

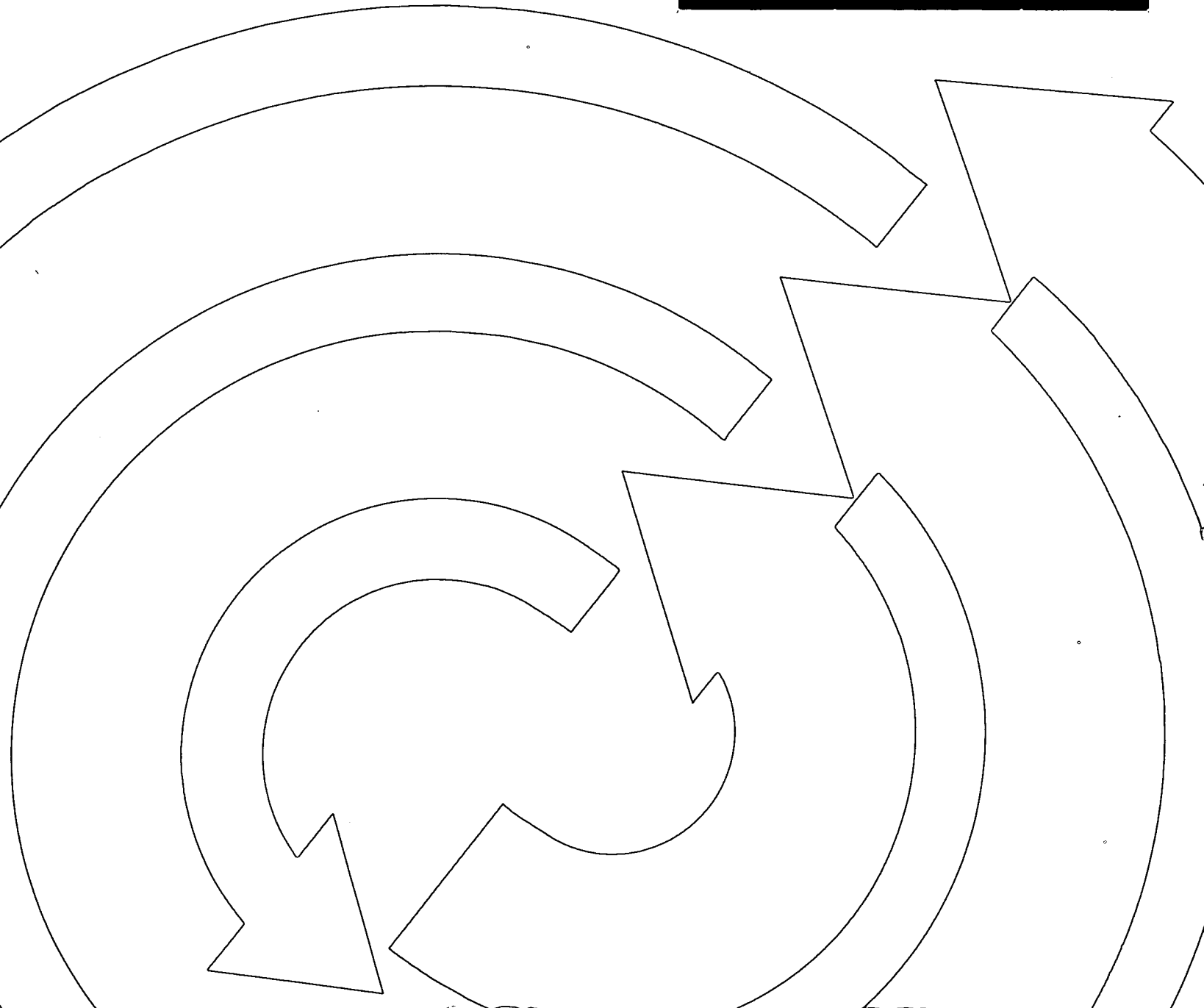
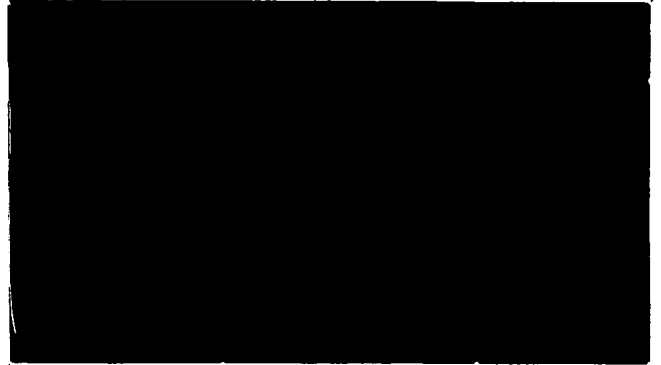


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GIVING AND RECEIVING SOCIAL SUPPORT:
A SPECIAL CHALLENGE FOR
LEUKEMIA AND LYMPHOMA PATIENTS
AND THEIR FAMILIES

by Barbara K. Chesney,
Mark A. Chesler and Mary Lou Abrigo

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April 1990

A Report to The Children's Leukemia Foundation

GIVING AND RECEIVING SOCIAL SUPPORT: A SPECIAL CHALLENGE
FOR LEUKEMIA AND LYMPHOMA PATIENTS AND THEIR FAMILIES

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GIVING AND RECEIVING SOCIAL SUPPORT: A SPECIAL CHALLENGE FOR LEUKEMIA AND LYMPHOMA PATIENTS AND THEIR FAMILIES

I. INTRODUCTION

Patients dealing with cancer face not only the potential of death, but also the immediate stresses and hardships of a chronic and serious illness. Cancer has been labelled "a family disease," for it invades not only the patient's life, but the lives of all those close to him or her. As Cassileth and Hamilton (1979) note: "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." Family members often "must be viewed as second-order patients in their own right" (Rait and Lederberg, 1989). Parents, spouses, siblings, and other family members join in a battle to fight cancer, helping and supporting their ill relative and each other. In much the same fashion as a patient's immune system struggles against the intrusion of threatening cells, "the patient's family rushes to the defense. But what starts out as a natural and healthy response to a crisis often turns into an endless emotional whirlpool that sucks the life out of the family" (Gruson, 1988). Just as cancer patients need all the support they can get, their family members, struggling with the demands of the illness, need assistance and added resources.

Major sources of support for family members experiencing cancer come from relatives, friends and neighbors, and members of specialized medical or community agencies. Relevant types of support include love and affection, help in dealing with emotions, practical assistance, attention to family concerns, and aid in gaining access to appropriate treatment and facilities. As researchers and clinicians focus increasingly on psychosocial adjustment in coping with cancer, social support has risen to the forefront as a key resource for alleviating the stressful impact of illness.

Most studies and service efforts dealing with psychosocial supports have focused on programs for children with cancer and their parents, and occasionally for adult patients. Few services are generally available for adult spouse/partners. Moreover, little research has identified the unique needs of this population, and little work has compared the support needed by young or older patients, their parents, and their spouse/partners.

The voices of patients diagnosed with leukemias/lymphomas and their family members are the most crucial element in any effort to determine their special support needs and experiences. This report focuses on those very voices -- the responses of young adult patients, adult patients, parents, and spouses in families impacted by cancer. It addresses the dynamics of giving and receiving social support, specifically from the standpoint of sources and types of support identified by patients and their families. It also explores the demographic backgrounds, reported life changes, and individual coping strategies associated with differential access to sources and types of support.

II. THE STUDY OF SOCIAL SUPPORT

Types and sources of social support are important foci of any assessment of the psychosocial needs of families facing cancer. This is evident both from an examination of key literatures and of the experiences patients and families themselves relate. To date, few comparative analyses of the experiences of patients and significant others, or of parents and partners of cancer patients, have been reported. With the goal of filling both theoretical and practical gaps in the literature and in psycho-social care delivery, we first develop a working definition of social support, and then construct a framework for this analysis from the current research literature. We pay special attention to the problems of giving and receiving social support, as well as to the special dynamics of social support for cancer patients and their family members.

Social Support: A Working Definition

There is an ongoing debate in the research and practice literature regarding the conceptualization, measurement, and effects of social support. Researchers provide various definitions of social support (DiMatteo & Hays, 1981; Gottlieb, 1983; House, 1981). Because research on social support is primarily a product of the past decade, it is understandable that uniform conceptualization has not yet been accomplished. With time, and as scholarly methods and theories improve, one can expect to see more consensus among scientists.

Caplan (1979) defines social support as "any input, directly provided by an individual (or group), which moves the receiver of that input towards goals which the receiver desires." He provides a two-dimensional construct for social support, with objective-subjective and tangible-psychological dimensions. Objective support refers to the actual provision of aid, while subjective support involves the recipient's belief or acknowledgement that aid has been provided. Tangible support concentrates on material or physical resources, while psychological support focuses on feelings, emotions, and values.

For example, objective-tangible support refers to "behavior directed toward providing the person with tangible resources that are hypothetically to benefit his or her mental or physical well-being" (Caplan, 1979). Objective-psychological support is defined as "behavior directed toward providing a person with cognitions (values, attitudes, beliefs, and perceptions) and toward inducing affective states that are hypothetically to promote well-being" (Caplan, 1979). Subjective-tangible support refers to a person's feeling (and report) that she/he has received help with practical matters such as financial assistance, childcare and household chores, and transportation. Subjective-psychological support includes the feeling of receiving emotional and informational assistance, and being helped to feel affirmed, listened to, esteemed, and in intimate contact with caring others. Objective support generally is determined by an outsider, and subjective support is measured through self-report.

We employ Caplan's notion of subjective social support in this project for several reasons. Individuals' perceptions of the subjective quality of their social networks, rather than the objective

characteristics of these networks, are most likely to be related to reported well-being (Israel & Rounds, 1987; Wethington & Kessler, 1986). Moreover, differences in background, personality, perceptions, and interpersonal behaviors are likely to affect a person's access to a support network and their responsiveness to or utilization of any assistance that is offered. For instance, House (1981) views social support as "effective only to the extent that it is perceived," and as such also favors such a subjectively-oriented definition. Both tangible and psychological forms of subjective social support are studied in this project.

In addition to the various types of social support received by patients and their family members, the scientific literature also highlights the importance of different sources of support. For instance, for patients with health problems, there is a variety of formal (professional) support systems that may be responsive and helpful. These include doctors and nurses, social workers and psychologists, and other members of the health care or social service staffs of the medical system or of community agencies. These formal sources of support are specialized and expert in nature, and they may or may not be able to respond to the unique circumstances and personality of each patient or family member in need. In addition, almost every member of a human community also has access to informal ("natural" or lay) sources of support: family members, friends and neighbors, co-workers and school companions, and perhaps even fellow patients. These informal sources of support are part of the fabric of everyday life, and they may or may not know how to be helpful in the particular circumstances of a serious health crisis. Some people (patients and their family members) have ready access to both formal and informal sources of support, while some have very limited access to either set of sources. Obviously, neither of these sources can deliver useful help unless they are accessible and available to people in need, and unless people receive the particular types of help that they desire.

While some controversy remains in the literature, there is substantial evidence of a key role for social support in the maintenance of health and well-being, as well as in the potential reduction of morbidity and mortality (Dunkel-Schetter, 1984). Social support can enhance individual coping strategies by directly affecting stressors, can indirectly buffer the effects of

stress on illness, and may directly impact a person's immunological and psychological defenses (Pilisuk & Minkler, 1985). Social support can be effective not only during stressful periods (Dunkel-Schetter, 1984), but also during recovery and coping (DiMatteo & Hays, 1981), and during periods of long-term adjustment (Dunkel-Schetter et al., 1987).

Giving and Receiving Social Support: Promises and Problems

Conflicting reactions toward help-seeking behavior exist in our society. Famed American literary theorists such as Emerson and Thoreau committed themselves to self-reliance, viewing dependency as a threat to freedom (Merton et al., 1983). Today even "our media cultivates the image, for women as well as for men, of the lone hero" (Pilisuk & Parks, 1983). These desires for self-control and for avoiding feelings of helplessness aid us in explaining negative attitudes toward help-seeking. In an atmosphere of negativism toward help-seeking and dependency, one may not be able to pursue aid without endangering his or her personal esteem and social status (Brickman et al., 1983). Consequently, very legitimate needs for assistance, even in times of crisis, may be ignored, avoided, and stifled.

There are similar constraints on the process of giving help to people who may be "in need." The notion that one gets what one deserves, grounded in a belief in a "just world," suggests that victims of tragedy or illness may even be "blamed" for their fate (Brickman et al., 1983). Such beliefs may be used by some as a conscious or unconscious rationale for not providing help or support. Others may fail to provide help if they do not expect a successful outcome, or if they think that offering help will intrude on others' privacy or compromise others' feelings of independence and competence (Chesler & Barbarin, 1984; Pearlin, 1985). Still others may be discouraged from helping by the time and energy involved (Nadler, 1983).

In some circumstances, we expect that favors given should be accompanied by favors returned (Froland et al., 1981), and that exchanges involving both giving and receiving may be necessary to ensure mutual satisfaction and lasting relationships (Clark, 1983). Then, recipients of help may feel indebted, and providers may feel that they are owed. This conscious or

unconscious set of assumptions may create distress and negative attitudes toward giving or receiving aid (Fisher et al., 1983; Greenberg & Westcott, 1983). After all, a person (or family) in need, often a victim of an accident or disease, may be unable to return such favors and aid. Fortunately, some relationships with family, friends, and significant others are communal, intimate, and altruistic in nature, and may encourage people to give and receive help without regard to obligations to return these gifts (Clark, 1983).

Cancer and Social Support

Cancer is a disease that invades not only one's body, but one's entire life. "Cancer arouses fear and feelings of vulnerability" (Dunkel-Schetter & Wortman, 1982), as one faces uncertainty, fear of pain, relapse, dependency, and possible death. But fear strikes the hearts of the healthy as well as the sick -- especially members of both the formal and informal social networks of persons diagnosed with cancer. Feelings of rejection and isolation, and of disempowerment and loss of control, are quite common. Under these circumstances, the need to feel connected with, close to, and supported by other people is paramount.

At the same time, however, several myths promote misunderstanding and negative feelings toward cancer. The public expresses fear of developing the disease, and harbors misconceptions about catching cancer and dying from it. Many believe that cancer is contagious, and most people generally overestimate cancer-related mortality rates. For example, the public believes that 1 in 5 cancer patients survive the disease, when, in fact, 1 in 3 do so (Dunkel-Schetter & Wortman, 1982). Such myths and fears can inhibit the solicitation, delivery, and reception of social support, and even of treatment itself.

The treatment of cancer may require intense and long-term therapy, and the support of others is a crucial element in the quality of life of patients and their families. Its very long-term character, however, may make it more difficult to continue to ask for or to provide ongoing assistance. Moreover, the specific dynamics of social support and chronic illness remain mysterious. While it is well known that support positively affects cancer patients' well-being and

long-term emotional adjustment (Dunkel-Schetter & Wortman, 1982; Rowland, 1989), details of the strategies and effects of social support in different kinds of families have been slow to emerge.

Social support in general has been found to be positively related to coping behaviors and psychosocial adjustment for parents of chronically ill children (Broadhead et al., 1983), and specifically for parents of children with cancer (Barbarin, 1987; Chesler & Barbarin, 1987; Krulik & Florian, 1986; Morrow et al., 1984). We can expect that it has positive effects for adult patients and partners as well (Bloom, 1982; Dunkel-Schetter, 1984; Goldberg & Tull, 1983; Jamison et al., 1978; Peters-Golden, 1982; Taylor, 1983; Wellisch et al., 1978; Wortman & Dunkel-Schetter, 1979). Rowland emphasizes the supportive role of those closest to the patient: "The next of kin or closest person to the patient is frequently cited as a critical figure in adjustment" (1989). Goldberg & Tull (1983) specify some of the critical roles that "significant key others" can play in aiding adults with cancer: promoting patients' autonomy, facilitating patients' expression of feelings, advocating for patients vis-a-vis the medical system, keeping open lines of communication between the patient and family members and friends, and maintaining other existing but harried or strained social support systems (e.g., with co-workers, neighbors, employers, church congregations, etc.).

One of the major debates in the literature and practice of social support for people with cancer involves the appropriate roles of formal and professional helping systems (psychologists, social workers, etc.) and informal or lay networks (family, friends, mutual support groups, etc.). For instance, most people and families experiencing cancer generally do not require psychotherapy or "deep emotional" counselling. However, since they are experiencing major trauma and stress, they often require supportive counselling. Moreover, much of what recently diagnosed individuals and families need is information and advice about the fateful experiences that they themselves are only anticipating. In these circumstances, veteran patients and their significant others may be better informed, more sensitive, and more timely helpers than are formally trained but experientially distant professionals. This is not to say that formal counselling is not helpful, or necessarily less helpful, than informal sources of support, but that the two are different sources,

with different resources and styles, often serving different needs. For many people with cancer and their family members, both are useful and appreciated. Thus, it makes sense that individuals should report the need for counselling in the form of support from others in similar situations -- counselling in the experiential sense (Morrow et al., 1982; Stein, 1986) -- as well as counselling in the traditional, professional sense (Lawther et al., 1989).

In this study, members of families of people with cancer rate the help they receive from various professional and lay sources. An exploration of their backgrounds permits us to determine whether such factors as age and gender and income influence the amount of help they receive. Informants also identify the types of support and help that most often result in positive life changes, such as new or renewed outlooks and competencies. This, after all, is the long-term goal of all efforts at social support and help.

III. METHODS AND MEASUREMENT

The data referred to in this report were obtained as part of a multi-method needs assessment project commissioned by the Children's Leukemia Foundation of Michigan. It was designed to target both younger and older leukemia and lymphoma patients and their parents and spouse/partners. Foundation registrant files and clinical files of non-registrants were sampled. Mailed questionnaires and telephone follow-up techniques were used, as well as a small set of in-person group interviews with interested informants in several regions across the state of Michigan. The study response rates varied from 62.4% for parents of younger patients, to 40.2% for spouse/partners of adult patients; the overall response rate was 53.8% (418 final questionnaire responses). Additional details on these issues and techniques are available in the final technical report of the needs assessment project (Chesler & Chesney, 1989). As indicated in that report, the study contains many more parents than young adult patients, adult patients, or parents/spouses of adult patients. That occurs because the parent population includes parents of

young patients under the age of 14 as well as parents of young adult patients over 14 years of age. The young adult patient population is limited to people over the age of 14 (and under 25).

Measures and Indices

Using individual items from the questionnaire, indices of key variables were developed. For example, the focus of this analysis lies in the use of measures constructed to tap various dimensions of social support. As the Appendix indicates, nine indices of social support were used to represent types of support -- emotional support, family assistance, instrumental help, empowerment, and treatment help -- and sources of support -- extended family, friends, work associates, medical professionals. In addition, two overarching indices were designed to measure the total amount of perceived support of all types and from all sources of support. Individual-item measures tapped other types and sources of support.

Some individual items and indices also were created to assess the worries expressed most potently by young and older patients, parents, and spouse/partners: concerns about the patient's future, about one's personal health, about finances, and about one's relationship with the medical staff. Finally, indices were constructed to measure informants' reports of life changes over the course of diagnosis and illness. The relevant coefficients of internal reliability, using Cronbach's alpha (Cronbach & Meehl, 1955), are listed for each index in the Appendix.

Demographic and Medical Data on the Four Study Populations

Table 1 presents basic demographic and medical status data for each of the four study populations -- young adult patients, parents of young patients, adult patients, and partners of adult patients -- and indicates via the F-test statistic which populations differ significantly from one another on a given demographic measure. As one would expect, the four populations differ significantly in age, due primarily to an average age of 18 for young adult patients compared to an average age of 52-53 for both adult patients and partners. Table 1 also indicates that the most wealthy and highly-educated families are those of children with cancer and their parents, probably

Table 1: Background Characteristics by Population Group

Demographics	Young Adult Patients (n=88)	Parents (n=161)	Adult Patients (n=91)	Partners/ Spouses (n=78)	
Age (mean years)	17.5	40.8	52.3	53.1	*
Gender %					
Female	47	88	52	64	*
Male	53	12	48	36	*
Family Income (mean)	\$32,000	\$30,000	\$21,000	\$24,000	*
Education (mean years)	9.8	13.6	11	12.8	*
Treatment %					
Off Therapy	43	53	38	32	*
Cured	32	23	15	12	*
Diagnosis %					
Leukemia	67	76	40	40	*
Lymphoma	33	24	60	60	
Years Since Diagnosis (mean)	8	7	6	NA	

* Statistically significant difference in means at the .05 level (using an F-test in a one-way ANOVA). ANOVA and F-tests are analytic techniques used to test whether the differences are large enough to be statistically significant (not-chance): the asterisk indicates that we can be confident that 95% of the time the differences shown in these rows represent true differences among the groups, and did not occur by chance.

a result of these parents' younger age and increased access to education in younger populations (although the young adults themselves -- many still in school -- have the lowest mean years of education). Clearly, the adult patient and partner populations contain a fair portion of retired or reduced-income earners. Parents included in the study are, like partners, primarily female. This finding is no doubt a reflection of the predominantly-female caregiver and informant role. On most background dimensions, adult patients and partners are quite similar; no significant differences exist in terms of age, gender, or income. However, the adult patient and partner populations differ significantly in attained educational level; partners are significantly more educated than are the adult patients.

Table 1 also indicates that the four study populations differ significantly in terms of their relative proportions off therapy. Moreover, nearly one-third of the young adult patients, as compared to 15% of the adult patients, report themselves as "cured"; comparable reports by their family members are slightly lower but still show the distinction between younger and older patients. To be sure, leukemias and lymphomas require different treatment strategies in childhood and adult populations, and demonstrate quite different rates of medical success (Gee et al., 1976; Goldberg & Tull, 1983; Holland & Rowland, 1983). They are more often "curable diseases" (60-90%) in childhood/adolescent patients than in adult patients. In keeping with national comparison data, it is clear that the leukemias are somewhat more common in the younger group of patients, while the lymphomas are more common among the older patients. The number of years that have elapsed since diagnosis is not significantly different for each of the four populations.

IV. TYPES AND SOURCES OF SOCIAL SUPPORT

In this section we examine differences and similarities in reported types and sources of social support received by the four study populations. Table 2 presents data on types and sources of social support for the four populations.

Table 2: Types and Sources of Support Received, by Population Group

Types of Support	Young Adult Patients (n=88)	Parents (n=161)	Adult Patients (n=91)	Partners/ Spouses (n=78)	
Emotional Support		2.86	2.81	2.32	*
Family Assistance		1.91	2.29	1.76	*
Practical Help		2.22	2.23	1.76	*
Help Getting Treatment		3.14	2.89	2.35	*
Help in Taking Action		2.12	2.26	1.79	*
Financial Aid		2.69	2.44	2.02	*
Total Types		2.49	2.57	2.08	*
<hr/>					
Sources of Support					
Formal Sources					
Medical Professionals	3.56	3.60	3.47	3.18	*
Social Worker	2.09	2.35	1.71	1.67	*
CLF Representative	1.69	1.81	1.68	1.49	
Informal Sources					
Spouse/Partner	1.29	3.33	3.34	3.26	*
Parents	3.78	2.98	2.50	2.52	*
Close Friends	3.02	3.31	2.93	3.06	*
Co-workers/Classmates	2.10	2.37	1.92	1.91	*
Church Leader	2.19	2.50	2.33	2.32	
Others in a Similar Situation	2.31	2.47	1.84	1.66	*
Total Sources	3.61	3.84	3.58	3.54	*

* Statistically significant difference in means at the .05 level (using an F-test in an one-way ANOVA). ANOVA and F-tests are analytic techniques used to test whether the differences are large enough to be statistically significant (not-chance): the asterisk indicates that we can be confident that 95% of the time the differences shown in these rows represent true differences among the groups, and did not occur by chance.

Types of Support

Types of social support reported as received by each population are presented in Table 2 for all but the young adult patients (these questions were not asked of them). The three populations differ significantly in their report of each type of social support. Partners receive the least amount of each type of support, and the lowest level of the total of all types. This general trend can be illustrated by comments some spouses made about the help they did or did not receive from the medical and psychosocial treatment staff. Several spouses expressed the view, in interviews, that to the extent psychosocial services were available, they were not provided to patients' family members. In expressing this view they gave vent to their own unmet needs and to the stressful impact of cancer on everyone in the family.

I said we were so pleased with our treatment and everything, but I felt like the professional people did not let me in on what was going on. They talked to the patient, but they deal with the patient not with the spouse.

My medical doctor, who handled the program, said the doctors nowadays deal with the patient not with the family and spouse.

One night the nurse who was very close to my husband asked me if I wanted to stay the night, and I said no, I had no intentions to. So I went on home and when I got home he called me and told me they had put him in another room down by the nurses so they could keep a better eye on him. Then I came to find out later they'd thought they were going to take him down to ICU that night but nothing was said to me.

Confusion about their own needs, and how to express them, affected partners' relations with a wide range of potential helpers. As a result, partners may be less likely to seek information and ask for assistance; others may overlook them or find it harder to identify their needs and reach out to them.

Parents receive the most emotional support, help in getting treatment, and help with medical bills and expenses. Adult patients receive the most family assistance, practical help, and help in taking action on their concerns. Thus, parents receive the most help related directly to the illness, while adult patients seem to gain greatest support for solving family and lifestyle problems. The advocacy and protective stance inherent in being the parent of a young patient

may explain why help-seeking and perceived support are more common for parents than for partners of relatively self-sufficient adult patients.

One of the most interesting findings relates to the ranking of types of help received by all three populations. Treatment help, emotional support, and help with medical expenses, respectively, are the most commonly reported types of help provided to all three populations. While parents, adult patients, and partners receive different amounts of support, they all agree on the ranking of types of help they receive most often.

Sources of Support

Comparisons of sources of support reported by all four populations also are provided in Table 2. Significant differences exist between the four populations for almost every source of support except church leaders and CLF representatives.

Parents report that close friends, co-workers, medical professionals, social workers, and others in a similar situation are more helpful to them than these sources are to any of the other three populations. Parents may have greater access to these helpful sources because they are younger and are more involved in work and community settings. With the exception of close friends, partners find all these same sources less helpful than do any of the other populations.

In the interviews, parents note how some of their friends were very helpful. In addition, every once in a while a stranger appeared to do something extraordinarily friendly. Consider the following parents' comments about friends and strangers.

As far as going to the hospital and my support system it was my friend, Sally. She still goes. I'll say, "Sally, this appointment is next week," and she says, "Oh, I'll see if I can get off work... if I don't have to work." She goes right in there, boy, when my son's checked she's going to know everything that's going on.

Right after my daughter was diagnosed my mom and she were at a large department store shopping. I mean the child was the best dressed kid in the world! And she sat down because she was emotionally exhausted and this woman came up to her, this saleslady, and she said, "Can we help you? Are you all right?" And she started talking about it and this lady who she'd never seen said, "Give this to her." And it was a St. Christopher medal. And she wore that the entire time she was in the hospital on a little chain and she wouldn't take it off. The last day when she was getting ready to be discharged and they had to do her chest x-ray to make sure she could leave and that everything was OK she lost that necklace. It

disappeared and we searched the whole area and could never find it again. So that's kind of a friend story.

Parents are reported to be more helpful by the young adult patients than by any other population, and spouse/partners are reported as more helpful by the adult patients than by any of the other three populations. Thus, older patients rely more on their spouses for support, while younger ones look to their parents for support -- a logical pattern. Some adult patients expressed the nature of the support they received from their spouses as follows:

My wife would go with me to any check-ups I had. She was in the hospital, about every other day on the average, and if she was not clear about something, she'd talk about it.

I was really lucky. My husband never stopped touching me. He'd give me a hug or he'd come in and rub my feet or something when I couldn't get out of bed.

Even though young adult patients report receiving a great deal of help from their parents, some found themselves quite concerned about their parents' emotional health. Some sought to support their parents; others tried to protect their parents from further distress.

My parents didn't really pity me, but they tried to understand. I think that it hurts them just as much as it hurts you. Sometimes you know if you're not doing well, but you hide it so that they'll still encourage you and themselves. You try to keep them from worrying, keep it all right.

The first time I ever saw my dad cry was after the diagnosis. And so I tried at the beginning to be upbeat and happy, to make them feel that everything was going to be all right. But after a while I just couldn't go on with it anymore. Now I let them know. I feel guilty because I must be so difficult to live with sometimes.

The two patient populations (young adult and adult) do not differ in their reports of support from friends, and from co-workers or classmates. And in terms of medically-relevant sources, only social workers and others in a similar situation significantly differentiate younger and older patients; younger patients report more support from both sources. The ideology and organization of care in children's hospitals and clinics generally pay more attention to psychosocial issues and make social worker resources and groups of peer-patients more accessible to these adolescents and young adults.

Some informal network sources of support also are significantly different for the parent and young adult populations. Parents report more support from close friends, perhaps indicating

yet another resource that the combination of age and life roles might produce. Younger patients, predictably, report more support from their own parents than does the parent population -- evidence of the key supporting roles of parents in the lives of these young adults.

These reports about various sources of support do not reveal adult patients and partners to have significantly different experiences (with the exception of help from medical professionals). On the other hand, they do report receiving significantly different amounts of all types of support; partners consistently report receiving less of every type. Thus, while adults may seek and receive help from basically the same sources, regardless of their patient or significant other status, the frequency and intensity of the types of help they receive appear to differ according to whether they are patients or the partners of patients.

V. THE RELATIONSHIP BETWEEN SOCIAL SUPPORT AND SOCIAL AND MEDICAL BACKGROUND

In this section we examine the relationships between types and sources of support reported by informants and various aspects of their backgrounds. Included in analyses of social backgrounds are factors such as gender, age, and income. Medical background factors include treatment status, adoption of an active role in the caregiving process, and registration with CLF.

Gender

Table 3 indicates that gender often has an effect on types and sources of support received by all four populations, although the effects are not always statistically significant. For instance, women constantly report receiving more of various types of social support than do men. This is true for female parents -- mothers -- who receive significantly more emotional support and practical help than do fathers. It is true of female partners/wives -- who report receiving significantly more assistance with transportation (and more emotional support) than do male partners/husbands. With regard to sources of support, female parents report receiving

Table 3: Types and Sources of Help by Gender, Within Populations

Types of Help	Young Adult Patients (n=88)		Parents (n=163)		Adult Patients (n=92)		Partners (n=76)	
	Male (n=46)	Female (n=41)	Male (n=20)	Female (n=141)	Male (n=44)	Female (n=47)	Male (n=26)	Female (n=46)
Emotional Support			2.40	2.91*	2.80	2.82	2.01	2.56
Family Assistance			1.53	1.95	2.13	2.42	1.76	1.73
Practical Help			1.75	2.28*	2.19	2.25	1.60	1.88
Help with Treatment			2.93	3.16	2.80	2.96	2.24	2.49
Transportation Assistance			1.80	1.94	2.32	2.38	1.46	2.05*
Financial Assistance			2.35	2.76	2.42	2.45	2.00	2.06
Sources of Help								
Informal Network								
Spouse	1.27	1.24	3.70	3.28	3.57	3.10*	3.70	3.05*
Other Children	3.78	3.77	2.15	2.88*	3.08	2.98	2.73	3.27
Extended Family	2.57	3.33*	2.75	2.84	2.44	2.55	2.39	2.49
Friends	2.84	3.24	2.55	3.14*	2.49	2.72	2.57	2.86
Formal Network								
Work Associates	1.93	2.31	2.60	2.43	2.15	1.69	2.50	2.00
Medical Professionals	3.44	3.72	3.35	3.64	3.60	3.35	3.00	3.30
Social Worker	1.93	2.26	2.25	2.38	1.79	1.63	1.65	1.63
Church Leaders	2.09	2.28	1.95	2.57*	2.44	2.23	1.95	2.57*
Others in a								
Similar Situation	2.25	2.38	2.40	2.46	1.74	1.93	1.43	1.83
CLF Representative	1.62	1.78	1.80	1.80	1.60	1.76	1.48	1.51

* Statistically significant difference in means at the .05 level (using an F-test in an one-way ANOVA). ANOVA and F-tests are analytic techniques used to test whether the differences are large enough to be statistically significant (not-chance): the asterisk indicates that we can be confident that 95% of the time the differences shown in these rows represent true differences among the groups, and did not occur by chance.

significantly more support from family members, friends, and church leaders than do male parents. Female partners also report receiving significantly more help from church leaders and from their children than do male partners. And female young adult patients report receiving significantly more support from their extended family (and from friends and medical professionals) than do male young adult patients.

The only exceptions to this set of findings are two other consistent findings: males consistently receive more support from their female spouse/partners than females report receiving from their spouse/partners; and males consistently report receiving more help from co-workers than do females (although this last finding is statistically significant only for adult patients).

Why do these patterns occur? The finding that females generally receive more help than do males, regardless of patient or family member category, has been reported in several other studies. It appears that women are more likely to publicly indicate their need for assistance, and are more willing to announce that they need help, than are men (Vaux, 1985). The male ("macho") image of self-reliance and independence evidently mitigates against asking others for help, or indicating needs for support. In addition, people in general are more likely to see women as needing assistance; as the allegedly weaker gender, they are expected to need help in dealing with difficult life circumstances. Thus, from the vantage point of both the seeker and the giver of help, we can expect females to receive more assistance than males. This is not to suggest that women actually need more help and support, but that they are more likely to indicate such a need and that others are more likely to perceive them as needy or deserving.

The reversal, the situation wherein female parents, patients, and partners report receiving less help from their spouses than do male parents, partners, and patients, probably reflects the general tendency for women to be primary caregivers in this society. Women are more accustomed to giving help and support to others, especially to their spouses and children. In turn, men are less likely (and perhaps less able) to provide such support to their wives and children.

Age

Age evidently is not as substantial a factor in determining amounts of support received as is gender, but some interesting findings do occur. In all three populations queried (parents, partners, and adult patients), younger informants consistently report receiving more help and support of various kinds. For instance, younger parents especially report receiving more practical help and financial assistance than do older parents. This finding may be a result of the greater need of younger families, their lesser financial status, and the special sense of tragedy and sympathy generated by cancer in very young children. In addition, younger adult patients report receiving more family assistance and financial aid than do older adult patients. Perhaps this reflects their greater need as well, or the greater availability of services for people at this stage of their lives (and the corollary diminution of services for older and/or retired people).

The younger people in all populations report more support from their extended family members, probably because their parents and siblings are still alive and available to help. On the other hand, older parents, patients, and partners consistently report receiving more support from their other children; these children probably are old enough and well-enough established to know how to provide support and to be able to provide it.

Income

There are few significant results in Table 4, suggesting that income levels are not generally associated with the receipt of social support. However, Table 4 does indicate that parents with lower income levels report receiving more financial assistance and more support from the social worker and the CLF representative. Social workers generally are the major link for contact with agencies that provide financial assistance to people in greatest need. CLF is one of the primary agencies providing just such assistance. Therefore, the connection between social worker, CLF representative, and financial assistance appears to work well for some families with lower incomes.

Table 4: Types and Sources of Help by Income, Within Adult Patient and Parent Populations

Types of Help	Adult Patients (n=92)			Parents (n=163)		
	Low (n=44)	Medium (n=28)	High (n=12)	Low (n=44)	Medium (n=63)	High (n=49)
Emotional Support	2.61	2.73	3.40*	2.78	2.84	2.89
Family Assistance	2.19	2.26	2.67	1.67	2.05	1.91
Practical Help	2.05	2.18	2.50	2.39	2.21	2.11
Help with Treatment	2.59	3.04	3.17	3.05	3.21	3.10
Transportation Assistance	2.48	2.14	2.36	2.07	1.84	1.92
Financial Assistance	2.34	2.38	2.73	3.03	2.74	2.38*
Sources of Help						
Informal Network						
Spouse	2.97	3.54	3.82*	2.71	3.59	3.43*
Other Children	3.00	2.83	3.17	2.46	2.95	2.81
Extended Family	2.45	2.65	2.27	2.86	2.98	2.63
Friends	2.66	2.50	2.33	3.02	3.08	3.14
Formal Network						
Work Associates	1.59	2.08	2.45	2.18	2.62	2.62
Medical Professionals	3.35	3.43	3.75	3.67	3.68	3.43
Social Worker	1.78	1.59	1.67	3.00	2.14	2.02*
Church Leaders	2.30	2.22	2.42	2.43	2.49	2.50
Others in a						
Similar Situation	1.79	1.85	2.09	2.37	2.59	2.38
CLF Representative	1.66	1.58	1.75	2.14	1.87	1.47*

* Statistically significant difference in means at the .05 level (using an F-test in an one-way ANOVA). ANOVA and F-tests are analytic techniques used to test whether the differences are large enough to be statistically significant (not-chance): the asterisk indicates that we can be confident that 95% of the time the differences shown in these rows represent true differences among the groups, and did not occur by chance.

On the other hand, Table 4 also indicates that people in families with lower income levels report receiving less support from their spouses than do people in families with higher income levels. Similarly, adult patients from families with lower incomes report receiving less emotional support in general. It appears that adult patients with higher income levels can get important kinds of help and support from their spouses and co-workers. Although the results are not statistically significant, several other types of help (family assistance, practical help, help with treatment, and help from others in a similar situation) also appear to be more available to adult patients with higher incomes.

One interesting aspect of Table 4 is that income levels do appear to be associated with different amounts of several types of support for adult patients (wealthier people receiving more), but not for parents of young patients. This suggests that the rarity and "special tragedy" of having a child diagnosed with cancer may be so compelling that the provision of support cuts across class and status lines. For adult patients, however, dealing with an illness that has become rather common, social support does appear to be affected by traditional class and status positions.

Treatment Status

The results indicate that when patients are on treatment they and their family members report receiving more support than when they are off treatment. This pattern partially reflects the different need for social support that may exist for families more newly diagnosed, undergoing more extensive treatments, or still in a crisis situation. It may also reflect their greater contact with the treatment center and service providing agencies. People who appear to be past a point of obvious crisis in their lives may lack such access, or may encounter in others an inability or unwillingness to continue to provide support. The need for support remains after treatment has ceased, but that does not mean that it will be provided.

Active Role in Care

The overwhelming majority of parents (95%) indicate that they played an active role in the medical care of their child. Even though this population is heavily skewed in the direction of an active role, the comparisons of active and non-active parents in Table 5 reveal that parents playing an active role report receiving more help and support of every kind, from many different sources.

In the partner population there is not as great a tendency to adopt an active role in care (77%). Nevertheless, Table 5 indicates that partners who are more active in the medical care process also consistently report receiving more support.

It would appear that people who are active in the caregiving process are more likely to announce their needs for help, to actively seek the kinds of assistance they need to care for their loved one, and thus to receive more support. In addition, actively involved parents and partners are more likely to have sustained contact with members of the medical care system, and with their extended family and friendship networks, thereby entering into a continuing cycle of contact and support.

Registration with CLF

People who are registered with CLF consistently report receiving more help from CLF representatives. This "common sense" finding points to an important underlying principle: people who do not receive assistance from CLF fail to do so because they have not been contacted, not because CLF fails to deliver aid to those it has contacted. Thus, new program efforts by the Foundation may not need to focus as much on service improvement as on expansion of the CLF network to make contact with more patients and family members.

Table 5: Types and Sources of Help by Active Role in Treatment,
Within Parent and Partner Populations

Types of Help	Parents (n=160)		Partners (n=69)	
	Active (n=152)	Not Active (n=8)	Active (n=53)	Not Active (n=16)
Emotional Support	2.90	2.29	2.53	1.79*
Family Assistance	1.93	1.50	1.84	1.66
Practical Help	2.26	1.30*	1.90	1.46
Help with Treatment	3.18	2.38*	2.45	2.18
Sources of Help				
Informal Network				
Spouse	3.31	3.71	3.18	3.57
Other Children	2.78	3.00	3.00	2.75
Extended Family	2.86	2.43	2.49	2.58
Friends	3.12	2.29*	2.83	2.29
Formal Network				
Work Associates	2.48	2.40	2.13	2.33
Medical Professionals	3.63	3.29	3.42	2.33*
Social Worker	2.38	2.00	1.89	1.15*

* Statistically significant difference in means at the .05 level (using an F-test in an one-way ANOVA). ANOVA and F-tests are analytic techniques used to test whether the differences are large enough to be statistically significant (not-chance): the asterisk indicates that we can be confident that 95% of the time the differences shown in these rows represent true differences among the groups, and did not occur by chance.

VI. THE RELATIONSHIP BETWEEN SOCIAL SUPPORT AND LIFE CHANGES/OUTCOMES

One way we can assess the impact of the cancer experience is to ask people about the extent to which their lives have changed over time. Some people adjust to the stresses and threats of cancer by making positive changes in their lives. Others are barely able to maintain a consistent quality of life; and still others feel their lives have changed for the worse. In this section we examine the relationships between a variety of reported life changes or long-term psychosocial outcomes and various types and sources of social support. The data are presented in Tables 6 and 7 in the form of coefficients of correlation.

Parents

Table 6 demonstrates many positive and significant relationships between parents' reports of social support and their life changes or psychosocial outcomes. Consistently, those parents who report receiving more support also report more positive changes in their lives. Indices of life outcomes measuring adjustment, social relationships, and physical health are correlated significantly with the greatest number of types and sources of social support. Emotional support and help in taking action are the types of support most significantly related to these life outcomes, while help from other children and work associates are the most significantly related sources of support. This does not mean that medical professionals, spouses, and other sources are not helpful, but that their help is not necessarily associated with positive life changes.

Since these data reflect correlations or associations, rather than causation, the findings may be interpreted in several different ways. For instance, it is possible that the receipt of support causes people to find and discover those resources that help them change their lives for the better. On the other hand, it also is possible that those people who are able to make positive changes in their lives are more likely to have the energy to reach out and gather more support, or to be seen as receptive by family members and friends who can support them. It is also possible that a third factor, such as general coping style and demeanor, can affect both support and life changes in ways we do not yet understand. Although any and all of these explanations are

Table 6: Correlations Between Life Outcomes and Social Support Received
by Parents of Children With Cancer

<u>Support</u>	Life Outcomes (n=155)				
	<u>Adjustment</u>	<u>Activism</u>	<u>Social Relationships</u>	<u>Physical Health</u>	<u>Concern for Others</u>
<u>Types of Support</u>					
Emotional Support	.18*	.13*	.24*	.21*	.15*
Family Assistance	.13	-.02	.20*	.13*	.08
Help with Treatment	.11	.10	.12	.16*	.08
Help in Taking Action	.16*	.18*	.23*	.15*	.13*
<u>Sources of Support</u>					
Informal Network					
Spouse/Partner	.14*	.01	.06	.18*	-.01
Other Children	.21*	.22*	.19*	.15*	.12
Extended Family	.11	.02	.12	.09	.08
Friends	.11	.03	.16*	.20*	.12
Formal Network					
Medical Professionals	.20*	.14*	.11	.20*	.13
Work Associates	.17*	.20*	.27*	.07	.15*
Social Worker	.07	.09	.05	.04	.04
Church Leader	.22*	.05	.23*	.08	.08
Others in a Similar Situation	.07	.13	.13	.08	.16*

* Statistically significant relationship at the .05 level of confidence, using the Pearson product moment technique for correlations. A statistically significant positive coefficient of correlation between two items (questions or scales) indicates that they tend to be answered in the same direction; a negative coefficient means they were answered in opposite ways. The larger the coefficient (closer to 1.0 or -1.0) the stronger the correlation or association.

possible, the most probable one, consistent with our original discussion, is that substantial and effective support buffers many of the stressful aspects of illness and treatment, facilitating more positive life changes.

Partners

Emotional support and family assistance are the types of support most significantly related to positive life outcomes for partners. The most significantly related sources of support are medical professionals and friends. Receiving less support in general, partners may well benefit especially from the attentions of medical professionals treating their spouses and from their friends' loving attention and practical aid.

Adult Patients

Few significant relationships exist between life outcomes and sources of social support for adult patients. The support they do receive evidently has little impact on their general outlook or psychosocial outcomes.

Young Adult Patients

Table 7 presents data on the relationships between young adult patients' reports of life outcomes and sources of social support. Overall, there are few statistically significant results. However, physical health is related negatively to help from co-workers/classmates and church leaders, suggesting that patients in poorer health may receive more help from these sources. Help from church leaders is positively related to improved social relationships, suggesting that for some young people the church may be an important social nexus.

Patients and Significant Others

In general, life outcomes are related to social support more often for the parents and partners -- significant others -- than for the patients. Patients may be so focused on the progress

Table 7: Correlations Between Life Outcomes and Sources of Social Support Received by Young Adults With Cancer

Sources of Support	Life Outcomes (n=81)				
	Adjustment	Activism	Social Relationships	Physical Health	Concern for Others
<u>Informal Network</u>					
Spouse/Partner	-.12	.08	-.10	-.16	-.06
Siblings	.16	.04	.14	-.04	.18*
My Parents	.16	.01	.17	-.03	.03
Friends	-.00	-.01	.00	-.16	.11
<u>Formal Network</u>					
Medical Professionals	.09	.03	-.02	-.01	.21*
Co-workers/Classmates	.03	.02	.06	-.27*	.06
Social Worker	.03	.11	.02	.06	.16
Church Leader	.05	.07	.24*	-.31*	.13
Others in a Similar Situation	.03	-.04	-.11	-.06	.13

* Statistically significant relationship at the .05 level of confidence, using the Pearson product moment technique for correlations. A statistically significant positive coefficient of correlation between two items (questions or scales) indicates that they tend to be answered in the same direction; a negative coefficient means they were answered in opposite ways. The larger the coefficient (closer to 1.0 or -1.0) the stronger the correlation or association.

of their disease and treatment that they fail to reflect upon the role of social support in contributing to their lives. The data in earlier tables indicated that patients generally receive more support than do their family members, but these data suggest that only in certain cases is that support related to positive life outcomes. In contrast, receiving less support in general, family members of people with cancer (parents and partners) appear to be able to utilize that support in ways that help them create positive changes in their lives. Perhaps because it is so difficult for significant others to get the help they need, when they do get it, it makes a substantial difference.

VII. PROBLEMS OF GIVING AND RECEIVING SOCIAL SUPPORT

The positive potential of social support as a resource for people with leukemia and lymphoma and their close family members is undeniable, as the discussions and findings in this report confirm. However, there are certain times when support may not be helpful, and certain types of support may even be detrimental to families coping with cancer. In addition, sometimes it is difficult to get access to the sources and types of support that may be needed. For everyone concerned -- patients, family members, friends and acquaintances -- it may be quite difficult to seek or to provide meaningful and useful help during such a crisis.

Not All Help Is Helpful

Difficulties in seeking and receiving support emerge as specific barriers to a high quality of life for cancer patients and their families (Chesler & Barbarin, 1984). For instance, the emotional impact of diagnosis and illness may preclude "normal" access to and use of one's usual support network. Interactions with other patients or family members of patients may lead to more depression, and can cause people to relive the pain of diagnosis and treatment. Patients and family members also may worry about increasing the sadness and concern that their support network already feels; thus they may avoid help-seeking altogether (DiMatteo & Hays, 1981).

The socially-constructed stigma of cancer may create a "non-normal" identity for patients and their families, and thus may alter friendships and limit the opportunities for social support. Parents and partners, and the patients for whom they care, may become increasingly concerned about appearing weak and vulnerable, as they try to understand and cope with a diagnosis laden with mystique, and so capable of frightening friends and family members (Sontag, 1979; Wortman & Dunkel-Schetter, 1979).

Existing friendships and relationships, born of caring and concern, have the potential to be intrusive. The emotional climate of a cancer diagnosis is so volatile that patients and their loved ones may be unwilling to give up their privacy and expose their feelings -- even in the case of previously sharing, close relationships. The fear of permanently altering friendships by making heavy demands for support and assistance also may prevent patients and their families from seeking help during their crisis (Chesler & Barbarin, 1984).

Feelings of intrusiveness, uselessness, and ineffectiveness also may be overwhelming for those people who wish to be helpful to patients and their families. They may feel unable to be adequate helpers. Patients and their family members, also concerned about their ability to cope with this crisis, may be wary of entering into new or existing helping relationships at the very time they need them most.

Societal stereotypes regarding gender role socialization also create barriers to the effective development of help and support by husbands and wives, mothers and fathers. For example, fathers and male friends and family members often cannot easily ask for help or adequately provide it; females traditionally are viewed in the role of primary nurturer and caretaker, especially in the case of younger patients and their parents (Gourash, 1978; Knapp & Hansen, 1973; Vaux, 1985). Thus, certain kinds of valid help may be viewed as inappropriate, and, within the context of gender role stereotyping, as actually deviant or harmful (Chesler & Barbarin, 1984).

These issues are not limited to the help people receive, or try to receive, from informal sources; they affect relations with professional helpers as well. For instance, the reports of

parents of young leukemia and lymphoma patients about their interactions with medical staff members indicate non-helpful support as well as positive assistance. Often, parents report exasperated feelings about medical care and about staff personalities, saying that care "...gets very repetitious and they all look the same, they all act the same, the same mannerisms."

Interactions with school and community personnel crucial to their child's successful re-integration to a normal lifestyle are also reported as far from ideal by some parents:

We had trouble with the board of health...There was just a lot of red tape getting letters explaining why she shouldn't have her shots. And I know it's going to happen again because she's starting high school in the fall and we have to go through it all over again.

The problem we had was that he was in high school and we had trouble getting help for him -- he was studying and wanted to go to college, and ...there weren't any tutors! ...And we went to the principal to try to get help and we could not get help. They said, "What do you want us to do?" and I said, "Well we want help for this boy so...we've got some confidence that he can go on to college."

When young adult patients talk about the things that the medical staff should be sure not to do, they also point to typical types of non-helpful help. Young adults caution the staff not to ignore them and their rights as patients, by "communicating only with parents, especially when the child knows it," or "treating them like babies or little kids," or "ignoring them or acting like they wouldn't understand just because they're too young."

Young adults clearly state that they do not want staff members to "make the child guess anything," "hold information back," "lie to them," or "leave the child out of conversations and explanations about their disease." Over and over, these young patients point to negative support from staff who are "unresponsive" or "evasive to questions."

In addition to recognizing their unique needs for medical disclosure, young adult patients are concerned about staff who "treat the patients like guinea pigs," or "act as if you're another number...with feelings." These young patients also recognize the potential negative effects of job strain on the staff, admonishing them not to "let their bad day affect the patients," or "be like workers on an assembly line."

The young adult population is equally clear in their descriptions of support and help from friends, crucial sources of peer support and aid, that is not really useful or helpful. They describe

friends' reactions to their illness that are understandable, but painful and not helpful or supportive.

Some people from high school started or thought up rumors that I had died or would die and actually came up to me and asked. It hurt. But I learned that they were ignorant of what happened to me.

I kept my two lives apart...hospital life and social life. They were not knowledgeable about my treatments and I didn't want sympathy.

Most of my friends avoided me or treated me like I was different -- like I'm not the same person or enjoyed the same things like I did before I was diagnosed. I hadn't changed. They had.

In fact, the responses of young adult patients reveal great insight into their friends; they understand what makes friends "make fun," "feel sorry," or "be cruel." However, these responses also echo the pain and hurt that non-helpful sources of support can cause, and highlight the reasons why some young patients find little comfort in their existing support networks. Instead, some indicate that meeting other young people with cancer would have been a more helpful source of support, given their special needs:

I would have liked more contact with people in similar situations as me. I still wish I had more. None of my friends can really understand.

That would have been nice. I didn't have any of that. I was fifteen at the time and on a pediatric ward, which was good because of the nurses. But everyone else there was two to three. So there wasn't anyone to talk to.

Access to Sources of Social Support

Although the findings of this report reflect the existence and positive value of social support for leukemia and lymphoma patients and their families, they also are conservative estimates of these phenomena. The reason is that the Tables presented so far include responses from some informants who had no real contact with certain sources of support, and thus could not realistically expect support from them. For example, in assessing the amount of support received from various sources, informants were asked to indicate whether each source was "very helpful," "somewhat helpful," "a little helpful," "not helpful," or whether they had "no contact" with that source. We reasoned that "no contact" means no help, and thus has the same meaning as "not

helpful"; we proceeded to code and compute these two responses similarly. However, if an informant had no contact with a social worker, or with a spouse, they could not possibly receive help from that source, and the form of computation we utilized may make it look as if the potential social worker or spouse is not helpful when, in fact, they could not be helpful because they do not exist (or the informant does not have access to them). In this sense, "no contact" and "not helpful" do not have the same meaning, and treating them as such may make each person's actual social network appear less helpful than it really is. Thus, one might argue that we should eliminate the "no contact" responses from our computations, and report only the amount of social support people receive from the sources with which they do have contact, that do exist in their networks. Would this make a difference?

Table 8 illustrates the differences between these two ways of computing responses, presenting the proportions of parents who report various sources of support as "very helpful" in both forms: including "no contact" responses in the first column, and excluding "no contact" responses in the second. As noted, all tables presented so far have included the "no contact" responses in computations. As Table 8 indicates, each and every source of support is reported as "very helpful" by a greater proportion of the parent population after reports of "no contact" with that source have been excluded (controlled). For example, computing on the basis of actual exposure, or actual access, to CLF representatives results in over twice the proportion (from 12.5% to 25.3%) reporting that source of support as "very helpful." In addition, presumably because those not employed outside of the home have no possible contact with co-workers, the proportion of parents reporting co-workers as "very helpful" rises from 25.7% to 35.9% when access is controlled -- that is, when the responses are limited to those informants who have contact with co-workers.

Similarly, Table 9 presents sources of support in these two formats for the partner population. Once again, when access to the various sources of support is controlled (when the "no contact" responses are excluded), the proportion of partners reporting those sources as "very helpful" rises considerably, especially for the formal support network. The proportion reporting

Table 8: Sources of Support by Access or Contact -- Parents

Percent Reporting "Very Helpful" (n = 161)		
<u>Sources of Support</u>	<u>Including "No Contact"</u>	<u>Excluding "No Contact"</u>
<u>Informal Network</u>		
Spouse	63.5%	68.2%
Close Friends	53.1	54.4
Other Children	40.3	46.2
Neighbors	27.5	31.7
Parents	47.4	53.2
<u>Formal Network</u>		
Others in a Similar Situation	25.2	34.2
Social Workers	28.0	39.1
Church Leaders	28.7	38.7
CLF Representatives	12.5	25.3
School People	30.5	35.7
Co-Workers	25.7	35.9

Table 9: Sources of Support by Access or-Contact -- Partners

Percent Reporting "Very Helpful" (n = 76)		
<u>Sources of Support</u>	<u>Including "No Contact"</u>	<u>Excluding "No Contact"</u>
<u>Informal Network</u>		
Spouse	61.8%	64.6%
Close Friends	39.1	40.3
Other Children	50.0	54.1
Neighbors	20.3	26.0
Parents	36.0	53.8
<u>Formal Network</u>		
Others in a Similar Situation	5.2	11.5
Social Workers	7.8	20.8
Church Leaders	24.6	35.4
CLF Representatives	7.9	22.7
Co-Workers	12.0	20.0

social workers as "very helpful," for example, nearly triples (from 7.8% to 20.8%), as does the change in reported help from CLF representatives (from 7.9% to 22.7%).

In both Tables 8 and 9 the percentage change from the first to the second column for informants reporting that spouses or close friends are "very helpful" is very small. This indicates that almost everyone has access to these sources, since excluding the data from those who do not have spouses or close friends results in minimal change. But the changes in percentages for some other sources of support (such as social worker and CLF representative) are considerable, indicating that some people simply do not have contact with or access to some of these sources. The implication is that for many of these sources an increase in their availability (increases in contact with them) might be as vital for patients and their family members as would be an increase in the quality of support delivered. Thus, we can emphasize the existence of two major barriers to the effectiveness of social support for patients and family members of patients with cancer: the availability of help and the quality of help provided or received.

VIII. RECOMMENDATIONS FOR POLICY AND PROGRAMS

A focus on the types and sources of social support received by leukemia and lymphoma patients and their families has numerous implications for CLF's policies and programs. These implications emerge in three basic patterns. First, from the responses of the four study populations it is possible to target people and groups in greatest need, based on reports of the sources of social support received. Second, the types of reported social support received vary in impact and importance for the four populations, and that variability highlights specific needs and therefore priorities in planning programs. Third, it also is possible to guide policy development and program focus based on knowledge of who can and should be targeted for service, and when that might be most effective.

The sources of social support received include both formal and informal support networks. Many informants mention receiving help from community-based agencies and medical personnel. As CLF attempts to refine and expand its strategies for service delivery, it may be easiest to tap

these existing networks of formal support and assistance in hospitals, clinics, and agencies.

Providers can be newly-informed and motivated by the specific findings in this needs assessment report.

The task of planning with an ear to informants' reports of informal sources of support, however, is more challenging. Spouses, friends, and neighbors are reported as major sources of informally-based social support. The task of linking CLF services to such private and informal support networks is difficult, but the need is clearly being voiced, especially by adult patients and their partners.

Mutual support or self-help groups for spouses and partners of adult patients might be especially useful. If CLF were to organize and increase the availability of support groups, that might allow more people to benefit from their activities. For others, the mere referral to "veteran" patients or family members who can be lay helpers may be a catalyst for help-seeking. Requests for help in the form of referrals to social workers, counsellors, and other forms of psychosocial service are quite evident in the needs assessment data, especially for adult patients and partners.

Parents may have a larger social support network, but less free time to adequately utilize it. Older patients and partners -- especially those who are retired -- may have a "surplus" of time, but a diminishing or inaccessible social network. Thus, psychosocial support programs might be directed at logistic help, such as babysitters, for younger parents interested in either group or individual support. Older patients and their families, on the other hand, might benefit most from services that enhance access to existing and new networks of friends -- gatherings to meet others, social events, transportation services, etc.

The specific types of effective support reported by the four population groups vary significantly. For instance, emotional support is reported least often by partners, yet emotional support and family assistance are the types of social support most highly correlated with positive life changes for partners. Even without controlling for access and usage, it is evident that emotional support has an indirect value for partners and spouses. Programs that provide referral

services and emotional support, perhaps in the setting of self-help or mutual aid groups, are likely to be most useful for this population.

The parent population reports receiving the most help from the formal, treatment-related support systems. Parents advocating for their children may have a stronger need for both informational and practical help with treatment problems and issues. Thus, parents are a key target population for programs providing information about and assistance with treatment, a successful focus of CLF in the past that is clearly warranted in the future.

Social support related to taking action during the course of the illness is another area requiring attention from CLF. Parents report the most support from taking action, while adult patients report the least. While adults may be able to rely on their own pre-existing resources as a basis for self-advocacy and action, the case may be quite different for parent-advocates of a young and dependent patient population. For parents, policies which recognize their collective experience of crisis, and programs which facilitate their potential for joint action, are critical. Simply hosting informational conferences and social events for parents provides an arena for meeting others in an atmosphere where key issues can be addressed and perhaps acted upon.

Financial aid has always been a mainstay of CLF's program, and as such it represents another type of support. Parents report the greatest amount of support through financial aid, and, once again, adult patients report the least amount. Even if adult patients do not use or need financial aid to a significant extent, they do report family assistance as helpful, indicating that their needs may be more practical than financial. Partners, in contrast, are the least likely to rely upon and receive practical types of help and support. These findings should help to target financial services and practical assistance programs toward those populations that indicate or express a specific need for them.

Specific needs assessment findings indicate who might best be targeted for CLF services and when that targeting might be most effective. Certain patient, partner, and parent demographics and background characteristics emerge as guidelines for both policy and program planning. Parents whose children are off treatment report the most support received from various

sources. Adult patients and partners report the least amount of social support from numerous sources, perhaps indicating that they are the populations with least access to help. Unless they have more resources than do the young adults or younger parents, they are in much greater immediate need for new programs and assistance.

Women generally report receiving more social support than do men. However, male patients report receiving more support from their female spouses than female patients report receiving from their husbands. In addition, less spouse support in general is reported by low-income respondents, and this is especially true for younger parents. Policies and programs which subtly recognize these gaps are crucial. Literature and targeted liaison work that enables male spouses and low-income families to be more effective providers of support would help address these articulated needs.

The extent to which informants take an active role in their own or their family member's treatment provides a final key to the success of using these needs assessment findings to guide future policies and programs. Persons who have taken such an active role are more likely to state their needs, and thus to receive the help they need. Talking together, and acting together, may have a healing effect, especially for parents. It also may enable them to make positive contributions to changes in the medical and psychosocial service system. Both informal and formal support networks are prime targets for such policies and programs. Community agencies and medical settings can initiate parent, partner, and patient involvement in care that can be successfully extended to individuals' informal networks of supporters. Just as these study participants voice their concerns through these data, so may CLF's policy and program development enable them to have an active voice in meeting their future concerns and social support needs.

IX. APPENDIX

Index and Variable Guide

<u>Social Support Indices</u>	Cronbach's Alpha for Each Population*			
	<u>Parents</u>	<u>Partners</u>	<u>Adult Patients</u>	<u>Young Adult Patients</u>
Emotional support emotional support, listen to private feelings, cheer me up	.85	.91	.88	
Family assistance cook meals and do chores, look after other family members	.74	.80	.81	
Practical help focus on solving problems, suggest action to take	.82	.82	.87	
Help in taking action focus on solving problems, suggest action to take, go with to take action, hear what others did in similar situation	.76	.81	.80	
Help in getting treatment give me info, help in getting proper treatment	.70	.78	.76	
Extended family parents, in-laws	.62	.67	.61	
Friends close friends, neighbors	.59	.56	.63	
Work Associates employer, co-workers	.87	.84	.90	
Medical professionals physicians, nurses	.69	.50	.51	.83

Social Support Individual Variables

<p>Medical expenses, bills Transportation Spouse/partner Other children</p>	<p>Others in a similar situation Social worker Church leaders CLF representative</p>
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Young adult patient substitutions for indices
 extended family: parents
 work: co-workers
 friends: close friends

<u>Total Support Indices</u>	<u>Parents</u>	<u>Partners</u>	<u>Adult Patients</u>	<u>Young Adult Patients</u>
Total type Emotional support, cook meals and do chores, look after other family members, listen to private feelings, cheer me up, focus on solving problems, suggest action to take, give me info, go with to take action, hear what others did in similar situation, medical expense/bills	.88	.93	.92	
Total source Spouse/partner, other children, parents, nurses, physicians, co-workers, close friends, social worker, church leader	.72	.54	.73	.61

<u>Life Changes Index</u>	<u>Parents</u>	<u>Partners</u>	<u>Adult Patients</u>	<u>Young Adult Patients</u>
Adjustment own mental health, sense of personal control, sense of who I am	.68	.73	.51	.69
Activism sense of what I can do as an individual, willingness to join up and change things	.54	.66	.50	.66
Social family relationships, time with friends, relationships at work	.64	.53		
family relationships, time with friends			.49	.42

Life Changes Individual Variables

Physical Health
 Ability to cope with tragedy
 Desire to change the medical system
 Concern for others

* A higher value of Cronbach's Alpha indicates a higher level of internal coherence or integrity among the items in a given index.

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