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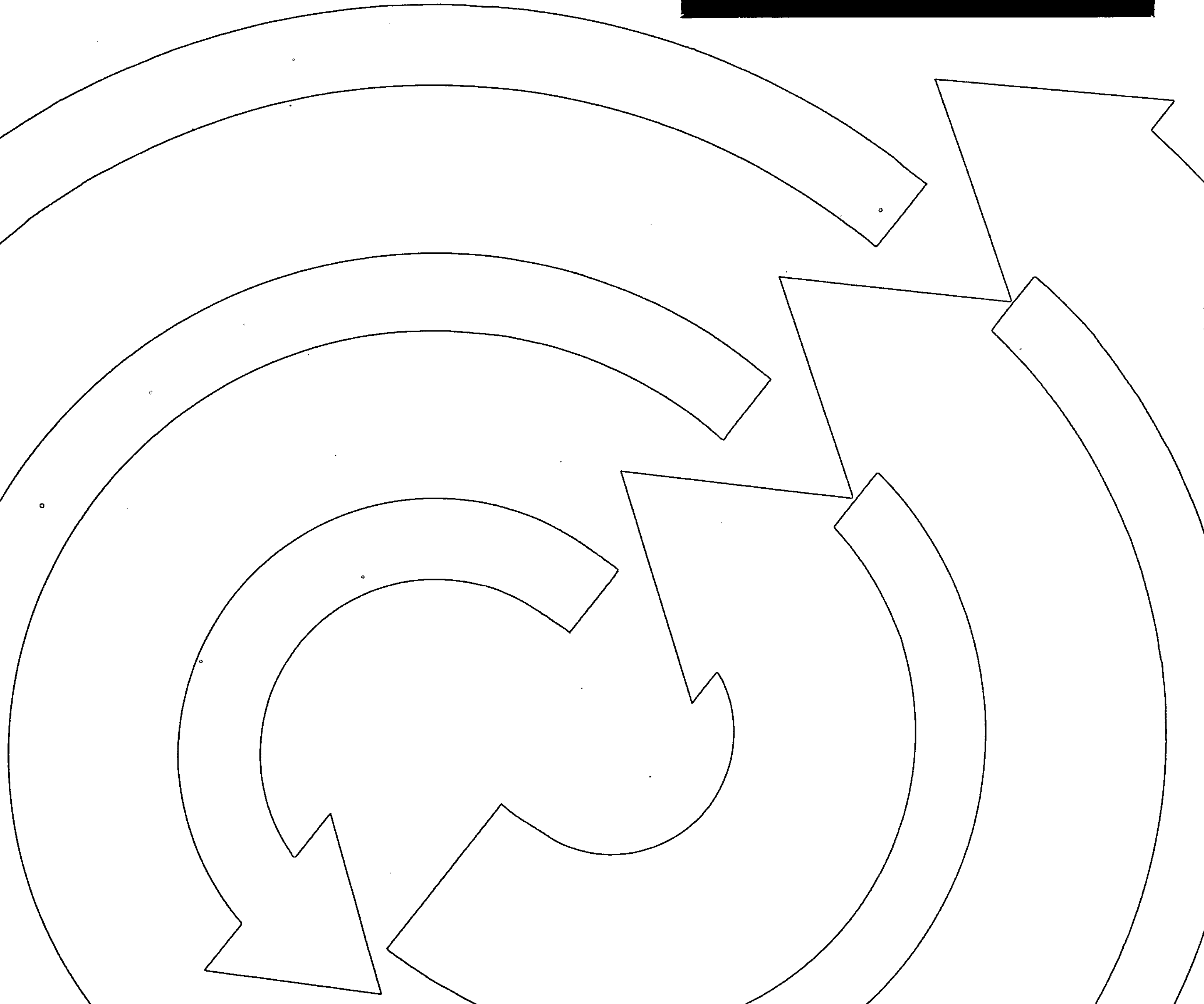

PSYCHOSOCIAL NEEDS-ASSESSMENT WITH FAMILIES EXPERIENCING CANCER: EXECUTIVE SUMMARY

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The Executive summary from the Report to the Children's Leukemia Foundation. September, 1989.

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PSYCHOSOCIAL NEEDS-ASSESSMENT WITH FAMILIES EXPERIENCING CANCER

I. EXECUTIVE SUMMARY

In the summer of 1986 Glen Trevisann and Myra Jacobs approached Mark Chesler and Barbara Chesney about conducting a psychosocial needs-assessment study for the Children's Leukemia Foundation of Michigan. The Children's Leukemia Foundation of Michigan, founded in 1952, helps adults, children and their families throughout Michigan cope with the effects of leukemia, lymphomas and related blood disorders through programs in service, education and medical research. Service and education programs seek to address psychosocial, financial and informational needs while research programs provide funding to study disease causes, improve treatments and support certification training for physicians.

The purpose of this psychosocial needs-assessment project was to gather information from patients and family members for use in improving programs and services for families experiencing leukemia and lymphoma (and related diseases) in the state of Michigan. It also was designed to advance the general state of practical and scholarly knowledge about the psychosocial impact of cancer on families.

Drs. Mark Chesler and Barbara Chesney are social psychologists associated with the Center for Research on Social Organization at The University of Michigan. They have been conducting research and action projects regarding psychosocial aspects of cancer, especially childhood cancer, for several years. Their work has included scientific research, policy and program planning, consultation with social service and medical care organizations, and direct assistance to local families and self-help groups (see, for example, Ayers and Chesler, 1987; Bogue and Chesney, 1985; Chesler and Barbarin, 1987; Chesler, Gidron, Chesney, Sutherland and Hartman, 1988; Chesney, 1989; Chesney, Rounds and Chesler, 1989; Yoak and Chesler, 1985).

This Executive Summary, which may be read as a separate, summarizes the full technical report of the needs-assessment study. It presents the background and methods of the study, describes the various populations in the form of univariate results, provides some bivariate analyses of the relationships among the four major population groups and key variables, and makes various policy/program suggestions. Further and more specific or detailed reports will be forthcoming.

We appreciate the collegial relations between the Center for Research on Social Organization and the Children's Leukemia Foundation, and the clerical and research assistance of Sheryl Lozowski, Tim Lawther, MaryLou Abrigo, Michelle Correnti, Rachel Hitch, Jennifer Smith, Dawn Newberry, Chris Heyerman, Julie Kettlehut, Carolyn Grawi, Michelle Lewis, Erna-Lynne Bogue, Susan Gold and Gloria Gibson.

People with Cancer and Their Family Members

Psychosocial research on the life experiences and service needs of people affected by cancer - either directly as patients or indirectly as close family members - has increased dramatically in the past several years. Increased success in treating cancer, and increased attention to psychsocial issues in all of medicine, have fueled this development. We do not review this extensive material in detail here, but some of the dominant themes in this growing research tradition bear notation.

Cancer is not a single-disease entity. It is a generic term that includes many different diagnoses, each with their own prognostic character, treatment design and life impact. Leukemias and lymphomas, the focus of the work of the Children's Leukemia Foundation and thus of this needs-assessment study, are relatively common forms of cancer. These two forms of blood and lymphatic disease account for approximately 45% of all the cancers of childhood and 8% of all the cancers of adulthood (American Cancer Society, 1988).

Some of the most important psychosocial research studies conducted with or about young people with leukemia or lymphoma are reported and collected in Kellerman (1980), Koocher and O'Malley (1981), Schulman and Kupst (1980), Sourkes (1982), Spinetta and Deasy-Spinetta, (1981) and Van Eys (1977). Recently, another series of psychosocial studies has begun to focus on young adults with leukemia or lymphoma who are off all treatment and have become "long-term survivors" of childhood cancer (Cella & Tross, 1986; Cella et al., 1987; Chesler, 1988; Copeland et al., 1988; Dobkin & Morrow, 1985-86; Chang et al., 1987; Fritz et al., 1988; Fobair et al., 1986; Lansky et al., 1986; Meadows & Hobbie, 1986; Mulhern et al., 1989; Mulvihill et al., 1987; Sawyer et al., 1989; Tebbi et al., 1989; Teeter et al., 1987; Teta et al., 1986; Wasserman, et al., 1987).* With regard to the psychosocial issues and service needs of the parents/families of young children with these forms of cancer, some of the more recent and

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*There are more studies in this rapidly developing tradition, many of them by these same authors or author-teams; they are omitted from this list simply because of convenience.

important research studies are summarized or reported in Adams and Deveau (1988), Chesler and Barbarin (1987), Christ and Flomenhaft (1984), Kupst et al. (1984), Spinetta and Deasy-Spinetta (1981). In terms of the work available with adults facing leukemia and lymphoma, outstanding material is collected in Ahmed (1981), Cassileth (1979), Cohen, Cullen & Martin (1982), Cooper (1984), COPING WITH CANCER (1980), Cullen, Fox and Isom (1976), Goldberg and Tull (1983). There is relatively little centrally collected material focusing explicitly on the experiences and needs of the spouses and partners of adults with leukemia and lymphoma, but extrapolation can proceed from studies of spouses of adults with other forms of cancer, such as breast, lung and colon disease. In addition to these monographs and anthologies, of course, hundreds of individual studies and articles have examined specific experiences of children, parents, adults and spouses in families facing cancer.

Reviews of these and other materials lead to some of the following assumptions about psychosocial experiences and needs:

1. The experience of cancer is stressful for patients and family members
    a. physically, including debilitating treatment and side effects.
    b. psychologically, including shock, fear and uncertainty.
    c. socially, including disruption of normal interpersonal, job or school relationships, and creation of isolation and discrimination.

2. The content of these stresses are numerous and variable, but include problems with
    a. information, especially related to diagnosis and treatment.
    b. emotional balance, both in terms of one's self and one's family and friends.
    c. practical aspects of daily life, including mundane tasks that can become severe hassles, and financial threat or loss.
    d. social relationships, with acquaintances and public agencies.

3. Relations with the medical staff are an important component of good psychosocial care. When available and effective, staff members can lessen some of the above stresses; when inadequate, they may add to a family's stress burden.

4. People (patients and family members) cope with these stresses in a wide variety of ways. Although some general guidelines for "good coping" exist, it is not clear how universal these guidelines are or should be for people with different cultural traditions, socio-economic resources or personal styles.

5. Most people affected by cancer reach for social support:
   a. of various kinds, relating to the kinds of stresses noted in 1 and 2 above.
   b. from various sources, including formal agents such as medical and psychosocial professionals, and informal agents such as friends and family members and mutual support groups.

6. Most people affected by cancer need additional psychosocial services and support, and an agency like the Children's Leukemia Foundation can play useful roles in understanding, publicizing, providing and advocating or brokering such services.

7. Background factors such as age, gender, education, income, diagnosis, prognosis, side-effects, and disease status (e.g., on treatment or off treatment) all may affect the above factors:
   a. especially age, so that a comparison of young people with cancer and adults with cancer is vital.
   b. especially status as a patient or a close family member, so that a comparison of children and parents or adults and spouses is vital.

Compared with the large body of literature on psychosocial aspects of cancer, relatively few studies, to date, have attempted simoultaneously to gather information from patients and their family caregivers or loved ones. Among those comparative efforts that have focused on childhood leukemias or lymphomas, both young patients and their parents have been studied by Blotcky et al. (1985), Fife et al. (1987), Katz (1985), Kazak & Meadows (1989), Levenson et al. (1983), Morrow et al. (1978), Kupst et al. (1984), and Spinetta (1981). As impressive as is this set of studies (and other articles by several of these author teams), Williams (1988) points out that the focus on both patients and family members is rarer in childhood cancer than in adult cancer. However, since leukemias and lymphomas are proportionately rarer in adults than in children, there are still few available studies that compare adult patients with leukemias/lymphomas and their spouses. Most studies of adult patients with cancer and their significant others focus on breast cancer, although there are a few with data from people experiencing colorectal or lung cancer (see, for example, Baider et al, 1989; Daiter et al., 1988; Gotay, 1985; Ell, 1988; Goldberg et al., 1984; Lichtman et al., 1987; Quinn et al., 1986; Sabo et al., 1986; and Vess et al., 1988). The only major study apparently focussing on adult cancer patients with leukemias and lymphomas and their spouses is by Daiter et al. (1988).

Rarer even than the simoultaneous focus on patients and family members is research comparing psychosocial aspects of cancer across the life cycle, specifically between children or adolescents and adults. Blanchard (1988), among others, does compare young adults (under 40 years of age) with older adults, but we have reviewed no empirical work that compares the psychosocial issues faced by children/adolescents with cancer with those faced by young/older adults. However, theoretical work of excellent quality has been published by Goldberg & Tull (1983) and by Holland & Rowland (1983). They argue that not only are the psychosocial aspects of cancer different for children than for adults, but that the physiological disease itself is quite different for people in these markedly different age groups; indeed, Gee et al. (1976) present research indicating that successful treatment for leukemia/lymphoma must differ substantially for children and adults. Finally, given these gaps in the literature comparing patients with cancer across the life cycle, it can be rather safely stated that nowhere has there been a study comparing the experiences of significant others of children (parents) with those of adults (spouses).

This needs-assessment study has gathered data on the psychosocial experiences of young people with cancer and their parents, of adults with cancer and their spouses. Thus, it will permit comparisons between patients and their caregivers or loved ones, and among both these sets of actors across the life cycle. As a result, this pioneering work should be able to extend some of the findings and comparisons provided by prior studies. It also should have relevance for many of the academic, professional and lay communities concerned with psychosocial aspects of cancer, far beyond the specific policy and program needs of the sponsoring agency, the Children's Leukemia Foundation.

Study design and method

The needs assessment study design was multi-phasic and multi-method, intended to gather information from four specific populations via several data collection modes. The following section describes the study's sampling goals and techniques, timing, types of instruments and procedures utilized in data collection, and response rates.

In order to create a large pool of potential informants, including some who were not previously affiliated with CLF, the staff had to generate a large list of people and families experiencing leukemia and lymphoma. CLF staff reviewed their own records, and in addition wrote to or visited physicians and oncology clinics throughout the state during the spring and summer of 1987. These outreach efforts succeeded in creating a population pool of over 2600 young adult and adult patients with leukemia and lymphoma, and their significant others, some of whom were registered with the Foundation and others who were not.

Sampling procedures were developed on the basis of a pool of 915 patients and family members, with the stated goal of ensuring a final study sample of at least 300 informants. Because of anticipated differences in response rates, we deliberately planned to over-sample certain groups of patients and their family members.

Preliminary instruments were pilot tested with CLF staff and reviewed by University of Michigan staff during the summer and fall of 1987. Our primary concern was to identify any questionnaire formats or item sets that might be problematic for actual informants. In addition, social work and medical staff at key treatment centers, especially those providing patients' names and addresses, were invited to react to the pilot questionnaires. These efforts confirmed the appropriateness of the questionnaire length and general content, and provided input on subtle changes in item wording.

CLF sent the entire sample pool an introductory letter on its own letterhead, introducing the study, in January of 1988. This material prepared informants for the University of Michigan letters and instruments which followed within 2 weeks. Each University of Michigan letter accompanying a study questionnaire was tailored to both the study sub-population (young adults, adults, etc.) to whom it was addressed and the purpose of the mailing (first mailing, second mailing). Second mailing letters, especially focused on the need for responses from all segments of the study population in order to achieve overall representativeness of the sample, were mailed in February of 1988. After two waves of survey mailings to all four study populations, follow-up telephone calls were made to all non-respondents (March - May, 1988).

Questionnaires for young adults between 14 and 17 years of age were mailed as enclosures to their parents' questionnaires, while young adults between the age of 18 and 25 received their mailings under separate cover. As such, human subjects' protection for this young population was provided via their parents' monitoring of the invitation to them to respond, as well as by their own willingness to answer questions. In all cases, questionnaires were to be mailed back to the University of Michigan office individually, providing for maximum privacy for informants of all ages. While parents of young patients under the age of 14 were queried via questionnaires, their children (for liability and vulnerability reasons) were not included in the sample.

After all questionnaires were returned and filed (Fall, 1988), six small group discussions were conducted with study informants. This group interview method permits us to verify in depth many of the themes discovered in the self-report questionnaires. The set of persons eligible for participation in these group discussions was obtained from the list of respondents who had declared, on the mail questionnaire, their willingness to participate in such discussions.

Table I-1 presents various populations' response rates and describes the entire sample. In the process of mailing and telephoning potential respondents, we discovered that 138 of the original 915 people in the potential sample were deceased or had moved without leaving a mailing address. These circumstances reduced the actual size of the potential sample to 777, and all response rate calculations are derived from this base.

The total response rates for the four population groups vary from 62.4% for parents of young patients to 55.4% for young adult patients to 54.8% for adult patients and to 40.2% for spouses/partners of adult patients. For individuals already registered with CLF the response rate is 54.9%, compared to a rate of 52.9% for non-registered persons. These rates vary as expected among the different population groups (i.e., we anticipated a higher response rate from registered populations and from parent populations) and thus justify the over-sampling decisions made earlier (and reflected in Table II-1 in the Final Report).

In addition to providing a good mix of populations of different ages and patient-nonpatient statuses, most of the four populations demonstrated a good range of income levels, educational backgrounds and treatment statuses. With the exception of the parental population, there is a substantial gender mix in each population as well. All four populations are predominately white. Unfortunately, there is a minimal number of informants from the upper peninsula of Michigan or from the upper portion of the lower peninsula; neither CLF records nor contacts with medical clinics permitted adequate sampling from these more rural areas of the state. Both these residential and

Table I-1

Total Actual Sample (and Sub-sample) Characteristics, Including Response Rates (%)

		Age of Patient		
		Young Adult Under 25 years	Adult Over 25 years	Total
Medical Status	Patient	88 (55.4%)	91 (54.8%)	179 (55.1%)
	Significant Other	161 (62.4%) Parents	78 (40.2%) Spouses	239 (52.9%)
	Total	249 (59.7%)	169 (46.9%)	418 (53.8%)

racial characteristics of the sample clearly limit the study's generalizability.

Descriptions of four populations

This section briefly describes each of the four populations queried in the CLF needs-assessment study. Our effort here is not to be exhaustive, but to illustrate the different types of questions asked, and some of the responses of each of the four population groups. For fuller information on any group's responses, or on the comparisons among groups, we refer the reader to Chapters III and IV of the full report.

Young adults with cancer. The young adult population includes 88 persons with cancer (leukemia and lymphoma) between the ages of 14 and 25. The data indicate a fairly good representation of young people with cancer of various ages, of different gender, from families of differing economic status, but the racial makeup is badly skewed toward an overrepresentation of whites. With regard to their medical treatment situation, it appears that the great majority are off all therapy (only 18% report they are currently receiving therapy), with a mix of those indicating they are in remission (64%) or cured (31%). Sixty four percent of this population was diagnosed with leukemias and 31% with lymphomas.

The extent of social support young adults with cancer report receiving from various sources reveals that mothers are the most prominent source of support, with doctors and nurses next most helpful. Fathers follow, with close friends and other family members being next in order of helpfulness. The low level of helpfulness of classmates may indicate (or mask) even more negative experiences with peer teasing, awkwardness and isolation. For instance, in the interviews several young adults commented on their difficult relations with peers.

> They don't understand. They ask, "Can you eat this, can you drink this, can you swim, does your hair fall off, is that a wig?" I've gone through wigs, I've gone through turbans. My friends were embarrassed when I went into the store where she works to try on hats just to show her that I wasn't feeling that bad about myself. I took off my turban and asked her if she had anything to cover my head. She was so shocked.
>
> My best friend at that time shied away from me. We're still friends but we're not as close as we used to be.
>
> People aren't that educated on cancer and leukemia. There was one girl who was sure that I was going to die.

And some friends, especially close friends, evidently were very helpful and comforting.

> Especially my boyfriend was terrific. When he saw me he asked to rub my head. I still see him and he helped me out a lot. He was there for me.
>
> There was one girlfriend that I became closer to. She used to write me letters telling me what was going on at school. She'd bake me cakes. I realized how much she cared, and have never forgotten that.

A high proportion of young adults report having "no contact" with social workers (and CLF representatives). The relative absence of these potentially helpful agents explains why they are rated rather minimally as a source of support: it is their lack of presence, rather than their lack of helpfulness, per se. Fifty-eight percent of the young adult population report being interested in meeting other young patients (26% stated they would like such meetings and 15% had particpated in or used such meetings) and 39% state at least a moderate level of interest in more contact with other patients.

Young adults' dominant worries center around their own physical health (46% worry a lot or some about whether they are as healthy as others, 41% worry about having a relapse and 39% worry about getting another cancer); personal and social relationships (51% worry a lot or some about how their body looks and 39% worry about losing friends); families and family finances (54% worry a lot or some about their parents' health, 40% worry about their parents' finances, and 36% worry about insurance), and their own futures (37% worry a lot or some about whether they can have children, 40% worry about job futures). On the other hand, few worry about long-term physical side effects like learning disabilities.

Despite these worries, seventy-one percent of the young adult population report that they feel they handled their illness "very well," and they overwhelmingly report positive growth and changes in their lives since their diagnosis. We are not sure of the baseline of these measures: do they represent real pre-post diagnosis assessments or comparisons between the depths of post-diagnostic despair and current good health status? However, these responses certainly represent a positive statement for the future!

All young adults do not react to the experience of childhood cancer in the same way, nor do they necessarily encounter similar relations with sources of social support, medical staffs and the like. Older young adults (18-25 years) report more worries about their medical futures (possibility of a relapse) than do younger persons (14-18 years). One reason for this difference may be that older young people may be less likely to utilize denial as a form of coping with the illness and its after-effects, and may be forced to come to terms with their fears more openly; they also may be more willing to admit to these concerns in public. Older young adults also worry more about problems in obtaining insurance, a realistic issue facing more older than younger cancer patients or former patients.

Young women in this population report receiving more support from physicians and from their siblings than do young men. They also report more worries about their medical status than do males, specifically concerns about having learning disabilities. Perhaps this is an indication of trends reported in other gender-related research, wherein females are more likely to voice their physical and emotional fears than are males. One result of public voicing may be that young women are more willing to seek and receive help from staff members (physicians); health care professionals also may find it easier to provide assistance to females than to males.

Young adults from families with higher income levels report receiving more social support from their fathers, perhaps because their fathers can afford to take time off from work and "be there" at home or in the hospital more often. They also report more use of psychological counselling for their worries, a service which they and their families probably can afford. On the other hand, young adults from families with lower incomes report receiving more support from physicians than do young people from higher income families. Young people from families with lower incomes also worry more about their parents' finances, another reasonable effect of income differentiation.

Young adults who report that they are cured indicate fewer worries about their future, greater positive changes in their physical health and sense of personal control, greater growth in their ability to act for change and more positive changes in their time with friends and participation in school. What a positive message for all survivors!

Adults with cancer. The demographic and medical situation data from the population of 92 adults with cancer indicate that although there is some representation across the entire age range, 40% of this population is concentrated in the above 60 year-old category. This is a welcome skew for the needs-assessment purposes of this study, since a substantial portion of the neediest population may be expected to lie in this age range. Various income levels are represented, although the large numbers of adults of retirement age results in a relatively small percentage of high income families. The racial skew is similar to that found in the young adult population, but a good gender mix is present here as well. A relatively small portion of this population is still receiving therapy (29%), with 38% indicating they are off all therapy and 15% reporting that they are cured. Thirty nine percent of this population was diagnosed with leukemias and 59% with lymphomas.

These adults with cancer indicate that practical help is the most widely received kind of help (help in getting proper treatment, assistance with transportation and bills, and with cooking and chores). Several kinds of emotional support (comfort, cheering up) also are quite important. Help in the form of someone to go with you to take action is also highly reported.

Adult patients generally indicate that the quality of medical care received is excellent and that most aspects of hospital relations are rated quite positively. There are no features of staff relationships that are rated very negatively, although some dissatisfaction is voiced with regard to interpersonal relations with the staff and with help obtaining social work or local community services. For example, the interviews contain both positive and negative comments on staff relations:

> The one person who did probably the most for me in the early days the first time I was in the hospital, was the head nurse. I don't remember her name, but she would come in and just talk to me.
>
> That doctor brought me some literature. He said, "I know you're probably interested if you want to read about it - the prognosis, recovery, remission." And he did, he brought it to me.
>
> I kept asking for material to read and I really didn't get it.
>
> In this hospital the medical system is not patient friendly and it doesn't do what's best for the whole person. It works on this medical model, and the medical model doesn't have feeling or compassion and it only wants to cure the disease.

Seventy six percent of this population report playing an active role in their own medical care.

The major worries expressed by these adults with cancer focus on their own physical health (getting another cancer, getting enough rest, getting tired, having a relapse, getting the cold or flu) and financial concerns (paying medical bills, obtaining insurance). Whether one's children might get cancer stands out as a significant concern, despite the evidence that leukemia and lymphoma are not genetically transmitted or communicated diseases. There is little worry expressed about the staff's reactions to complaints, verifying the high degree of comfort and satisfaction these patients feel with regard to their medical care providers. In sharp contrast to the young adult population, however, adults worry little about losing friends. It stands to reason that the friendship patterns of adults may be more stable and resilient than those of adolescents and young adults. Sixty six percent of the adults with cancer report feeling that they handled their illness "very well." Once again we are not sure of the baseline for these measures, but the adults' reflections are on balance much less positive than are the young adults'.

Information about treatments and nutrition are the most commonly <u>used</u> social services, with various forms of psychological and supportive counselling next most common. Financial and insurance assistance, and assistance in dealing with stress, appear to be the most heavily <u>desired</u> services. Eighteen percent of this population said they would like to meet with other patients with cancer (and 21% have done so). Eighty five percent of this adult population received financial help of some sort, and they used it primarily to pay physicians' bills, hospital costs, tests, etc. These monies came from various sources: although health insurance programs (including Medicare and Medicaid) provided the vast majority of aid for most. CLF provided financial aid for 21% and family resources supported another 20%.

Just as all young adults do not experience their cancer in identical ways, neither do adults. Younger adults (under 40, primarily) with cancer report receiving significantly more support from their own parents, while older adults report receiving more support from their own children. It may be that the children of older adults are themselves old enough to be helpful to their parents, rather than requiring a great deal of help from them during this traumatic period of illness. Younger adults with cancer also report receiving more help with informational and practical matters (giving information, looking after other family members). These patients, with more young children at home, probably are in greater and more obvious need of family-related practical assistance than are their older peers.

Adults with cancer from higher income families report receiving more support than do adults from lower income families. Perhaps these data reflect the ways in which people with different incomes are responded to differently in the society, or perhaps they reflect different cultural norms about giving and receiving support in communities of different income levels. People with lower income levels report more worries about their ability to pay their medical bills, yet they report the highest satisfaction with staff members' help in obtaining needed services.

Adults with cancer who describe themselves as cured report receiving more support from their workplaces (employers and co-workers), and more informational help, than do adults who do not indicate they are cured. Adults who report they are cured also worry significantly less about paying medical bills and getting colds or flu, and they report more positive changes in their own mental health. Adult patients who indicate being off treatment report more positive interpersonal changes (time with friends, family, relationships) and action-oriented behaviors (joining up for change, sense of what they can do) since their diagnosis than do those not reporting themselves as off treatment.

<u>Parents of young adults with cancer</u>. A total of 163 parents of children and young adults with cancer responded in this study. Most are under 45 years of age, as befits a sample of parents of children,

adolescents and young adults, and there is a fairly good income mix in the population. The same racial skew reflected in the remainder of the population also is represented here. The overwhelming portion of this parent sample is female (88%), probably reflecting the nature of the process by which persons fell into the sample, the role of mother as primary medical contact and caretaker, and women's greater willingness to fill out questionnaires on these matters.

Parents of children with cancer report receiving support from various sources, but one's spouse, and physicians and nurses are the most common sources of very helpful support. The ill child, close friends and one's own parents follow closely. Social workers and CLF representatives are among those potential sources with whom informants report having the least contact, and thus as being least helpful.

Practical help in getting proper treatment is parents' most frequently reported form of help (as with adults with cancer, perhaps it is the most critical issue). Emotional types of support (comfort, cheering up, listen to feelings) are the next most common and potent kinds of help received, with some types of informational and financial help (paying bills) also reported prominently.

Parents also report a quite positive set of experiences with and orientations toward the medical staff, especially with aspects of medical care delivery (quality of care and information) and social relations (staff relations and communication). Ninety-five percent of this population report that they played an active role in their child's medical care, and 43% indicate that they had to intervene in medical care to prevent or correct a "mistake."

Parents' primary worries center on their child's medical status and health: 78% of the parents worry a lot or some about their child's pain, 76% worry about a relapse, 60% worry about their child getting a cold or the flu, 56% worry about their child's death and 56% worry about whether their child can have children. In the interviews, for instance, parents gave clear voice to these concerns:

> It's still not pleasant. She has a cold right now and I'm insane about that because she has this cough. See this cough sounds the same as the first time. That's what's making me nuts right now. That was why we took her to the doctor. She wouldn't quit coughing and wouldn't quit, wouldn't quit, and then she caught cold. She's only had it 10 days but you know... Every time she coughs, my stomach goes bananas.
>
> It never goes away. It's always in the back of your head. Something like that just doesn't go away and you can't ever remove yourself from it. Because she was in such a new study then and the age group. I mean they don't know what's going to happen 5 years from now. I don't even use the word, cured.

In addition, a considerable portion of the parent population expresses concern about the impact of the illness on the rest of the family, and about their family's financial (and insurance) situation. Substantially fewer parents report that they worry much about their own health. Consistent with the data reflecting their positive experience with the medical staff, these parents report little worry with regard to staff relationships or the staff's negative reactions to their concerns or complaints.

Parents' reflections on the ways in which their lives have gotten better or worse since the diagnosis basically are encouraging. Excepting the report of a worsening of their own physical health, and of course the continuing fears noted above, all other changes are generally positive. Chief among the positive changes are increases in spiritual well-being and an ability to cope with tragedy, a greater sense of one's own identity and coping abilities, a greater concern for others and more satisfaction with family life. The interviews capture some of these changes quite poignantly:

> I think I pay more attention to life a little bit more. I don't take it so much for granted. It's not always going to be the other guy. It's not somebody's name in the paper who has cancer or some child you see with their hair out, know that they're on chemo. It was my child. Now I have grandchildren and I don't take their health for granted anymore. I think you just learn to accept the things that come along, you know, that it's not always going to be the other guy. So you brace yourself in hopes that you can handle something else that comes along.
>
> You appreciate life a little more. You appreciate life a whole lot more when your son is near death four or five times and he lives and you are closer to God, and you just appreciate life.

Consistent with the latest series of studies of family and marital functioning (see Chesler & Barbarin, 1987), greater rather than lesser satisfaction with family life is reported as an outcome of coping with this serious and chronic childhood illness. Overall, fifty three percent of this population report that they handled their child's illness "very well."

Parents with lower family incomes report less help in some practical matters (looking after the family) than do parents with higher family incomes. However, these families also report greater satisfaction with the quality of social services and with facilities for needy travelers than do more affluent parents. Lower income family members also report more worry about their family finances and about their child's pain, perhaps indicating a more acute sense of vulnerability. In terms of service usage, parents from families with higher incomes use various forms of advice and financial assistance more than do less wealthy parents. Finally, parents in families with lower income levels report desiring more nutritional and career-related information than do parents with higher incomes.

Parents of children who are currently receiving therapy report less satisfaction with staff relations (help with community agencies, coordination of expertise in hospital) - a negative evaluation from current consumers of therapy! Also consistent with the demands of current treatment, parents who report their children currently receiving therapy evidence less positive changes in their relationships with friends and co-workers, and in their ability to cope with tragedy. Parents of children who are still on treatment also report less use of counselling services, perhaps because they are still too busy dealing with daily medical and household tasks; however, they also report more desire or need for these same services. Parents who report that their child is cured are less likely to report that they worry about their child's pain, death, body appearances or the child's possibilities of getting a cold or the flu. They also are more likely to report positive changes in many aspects of their lives: their own physical, mental and spiritual health, sense of personal identity, and the level and quality of their relationships with friends. In general, these reports indicate that parents whose children were still receiving treatment experience less help and more psychological frustration.

<u>Spouses/partners of adults with cancer</u> There is a total of 76 spouses and partners of adults with cancer in this population. Their age and income data parallel those of the population of the adults with cancer, with concentrations in the older ages and middle income categories. Like the other three populations, this one also is skewed

toward an overrepresentation of white persons. Somewhat like the parent population (but unlike both young adults and adults with cancer) there is a preponderance of females in this group (63%). Twenty-five percent of the spouses/partners of this group who are patients are currently receiving therapy, 31% are off all therapy, and 11% are reported as cured. Thirty eight percent of this population are spouses/partners of adults with leukemias, and 43% are partners of adults with lymphomas.

Items documenting satisfaction with staff and facilities were not asked of this population; however, seventy eight percent of these spouse/partners indicate that they played an active role in the medical care of their spouse, and 27% report that they had to intervene to prevent or correct a medical "mistake".

The spouse population's primary worries emphasize concern for their partners' physical health (pain, relapse, death and future treatments). The struggle to care for the rest of the family is next most common, as are closely related financial concerns (family finances, paying medical bills). Members of this population, perhaps as befits an older population, also report considerable worry about their own state of health or fatigue (49% report a lot or some worry about tiredness, and 54% report worry about getting enough rest). Both their concern about their own and their partner's physical and mental health is reflected in the interviews:

> It's harder for me when he feels better like right now. His mental state is hard to cope with. I don't know if you'd call it depression but when he's ill I can handle it better; he's easier to handle and to take care of when he's ill than well. I can handle the illness, but his depression that he's kind of going through now is very difficult for me. I feel like I bend over backwards and yet I'm always wrong.

> Well, I would say probably our relationship has gotten better although it's been an awful lot more trying cause the things we mentioned. I mean I got to constantly say "Can you do this now?" You know, you're always doing something, or you're not being supportive enough, or you're not this, and you never know if you're putting demands on somebody. I think we've investigated a lot of things like living and dying and getting along and sorting things out but we're still sorting things out.

Spouses/partners report significant positive changes in some aspects of their lives: spiritual well-being, and personal and social identity (sense of self, ability to accomplish things, coping with tragedy). A greater concern for others and an improved ability to work with and respect the medical system - all positive changes in relationships with others -- is also reflected in these data. The areas of greatest change for the worse involve lessened physical health, a loss of time with friends, as well as a lessening of one's own mental health and sense of control over one's life. Forty percent of this population report that they feel they handled their partner's illness "very well."

The services these spouses and partners <u>used</u> most often include information - about the treatment, about nutrition, and about insurance. Twenty-nine percent report receiving financial help from CLF. The most important <u>unmet</u> needs, areas in which people desire services that they had not used substantially, focus on psychological support or counselling - for worries, for coping, for one's partner, for handling stress and meeting with other families. Moreover, many of the same informational items that are most used also are listed prominently as matters on which people want even more assistance - a notable mandate for future service planning and development.

Female spouses report receiving a greater amount of various forms of help and social support than do males: emotional support (listening to private feelings), and practical support (assistance with transportation, accompaniment in taking action on their situation). In addition, spouses with more education report receiving more emotional support, and more help from hearing other spouses' similar experiences, than do spouses with lower attained educational levels.

Spouses in families with lower income levels report more worries about financial matters (paying medical bills and family finances in general) than do partners from wealthier families, and they also worry more about possible future treatments for their partners. In most other respects income levels do not demonstrate substantial differences in this population.

Finally, spouses who report that their partners are cured worry less about the effect of their partner's illness on the rest of the family, and they indicate many more positive life changes than those who report a different medical status. Spouses of cured adult patients report a more positive sense of their own identity, their spiritual health, their ability to cope with tragedy (a tragedy overcome - at least for the time being) and their relationships at work.

Education also appears to affect the service usage patterns of partners of the adult patients. Spouses with more education report using more psychological counselling, financial assistance and religious counselling than do those with less education. Finally, those spouses whose partners are still receiving treatment report greater need for psychological and marital/family counselling. It appears that the need for psychological services is greatest for adult patients and their family members when treatment is still active.

Views of CLF and CLF services

The data on these four populations' views of and experiences with CLF suffer from a serious problem: there is so much missing data with regard to CLF matters. Part of the missing data problem is an artifact of the sampling process used in the study. Since we deliberately sought to include in the overall sample approximately 50% of informants who are not registered with CLF, we can expect that a sizable portion of all four populations is not familiar with CLF and its services. In addition, even some of those who are registered with CLF, and may make use of some services, are not familiar with the entire range of available materials and assistance. Therefore, results describing CLF services and usage are useful but limited in their capacity for inference.

Twenty-four percent of the young adults with cancer report that a CLF representative was very or somewhat helpful to them, while 63% report no contact with CLF. The most popularly used programs appear to be those involving informational efforts, summer camps and parties and in-patient snack services.

Twenty-two percent of the adults with cancer report that a CLF representative was very or somewhat helpful to them, while 57% report no contact with CLF. Seventy percent of the adults indicate that they have heard of CLF, a percentage second only to those who have heard of the American Cancer Society. The media (28%), hospital staff (31%), and word of mouth from friends and family members (14%) are the primary sources of this information. Twenty one percent received financial assistance from CLF. Most adults with cancer make little use of other CLF services, aside from those focussed on hospital visits and information. CLF's information services also are among the most heavily desired services as well.

Eighty-nine percent of the parents of youngsters with cancer have heard of CLF, with the hospital staff (61%), media (17%) and word of mouth (23%) being the primary sources of this information. Twenty-six percent indicate that a CLF representative was somewhat or very helpful to them, while 51% report no contact with CLF. Twenty-three percent of this population report that they received financial help from CLF. The most significant CLF services used by the population of parents of children and young adults with cancer include informational materials (about treatments and general newsletter items), financial assistance and social or recreational activities for their children (including parties and summer camps).

Seventy-one percent of the spouses/partners of adults with cancer indicate that they have heard of CLF, with the hospital staff (32%), media (19%) and word of mouth (25%) being the primary sources of this information. Thirteen percent indicate that a CLF representative was very or somewhat helpful to them, while 66% indicate no contact with CLF. Twenty nine percent of these spouses report receiving financial assistance from CLF.

Table I-2 presents various populations' reports of their use of CLF services and programs, differentiated by a variety of background and medical status characteristics. For instance, young adult patients who are in remission report making more use of public information about their disease and treatment, and those who are off all treatment report having made greater use of summer camps. Many of these same factors appear to have a much more powerful and wide-ranging efect on the service usage patterns of parents of these young patients. Parents who are younger report receiving more help in finding community services, utilizing respite care programs, using financial and transportation assistance and participating in CLF-sponsored recreational activities than do older parents. It is unclear at present whether it is the parents' age that accounts for these service use patterns, or the age of their child, or both.

Parents whose children are off all therapy report greater use of many social and recreational programs, while parents whose children are still on treatment report less use of many of the same programs. One possible explaination for these dramatic patterns is that parents of children who are still receiving treatment may not have the time and energy available to discover and make use of services. On the other hand, it is just as possible that CLF does not find these parents and deliver services to them until they have been "in the system" long enough that their children are past the crisis stage of treatment.

Adult patients who are younger report more use of several informational services provided by CLF, as well as financial assistance from the Foundation, than do older patients. In addition, patients who are in remission report more use of patient information and physician referrals. Finally, patients with higher income levels report more use of family support groups than do patients with lower incomes.

Table I-2
Social and Medical Characteristics and Use of CLF Services By Varied Population Groups

Young Adult Patients
- In remission report more use of information for the public
- Off-treatment report more use of summer camps
- From less wealthy families report more use of financial assistance

Parents of Young Patients
- Who are younger report more use of:
  - help in finding community services
  - respite care
  - financial assistance
  - transportation help
  - of recreational activities
- From less wealthy families report more use of transportation help
- Whose children are still receiving treatment report less use of:
  - newsletter
  - help in finding community services
  - recreational activities
  - holiday parties
- Whose children are off all therapy report more use of:
  - family support groups
  - summer camps
  - recreational activities
  - holiday parties
  - community health fairs

Adult Patients
- Who are younger report more use of:
  - information for patients
  - information for the public
  - financial assistance
- Who are from wealthier families report more use of family support groups
- Who are receiving treatment report less use of physician referrals
- Who are in remission report more use of
  - information for patients
  - physician referrals

Spouses/partners of adult patients
- Who are younger report more use of:
  - financial assistance
  - home/phone contacts
- Who are from wealthier families report more use of family support groups
- Whose spouses are in remission report more use of information for patients
- Whose spouses are off treatment report more use of hospital visits
- Whose spouses are cured report more use of:
  - financial assistance
  - holiday parties

Patterns of service usage in the spouse/partner population mirror those of the adult patient population, with younger spouses, spouses from wealthier backgrounds, and spouses whose partners are in remission reporting similar usage patterns to the patients themselves.

Some of these same background and medical status variables differentiate various populations' desires or needs for additional services that may be provided by CLF. For instance, parents of the youngest young patients report greater need for CLF recreational and social events than do parents of older young patients. Parents with greater education report more need for information directed at the patients, and for participation in information or service oriented community health fairs, than do parents with less education. Parents whose children are still receiving treatment report greater need for various informational and social recreational activities. Additional information, for themselves and the public at large, also is desired by adult patients who are still receiving treatment - more so than by adult patients who are off all treatment. Moreover, adult patients who are still in treatment report greater need for assistance in physician referrals and transportation in treatment sites. Educational level, income, and the patient's medical status all differentiate service need in the spouse/partner population. For instance, spouses who are more highly educated report greater need for a lending library, physician referrals, family support groups and hospital visits than do spouses with less education. And spouses from wealthier families report more need for these same sorts of services than do spouses from less wealthy families. These two sets of findings confirm the high degree of association between education and income in this sample: those with higher education also are from wealthier families. Finally, spouses whose partners are off all therapy report greater need for information, family support groups, and hospital snacks and visits.

Although some of these patterns of CLF service usage (and desire for services) are intriguing, they must be treated with caution. The large amount of missing data in responses to these questions make the conclusions and comparisons tentative.

Comparing the four populations

Table I-3 presents basic demographic and medical background data on all four population groups. This table represents a synthesis of some of the text material presented earlier for individual groups. The mean ages for the four groups of informants are distributed as expected, given the sampling design and the distribution of questionnaire responses in the study. The average age at diagnosis of patients varies, of course, across age-based populations, but the distribution is of interest. The average age at diagnosis of the young adult population was 10.4 years, indicating that, when compared to their current age (17.5), many of those young adult patients are currently at least seven years post-diagnosis. Similarly, the mean age of adult patients reveals that they are, on the average, six years post-diagnosis. These findings suggest that the study attracted at least a fair number of "cancer survivors."

Table I-3
Background Characteristics by Population Groups

Background Characteristic	Young Adult	Parent	Adult	Partner	Sig.
			Population Group		
Age (years)	17.5	40.8	52.3	53.1	*
Age at diagnosis (years)	10.4	n/a	46.2	n/a	*
Educational level (years)	10.9	13.6	11.0	12.8	*
Family Income (thousands)	32.0	29.5	21.6	23.4	*
Marital Status (%)					
Married	2	83	84	94	*
Divorced	0	16	6	3	*
Residence (%)					
Metropolitan Detroit (CLF Region 1)	45	46	46	45	
Mid-State (CLF Regions 2-7)	44	42	46	44	
Out-State (CLF Regions 8-12)	12	12	9	11	
Treatment type (%)					
Chemotherapy	87	95	91	92	
Radiation	77	65	45	48	*
Surgery	35	31	37	41	
Blood transfusion	67	64	38	47	*
Bone marrow transplant	14	11	7	8	
Treatment status (%)					
Receiving treatment	18	27	29	24	
Off all treatment	43	53	38	32	*
Remission	65	72	48	59	*
Cured	32	25	15	12	*
Not sure	5	3	16	27	*

*Statistically significant difference in means at the .05 level, (using an F-test in an one-way ANOVA). This means 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. ANOVA and F-tests are analytic techniques used to test whether the differences are large enough to be statistically significant (not-chance).

Parents of youngsters with cancer are the most highly educated adult population group, with some college attendance (beyond 12 years of schooling) being typical. Adult patients typically have been limited to receiving a partial high school education, while their spouse/ partners have, on the average, completed high school. The higher family incomes of parents and families of young adults, who are younger than the adult patients and their spouses, appear to confirm the modern trend of higher average household incomes for younger adult wage earners. In addition, a substantial portion of the older patient and spouse/partner population is unemployed, underemployed, or retired, further accounting for these mean differences.

A substantial portion of the sample (45-46%) resides in the Detroit Metropolitan area, classified as Region 1 by the Children's Leukemia Foundation: this area includes Monroe, Wayne, Washtenaw, Livingston, Oakland, Macomb and St. Clair Counties. Another substantial portion of the sample (42-46%) resides in the Mid-State area, encompassing CLF's regions 2-7, cutting across the entire width of the state of Michigan at about the level of the thumb. A small (9-12%) portion reside in the Out-State area, which includes the rest of the state, the upper portion of the lower penninsula and the entire upper penninsula, and any non-Michigan responses. It is classified as regions 8-13 by CLF.

The distribution of patients currently receiving treatment is not significantly different across the four population groups, but the populations do vary in their reports of other treatment statuses. The young children of parents and the young adult patients are more likely than adult patients to be currently in remission (72% and 65% vs 48%), and off all treatment (53% and 43% vs. 38%). While the reported levels of cure are low (no doubt due, in part, to incomplete usage of this option on a multiple-response question), the young adult patients and parents of young children are more likely to report a cure, while adult patients and partners are least likely to have made that step in evaluating their own or their partner's treatment status. Persons not sure of their own treatment status, or that of their significant other, are most likely to be partners--those most removed from the actual treatment process. The differences in these populations' report of cured and not sure statuses also may be a function of the different prognosis for cancer in youth and adult populations. If, as current research suggests, childhood cancer is more often curable than is adult cancer, we might expect exactly these reports from these patients and their families. Young adults may indeed be more likely to be cured, while the same long-term remission status may merely permit older patients (and especially their partners) to feel unsure about their status.

Table I-4 compares the four population groups with regard to their worries or concerns. The data are presented in the form of means (averages) for each of the four population groups. The means are based on scores ranging from 1 (never worry) to 4 (worry a lot), so that a higher mean score reflects greater worry. The n/a entry in this and other tables indicates that not all questions were asked of all populations. In terms of concerns about one's own physical health, the most substantial significant differences appear to occur on the basis of age. Young adult patients express the greatest degree of worry about their own health related to others their age, and both

Table I-4
"Worries" Expressed by Population Groups

Worry	Young Adults	Parents	Adults	Partners	Sg
	Mean Report of Worries				
Own physical health					
Health relatives to others my age	2.31	1.91	2.051	2.03	*
Having headaches	n/a	1.94	1.65	1.95	
Getting tired	2.00	2.10	2.42	2.42	*
Getting (another) cancer when older	2.23	2.28	2.40	2.25	
Getting enough rest	n/a	1.88	2.15	2.44	*
Patient's physical health					
Having a relapse	2.34	3.15	2.72	3.26	*
Death	2.07	2.73	2.22	2.94	*
Pain	n/a	3.26	2.29	3.27	*
Future complicated treatments	1.85	2.25	2.13	2.48	*
Get cold or flu	1.82	2.52	2.35	n/a	*
Patient's future					
Can have children	2.22	2.62	1.30	1.32	*
Getting or changing a job	2.19	1.78	1.76	1.62	*
Staff relations					
Staff reaction to complaints	1.37	1.35	1.36	1.44	
Getting along with staff	n/a	1.52	n/a	1.75	
Social relations					
Losing friends	2.14	1.48	1.43	1.74	*
How body looks	2.57	1.93	2.01	n/a	*
Finances					
Family finances	2.34	2.67	n/a	2.73	*
Paying medical bills	n/a	2.32	2.41	2.39	
Getting life/medical insurance	2.01	2.33	2.04	2.05	

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*Statistically significant difference in means at the .05 level, (using an F-test in a one-way ANOVA). This means 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. ANOVA and F-tests are analytic techniques used to test whether the differences are large enough to be statistically significant (not chance).
n/a Indicates question not asked of the group.

adult patients and their partners (the oldest groups) express the greatest worry about getting tired and getting enough rest. No one group reports worrying about getting cancer when they are older more than the other groups, nor are there significant differences in concerns about headaches.

One's status as a patient or a significant other seems to be strongly related to the extent to which informants worry about their child or partner's physical health. Parents and partners worry more about their child or spouse having a relapse, dying, being in pain, or having future complicated treatments, than do the patients themselves; patients (young adult and adult) are less concerned with all of these issues. In the two patient groups, young adults consistently report even less concern than do the adult patients. Perhaps loved ones who must "watch" a serious illness worry more about such events; perhaps recovering and recovered patients simply are too busy coping to worry; or perhaps patients under-report or fail to disclose the real extent of their own worries and feelings of vulnerability in order to protect the feelings of these other family members.

The table also indicates a significantly higher level of concern about the possibilities of childbearing on the part of the parents and young adults. Quite logically, parents and young adults report significantly more of such worries because these young patients are yet to enter (or are just entering) a child bearing age interval. Since the older population (average age over 50) is beyond child bearing age neither partners or adult patients report having much concern in this area. The young adult popuation also is the one most worried about getting or changing a job--yet another common future concern for persons of a younger age group.

Table I-5 presents each population group's report of the amount of each kind of help they received. Responses were scored on the basis of 1 (no help) to 4 (a lot of help), so the higher means indicate more help received. The table indicates that partners report receiving significantly less of all types of emotional help: comfort or support, having someone listen to their private feelings, and being cheered up. It appears that they are the population whose emotional needs are most likely to be ignored, as the focus of help often turns to patients themselves or to the parents of young patients.

Partners also indicate lower levels of practical help received, although the differences here are neither as great nor as consistent as in the previous category. Adult patients report the greatest amount of practical help with cooking and household chores, and with transportation, while parents of young children report the most help with bills and medical expenses. These responses raise a question of need as opposed to usage: do parents of young adults express greater practical and financial needs than do partners of adult patients, and thus report receiving (slightly) greater help of this sort? Or do they simply receive more help?

Informational types of help are also reported at the lowest level by partners, as is help in taking action. Parents report the most help from hearing what others did in a similar situation and from being given information in general. Adult patients report

Table I-5
Kinds of Help Received by Population Groups

Kind of Help	Parents	Adults	Partners	Signif.
	Mean reports of help			
Emotional support				
Comfort and emotional support	3.18	3.14	2.53	*
Listening to private feelings	2.55	2.36	2.03	*
Cheering me up	2.83	2.90	2.30	*
Practical assistance				
Cooking meals and doing chores	1.66	2.40	1.74	*
Looking after the rest of the family	2.17	2.09	1.75	
Assistance with transportation	1.92	2.37	1.81	*
Help getting proper treatment	3.20	3.00	2.21	*
Help with bills and expenses	2.69	2.44	2.02	*
Focus on solving problems	2.25	2.20	1.79	*
Informational assistance				
Giving me information	3.09	2.83	2.38	*
Hear what others did in similar situation	2.24	1.96	1.90	*
Help in taking action				
Suggest action to take	2.17	2.19	1.73	*
Go with me to take action	1.72	2.42	1.55	*

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* Statistically significant difference in means at the .05 level, (using an F-test in a one-way ANOVA). This means 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. ANOVA and F-tests are analytic techniques used to test whether the differences are large enough to be statistically significant (not chance).

significantly more help in the form of someone going with them to take some action, and slightly more help from suggestions of action that should be taken.

There also are significant differences across the four (or three) populations in the level of helpfulness of friends and neighbors. Parents report more help from close friends and neighbors than does any other group, and adult patients report the lowest amounts of help from both these sources. In addition, parents and young adults report that other persons like themselves are significantly more helpful than do partners and adult patients. This suggests that the mutual support phenomena often observed in self-help groups, or in one-on-one discussions with those in one's own situation, may be more potent for those diagnosed with or associated with childhood illness than for those involved in adult illness. In contrast, considering the quite different extent to which these four populations report "no contact" with others like themselves (young adults - 27%, parents - 26%, adult patients - 44%, spouses/partners - 54%), it may indicate the relative lack of access to this potentially important source on the part of adult patients and their family members.

When asked whether they played an active role in the treatment process, 95% of the parents of young children with cancer answered affirmatively, compared with 76% of the adult patients and 77% of the spouses or partners of adult patients. Moreover, when asked whether they had to "intervene" in the medical treatment process at any point to prevent a "mistake" from being made, 43% of the parents answered affirmatively, compared with only 27% of the adult patients and 24% of the partners of these adults. These data suggest the primary relevance of the age of the patient, rather than the medical status of the informant, in understanding levels of participation or activism in the treatment process. Parents are most likely to be active in a caretaking or protector role with regard to their children.

In general, most of the mean reported levels of life change for all populations are between no change (scored as 2.0) and change for the better (scored as 3.0), as shown in Table I-6. Changes for the worse were scored as 1.0, so that higher means indicate more positive life changes. Most people report making positive changes in their lives as a function of coping with their own or their family member's cancer. Life changes involving one's own physical and mental health vary significantly, with young adult patients reporting more positive changes in their own physical and mental health than do parents, partners, or adult patients. This is an especially optimistic message about survival from the youngest population!

Some aspects of informants' changes in their relationships with others and their personal identity also vary significantly across the population groups. Family relationships, individuals' concern for others, their ability to cope with tragedy and their sense of who they are all change in a positive direction, but this is not significantly different for different populations. However, more positive changes in time spent with friends--echoing the findings on worries and concerns discussed above--and sense of personal control are reported by young adult patients. Of the three adult populations queried about changes in their relationships at work, adult patients report slightly more negative changes than do either partners or parents, and parents

Table I-6
Life Changes Reported by Population Groups

Life change (positive)	Mean reports of life changes Young Adults	Parents	Adults	Partners	Signif.
<u>Physical and mental health</u>					
My physical health	2.22	1.83	1.79	1.82	*
My mental health	2.34	2.07	1.99	1.96	*
My spiritual well-being	2.38	2.44	2.38	2.31	
<u>Relationships with others</u>					
Concern for others	2.55	2.55	2.40	2.36	
Family relationships	2.40	2.32	2.42	2.21	
Time with friends	2.24	2.11	2.07	1.89	*
Relationships at work	n/a	2.17	1.91	2.09	*
<u>Personal identity</u>					
Sense of who I am	2.38	2.36	2.27	2.23	
Ability to cope with tragedy	2.38	2.44	2.30	2.25	
Sense of personal control	2.36	2.04	2.03	2.00	*
<u>Action potential</u>					
Sense of what I can do	2.41	2.43	2.21	2.24	*
Willingness to join others for change	2.30	2.26	2.06	2.09	*
Desire to change the medical system	n/a	2.12	n/a	2.10	

* Statistically significant difference in means at the .05 level (using an F-test in a one-way ANOVA). This means 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. ANOVA and F-tests are analytic techniques used to test whether the differences are large enough to be statistically significant (not chance).

report more positive changes than the other groups. These data suggest the need for further analysis by gender, employment status, and treatment status--all characteristics which will be explored separately in later work.

One intriguing aspect of life changes over the course of an illness is the change in action potential the experience presents. Young adults and parents report the most positive changes in their sense of what they can do as individuals, and these same two groups report the most positive changes in their willingness to join up with others to change things. Perhaps the experience with childhood illness offers more opportunities to develop this sense of empowerment over such a volatile and challenging period of time than does the experience of a serious adult illness.

The general trend of these data are confirmed by responses to the question of how well they coped with the entire illness/treatment experience. Seventy-one percent of the young adults say they coped very well, compared with 53% of the parents, 66% of the adult patients, and 40% of the spouses providing this response.

The data in Table I-7 compare reports of usage and preference regarding varied information and services. In terms of information services, young adults report the lowest use of information about diet/nutrition and about health insurance, and the highest use of career information. Young adults also report the highest interest in additional career information and family planning information--quite logical for people in this age group. Parents of youngsters report the greatest use of practical and relevant information about both health insurance and illness/treatment. The levels of use of illness/treatment and nutritional information are quite high for all population groups, signalling a common concern by all those diagnosed and all their family members.

Significant differences between the four population groups also are evident in the counselling services for which they report usage or in which they express interest. Parents of young children and adolescents express the most use and interest in various forms of psychological counselling. Partners of adult patients generally report making less use of various counselling services than do adult patients, but these partners indicate a substantially greater desire for such services than do the patients themselves. The higher level of desired counselling services reported by parents and partners probably is a response to their higher (higher than youthful or adult patients) level of reported worries about their loved ones' condition and future.

Parents report receiving more help with medical bills than do partners or adults, although overall assistance from health insurance plans is quite high for all three groups. It is evident that parents of young children receive special help from the state's Crippled Children Program and from Medicaid. Differences between study populations in Medicare assistance--reported as significantly lower for parents--are clearly an artifact of informant age. Informants do not differ in the extent to which they receive help with medical bills from their families or from CLF, the other major sources of assistance. Financial aid from the Hodgkin's Disease Foundation was virtually non-existent, as was aid from the Leukemia Society of

Table I-7: Information and Service Usage and Need by Population Groups

	Percent used					Percent would use				
Services	Young Adult	Parent	Adult	Partner		Young Adult	Parent	Adult	Partner	
Information										
About illness/treatment	43	64	49	50	*	15	15	20	21	
About diet/nutrition	23	31	34	25		17	30	18	20	*
About health insurance	10	28	15	20	*	27	21	27	25	
About family planning	6	5	3	3		23	4	11	11	*
About careers	14	4	7	n/a	*	40	23	13	n/a	*
Counselling										
Assistance with stress	7	25	11	8	*	20	34	23	28	
Psychological - during hospitalization	23	29	16	12	*	8	17	9	21	*
Psychological - for learning to cope	19	25	15	11		7	26	11	29	*
Psychological - for worries	15	23	14	7	*	17	27	18	33	
Religious	17	37	23	24	*	8	12	3	13	
Genetic	2	5	3	3		17	22	13	14	
With job problems	2	5	4	1		15	14	10	12	
For family	7	12	5	9		13	19	8	13	
Other services										
Meeting with others in situation	14	36	18	11	*	24	24	16	26	
Financial assistance	19	41	13	13	*	17	18	23	24	
Legal advice	5	5	4	8		8	10	17	15	
School advice	24	31	5	n/a	*	18	17	10	n/a	*

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

Michigan and the American Cancer Society, and this does not vary across groups.

With specific regard to use of CLF services, the greatest use and interest in future use are reported consistently by parents and young adult patients. This is especially true of services and programs with an information focus. The levels of use of physician referrals, medical equipment, financial assistance, and snacks for hospital patients also are somewhat higher for parents and young adult patients. Their continued interest in additional CLF services also is generally higher, except for financial assistance; in this latter category, adult patients and partners express a greater need for additional CLF services.

Registration Status

This needs-assessment study was conducted with a sample of patients (and their families) who are not registered with the Foundation as well as with a sample of the registered population. The reason for this choice was to provide a data base that might expand our understanding of the needs of the population at large affected by leukemia, lymphoma, and related illnesses. An examination limited to registered families stays within the paradigms of service and care that already have been established; inquiry with a non-registered population may expand these horizons. Moreover, information from the non-registered population may shed light on why and how CLF is attractive to some people and not to others, how it may serve others it does not yet serve, and what new service directions might be considered.

There are two possible working definitions of registered and non-registered status: (1) CLF's records of names on file with the Foundation; (2) informants' self-reports of whether or not they are registered with the Foundation. CLF's records are clear; whether accurate or not, they provide a clear yes-no choice for everyone in the final sample. The self-report data are not as clear; in addition to accuracy issues, some informants report that they do not know whether or not they are registered with the Foundation, providing a "Don't Know" as well as "Yes-No" categories.

There are very few statistically significant differences between those young adults with cancer who are registered with CLF (according to CLF's records) and those who are not. The registered subgroup does report, however, more help from the social worker, and the non-registered group reports several more favorable life changes. The key explanation for this set of findings may lie in the evidence that the registered subgroup is significantly less likely to report that they are cured (18%) than is the non-registered subgroup (43%), and more likely to report that they are still receiving treatment (31% vs. 8%); thus they probably have greater current needs for help and a less favorable general outlook.

There also are some statistically significant differences between registered and non-registered (according to CLF records) adults with cancer. The registered population reports more medically related worries (dying, future treatments) and more concerns about their finances than does the non-registered subgroup. They also report, either as a cause or an effect of their registration with CLF, a greater satisfaction with social work services and with assistance in obtaining needed community services. The registered subgroup of adults with cancer also indicates receiving more support from various sources, such as friends and parents and co-workers, as well as social workers and CLF representatives, than does the non-registered subgroup. This pattern may reflect the tendency for some people to "go public" with their concerns and to ask for help -- by contacting social workers and social service agencies, by asking friends and family members for assistance, and by registering with CLF. Consistent with this pattern, adults' reports of their utilization of various services indicate that registered adults are more likely than the non-registered subgroup to use informational, financial, and family counselling services. The combination of greater felt need, greater willingness to ask for or seek aid, and greater access to those agencies and persons that can provide assistance may explain these outcomes.

The subgroup of parents of young people with cancer who are registered with CLF reports more worries about their child's medical condition and less positive life changes than does the non-registered subgroup. As was the case with the young adults themselves, however, a much greater proportion of non-registered parents indicate that they feel their child is cured (35% vs. 12%), and this may explain in very direct terms why the non-registered subgroup is more relaxed and experiencing greater positive growth in their lives. Similarly, registered parents make more use of psychologically-oriented services (not shown), those that may serve to reduce their worries and increase their coping capacities. In the interviews several registered parents elaborated on the value they found in their association with the Foundation and with Foundation activities:

> It's neat because it's something that you can do - because I think that it's the hardest thing of all, being a parent of cancer patients - there is nothing that you can do. I felt so hopeless and helpless: you can't kiss it and make it better - there is nothing to do. If making a batch of cookies helps with cancer research then fine.
>
> We did belong to the CLF - and we were in the local chapter, and we did fund raising things. Along with the fund raising, at least you were sitting next to someone, and you could talk to them too. I think it was settling, because then you could call and talk to somebody - you had a roster to go from.
>
> The CLF would help pay for prescriptions that you needed if you had leukemia, but if you had a headache, you couldn't get asprin, or something like that. But, at least it was some help. And I do know that the hospital let them know if they could help some people. It would ask them, you know, as tactfully as you could, if they needed financial aid. Some people need someone to talk to, because some people don't have anyone to talk to.

Finally, the registered subgroup of spouses reports more worries on many of the items queried, most notably in their staff relationships (getting along with the staff and concern that the staff might become unhappy if they complained), and financial matters (paying the bills, our finances in general and getting/keeping a job). They also, however, report more positive life changes, especially with regard to respect for the staff. This is an apparent contradiction to their greater worry about staff relationships, although it may reflect the distinction between having worries at a certain point in time (perhaps early in the treatment process) and reporting change in feelings about those issues over time. Financial assistance appears to be used more often by registered spouses than by non-registered spouses.

Consistently, registered populations indicate that the social worker and the CLF representative are more helpful to them than do non-registered populations. Moreover, registered populations consistently report receiving more help from various sources and of various kinds than do non-registered populations. The only exception to this trend is in the case of spouses of adult patients, where non-registered informants report more help from their doctors and their own children than do registered informants. If we understand registration to be an indication of a need for help, or of a willingness to go public with one's need, then the relationship between registered status and the receipt of greater amounts of help from other sources makes good sense.

Registered adult patients and their spouses, and registered parents of young patients, all report higher levels of concern about future complicated treatments and/or dying, and about interactions with the medical staff, than do non-registrants. Thus, it is no surprise that non-registered informants report more positive life changes. Both findings may reflect the fact that the non-registered informants more often report being cured and experiencing less consuming treatments (they or their family member who is a patient). The registered populations are younger than the non-registered populations and more often still in the midst of the treatment process; perhaps they also are experiencing a more difficult course of treatment.

We indicated previously that there are substantial amounts of missing data, instances wherein informants did not answer the question, in the section of the questionnaire regarding use of (and desire to use - need for) CLF services. In general, the rate of missing data is higher among non-registered informants than among registered informants. Among those who do respond, adult patients and adult spouses/partners appear to make much less use of CLF services than do young adult patients and the parents of young patients. The adults and their spouses/partners also express less desire/need for CLF services, in all probability reflecting their level of knowledge and access to services as much as their real level of need. After all, the non-registered sub-populations systematically (e.g., in all four population groups) report less use of services than do the registered populations. The fact that the greatest number of significant differences between registered and non-registered sub-populations occurs in the parent sample suggests that this is the population toward which CLF probably targets most of its services and literature; as a result it is here where registration makes the most difference.

Program Implications

The results of this needs-assessment have important implications for the programs and services that might assist families experiencing leukemia and lymphoma, and for the Children's Leukemia Foundation's efforts to provide such services. Chapter VI of the Final Report discusses these implications and program suggestions in some detail, but they are briefly summarized here. The major policy implications concern the following areas:

Family-based services
Financial assistance
Informational services
Psychological counselling and support
Education of health care staffs
Specific services for specific populations
Awareness and outreach services of CLF
Liaison with medical staffs

Continuing research and evaluation on psychosocial issues and services

The findings indicate that all family members are affected powerfully by the diagnosis and treatment of cancer; almost everyone worries, tries to cope well, seeks social support, experiences some loneliness and awkwardness in social relations, struggles to relate well with the medical staff, etc. In addition, people's relationships with their loved ones - their spouses, children, parents and siblings - are affected. Services should be designed in ways that speak to these family-based needs, and that do not overlook the integrity of family life by focusing solely on the patient.

Financial assistance programs comprise a substantial portion of CLF's current services to families experiencing cancer, and it appears that this is a necessary and important service to continue. In addition to direct financial assistance, families also need help in deciphering health insurance procedures and policies and in establishing future health and life insurance programs. This is an especially important priority for young adults. As they enter the work force they need independent health and life insurance coverage, but may experience difficulty in getting such coverage due to their cancer history and insurers' reluctance to provide equitable and financially affordable policies.

The Foundation's informational services, reflected in newsletters and a lending library, are well used and appreciated. So, too, are the efforts that physicians and health care staffs make in this regard. At the same time, patients' needs for information are immense and continual, and many informants express a need for even greater information - about their disease and treatment, about social support systems, about diet and nutrition guidelines, and the like. The expansion of such services seems appropriate.

Psychological counselling and support services are desired by many groups of informants, cutting across all the patient and significant other populations. Services to meet these needs must be varied in nature, including facilitating access to professional counselling, operating seminars or workshops in stress management, creating one-to-one visitor linking chains or telephone trees, establishing and promoting mutual support or self-help groups, assisting the organization of family and friendship networks, and generating public education programs that make it easier for families with cancer to get support from other community agencies. Since medical staffs' abilities to fund and provide such programs are very limited, CLF's role in meeting these needs is vital.

Despite the generally high regard informants have for their physicians and nurses, they express a number of important concerns about the manner in which health care is delivered. Programs that attempt to (re)educate medical staffs with regard to patients' psychosocial needs, to support the modification of grotesque medical bureacracies, to encourage new forms of sensitive and caring interaction between patients and caregivers, to supplement the training of new generations of providers, all could lead to more humane and caring staff operations. Educational materials, patient-agency-staff feedback sessions, special presentations to clinic staffs, and workshops and seminars are examples of the context within which such (re)education might occur.

The findings of this study indicate that specific populations, or sub-populations, have some specific needs that require special programming. For instance, the spouses of adult patients consistently report feeling that they receive little help and often are left out of necessary services. Over and above the services that all groups need, this population requires special services that address their particular concerns as caretakers, advocates, supporters, etc. Young adult patients also express some needs particularly relevant to their experiences and developmental status: assistance and advice with schooling, with career preparation, with family planning and genetic counselling. Long-term survivors of cancer (children and adults) need special programs to help them find knowledgeable and sensitive medical services outside of major cancer treatment centers, to help them cope with the long-term worries and psychological concerns that typify their recovered or "cured" status, and to help them deal with social agencies that discriminate in educational, employment or insurance opportunities. People of color - Black people and people of Hispanic origin especially - are dramatically underrepresented in this study, despite the fact that a substantial percentage of these samples come from the Metropolitan Detroit area. Their needs are not addressed in this research, and their absence from the sample, and parenthetically from CLF's registration lists or from the patient lists of the clinics CLF has had access to, indicate the presence of a serious problem in equal or equitable access to Foundation programs. Male parents, too, fathers, are seriously underrepresented in the sample: here, however, one can begin to derive the special programs that might suit their needs from the data that is present. Finally, another underrepresented sample is comprised of those many patients and family members who are not touched by CLF's current network. The data from the non-registered sample speaks to this population's needs, since non-registered informants were, prior to their inclusion in this sample, outside CLF's net. The same procedures that were utilized to gain access to non-registered families for the purposes of this needs-assessment study can be expanded to reach others and to swell CLF's roster of people to whom it wishes to provide services.

General public awareness of CLF, at least within the communities of people who are concerned about cancer, is high. But knowledge of CLF's particular services, and access to them, is not as widespread or as positive. The name of the Foundation presents problems for some people. For instance, some adults do not think about relating to the Foundation because of its title as The Children's Leukemia Foundation; some people with lymphomas or other diseases do not think about relating to the Foundation because of its title as The Children's Leukemia Foundation. Aside from these issues, CLF can gain from a greater public relations presence and from broader presentations of its services, and the utility of these services to people in families facing leukemia and lymphoma.

In addition to general public education, CLF can meet many of its objectives better by expanding its liaisons with clinics, hospitals and medical practitioners throughout the state, as well as with other social service agencies. In this way it can increase the possibilities of professional referrals and can establish contact with larger populations of people affected by these diseases and in need of services.

A final program priority is to continue the needs-assessment work begun here. Although the scope of this research and needs-assessment effort is quite broad, it does not touch all the important issues or all the important populations of concern to the Foundation. For instance, no data has been collected from agency personnel or medical and psychosocial service providers. Thus, their perspectives on the needs and service priorities of patients and family members experiencing leukemia and lymphoma have not been discussed. These staffs' views also would be helpful in understanding some of the reasons why service gaps exist, as well as providing vital information for planning new services and programs. In addition to raising additional questions with additional populations, further research also could serve a monitoring/evaluation function, providing patients, family members, Foundation staff and medical staffs with feedback on their progress in meeting the needs of families encountering leukemia and lymphoma.

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