

"Dilemmas of Providing Help in a
Crisis: The Role of Friends with
Parents of Children with Cancer"

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This article is part of a continuing series of Working Papers reporting our studies of psychosocial aspects of childhood cancer. Other Working Papers in this series include:

- 243 "Role of Informal Networks and Medical Care Organizations in Helping Families Cope with Childhood Cancer: Prospects for Collaboration," August 1981, Mark A. Chesler, Oscar Barbarin, Joan E. Chesler, Diane Hughes and Judy Lebo, August 1981, \$3.50.
- 283 "The School Experiences of Children With Cancer: Views of Parents, Educators, Adolescents and Physicians," December 1982, Oscar Barbarin and Mark A. Chesler, not available from CRSO. Published in expanded form as Children with Cancer: School Experiences and Views of Parents, Educators, Adolescents and Physicians, Eterna Press, P.O. box 1344, Oak Brook, Illinois 60521.
- 285 "The Organization of Self-Help Groups for Families of Children with Cancer," April 1983, Mark A. Chesler and Meg Yoak, \$2.00.
- 290 "Self-Help Groups of Families of Children with Cancer: Patterns of Stress and Social Support," June 1983, Mark A. Chesler and Meg Yoak, not available from CRSO. Soon to be published as a chapter in H. Roback (Ed.) Group Intervention with Medical-Surgical Patients and their Families, Jossey-Bass, 1984, San Francisco.
- 306 "Self-Help Group Structures and Activities: Implications for Professional Roles," December 1983, Meg Yoak and Mark A. Chesler, \$2.00.

Abstract

Parents of children with cancer experience substantial stress over a long period of time. One way parents cope with such stress is to seek social support from various sources, and especially from close friends. Interviews with a sample of these parents, as well as with some of their close friends or informal "helpers", illustrate the dilemmas involved both in seeking and in providing help in the midst of a crisis. Among the major dilemmas parents and their close friends report are managing the emotional impact of the illness, concern about intruding on privacy and prior boundaries of relationships, avoiding the creation of stigma or an aura of non-normality, finding ways of being useful and feeling effective, and dealing with typical sex-role barriers to a full range of helping interactions. These dilemmas are discussed and analyzed primarily in a qualitative framework; special attention is paid to deriving an understanding of the meanings of these dilemmas from the actual experiences and reflections of parents and friends engaged in the helping process.

The experience of childhood cancer is a stressful series of events for children and their families. Substantial research on families of children with cancer indicates that psychological trauma and turmoil are typically associated with the diagnosis (Adams, 1979; Binger, Ablin, Feuerstein, Kushner, Zoger & Mikelsen, 1969; Hamburg & Adams, 1967; McCollum & Schwartz, 1972; Spinetta, Spinetta, King & Schwartz, 1976). For these parents and children, moreover, the diagnostic phase is only the beginning of a long period of stress and stress coping responses - the process of medical treatment and its side effects, prognostic uncertainty and general disruption of family life goes on for years (Adams, 1979; Ross, 1978; Spinetta et al, 1976). While some research suggests that the long-term psychosocial outcomes for family life often include pathology, marital conflict and divorce (Kaplan, Grobstein & Smith, 1976), other recent reports present a more optimistic view of parental and familial coping (Kalnins, 1983; Lansky, Cairns, Hassamien, Mehr & Lowman, 1978; Stehbens & Lascari, 1979). Many families seem to cope quite effectively; they maintain a sense of personal integrity, develop meaningful explanations of the illness and often respond to stress by trying to enrich their individual lives and foster family cohesion. Like other individuals facing trying circumstances, parents of children with cancer often rely heavily on family members and friends for help in coping with the psychosocial stress associated with the illness. In this paper we explore the process of seeking and providing help for families of children with cancer; in particular we focus on the dilemmas of helping experienced by parents of ill children and their close friends or informal helpers.

Stress and Social Support

Recognition of the the psychosocial and medical stresses confronting the family of a child with cancer has influenced human service organizations to increase the availability of professional assistance to these families. However, as several scholars have observed (Froland, Pancoast, Chapman and Kimboko, 1981; Gourash, 1978; Kulka, Veroff and Douvan, 1979; Taylor, 1983), "typically people do not seek professional help in dealing with personal problems. They use their social networks and individual resources. . .", (Taylor, 1983, p. 1161). Awareness of the importance of informal networks has produced a groundswell of scholarly interest in the process of help-seeking and help-giving (Collins and Pancoast, 1976; Cowen, 1982; Fisher, Nadler and DePaulo, 1983; Gottlieb, 1981; Wispe, 1978; Wortman and Dunkel-Schetter, 1979). In fact, several scholars emphasize the complexity of this phenomenon, noting that there are a great many variations in the form and substance of informal help or social support, (Caplan, 1979; DiMatteo and Hays, 1981; Gottlieb & Schroter, 1978; Hirsch, 1980).

A number of scholars also have argued that social support can buffer or reduce the stresses associated with life crises (Antonovsky, 1974; 1980; Bloom, Ross and Burnell, 1978; Caplan, 1974; Cobb, 1974; Dean and Linn, 1974; Gottlieb, 1981; Hirsch, 1980; House, 1979; Pilisuk and Froland, 1978), and this work has been extended to parents of chronically and seriously ill children, such as those with cancer (Adams, 1979; Futterman and Hoffman, 1973). But the same "significant others" who are sources of positive help and support also may be sources of added stress for parents of ill children (Cassileth & Hamilton, 1979; Hymovitch, 1976; Katz, 1980). As researchers have reported in other contexts, not all potential helpers actually deliver

helpful help, and some even add to patients' or parents' sense of pain, isolation or inadequacy (Coates, Renzaglia and Embree, 1983; Shinn and Lehman, 1985).

When helpers also are close friends they are operating in the context of an on-going relationship (Froland et al., 1981), a relationship formed long before the current crisis. Thus, as parents and helpers deal with issues triggered by childhood cancer they have to find new ways to manage the boundaries and rules that governed their prior interactions. In addition, the sheer chronicity of the stresses of childhood cancer, and the potentially long-term character of the helping relationship, also may create difficulty over time. These issues in helping relations with parents of children with cancer might have been simpler two decades ago, when such children routinely died within a few months of diagnosis. Now, with a longer period of life and even potential for cure, friends' help and support for the child and family is more extended and complicated.

Although existing research has developed useful mini-theories regarding the outcomes and dynamics of informal support, it has not captured well the detailed conditions which facilitate or impede the actual helping process. In this paper we draw from a series of interviews with parents of children with cancer, and from interviews with some of their close friends, to identify dilemmas of seeking and providing help. The dilemmas we identify are derived inductively from reading and categorizing parents' reports of how they sought help from their friends, their perceptions of their friends' reactions to being asked for help, and their reports of the outcomes of that process. Five key issues or dilemmas were identified in this manner: (1) concerns about the emotional impact of childhood cancer on their friends;

(2) concerns about a helping process that might invade prior domains of privacy and alter a friendship; (3) concerns about stigmatization as a result of needing help; (4) concerns about the effectiveness of help; and (5) difficulty in overcoming traditional sex-role barriers to receiving help.

Several of these dilemmas or difficulties have their parallels in other research on social support or helping processes in general and some in studies of childhood cancer in particular. For instance, since the literature on childhood cancer suggests that the diagnosis is shocking and fearful for parents, we may expect it will have a similar effect on others closely related to the child and family. Wortman and Dunkel-Schetter's (1979, p. 131) discussion of adult cancer patients' interpersonal relations suggests that for others in the social environment cancer "...arouses fear and feelings of vulnerability." Several scholars also have reported the feelings of pain, stress and even burnout affecting medical practitioners dealing with adult cancer patients (Levine, 1975; Vachon, Lyall and Freeman, 1978) or with pediatric oncology patients (Rothenberg, 1967; Steutzer, 1980; Vaux, 1977). Close friends of the parents of children with cancer, probably even more closely identified with the family than are these professionals, may be profoundly affected by their concerns for the ill child and for the parents of the child as well. Reasonably sensitive parents may anticipate such reactions from their friends, especially when they have observed them in themselves and other family members, and be concerned about the emotional impact of the diagnosis, treatment and prognosis on these intimates. As Dimatteo and Hays (1981, p. 141) indicate, "patients often are distressed by the 'burden' that they place on their

loved ones..." when they seek psychological support.

Another issue permeating informal helping relationships is the problem of privacy and the management of interpersonal boundaries or degrees of closeness. Literature on the functions of privacy suggests that it shapes interpersonal distance and self-disclosure between individuals and their friends (Altman, 1975). Moreover, the optimum degree of privacy (i.e., the closeness desired and permitted among friends) may vary considerably as changes occur in the life circumstances of parties to a relationship. In this context, the diagnosis of a life-threatening disease for a child sets the stage for changes or renegotiations in the degree of desired intimacy among parents and their friends. The actual transition to increased levels of intimacy and self-disclosure, moreover, may be awkward and uneasy. Requests and assurances, cues and feedback, and new levels of engagement have to be tested before such closeness can be welcomed and utilized.

Cancer is a frightening disease, and the label itself often is associated with mystery and death in this society (Sontag, 1979; Wortman and Dunkel-Schetter, 1979). As parents prepare to "go public" about their child's illness they may experience concern about the stigma attached to cancer. In addition, parents often may worry whether they are acting "normal" and will be perceived and treated normally by their friends. As Goffman (1968) and others have noted, people related closely to a person with a stigmatizing condition often treat themselves and are treated by others as stigmatized. In addition, some scholars suggest that just admitting a need for help creates feelings of inequality in a relationship, and could generate a secondary stigma of the parent as a non-active or weak person (Fisher, Nader and Whitcher-Alagna, 1983; DiMatteo and Hays, 1981;

Brickman, Kidder, Coates, Rabinowitz, Cohn and Karuza, 1983).

Several researchers suggest that parents of children with cancer feel powerless and a loss of control in the face of this diagnosis (Futterman and Hoffman, 1973). Such powerlessness, and concerns about whether or not they have the energy and ability to utilize help, may affect parents' interest in seeking help and potential helpers' willingness to provide it (Brickman, Rabinowitz, Karuza, Coates, Cohn and Kidder, 1982; Voysey, 1972). These latter researchers also suggest that help is more likely to be offered if potential providers receive information that they really can do something that might make a difference. Thus, the cues parents can give helpers regarding the kinds of help that will be effective may be a critical variable affecting the entire process.

Finally several studies of sex roles and life stress in general indicate that women seek and use various kinds of help more often than do men (Gourash, 1978; Greenley and Mechanic, 1976; Pearlin, 1975; Vaux, 1985). With regard to parental role distinctions, Knapp and Hansen (1973) report that fathers of children with cancer tend to be less open and emotionally accessible than mothers; a similar phenomenon has been reported in studies of fathers of children with other serious and chronic diseases, such as cystic fibrosis (Boyle, Saint A'gnese, Sack, Millikan and Kulczcki, 1976) and hemophilia (Mattsson and Gross, 1966).

In addition to analyzing parents' reports of these dilemmas, we also examine a similar set of dilemmas reported in interviews with parents' close friends, those people who provided actual help and support. In an inductive process similar to that utilized in the discovery and articulation of parents' dilemmas, we derived friends' dilemmas by reading

through their interviews and categorizing the themes present in their discussions of how they provided help to parents of children with cancer.

There are very few prior studies exploring the reciprocal strains and ambivalences which make people reluctant or unable to reach out for or to extend help (Shumaker and Brownell, 1985). Taken together, the two sets of interviews utilized in this report illuminate the social interactions among people coping with the impact of a shared crisis, and help explain how childhood illness effects others outside the immediate family. They also provide unique "snapshots" of the ways in which intimate and compassionate relations are maintained in the midst of a long-term crisis with an uncertain outcome. Informal help that occurs within the context of intimate friendships must deal with all the interactive and reciprocal problems and potentials of these friendships, as well as with the unique tasks of seeking and providing help.

Method

The data discussed here are drawn from a larger study of stress and coping patterns among families of children with cancer (Chesler and Barbarin, 1984; Chesler, Barbarin, Chesler, Hughes and Lebo, 1981). In that study 55 families (including single and dual adult households) were sampled from a pool of several hundred families of children with cancer being treated at a major midwestern medical center and children's hospital. Ninety five parents of children with cancer were interviewed, of whom 75 were parents of children living with cancer and 20 were parents of deceased children. All interviews took place in the homes of the families, and each parent was interviewed separately. Interviewers were graduate and undergraduate students who had previously worked in the hospital with

children with cancer.

The sample was deliberately stratified on the basis of the type of cancer and the age and life-status of the child, so that it would be broadly representative of the population of families experiencing childhood cancer. The sample is described in Table 1. Almost 80% of the families contacted agreed to participate in the study, and when neither parent in a given family consented to an interview another family of a child with a similar disease and age status was substituted. All interviews took place at least 9 months past and within 5 years of diagnosis.

Insert Table 1 here

The study utilized both open- and closed-ended questions, with pre-planned probes to clarify initial responses. The interview covered issues such as the nature of the diagnosis and prognosis, course of illness, problems the family encountered, interactions with the medical system, social support received from family members and friends, and ways the family related to people and institutions in the community. When an interview was completed each informant was asked to fill out a six-page structured questionnaire and mail it back to the investigators; 90% of these questionnaires were returned.

We assumed that support would take many forms and allowed for the possibility that it might be defined differently by each person interviewed. Using open-ended questions and structured ratings, parents were asked to indicate who helped them, how much they helped, and in what ways they helped. Sample questions in the interview include:

Was it difficult to share the diagnosis with friends? How come?

How did friends react? How were they helpful? In what ways were they not helpful?

What might they have done to make this period easier? How could friends have been (more) helpful?

Other comments about friends' behaviors were sprinkled throughout the interview, often in response to other questions. In general, in the interviews and in this paper, "support" is used synonymously with "help". Although we subscribe to the notion that instrumental aid, emotional comfort, personal affirmation, positive affect, and information all are central components of social support (Barrera, 1978; Caplan, 1974; Dimatteo and Hays, 1978), our working definitions and examples are drawn from parents' own responses to these interview questions about the things friends did to help them, and what might have made things easier for them. In the questionnaire, we provided parents with a list of 14 common "sources of support and help" (spouse, close friends, physicians, etc.), and asked them to indicate, on a five point scale (5=very helpful, 1=not helpful) "how helpful each of those sources has been" for them.

In order to generate information about the helping process from the perspective of helpers, we also interviewed a number of "close friends" who these parents of children with cancer identified as having been particularly helpful to them. The helpers' sample was created by asking six articulate and receptive families of children with cancer (4 families with a living child with cancer and 2 families with a deceased child) each to nominate 2 other families who had been helpful to them. Twenty-one out of the 24 helpers who were nominated agreed to be interviewed (one couple and one husband refused) and we interviewed and administered questionnaires to at

least one adult in 11 of these 12 families. The interviews with helpers were conducted individually and covered some of the same questions as the interviews with parents of children with cancer. In addition, they included specific questions on the helping process: what help was provided and by whom, ways decisions were made about what help was appropriate and for whom, and the issues or problems involved in being helpful. All helpers were married and this sample was almost divided equally between 10 male and 11 females. All had children, but only one couple (two parents) themselves had a child with cancer. Forty five percent were college graduates, 30 percent had attended some college, and 25 percent had not attended college. They were roughly of the same age as the parents who had nominated them as close friends and helpers. Obviously this small and select sample of helpers is representative neither of the total pool of helpers used by this sub-sample of parents, nor of the total social support network available to the larger sample of parents. However, intensive examination of the experiences of this sample has generated rich materials and general themes that are quite instructive; they may be tested in detail later with larger and more representative populations.

Results and Discussion

In this section we present the sources of help parents of children with cancer reported utilizing, and the different meanings or kinds of help they received from their friends. Then we present our analysis of the dilemmas parents and friends encountered in providing or receiving such help.

Demographic factors and help from close friends

Parents of children with cancer utilized various sources of social support and help, including family members and professional medical and

social service staffs as well as friends and neighbors. Seventy-three percent of the parents reported that their spouse was "very" or "quite helpful" and close friends were reported as "very" or "quite helpful" by 70 percent of the parents; social workers and psychologists/psychiatrists were reported as "very" or "quite helpful" by 25% and 7% of the parents, respectively. Table 2 presents the rankings of all 14 sources of support and help, based on the means of parents' ratings; it underscores the importance of close friends in the larger network of help and support parents received.

 Insert Table 2 here

Analyses of the relationships between parents' demographic statuses and their reports of help and support from close friends resulted in few significant distinctions. With regard to characteristics of the child, a one-way ANOVA indicates that parents of deceased children reported more help from close friends ($\bar{x}=4.2$) than did parents of living children ($\bar{x}=3.9$, $F[1,90]=3.75$, $p.<.05$). However, this difference is primarily a function of lower support scores reported by parents of living children between 6 and 11 years of age at the time of interview ($\bar{x}=3.5$), than by parents of living children under 6 years of age ($\bar{x}=4.2$) or over 11 years of age ($\bar{x}=4.0$). The age of the child at diagnosis and the length of time elapsed since diagnosis are not significant discriminators of parents' reports of support and help from their close friends. However, a one-way analysis of variance shows that parents of living children with different diagnoses report significantly different amounts of support and help from their close friends

($F[4,59]=3.51$, $p.<.01$). Parents of children diagnosed with Wilms' Tumor reported substantially less help from close friends ($\bar{x}=2.86$) than did parents of children with other diagnoses, and parents of children with Lymphoma ($\bar{x}=4.43$) and Osteogenic Sarcoma ($\bar{x}=4.22$) reported substantially more help. Wilms' Tumor youngsters generally are diagnosed at a very early age (under 2 years), and have the shortest treatment duration (6 months to a year) and the highest long-term survival and cure rates of any of the childhood cancers. Youngsters diagnosed with Osteogenic Sarcoma and Lymphoma generally are the oldest age group at diagnosis; their treatment generally extends over a longer time period and recovery rates, at least for Osteogenic Sarcoma, are not as high as for Wilms' Tumor. Since age at diagnosis and elapsed time since diagnosis do not relate significantly to parental reports of social support from friends, it may be that these factors interact with the physical and prognostic characteristics of each particular type of childhood cancer to influence parental support systems. Analyses of the interaction of these variables cannot be pursued further within this small sample.

Only one demographic characteristic of the parents themselves approached statistical significance in its relation to their reports of support and help from their close friends: educational level. A one-way ANOVA performed with education as the independent variable ($F[2,82]=2.61$, $p.<.08$) indicated that parents with higher education reported more support from their close friends (no college, $\bar{x}=3.63$; some college, $\bar{x}=3.69$; college graduate, $\bar{x}=4.28$). This finding is not surprising, since substantial literature on social support systems and life stress suggests that persons with higher educational levels report receiving more social support in general

(Gourash, 1978; Greenley and Mechanic, 1976). Other demographic statuses of parents, such as age, gender, income, distance from their own parents did not differentiate their reports of help from close friends.

The process of seeking and receiving help is initiated when parents of a child with cancer publically announce or "share" the diagnosis. Forty-one percent of the parents who responded to the question indicated they had experienced difficulty in sharing their child's diagnosis with their close friends. A chi square analysis indicated that there was a statistically significant relationship between parents' reports of difficulty in such sharing and support they received from their close friends ($X^2=4.5$, $df=1$, $p.<.05$): the more difficulty in telling the less support received. Some parents obviously were not comfortable telling their close friends of their child's illness, or at least not at first. Why not? Clearly, "going public," even with close friends, is a stressful event, and could be considered a dilemma in and of itself. However, parents' telling, and friends' response to this shared information, more importantly represent the first steps in the creation of a helping relationship and a new phase in a long-term friendship. Thus, it sets the stage for the ongoing dilemmas parents and their close friends experience in trying to seek or provide support. Our subsequent analysis of the dilemmas both parents and friends report not only illuminates some of the issues surrounding the process of telling but underscore some of the continuing issues involved in creating and maintaining a helping relationship among peers.

Kinds of help

Parents and their close friends or informal helpers provided several different meanings for the terms social support and help, and defined or

identified several different kinds of help they received or provided. A brief inspection of these alternatives should aid identification and discussion of the helping dilemmas that follows. Sometimes the most important form of help parents received was quite non-specific, and responded to their generalized emotional need for social contact. In this regard many parents reported that they were grateful that someone "was there" or "listened" or "cared". Caplan (1979) calls this "psychological support" and Gottlieb (1981) refers to it as "emotionally sustaining behavior". Consider parents' examples of this form of help:

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

One friend would go out for coffee with me and just talk. Mostly this guy just listened. Knowing he was there was great.

Friends of parents also discussed the ways in which they provided such emotional support.

We talked about the quality versus the quantity of living. If you can talk about it, consider it, share some of your feelings about it, then it doesn't loom out there as a catastrophe.

What I did in those situations was to listen, support, advise, help with problem solving, let them express anger and do a lot of anticipating of grief.

A second form of help parents reported was quite specific and responded to practical tasks or needs. For instance, many mothers and fathers reported receiving help with key household or caretaking chores such as cleaning, cooking, ironing, raking, changing light bulbs, fixing bikes, etc. In addition, some tasks related to care of the ill child (such as visiting, checking doctors' appointments) and siblings (babysitting, transporting, entertaining) were assumed by others. Caplan (1979) labels these "tangible supports" and Gottlieb (1981) refers to them as "problem-solving behaviors".

Some of these specific forms of help required friends to know the family well enough to know what was needed, and some required just common sense.

Parents' examples of such practical help included:

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

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

Friends also reported examples of such practical assistance to the family.

I cooked several meals and sent them. We took her to one of her medical appointments. When the child was released we took her up North with us for the weekend.

Unfortunately we cannot take their pain away. But we can and did make their life less complicated so they can deal with it.

Several helpers indicated another form of help they provided to these parents, an indirect form. Rather than, or perhaps in addition to, engaging in intimate interpersonal assistance, they organized the larger neighborhood or community to generate additional practical resources. This kind of help is often overlooked in a research literature that emphasizes dyadic and interpersonal transactions (Shumaker & Brownell, 1985). Consider the following reports from friends:

It is important to find someone in the neighborhood to organize help. I was like a cog in a large organization. When one couple called and said today is our day to take food to the family up at the hospital I went and did it.

I was one of the principal people who helped organize a raffle drive to get some extra money for them. They got the money when the child was in his last stages and they didn't have enough money for the trips to the hospital and for the funeral. So what we raised from the raffle came in handy.

Parents seldom mentioned this form of help from friends; although they indicated that they received the help they did not necessarily know how it

had been organized. At times, however, parents also reported that they organized local resources.

We synchronized who was coming up to the hospital so we didn't have a mob there. Whoever would want to come would call my father or one of my close friends and then they'd come at a good time.

Dilemmas of helping

With this description of some of the sources and kinds of help and support as background, we can delineate the dilemmas involved in parents seeking/receiving and friends providing/offering help. Analysis of extensive interview material leads to the illumination of five core dilemmas: concern about emotional impact, maintenance of privacy and prior boundaries of a relationship, concern about stigma, effectiveness of help, and attempts to deal with traditional sex-role stereotypes in the helping process. Most but not all of these dilemmas are reported both by parents of children with cancer and by their friends or helpers; we take care in the following sections to make this distinction clear. Because the questions we posed regarding problems encountered in the helping process were open-ended, and different informants responded out of their own individual contexts, it is not instructive to create a quantitative analysis of the frequency or distribution of these dilemmas. However, each dilemma we report was mentioned by several parents or several helpers as potent and poignant for them.

Emotional impact of childhood cancer One potent dilemma reported by parents and friends relates directly to the emotional shock and stress associated with the diagnosis of childhood cancer. Noting that the prospect of talking about the situation sometimes made her pain even more unbearable, one parent remarked:

I didn't want to talk about it because it was something I wanted to shut in the back of my mind and have go away. It doesn't go away but I want it to. I didn't want to talk about it because that brought up my unconscious fears.

And many parents indicated that they knew or expected that talking would bring shock and similar pain to their friends.

It was difficult talking about it with them because our real close friends were really shocked. They were shocked and cried and didn't want to believe it. It was just like us at first.

The remarks of helpers and friends support the parents' perceptions that sharing the diagnosis would have a major impact on friends and on their lives.

I felt absolutely like someone had hit me. I was just very shocked.

Amazed. Shocked. Incredulous. How could this be happening to anyone we know?

Other friends indicated that one initial response was a concern about their own children and for the fragility of life itself.

The impact has been that I really took a good look close again at my own children and how much time I spend with them. I just thank God that they are healthy.

Beyond the initial diagnostic period, friends reported the continuing emotional impact of relating closely to these parents and their ill child.

There would be times when my husband and I would be exhausted from talking with them or each other—we'd be zero. We'd go to bed and barely have enough energy to say goodnight to each other, we were so emotionally played out.

I felt drained. You can only hear so much. I love them dearly but I can't deal with the child's illness for seven days a week for a long time, because we have a life too.

Thus, the compassion that friends felt for the parents of ill children, and their desire to help, obviously was complicated by their own emotional distress. Over time, the sheer chronicity of the disease/treatment, and

thus of the helping process, was debilitating. As one helper/friend reported:

This wasn't just a one month crisis. We're talking about a couple of years as an intense period of crisis in which the thing was really impacting on their family and anyone they were relating to including us.

Invasions of privacy. A second dilemma reported by both parents and their friends focusses on the potential for mutual invasion of privacy or for dramatic alteration in the prior boundaries of their relationship. Several parents commented, for instance, on their own concerns about emotional intimacy and openness.

It was hard to tell my friends because it was a long time before I could talk about it without crying. In a way I wanted to talk with them and in a way I didn't.

In addition, parents noted that some of their friends had difficulty defining or crossing these same boundaries:

Some friends who came to visit didn't want to hurt our feelings by discussing it (the illness) so they would sit in silence, which made us feel very uncomfortable.

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

Although many friends saw these parents in need of help, they often expressed concern or discomfort about being intrusive and "invading their space." The concern about intrusion is not an abstract problem; it reflects discomfort or confusion about the new boundaries involved as peers create a helper-helpee relationship. Consider the following friends' comments:

There were a limited number of things asked of me and I felt it was hard to invade their space and say what I would do.

I didn't want to be intrusive, in terms of where they were at, but I wanted to be supportive.

Not all parents' friends experienced the issue of privacy or of a

changing relationship as a dilemma. As suggested by DiMatteo and Hays (1981), some felt they knew parents' expressions and needs well enough so they had "cues" as to what would be helpful. Even when good cues were not available, however, some friends felt that the pre-existing relationship was strong enough and/or the boundaries certain enough that potential intrusion was not a problem.

When it first occurred I didn't know what to do. I wasn't sure whether to approach them or not, but decided I would call and offer to help and let them make the decision.

As far as intruding was concerned I don't think that was a problem. We're close enough that they know I wouldn't be hurt if they said, "That's enough."

Stigma and de-normalization. In the face of concerns about the stigma of cancer, some parents were hesitant to share much information and chose to limit their disclosures. Among the others who did approach their friends, some reported negative experiences:

I found out that people are scared of the word cancer.

They asked how he was doing but never came to see him. They acted like, "Keep him away from me, it's catching."

Other parents reported their discomfort with the stigma of appearing and being treated as "needy" or "abnormal", regardless of the specific cancer label.

I didn't like that kind of pity or sympathy.

My husband's friends weren't able to be real helpful because he didn't want to see or talk with them while our daughter was sick because he was afraid he'd break down.

Friends seldom reported the concern about cancer as a stigmatizing issue, but several identified their attempts to avoid the more general stigma associated with treating parents in inappropriate or condescending ways.

We'd tried not to pity them. We knew they didn't need pity, just companionship.

I wanted to help them feel normal, that everyone in their situation experiences strong feelings and that they're not strange or sick or crazy because they feel sad or want to cry.

The last excerpt, above, was reported by a close friend and helper who herself was the parent of a child with cancer. She understood the concern about normality quite well!

Effectiveness of help. A fourth dilemma reported by parents and friends centered around the effectiveness or potency of the help provided. Parents indicated quite clearly that some friends responded in ways they experienced as non-useful, or worse. Perhaps some friends were not sure of what help was needed or how to offer it, but it was hard to avoid the twin pitfalls of not raising some issues or of pushing too hard on other issues. We have already discussed avoidance as a boundary problem; here parents illustrate their feelings about advice intended to comfort them or to enhance their ability to cope, but which was innocuous, unhelpful or even distressing.

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

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

And some parents indicated it was hard for their friends to be really helpful because they themselves weren't really sure they wanted help.

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

Friends agreed that it was hard to help some parents.

I tried to indicate to him that he mattered and wasn't expected to be quiet, strong and long suffering.

As friends wrestled with the dilemma of how to provide effective help they often reported the usefulness of cues and feedback from parents (Shinn, 1985). For instance:

Sometimes they would say, "People are afraid to ask us because they don't want to bring up the negative topics, so they rely on us to do it." So they gave us clues to know what they did want people to notice and talk about.

It was clear we were useful and helpful. They've been very direct and open about their appreciation of our support.

Despite these aids in the helping process, the sheer magnitude of the medical and emotional traumas being faced by parents of children with cancer sometimes overwhelmed even these helpers. For instance, some friends noted their frustration in feeling helpful at all, or as helpful as they wanted to be.

A lot of it was easy to know what to do. But the hard part was that I always felt that I wasn't doing enough, or that I wished I could do more.

You never feel as though you're quite as useful as you think you should be. You think, "I should be doing more."

Indeed, some close friends clearly recognized the objective limits of the help they could offer, reporting that the most important kind of help was not within their power to provide.

The best help that anyone could give them would be to find a cure.

No matter what you wanted to do, no matter what you did for them, you could never take away the pain from them or their child of this sickness.

Under these circumstances friends reflected on an important aspect of this tragic illness and a realistic limit to the helping process.

Sex-role differentiation in sources and targets of help. Although parents' gender did not distinguish the amount of help they reported (on the structured questionnaire) receiving from their close friends, comments in

the interviews do suggest the relevance of sex-role issues in the helping process. One father of a child with cancer presented the issue of sex-role differentiation openly, as he discussed his pain in not getting the help he needed as well as the way he may have withdrawn from dealing with his feelings openly.

I think if I knew someone in my position one of the things I'd like to ask him is how are you coping. 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. If I could wish for anything it would have been more of that. Probably there are things I could have done to make that happen though.

Some friends commented further on gender-related issues in their attempts to provide help to mothers versus to fathers.

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. We didn't talk like she and I did.

On a pragmatic level, more of the practical tasks generally performed by women, (e.g. household chores, cooking, shopping and sibling care) could be temporarily performed by close friends. Men's typical tasks, such as going to work, could not be as easily substituted. In addition, research on sex role relations suggests that fathers generally may have a more difficult time asking for intimate emotional help, or in being open and vulnerable to such help, than do mothers (Gourash, 1978; Pearlin, 1975). Male images of strength, of denying or dealing covertly with feelings, of competence and independence, and of family leadership may stand in the way of expressing emotional needs and receiving certain kinds of help from friends. Thus, there may be an interaction between the kind of help offered or sought (emotional v. practical) and the gender of the recipient (women v. men).

Although the quantitative analysis of gross support from friends fails to indicate this level of complexity in gender-related interactions, if we had asked parents to distinguish in the questionnaire between emotional and practical support provided by friends we may have been able to verify these interview findings.

The gender differences are complicated further because male helpers may be as reluctant or cautious as these fathers of children with cancer. For instance, several male helpers indicated that their role was limited, partly because of time availability and partly because they themselves were uncomfortable dealing with intense feelings.

My wife was running back and forth a lot and I was babysitting at home. I was sort of a back-up person and didn't see as much of them as my wife did.

I would have liked to talk with him more about what was going on with him in terms of his thoughts and feelings. I didn't feel comfortable that he would have felt comfortable talking with me about those sorts of things. I felt a little helpless in that regard.

Thus male friends, who might have been in a particularly good position to help fathers often were unavailable or felt awkward about inquiring into or responding to their needs for help. This may be especially true when help takes the emotionally-oriented form of sympathetic listening, advice, and self-disclosure. Male friends may be more able to help with chores and practical assisting and less able to raise painful issues, discuss personal feelings, and provide emotional comfort to other men. They may have their own well-socialized barriers to expressing feelings to deal with as well as the fathers' cautions. One male friend evidently was able to overcome these barriers within himself and in the man he related to, as he reported a particularly energetic and creative process of helping the father of a dying

adolescent.

I would bake bread, bring it to the house, and just shoot the breeze with the father. As our relationship grew, I invited him to go fishing and then take a week-end trip in the woods. Later he told me that these vacations and our closeness helped him deal with his feelings and cope.

Some friends set the issue of sex-role differentiation within the context of the marital couple and the family as interdependent social systems. Both parents obviously share in the distress of childhood cancer and in the emotional and practical tasks that must be performed. Within each family there may be a well-established pattern of coping and a division of labor for these tasks, as well as with regard to the management of relationships with close friends. For instance, several close friends indicated their understanding of the family/couple as a unit when it came to seeking or using help.

There were times when he (the father) would break down and cry, but this was hard on his wife.

I helped him by helping her.

Thus, some parents and friends resolved the dilemmas of sex-role differentiation by accepting these traditional roles in the midst of crisis, while others created new relationships that altered prior sex-role stereotypes and norms.

Conclusions

The data indicating how much help and support parents of children with cancer generally receive from their close friends (Table 2) suggests the importance of the role played by these friends. In addition, the qualitative analysis of parents' and friends' reports of their experiences in the helping process illuminate the dynamics of this role quite forcefully. The high degree of emotional stress associated with childhood

cancer, and the chronicity of this disease and treatment, affect parents' individual responses and coping styles, as well as the nature of their relationships with informal helpers.

The dilemmas indicated here may have potent consequences for all parties. Not only may they make it difficult for parents to seek help and for friends to provide help, but they may create added stress, as the intricacies and difficulties of the helping process exacerbate fragile feelings (e.g., emotional trauma, privacy, stigma) and cause some help to be ineffective and/or unsatisfying. Some friendships may be damaged fundamentally, or worse - terminate - as a result. Recognition of these dilemmas may aid parents seeking help and friends providing help to avoid these traps. But it is clear that each dilemma does not exist in isolation from every other, and that the issues friends face are not unconnected from those parents face. In fact, many of the dilemmas are interactive or reciprocal.

Reciprocity of helping dilemmas

The provision or receipt of help is not a unilateral process, and the interaction between helpers and helpes occurs as part of an ongoing relationship. This interactive or reciprocal characteristic of some of the dilemmas parents and friends have described are portrayed in Table 3.

 Insert Table 3 here

The reciprocal nature of dilemmas in seeking and providing help springs from the mutual concern and empathy that parents of children of cancer and their friends or helpers appear to have for one another. In its most

self-conscious and articulated form both see the mutual benefits of giving and receiving help, and both are aware of the risks or vulnerabilities involved. In Mead's terms, recognition and resolution of the reciprocal dilemmas involves taking the role of the other, in which "The taking or feeling of the attitude of the other toward yourself is what constitutes self-consciousness" (1934, p. 171). Such self-consciousness of self and others' feelings and roles is a hallmark of sustained intimate social interaction, and of a friendship that is capable of surviving time and stress.

Some scholars examining helping interactions have attempted to apply principles of exchange relationships developed by Homans (1961) and Gouldner (1960). The experiences and dilemmas reported here do not appear to conform to such exchange principles, at least helpers do not indicate any expectation of being repaid for their efforts. Their concerns more closely follow the principles of a reciprocal or altruistic relationship (Hatfield and Sprecher, 1983; Schwartz, 1977), one embedded in communal rather than exchange norms (Clark, 1983). The sincere desire to help, borne of a mutuality of caring among close friends in a crisis, appears to be the dominant theme. It is more likely that the parents of children with cancer would feel indebtedness as a function of receiving help (Gouldner, 1960). In this regard, it is possible to interpret some parents' reluctance to ask for help, and to fear alterations of their prior relationships with friends, as reflections of the concern about becoming indebted or entering an exchange form of relationship. However, there is no direct discussion of exchange norms and no clear support for such an interpretation in parents' reports. If occasional feelings of indebtedness occur for parents they did

not surface in these interviews.

This non-finding regarding indebtedness, as well as some of the positive findings regarding the reciprocal dilemmas, may be a function of the special nature of helping relations among parents of children with cancer and their close friends. Or, they may be due partly to the fact that all informants in this study are drawn from one regional medical facility. On the other hand, despite the particular population focus of this research, the dilemmas illustrated here may be quite generic and quite typical of a broader array of intimate and communal helping relations. More intensive research on this set of problems, with different populations of helpers and helpees, is in order.

Some of the results also may be limited by the small sample of parents in this study, and the even smaller sample of close friends. Fortunately, the depth and richness of the interview material, and the qualitative analysis utilized, sometimes generated findings not discernible through the quantitative analysis alone. For instance, the quantitative analysis of parental responses to questionnaire items regarding amount of support from close friends failed to indicate significant differences by gender or length of time elapsed since the diagnosis. However, the qualitative analysis of interview material regarding interactions with friends revealed the potent role of chronicity and of sex-role attributes in the provision and receipt of help. Despite these occasional confusions or contradictory tendencies, the use of both types of questions (open-ended and interviewee-generated and closed-ended and pre-structured) and both forms of analysis (qualitative and quantitative) enriches and deepens our potential understanding of the helping process. Further research that pursues some of these dilemmas and

their intricacies, through both inquiry modes, might further develop these findings into testable hypotheses, and clarify remaining confusions regarding the helping process more generally.

Implications

The importance of friendship systems for providing help and support to parents of children with cancer, and these particular dilemmas in the helping process, carry important implications for more effective personal behavior and professional practice. Parents of children with cancer, as seekers and recipients of help, can more clearly specify their needs, and the conditions under which help from friends might be most effective, as early as possible. Given the vital importance of feedback and effective cues, parents can use these tactics to extend their repertoire of effective help-seeking behaviors. The immediate family of the child with cancer may play a useful role by including friends in information sessions or family events, and in providing cues about various members' needs.

For their part, friends or helpers who understand the importance of sensitive and assertive forms of help may realize that waiting to be told what to do often is the death knell of a helpful scenario. Moreover, they may have to keep on trying, maintaining their commitment and energy over the "long-haul" of this chronic disease, and perhaps despite occasional episodes of withdrawal by the parents. At the same time, "barging in" with help that is not tuned to parents' needs and styles may be useless, or worse. Above all, it appears clear that these friends have to prepare themselves for their own potent and chronic stress.

Health care professionals, those persons invested with the social responsibility of providing services to children with cancer and their

parents, also can glean signposts from these findings. While substantial prior literature has focussed on the importance of the spouse and family system as a source of help for parents of children with cancer, these data emphasize the need to include close friends of the family. Several scholars have critiqued the ways in which professionals and professional service agencies ignore or overlook families and friends of ill adults (Froland, et al., 1981; Wortman and Dunkel-Schetter, 1979), and as Sourkes argues (1982, p. 39), "Relationships which do not fit a clear family category are often overlooked by the caregiving staff...(friends are) rarely accorded comparable recognition and support." New practice built on these findings may encourage medical staffs (and social service staffs working in medical institutions) to suggest to parents that they quickly involve their close friends in learning about the diagnosis and in establishing a system of social support. They can encourage the family to "go public" and immediately to share information and needs with close friends. They also can inquire directly into parents' relationships with close friends as a matter of routine. Just as some medical staffs are beginning to develop outreach programs in community institutions dealing with children with cancer and their families, such as schools and employing institutions, professionals also may work directly with friendship networks and potential support systems (with parental approval). Information about the child's diagnosis and prognosis, as well as treatment details and information about potential stressful situations for parents, may be shared with family friends in public sessions - either each friendship network alone or in public meetings explicitly designed for friends of the family. Some of these sessions should attend to the stresses friends face as they deal with

childhood cancer, and not assume that parents are the only actors who are in pain and need "help."

The recognition of these dilemmas, and action on them, may help parents, informal helpers and professionals improve the delivery of support and help to parents of children with cancer. Recent psychosocial research on childhood cancer discusses it as a "family disease," emphasizing the ways in which all family members are impacted by the stresses of the illness and treatment. Our findings draw attention to childhood cancer as a "community disease" emphasizing the ways in which others in the social network of the family of an ill child may be affected by this crisis. These themes can also provide direction for further research into the complex and intimate details of the real world of social support.

Table 1
 Characteristics of the Sample of
 Parents of Children With Cancer

Characteristics	Number of Parents (n=95)	Percentage of Parents (100%)
Life status and age of child at time of interview		
Under 6 years	16	17
Between 6-11 years	30	32
Over 11 years	29	30
Deceased	20	21
Nature of child's diagnosis		
Leukemias	24	25
Cancers of the central nervous system	13	14
Lymphomas	15	16
Bone cancers	9	10
Wilms' tumors	8	8
Connective tissue cancers	5	5
Other	1	1
Deceased	20	21
Sex of parent		
Male	42	44
Female	53	56
Parental level of education		
Some high school	8	8
High school graduate	22	23
Some college	26	27
College graduate	14	15
Postcollege study	15	16
No response	10	11

Table 2
 Ranking and Mean Scores of Help/Support
 Reported by Parents of Children With Cancer
 (N=84)

Source	Mean	St. Dev
Spouse	3.86	1.6
Close Friends	3.67	1.4
Nurses	3.63	1.4
Physicians	3.37	1.4
My Parents	3.36	1.6
Other Parents of Ill Children	3.02	1.5
Other Relatives	2.99	1.4
School Staff	2.92	1.6
Other Friends	2.91	1.3
My Other Children	2.91	1.6
Neighbors	2.86	1.5
Church People	2.75	1.7
Social Workers	2.21	1.5
Psychologists	1.52	1.2

Table 3
Concerns Creating Reciprocal Dilemmas in the
Helping Process for Parents of Children with
Cancer and their Friends

Source of Concern	Dilemma	Target of Concern	
		For Parents	For Friends
By Parents	1. Emotional Impact	Get more depressed Relive pain	Make them sad also Create more worry
	2. Privacy Invasion	Give up privacy Expose feelings	Ask too much of them Alter the relationship
	3. Stigma	Appear weak Mystique of the cancer label	Fear of scaring them off
	4. Utility	Will get no help Will be hurt by unhelpful help	Will be unable to help Will feel useless
	5. Gender Role	Fathers cannot easily ask for help Kinds of help available is inappropriate	Men cannot provide help very well
By Friends	1. Emotional Impact	Make them more depressed Hesitate to bring up painful topics	Feeling exhausted and distraught Concern about own children Become depressed
	2. Privacy Invasion	Invade their privacy Not know what they are ready for	Being consumed by parents' needs (and resenting it)
	3. Stigma	Not treat them as special	
	4. Utility	Desire not to hurt Not know what help they need	Feeling impotent and inadequate Desire to be more assertive
	5. Gender Role	Fathers may not be open Comfort in concentrating on mother	Males' difficulty dealing with own feelings

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