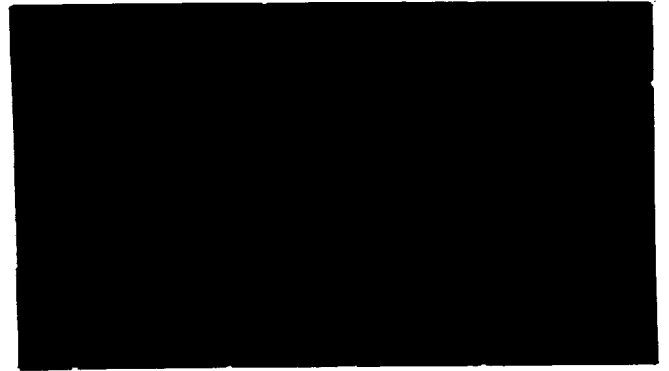# CRSO

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SERVICE USAGE AND NEED:
REPORTS FROM PATIENTS AND
SIGNIFICANT OTHERS DEALING WITH
LEUKEMIA AND LYMPHOMA

Timothy Lawther, Mark Chesler,
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WORKING PAPER SERIES

A Report to The Children's Leukemia Foundation

Service Usage and Need: Reports from Patients and Significant Others

Dealing with Leukemia and Lymphoma

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SERVICE USAGE AND NEED: REPORTS FROM PATIENTS AND SIGNIFICANT OTHERS DEALING WITH LEUKEMIA AND LYMPHOMA

I. PSYCHOSOCIAL NEEDS/SERVICES IN LEUKEMIA/LYMPHOMA

The experience of cancer is threatening to the physical, psychological and social well-being of patients and family members. Recent research in this area has elaborated the concept of "psychosocial morbidity" (Cohen, 1982; Fobair & Mages, 1981) to draw specific attention to the challenges normally triggered by a diagnosis of cancer. This welcome addition to a prime focus on biophysical treatment or physical rehabilitation has encouraged the development and expansion of mental health services.

Certainly adequate psychological counselling and mental health services must be made available for people experiencing morbid symptoms of clinical depression or dysfunction. But at the same time, as Rainey & Cullen (1981) note,

> ...much more attention needs to be given to developing psychologic perspectives on those who cope well with the disease...Much attention has been focused on the psychosocial casualties of cancer, but little has been said about the much larger group of patients and families who cope adequately with cancer. It is not enough to refer to them as being 'within normal limits' or 'without significant psychopathology' (p. 41).

Thus, it is important not to approach these issues or this population solely with a concern about negative effects and mental illness or morbidity. We also need to support mental health and encourage positive effects. Psychologically normal and healthy people, like anyone else, are likely to be severely challenged by the diagnosis and treatment of cancer. Indeed, everyone experiencing cancer needs assistance in dealing with this substantial threat and challenge to their life and lifestyle.

One way of understanding the psychosocial issues faced by patients and family members experiencing cancer is to conceive of a series of threats or stresses that typically accompany the disease. In addition to the medical issues of life and death, of debilitating treatment, of continued

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clinic visits or hospitalization, of surgery and perhaps extended radiation and chemotherapy, there

are a series of related psychosocial stresses. Figure 1 illustrates some of these typical

psychosocial stresses faced by the patient and by close family members - "significant key others"

in Goldberg and Tull's language (1983).

Figure 1
Psychosocial Stresses Experienced by Patients
and Family Members with Cancer

Categories of stress

Informational
Confusion
Ignorance about where to go for treatment
Ignorance of medical terms
Ignorance about where things are in the hospital
Uncertainty about who the physicians are
Lack of clarity about how to explain the illness to others

Practical
Disorder and chaos at home (cooking, chores, childcare)
Financial pressures
Lack of time and transportation to the hospital
Need to monitor treatments
Difficulties at work

Interpersonal
Spousal relations
Needs of other family members
Friends' needs and reactions
Relations with the medical staff
Behaving in public as a person (spouse/parent) with cancer

Emotional
Shock
Lack of sleep and nutrition
Feelings of defeat, anger, fear, powerlessness
Physical or psychosomatic reactions
Worry about the future

Existential
Confusion about "why this happened to me/us"
Uncertainty about the future
Uncertainty about God and fate

In their attempt to deal with this potent range of psychosocial threats and stresses, people need and use assistance in the form of various kinds of social support and social services. Substantial research indicates that members of a social network may provide patients and family members with several different kinds of support: tangible material support, affirmation of their identity, emotional support, information and social affiliation (Bloom, 1982; Gottlieb, 1978). Clearly some kinds of services and supports are more or less relevant to particular stresses. For instance, information provided by the medical staff is most likely to ease a person's informational stress, but probably not affect practical problems. The provision of financial aid or transportation certainly can ease practical stress, but it is not likely to affect the emotional ups and downs of hope and fear related to the illness.

Several major research studies suggest that informal support from family members, friends and neighbors can lead to better health outcomes, both in terms of mental health or psychosocial adjustment and in terms of physical rehabilitation or recovery (Bloom, 1982; House, 1981). Each person who is part of a social network may expect members of that network to be helpful during this time of great stress. However, not everyone receives help from their social network. Some people may not be part of an active and responsive network. Even more problematic, some social network help is not very helpful, and may make matters worse by providing help with pity, by imposing bargains and conditions, or by imposing a stigma of weakness on the patient or family member (Bloom, 1982; Chesler & Barbarin, 1984; Wortman & Dunkel-Schetter, 1979).

In addition to these informal sources of social support, professional health care systems and community agencies also can provide useful psychosocial services to patients and family members. Some of the organized services that appear to be most vital and useful include information (Blanchard, *et al*, 1988; Dyck & Wright, 1985; Goldberg & Tull, 1983); psychological counselling (Goldberg & Tull, 1983); and access to group meetings with other patients or family members (Fobair & Mages, 1981; Goldberg & Tull, 1983; Holland & Rowland, 1983; Kupst *et al*,

1984; Monaco, 1988;). Help from other people like themselves may be especially useful, as Holland and Rowland (1983) argue:

> 'Veteran' patient support should be encouraged. The psychological gains from ventilation and discussion with others who have had the same tumor and similar treatment has proven increasingly valuable (p. 30).

All of these suggestions are made across the board, for patients of almost all ages. Moreover, it often is urged that they be provided on a family basis, to all members of a family and not merely to patients (Ell *et al.*, 1988).

In this report we examine the kinds of social services that are most needed by and used by a sample of patients and family members experiencing leukemia and lymphoma. As part of a needs-assessment study of families experiencing these forms of cancer (Chesler & Chesney, 1989), informants were queried regarding their patterns of use of, desire for and total need for a variety of informational and counselling services. The following list of services was presented to informants:

Career information
Advice about school
Information about the illness and/or treatment
Information about diet and nutrition
Information about health insurance
Family planning information
Legal advice
Genetic counselling
Psychological counselling during hospitalization
Psychological counselling for learning to cope
Psychological counselling for worries
Religious counselling
Marital/family counselling
Assistance in handling stress
Help with job problems
Meetings with other people in similar situations
Financial assistance

Informants were asked to indicate whether or not they had used such services, and whether or not they had a desire to use such services.

These questions were answered by a representative sample of four population groups experiencing leukemia or lymphoma in the state of Michigan: 91 adult patients (ages 26-80), 88 young adult patients (ages 14-25), 78 spouses or partners of the adult patients, and 161 parents of children and young adults with cancer (both of the 88 young adult patients and a number of children with cancer under the age of 14). The inquiry methods, sample and additional findings of this study are described by Chesler & Chesney (1989; 1989a).

II. THE MEANING OF SERVICE NEED AND USE

The investigation of the use and utility of supportive services for people in need can be pursued in many different ways. In this report we distinguish between informants' use of services and their desire for services. On this basis we develop indicators of total need for services, and the existence of unmet needs.

Use of services simply refers to informants' reports that they have used a particular service, and it presumably points to needs that are being met by social service agencies and their programs. Informants' desires for services refer to reports that they would like to use a service, but have been unable to do so for various reasons. These reasons may include a lack of available services and programs, an individual lack of access to locally available services, or an unwillingness or hesitancy to make use of services that are available.

Both use and desire for services point to very specific aspects of service provision. When combined, they indicate the services most needed by people experiencing leukemia and lymphoma in their family. For instance, if 10% of the adults with leukemia report that they used a service and 40% would like to use the service, the total need for that service is 50%. Thus we use the term need (or total need) to include those reports of a use of a service *and* those reports of a desire to use a service.

Finally, and perhaps of greatest import to social service agencies, is a measure of unmet needs. We consider a need to be unmet when the percentage of people reporting a desire for a service is higher than the percent reporting its use. For example, if 10% of the parents of children with leukemia/lymphoma report that they used a service, and 40% would like to use the service, then that service need will be considered unmet for 30% of that population. By viewing needs in this light, we highlight those services that seem to be most drastically unmet in a significant portion of the population, and that social service agencies and clinics should attend to immediately.

III. THE SERVICE NEEDS AND DESIRES OF VARIOUS POPULATIONS EXPERIENCING LEUKEMIA/LYMPHOMA

In this section we present the most common services used and desired by each of the four population groups queried in this study -- parents of children and young adults with cancer, spouses or partners of adults with cancer, adults with cancer and young adults with cancer. We then emphasize the differences and commonalties in service need across the four populations. Tables 1-3 present basic information on the percentages of parents, partners, adult patients and young adult patients who report, respectively, need, use and desire for various services. These tables also indicate occasions when the four different populations report substantially different patterns of use and need for specific services.

Parents of children and young adults with cancer

The parents in this study report that information about diagnosis and treatment is their most common need, with 85% reporting that they have used or would like to use this service. Several examples of the need for information and the continuing (or even increasing) need for information are expressed in the extended interviews with parents:

> What I got I had to search for, except that the first or second day she was admitted they brought these little type-written papers with a little bit of information, but not much. I learned more when she was at school, because whenever she had to write a paper on anything that's what she wrote on and I read them. She did her own research basically.

> They (the medical staff) don't realize that at the time they give you information you have blinders on. You have hands over your ears because your heart is on the table. You can't deal with anything right then, but then maybe you want to follow it up later.

> I want information now, but I didn't want it then. They threw a million books at me but I said just, "Get away from me." I didn't want anything then, but you know, I think I want it today, because of the fear I have of it coming back.

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Information about diet and nutrition (66%), financial assistance (66%) and meeting other parents (65%) also are widely needed by parents. Approximately half (50%) of the parents also report a need for insurance information, religious counselling, advice about their child's schooling, and counselling for learning to cope with their problems and dealing with their stress.

Some examples of their needs for financial information and assistance also are reported in detail in the interviews:

> With their sophisticated treatment and the miracles that come, and the financial need of bone marrow patients, the bill was over $100,000. We would have been wiped out financially if we had not been offered a great deal of freedom of communication and ease of facilitation of offering financial aid -- because the first year of treatment would have just, like I said, blown us off the map as far as money.

> There was only money and help to pay the bills. I mean there wasn't time to go K-marting. That's where we spend a lot of dollars. We didn't buy groceries at all for the whole summer. My daughter would eat at my mother-in-law's or when we were all home. I bet you I spent maybe $50 on groceries the whole summer. Friends brought stuff over or we'd eat stuff out. She wasn't out of the hospital that much. She was in the hospital for most of that time.

And the need for advice about schooling was expressed as follows:

> There was no directive from the administration...there was no effort on the administration's part to take the teachers aside and say, "Look, this is a special case -- you need to have a special system."

> The problem we had was that he was in high school and we had trouble getting help for him -- he was studying and wanted to go to college, and he didn't get the help he needed with his math and his chemistry -- and there weren't any tutors! We worked it out some so that the hospital teacher would help him when he was in for treatment -- she said to just call her and tell her when we would be there, and she would help. And we went to the principal to try to get help and we could not get help. They said, "What do you want us to do?", and I said, "Well, we want help for this boy so we can get some proof -- so we've got some confidence that he can go to college."

> We had trouble with the board of health. When I enrolled my daughter in kindergarten she didn't have shots. She couldn't have any of those shots when she was younger and they wouldn't let her in school because she didn't have her shots. There was just a lot of red tape getting letters explaining why she couldn't have her shots. And I know it's going to happen again because she's starting high school in the fall and we have to go through it all over again.

Her greatest complaint...she got very emotional a couple times after school, was the kids treating her different. She said, "They act like they don't want to talk to me or they think I'm going to die over their talking to me. There are kids that just avoid me. I walk up and they just want to talk about other things."

As expected from the above findings, information about diagnosis and treatment, financial assistance and meeting others also are among the most widely used services by parent informants. Over two thirds (69%) of the parents report that they have received information about diagnosis and treatment, 45% have received financial assistance, 39% indicate that they have met with other parents and 40% have used religious counselling. Overall, a relatively high proportion of the parent population indicates that they used many of the listed services.

Parents also report relatively high levels of service desire. Over one-quarter (25%) of these informants indicate that they would like to use information about careers, assistance in coping, assistance in handling stress, meetings with other parents, information about diet and nutrition and insurance information. These are services that a significant number of people have not used, but for which they do have a need.

Only two of these 12 service needs clearly are unmet in the parent population: career information and assistance in dealing with stress. Five percent of the parent informants used career information and 26% would like to use it, resulting in 21% of the parents whose needs for career information are presently unmet. Although 27% of the parents have used stress assistance, 38% report desiring it, indicating that 11% of this population's need for this service is unmet. This is a fairly minimal indication of unmet needs; it appears that parents generally are being well-served by local agencies/clinics and programs.

Partners of adults with cancer

Partners also have a high level of need: information about diagnosis and treatment, insurance information and information about diet/nutrition are the three most widely reported needs in this population, with 81%, 53% and 52%, respectively, reporting that they have used or

would like to use them. Each of the remaining services (except for career and school information, which were not asked of the partners) are needed by more than 40% of those responding.

Information about diagnosis and treatment is by far the single most widely used service in the partner population, with 57% reporting its use. Approximately one-quarter of the partners have used religious counselling, insurance information, and information about diet/nutrition. Partners report very little use of services focused on helping them cope better or on assisting them in handling stress.

There are several services that relatively large portions of the partner population indicate a desire to use. Six stand out: counselling for worries (40%), assistance in handling stress (38%), counselling to learn to cope (35%), meetings with other partners (32%), insurance information (30%) and financial assistance (28%).

In the partner population, the most drastically unmet needs focus on psychological counselling: counselling to deal with worries (32%), in handling stress (27%) and counselling for learning to cope (22%) are substantial unmet needs in this population. Some examples of this unmet need are reported as follows:

> My wife and I...could not help ourselves in this situation, and we were very disappointed with the lack of holistic treatment approach at the hospital. I mean the support was rather minimal. There was a chaplain and someone else who came around, but when you asked for help they kind of looked at you like, you know, "Why are you asking for help?"
>
> Well, they have a "cope group", but being as far away as we were, we didn't go.
>
> As far as I know, no one from the hospital ever came to us and asked us how we were doing or whether we wanted help. A social worker never even took an inventory of us and no one tried to be concerned about this aspect of it...you know, the emotional and coping problems that people in this situation have.

The need to meet with other partners (19%), for financial assistance (12%) and for insurance information (7%) are also unmet for this population.

<u>Adults with cancer</u>

There are three predominant service needs expressed by adults with leukemia/lymphoma. Information about diagnosis and treatment is reported as a need by 76% of the adult patients. Examples of the specific meaning of this need are available in the interviews with adult patients:

> I wanted just to ask questions. The day I was diagnosed I, myself, called our family doctor at the time, a hematologist at the hospital and another friend, a physician friend. My desire is to ask as many questions as I can.

> There was one doctor, one attending, who was recommending that I not have this second and third round of chemo, that maybe I could get by without it. Well, if I had known that I might have said, "Forget it," and just gone through that once, instead of three times. I guess it is a tough decision, but I think if you want the information you ought to get it straight.

> I kept asking for material to read and I really didn't get it.

Information about diet/nutrition and insurance information are reported as needs by approximately half (59% and 47%, respectively) of the adults surveyed. A need for financial assistance (42%) and meetings with other adult patients (39%) are also important needs in this population.

The most widely used services are information about diagnosis and treatment (54%), information about diet (38%), and religious counselling (26%).

Insurance information, financial assistance and assistance in handling stress are desired by approximately one-third of the adult informants (30%, 27% and 27%, respectively). Information about diagnosis and treatment is desired by 22% of this population and meetings with other patients are desired by 19%.

Several service items could be considered unmet needs with respect to the adult population, although they are not very substantial. Most prominent are financial concerns, those focused on information about insurance (13%) and financial assistance (12%). A need for assistance in handling stress appear not to be met in 14% of the adult patient population. Two examples of the need for assistance in handling stress are available from the interviews: one informant reports that this need was met and the other informant reports that it was not met:

If it was forthcoming it would be good to get someone to take care of mental health issues, and to get someone to work with my family and spouse.

Fortunately I now have the time to deal with headaches caused by muscle contractions from stress. I went to biofeedback for three or four months and I went to a neurologist to learn to relax and it's really great!

Young adults with cancer

The youngest population in the study reports that the service they most often need is information about diagnosis and treatment (64%). Second most vital is career information, with 57% of the young adult patients reporting use or desire for such assistance. School advice, information about diet and nutrition, meetings with other young patients, financial assistance and insurance information are reported as needed by over 40% of these informants as well.

The young adult patients report that information about the diagnosis and treatment is the most widely utilized service (48%). School advice, financial assistance and information about diet and nutrition are the next most widely utilized services, although less than 30% report using any of these services.

Young adults have a strong desire for career information: 42% report that they would like to use this service. Insurance information and meetings with other patients are other relatively highly desired services (29% and 26%) in this population.

There are several needs that are not being met sufficiently in the young adult population. The need that stands out is career information: 27% of the aggregate population reports that their needs are not met with respect to this issue. This is the most needed service reported by young adult patients and, unfortunately, also is the one need most likely not to be met by current service programs. The desire for additional career information is no doubt stimulated by concerns about the future employability and job discrimination. In the interviews two young adult patients addressed these concerns as follows:

Dealing with jobs is tough and it's hard deciding whether to tell the employer that you're sick.

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At first, I needed a job in the summer so badly that I didn't tell them and I think
that I should have. But I was afraid I wouldn't have gotten the job.

Insurance information is the other need most likely to be unmet in the young adult population

(18%), and assistance in handling stress and meeting other patients are reported as unmet by at

least 10% of this group. The desire for additional meetings with other young adults with cancer

also is addressed in detail in the interviews:

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

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

Comparing the four populations

The four different populations of people impacted by leukemia and lymphoma report some

different service needs, both in the aggregate and with regard to specific services. In this section

we compare the responses of the four populations to discover their commonalties and differences.

Table 1 presents comparisons among the four populations with regard to their expressions

of (total) need for services, an aggregate of use of services and desire for services. The table

indicates the percent of each population reporting a need for each service, and whether the

differences in percentages among the four populations are great enough to be statistically

significant: that is, whether the difference could have occurred other than by chance. This table

indicates that parents and partners generally express the greatest needs for service: over 50% of

the parents report a need for 11 of the 12 services listed, and over 40% of the partners indicate a

need for all 10 of the services they were asked to consider. The percentage of parents expressing

these service needs is consistently higher than that of any other group, except for young adults'

expressed need for career counselling. Both patient populations (young adults and adults)

consistently report (statistically significant) less need for almost all services.

Information about the disease and its treatment is universally reported as the most common need by all four population groups. A significantly higher proportion of parents report a need for financial assistance, for meetings with other people like themselves, and for information about treatments. Many more parents and young adults report a need for services related to career and school counselling than do partners or adult patients.

Table 2 presents a similar analysis with regard to each population's report of their actual use of services. Once again, there are statistically significant differences among these populations, and once again parents report more use of these services (with the exception of career counselling) than does any other group. However, this table also indicates that when we consider use (as opposed to total need), partners' needs are more similar to those of adult patients (their spouses) than they are to the parents (the other group of significant others). Parents and youth also are quite alike in some of their reports of service usage: with regard to school advice, counselling for coping and financial assistance they report more use than do either adult patients or their partners.

Table 3 indicates that when we consider different populations' expressions of their desire for services, there are not many substantial or significant differences. Many more young adult patients express a desire for career counselling than do people in any other population; more parents and partners express a desire for psychological counselling related to their coping skills and their stresses than do other populations. But all four populations' reports of their desires for other sorts of services are quite similar.

In summary, several conclusions can be derived from these discussions of the service needs and desires of various populations and of the comparisons among them.

1. There are consistent differences in the needs expressed by various populations, especially with regard to their patterns of use of or access/availability to various services.

2. The service that is consistently most often reported in all populations as needed (used or desired) is information about the illness and treatment. Information about

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diet and nutrition is the second most often reported need in all populations. Information about insurance, financial assistance and meetings with others (patients or family members) in a similar situation are the next most often reported needs.

3. Information about the illness and treatment, and about diet and nutrition, generally are reported as the services that are most often used. Thus, while these are very common needs, they typically are well met by the current systems of social and informational service delivery.

4. Among all populations, the greatest service desires are expressed for assistance in handling stress and worries, meeting with others in a similar situation and information about insurance.

5. The most often reported unmet needs, across all populations, are for psychosocial services that might help reduce stress, help people deal with their worries, provide information about careers, provide insurance information and financial assistance and provide access to meetings with others who are in similar life circumstances.

6. While there are substantial differences among the four populations with regard to their most common needs -- both their use of services and in their desire for services -- there are not substantial differences in their patterns of unmet needs: the unmet needs are expressed quite similarly by all four populations.

7. A greater proportion of parents express a need (total) for services than does any other population. Moreover, a greater percent of parents report that they have made use of most of these services than does any other population. This finding probably reflects both parents' greater need for and greater access to (use of) services that have been made available to them.

8. A greater proportion of partners report unmet needs, and more unmet needs, than does any other population. This suggests that important services either are not provided to this population, or are provided in ineffective ways.

9. The age of the patient is a relevant consideration in terms of services such as career counselling and school advice, since both parents and young patients report more need, more use, and more desire for these services than do adult patients and their partners.

10. One's status as a patient or significant other is a relevant consideration with regard to services such as psychological counselling (for learning to cope and deal with stress), since both more parents and more partners report a need and a desire for such services than do young adults and adult patients.

Table 1.
Percentage of people in the four study populations reporting the total need
(use and desire) for information and counselling services.

SERVICE	PARENT	PARTNER	ADULT	YOUNG ADULT	SIG*
Information re: career	31%	NA	21%	57%	*
Information re: school	52%	NA	17%	46%	*
Information re: insurance	54%	53%	47%	40%	NS
Information re: diagnosis and treatment	85%	81%	76%	64%	*
Information re: diet	66%	52%	59%	43%	*
Counsel re: religion	52%	44%	30%	27%	*
Counsel re: coping	56%	48%	30%	29%	*
Counsel during hospital	51%	40%	30%	32%	*
Counsel for worries	55%	48%	37%	34%	*
Stress assistance	64%	48%	40%	30%	*
Meet with others	65%	44%	39%	41%	*
Financial assistance	66%	44%	42%	40%	*

*Statistically significant difference in percentages at the .05 level (using a Chi-square). 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. Chi-squares are analytic techniques used to test whether the differences are large enough to be statistically significance (not chance).

Table 2.
Percentage of people in the four study populations reporting the actual use
of information and counselling services.

SERVICES	PARENT	PARTNER	ADULT	YOUNG ADULT	SIG*
Information re: career	5%	NA	7%	15%	*
Information re: school	33%	NA	6%	26%	*
Information re: insurance	31%	23%	17%	11%	*
Information re: diagnosis and treatment	69%	57%	54%	48%	*
Information re:diet	34%	29%	38%	24%	NS
Counsel re: religion	40%	28%	26%	19%	*
Counsel re: coping	27%	13%	18%	21%	*
Counsel during hospital	32%	14%	20%	24%	*
Counsel for worries	26%	8%	16%	16%	*
Stress assistance	27%	11%	13%	7%	*
Meet with others	39%	13%	21%	15%	*
Financial assistance	45%	16%	15%	21%	*

*Statistically significant difference in percentages at the .05 level (using a Chi-square). 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. Chi-squares are analytic techniques used to test whether the differences are large enough to be statistically significance (not chance).

Table 3.
Percentage of people in the four study populations
reporting the desire for information and
counselling services.

SERVICE	PARENT	PARTNER	ADULT	YOUNG ADULT	SIG*
Information re: career	26%	NA	14%	42%	*
Information re: school	19%	NA	11%	20%	NS
Information re: insurance	24%	30%	30%	29%	NS
Information re: diagnosis and treatment	16%	24%	22%	16%	NS
Information re: diet	32%	23%	21%	18%	NS
Counsel re: religion	13%	16%	4%	9%	NS
Counsel re: coping	29%	35%	13%	8%	*
Counsel during hospital	19%	26%	10%	8%	*
Counsel for worries	30%	40%	21%	18%	*
Stress assistance	38%	38%	27%	22%	NS
Meet with others	26%	32%	19%	26%	NS
Financial assistance	21%	28%	27%	19%	NS

*Statistically significant difference in percentages at the .05 level (using a Chi-square). 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. Chi-squares are analytic techniques used to test whether the differences are large enough to be statistically significance (not chance).

IV. SERVICES BY BACKGROUND ITEMS

In this section we examine the relationships between various social background or demographic characteristics of informants and their reports of service need and usage. Our objective is to understand whether and how, within each of the four populations, characteristics such as age, gender, income, time since diagnosis, treatment status, and registration status (with CLF) relates to the need, use and desire for various services.

Age

Age is significantly related to the need, use, and desire for several different kinds of services in several of the populations. Nowhere is this more evident than in the ADULT PATIENT population where younger adults more often report need, use, and desire for: religious counselling, school advice, career information, and meeting with other patients. This finding fails to confirm some prior literature, since it suggests that age is not related to the need for medical information. Cassileth & Zupkis (1980) report that younger adult patients appear to want more information than do older patients. We found, however, that while younger adult patients more often report a need for insurance information, that pattern is not maintained in the case of information about diagnosis and treatment or about diet and nutrition.

YOUNG ADULT PATIENTS demonstrate a different pattern in terms of the age-service relationship. Older YOUNG ADULTS more often report a need, use, and desire for services than do younger informants. This effect is especially strong with regard to insurance services. The evidence that older YOUNG ADULT PATIENTS and younger ADULT PATIENTS have more need for insurance information is readily understandable. Young people under the age of 18 generally have not yet dealt with personal insurance policies, and people over the age of 45 probably have a well-established policy with their insurance companies. Thus it seems reasonable that patients between the ages of 18 and 45, older YOUNG ADULTS and younger ADULTS, are the people most likely to need insurance information.

The pattern of younger people significantly more often reporting need and use of services is much less evident in the PARTNER population, where younger PARTNERS more often report only a need and use of financial services.

Younger PARENTS more often report the use of meetings with other parents, but older PARENTS more often report a desire for such meetings. This finding suggests that support groups and other opportunities to meet other parents in similar situations have been geared toward and available to a younger PARENT population; however, older PARENTS have similar desires which often are unmet.

Gender

There are very few differences between the sexes in terms of their service needs and desires, and no differences between them in terms of service usage, regardless of the population queried.

Gender has the most impact in the PARTNER population, where women more often than men report a need and desire for counselling to learn to cope and for meeting other partners. Perhaps the male PARTNERS are denying their needs, are unwilling to state or pursue those needs in public, or have less energy and opportunity available to take advantage of available services. Since the PARTNER population is older, on average, than the PARENT population, it is possible that this denial or unwillingness reflects the times in which these people were socialized. If this were true, however, we would expect the ADULT PATIENT population (of the same age cohort as the PARTNER population) to report similar patterns. They do not. Perhaps the experience of actually having cancer requires patients to overcome some of the gender-based differences in socialization or in role performance that are related to the expression of psychosocial needs and the search for assistance.

<u>Family Income</u>

Income is related to service need only occasionally. For the most part, those informants with lower family incomes more often report need, use, and desire for services -- especially financial services and career information. This finding is supported by the research reported by Houts *et al* (1985), in which ADULT PATIENTS with incomes of less than $20,000/year had drastically more out-of-pocket expenses than did those with higher incomes -- and therefore had a greater need for financial assistance. Lansky *et al* (1979) and Meadows & Hobbie (1986) also report the considerable out-of-pocket expenses incurred by PARENTS of children with cancer, and Chesler & Barbarin (1987, p.61) note that "Those parents who report the (financial) impact (of childhood cancer) as 'somewhat serious' or 'serious' are disproportionately concentrated in lower-income groups." People with less income and wealth are more likely to have less substantial insurance policies, and as such may have to spend more of their own money on treatment, transportation and related expenses. Thus, it makes sense that poorer people would have more need for financial assistance programs and insurance information services.

PARENTS with higher family incomes used school advice more often than did less wealthy parents, but PARENTS in less wealthy families more often report that they would like to use this advice. These different patterns for use and desire of school services may be attributed to the fact that wealthier families are more likely to live in "better" neighborhoods with "better" school systems, and that these school systems may be more willing and able to offer help. Wealthier parents also may be more comfortable in expressing their needs to hospital and school staffs, and in pressuring for adequate responses to those needs. The fact that poorer people have a desire to help their children with their educational needs, but less often have been able to find the assistance to do so, emphasizes the need for added services related to school re-entry and performance.

<u>Treatment Status</u>

PARENTS whose children are no longer receiving therapy more often report use of religious counselling and school advice than do those parents whose children are still receiving treatment. On the other hand, PARENTS whose children are still on treatment more often report a desire for these same services. This pattern suggests that during therapy, PARENTS may be too busy with managing the practical aspects of cancer -- treatment regimens, transportation, nausea, and the like -- to have the time, let alone the energy, to take advantage of these community-based services. Only when treatment is over may PARENTS find it possible to search for and use such services. The fact that they would like to use them while their children still are on treatment also suggests that access may not be as effective as it might be. If PARENTS of children still in treatment lack the energy or information to gain access to such services, perhaps hospitals and community agencies must expand outreach to these needy populations.

Financial services, insurance information, and meetings with others are also more often desired by ADULT PATIENTS and the PARTNERS of those adults who are still on treatment. The PARTNER portion of this finding is supported by Oberst & James' (1985) research, which indicated that spouses of adult cancer patients experienced more anxiety in the initial phase of treatment than did the patients, but that this pattern reversed with time. They attributed this result to an increased sense of control when the partners were on their "own turf" -- away from the hospital. In addition, it may be attributed to the way in which anxiety about treatment may lead to increased service needs; PARTNERS whose spouses are still on treatment (as opposed to those who have completed treatment) thus more often report a desire for various services.

<u>Time Since Diagnosis</u>

PARENTS whose children were diagnosed more recently more often report use of insurance information. People just starting in the illness process probably are just getting

acquainted with the insurance system, and are discovering most dramatically the gaps in the care-giving system.

The relationship between services and time since diagnosis demonstrates some similar trends in the YOUNG ADULT PATIENT population. Those patients who are closer to the time of diagnosis more often report use of information about diet/nutrition and information about diagnosis and treatment, but those further from diagnosis report the greatest use of meetings with others. Perhaps the beginning of the cancer experience is the crucial time for basic information; later in the experience patients may be more capable and interested in getting together with others to discuss their experiences. Mullan (1986) supports these findings in his description of three different stages of the cancer experience. He argues that immediately after diagnosis, treatment is the focus; soon psychosocial needs become the focus of concern; but after several years (6 years in his study) people have fewer special needs. As a sidelight, Mor *et al* (1987) suggest that more time since diagnosis leads to the development of more concrete needs for services, such as physical rehabilitation. He does not study the need for psychosocial services, however, so his work can not easily be applied to the present study.

Having cancer forces a person to wrestle with a new identity and social role. Patients often have to reshape their thoughts about life and death and their place in the universe (this is especially true for younger patients with fewer life experiences from which to draw). Faced with such awesome tasks, it makes sense for people to take one step at a time. They do what needs to be done to survive, and when they regain some semblance of control, they may be more interested in talking about their deep-seated feelings with others who have "been there".

Distance from a Treatment Center

We did not find substantial (statistically significant) differences in the need or use of services between those informants and their families who live closer to a treatment center and those who live further away.

Registration Status

Those people who are officially registered with the Children's Leukemia Foundation more often report a need for a variety of services. The registered PARENTS more often report a need for stress assistance; the registered PARTNERS more often report a need for financial services; the registered ADULT PATIENTS more often report a need for insurance information and financial services; and the registered YOUNG ADULT PATIENTS more often report a need for religious counselling.

All these needs may be the reasons why these individuals registered with the Foundation in the first place -- they had a need and they saw the Foundation as an avenue toward fulfilling that need. Or, it may be why treatment centers which offer such services also referred their patients to the Foundation. Consistent with either of these explanations is the finding that registered PARENTS more often report use of information about diet/nutrition and about diagnosis and treatment. This finding, coupled with the finding that ADULT PATIENTS who are not registered with CLF more often report a desire for these informational services, suggests that the Foundation, the treatment center, or various agencies are providing useful information about diet/nutrition and about diagnosis and treatment to registered families (with young and old patients).

ADULT PATIENTS who are registered with CLF more often report a desire for insurance information. Perhaps these patients need more information of this type than they are getting -- their needs may be getting met, but not to the extent that they would like. It is also possible that they may have registered with the Foundation to get this type of information and have, therefore, reported a desire for it. The choice between these explanations may depend on the time that they have been registered with the Foundation; if they are recently registered, their void of insurance information probably is a function of need alone; if they registered some time ago it may reflect a lack of adequate service provision. Without time-line information, it would seem appropriate to be aware of both possible explanations.

It is also possible that people who are registered with CLF are more out-going and more willing to seek help than those informants who do not register. If this is the case, registrants will report more need, use, and desire for services because they are the type of people who more actively seek out help, not necessarily because their objective levels of need are any greater than others.

V. PSYCHOSOCIAL FACTORS AND THE NEED FOR SERVICES

In this section we explore the relationships between a variety of psychosocial factors and peoples' reported need for services. Specifically, we examine the extent to which informants' reports of their worries, coping styles, informal social supports and life changes are related to the use of and desire for varied services. These relationships are examined separately within each of the four population groups.

Parents

Parental worries are a crucial link in the service development and planning chain, since increased worries often point the way to needed interventions (Schag et al, 1983). Parents who worry more about their child's medical future and their own general health more often report a need and desire for assistance in dealing with stress and for psychological counselling services. Parents' concerns about their child's relapse and more intensive illness undoubtably produce substantial stress, explaining the way in which greater worry may lead to the need for help. Helping parents learn to cope with the stress involved in living with a child with cancer must be seen as one of the most important services a social agency and/or hospital can provide.

Parents who report greater financial worries more often report a need and desire for financial services, as well as for career information and stress assistance. Having a child with cancer often is expensive. Over and above strictly medical costs (that hopefully are borne by insurance policies), there are a number of out-of-pocket expenses associated with cancer that can produce financial strain (Lansky et al., 1986).

Social workers are the single most pertinent source of help in relation to meeting patient and family members' service needs, and as such are a vital link in the service delivery network. The more often parents report these health care professionals as helpful, the more often they report a need for and use of information, counselling, and financial services. The recognition of

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the broad impact of cancer on the lives of patients and family members has led to the increased involvement and importance of social workers in the health care system (Polinsky & Ganz, 1987), particularly in the care of children with cancer and their parents (Ross, 1978; 1980). Stoneberg (1981) defines the increased role of the social worker as follows:

> Social workers must be able to help the patient and the family to adjust to and cope with all aspects of cancer. This often involves being a program developer, patient advocate, treatment coordinator and counsellor... (p. 710)

The numerous positive relationships between social worker helpfulness and service usage suggests that this role is being adopted by many local social workers and accepted by patients and their families.

Parents who report receiving more help from other parents more often report the need for and use of stress assistance, information services, and aid in learning to cope. By meeting others in similar situations, parents get a chance to learn what others have done and may thereby adopt alternative ways of coping with their own situation. Instead of being limited to medical professionals' advice or assistance on these issues, parents can discover a forum from which to gain valuable insight into how to deal with childhood cancer from those with experiential knowledge -- other parents of ill children (Borkman, 1976; Reinharz, 1981). Although the evidence is mixed regarding just how effective and supportive social workers are in encouraging parents to seek help from organized self-help groups (Katz, 1981; Kleinman *et al*, 1976; Yoak and Chesler, 1985), many social workers obviously do encourage parents to meet with other veteran parents and to take advantage of mutual support activities (Adams, 1979; Belle-Isle and Conradt, 1979; Martinson, 1976; Ross, 1979).

Parents who report that their life has changed for the worse since their child's diagnosis with cancer, in terms of their ability to cope with tragedy and their overall emotional adjustment, more often report a need and desire for psychological counselling and stress assistance services than do those who report that their lives have changed in more positive directions. They need these psychological services, it seems, to help them learn new coping skills in dealing with the crisis that has already occurred and the inevitable changes that will continue to occur.

Further support for this argument comes from the finding that parents who report that they have not coped very well with the illness more often report a need and desire for these psychological services than do those who report that they did cope well. Parents who report that their life has gotten better over the duration of the experience also more often report that they have used counselling and stress assistance services. The utilization of these services may make a difference, because those parents who reported that they coped very well more often also used information services. Utilization of information is one of the most basic coping mechanisms that a person can employ, and therefore one of the most needed services (Felton & Revenson, 1984). Assistance in handling stress obviously also is vital.

Partners

Partners' worries about the future and their own general health demonstrate a relationship with services that is quite similar to that found in the parent population. People with greater worry more often report need, use, and desire for several services -- mainly information and counselling.

This population of significant others also is very similar to the parent population in terms of the relationship between the receipt of informal support and the need for services. Partners reporting greater amounts of social support more often report service need, usage, and desire. Help from social workers is related to the partners' need, use, and desire for information, financial assistance, counselling services, and meeting other partners. These health care personnel obviously have a tremendous impact on which services people are made aware of and to which they are referred or given access. For this reason, their role in the experience of significant others in general is extremely important.

In contrast to the positive role of social workers, the helpfulness of the medical staff itself is not related significantly to partners' need of or desire for any services; they simply are not the key actors in making services available to these family members. Since partners are often

ambivalent or cautious in dealing with the medical staff (physicians and nurses), social workers become their primary liaison to the medical establishment -- and to needed services.

Partners seem to meet with other partners (people in similar situations) for social support less often than do the parents. There is, however, a significant relationship between finding other partners helpful and the need for and use of information. It appears that the relationship between partners and other partners is primarily one of an informative nature, whereas the relationship between parents and other parents primarily involves emotional support. This may be due to the different ages of parents and partners or to the different way they have experienced cancer -- as a spouse or as a parent.

Partners who report that their lives have gotten better over time, especially in terms of their ability to cope with tragedy and their sense of personal empowerment, more often report need and use of psychological counselling services and meeting other partners. This is in sharp contrast to the parents' reports, where improvement in one's life was related to fewer reports of service need and use.

Adult patients

As with other populations, adult patients who are more worried about the future and their general health more often report a need and desire for stress assistance, information, psychological counselling, and meetings with other patients. Also as reported by other informants, greater financial concerns are related to a need and desire for financial and insurance information. What is unusual, however, is the strong, positive relationship between worries and the need for meetings with other patients -- a finding not present in other populations. Adult patients obviously recognize the expertise of other patients as being able to alleviate some basic concerns about their disease in a way that is not present in the significant other populations.

Adult patients' patterns of social support demonstrate some very different trends than do the two significant other populations. The direction of the relationships is the same however, people reporting greater support more often need, use, and desire services. But the services are

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different. Adult patients who find social workers very helpful more often report a need and desire for career information, financial information, and insurance information. This would suggest that adult patients use social workers primarily as links to practical support and services, whereas parents use social workers primarily as a source of emotional support and partners use them primarily for information.

Adult patients whose lives have changed for the better, in the sense that they feel more empowered, more often report a need for information and financial services. The adult patients with an improved sense of empowerment also more often report the use of financial services, several information services, and some counselling services. Through the cancer experience these patients evidently learned how to advocate for themselves, and how to act positively to get what they need from the medical and social service system.

Young Adult Patients

The general association between worries about the future, worries about one's general health and the need for services seems to be parallel across all four populations. Within the young adult population, as with the others, those informants who report more worry about the future and about their general health, more often report the need, use, and desire for information services, psychological counselling services, and stress assistance.

The relationship between greater amounts of social support and greater use of services is evident here as well. Those informants who report greater social support more often need and use various services, and less often express a desire for additional services. Young adult patients who find their social workers more helpful more often report a need for counselling and stress services, and for financial assistance; they also more often use counselling services and insurance information. These data suggest that young adults and social workers have a multi-faceted relationship, as young patients use this source of support both for practical help and for emotional or psychological support.

The relationship between young adults' life changes and service needs is different from the adult patient and partner populations, but like the parent population. In the young adult population, people who report that their life has gotten worse more often report an increased need, use, and desire for services. When they feel that their ability to cope with tragedy has worsened with time, they more often report a tendency to use meetings with other patients -- perhaps looking to other patients for clues on how to improve in that arena. Young patients who report that they have coped very well with their illness more often report a need for psychological counselling services and for stress assistance. These seem to be patients who are out-going and have the ability to actively seek out counselling services when they need them. Those who coped less well with their illness more often report a desire for information. This provides support for the widely-held notion that information is such a basic part of the cancer experience that patients who have not received adequate amounts of it will experience more difficulty coping with their illness.

VI. SERVICES/PROGRAMS PROVIDED BY THE CHILDREN'S LEUKEMIA FOUNDATION

More specific questions about service need (use and desire) were raised in the context of assessing informants' experiences with services provided by the Children's Leukemia Foundation. Unfortunately, large numbers of informants did not respond to these questions, rendering a detailed analysis of their views of CLF services quite problematic. However, the responses that have been calculated and presented in Table 4 are quite instructive, in that they largely confirm the views of general services discussed earlier.

For instance, information-focused services (information about the illness for patients, information about the illness for the public, and newsletters) are by far the services most commonly needed by all four populations. Needs for financial assistance appear to be second most common. Social and recreational activities (holiday parties, recreation activities, snacks for hospitalized patients) and psychosocial support services (family support groups, teen support groups, camps for kids) also are needed quite often. Other services are needed by less than 25% of any population group.

In almost all cases, parents and young adult patients report greater need for these services than do adult patients and their partners. In addition, these two groups also report the greatest incidence of unmet needs (services where desire is greater than use). For parents, unmet needs involve teen support groups, sibling support groups, community health fairs and aid in getting community services. For young adult patients, teen support groups, home-phone contacts, community health fairs and aid in getting community services are unmet needs. For adult patients, patient support groups and aid in getting community services are unmet needs. And partners of adult patients indicate that information directed at the general public and aid in getting community services are important unmet needs. Although there are some differences among the four populations in their reports of unmet needs, there also is a remarkable consistency. Support groups, help in getting information and access to local community services seem paramount.

Table 4.
Percentages of the four study populations reporting
the total need (use and desire) for CLF services.

SERVICE	PARENT	PARTNER	ADULT	YOUNG ADULT	SIG*
INFORMATION ABOUT ILLNESS					
Information re: illness	61%	47%	46%	59%	NS
Information for public	42%	33%	32%	52%	NS
Newsletter	62%	33%	45%	51%	*
Lending library	20%	8%	9%	N/A	*
FINANCES					
Financial assistance	38%	21%	34%	33%	NS
Medical equipment	12%	4%	6%	17%	NS
RECREATION					
Holiday parties	33%	4%	4%	27%	*
Snacks for hosp patients	22%	14%	12%	45%	*
Recreation activities	33%	11%	6%	24%	*
PSYCHOSOCIAL SUPPORT					
Family support groups	31%	8%	13%	20%	*
Teen support groups	15%	4%	2%	21%	*
Home/phone contact	15%	20%	15%	14%	NS
Hospital visit	21%	10%	6%	18%	*
Meetings for siblings	15%	N/A	N/A	10%	NS
Camp for kids	31%	2%	3%	30%	*
COMMUNITY ACCESS					
Community health fairs	18%	10%	6%	13%	NS
Help find community services	25%	16%	18%	18%	NS
PRACTICAL ASSISTANCE					
Respite care	7%	4%	2%	N/A	NS
Transportation to treatment center	12%	10%	15%	18%	NS
Referrals to doctors	18%	20%	22%	26%	NS

*Statistically significant difference in percentages at the .05 level (using a Chi-square). 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. Chi-squares are analytic techniques used to test whether the differences are large enough to be statistically significance (not chance).

VII. RECOMMENDATIONS

The primary conclusions and recommendations that can be generated from this analysis of psychosocial needs and services can be grouped into three major categories: (1) generic recommendations that apply to services relevant for all four population groups; (2) targeted recommendations that suggest the different services that are of highest priority in meeting the different needs of the various population groups; and (3) recommendations relevant for populations omitted from this study, such as the very poor and people of color in urban or rural areas.

Generic recommendations

1. It is important to continue to provide informational services to all populations. Information about the illness and treatment, and about diet and nutrition, are the services most often reported as needed by all populations. They also are the services that all populations report as being used most often, so current procedures for delivering such information appear to be effective, and need only be expanded rather than restructured.

2. It is important to expand and experiment with new procedures for delivering psychosocial support services in the areas of stress assistance, aiding people in learning to cope, aiding people in handling their worries, and meetings with other people like themselves. This is the area where the greatest desire for services and the greatest expression of unmet needs occur.

3. Access to and liaison arrangements with social workers should be expanded. Social workers are reported by all populations to be the most helpful source of social support and services, and an important informational link to the availability and use of a wide range of relevant services.

<u>Targeted recommendations</u>

4. Programs to provide services to parents should be sustained, as they appear to be the population whose needs are best met, and who are most satisfied with current patterns of service delivery. This population reports the lowest level of unmet needs.

5. Services should be dramatically expanded and altered to meet the needs of the spouses or partners of adult patients. This population reports the greatest number of unmet needs, of desired services to which they do not have access. This is especially important with regard to psychological issues such as stress, worries, problems in coping and meetings with other partners. It also appears that female spouses or partners indicate more vital needs in this area than do males, but that should not be taken at face value, since males may be constrained from expressing their needs as strongly as females by provider assumptions and behaviors, as well as by current family logistics and their own early socialization patterns.

6. Adult patients express strong unmet needs for services that address their concerns about insurance and about the management of stress.

7. Young adult patients indicate strong unmet needs in the areas of information and advice about career options and about the management of stress.

8. All people from families with lower income levels -- patients and significant others -- more often indicate a need for information about career options and about financial matters, such as insurance information and financial assistance. Parents from families with lower incomes more often report a need for information and advice in educational matters and in dealing with school people working with their children. These findings touch on the necessity for expanding services of all kinds to underserved populations, to people with less financial resources, advantages and access.

9. Patients who have been diagnosed more recently more often report needs for additional information about their illness and treatments, and about diet and

nutrition. It appears that people do receive such information, but generally rather late in the course of their treatments. The issue here is not expansion of these services as much as delivery to people earlier in their process of treatment.

10.   The desire to meet with other patients and family members is expressed by substantial numbers of persons in all four populations. This is in part a particular need for contact and association; it also represents a mandate for a different form of service delivery. Relevant agencies are encouraged to experiment with mutual support and self-help groups that might be the arenas within which many of the services related to stress, worries and coping may be delivered.

Omitted populations

11.   We repeat the note that this survey of patients and family members affected by leukemia and lymphoma suffers from limited access to some population groups. Most important, people with lesser financial resources and people of color are systematically underrepresented or unrepresented in this study. Thus, we can only assume their service needs. Any reasonable assumption, however, based on research on epidemiological and service delivery patterns throughout history, suggests that these populations' needs are quite high, and that they probably have many unmet needs and high desires for services. Special program efforts should be made to reach out to the communities of people of color, especially in urban and rural areas, to assess their generic and targeted needs and to provide equitable and effective services to them.

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