we warn the careful reader that this is an interim report which presents preliminary analyses of a very rich data set. In preparing this report we have been limited so far to bivariate statistical analyses; we look forward to other intriguing questions that can be investigated only with multivariate techniques. Moreover, much of the analysis in this report utilizes findings from the questionnaire; we have ahead of us some intriguing questions that can be answered only with close analysis of more of the interview material. As in much research on important and complex human issues, this report raises at least as many questions as it provides answers. Our hope is that we have advanced and improved the quality of the questions.

SOURCES OF STRESS IN FAMILIES WITH CHILDHOOD CANCER*

The experience of childhood cancer presents families with a new and difficult situation. A number of unanticipated and powerful stressors must be dealt with - by the patient, by the parents, and by all family members.⁶ In this paper, we explore parents' reports of the major stressors they experienced. Some of these stressors are products of the disease itself; some are the result of ways in which the particular person or family interacts with or copes with the disease; and some are the result of ways the disease affects other aspects of family life. As Cassileth and Hamilton note, for instance, cancer is a family disease:

A cancer diagnosis in any member of the family imposes change, disrupts the family's homeostatic balance, and unsettles the operational guidelines for interpersonal behavior (1979, p.234).

After describing the variety of stress experienced by most families, we examine some of the ways in which these stresses may have impacted on different family members or different families. Families with different experiences with childhood cancer, or families in different life situations and resource bases, report different kinds and amounts of stress. The data base consists primarily of interviews and questionnaires with the 94 parents described in the INTRODUCTION.

*The lead author of this paper is Mark Chesler, with collaboration and assistance from Oscar Barbarin and Joan Chesler.

The family experiencing childhood cancer immediately is faced with a number of stresses it must respond to, or problems it must solve. One set is instrumental or practical in nature, and include: deciding about treatment options, negotiating the medical system, coping with the treatment and its side effects, returning the child to a relatively normal set of relationships with friends and schooling, returning the family to a relatively normal state of existence, and dealing with new financial pressures. There are also a number of intellectual problems that must be solved rather quickly: understanding the nature of the diagnosis, understanding the (potentially uncertain or conflicting) prognostic statements made by the medical system, understanding treatment protocols and side effects, and determining where helpful resources are. In addition, a variety of social and emotional problems must be dealt with, including: mobilizing one's own personal and social resources to deal with the disease and its effects, coping with sadness and a sense of tragedy, dealing with anticipatory mourning reactions, finding sympathy and help from one's friends and family, and dealing with problematic reactions from inquiring neighbors and school classmates or professionals. Finally, the family faces existential problems or dilemmas, including: making sense out of these fateful circumstances, understanding the meaning of faith or one's commitment to spiritual integrity, integrating the events of childhood cancer into a coherent view of the world, and redefining one's existence as a victim. Klein and Simmons, in their discussions of families of children with chronic kidney disease, suggest a similar list: practical or general disruptions, emotional disruptions and financial disruptions (1979). The parents in our sample seldom mentioned financial problems directly, so we have included them as a subset of practical concerns.

Serious and chronic childhood illness is, after all, a challenge to the ways in which most of us understand and organize our views of the world, as well as our patterns of daily living. Death is conceived as occurring mostly to the elderly,

perhaps to the evil or warlike, certainly not to the young and innocent. That it happens, and is happening to us personally, disrupts normal existence. It also often challenges our images of normal existence, and our faith in an orderly and just world. It also alters the typical topics of conversation that evolve when friends meet, or when parents and teachers talk. It requires people to make public vulnerabilities normally kept from others, and in turn calls for help and love friends and neighbors may be unused to giving. And it alters previously predictable roles within the family, making independent adolescents temporarily dependent, making older children the sudden focus of nurturance to the exclusion of their younger or older siblings, making independent adults feel impotent and helpless, etc.

All these new experiences and challenges constitute stress for families (and often for the friends of families) encountering childhood cancer. But all these stresses or problems are not necessarily tragic or negative. Many people experience or deal with such stress as a series of positive tasks or challenges, as opportunities for learning, for growth, for renewed faith and meaning, for a better life than life as it was lived previously. These challenges can be resolved in the direction of positive growth, not just toward stasis or a return to prior definitions of "normality", and certainly not just as negative influences to be suffered through or minimized. Many people have discovered previously untapped internal strength and new sources of courage and caring in the midst of their struggle to parent a seriously ill child.⁷

Coping with childhood cancer is, then, an existential and socio-emotional challenge, as well as an intellectual and pragmatic task. With this reality in mind, we talked with parents (and children and their siblings) about the experience of childhood cancer. In this report we focus on parents' reactions.

Identification of Major Stress Events/Forces.

Based upon our own experience, our informal conversations with other parents and patients, and our prior review of the literature, we were able to identify a

number of potentially stressful events and problems relating to childhood cancer. Some of these, such as the fact of illness and treatment, clearly are objective stressors. Others are more subjective in nature, and depend for their existence, no less their impact, on the particular character of families' perceptions and experiences. This distinction occurs in almost all research into stressful life events. Lazarus et. al., (1974) and Antonovsky (1980) have argued that a stressor is a transactional phenomenon based upon the meaning a stimulus or event has for the perceiver. Moreover, Dohrenwend has argued that stressfulness of life events depends on how they are perceived, and that "...individuals' perceptions of the stressfulness of particular life events are the best predictors of whether their life events will be followed by illness or not (1974, p. 325)." Although it is undoubtedly true that what is stressful for one person, or one group, may not be so for another, the fact of childhood cancer, and related problems such as those noted earlier, are reported as stressful to varying degrees by most parents.

We sought to understand the different potency or impact of various stressors associated with childhood cancer by asking parents about the stress they experienced in several different ways:

1. In the structured questionnaire, we included a list of 16 major stressors, and asked parents to rate the degree to which they experienced each of them.
2. In the interview, we asked parents directly "what were the toughest times" for them.
3. In the interview, we presented parents with a "stress chart", a self-anchoring timeline on which they could report the nature and degree of stressful events they had experienced.

Although these different inquiry modes generated different information, there was substantial similarity in the ways parents responded to all questions about stress.

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In responding to questionnaire items about which events caused "very strong" stress, parents emphasized several medical or disease-related issues:

- the fact my child has cancer (81%)
- fear of my child's death (63%)
- reaction to treatment (side-effects) (55%)
- fear of a relapse (52%).

In response to interview questions about their "toughest problems", parents also stressed disease and treatment-related issues. Clearly, these are direct and major stressors - immediate and concrete challenges to parents' ability to respond in instrumental and pragmatic fashion. They also reflect the basic fears stimulated by the crisis of childhood cancer.⁸

Parents also indicated other stressors as "very strong", but less often:

- fear my child will learn about seriousness of the disease (31%)
- concern about my family if something happened to me (27%)
- fear my other children will get sick (19%)
- worry about the effect on my other children (15%)
- financial problems (15%)
- tense relations with the medical staff (15%)
- fear of "spoiling" the child with cancer (9%)
- fear of a nervous breakdown (9%).

This secondary list focusses on socialization issues and social relations. They clearly are disease related as well; they would not exist if the disease had not occurred. However, they just as clearly focus on relationships with self and others, and not on the illness itself.

Parents' distinction between major and (relatively) minor stressors may indicate a pattern of "crisis coping".⁹ For instance, it may take so much time and energy to cope with the direct medical crisis that personal and family issues may be shelved

for the time being. Moreover, the child's future life and possibility of survival may depend upon parents' ability to understand and cope with new medical routines. Thus, instrumental and intellectual stresses appear to be dealt with first. If the essential struggle with the disease's threat to life can be managed, then perhaps other issues and feelings can be acknowledged. This does not suggest that other issues (emotional and social relational) are irrelevant: indeed, parents did not suggest that. However, they may be less immediately relevant, and when time and disease/treatment conditions permit, parents may well turn full attention to family and social pressures and problems. These "stages" of crisis coping may vary with the course of disease and treatment, as well as with the severity of relationship concerns.¹⁰ Of course, the continuing uncertainty of disease-related stresses maintains and may escalate the potency of the stresses regarding socialization and social relationships.

In addition to these questionnaire and interview items, we asked parents to fill out a self-anchoring chart, indicating the times/events of greatest stress during the experience of childhood cancer. The precise nature of this question, and of composite representations of parents' answers, are presented in Figures 4 and 5 (Figure 4 presents a composite of parents of children living with cancer, and Figure 5 presents a composite of parents whose child is deceased). The data indicate that the time of diagnosis was one of the greatest stress periods for parents, whether their child was living or deceased. It is the most often mentioned stressor. Moreover, 20 informants mentioned diagnosis as the most potent stressor (the one with the highest stress line). Relapse was mentioned as the most potent stressor by 11 parents, surgery most potent by 12 parents, and treatment side-effects by 10 others. Other events or stressful times were mentioned substantially less often or with much less potency. Interestingly, these self-stated events and situations (stated by parents before they received the post-interview questionnaire) conform to the answers provided by parents on the structured questionnaire. Once again, there is substantial focus on the disease

process, and on treatment and its side effects.

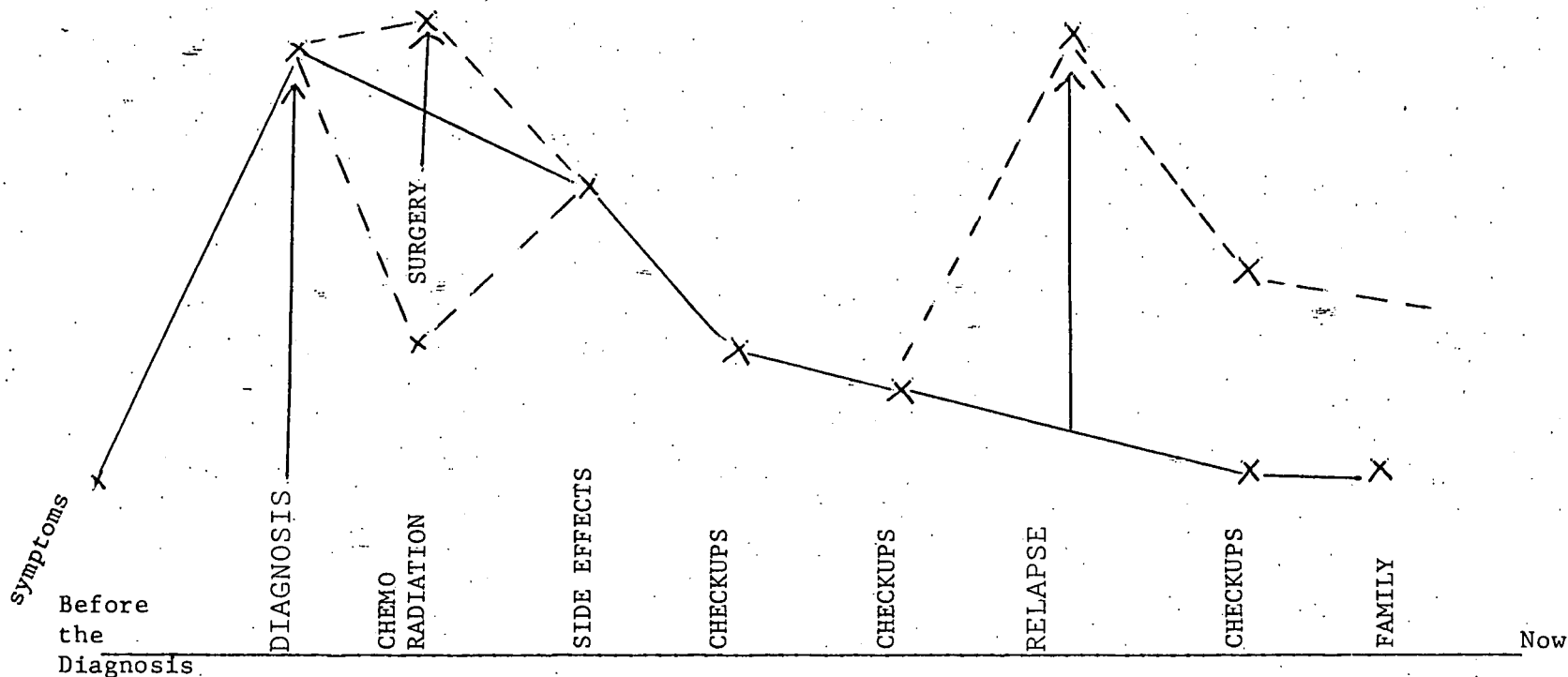
Our representations in Figures 4 and 5 do not include all the stressors parents mentioned, merely those mentioned most often and most potently. The dotted lines in Figure 4 indicate that not very many parents mentioned surgery or relapse as a stress event; however, for some of those who did, it was even more potent than the diagnosis.¹² Not all (nor even a major portion) of the children in families we interviewed had experienced these events, but all had encountered the diagnostic phase, treatment and its after-effects, checkups, and the like.

Figure 5 also indicates that these trends are somewhat different for parents of deceased children. For them, the relapse took on continuing importance. It was the start of the turn in the road. Hope, kindled by remission, started to be challenged severely...and in these cases finally, by the relapse. While diagnosis is still the stress mentioned most often by these parents, it is not as potent as some other stressors, notably relapse, deterioration or terminal phases, and sometimes death.¹³ Reminders of life and death, such as birthdays, anniversaries and important family events also were mentioned often by these parents.

The rise and fall of these stress points reflect portions of what Adams has called the typical "illness cycle" (1979, pp.17-21). Other observers, noting a rhythm to families' stress at different phases of illness, or different phases of adjustment to illness, suggest providing different kinds of help or social services at different points of such a stress-line (Ross, 1978; Kaplan, et.al, 1973; Obetz, et.al, 1980).

HERE IS A CHART, A TIMELINE, THAT CAN BE USED TO DESCRIBE THE TIME THAT HAS ELAPSED FROM BEFORE YOU LEARNED THE DIAGNOSIS UNTIL NOW.

1. MARK ON THIS LINE THE CRITICAL EVENTS OR STAGES IN YOUR EXPERIENCE WITH YOUR CHILD'S CANCER. INDICATE THE APPROXIMATE DATE OF EACH.



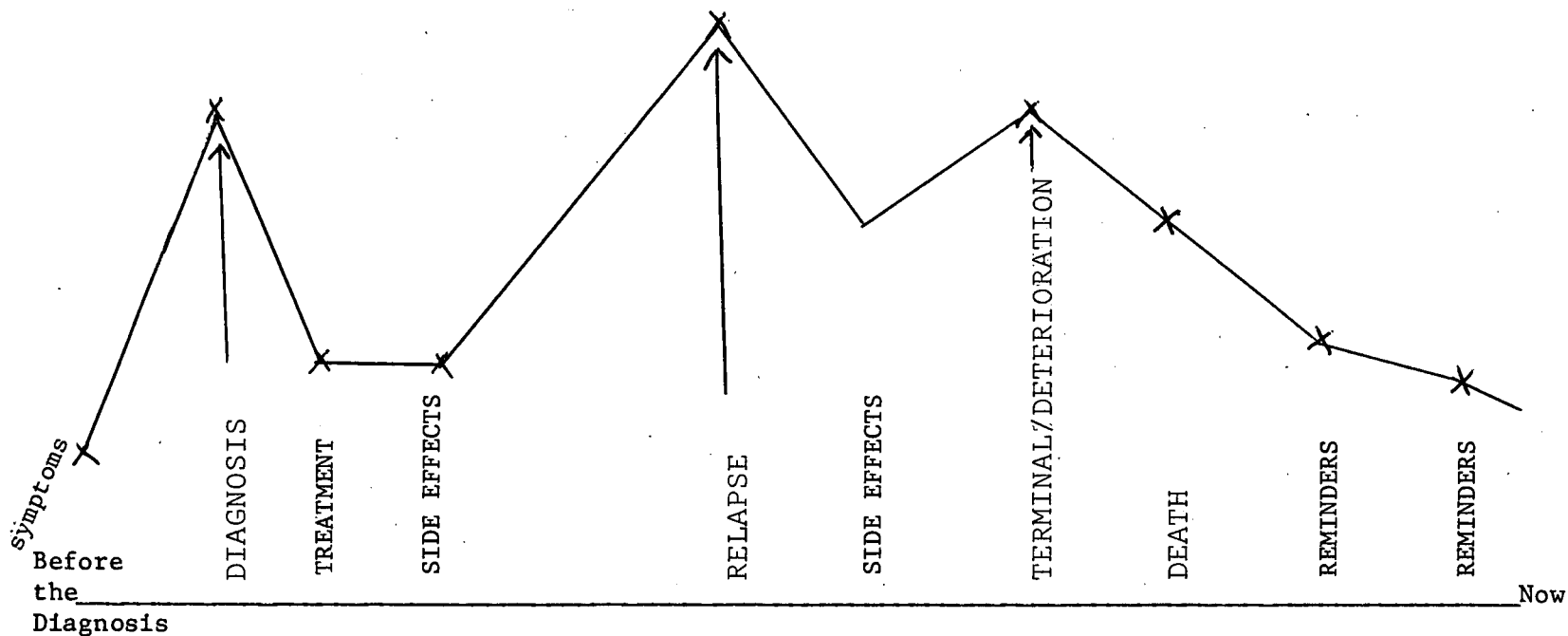
2. WHICH OF THESE EVENTS OR STAGES WERE MOST STRESSFUL? DRAW AN ARROW FOR EACH EVENT, INDICATING WITH A HIGH LINE THE HIGHEST STRESS TIMES OR EVENTS, AND WITH A LOW LINE THE LOWER STRESS TIMES OR EVENTS.

COMPOSITE STRESS CHART OF PARENTS OF LIVING CHILDREN 11

Figure 4

HERE IS A CHART, A TIMELINE, THAT CAN BE USED TO DESCRIBE THE TIME THAT HAS ELAPSED FROM BEFORE YOU LEARNED THE DIAGNOSIS UNTIL NOW.

1. MARK ON THIS LINE THE CRITICAL EVENTS OR STAGES IN YOUR EXPERIENCE WITH YOUR CHILD'S CANCER. INDICATE THE APPROXIMATE DATE OF EACH



2. WHICH OF THESE EVENTS OR STAGES WERE MOST STRESSFUL? DRAW AN ARROW FOR EACH EVENT, INDICATING WITH A HIGH LINE THE HIGHEST STRESS TIMES OR EVENTS, AND WITH A LOW LINE THE LOWER STRESS TIMES OR EVENTS.

COMPOSITE STRESS CHART OF PARENTS OF DECEASED CHILDREN

Figure 5

Reactions to diagnosis. The report that diagnosis was the most stressful event for many parents, and at least a potent event for all others, is quite reasonable, and quite consistent with other theoretical and empirical investigations of childhood cancer.¹⁴ It is at this point in time, whether in an instant or lasting hours and days, that life is ripped from its normal context. Parents' prior reality is shattered and they enter a new reality, with new definitions of themselves and others. At whatever level of consciousness they may have, they know they are embarking on a long and difficult struggle. They may hope for a good outcome, and perhaps a rapid return to a "normal" existence, but they know they can never return to life as it was before.

We can get some indication of the potent stress and shock of diagnosis by reviewing some parents' comments. Their sense of unreality, of numbness, is quite clear in some of these reports:

I cried a lot. We were all scared. It was like being in a deep black hole.

I felt like my heart had been torn right out of me. I was terribly despondent at first. I was bitter and asked myself why it had happened. It was very rough to take.

I felt numb from the time I found out he had a tumor. I just felt numb. I didn't sleep at all.

For a while I didn't deal with it; nothing they told me sunk in. They had to tell me three times before I was grasping it. They told me things and two minutes later I couldn't tell you what they told me in terms of medicine, treatment and stuff.

I left the room, I ran. I don't know where I went. I know I ended up on the 7th floor. I know that I was trying to dial numbers and couldn't see the phone. I know I must have called four people before I was aware of what I was doing. I was so totally alone I didn't know how to function. I was going up and down the stairs of the hospital. It certainly was the worst day of my life. I thought the day that my Dad fell dead was the worst experience of my life, but this was the worst.

It tore me up. I didn't know from one minute to the next whether he was going to be with us. You know, I worried

a lot. I felt bad. I was hurt. He was my only boy. I didn't want to lose the only son I had. Half the time I didn't know if I was there myself. I would go driving...

These feelings continue. They may abate over time, and be moderated by experience, time, hope and recovery, but these feelings return again and again throughout the course of treatment. After all, cancer in children is not a one-time event; it is a chronic, and chronically life-threatening disease. Every symptom, every side-effect, every checkup may carry a dangerous message. As several parents noted:

Everytime we get over one hump, something else happens. I sometimes feel like, "Hey, God, lay off her, she deserves a break..."

I worry when he says, "Mom my stomach hurts." And I worry what's going on there, "Oh, no!" But as time goes on you learn what to worry about and what not to. It could be the flu or something.

Regular CAT scans worry me, because they show potential progress of the disease. Each subsequent scan has been stressful, but they're getting less stressful, because they're coming out well. It is hard for me to wait for the results from the tests because they could show evidence of the disease.

As Cassileth and Hamilton note, even a series of successful checks and a "cure" can be stressful (1979):

Having made some sort of adjustment to impending death, the patient and family suddenly faced with the likelihood of cure must once again make major new adaptations to this changing reality (p. 239)

In the case of childhood cancer even the pronouncement of "cure" carries a risk (5-10%) of future relapse, of a later second cancer, or of late side effects (Simone, et.al, 1978; D'angio, 1980; Eiser, 1978; Li and Stone, 1976).

Thus, much of the stress reported as occurring at diagnosis is sustained over time. Parents continue to experience, and to be concerned about, the uncertain progress of the disease. There seldom is a time in the near future when certainty of any sort can be provided. For most, the uncertain waiting and hoping against a

relapse can not be predicted at diagnosis, and is maintained for years. Constant alertness to small signs of recurrent disease, constant adaptation to new treatments and their side effects, all bring new problems and new feelings. Moreover, as children grow and develop, parents must decide how to handle typical problems of childhood and adolescent development (peer relations, psychosexual exploration, rebellion, school anxiety) in the context of the disease and treatment process. However hard parents may try to divorce these issues, and to treat the child as "normal", subtle baggage remains for most.

People and Relationships as Stressors

Regardless of the immediate shock of the diagnostic period, there are other matters to attend to, people to relate to, and a world to continue to live in and cope with. Even when parents adopted crisis-coping as a major behavior pattern for a while, the inevitable fallout of shelved feelings and relationships had to be dealt with sooner or later. Over time, parents turned their attention to the other people in their world, and to the other issues and relationships in their lives. Each of these other people or groups of people, became potential stressors; sometimes their reactions increased the stress already experienced by the parent. They also often relieved stress; many responded in ways that provided essential help and support, making parents' tasks easier. As in our discussion of other stressors, it is important to remember that although many social relationships were redefined, these changes were not necessarily for the worse. Many parents reported that they were much closer to family and friends now than they were before the illness, and that they had made changes for the better in their lives.

One of the critical tasks the parent(s) of a chronically ill child must face is "going public", sharing the new reality, and as much of its meaning as they wish, with families and friends. This is a self-redefining set of acts; in its accomplishment the parent informs him/herself and others of a life-changing status he/she and others

have just assumed. Voysey (1972) discusses the potential stigma associated with parenthood of seriously ill children. In addition to dealing with the child and disease:

the management of children in encounters with others is perhaps normally the most problematic area for parents (Voysey, 1972, p. 81).

Uncertainty about the social rules governing the behavior of seriously ill children, concern about how others will react, and a desire to give the "right" impression to others all create awkward social situations. As Goffman (1968) notes, people related to a stigmatized person often are treated by others as stigmatized themselves. Moreover, they often internalize the same reaction to such stigma. No one likes being labelled or stigmatized, and denial or silence about the illness may be a way to avoid further social stress (and not just a psychological defense against a threatening disease).

We asked parents whether and with which family members it was hardest to share the diagnosis. Their answers, presented below, begin to define some of the important people in parents' lifespaces. They also indicate how broadly stressful was the "telling process."

Figure 6

Parents Reporting "Which family member was the hardest to tell about the diagnosis?"

Who was the hardest to tell?	%
Spouse	8
Child with cancer	14
Siblings	24
Grandparents	35
Other relatives	2
Everyone	17

Telling may be the first, but by no means the only, stress parents experienced in

their social relationships with others. As we explore each of the following categories of persons parents indicated above, we try to draw attention to a variety of stressful situations and events reflected in the interviews.

Spouses. Parents reported that their spouse was the most helpful person in their attempt to deal with the experience of childhood cancer. However, some parents also reported added stress from their spouse's reactions to the disease and its treatment, etc. In many cases, only one spouse was present at the initial diagnostic meeting, and had to carry this enormous message back to their partner. In our sample, 80% of the parents reported that the mother was the primary caretaker of the ill child (closely related to mother as primary caretaker of the child, period), and thus the primary link to the medical system.¹⁵ New divisions of labor and new family roles may have been created during this diagnostic period, and many of them were maintained over time. In numerous cases, mothers and fathers with different medical information and contact experienced a number of other stresses differently as well. A new imbalance was created in some families, an imbalance in normal functioning that had many side effects for the family as well as the marital relationship. Parents who experienced substantial depression or anger may have been unable to create intimate time and space with their partners, stretching the marital bond considerably.

Regardless of the specific role divisions parents adopted vis-a-vis the medical system and the ill child, parents now had a new situation to deal with. How they dealt with it together was a potential alleviator or escalator of stress. Consider the following comments from parents about how spouse relations could have been added stress factors.

My husband insisted it be kept a secret. It was 2 weeks before he could pronounce the diagnosis. Since my husband saw death as imminent, I had to persuade him not to be so pessimistic.

The overriding pessimism of my husband was detrimental.

I knew my biggest task was going to be to try to hold his mother together.

My wife went crazy and I had a daughter to take care of, plus the child who was sick. I suppose I accepted the traditional role of being the strong guy. I think I tend to be an optimist and my wife tends to be a pessimist. She assumed the worst and I assumed the best.

The child with cancer. The child with cancer was hard to tell about the diagnosis, primarily because parents were concerned about the child's reaction - not an unreasonable concern given what parents shared about their own reactions.¹⁶ As was the case with attendance at the initial diagnostic meeting, in most families the mother was the parent who informed the child of the diagnosis.

We asked parents what their child's reactions were to being told.

Figure 7

Parents' reports of their child's reaction
to the diagnosis

Reaction	%
None or not told	22
Mild negative reaction	36
Strong negative reaction	14
Positive reaction	28

What constituted a positive reaction? A number of parents reported that their youngster accepted the diagnosis with optimism and hope, and showed courage and strength. Negative reactions included passive resignation, regression and increased immaturity, or anger at feeling cheated. Any of these responses, including especially anger and denial, or hope and faith, may be more or less healthy or adaptive at various stages of the disease-coping process. And any of them may be more or less effective for different youngsters, regardless of their stressful meaning and impact on

the parents.¹⁷

Parents of adolescent patients more often reported that their child had a positive reaction to the diagnosis than did parents of younger children. The most negative reactions were reported by parents of younger school-age children (ages 6-11). Below this age, children may not have understood (or were not told) enough of the serious details of their illness to react very negatively. Indeed, parents confirmed that they told more about the disease to older children. Above the age of 11 a clear split occurs, with about half the parents of adolescents in the sample reporting their children had a "positive reaction" (compared with 28% of all the parents).¹⁸

However positive the child's adjustment to the disease and treatment, and to the many new or altered life situations it brings, the child's reaction created stressful situations for many parents. Some examples of the stresses parents' reported experiencing as they tried to deal with their child with cancer include:

Trying to avoid overprotection, and coping with life as usual without panic or stress.

Because he has been sick for such a long time, some of his development of responsibility is lagging behind. It was an achievement just for him to go to school when he was so sick. So now that he's well, he isn't interested in chores such as cleaning his room, helping in the house and garden, and things like that. Now that he's well we want him to do these things and he refuses. These skills and attitudes are built into other children a step at a time, but they are missing in him, and its hard for me to be patient, and build them in now, little by little.

Living with him has been hard. He can be super angry and two seconds later he can break down in tears and then be sound asleep. This can all be in two minutes. The medicine really messes him up.

The child does not exist in a vacuum, nor can the family protect him/her from other events in the world of children.¹⁹ Some parents' responses to the non-

normalized outside world, and its effects on their children, were also poignant. The excerpts below reflect the kinds of stigma and reactions to stigma suggested by Voysey and Goffman earlier.

I was watching him play through the window one day and he went up to ask if he could play, and the other children told him no. That's when I became very emotional and upset...I really went into a rage and shook this little boy and yelled at him. Then the little boy apologized and I had to grab myself and think that this little boy never knew anyone that was different. I ended up apologizing to him.

I think the hardest time was when he first had the surgery on his leg - he had his cast on for quite a while. When I sent him to school, the school complained about an odor coming from the cast. The bus driver came out right flat and told me: "Hey, give your kid a bath, he stinks. You better do something or I ain't picking him up anymore."

Siblings. Parents also reported that the reactions of the ill child's siblings could be quite stressful. Other research has reported how typical it is for siblings to develop feelings of guilt about who was sick and why, and jealousy or anger about sudden shifts in the amount of attention they received.²⁰ In some families, siblings acted as "safety valves", acting out or blowing off when internal family tension became too great. In other instances they acted as "reality challengers", indicating to parents when they really were paying too much attention to the ill child. If childhood cancer and its associated stresses disturb the family's prior pattern of role relations, it certainly can threaten the existing role relationships between the ill child and his or her siblings, and between parents and the siblings. For instance, some of the concerns parents reported about siblings' responses and relations to the ill child include:

My oldest son spaced out. At first he felt concern but then he began feeling jealous and left out.

When I got home I told my older daughter, and she just

screamed and really carried on. I still can't think about it.

Our only real problem is that I think its hurt his sister emotionally. She always feels like she's competing...they're real close in age.

Grandparents. The persons most often reported as "hardest to tell" were the child's grandparents, the parents' own parents. Why might this be so? First, grandparents often lived outside of the immediate family neighborhood, and telling them could not be done in a face-to-face manner. Thus, very delicate and shocking information had to be relayed over the telephone.²¹ Second, grandparents shared many of the same concerns about the child's life and welfare as did parents themselves. They, too, perhaps from the uniquely painful perspective of their own years and experience, felt that the natural order of life and death was being reversed. Third, grandparents also were concerned about the trauma and struggle that their own children - the parents themselves, were going through. When grandparents responded by needing help and attention, instead of being able to provide it, they further taxed the family resources (a phenomenon McCollum points to as a "reversal of roles", 1975).²²

Some of these issues are captured by parents who expressed their concern and feelings of stress about their own parents' (or in-laws') reactions to the diagnosis.

My father-in-law was the hardest to tell. He thought our daughter would die the minute he heard it. He was already in mourning. He couldn't look at her without crying. Even today if they talk about it very long he has to leave the room because he starts to cry.

My mother became so depressed that a while later she had a heart attack. She is better now, and my husband and his brother are more brother than they ever were. He came to help!

My father. It hit him harder because at his age, he felt, "Why him and not me".

My mother was dying of cancer at the time. When they told her about my son it crushed her. She had accepted her own cancer, because she was older, but that her grandson had cancer just about killed her. It helped my son that his grandmother had cancer, because he saw her taking so much,

and he felt that if she could take it he could too.

My mother is from the old school and felt that God was punishing us. She wanted to know what we had done. Now she has come around 200%. I called my in-laws and after about 5 days I realized that my mother-in-law was not accepting what I was saying. I talked to my sister-in-law and she said that what I told her was nothing at all like what my mother-in-law relayed to them.

Friends. We explore parents' relationships with their own friends in the next paper in this report. Suffice it to say here that some parents reported stress and distress associated with friends' responses and reactions.

You go back to work and everything's pretty calm for a while. And people at work don't know what to say. So they're afraid to say anything.

Some of the people who we thought would be our best friends never showed up for at least a couple of months after. That was particularly tough at the time, because you expected them to be right there at your doorstep. As you get through this stage, the crisis stage, you find out that the reason they weren't there is because they couldn't handle it themselves. And some people you didn't expect much of anything from were practically parked on the doorstep all the time. That's not to say that those who were our best friends aren't now, or that they're fair-weather friends. They just couldn't handle it.

The medical staff. Some parents reported that characteristics of the medical care organization, or the actions of certain doctors and nurses, added to their stress. On the whole, parents reported great respect for the medical personnel they encountered (a finding explored in greater detail in the final paper in this report), but the stresses they experienced were important nonetheless. For instance, even if parents agreed that doctors had done all they could under the circumstances, the nature of their interaction may have had undesirable impact. Consider the following comments:

Doctors keep changing, and many come in without having even bothered to sit down and read the records, and don't know what's going on. You have to keep constantly telling them things over and over. You feel you have to be there or she won't get taken care of.

Being far away and not feeling like the doctors or hospital there was adequate or competent.

The amount of pain he had and the blatant lack of concern by the doctors. They put him through hell, and it wasn't necessary, because of their apprehensiveness to treat pain aggressively.

The doctors were cold and unpleasant. It would help if medical people would accept the validity of your feelings.

Other aspects of the complex interaction between parents and doctors are examined in a separate paper in this report. For the moment, it is important to draw attention to the possible relationships between the operation of the medical care system and the stresses parents reported.

By way of a summary. This discussion of social stressors indicates some of the ways in which families' structures and role relations may be strained by the impact of childhood cancer. In turn, these relationships may become stressors for families experiencing childhood cancer. What are on the one hand sources of great help and support may, on the other hand, be sources of stress and pain. The attempt to convert stress to support, awkwardness or pain to growth, is part of the overall challenge of coping with childhood cancer.

The Distribution of Stress: Which Families/People Experience More or Less

Identification of some of the major stressors or stressful experiences parents report helps describe the reality these parents encountered. However, as the differences between Figures 4 and 5 indicate, not all families and parents experienced these stressors, and the general situation of childhood cancer, in the same way. First, the course of the disease and its treatment differed for different children; therefore, their families had to deal with very different objective circumstances. The family with a child who died from cancer is in a different situation than the family of a child who is living with cancer. There also is considerable variation within the category of families of children living with cancer...according to the nature of the disease, the vigor and trauma of treatment (surgery or not, for instance), and the

occurrence of a relapse.²³

Second, families in different social situations may experience similar stressors in different ways; and they also may experience some quite different stresses. With different backgrounds, and therefore varying perspectives and available resources, families are in quite different subjective circumstances. Income levels, geographic location vis-a-vis a major children's cancer center, and the nature or intactness of nuclear family relations are only a few of the variables defining the social situations of families, and therefore the potentially different impact of stress on them.

Third, different stresses mean different things to different people. Based upon prior personal experiences and psychological style, each person has a unique perspective. Thus people of different sexes, with different personal coping styles, with various experiences with cancer, and with differing needs for support, stability and autonomy, will encounter different subjective realities in the attempt to deal with childhood cancer.²⁴

Attempts to deny or overlook these differences, to describe the experience of childhood cancer as common or universal, blur the many real-life distinctions that matter. Moreover, such approaches tend to dehumanize the persons and families involved, seeking facile generalizations at the cost of a thorough examination of the many varieties of stressors and responses to stress that exist. While our rich data set is still in the early stages of analysis, we can begin here an exploration of some of these complex themes.

One basic distinction suggested above lies in the different course of the disease and its treatment. On the structured questionnaire, we saw no substantial differences in the ways in which parents of living children and parents of deceased children responded to the total of all stressors, to the combination of different kinds of stress. The total stress score means for deceased parents (29.4) and for parents of living children (28.1) were not very different. However, when we examined these

groups of parents' responses to items about stress that were closely related to the disease itself (see the distinction made on page 20 of this report), we found that parents of deceased children more often reported higher amounts of stress than did parents of living children (mean = 10.7 v. 9.8, $t = 1.74$, $p = +.10$). Similarly, parents whose children had experienced a relapse reported more stress related to the disease and its treatment than did parents of children who have remained in remission (mean = 10.6 v. 9.5, $t = 2.20$, $p = +.05$). These findings are reported in another format in Figure 8.

Figure 8

Parents' Differential Reports of Stress from the Nature
of the Child's Disease and Treatment²⁵

<u>Parent Group</u>	Amount of Stress from Disease and Treatment		
	<u>Low</u>	<u>Medium</u>	<u>High</u>
Parents of Living Children (N=67)	37%	37%	26%
Parents of Deceased Children (N=18)	17%	28%	55%

$$\chi^2=6.3, df-2, p+.05$$

<u>Parent Group</u>			
Parents of Children who have not relapsed (N=55)	40%	38%	22%
Parents of children who have relapsed (N=30)	20%	30%	50%

$$\chi^2 = 7.6, df-2, p+.05$$

These data suggest that specification of different kinds of stressors, rather than stress in general, is quite important in understanding the differential impact of stress on families.

When parents themselves specified the stresses they experienced, on the self-anchoring stress charts (see Figures 4 and 5), a very similar picture emerged. Here

parents of deceased children mentioned more stressful times or events, and the total potency of all stressors was greater for them than the parents of children living with cancer. As we noted earlier, most of the stressors indicated on these charts were related to the disease and treatment process.

Figure 9

Number and Power of Stressful Events, From Stress Charts,
By Life-Status of Child

<u>Parent Group</u>	<u>Mean Number of stressful events</u>	<u>Mean Power of all stressful events</u>
Parents of Living Children	7.3	31.77
Parents of Deceased Children	9.9	48.25
	T-test = 2.26, p. + .05	T-test-2.17, p. .05

In addition to these different responses as a function of the course of the disease, we also explored some issues related to families' different social situations. For instance, it appears that socio-economic status is related to some forms of stress, although not to all. Members of more affluent families, with incomes over \$25,000/year, reported experiencing somewhat less total stress than those families with incomes of under \$25,000/year (mean of 27.7 v 28.9), but this difference was not statistically significant. However, when we disaggregate the total stress scale into component subscales, we find family socio-economic status to be a relevant factor in several instances. Stress emanating from the course of the disease is not differentiated by family income; it cuts across all classes and statuses with a force that evidently diminishes the power of socio-economic distinctions. However, Figure 10 does indicate that four other stress subscales, all focussed on social situational and relational issues, are related significantly to measures of socio-economic status.

Figure 10

Parents' Reports of Social-Relational Stress-
Differentiated by Income Level and Education

<u>Family Income</u>	Parents Reporting Higher Stress About			
	<u>Child Social Adjustment*</u>	<u>Personal Ability to Cope*</u>	<u>Nuclear Family Relations*</u>	<u>Extended Family Relations**</u>
Low (N=16)	62%	62%	55%	56%
Moderate (N=30)	50%	33%	46%	30%
High (N=34)	32%	29%	28%	21%

<u>Parent's Education</u>	Parents Reporting Higher Stress About			
	<u>Child Social Adjustment</u>	<u>Personal Ability to Cope*</u>	<u>Nuclear Family Relations</u>	<u>Extended Family Relations**</u>
High School (N=29)	50%	52%	44%	45%
Some College (N=26)	38%	42%	43%	23%
College Graduate (N=29)	38%	24%	44%	21%

*chi square significant at $p+.10$

**chi square significant at $p+.05$.

Parents' stress flowing from concerns about the child's social or emotional adjustment was differentiated by family income level. Items grouped into this set of concerns included:

- fear my child would learn about the seriousness of the disease
- fear of "spoiling" the child with cancer

Higher income families reported less stress from this factor than did lower income families.

In addition, parents' reports of stress from their personal fears and coping abilities were differentiated by education and income. These items included:

concern about family if something happened to me
 fear of a nervous breakdown
 fear my other children will get sick

Families with higher income and education reported less stress from this factor than did lower status families.

In a similar fashion, parents' stresses related to other nuclear family members differed by income level. These items included:

worry about the effects on my other children
 sibling problems
 marital problems

Persons with higher incomes reported less stress from these factors than did people with less education.

Finally, stresses located outside of the immediate family, in the grandparents or the friendship system, were related to educational and income levels. These items included:

relations with parents
 relations with friends and neighbors

Once again, higher income and higher education families reported less stress than did families with lower income or less education.

Why might this be so? Why might income level or education be associated with different family experiences with stress? Or, why does stress impact differently on families in different socio-economic situations? The reasons may be multiple. First, at the extremes, income may make a difference in a family's ability to afford various necessities, particularly if added medical expenses or insurance inadequacies thrust an economically marginal family into financial crisis. Reports from parents bear out this potential relationship between economic resources and the economic crisis of chronic medical care. When we asked parents what the financial impact of the illness was

upon the family, 62% said it was "none" or "slight". Those parents who reported the impact as "somewhat serious" or "serious" were disproportionately concentrated in the lower income groups ($X^2=7.8$, $df=2$, $p+.05$). Indeed, a few parents in the lower income group reported that they had to make major changes in their living style in order to cope with the financial demands of a child with cancer. Consider the following comments:

We had to sell our house because he went through most of my health insurance policy in 6 months. Recently, my husband's been laid off again, and we're going through the financial strain again.

The bills are bad. I work, but I'm still in debt.

Second, a family's financial resources may make an indirect contribution to stress because lower income families may be less able to buffer themselves from the impact of the disease than more affluent families. For instance, more affluent families are better able to afford second opinions regarding diagnosis or treatment formats, find it easier to travel to specialized treatment sites, and can hire social workers and psychologists if they are not freely available. More highly educated families may be more comfortable seeking and using these stress-reducing resources. Less related to the disease process, per se, more affluent families are better able to absorb or avoid the financial stresses associated with hospital parking fees, motel costs incurred when the child is an inpatient, extra costs of eating in the hospital cafeteria, taking time off from work to be on hand, spending money on relaxing vacations, hiring extra baby-sitters for children at home, and so on.

Third, we know enough about the meaning of socio-economic status in American life to know that people's lives are affected by these factors in a variety of subtle ways. Financial resources and educational opportunities make a difference in the life experiences of all families, and they establish a context for living and for dealing with a myriad of problems. Several students of stressful life events suggest that

lower income families are exposed to more unfavorable living conditions and stress of all sorts in our society, and the addition of childhood cancer exacerbates an already unequal life situation.²⁵ Parents' whose economic status or educational experience makes them normally concerned about whether their child can be upwardly mobile in a heavily tracked and stratified society, may become especially concerned or anxious when their child is stricken with the added burden of cancer. Parents who assume, and whose status can more or less guarantee, an affluent life for their child, may not feel that the fact of cancer jeopardizes this status in any serious way. Further, parents of higher economic and social status, perhaps themselves professionals, may find it easier to relate effectively with other professionals - educators and social service workers. In addition, of course, professionals may respond differently to parents of different statuses (Adams, 1979)...these professionals are no more free from class and educational biases than the remainder of the American populace.

Fourth, families of different social and economic statuses may not experience (or report) stress in the same ways. For instance, considerable research suggests that various cultural and ethnic groups respond to pain and illness in different ways, and the same may be true of people in different social classes and statuses (Antonovsky, 1980). Moreover, with particular regard to children, Campbell reports "a stiff-upper lip, business as usual approach to illness on the part of children whose parents are in the higher levels of the status structure (1978, p. 46)". If this is true of children, it may also be true of the parents they learned it from, helping to explain why higher status parents report less stress.

A Brief Summary

Our discussion of the stresses reported by parents of children with cancer highlights a number of important issues. First, it is clear parents experience several different kinds of stress. Some are rooted in aspects of the disease itself, and in its treatment: they are connected directly to the course of illness, and to the

possibilities of life and death. Other stresses are rooted in the social and personal environment of the family and community in which parents exist. It makes sense to distinguish these different kinds of stresses, and to consider their differential impact.

Second, these distinctions, and parents reports of their experience, make it clear that the impact of childhood cancer on a family continues over time. Although the shock and sudden changes accompanying diagnosis may make that the most stressful time for most parents, continuing treatments and checkups (even when the outcomes are positive) also are stressful. Moreover, the social stresses associated with the disease and its impact on family life persist. The difficult need to tell others, and to share one's new status as the parent of a seriously and chronically ill child, recurs in different times and places. Even parents of children who have died report continuing stress related to anniversaries, memories, new family patterns, and reorganized social relationships. While these stresses may be moderated by successful treatment of the disease, or exacerbated by relapse and/or death, they continue to have long term impact on parents' feelings, orientations to their children, and ways of managing their personal and social tasks.

Third, it is clear that families in different medical or social situations experience and/or report stress quite differently. The fact of cancer in a child, and the progress of this disease, has major impact across a variety of social situations and socio-economic statuses. The powerful reality of life and death, of relapse or remission, cuts across a variety of social distinctions, rendering all families vulnerable to tragedy. However, the family's socioeconomic status appears to mediate the social impact of childhood cancer in a variety of ways. Families of higher social status report less stress in their social relationships than do families with lower incomes and educational levels.

These findings suggest quite clearly that families in different medical and social situations experience different realities, within a fairly common set of stressors. As

such, they probably require and seek different kinds of help and support. The next paper in this report examines parents' reports of the sources and kinds of help they desired and received.

PARENTS' ACCESS TO INFORMAL SOURCES OF HELP AND SUPPORT
IN COPING WITH CHILDHOOD CANCER*

People cope with the stressful situations we have been discussing in different ways. One common coping pattern is to reach out to others for help and support. In the attempt to gather such support, some parents and families were quite successful. On the other hand, some families never found the help they wanted, and ended up feeling isolated, lonely and frustrated. A few other families appeared to eschew help and support from "outsiders." In this paper we concentrate on various kinds of help parents received, and on the sources of help and support they used.²⁷ We also examine reports from help-givers, the friends of families of children with cancer.

There probably is a complex interaction between the kinds of stress a parent experiences, the general coping mechanisms he/she adopts, and the kinds of help and support from others he/she finds most useful. For instance, in the first paper in this series we suggested that parents experienced instrumental and intellectual stressors as most potent aspects of their child's illness. Their primary needs were to deal with the direct impact of a life-threatening disease, and to find out as much as possible about that disease. Parents also experienced stress rooted in their socialization concerns and their social relationships, as well as in their existential ordering of the world. However, these problems of coping with nuclear family members, with personal fears, and with "bringing up" their children were rated as less potent than the fact of the disease and its treatment and side effects.

*The lead author of this paper is Joan Chesler, with collaboration and assistance from Mark Chesler and Oscar Barbarin.

It makes sense that parents who experienced a primary need to gather information would most appreciate help that responds to that particular need. Not only does this need specify the kind of help most required, it may also specify the most appropriate sources of help. Information on the disease and its treatment are most likely to be forthcoming from doctors and nurses, and perhaps from parents of other children with cancer. By the same token, parents who felt overwhelmed by the instrumental tasks they had to perform probably would most appreciate help that solves these problems, that helps them deal with the routines of treatment and put their house and family back in order. Here, friends, family and neighbors, as well as health care professionals, are probably the most useful sources of help and support. Parents most affected by concerns about social and emotional relations, within their family and themselves, may need help in dealing with these personal and interpersonal relations. Help and support of a non-specific and emotional character, from nuclear family members and close friends might be most critical. The assistance of psychologists and social workers also might be relevant. Finally, parents struggling primarily with the existential problems of meaning and faith may find it most useful to seek help from specialists in these issues, psychologists and members of the clergy.²⁸

In the present paper we only touch briefly on these intriguing relationships and interactions among different kinds of stress and help. We feel it is most important to sketch first some general findings about help and support reported by this sample. If we can describe the different kinds of help and support parents received, and the sources they utilized, we will be able in other papers to draw the paths that connect stress and help/support more fully. Moreover, this paper concentrates on informal sources of help and support for families of children with cancer, such as friends and family. The role of health care professionals is explored in the final paper in this series.

What constitutes help and support from friends and family?

As we consider families' search for help and support from others, it is important to describe the kinds of help and support that mattered? This is not only critical from an analytic perspective, but also from a practical and humane stance. Many people appear quite reluctant to offer help to parents of children with cancer. Indeed, many people appear reluctant to offer help to various people in obvious need. Often the reluctance is based on discomfort with offering help or not knowing how to help. "I don't know what to do" is a common statement, as is "What kind of help do they need?"

Voysey (1972) identifies two factors underlying this reluctance, perhaps explaining how others such as friends view the possibility of offering help: (1) perceptions that actors are not themselves responsible for their problem or situation; and (2) perceptions that any help actually might have a positive impact.²⁹ For instance, in an illness of unclear origin, like childhood cancer, parents have minimal responsibility for its occurrence (despite any irrational guilt). Therefore, they are more likely to receive help than if they were seen as responsible for the situation (such as for child abuse or a preventable accident). Moreover, the increasing possibility of survival and even cure for children of cancer may allow friends to feel more effective about their help than if the situation was quickly fatal. Growing recognition of the necessity of a positive support system for the child with cancer and his family also makes it clear help might have positive impact. On both counts, parents of children with cancer are increasingly likely to receive help from their friends and family, at least to the extent that these perceptions are shared. Obviously, the general public doesn't necessarily evaluate these circumstances as we have done here, and that is one reason many parents may not receive all the help they desire and need.

Parents indicated that several different kinds of help were important to them.

Sometimes the most important kind of help was quite non-specific, and responded to a generalized emotional need, or to the desire for stable social relationships. For instance, many parents reported being grateful that some people were "just there", "listened well", or "cared". This kind of help may have been especially difficult to provide, for the well-intentioned giver may feel that he or she was not really "doing much". But it was important nevertheless. Examples of this kind of help reported by parents include:

Our friends were helpful, very, very sympathetic, and understanding and compassionate.

Its good to have somebody that isn't in the family and not directly related. They gave me a shoulder to lean on, they cried with me and were very understanding... stayed by my side.

My daughter got over 400 cards and we got over 100 cards. They told us they cried for us and wanted to do anything possible.

They helped me as far as feelings...I could talk easily with them about "What am I going to do when she dies?"

By calling and inquiring about how he was doing. If we needed their help in any way, we just had to let them know. They didn't want to keep pestering us, but if we needed them all we had to do was to pick up the phone and they'd get it done.

One friend would go out for coffee with me and just talk. Mostly this guy just listened. He was somebody I could talk to and he'd sit and listen. Knowing he was there great.

A second kind of help was quite specific, and responded to particular instrumental needs or tasks. For instance, many people helped mothers or fathers with key household or caretaking tasks, such as cleaning the house, cooking dinner while they were at the hospital, providing transportation, entertaining siblings, visiting the ill child, filling in for an employed parent, etc. Some of these specific forms of help required the giver to know the family well enough to know what was needed.

Examples of this kind of help reported by parents include:

His side of the family was helpful with the practical things like babysitting, cleaning the house, taking us out.

They brought us food and our neighbors offered their homes to our relatives who came to the funeral.

They always came up to the hospital to relieve us for a while so we could get out.

Our friends and neighbors brought over food for the kids. Our kids spent the night with neighbors lots of times. The neighbors took them places. Neighbors would come over and spend the night with our sick child so we could get some sleep.

The people in our church and our friends brought in meals, provided us transportation to the hospital, and accompanied me to the hospital if my husband was working.

Our friends took turns coming in and staying with the kids when my daughter was in the hospital. Food was brought in and if I was at the hospital all day and one of the other kids got sick at school, one of our friends would go get them.

A number of these comments describe quite effective and moving efforts to respond to human stress and crisis. Anyone who doubts that people can and do reach out to one another in this society should be reassured somewhat by these reports.

However, not all friends and family members responded in such generous and meaningful ways. Perhaps some persons were not sure how to offer effective help or what was needed. In the first paper of this series, we discussed ways in which various groups of people added to the stress faced by parents of children with cancer.³⁰ With regard to attempted help-giving, parents noted that one non-helpful behavior involved friends or family members who "stayed away", who avoided interaction with the family of the child with cancer.

Several friends couldn't cope with it. They didn't understand, and actually avoided it. It was easier for them not to ask.

Some friends we didn't hear from. They didn't want to say the wrong thing so they didn't say anything. That's bad. That's the wrong decision.

They were helpful at first, but later, as time drags on, no. The first time you are in the hospital everybody sends you cards and toys. Later on nobody pays attention.

A second behavior parents reported as non-helpful included interactions which denied or avoided the illness or the ill child.

Some friends were afraid to come visit because they didn't know what to say, they were afraid they'd hurt our feelings by discussing it, so they would sit in silence and make us feel very uncomfortable. Even close friends didn't know how to handle it.

Their not talking about it made it worse.

My husband's parents won't talk about my child at all. They act as if she never existed. That really hurts.

It wasn't helpful when one would say, "maybe you'll get pregnant again and replace her." They don't understand that you don't replace a person.

Finally, parents also reported that friends who "pushed too much", or who offered help where it wasn't wanted, were not helpful.

The ones that weren't helpful weren't sincerely honest.

Some people kept trying to push help on me that I didn't want.

A lot of parents we talked with said they wouldn't have put their child through chemotherapy.

Sources of help and support

Having explored some of the meanings associated with helpful and supportive behavior (or its lack) from family and friends, we can now examine the different sources of help and support parents utilized. On the structured questionnaire we asked parents to indicate on a 5-point scale how much support they had received from each of 14 categories of people. Figure 11 presents information on the percent

of parents who reported that each of these groups were very or quite helpful. In tabulating these responses, we computed percentages on the basis of the entire population answering the question, including persons who had "no contact" with some of these groups.

Figure 11 indicates that the group most often mentioned by parents as very or quite helpful was their spouse. Close friends and nurses were close behind, followed by grandparents and physicians. If intellectual and instrumental stresses were most potent, then these rankings may reflect relationships with those people most able to provide information about the disease and its treatment, and most able to perform practical support tasks that could facilitate parents' efforts to cope with the disease and their immediate family responsibilities.

Social workers and psychologists were at the bottom of the list, e.g., they were mentioned least often by parents as very or quite helpful. There are several potential explanations for the low ranking of these human service professionals. Some parents did not reach out to these persons, or did not accept their help when offered, because they did not wish to be stigmatized as needing "special help". Moreover, the kinds of special help social workers and psychologists often are perceived to offer, emotional and non-specific support, might not have been potent for many parents. Thus, the social and emotional support forthcoming from family, friends and neighbors may have seemed both adequate and more "normal". For the sample studied here, part of the explanation of these data also may lie in the general inaccessibility of such professional resources to parents. At this particular hospital, there are minimal social work and psychological services available to families of children with cancer. Even fewer resources were available in previous years, when many of the families in this sample experienced their most stressful periods. Moreover, most of the social work services are available only to in-patients, with minimal out-patient outreach or service. Thus, it may not be the competence or helpfulness of the social work staff

that is being responded to in these reports, but rather the general failure of the medical care organization to provide adequately staffed services that reach out to parents. Several other children's hospitals provide much more extensive social work services to families of chronically ill children; in these hospitals we might expect a very different ranking of these sources of help and support.

Figure 11

Parents' Reports of Sources of Help and Support

<u>People/Group</u>	<u>Percent reporting group as "very" or "quite" helpful</u>
Spouse	73
Close friends	70
Nurses	69
My parents	56
Physicians	53
Other relatives	47
Other parents of ill children	44
Neighbors	44
School people	43
Other friends	38
Church leaders	37
My other children	37
Social workers	25
Psychologists/Psychiatrists	7

Figure 12 permits an partial examination of this explanation. In this figure we retabulated the percent of very helpful or quite helpful responses, using as the base the number of parents who reported that they had some contact with the group in question. On this basis, some groups' reported helpfulness jumps considerably: psychologists/psychiatrists move 40%, from 7 to 47%; social workers move from 25 to 44%; my other children move from 37 to 56%; other parents of ill children move from 44 to 62%; schoolpeople move from 43 to 61%; and church leaders move from 37 to 52%. The range of least to most helpful group, which was 7% to 73% in Figure 11, is narrowed considerably, to 42% to 76%. Each of those groups with the greatest advance represents a group with which parents had selective contact. For instance, almost everyone (at least 81/85) had contact with spouses, close friends, other relatives, doctors and nurses. Thus, these percentages change minimally when recomputed. However, only parents with school age children were likely to have had contact with schoolpeople, so controlling for their contact makes sense. Similar reasoning explains the change in reported helpfulness of my other children; only parents with other children could be expected to find them useful. Parents of other ill children have been organized into an identifiable and available resource in this hospital only within the past two years; before this time new parents would have had to locate and make contact with other parents individually. Thus, SHARE did not exist as a resource, much as social workers and/or psychologists did not exist as available resources. The basic meaning of these tables is that theoretically helpful resources will not be helpful to parents with ill children unless these resources are easily available and accessible. The access problem is at least as great an issue in the service delivery system as is the conception and competence of the resource itself.

Figure 12

Parents' Reports of Sources of Help and Support:
Controlled by Report of "Contact"

<u>People/Group</u>	<u>Percent with contact reporting groups "very" or "quite" helpful</u>
Spouse	76
Close friends	72
Nurses	71
My parents	62
Other parents of ill children	62
School people	61
Physicians	57
My other children	56
Church leaders	52
Neighbors	50
Other relatives	48
Psychologists/Psychiatrists	47
Social workers	44
Other friends	42

The special role of close friends. When we examine the ways in which parents utilized or responded to these sources of support, the special role of close friends becomes quite apparent. In both the interview and the questionnaire we asked about the role of close friends. The results in Figure 13 indicate that close friends, as a group, played a vital role in relating or linking parents to several other sources of support. The first column in Figure 13 demonstrates the relationship between parents' reports, in the interview, that they received help from their friends, and their reports about various sources of help and support on the questionnaire. The numbers in this column represent chi-square values, with the higher values reflecting a greater pattern of association between these variables. Asterisked values indicate associations strong enough to be more than chance occurrences. The second column demonstrates the relationship between the close friends item in the questionnaire and the other sources of help and support parents indicated on that form. The numbers in this column represent r values for Pearson product-moment correlations, with the larger values also reflecting a greater pattern of association. Both columns make it clear that support from close friends is most powerfully related to help and support from other friends and neighbors, and from other relatives. Moreover, parents who on the questionnaire reported high support from their close friends, also reported receiving significantly greater support from several other groups of people.³¹

Figure 13

Parents' Reports of Help From Friends,
Related to Other Sources of Help and Support

<u>Other Sources of Help and support (Questionnaire)</u>	<u>Support from Friends (Interview) Chi-square value</u>	<u>Support from Close friends (Questionnaire) r value</u>
Close friends	9.7**	
Other friends	9.4**	.65**
Neighbors	6.6**	.52**
Spouse	.9	.05
My other children	3.7	.32**
My parents	.6	.09
Other relatives	4.7*	.42**
Nurses	1.6	.20*
Physicians	3.9	.05
Social Workers	2.0	.19*
Psychologists/Psychiatrists	2.4	-.07
Other parents of ill children	1.0	.19*
Church leaders	2.0	.19*
School people	3.9	.29**

**represents an association that is statistically significant at p. + .05.

* represents an association that is statistically significant at p. + .10.

One variable significantly associated with the report of high support from friends is the ease with which parents were able to share the diagnosis with friends. Figure 14 demonstrates this relationship. Why would it be difficult for some parents to share the diagnosis with their friends? First, some parents were concerned about their friends, and about the impact of the news on them. Second, "telling" publicly acknowledges a new identity, an acceptance of self as the parent of a child with cancer. Not all parents were comfortable acknowledging that reality, to themselves or others. Third, telling close friends was an admission of need and vulnerability and, in the case of friends who cared and were able to act on their caring, a beginning of the process of giving and receiving help. Parents who were not sure they really wanted help, or parents who felt uncomfortable with help when they got it, or parents who didn't wish to be so publicly vulnerable, did not tell their friends with ease.³² Fourth, the ability to tell one's friends about the diagnosis was an initial test of one's ability to communicate about such issues. Without these skills, it should be hard to ask for various kinds of help later in the treatment process.

The ease or difficulty with which parents shared their child's diagnosis with friends appears to be an important part of their ability to receive help from friends. Those parents who did find effective ways to share the diagnosis with their friends, and who were able to identify and articulate their needs for help, were more likely to be rewarded by these friends. In turn, receiving help from friends was a touchstone for the entire process of receiving help from other groups. In light of these findings, it would make sense for medical and social service professionals to try to help parents stay connected with their friends throughout these difficult initial periods. For instance, they might start by asking newly diagnosed parents the following questions: "Have you shared this information with your close friends?" If yes, "How did it go? "What did they say, What more information do they want? Can I help share information with them?" If no, "Why not? "Who have you not told?

"Perhaps you could do it soon. They may be able to help." In this way social isolation and alienation of the family may be reduced or avoided from the start.³³

Figure 14

The difficulty of sharing
the diagnosis with friends, related
to support from friends

<u>Degree of Support</u>	<u>Percent of Parents Reporting Difficulty Sharing Diagnosis With Friends</u>	
	<u>Not Difficult</u>	<u>Difficult</u>
From close friends		
Low (N=22)	41%	59%
High (N=44)	68%	32%

$$x^2=4.5, df=1, p=+.05$$

From other friends		
Low (N=38)	47%	53%
High (N=28)	75%	25%

$$x^2=5.1, df=2, p=+.05$$

In our prior discussion of the kinds of stress families of children with cancer experienced, we discovered several interesting relationships between stress and socio-economic status. Exploration of these status variables with regard to help and

support from friends revealed that parents of higher education status reported receiving more help from their friends than did persons of lower educational status.

Figure 15

Parents' Reports of Help From Friends,
Differentiated by Parents' Education

<u>Parent's Education</u>	Percent of parents reporting very or quite helpful support from		
	<u>Close Friends</u>	<u>Other Friends</u>	<u>Neighbors</u>
College graduate (n=29)	86%	55%	55%
Some college (n=26)	69%	27%	42%
High school or less (n=29)	59%	38%	28%
	$x^2=5.5, df=2$ p+.10	$x^2=4.7, df=2$ p+.10	$x^2=4.5, df=2$ p+.10

Analysis of the relationship between family income levels and reports of help and support from friends showed similar trends, but not of the same magnitude (and not approaching statistical significance).

The literature on psychosocial aspects of childhood cancer contains almost no research, and very little informed commentary, on the role of the family's close friends and neighbors.³⁴ A number of prior studies of children with cancer indicate how important it is for these young people to maintain good relations with friends and schoolmates. Moreover, Wortman and Dunkel-Schetter's review (1979) also suggests, at least for adult patients, that "virtually all the studies that have examined the predictors of good coping and adjustment to cancer have found that individuals who are able to maintain close interpersonal relationships with family and friends

despite the illness are more likely to cope effectively with the disease than individuals who are not able to maintain such relationships (1979, p. 123)." What works for patients also may be critical for parents and others trying to help and support patients. Our experience, and these data, suggest that supportive relations with friends and neighbors may be a critical variable in parental coping with the disease. Close friends may help re-integrate all family members - parents, child with cancer, siblings-to a more normal existence.

Support from the medical and nursing staffs. Figures 11 and 12 indicated that a sizable percentage of parents reported receiving a great deal of support from the medical professionals with whom they dealt. However, not all parents and families received the same kinds or amounts of support. When we combine the items asking about help from physicians and from nurses into a single variable, help from medical personnel, high support from friends was related to low support from medical personnel ($\chi^2=4.95$, $df=2$, $p+.10$). One explanation for this finding is that medical personnel - doctors and nurses - may have been the court of last resort, saving their helpful resources for the most isolated parents, those who needed their help the most. Another possibility is that some parents responded to the onset of the illness in ways that did isolate them from their friends and associates. Mothers of young children, especially, tended to live in the hospital with their children, and sometimes seldom left their children's rooms. In discussing a program that encourages parent participation in the care of their sick child, Adams (1979) notes this problem; "...one parent, usually the mother, remains overnight in the hospital with her child for days on end. Often she refuses to go home or refuses to leave the child even to go for walks (1979, p.75)." In our sample, parents with low support from close friends were isolated from their friends and extended family; thus they may have relied extensively on the immediately available medical and nursing staffs. This also may be a common pattern for parents who lived a substantial distance from regional care centers, and

who could not return frequently to their homes and local neighborhoods. It is also possible that close friends and medical staff members were providing very different kinds of help; if so, we should not necessarily expect them to be highly related. For instance, families experiencing the intellectual and instrumental stresses of childhood cancer, needing information and help in dealing with the treatment and the hospital, may have sought (and received) primary support from the medical staff. Most friends would have been of little value in meeting these specific needs. Families primarily dealing with other instrumental stresses, such as caring for their other children, or the social stresses of isolation and loneliness, may have found their friends most useful. The medical staff might have been quite irrelevant to these needs. Our understanding of the sources of help parents utilized will be enriched when we investigate these relationship between these sources, the specific stresses parents were experiencing, and the particular needs for help and support they had at different points of time.

Family support systems. Parents quite consistently reported a high degree of help and support from other family members. Moreover, 61% of the parents indicated that their family had grown closer together since the onset of their child's illness.³⁵ Thus, family support was not only a critical aid to many parents; sometimes it also led to second order improvements in the quality of family life. The following statements by parents reflect increased closeness in the marital relationship:

My husband developed a lot of respect for my style, and I had to learn to share the responsibility of caring for the child who was ill with my husband. It was hard at first to let go of that.

Our marriage was in trouble before. We were going to separate but my husband said he couldn't leave our child, so he stayed. We had to bring our troubles out in the open, and work on our problems so we could live together. Now we're closer than we've ever been and have real strength in our marriage.

We've gotten closer, because I now talk to her more than anybody. We really grew close when he was in the hospital going through his first treatment. Instead of just sitting around watching TV, we talk and communicate more.

Being able to talk has been real important. If anyone's afraid of something we tell each other. Sometimes when you talk about it, you're not as afraid as before. It doesn't go away, but it's not as bad.

Although both mothers and fathers reported receiving a lot of support from their spouses, mothers reported less support from their spouses than did fathers. This finding is consistent with other research indicating fathers' somewhat more withdrawn role during serious childhood illness.³⁶ It also may reflect mothers' greater needs for help and support, perhaps a product of their greater involvement in the direct medical care of their hospitalized or home-bound children.

Exploration of the relationship between socioeconomic status and reports of help and support from family members did not produce clear findings. However, parents of children with cancer whose own parents were living relatively close to them, less than fifty miles away, reported significantly more help from their parents, than did informants whose parents lived further away. However, these parents also reported significantly more stress in their relations with their own parents. Thus, people who moved from their families of origin (or whose parents have moved from them) experienced both less help and less added stress from their extended family members. These more mobile families, who lived geographically further from their extended families of parents and siblings, reported higher levels of income and education. Thus, despite the lack of a direct link between socioeconomic status and family help and support, the interviewing variable of mobility may provide a connecting link.

Support from other parents of children with cancer. The development of a parent support and education group, such as SHARE itself, suggests that parents have some interest or need in giving and receiving help from others. Obviously this is not true

of all parents, but a substantial number reported that parents of other ill children were very or quite helpful (44% of all parents in the sample, and 62% of parents who had contact with other parents of ill children).

I went to the SHARE meeting and shared my experiences with them. When I see someone else who is going through the same thing I am, and they can handle it, then I can conquer it too.

As far as moral support or anything like that, just the families of other kids who were at the hospital were helpful. We did grow to know some of them.

It would be helpful to have someone who has been through this at the very beginning. No one else knows what you're going through until they've been there. You can tell someone who's been through it how you feel and ask should you or do you have the right to feel that way.

SHARE meetings are really good. The first few tore me up when everyone was talking and I found out I was in the same boat as them. Then I thought I was lucky because some had it so bad.

The two-way street of giving/receiving help to/from parents of children with cancer is a vital part of self-help groups. For instance, Leiken and Hassakis (1973) explain the role of self-help groups in terms of their report that "the most frequently used helpful coping mechanism was the 'doing defense' (p. 55)." One example of this mechanism includes helping other children and parents with similar problems. While this pattern often is discussed in the literature as a potentially maladaptive defense mechanism, it obviously can have pro-social outcomes for helpers and helpees. As one parent noted:

The leukemia foundation which I am working on gives me something positive to do. I feel I am helping someone down the road, and changing things in a positive constructive and manner.

Some parents, in fact, suggested that only another parent "in the same situation" could be helpful to them.

Numerous reports exist of parent or patient support groups organized and operated by hospital staff members, usually social workers and nurses.³⁷ There are fewer reports of more spontaneous or independent groups initiated and directed by parents of ill children. Professionals often are wary of independent self-help groups because of concerns about potential harm: they fear that misinformation might be multiplied by lay persons, cultish approaches to medical treatment could be fostered, and delay or resistance to medical procedures generated. Undoubtedly these issues might exist, but there is little evidence, in this sample or otherwise, to suggest substantial danger. In our sample, the degree of support parents reported from the medical staff and the social service staff bore no relation to their involvement in the self-help organization. Clearly, organized parents and medical/social service professionals can work together on these issues, even if there are occasional clashes or different interests over time.³⁸

The literature on parent self-help groups suggests that we can make distinctions among several different kinds of group foci, and thus identify different kinds of help parents receive from one another.³⁹ One focus, and one kind of group, can be educational or informational in nature, helping to inform parents about the disease and its side-effects, potential child-rearing and discipline issues, the specific nature of the hospital and hospital staff characteristics, and so on. A second kind of group can focus on emotional support and peer counselling. Parents may talk with and provide support to one another, sit up with sick or dying children, meet to discuss feelings and anxieties and help each other solve problems in family relations, etc. A third kind of group may focus on changes in the medical system. Such a group might try to alter the structure or substance of service delivery systems, help the hospital improve its services, fund special hospital programs, or hold certain hospital services accountable to consumer scrutiny. All three of these foci may be important for parents of children with cancer. All three may be useful responses to the different

stresses (ignorance and confusion, social isolation and a need to connect with others, anger and concern about the quality of services delivered) parents have indicated.

Preliminary analysis indicates that at least one member of 40% of the families in this study attended at least one meeting of the self-help group, SHARE. Those who chose to participate did not differ from others in terms of income and education, sex of the active participant, life-status of the child (either the age of child or whether living or deceased), and degree of stress reported. A trend, although non-significant statistically, did appear with regard to the amount of time that had elapsed since the child was diagnosed as having cancer. Figure 16 indicates that those parents with living children were more likely to be involved in SHARE if their children were diagnosed 1 to 3 years previously. Parents whose children had been diagnosed less than one year previously evidently were too preoccupied with the physical and emotional demands of the illness to invest time and energy in the self-help group (this finding is consistent with the tendency for parents to emphasize disease-related stresses early in the illness process, and to identify social and familial stresses only later, after the immediate crisis had passed). On the other hand, parents whose children were still in remission for 3 years or more may have felt they no longer needed support from a self-help group of this kind. No clear trend exists in this sample for involvement by parents of children who died.

Analysis of the data also indicated that parents active in SHARE were more likely to have intervened in the medical care process than parents not active in the group. Perhaps SHARE helped stimulate or reinforce people to play a more active role in treatment; or perhaps people playing an active role in treatment also sought a broader range of support. Further, SHARE "members" reported that participation in the group had been important in providing the information, emotional support and confidence needed to cope with childhood cancer. In contrast, parents not participating in SHARE felt it was inaccessible or unhelpful to them because: (1)

meetings were too far away or at inconvenient times; (2) they feared the meetings would be too depressing, or; (3) they no longer felt the need to cope actively or differently with illness.

Figure 16

Parental Involvement in SHARE:
by time since diagnosis

Time since diagnosis (Parents of children living with cancer)	Parental Involvement in SHARE	
	<u>Yes</u>	<u>No</u>
1 year or less (N=5)	20%	80%
1-3 years (N=25)	44%	56%
more than 3 years (N=35)	23%	77%

$\chi^2=4.5$, df-2, NS

A summary note. The images of help and support we have drawn from the data in this section are complex. Many parents felt the need for help and support in dealing with childhood cancer and with a series of life-disrupting events. However, different parents and families appeared to utilize and receive different kinds of support and help; not all families experienced the same stresses, nor did all families adopt similar coping mechanisms. Moreover, even families who coped in similar ways in general drew on different specific resources. What is helpful to one family, in one set of circumstances, may not be helpful to another. The attempt to determine what kind of help and support each family needs and wants is a considerable challenge for service providers, and for friends and family members.

The process of giving help to families with childhood cancer.

In addition to studying parents' reports of the help and support they received, we sought to understand the other end of the "helping chain". What was it like to give help to these families? What were the experiences of people who tried to respond to these families' needs? Wortman and Dunkel-Schetter (1979) suggest, at least for friends responding to adult patients, that this is likely to be a difficult process. They report a variety of communication barriers, including friends' confusion about a need for optimism and cheerfulness in the face of negative feelings about the illness, and the assumption that people should avoid thinking about their problems. The research focus on understanding patients' and families' responses to illness, such as it is, seldom empirically examines friends' and helpers' issues. In the following pages we report a first step in exploring friends' reactions and responses.

Subsequent to the completion of the interview study with parents, described in the INTRODUCTION to this report, we sought to interview a small number of friends and neighbors who were reported to have been particularly helpful. We thought that such an effort might be useful in several ways. First, it might shed additional light on a family's mechanisms for coping with childhood cancer, by adding the perspective

of others outside the immediate family. As such, interviews with external persons might help validate parents' own reports. Second, these interviews might help us understand the wider impact of childhood cancer on others who were not immediate family members. How did others who were not related to the ill child react to the illness? Third, just as we examined the process of asking for or seeking and using helpful resources, we were interested in the process by which concerned people offered and gave help. Finally, as with our primary concerns throughout the study, we thought these data might provide other people with a set of practical guidelines for how they could be helpful to families undergoing a long term crisis.

In order to maximize the depth of material we might gather, we decided to identify and interview a small group of families who were reported to have given substantial help and support to families of children with cancer. While we recognize that such a sample selection process fails to examine the full range of potential helpfulness, or friends' responses in general, it does permit an intensive examination of a smaller range of people who did respond successfully to others' needs. We identified these "helper families" by asking 6 families in our original sample of 55 families to identify 2 other families who had been helpful to them. Four of the 6 families we asked to identify helpers had children living with cancer, and 2 families had children who had died of cancer. We prepared a letter to each of these 12 nominated "helper families", explaining our purpose, and enclosing permission from the family with cancer. We then interviewed and administered a self-report mail-back questionnaire to a total of 20 helpers in these 12 families.

Some general findings. In this paper we do not report in depth the data from the helper study, but some general findings do stand out. First, these helpers reported that the impact of the child's illness on them was quite substantial. They, too, experienced shock and stress related to their concerns about the child and the family's general welfare. Most reported that the entire experience brought them

closer to the family of the child with cancer.

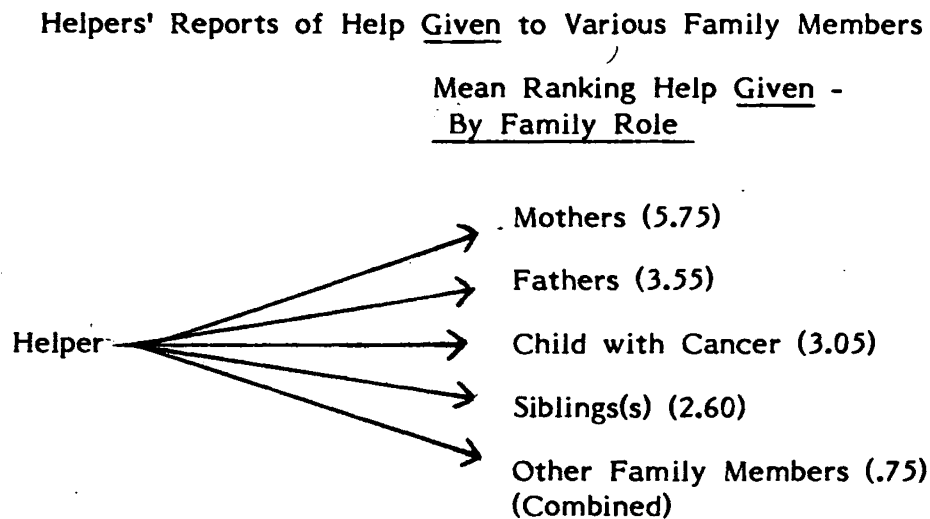
Second, friends reported providing a variety of kinds of help and support, both of an emotional and instrumental character. However, they often reported that just "being there", the nonspecific and emotional form of help noted earlier, was the greatest gift they shared.

Third, one family had named another family with a child with cancer as most helpful to them. The kinds of help this family provided was markedly different from that provided by other helper families. For instance, this helper family had met the family they helped while both were in the hospital. All the contact they had and the help they gave occurred in the hospital. The help and support they provided concentrated on medical information issues, and on the emotional responses of the child and the family to the illness. They focussed very minimally on family maintenance or communication issues. Clearly, the point of interaction with the family they helped was centered on the medical system, the disease and its treatment. Other helper families, those who had known the family they helped for some time, and who interacted with them out of the hospital as well, dealt with a broader range of issues and relationships.

Who received what kind of help from whom...corroborative findings. We gave each helper a list of six categories of family members, with instructions to rank the family members in the order in which they provided help to them. Thus, generally, we received a 0-6 ranking of help given. We tabulated these rankings for the entire sample of 20 helpers, and present, in Figure 17, the means of these rankings of help given. The data indicate that helpers reported giving more help to mothers of children with cancer than to fathers, and more help to the parents than to other family members. That parents were given more help than other family members makes sense, because we interviewed helpers who were nominated by parents as helpful to them. If we had interviewed patients' nominees we might have discovered

different patterns.

Figure 17



How do we explain the finding that mothers were given more help than fathers? In general, it appears that mothers were able to express a fuller range of feelings to their friends. Thus, it was easier for friends to figure out what kinds of emotional support might be useful. In addition, more of mothers' instrumental tasks were accessible for friends to take over and accomplish. Household chores, for instance, could be turned over to or shared by friends; as reported earlier, they often did house-cleaning, washing and ironing, cooking, shopping, child caring, etc. On the other hand, fathers' normal tasks, such as going to work, could not be substituted for or supplemented by most friends' actions.

In addition to the role issues indicated above, it appears that fathers often had a harder time asking for help, and making themselves open or vulnerable enough to receive help from their friends. Male sex-role images of strength, competence and independence may have stood in the way of expressing these needs.⁴⁰ In addition, of

course, helpers had to wade through their own feelings about offering help to men, not wanting to render a man vulnerable if he didn't want to be. Thus the questions is not just how a man opens himself up to help(ers), but how helpers give help to an apparently strong (or even fragile) man?

Some of the comments helpers made about the differences between the men and the women they gave help to provide more detail on these findings. The following excerpts from the helpers' interviews highlight differences in helping mothers and fathers in 3 different families:

Female friend: I helped him by helping her. As far as giving him support, I don't think anybody could at that point. He was in a position of having to be the rock. I felt bad for him because he couldn't draw that much support from anyone, because everyone was drawing support from him...We were there for him too, but I'm not sure I helped him emotionally that much, even though I tried to give him support. We didn't talk like she and I did.

Female friend: He didn't seem to need us the way she did. He had his work and we couldn't help with that. We helped with housework--and talked some as a threesome and as a foursome.

Male friend: We gave him moral support. I think being around and talking about other things helped.

Male friend: I gave the same kind of support to him as to her, only it was less intense and more distant. He had less impulse to use me as a resource.

Female friend: I tried to indicate to him that he mattered and wasn't expected to be quiet, strong and long-suffering while she was able to talk about things.

Male friend: I helped her the most because she expressed her needs the most. I'm sure they both had the same needs, but he didn't express them. I therefore resisted bringing it up in conversation.

Some fathers of children with cancer verified these sex-role distinctions, openly discussing the ways they withdrew or protected themselves emotionally.

Maybe my wife feels like I've grown farther apart because I locked myself in. These are things I just don't talk about. If you had tried this interview a year ago, I couldn't have talked to you. I know this upsets her, but my way of not going crazy is not to think or talk about it.

My wife accuses me of not talking.

The way I am, when it first came out, and everybody just wanted to help, I just wanted to be left alone. There probably are a lot of people who don't; they want a hundred people around. If they stayed away, it was the best thing they could do to help me.

One father, who admitted he found it difficult to be open with his feelings, also regretted that his friends didn't pursue him enough:

I think if I knew someone who was in my position, one of the things I'd like to ask him is how are you coping with it. I did not experience that much, only a couple of people asked me how are you doing. I think my wife experienced that a lot with her friends, but I only had a couple of friends who asked me how are you doing. If I could wish for anything, it would have been more of that.

One by product of the experience of childhood cancer is that some of these intra-family and sex related roles and behaviors may have changed. For instance, fathers reported making more changes in their family-related roles than did mothers (mean 7.2 v 6.7, $t=1.94$, $p=+.05$), responding to items about "taking vacations with the family", "spending less time working" etc.⁴¹

Helpers also reported that they gave more help to parents of living children than to parents of deceased children. Perhaps there were more useful kinds of help to give to these parents. For instance, the model of helping outlined by Voysey (1972) and by Brickman, et.al, (1980) suggests that one of the key variables is

whether potential helpers see themselves as being able to do something effective about the problem. These helpers may have seen more they could do for the parents of living children.

The two variables we have been discussing, living or deceased children and sex of parent, combine to provide the data in Figure 18. Fathers of deceased children clearly were provided the least support by these close friends.

Figure 18

Help Given, By Parents'
Sex and Life Status of Child

<u>Life Status of Child</u>	<u>Mean Ranking Help Given to Mother</u>	<u>Father</u>
Living	5.71	4.07
Deceased	5.83	1.83

The limits of the macho image of men unable to ask for help, unable to find friends to give it to them, were captured in an interaction that occurred during a meeting of the parents' group, SHARE. We had divided parents into two groups, one for males and one for females. Mothers and fathers met separately for an hour and a half. In the relative safety of a same-sex group, people talked about their children, the impact of the disease on them, their jobs, their fears and hopes for their families, their relations with their spouses, their sex lives, and the like. When each group returned to the entire meeting, parents reported some of their prior discussions. One woman complained a bit about her family's life style, indicating that her husband never shared much of his own emotional feelings and concerns with her and her child. Her husband responded, noting that it was alright for his wife to get upset and cry, but not for him. He, after all, "was the rock on which the family rested."* It was important for him to be strong. Another father noted immediately to the group: "You're going to find out in a while that you're a very mushy rock. Things happen that you have to cry about."

*This is a different family than the one discussed in the excerpt on page 72, but the interesting image of the "man as the rock" appears again.

A summary note

This discussion of the kinds and sources of help parents received from their friends and families highlights a number of issues in families' coping with childhood cancer. First, it is clear there are different kinds of help and support patients need. Help that is informational in character is most likely to come from the medical staff, and is unlikely to be provided by other family members and friends. Friends' help is most likely to be of two sorts: (1) specific help directed at the solving of instrumental tasks, such as caretaking other children, providing transportation, performing household chores, etc.; (2) non-specific help directed at meeting general socio-emotional needs, such as listening, "being there", caring, etc.

Second, parents utilized a variety of sources of help as they dealt with the stresses of childhood cancer. On a theoretical level they probably sought help from the people who could respond to the specific stresses they experienced. Spouses, close friends, and nurses were among the most helpful groups. It also appears that socioeconomic status mediated the sources of help parents utilized: parents of higher educational status reported more help from their friends - close and otherwise - than did parents of lower status. On the other hand, lower status parents reported receiving more help from the medical staff.

Third, it appears that the process of getting help involves certain values and skills, and that these orientations or styles may not have been present for all parents. Parents had to decide they wanted/needed help, as a starting point. The act of sharing diagnostic information, of telling friends and neighbors that one's child had cancer, was another difficult element of the help-seeking process. Parents who had difficulty telling friends about the diagnosis were not as able to get help as were those who mastered this task more easily. The ability to find relevant others, "helpers" who could be useful, also made a difference to parents. Parents who were

not able to make contact with potentially useful resources simply did not get help from these sources. And finally, parents' ability to identify the help they needed made it easier for friends to help them. Parents who remained emotionally inaccessible to friends, or who could not signal what their friends could do for them, did not receive as much help.

The parallel investigation of the experiences of friends who helped these families sheds additional light on some of these issues. Friends reported providing both instrumental help and general emotional support to families. Moreover, friends reported giving more help to mothers than to fathers. Both givers and receivers of help indicated the common pattern by which fathers withdrew, remained emotionally inaccessible, or could not identify specific helping needs as much as mothers. Friends reported also giving more help to parents of living children than to parents of deceased children, but our sample is far too small to make much of this finding at this point.

This discussion of the helping process, giving and receiving, illuminates one pattern of coping utilized by families of children with cancer. In the next paper we examine a second major pattern, becoming active in the medical process and relating effectively to the medical care organization.

PARENTS AND THE MEDICAL CARE ORGANIZATION*

In this paper we describe selected aspects of the relationship between parents and the medical care organization. The medical care organization, for our purposes, is defined as the hospital and its staff of physicians, nurses and allied medical professionals. The growing sophistication and effectiveness of treatments for children's cancer have been accompanied by increasing interest in participation in this process by patients' families. In part, this interest is stimulated by a burgeoning number of treatment choices and the sometimes grave iatrogenic consequences of these choices. The interest also is stimulated by the chronicity of the illness: as childhood cancer becomes a long-term chronic illness, with most of the daily care provided by parents, parents become partners in the treatment process. In this context, parents seek ways to develop positive reciprocal relationships with the medical staff. When satisfying, these relationships are characterized by parents' appreciation of the staff's skills and dedication, and their genuine desire to care for their children. By and large, satisfying parent-staff relationships are characterized by shared information, harmony and support, mutual respect, a sense of partnership, and occasionally friendship. However, when relationships are unsatisfying, poor communication, disagreement and conflict occur between medical staff and parents; this makes an already difficult situation unbearable for everyone.

*The lead author of this paper is Oscar Barbarin, with collaboration and assistance from Mark Chesler and Joan Chesler

This paper is organized around the major factors used by parents to characterize the quality of that relationship. Although presented only from the perspective of parents, it is no less a compelling and important account. It is a story of contradictions, replete with adulation of staff by parents, as well as occasional anger and disappointment.

In the INTRODUCTION to this series of papers we indicated that the sample for this study was drawn from a population of families being treated at one institution. As such, some of their experiences were with a single medical care organization and a relatively constant professional staff. However, particularly with regard to parents' reports of their experiences with doctors and medical treatment facilities, there are some important differences. Many families initially encountered the medical system, and the diagnosis of cancer, at a rural or small town facility, or in their local pediatrician's office. Some of the problems with medical staffs reported in this paper occurred far from the University of Michigan's Mott Children's Hospital. The following examples of positive and negative experiences are drawn from syntheses of parents' encounters with local hospitals, private doctors' offices and Mott Hospital.

Some general comments from parents

The relationship between medical professionals and parents concerned with childhood cancer is delicate. It begins in moments of great tension and anxiety, and proceeds through a period of uncertainty and physical as well as emotional pain. Regardless of the eventual outcome, parents and professionals are bonded by the child's illness; they are caught in an ongoing relationship defined by the child's progress. No wonder many observers have expressed concern for the quality of this ongoing relationship. Its quality is essential for the comfort of the family and the professional. As indicated in prior papers, the medical staff's actions and relation with parents may add to the family's stress, or may provide a continuing source of help and support. From the point of view of doctors and nurses, it can help make

their daily work even tougher, or provide a series of relaxing moments of mutual contact and commitment in the midst of a tough job.

Overall, parents in this study expressed a great deal of positive regard for the medical staff with whom they dealt. Seventy-four percent of the parents responding to the question evaluated their experiences with doctors and nurses as positive or very positive. Fifty-four percent of the parents reported receiving very or quite helpful assistance from doctors, and 69% reported that nurses were very or quite helpful. Moreover, the entire sample reported a shift in their views of doctors and the medical profession as a function of their experience: 51% reported having more respect for the medical system and feeling better about doctors now than they did before their child had cancer. Thus, the parents in this study, by and large, reflect a positive and mutually respectful relationship with the medical personnel they encountered.

Some parents expressed these positive views vigorously, as in the following comments:

I have faith in the medical field, faith in the doctors, and faith that my child has made it.

The doctor holds a very soft spot in my heart. He saved my daughter's life. I have all the letters she ever sent him and vice versa.

With the results we had from the operation our response would of course be positive. If some families had a child who had died, they would probably have had a negative outlook.

Despite the generally positive trends in these data, and the grateful tone of these reflections, no one would suggest that there were no problems, or that improvements could not be imagined. Twenty-five percent of the parents reported finding doctors only a little helpful or not helpful, and 17% reported such experiences with the nursing staff. Despite the overall theme of changes in a positive direction, not all parents reported newly positive feelings toward the medical system. Given

the general views we have been exploring in this series of papers, these contradictions are not surprising.

The Distribution of Parents' Views of the Medical Staff/System

What do we know about parents who reported receiving more or less support from the medical staff? Figure 19 presents data on two family characteristics, whether the child is living or deceased and income level. Parents of living children report receiving more support from medical personnel (doctors and nurses) than do parents of deceased children. It is possible that parents of deceased children may have assessed the medical staff as having failed their child, and thus saw death itself (and the failure of treatment) as an indication of a lack of help. In these terms, of course, nothing less than survival or "cure" of their child may truly create parents "satisfied" with the medical system. Moreover, parents of deceased children may have had significantly greater needs for support; they certainly reported greater stress from the disease and treatments. Thus, even if they received the same amount of help and support as parents of living children, their greater need might have led to an assessment of comparatively lesser support. Then, too, when parents who cared for a chronically ill child for several years no longer had this child to care for, and were no longer functionally integrated into the life of a hospital and medical care team, they may have felt the loss of their friends and partners. They may have missed going to the hospital and seeing their "co-workers", the people who cared for them as well as their child.

Figure 19

Parents' Reports of Help and Support from the Medical Staff
Differentiated by Family Characteristics

<u>Family Characteristics</u>	<u>Percent of Parents Reporting High Support From the Medical Staff</u>
Parents of Living Children (N=67)	58%
Parents of Deceased children (N=18)	33%
$\chi^2=3.5, df=1, p=+.05$	
Low income level (N=16)	75%
Moderate income level (N=30)	63%
High income level (N=34)	33%
$\chi^2=10.1, df=2, p=+.05$	

But this analysis deals with only one party in a bilateral relationship. In fact, the medical staff also may feel a sense of failure and loss; no amount of professionalization or rationalization fully compensates for what some doctors have referred to as the "loss of several of my young friends every year." Informal conversations with medical personnel, and a series of recent reports, indicate they may withdraw from interaction, and in fact offer less support, as a child and a family approach death.⁴² Medical professionals may not be clear on how to act during terminal phases of a child's illness, and they may be cautious about intruding on a family's privacy. If, on the one hand, parents fear the loss of their medical colleagues as death approaches; and if, on the other hand, medical personnel become increasingly protective of their own feelings and cautious about encroaching on what they see as a private family matter; we have a catch 22 situation. Several residents and interns have asked us: "Should we go to the funeral?" How does one answer such

a question?⁴³ If a caring relationship exists, and doctors and nurses wish to attend a child's funeral, we know that parents are extraordinarily grateful for this human act: it is remembered and remarked upon for some time afterwards. If a caring relationship does not exist, or if doctors and nurses are acutely uncomfortable, of course they should not go. They have enough to do, and need to be protected against their own sense of loss, overcommitment and burn-out.⁴⁴

Figure 19 also indicates that parents with higher incomes reported receiving less support from the medical personnel. The primary factor in this relationship is between income and support from doctors; the relationship with nurses is less potent. In our sample, some of these more affluent parents had relatives who were hematologists and psychiatrists; this made them less dependent upon the medical staff for information and counsel. Or knowing more, perhaps they had less need for the informational support the medical staff was prepared to provide. Or knowing more, perhaps they wanted and expected more from the medical staff. Or perhaps they only thought they knew more, and this stance itself may have created alienation and distance. As is the case with parents of deceased children, we cannot tell from self-report data whether these more affluent parents actually received less help than others, or whether they simply wanted more than they received.

In addition to these questions about help and support, we asked parents specifically whether and how their views of the medical system had changed as a result of their experience with childhood cancer. Particular items included in the questionnaire pertaining to this variable were:

- Respect for the medical system
- Feeling good about doctors
- Anger towards the medical system (reverse coded)

As noted, 51% of our sample reported changing in a positive direction (more respect, more good feeling, less anger); 25% reported no change, and 24% reported changing in a more negative direction. In figure 20 we indicate some of the characteristics of

parents who responded to this issue in various ways. Clearly, the potency of the disease process, and their child's reaction to it, had an impact on parents' views of the medical system. Parents of children who died, and or who had relapsed, reported more negative views; parents of children who are still living with cancer, and who have not relapsed, reported changing their views of the medical system in a more positive direction.⁴⁵ Parents of children who died or relapsed have experienced what they may see as medical failure. Moreover, they probably have experienced a painful and lengthy treatment process, with more tense and negative experiences with the disease, the treatment and the medical staff. As some of the earlier excerpts indicate, parents whose children are in remission, and who are free of relapse often feel enormous gratitude towards their doctors. While parents of deceased children may gain respect for a sincere and committed effort by medical professionals, parents of children in remission (especially if the remission is lengthy) may feel the medical staff has rescued their child from death itself. Given the shocking and life-threatening character of the diagnosis, a continuing remission often is extremely potent evidence to parents of a good medical system.

In addition, this figure indicates that parents' socio-economic status is related to their views of the medical system. Parents from lower strata (by income and/or education) report changing their views of the medical system in a more positive direction; parents of higher status more often report retaining their views or changing in a more negative direction.⁴⁶ These reports are consistent with prior findings regarding socio-economic status and views of help and support.

Figure 20

Parents' Reports of Changed Views of the Medical System
Differentiated by Family Characteristics

<u>Family Characteristics</u>	<u>Percent of Parents Reporting More Positive Views</u>
Parents of Living Children (N=67)	57%
Parents of Deceased Children (N=18)	28%
	$\chi^2=4.8, df=1, p+.05$
Parents of non-relapsed children (N=55)	62%
Parents of Relapsed Children (N=20)	30%
	$\chi^2=7.9, df=1, p+.05$
Low income (N=16)	56%
Moderate income (N=30)	67%
High income (N=34)	39%
	$\chi^2=6.5, df=2, p+.05$
High School or less (N=19)	72%
Some College (N=26)	54%
College Grad (N=29)	28%
	$\chi^2=11.8, df=2, p+.05$

Since the disease-related and status-related findings regarding these two aspects of parent's views and experiences with the medical system were so similar, we explored the relation between support and changed views. Figure 21 demonstrates that parents who reported receiving less help from the medical system also reported less positive changes in their views of the medical system. Figure 21 also indicates that parents who indicated that they encountered greater stress from "tense relations with the medical staff" also reported more negative changes in their views of the medical system. Parents experiencing greater stress also reported receiving less help and support from doctors and nurses ($\chi^2=5.0$, $df=1$, $p+.05$). Parents' reports of stress emanating from tense relations with the medical staff were not related significantly to other forms of stress (e.g., from the disease, etc.) nor to other forms of help and support (e.g. from spouse or friends). Thus, it appears to be a specific stress factor, related solely to interactions with the medical staff, and not to stress or support in general.

Figure 21

Parents Reports of Support and Stress From the Medical Staff and Their Reports of Changed Views

<u>Amount of Help from Medical Staff</u>	Percent Reporting Changes in Views	
	<u>More Negative or Same</u>	<u>More Positive</u>
Low (N=40)	70%	30%
High (N=45)	31%	69%

$\chi^2=12.8$, $df=1$, $p.<.05$

<u>Amounts of Stress from Medical Staff</u>	Percent Reporting Changes in Views	
	<u>More Negative or Same</u>	<u>More Positive</u>
Low (N=47)	34%	66%
High (N=38)	68%	32%

$\chi^2=9.9$, $df=1$, $p.<.05$

Parents' perspectives on a high quality relationship with the medical care system.

Given these variations in the generally positive regard with which parents hold the hospital and the medical professionals who dealt with them, at least in this medical context, we inquired further into the specific components or elements of their relationship. To the extent we are able to specify the dimensions along which good relations and high respect occur, we may be able to create more positive interactions in other times and places. One question we posed to parents was "Have you ever had any problems with any of the doctors or services of the hospital (surgery, radiology, emergency room, nursing staff)?" This question was followed by a series of probes and specific requests for information. The question deliberately was worded in a negative frame, because we wished to avoid placid generalizations of good care, and to encourage parents to identify and discuss issues and problems. We also felt that framing the question in this manner would lead to a more complex set

of answers and specifications. Despite this "bias" in wording, the general tenor of parents' responses was, as indicated above, positive.

In response to this and other questions, we received a variety of descriptions which included examples of specific problems, but which also broadly characterized a certain relationship between parents and family and the medical staff. According to parents' views, the quality of a relationship tended to be specified by six major dimensions: 1) An information exchange between parent and staff; 2) The personal relationship between parent and staff; 3) The staff's responsiveness to and empathy with the child; 4) The ability to resolve occasional conflicts or disagreements; 5) A sense of parental efficacy in the relationship and in the treatment - acceptance and encouragement of parental competence; and 6) Perception of staff competence. In the discussion that follows we present parents' descriptions and specifications of these dimensions, trying to identify exactly what they mean.

Information. A number of scholars report that many parents respond to the stress of childhood cancer by seeking information and understanding of the disease and its treatment process.⁴⁷ It allows them to cope with their own anxieties, loss of control, and sense of shock. Indeed, Futterman & Hoffman note that some parents "use intellectual mastery to gain some sense of control, as though knowledge actually were power" (1973, p. 133). If parents are to be involved in the long-term care of chronically and seriously ill children, they must have adequate information. Getting information may be critical to the child's survival, as well as to parents' emotional stability and integrity.

Part of what is difficult and even shocking for the parent of a newly diagnosed child with cancer is the rapid transition to a different culture, with different rules, roles and language. The particular jargon of the medical system often makes it difficult for parents to understand what is happening to them and their child. As

Cassileth and Hamilton point out:

Entering the new environment of chronic illness... (language)...typifies one of the challenges faced by the family recently brought into the illness sub-culture. A different style of indoctrination, one which employs the listener's vocabulary and responds directly to their concerns, provides that family with a more secure basis on which to construct its hold on this new reality (1979, p. 243).

A "different style of indoctrination" may not be easy for health care professionals to adopt. As these same authors note, the current style of medically directed communication to families may suit the needs of doctors quite well, and may help them maintain emotional distance from their own discomfort as well as from the discomfort of others.⁴⁸

Parents' general point of view regarding information was well expressed by two informants:

Never put a doctor on a pedestal because your kid's health is at stake. It's easy for a parent to be intimidated by a doctor, and maybe that's one thing a parent should contemplate. Ask them what they are doing and why. You have to because we ran into various situations where the doctor was wrong.

The parents should be aware enough to ask questions, and to do some reading. I think some more information should be readily available for parents to read.

Many parents in this study indicated that the quality of the relationship between the medical system and the family of a child with cancer is determined in part by the amount of information provided to the parents.

Some parents expressed their need for information directly to the medical staff and, as these comments indicate, felt their concerns were responded to quite adequately.

What impressed me most was the time they took to answer my dumb, stupid questions. Whatever it might be, they took that time.

There was no printed information available on Wilm's tumor for lay people. But on my request one doctor told a nurse to xerox the information available in the Pediatric Oncology book for me. The nurse did it and I received great information. That doctor was a great help.

Other parents, faced with the same need, did not feel their concerns were met appropriately.

There was a communication gap between the doctor and us parents. The hematology staff would tell the residents who would tell the medical students who would tell the residents again. By funnelling the information through in this way sometimes it is not all gotten, and there is a chance it will get muddled. Therefore, a more direct communication and relationship between parents and doctor would be helpful.

When I brought a book on hematology and wanted to discuss something in it with a nurse, she tended to discourage rather than encourage my reading from other sources. None of them could understand why I wanted second opinions on some of the treatments.

The doctors don't communicate enough...some don't care and some are too busy. Especially, the ones who care are too busy.

Radiology was not willing to answer any questions.

The extent to which information was sufficient and complete was important, as was the degree of honesty versus false assurance which accompanied the communication.⁴⁹ Some parents expressed their concern about the degree of honesty and straightforwardness they could expect in conversations with the medical staff in the following terms:

The doctors weren't straightforward. Even at diagnosis they said, "we've found a few bad cells." They didn't tell us that she had the worst kind of a cancer tumor. They didn't tell us it had a very poor prognosis. The doctors didn't tell us it was a very aggressive type of cancer. Maybe if they had told us, we'd have been angry and rejected it anyway but we weren't given the chance. It was never indicated it could be as bad as it was.

In another city, I felt like the doctors were

not honest with us at the beginning. They didn't tell us about the side effects of chemotherapy...

They weren't honest with us about the surgery.

I prefer that the doctor say, "This is the way it is and these are the options you have."

Finally, the steadiness or regularity in the communication between doctors or nurses and the family served to provide evidence that the staff was considerate of the feelings or needs of the parents and tended to view them as partners to be involved in the medical care process.

Not all parents were concerned about receiving a lot of medical information. Some were already overwhelmed, others chose not to use "intellectual mastery" as a coping device, and still others said they didn't know what they would do with information if they had it. They were prepared to place their trust in the information the medical staff had.

How did I know what was better for him? I didn't even know what was going on. I figured they knew whatever they were doing, and they were doing whatever had to be done.

Quality of the interpersonal relationship. Another dimension parents reported as effecting staff/parent relationships is the quality of social and emotional contact between parents and physicians. To the extent these contacts exhibit mutual respect and caring, or tension and suspicion, the relationship may be ultimately satisfying or a source of continuing stress and dissatisfaction.

Some parents felt what was important for a good relationship was warm, caring and sensitive doctors. Consider the following comments:

The doctor was very helpful. He let us handle the situation the way we wanted to, when it was apparent that my daughter would die. He also came to our home for the week before she died. I am very grateful for this.

The doctors were horrible, they were cold. There was one good one who really cared. He came to the funeral.

In an earlier section of this paper we reported the meaning to parents of doctors' attendance at a funeral, as well as some of the conflicts experienced within the health care system on this issue.

When the quality of the interpersonal relationship was judged to be poor, the family typically perceived rudeness and lack of sensitivity on the part of the medical staff to their emotional stress accompanying childhood cancer. In some cases, doctors were described as uncouth, untactful, and unsympathetic, and exhibiting mannerisms that were cold, distancing and distracting. In other cases, there was simply an absence of mutual respect and trust. For example, one family reported that the physician appeared reluctant to speak to women. In spite of the husband's disinclination to involve himself in the details of the illness and treatment, the doctor preferred to speak to the husband and exhibited discomfort in having to discuss technical matters with the wife. Staff distancing often came in the form of a brusque style of interaction, rather lacking in affect. As some parents noted:

One doctor was just too curt with me. He hurt my feelings somewhat. He was a little too businesslike with what was a very emotional problem. I needed to be handled delicately.

The majority were very helpful. But some of the lesser trained ones were less so. Training in bedside manner ought to be a high priority. They need to emphasize handling people.

I didn't care for the doctor that explained the treatment for his type of cancer. I didn't care for him at all. He treated me like a shop rat and my wife like a dumb hillbilly. He acted like we were too dumb to understand what he was talking about.

At times, the bureaucracy of the medical care organization, at least as implemented by professionals, marched right over parents' needs and feelings.⁵⁰

One nurse turned the light out in the room while I was kneeling and praying, because she said I'd bother the children. However, every child was sound asleep. I don't think she had a right to

insist I turn the light out immediately. I was so upset that I cried for hours. She disrupted the only comfort I had found - praying.

Research on the doctor-patient relationship, especially as it occurs in an institutional setting, suggests that many doctors have difficulty expressing care and warmth in this situation. As Cassileth and Hamilton note:

The standard medical school orientation thus does little to help students deal with patients' conjoint needs for expert technologic care and personal supportive relationships (1979, p. 311).

With regard to the particularly potent issues of childhood illness, the physician's typical pattern of affective neutrality may clash with parents' affective needs and expressiveness (Meadow, 1968). As noted earlier, these typical problems in role relationships are exacerbated by doctors' own strong feelings of discomfort or threat when confronted by childhood cancer.

Given these role definitions and constraints, it is not surprising that some parents did not expect interpersonal or emotional help and support from medical professionals.⁵¹ As one father noted:

If they did offer any type of emotional support I resisted it because it's not their function. You have clergymen for that type of thing. They have social workers for that. The doctor is there to answer questions and be honest.

While these and other parents respected the technical competence of the staff, they decided to go elsewhere to meet their other needs. In the long run, such choices deprive parents and professionals of meaningful contact and exchange.

Responsiveness to the child. Of all the factors creating serious concern, the source of the strongest feelings parents had about the medical staff (both positive and negative) related to the ways physicians and nurses dealt with the child. To the extent that the staff behaved in an engaging, warm, caring way with the child, they were able to establish a more meaningful relationship with the family.⁵² The crucial determinants of the quality of the relationship were the amount of attentiveness,

concern about the pain and side effects of treatment, and positive affect in the relationship.

Parents often expressed concern about the attentiveness of the staff in watching and checking on children's I.V.s, changing bandages, and monitoring reactions to drugs. However, this did not mean the staff was expected to cater to every whim and fancy of the child. In fact, some parents reported a great deal of respect for the ability of the physicians and nurses to strike a balance between empathy with the condition of the child and the maintenance of some control with respect to behavior. One parent, in praise of doctors, said:

They're great -- they don't take nothing
from the kids either.

On occasion, parents interpreted lack of attentiveness to their child's needs as indifference, and personalized this to the point that conflicts developed between parents and the medical staff. When medical personnel made side comments that indicated insensitivity, it drove this point home to parents.

The radiation people told my son he might
be sterile. My son thought he meant he
couldn't have sex.

The radiology technician said to me, in
front of my young son, "he will be like
a woman now". My son was very upset,
and wanted to know what he meant.

Sometimes the lack of parent-staff involvement, and parents' judged incompetence of the staff, eventuated in continuous conflict between parents and medical staff. One parent described a situation in which his hospitalized child developed diarrhea, resulting from the budding of her first teeth. The nurse insisted on a 24-hour urine sample even though they couldn't fit the bag properly. In the process of putting it on and tearing it off, soreness was created for the child. In this same family, other issues of control became apparent. For example, there were differences between the nursing staff and family about the amount of sugar the child should receive. The

parents became irate when their young child was given milk, orange juice and 7-Up to treat diarrhea. Issues which ordinarily might have been resolved easily, in the context of a give-and-take relationship, escalated to the point of open conflict and animosity.

Parents sometimes felt they had to protect their children against incompetent, insensitive, uncaring staff members. Parents were especially sensitive about the frequency with which their children were cleaned, the carefulness with which their medication and food intake were monitored, and the skillfulness and patience with which the staff gave injections, radiation, and inserted I.V.s. When these factors were favorable, parents tended to show a great deal of trust, caring and support for medical staff. When they were judged to be absent, animosity often abounded.

Ability to resolve conflict. The occurrence of conflicts may push both parents and medical staff over the brink of a delicate relationship. It creates tension and unpleasantness that is difficult for all parties to tolerate. Conflicts often arose when parents did not trust the staff, or did not consider them to be sensitive and responsive to their children's needs. For example, the issue of injections and I.V. insertions often created conflict. The situation for the parent is that they may observe the child in a great deal of distress and pain, and attempt in some way to mediate and lessen this stress. One parent described the situation this way.

My son had very small veins and the doctor attempting to do an I.V. insertion was too old to be giving treatment to a child. One time it took three physicians 2-3 hours to get one started. For those who are good, it's one poke and it's in.

This bothered the father, especially because there were a number of people he felt were good at giving I.V.s who could have done it more easily. He reported that it drove him nuts when he heard his son cry, and he had to step out of the treatment room. Now the parent refuses to let "unqualified people touch his son". He says

"let them go poke older people who can handle it."

One particularly painful scenario in which conflicts occurred centered around decisions about the cessation of treatment, death and resuscitation. As several parents noted:

We wanted her taken off the machines, which they wouldn't do. When she died they tried reviving her. We asked them not to. Her doctor was not around, and the ones working on her were internes. If we had known she was dying we would have kept her home and let her die peacefully. We wanted to be alone with her and they wouldn't allow it.

She was not allowed to die peacefully. After she died they tried to resuscitate her, and we had to call an intern at his home to make them stop. Why would they want to bring a body full of cancer back to life? It was as if they were proceeding right from the textbook. They ignored our wishes completely and made us leave the room.

As we noted earlier, physicians' own discomfort and confusion appears to escalate when their young patients take a turn for the worse. Levine (1975) discusses the hero element present in many physicians' self-concept, and the sense of guilt associated with "failure of treatment". Both Vaux (1977) and Binger, et.al (1969) report parents' feelings that the medical staff withdraws as death approaches and decisions about how to handle death become prominent. As Binger notes:

The professional has his own problems in coping with the imminent death of a child...Faced with these conflicts, he often avoids the patient or family or makes himself unapproachable by presenting a facade of busyness, impatience or formality (1969, p. 415).

The time of a child's death is filled with enough pain and anger. When impersonal roles, unclear communications, or unresolved conflicts increase parents' stress, we have multiplied the family's tragedy.

In any large organization, especially where different groups of people are

interdependent with one another, conflicts are bound to exist. What is true for government and industry, and schools and communities, is true for hospitals as well. Conflicts occur within families, and within departments or roles of the medical system. It is natural, then, that they should occur occasionally between those doctors and nurses who are service providers, and those patients and parents who are consumers. The issue parents raise as critical is the way in which these conflicts are handled. Are all conflicts to be resolved in the way doctors (or as in the above examples, nurses and interns) decide? In parents' favor? Or can compromises occur that may suit various groups' preferences? Often the differences in status and information between doctors and parents provided little basis or precedence for effective conflict resolution. An absence of negotiation behavior sometimes led all parties to escalated feelings.

I said put it down in the record that that doctor is not going to touch our child again. Another doctor became quite incensed over my comments. He got quite upset about that. He came down to our room and called me a "rabble-rouser", and said if I did not allow whomever was there to work on our child she would not be treated at the hospital. They said if we didn't like it we could take her someplace else. I think at that point we made some comments about contacting our attorney, because we weren't going to put up with that. Since then we have talked about it and there have been no more problems.

Faced with a similar set of concerns, another parent reported satisfaction with the outcome.

I went directly to the head doctor and told her about it. She took care of it.

In another conflict-laden scene, a parent raised questions about plans for massive amounts of radiation to be administered to her child. These questions were not heeded or responded to satisfactorily, according to the mother. Undaunted, the parent contacted other physicians across the country to get their opinion of the need

for this amount of radiation. Some of these physicians, in turn, agreed with the parent's questions, and suggested that such a dosage might be injurious. When this information was presented to the staff, the parent reports that the physician responsible for the treatment of the child made them feel that, "we were stupid unintelligent laypeople, and that we were playing with the life of our child." The parents removed the child from treatment and placed him under the care of a physician at another hospital, who shared their concern.

These are delicate matters. For the physician or the nurse, pride in one's work and reputation may be at stake. Moreover, for the medical professionals who feel certain actions are necessary, professional judgement lends certainty to their actions. Parents who are concerned about the treatment their child is receiving always wonder whether or not they are acting and reacting appropriately. As noted earlier, parents often are intimidated by the status and knowledge of doctors. Moreover, some parents are reluctant to voice their disagreements or conflict because they fear subtle retaliation from the medical staff - a staff that, after all, appears to hold life and death power over children with cancer. One parent reports such high stakes in the following context:

Some can't handle dying kids. If I
confronted the nurses with how I feel
about some of them, my child would suffer.

Thus, parents are in a low power position vis-a-vis conflict resolution with the medical care organization.

It is worth repeating that we expect some degree of conflict to be natural and unavoidable in these situations. The critical issue is not how to avoid such conflict, but how to deal with it when it occurs. If conflicts can be surfaced and negotiated with mutual respect and shared concern, creative resolutions may occur. If conflicts are driven underground, out of fear or ignorance, or out of threat and anger about "interference", they are likely to fester and explode in more destructive forms later.

If all conflicts are managed by the rules inherent in an asymmetrical power relationship between practitioner and patient/parent, parents' sole option may be to reduce that asymmetry. If other conflict management techniques are available they will be used.

Parental Efficacy. The typically passive and low-power position of patients undoubtedly influenced parents' concerns about their own involvement in the care of their child.⁵³ Antonovsky (1980) raises several important questions about the model of medical practice that concentrates power in the hands of physicians. Except in extreme circumstances, he notes, it unnecessarily strips patients of some of their most important resources - self-esteem, coherence, assertive posture toward their illness, etc. Taylor (1979) reviews a number of studies of the "passive role" expected of hospitalized patients in particular, suggesting that the "loss of control" these patients experience may have negative effects for themselves and for the medical care organization. If the problems of patient "loss of control" and "learned helplessness" are typical of doctor-patient relationships, they are even more problematic in the case of children, who are generally less likely to know how and when to assert themselves with unfamiliar adults. Moreover, they also may be more problematic for parents who have been shocked and numbed into temporary paralysis by the feelings of helplessness and chaos often generated in the diagnostic conference. Reestablishment, whenever possible, of parents' prior roles as primary care-givers for their younger children may be a critical element in the normalization of family life.

Many parents felt the medical care organization exhibited a great deal of ambivalence about the appropriate role and involvement of parents in the treatment of their sick children. One parent captured this tension between her own needs, and the apparent reaction of the medical care organization, in the following terms:

The nurses didn't seem to want me around

and they didn't wish to talk with me.
They also didn't give me enough control
or let me care for my daughter myself.

Not all parents had such desires or experiences. And not all parents were sufficiently able to care for their seriously ill children that a nurse or other professional should have given them all the control they wanted. But all too often these issues weren't negotiated or resolved in ways that met parents' needs or appeared consistent with good medical practice. On the one hand, parents acknowledged the high degree of competence, training and professionalism in the medical care organization. At the same time, they were aware that there were some choice points or decisions to be made which could not be based solely on technical skill and knowledge, but also on moral judgement. In addition, because of the size of many medical care organizations, and the complexity of relationships within the staff itself, parents at times found themselves in the position of a liaison between different groups of helping personnel.

Parents invested in monitoring the treatment and progress of their children often had a degree of knowledge and information which was not fully utilized by different doctors, nurses, and allied medical specialists. A number of parents noted that they were, to a certain degree, "experts" about their own child. In this context, their active participation was not just a means of meeting their own psychological needs, but a useful aid in medical care.⁵⁴

I have only come across one or two doctors I didn't care for. They didn't seem concerned with what I had to say or that I knew anything. I knew which leg was best for I.V., and most doctors welcomed my knowledge. But this one doctor poked and probed until my daughter was screaming. He wouldn't listen to me. He finally ended up with the I.V. where I told him to put it, and it went alright.

Another family of a child with cancer was over one day and I told them about my son's strange behavior and pains. They said it happened to their child too, and that it was one of the drugs. Then

we knew what to do. I backed the doctors against the wall, and they backed off the dosage. And then he was much better...I don't want to tell the doctors what to do but I know there have been some cases where doctors have made bad misjudgements. I feel like the parent should be included in the deciding of dosages. I know that the doctors have their training, but I live with my child everyday. I know him. Every child is unique.

In one elaborate vignette, a parent shared her experience with powerlessness in the face of what she felt was professional insensitivity. Unless addressed, this powerlessness can result in guilt about abandoning the child to strange and apparently non-responsive staff members.

The hospital wouldn't let me go into the treatment room with my child. I thought that that was wrong. Here you are, a little three year old child with six doctors holding you down, doing something to you that hurts, and you don't understand it. I think that this is very frightening to a child. The doctors brush it off and say he is going to have to be mature and take this like an adult. I don't feel that way. I feel a three-year old child can't be mature and if the parents want to (and the parents can handle it), they should go in with the child. They should be able to. We argued about this lots of times. I finally told them that if I can't go in, my child's not going in either. In a strange way the child may begin resenting the parent for handing him over to the doctors to hurt him. I think a child and adult can face anything if they know what to expect. Since I am able to go in I have been a real help to the doctors. I know how to hold him. He doesn't kick. He doesn't do anything with me there. It gives him confidence.

Another parent described his attitude about involvement in treatment in this fashion:

I say that I am not being totally objective, but they were just so calculated about giving him more and more radiation. It looked to me like he was dying. And finally I told them that they were going to split the vote, everytime they would make a decision,

I would get one-half the vote and they weren't to do a single thing until I agreed upon it because I began to find out that their mistakes had died. I wasn't going to let my boy be one of them. I have some problems, but I would say that for every patient who goes to the hospital to stay awake. They're not God, and you should demand to know what's going on. I don't think one should be aggressive, especially in the hospital setting, because they are trying. But you have to be assertive. I think that if you are very clear with them, they do hear you.

Certainly the hospital hears. One father described several occasions when he made suggestions regarding medical procedures, noting that:

The Drs. were good listeners, and followed up my suggestions in both situations.

And another parent commented:

I got a lot of help from the hospital. It does help to know the hospital, and how to use my rights as a patient to get things done.

Persistent assertive behavior did get results for parents who wanted to be active in the care of their child.

Staff competence. A final factor parents report as contributing to the quality of parent-medical relationships is their perception that the medical staff is competent.⁵⁵ Parents sometimes raised critical questions about the competence of the medical staffs they met at outlying hospitals. Their own pediatricians, close and caring, also sometimes were reported to be quite overwhelmed by the special character of this disease and its diagnostic and treatment problems. However, parents agreed almost universally that the Mott Children's hospital staff was competent beyond question. Moreover, parents were, for the most part, accepting and relaxed about the hospital's role as a teaching institution, and the need for medical students, interns and residents to "learn" on their children. They did object, however, to abuses of this learning situation, and to rudeness and miscalculation by

young medical practitioners learning their trade in very delicate and tense situations. When young doctors tried to "tough it out", to hide their inexperience behind bluff and brusque behavior, parents became quite upset.

Despite the obvious and understandable disadvantages of certain aspects of medical care at a high technology, tertiary care, research/teaching institution, most parents willingly accepted these problems. They felt it was part of the package of special expertise to which they owed their children's potential for life.

A summary note. What can we conclude from these data and comments regarding doctors, nurses and the medical care organization? A list of the factors that parents reported contribute to a high quality of relationship between the family and the medical care organization is presented in Figure 21. In a situation many families find stressful and uncontrollable, a positive relationship with the medical care staff can provide some degree of security and control. A relationship characterized by warmth, respect and mutual trust, as opposed to one that is distant, businesslike, and denigrating, appears to make families feel a little better.

Parents' need for predictability and control is expressed in terms of their need for information that is accurate and understandable, and through a desire to have the staff listen to and accept information from them. Parents' need to feel some degree of potency or efficacy is expressed through desires to participate in the care of their child, and through influencing the thinking of physicians and the medical staff with respect to the general care of the patient and treatment decisions. Parents' concerns about emotional support and trust are expressed through interactions that are open and honest, and intimate enough to allow for disagreements without jeopardizing the relationship.

Figure 21

Parents' Reports of the Characteristics
of a High Quality Relationship with
the Medical Staff.

1. Adequate quantity, quality and regularity of information and communication from the medical staff.
2. Mutual respect and sensitivity in interpersonal contacts between the medical staff and parents.
3. Attentiveness to and concern for the child's physical and psychological status on the part of the medical staff.
4. Ability of parents and medical staff to negotiate their differences and resolve conflicts.
5. Sense of involvement and efficacy in the treatment/caretaking process.
6. Staff competence.

One mother summarized several of these aspects of a good relationship by asking for the following behaviors from doctors:⁵⁶

a good bedside manner
attentiveness
know what is going on
explain everthing to parents and child
come back with test results
converse with the patient and ask him
what he thinks

In all probability, a similar list of dimensions of a good relationship could be generated for parents, by doctors and nurses. There probably are ways that parents could behave to develop a more effective partnership with the medical care organization. On this list, doctors and nurses might include trust in physicians and nurses, consideration for time/energy problems, acceptance of professionals as human beings rather than as Godlike (although many professionals would encourage a certain

amount of deference), willingness to be active without being intrusive, questioning without abrasiveness, a conviction that the medical staff is working in the best interest of the child, etc. We would welcome a parallel investigation that delved into physicians' and nurses' views of their experiences with families of chronically ill children. If they, too, were to specify characteristics of an effective working relationship, both service providers and service consumers might know better how to understand and deal with one another.

These parents' perspectives on desired dimensions of the doctor/medical staff - patient/family relationship are consistent with several reformulations of the traditional practitioner-patient relationship. In this study, we have seen parents challenge several aspects of the classic definition, especially those stressing professionals' affective neutrality (distant and controlled feelings) and universalism (like treatment of all patients).⁵⁷ The concerns for partnership, for warm and supportive behavior from medical practitioners and for responsiveness to the child's feelings, challenge the principle of affective neutrality. The concerns for efficacy, for the introduction of their own expertise into the treatment process, and for attentiveness to the psychologic uniqueness of each child and family situation challenge the principle of universalism. This is a clear "clash of perspectives" (Freidson, 1970)!. It is not surprising that the reactions and desires of parents in this study should challenge traditional definitions of the practitioner-patient relationship. Both the nature of this sample and various reformulations of the classic model explain the situation.

First, parents in this sample are not patients themselves, they are the guardians and advocates of patients. When patients are too young, weak, dependent, or ignorant to advocate for their own interests, parents are there to do it for them. Thus, parents may be more likely than patients themselves to be active consumers, and to protect patients' interests. Parents, like patients, are dependent on the medical system, somewhat powerless, vicariously part of the "sick role", and caught

in the stigma of cancer. However, they are not the patients. The anger and desire to re-assert control that this sample of parents has described lend power to their advocacy.

Second, these parents/patients are involved with a chronic disease process. The extended time period in treating this illness is a factor which Szasz and Hollander (1956) suggest would help move the practitioner-patient relationship from a deeply asymmetrical "active-passive" pattern to something more like a "guidance-cooperation" or even "mutual participation" model. While the seriousness of the illness, the complexity of treatment, and recurrent hospitalizations may accentuate the medical staff's power, the experience of chronicity educates parents/patients to a more knowledgeable and active role regarding the disease, its treatment, and the medical care organization with which they deal. Moreover, the fact that long-term patients monitor much of their own care (or that parents monitor it for them), helps alter the power asymmetry of the typical patient-practitioner relationship.

Third, the parents in this study repeatedly have stressed their concerns about the quality of life of their children living with cancer, and about the quality of living and dying of their deceased children. A concern for such lifestyle issues clearly presses physicians beyond their predominant technical expertise, to more social, philosophical and moral issues. Moreover, parents' emphasis on quality of life issues accentuates aspects of interpersonal relations with medical practitioners that the classic model overlooks.

Fourth, the data indicate that all parents are not always acquiescent, and do not readily accept all aspects of an asymmetrical power relationship with doctors. They may at first, numbed by the diagnosis and the initial stages of "crisis-coping". Moreover, parents may decide to appear compliant (indeed, we have seen some suggest it is quite politic to do so). However, they do evaluate and make demands on physicians,⁵⁸ and many parents are seeking a more active form of partnership.

Parents' increasing sophistication as medical consumers has contributed to their move from clients to consumers, and perhaps to consumer advocates.⁵⁹

Finally, because children with cancer encounter continuous long-term care at a secondary or tertiary medical care organization, they interact with many doctors, nurses, residents, interns, technicians, and social workers. They seldom are limited to the one-to-one, single practitioner form of medical practice. While hospitalization may accentuate the sick role, and intensify dependency on physicians, it also may multiply the number of medical actors with whom patients can engage. The bureaucratization of care means that some patients may "shop around" the hospital for the practitioners with whom they can relate most satisfactorily. Within a hospital organization, each young patient may have a preferred doctor or nurse, and (try to) insist on having procedures performed by this staff member. However, this is not quite the same as the free market notion of shopping around for a favorite doctor. In terms of institutional sites for treatment, most children with cancer and their families realistically cannot shop around. Of course, some do. Some patients/parents ask for second opinions and seek treatment by doctors whose opinions, treatment program, or interpersonal style they prefer. Other patients/parents reject the traditional medical model and seek radically alternative therapies with doctors practicing radically alternative styles of medicine. However, while these choices gain media attention, they are relatively rare. Given the seriousness of childhood cancer, and the increasingly standard treatments at childhood cancer centers across the nation, choices are limited.

The search for partnership is not necessarily understood and negotiated ahead of time. Many parents developed an interest and commitment to these ideas and actions during or as a result of their encounters with childhood cancer. One form that the request for partnership and active collaboration in care took was portrayed by parents who said they intervened in the medical process. In the next section we explore this

form of partnership.

Parents as Intervenors in the Treatment Process.

One part of the reality of being a parent of a child with cancer is that the parent must learn a great deal about the disease and its treatment. The parent who already is an expert in the makeup and behavior of his or her child, also must become somewhat of an expert in the treatment of pediatric cancer. The very nature of a serious and chronic illness demands such knowledge; without it, the parent cannot be a partner in the care of his or her child, and cannot help safeguard the child's welfare. As the "permanent" parent deals with a changing series of medical professionals, and sometimes a changing medical care organization, he or she may be the only constant link in the medical care chain. Many parents have reported that their knowledge and experience with the treatment of childhood cancer was an essential ingredient in good care. Sometimes, in fact, parents had to advise, correct or challenge medical practitioners regarding proper or innovative treatment of their child.

The suggestion that parental intervention to correct or improve medical procedures occurs, especially with any regularity, does not set easily with many medical practitioners and scholars. For instance, Mattson (1979) is representative of a generation of observers who are quite cautious about such roles, and about reports of families' actions on behalf of their children. He suggests that active parents may be acting out their unresolved psychological problems in adjusting to the illness, rather than performing truly useful acts. Consider these interpretive comments:

Strong unresolved feelings of guilt for the child's illness are often present in (such) detached and uncooperative parents. They may talk angrily about all the inconvenience their child's ailment causes their family, and they often blame crises and complications on the child or medical staff (p. 259.)

They may also displace and project helpless and

angry feelings about their child's condition onto various medical professionals, and blame them for delays and mistakes in treating their child (p. 260).

It is common...to show attitudes of critical superiority toward health specialists, particularly toward house officers. Some of this criticism may be valid, but one also senses that parents are trying to ward off, by denial, their long-standing helpless feelings in this regard (p. 260).

Do these things occur? Do parents inappropriately "blame" the medical staff, "displace and project", act with inappropriate "critical superiority"? Are all or most of the mistakes parents find really examples of their own overprotection? Are they acting out of unresolved guilt and anger and powerlessness? Certainly these psychological mechanisms are at work for some parents, and certainly some criticism of medical staffs and procedures are ill-founded and inappropriate. At the same time, much of it appears to us to be well-taken and necessary.⁶⁰ The defensiveness evidenced here does not bode well for our concerns about "partnership".

In an attempt to explore the phenomenon of parental intervention, and to expand consideration of parents' roles in the care of seriously and chronically ill children, we asked parents the following question: "Have there been situations in which you had to intervene to prevent a mistake from occurring in the treatment of your child?" Just about half (50%) the parents, and at least one person from 75% of the families, reported they were involved in some sort of intervention.

The most common interventions occurred with regard to the following issues:⁶¹

1. I.V. insertions
2. Dosages and medications
3. Radiation treatment procedures
4. Continuity of care between services and departments of the medical system
5. Interpersonal relations between staff and patient

Some of these issues have life-threatening consequences, but not all do. In some cases, parents felt these were serious medical issues, and in other cases they were important but not particularly critical. Not all the examples on this list are, precisely

speaking, mistakes. Some are examples of poorly implemented policies, of errors of omission rather than commission, and of things that might have been done just a little better. It is in this frame, as examples of what might be improved rather than a charge of major mistakes, that we wish to consider these reports.

The issue of chemotherapeutic overdose (or wrong drug) is the most visibly life-threatening problem. IV problems, and concerns about the continuity of care, were less medically dangerous, but certainly physically and emotionally uncomfortable for parents (and in some cases for children as well). Comments about radiation procedures had much in common with concerns about the interpersonal relationships between the medical staff and patients and their families. Clearly, however, they all represent issues around which parents wished to have a more effective partnership with the medical system. Only their own access to information, and their long-term experience with their child and the medical system, made it possible for them to intervene to improve treatment procedures or to "correct mistakes".

The decision to intervene in treatment is not made lightly. Although parental action may occur quickly, and without much forethought, it is not easy to do. Parents often are intimidated, even if they are knowledgeable. They often are concerned about being wrong and raising an inappropriate question, criticism or challenge. In addition, even when they are right, parents are concerned about offending professionals, about being told to mind their own business, or about retaliation to their child. Intervention represents a stance of vigilance, buttressed by some degree of familiarity with medical procedures, that lends confidence or a sense of desperate necessity to parents.

Who is likely to intervene? Since almost half the parents in the sample reported intervening at some point in the course of their child's illness and treatment, we inquired into characteristics of these people. Figure 22 indicates some of these findings. First, mothers were more likely to intervene than fathers. We had

expected that those family members most likely to spend large amounts of time at the hospital, typically mothers, would have more opportunity for intervention. This does appear to be the case.

Figure 22 also indicates that parents with higher levels of education reported intervening more often than did parents with less educational credentials. Although not reported in this figure, a similar (but non-significant) trend was evident with respect to income levels. In earlier figures, we reported an association between higher socio-economic status and more critical views and experiences with the medical system; this relationship may help explain why both higher status parents and parents with less positive views of the medical system reported intervening more often.

On the other hand, intervention is not significantly related to parents' reports of changes in their views of the medical system, nor to reports of tense relations with the medical staff. Thus, it is not clear exactly how intervention is related to general views of the medical system. In fact, intervention may be a much more specific response to a concrete medical situation. It may be related more to active coping patterns and to concerns for partnership, than to a broad sense of deficiencies or negative orientations toward the medical care organization.⁶²

Figure 22 also indicates that parents involved in the self-help group, SHARE, were more likely to report having intervened than parents not involved in that organization.⁶³ Once again, we are unable to determine with certainty whether SHARE involvement sensitized parents into a monitoring and more active role vis-a-vis the medical care organization, or whether parents with more active outlooks gravitated to SHARE. Both, of course, may be the case. Parents involved in the self-help group would appear to be more active on several dimensions of their child's experience; and SHARE's activities certainly were designed to prepare parents for a more informed and active role in treatment.

Figure 22

Selected Characteristics of Parents
Who "Intervened" in the Medical Process

Parent Characteristics (Parents of Living Children Only)	<u>% Reporting Intervention</u>
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Sex

Mothers (N=36)	61%
Fathers (N=30)	40%

$\chi^2=2.9, df=1, p+.10$

Educational Status

High School or less (N=23)	52%
Some college (N=20)	30%
College graduate (N=22)	73%

$\chi^2=7.7, df=2, p+.05$

Views of the
Medical St/Svcs.

Positive (N=35)	40%
Negative (N=12)	75%

$\chi^2=4.3, df=1, p+.05$

Involvement in SHARE

Yes (N=34)	47%
No (N=29)	24%

$\chi^2=3.6, df=1, p+.05$

We were curious whether intervention was related in systematic ways to the stress parents experienced. Evidently not, at least not by most measures we have been using. The most prominent stressors discovered in this study, those regarding the disease and its treatment, were not associated with reports of intervention. The only stressors significantly related to reports of intervention were those associated with concerns about one's ability to cope with the situation - to avoid a nervous breakdown, etc (see p. 39-40). Parents who expressed the greatest concern about their personal coping resources more often reported interventions. These findings continue to suggest that intervention is not related strongly to general experience with the disease or the medical care organization (at least not for parents of living children), but to specific coping patterns and concrete medical situations and events.

Since intervention appears to be a risky act for parents, we wondered where and how they got support for such activity. Figure 23 presents the relationship between sources of help and support parents identified and their report of intervention in the medical care process. The questions we asked about help and support were general in nature, and did not refer to support around acts of intervention, per se. However, the results do help identify the network of positive/negative relations in which various parents were embedded, and confirms some of the themes developed in Figure 22. For instance, parents who intervened reported receiving less help from all sources combined. Moreover, parents who intervened generally reported less support from doctors and nurses, although only the latter finding is statistically significant. Is this perhaps why they intervened? Or did intervention result in less support? Or both?

Figure 23 also indicates that parents who reported intervening reported less support from their spouse (and their own children) than did parents who did not intervene. How can we explain this finding about the nuclear family? One possibility is that parents who felt less support, who felt confused or isolated, focussed their attention (and perhaps anger) on aspects of the medical system.

Another possibility is that the situation promoting and flowing from intervention was fraught with such tension and conflict, that these acts themselves caused alienation within the family. If both mother and father witnessed medical actions that were questionable, or so emotionally painful that they considered acting on them, intra-family tension might have been very high. If one parent decided to act on it, and the other didn't, this imbalance may have been a source of continuing conflict and alienation in the nuclear family. At present, these explanations are purely speculative; further analysis of the interviews should shed additional light on these intra-family patterns.

Figure 23 also indicates that parents who reported intervening reported more support from their close friends. Such support should have been critical, especially when support from one's spouse and the medical professionals was less. Like the finding that people involved with SHARE were more likely to intervene in the medical system, this finding may indicate some of the special ways friends and comrades provided assistance to parents of chronically ill children - supporting their efforts to do what they felt was necessary, even if it was risky. With more distance than the marital partners, perhaps close friends could provide more support to parents wrestling with their sense of an active role in the medical care process. However, neighbors and churchleaders did not follow this supportive pattern; parents who intervened reported them much like other groups providing less support.

We appear to have a picture of parents who intervened as being isolated from several critical sources of support and help. One interpretation, consistent with some of the prior medical literature, would suggest that these isolated parents were angry and frustrated, and took action on this basis vis-a-vis the medical system. Another interpretation, consistent with other portions of the literature, would suggest that parents who did intervene created such discomfort and conflict for others who watched (and who perhaps deliberated similar actions) that distance and a lack of

support was created thereby. Certainly, some of the actions parents reported taking did escalate existing conflicts, and some did appear (at least according to these reports) to be necessary and ultimately helpful actions. Thus, it would seem difficult to argue that they were borne solely or predominantly of inappropriate frustration and rage. Perhaps we will be able to solve this puzzle with more data later.

Figure 24

Characteristics of the Support System
Reported by Parents Who Intervened

<u>Sources of Support</u>	<u>% Parents reporting intervention</u>
All sources	
Low (N=17)	53%
Medium (N=26)	65%
High (N=23)	35%
	$\chi^2=4.6, df=2, p+.10$
Spouse	
Low (N=25)	76%
High (N=41)	37%
	$\chi^2=9.7, df=1, p+.05$
Other Children	
Low (N=36)	61%
High (N=30)	40%
	$\chi^2=2.9, df=1, p+.10$
Close Friends	
Low (N=22)	36%
High (N=44)	59%
	$\chi^2=3.0, df=1, p+.10$
Neighbors	
Low (N=35)	63%
High (N=31)	39%
	$\chi^2=3.84, df= 1,, p.=+.05$
Nurses	
Low (N=21)	67%
High (N=45)	44%
	$\chi^2=2.8, df=1, p+.10$
Doctors	
Low (N=25)	64%
High (N=41)	44%
	$\chi^2=2.5, df=1, NS$

Some concluding notes on an effective partnership.

We have not here attempted an evaluation of medical care, nor a delineation of "charges" regarding the quality of treatment. Most parents report being well satisfied with the quality of the medical care they and their child received. But satisfaction does not mean that parents were or are prepared to permit doctors and other medical personnel to "go it alone".

Parents of seriously and chronically ill children experience substantial stress during the course of their child's illness. Becoming active in the care of their child is one way of coping with these stresses. In this sense, an active partnership between parents and professionals helps meet many parents' psychological needs. Thus, for doctors and nurses to advocate and support such efforts provides an additional service to the family of the ill child. By the same token, recent research on professional burnout suggests that partnerships between professionals and consumers can help reduce the burden of loneliness and potential adversariness that professionals often experience.⁶⁴ Partnership is a two way street. In several hospitals, parents and parent organizations have tried to support doctors' efforts to gather research funds, gain tenure, exert influence for resources from the larger hospital system, and so on. Thus, effective partnership may help improve the quality of the medical environment, within which doctors and nurses work, as well as the quality of the family environment. Indirectly, a partnership can improve the quality of the environment the ill child lives in, with a potential impact on the quality of the child's life during and after treatment.

In addition, however, parents of chronically and seriously ill children can make a direct contribution to the quality of medical care their children receive. No medical care organization operates with perfection. And no doctor or nurse is likely to know a child's unique characteristics as well as a parent. If parent and professional can establish a partnership, parents can help improve the treatment process itself. Their

contributions may take any of the several forms discussed previously: they may inform the medical personnel of ways of treating their unique child, and thus improve the treatment process; they may be watchful and knowledgeable about treatment, and thereby help "correct" any mistakes that may be made.⁶⁵ In this sense the quest for partnership can result in improved medical care, over and above its positive psychosocial effects.

BY WAY OF A CONCLUSION:
SOME NOTES FOR THE FUTURE

This series of papers requires no concluding remarks, because we are still in the process of developing and analyzing the major themes present in these data. As noted earlier, we can now see the directions of a future analysis, and now are undertaking more complex multi-variate analyses of the ways in which data on stress, coping patterns and background factors may fit together.

We also know the data set well enough to be able to predict other papers that will be generated over the next year. Of course, each of the themes developed in these 3 papers can and will be extended. But in addition, readers may look forward to materials of a sort similar to those developed here, on the following topics:

Intra-family relations

support roles and conflict within the nuclear family,
including especially husband-wife roles, and reports
from and about siblings

The role of close friends in support and help

more on the interactions between parents of children
with cancer and their close friends

Preparing for death and dealing with its aftermath

Adolescents' perspectives on childhood cancer

analysis of the interviews with adolescents and
of other family members' views of adolescents

The family's relationship with the school*

The self-help process

description and analysis of the role of SHARE

The relationship among particular stressors, particular
coping patterns, and particular sources of help.

*In fact, with seed money from the Spencer Foundation we have begun a series of interviews with the principals and teachers of some of these children with cancer. Dr. Barbarin is conducting this study, and will soon be able to report educators' perspectives on the process of normalization, their roles and activities (as well as anxieties), options for better hospital-school-family coordination, etc.

Footnotes

1. Mark Chesler is an Associate Professor of Sociology at the University of Michigan, and a member of the Steering Committee of SHARE: Families of Children with Cancer. He and Joan Chesler are parents of an adolescent with cancer. Oscar Barbarin is an Assistant Professor of Psychology at the University of Michigan, specializing in family and community studies. Joan Chesler is the Director of The Corner, an adolescent health and education clinic in Ypsilanti, Michigan. She also is a member of the steering committee of SHARE. Diane Hughes and Judy Lebo are graduate students in Community Psychology, University of Michigan.
2. See also the discussions of medical progress in Siegel (1980) and Simone, et.al., (1978).
3. We appreciate the grant received from the University of Michigan's Committee for the International Year of the Child. That support, and the volunteer labor of student interviewers made the study financially feasible. The collaboration of the Pediatric Oncology/Hematology staff of Mott Hospital, SHARE's Research Advisory Group, and several colleagues made it politically and intellectually feasible as well. We especially appreciate the intellectual support and assistance of Henry Mayer, Ron Kessler, Elaine Selo and James Rothenberg. Sheila Wilder, Judy Kerr, Noelle Smith, Carol Crawford, Janet Somers and Mary Hartness provided invaluable clerical and administrative support.
4. In most cases (13/14), the one parent was the mother, for several potential reasons: (1) in divorced, separated and/or remarried families, the mother usually had continuing custody of the child; (2) mothers more often were willing to talk, probably because (a) they were more in touch with emotional feelings and issues and (b) they had a larger role in child health care, and thus greater information as well as need/willingness to share their experiences. In one family, no parent was willing to be interviewed, and an older sibling (acting as the substitute mother in that family) was the sole family representative.
5. Indeed, this distinction is a source of continuing debate in research on victimized populations. Quite clearly, we think that some of our joint roles as scholars and as parents of children with cancer enhance our perspectives on these issues, as well as our access to meaningful data. As we report and utilize these data, and as others respond to it, we hope the specific nature of these enhancements (as well as limitations) also can be examined and discussed.
6. Pearlin and Lieberman refer to the serious illness of a child as a non-normative event, in that it generates an "unexpected" and "unpredicted" crisis (1979). In a similar vein, Futterman and Hoffman (1973) refer to the "situational crisis" of childhood cancer, to differentiate it from the normal developmental tasks or crises of children and families (e.g., first parenthood, sibling rivalry, adolescent independence, aging).
7. A similar perspective on positive adaptations to these stressful circumstances is emphasized by Adams (1979), Desmond (1980), Futterman and Hoffman (1973), Kellerman (1980), Hymovich (1976), Sussman, et.al., (1980). Desmond, in particular, objects to the literature's bias in "viewing the experience of strong and distressing emotions as maladaptive rather than adaptive behavior" (1980, p. 123). Kellerman also cautions against "the tendency to overpathologize - to interpret maladaptive processes from routine responses" (1980, p. 199). Tavormina and associates, in their study of several childhood illnesses, note that the concern with pathology "...obscures the fact that most of these children are adapting successfully in spite of their feelings (1976, p. 1090)." None of these authors, nor ourselves, wish to romanticize these quiet struggles, but we do wish to emphasize our concern with the actions of normal persons to a series of stressful situations. As Hymovich notes, "A crisis may also be viewed as a turning point. If it is managed well, it can become a growth

producing event for the individual and the family. If the family is not able to cope well with the event, they may emerge from it in a weaker state" (1976, p. 10). Antonovsky (1980) and Reigel (1974) make similar points about the general literature in stress and coping.

8. As de Traubenberg notes with regard to childhood heart disease, "the fear of a disaster and the specter of a fatal seizure are always present, overshadowing every other consideration" (1973, p. 81). Scholarly discussions of current treatment regimens for childhood cancer indicate the potent side effects of surgery, radiation and chemotherapy, and clearly suggest how they might be stressful for any patient or parent (Katz, 1980; Hughes, 1976). Aside from the direct physical impacts of these treatments, Clapp (1976) and Koocher and Sallan (1978) discuss how their (sometimes lasting) side effects may threaten children's social and psychological well-being.

9. It is worth noting that this pattern of responses also could be an artifact of the interview situation, wherein each informant had to decide just what was appropriate to talk about in this context. Given an announced study of childhood cancer and its impact, parents may have been oriented primarily to describing their responses to the disease and its treatment. If this had been announced as a study of family dynamics, especially as an outgrowth of childhood cancer, parents might have attended more immediately to a discussion of relational issues.

10. Here is where a longitudinal study would be most helpful. It could verify this "stage" notion of coping, and might pinpoint the times when parents and families shift their dominant concerns from one set of issues to another.

11. Parents' drawings of their stress charts were coded for the kinds of events or stages they mentioned, as well as for the vertical height of each line they drew. Events or times with the highest average lines (height in the entire sample divided by number of times mentioned) are reported in Figures 4 and 5. However, to distinguish between those events mentioned by almost all parents (diagnosis, side effects, checkups), and those mentioned by relatively few (surgery, relapse), we have used dotted lines for the latter.

12. Futterman and Hoffman (1973) and Ross (1978) note the ways in which relapse may be even more stressful than diagnosis; parents and child literally must "start all over again." The utility of denial as a defense loses effectiveness and the "fear of the child's death again becomes potent" (Coping With Cancer, 1980).

13. Lascari and Stehens (1973) report that the parents of deceased children who they interviewed were divided evenly as to whether diagnosis or death was the most difficult period.

14. Binger, et. al., (1969), Knapp and Hanson (1973), Adams (1979), Hamburg and Adams (1967), McCollum and Schwartz (1972), Koch, et.al.,(1974) and Ross (1978) all have discussed the shock associated with the initial diagnosis. Meadow (1968) reports a similar shock for parents of deaf children.

15. Several studies of families of children with cancer report similar findings and Klein and Simmons (1979) note it with regard to childhood kidney disease.

16. The majority of parents who indicated, in Figure 6, that their child was the hardest person to tell about the diagnosis, were parents of adolescents. Evidently, younger children were easier to tell; or perhaps they never were told. Share (1972) presents an incisive review of medical and psychological perspectives on this aspect of family communication patterns, and Bluebond-Langer (1978) sensitively records patterns of concealment and "mutual pretense" between dying young leukemic patients and their parents and doctors. She suggests that some parents who conceal information from their children do so in order to maintain their own sense of control and efficacy, and to protect their children's sense of hope. Despite this informed controversy about whether, how and how much children should be told about their serious illness, both Bluebond-Langer (1978) and Vernick (1973) suggest they often find out on their own. As Vernick notes, "very little escapes the sick (and consequently

sensitive) child even in the pre-school years" (1973, p. 113). He provides several delightful anecdotes about children's inquisitive behavior on hospital wards, and the process by which they discover and share diagnostic information. In another vein, Spinetta (1980, 1978) discusses a number of important issues in family communications about childhood cancer, especially concerning "how to tell" the child about the seriousness of the illness.

17. O'Malley, et.al. (1979) indicate that the diagnostic period is a critical stage for the child with cancer, as well as for the parents: "The way patients reacted to learning their diagnosis (relief or shock) is related to their later adjustment" (p. 165). Although many factors no doubt influence the child's reaction to the illness, parents' feelings, and the way parents and professionals approach sharing the diagnosis with the child, must be crucial variables. A number of scholarly articles discuss children's responses and coping patterns; in a later paper we will examine the reports of youngsters in this sample.

18. This may be one reason we received the fewest refusals to be interviewed from parents of this age group. Their children's greater information and more positive reaction may have predisposed these parents more favorably to the conversations with themselves and with their children. Only 10% of the families of adolescents we contacted refused to be interviewed, compared with 25% of parents of children under 6 years of age, 23% of the parents of children 6-11 years of age, and 31% of the families of children who had died. (See Figure 3.)

19. Katz (1980) discusses the importance of peers' reactions to the child with cancer, and the child's potential reintegration into normal social relations. These peer issues may be even more delicate when the nature of the child's disease is known. Wortman and Dunkel-Schetter (1979) discuss the negative stereotypes which many adults hold about cancer, and about people with cancer. No doubt the same negative images are common among youth.

20. Spinetta and his colleagues (1976) have done especially fruitful and illuminating work in this area, including preparing materials for parents that stress the need to manage siblings' feelings in a forthright fashion. His work, Sourkes' (1980) recent review of the literature, and work by Gogan, et. al., (1977) are very useful.

21. Some families orchestrated creative responses to this problem by calling family meetings, making sure grandparents' friends or relatives were told first and were on hand when the call came, having the child talk on the phone to reassure the grandparents, etc.

22. Although there are few studies of relations with grandparents, Binger et. al., (1969) report that half of their sample of parents reported grandparents were a burden or hindrance, while many other parents reported they were supportive.

23. Several reviews discuss these and other factors that may account for such differences in stress (Hamovitch, 1964; Pless and Pinkerton, 1975; Adams, 1979).

24. Several anthologies of research on stressful life events discuss the role of these social and psychological filters, resources, etc. See, for instance Dohrenwend and Dohrenwend (1974) and Datan and Ginsburg (1975).

25. The "relapsed" category includes children who are living, but who have had at least one relapse, and children who have relapsed and died. Thus parents of children who have relapsed includes the parents of deceased children.

26. This is a voluminous literature with many major studies. See, for example: Dohrenwend, (1970); Myers, et.al., (1974); Pearlin and Schooler, (1978).

27. Cobb (1974) and Antonovsky (1974, 1980) discuss the importance of social support, or ties to others, in mediating the negative impacts of a variety of stressful life events. Wortman and Dunkel-Schetter (1979) review a number of studies emphasizing this variable in the lives of adults with cancer, and Futterman and Hoffman (1973) discuss these issues for parents of children with cancer.

28. This listing is only illustrative, of course. As more specific problems or

stressors arise, such as in school, more specific sources of help, such as school-people, might be utilized. Moreover, as our discussion of "crisis-coping" suggests, stressors, coping patterns, and thus preferred sources of help may change over time.

29. Recently, Brickman, et.al, (1980) have elaborated these distinctions in a coherent synthesis of the problems of giving and receiving help.

30. In a discussion of the general importance of social support to families of fatally ill children, Futterman and Hoffman also note some non-helpful responses from family members and helping professionals: "ministers, nurses and mental health workers were more likely to advocate either unrelenting cheerful hope for survival or resigned acceptance of the child's anticipated death than to recognize the legitimacy of the parent's rage and grief and to foster expression of these feelings" (1973, p. 138).

31. This is unlikely to be a simple "halo effect", or merely a test of reliability between the interview and the questionnaire formats. The interview item on friend's support does not relate significantly to all questionnaire items on sources of support, only to these noted. The questionnaire item on close friends' support does relate significantly to several more items, but some clear distinctions still can be drawn. On balance, the data clearly suggest the generalizability of support from several different and non-medical sources.

32. Wortman and Dunkel-Schetter discuss some of the attitudes and stereotypes about cancer that often cause friends to withdraw, and that result in social isolation for the cancer patient (1979). In a discussion of the mysteries and fantasies generated by much of the popular literature on cancer, Sontag notes that "a surprisingly large number of people with cancer find themselves shunned by relatives and friends and are the object of practices of decontamination by members of their household as if cancer, like TB, were an infectious disease (1979, p. 6)." The stigma associated with cancer must make parents concerned about publicly acknowledging their child's new status as abnormal, and by reflection their own status. When parents further perceive some of their friends as cautious or withdrawing, the cycle of silence, denial and isolation is firmly set in motion.

33. Wortman and Dunkel-Schetter make just such a suggestion, urging health care professionals to "inquire into the social support network that is currently available to the patient (1979, p. 147)," and to take active steps to involve others in the patient's care.

34. Although as indicated in footnote 27, it is an integral part of most general models of coping with stress.

35. Although this is a common research finding, some prior studies also report a high incidence of emotional isolation, breakup and distancing in families with chronically ill children (Kaplan, et.al., 1976). Desmond suggests caution in distinguishing between reports of closeness as expressions of a need for closeness vs. its real occurrence. In her own study, "the parental perception of 'closer together' was based on denial and avoidance of conflict rather than upon increased resolution of conflict or increased collaborative interaction" (1980, p. 115). We cannot resolve this debate with any certainty in the current study, especially because of the limited extent of our data and the time frame of these families' experience with childhood cancer.

36. See, for instance, Knapp and Hansen (1973), Binger, et. al., (1969), and Wagner (1981), as well as our discussion in the following pages.

37. See: Ross (1979), Knapp and Hansen (1973), Adams (1979), Sachs (1980), Thomas (1980), Heffron (1975), Stolberg and Cunningham (1980). The particular utility of such groups for bereaved parents is stressed in Martinsen and Jurgens (1979) and Pollit (1976).

38. That such clashes exist, and need to be acknowledged to be overcome, is addressed in Kleinman, Mantel and Alexander (1976).

39. See, for example, the discussion in Gartner and Reissman (1977), Killilea (1976),

Katz and Bender (1976) and Lieberman and Borman (1979).

40. Knapp and Hansen (1973) also report that fathers of children with cancer tend to be less open and emotionally accessible than mothers. Similar phenomena have been reported in studies of fathers of children with other serious and chronic diseases, such as cystic fibrosis (Boyle, et.al 1976) and hemophilia (Mattson and Gross, 1966). Other studies of sex roles and life stress in general indicate that women seek various kinds of help more often than men (Pearlin, 1975; Greenley and Mechanic, 1976). Some scholars argue that this occurs because women are exposed to more stress, or are more vulnerable to stress, or have been trained to be more dependent on others and thus more willing to seek and accept help regardless of the amount of stress they experience.

41. In a recent paper, Wagner (1981) reports similar changes in the orientations to work and family on the part of fathers of seriously ill children. His research also points to these fathers' feelings of being "left-out" of friends' help to mothers.

42. Adams (1979) suggests that the medical staff also may be uncomfortable or guilty about the death of a child, and may not be able to offer much support to the family of a child dying from cancer. Similar commentary has been made by Vaux (1977), Levine (1975) and Binger, et. al, (1969).

43. Some interns have reported that senior colleagues advise them not to attend funerals, and not to get "too involved". It seems to us that such policies, like treatment protocols, always must be adjusted to meet the human and emotional needs of all actors in a situation.

44. However, a number of analysts have argued that it is precisely professionals inability to grieve (whether at funerals or not), and to share their feelings of stress and failure and loss with patients, that escalates the sense of loneliness and frustration causing burn-out (Maslach, 1976). Hurt shared is hurt cared for, and this is as true for doctors and nurses as it is for friends and families.

45. Binger, et. al., report that "the parents with the most negative attitudes toward the professional staff were those whose children had had the shortest course of illness (1969, p. 415)." He studied only parents of children who had died from cancer, but the same trend should apply to comparisons between parents of living and deceased children.

46. Levine (1975) offers a view of the medical system that also may help explain these findings. He notes that the discomfort oncologists feel in the face of serious illness or death may be escalated when the doctor (or in his case the young "oncology fellow") deals with a patient of his own social class and educational level. Here the problem of identification and pain may be greatest for the doctor, and he may be least able to offer help and support.

47. See, for example: Futterman and Hoffman (1973), Lazarus (1966), Friedman, et. al (1963), Hamovitch (1964), McCollum and Schwartz (1972), Lascari and Stehbens (1973), and Adams (1979). Hamburg and Adams note that in their study of parents of (fatally ill) leukemic children, "There appeared to be an intense need to know a great deal about the disease (1967, p. 279)." Parents sought some of the information in order to understand and reduce their own sense of guilt and responsibility for the disease. Other information was sought to buttress conversations with doctors, and to explore alternative cures, since "parents felt there was a significant limitation on how much could be accurately retained after talking with a doctor (p. 280)." And some information was sought to help manage daily problems, such as fevers, decisions about when the child could return to school, go to a movie, etc. Our own experience with a local parent support group confirms these reports. SHARE's development of a library of technical and non-technical publications on childhood cancer was undertaken in response to many parents' requests, and we are now providing periodic annotations of articles in the Newsletter.

48. Several authors have noted that it is not only parents (and patients) who find

the time of diagnosis and "telling" very stressful. Health care professionals also experience discomfort, pain and sadness during these times, and a variety of doctor-parent or doctor-patient interactions are strongly influenced by the professionals' tension and strain. See for instance: Cassileth and Hamilton (1979), McFate (1979), Richmond and Waisman (1955), and Vaux (1977).

49. Binger, et.al (1969) report that the parents of leukemic children in their study singled out the honesty and frankness of the physicians as a key factor in their ability to hear and adjust to the initial diagnosis.

50. One framework for understanding such behavior is provided by Rutherford's (1977) discussion of self-serving" and "patient-serving" aspects of institutional care for sick children. Another approach is provided by Harris' (1978) effort to discuss the "patient orientation" of professional organizations. He defines patient orientation as "the extent to which the health organization is aware of, has concern for, and is responsive to the patient as a 'whole' person (p. 383)."

51. Wortman and Dunkel-Schetter note that adult cancer "patients may feel that it is inappropriate to express emotional concerns to their doctors, both because they feel doctors are too busy for such conversation and because they believe the doctor will react negatively if they express their feelings" (1979, p. 130). DiMatteo (1979) reviews several studies suggesting good rapport is important to patients. Especially interesting are his comments on a study by Cobb, in which cancer patients "rejected the medical establishment and sought help from nonmedical healers because of a lack of understanding and reassurance from their physicians, and a lack of sufficient information about what was being done for them (1979, p. 19)".

52. Of course, it is not just parents who judge the staff's caring and commitment: children with cancer often made their own judgements, and thereby may influence their parents. Vernick (1973) suggests that children with serious illnesses are both concerned and sophisticated about the medical staff's relationship with them. In his view, children "evaluate staff members in terms of their professional skills as well as their ability to communicate meaningfully with the children. Staff members who can get across to small patients are a minority in any hospital (p. 111)."

53. Adams (1979) describes a hospital situation wherein parents were encouraged to participate in the care of their child during hospitalization. This is critical preparation for the time (extended, we hope) when the child is at home or returning to a normal life. Richmond and Waisman (1955), Hamovitch (1964) and Futterman and Hoffman (1973) also have argued for such participation on grounds that it helps relieve parents' feelings of guilt, helplessness and impending loss.

54. A number of sensitive practitioners and scholars have observed the "need of parents to participate in the physical and emotional care of their sick children" (Futterman and Hoffman, 1973, p. 135). Such involvement is seen as helping parents deal with their feelings of impotence and helplessness. Indeed, this may be the case, but as the following examples suggest, much more may be at stake. Often, parental involvement and efficacy is more than a matter of physicians caring for or "cooling out" concerned parents, these parents can and do make a positive contribution to the medical care of their children. Moreover, as we indicate later, they may help prevent medical "mistakes". Good medical care, and not just "concern for upset and stressed parents", is what many of these parents' focus on. The other side of the ledger is that physicians and nurses sometimes see assertive parents as overcontrolling, overprotecting and interfering (Futterman and Hoffman, 1973), or as sacrificing other family responsibilities and members (Richmond and Waisman, 1955). While this may be the case on occasion, it by no means appears to be the rule in this sample.

55. Mechanic (1978) notes how difficult it is for patients to judge adequately the technical competence of a physician. The cues typically used are social in nature, very much like those included in our prior dimensions of interpersonal relations and

attentiveness to the child.

56. This list, and the 6 dimensions, are quite close to Mechanic's (1964) data on what mothers saw as constituting a "good doctor". His respondents identified 3 factors: competence and qualifications, friendship and sympathy, and personal interest in the patient (including caring, taking time and listening).

57. These classic aspects of the practitioner-patient relationship were developed originally by Parsons (1951), and have been modified by later observers such as Freidson (1970), Szasz and Hollander (1956), Mechanic (1978), and Stone (1979).

58. While they are making demands, it does not appear to us that parents are challenging the current structure of professional practice in the sense that Haug and Lavin (1978) or Haug and Sussman (1969) describe; there is no "revolt" here.

59. This is by no means a local trend, nor is its focus limited to local issues. In communities across the country parents of children with cancer have organized to articulate and press their concerns. At the national level, several coalition organizations (including Candelighters) have presented these parents' concerns to medical organizations, national health care agencies and legislative bodies.

60. The above interpretations are uncommonly similar to a style of scholarship on social minorities (blacks, women, young people) and other victimized groups (victims of rape and crime) that "blame the victim" for a bad situation, rather than focus on exacerbating factors in the social environment. In this case, Mattson focusses on parents' internal psychic mechanisms rather than taking a good hard look at contributing factors in the role interactions and social structures of the health profession and medical care organizations.

61. This question was asked only to parents of living children. As some of the prior excerpts suggest, parents of children who died might have added a concern: 6. good management of the dying process.

62. It also may be an error factor, resulting from differences between the interview format and the questionnaire format. The items about change in views of the medical staff, and tense relations with the staff, all come from the questionnaire. Other reactions to and evaluation of the medical system we have been using are drawn from extended comments in the interviews. Some persons did not respond to these latter questions; perhaps their answers would have been weakly positive, dramatically altering the findings. Moreover, only parents of children living with cancer were asked these questions in the interview, and their responses to the medical system generally are more positive than parents of deceased children. For the moment, then, we are confused.

63. Since many of the parents in the sample were involved in their child's care, and in any possible intervention, prior to the initiation of SHARE, the date in Figure 22 probably underestimates the relationship between SHARE involvement and parental intervention.

64. See, for example, Maslach (1976) and Cherniss (1980). Discussions of "burn-out" particularly focussing on professionals working with childhood cancer include Stuetzer (1980) and Rothenberg (1967). Perhaps most poignantly, Richmond and Waisman (1955) note that physicians who can share some of their own feelings of anxiety and helplessness may be surprized by the depth of positive feelings and support parents can provide in reciprocation.

65. It appears appropriate to reiterate that many parents did not object to the occurrence of mistakes, per se. In noting the need to intervene, parents indicated their understanding that doctors and nurses were busy, had good intentions, etc. Thus, mistakes, in and of themselves, were not seen as evidence of failure. Rather, parents became incensed when professionals refused to acknowledge these mistakes, blamed parents for their occurrence, or made them over and over again.

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