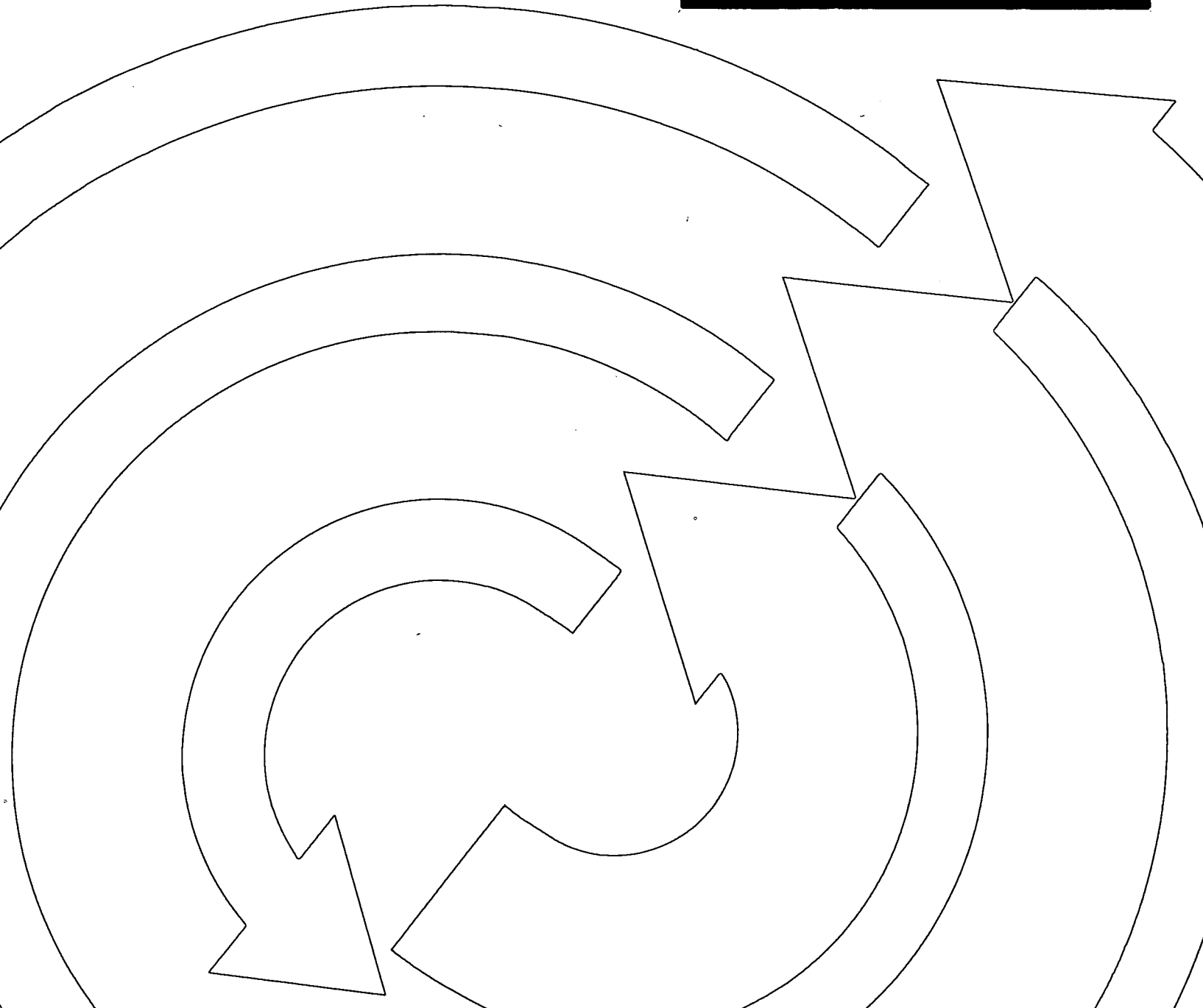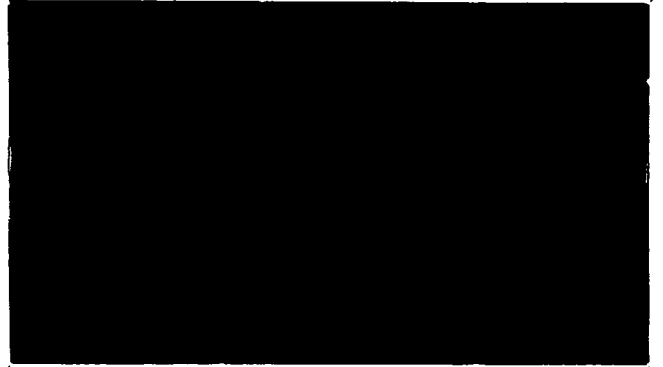# CRSO

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PSYCHOSOCIAL AND SOCIAL-ENVIRONMENTAL
PROBLEMS AND NEEDS FOR SUPPORT
SERVICES OF OFF-TREATMENT
SURVIVORS OF CHILDHOOD CANCER

by Mark Chesler

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# PSYCHOSOCIAL AND SOCIAL-ENVIRONMENTAL PROBLEMS AND NEEDS FOR SUPPORT SERVICES OF OFF-TREATMENT SURVIVORS OF CHILDHOOD CANCER

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## PSYCHOSOCIAL AND SOCIAL-ENVIRONMENTAL PROBLEMS AND NEEDS FOR SUPPORT SERVICES OF OFF-TREATMENT SURVIVORS OF CHILDHOOD CANCER

The focus of this paper is a review of the state of research and services relevant to the problems encountered by survivors of childhood cancer. Since the literature on survivors' needs and on suggested services is much more voluminous than I can effectively review here, I only include most recent and/or illustrative studies and reports in each area of concern. I supplement the literature with recent data from a Candlelighters Childhood Cancer Foundation (CCCF) study of approximately 275 off-treatment survivors over the age of 14, and a continuing Foundation survey into service innovations for survivors of childhood cancer.* The data from the CCCF study are quite preliminary, and for the most part simply descriptive as of this writing; later work will include multivariate analyses of these data, and the integration of group interviews and survey results. This paper treats the following issues sequentially:

## I. BACKGROUND

The "good news" of the past three decades of scientific research and medical advance is that many more children with cancer are successfully completing their course of treatment and are joining the ranks of suvivors of cancer. Whereas in the 1950's only 5-25% of those youngsters diagnosed with cancer could expect to recover from this illness and live a nearly normal life and life span, by the 1970's 20-80% could expect this miracle to occur, and by 1988 we can entertain this hope for 40-90%. We have yet to understand fully, however, how to improve the "quality of life," or psychosocial and socio-environmental success, of these survivors. In order to do so we need better information on the issues and concerns faced by off-treatment survivors, and on this basis develop improved treatment programs and social support services tuned to their needs.

### What do the knowledge base and service system look like in general?

The knowledge base in this area is murky, sometimes contradictory, yet with some clear trends evident. The research is murky for several reasons, primarily because of disagreements or limitations in the design of studies. Until fairly recently, too few children survived childhood cancer to represent a large enough pool from which to create viable samples or to conduct reliable studies. Even as the pool enlarged, young people were treated at many different institutions, each often with their barriers to cooperative study. The need to gather large enough pools of survivors of different kinds of childhood cancer, of different ages and treatment histories, etc., further complicated design issues. While small sample studies do illuminate important issues, they have not necessarily been convincing to the decision-making population which suggests and establishes new psychosocial programs and services. Large-scale psychosocial studies also require considerable investments of resources, and such funds for studies of survivors have not been readily available from the medical research establishment. Funding priorities appear to be focused on studies of children in treatment, using standardized psychometric instruments and emphasizing biomedical or epidemiological factors and research paradigms.

Moreover, all observers agree that the issues of concern to us here are subtle and difficult to measure. Indeed, their precise definition, no less measurement, is often open to debate. In addition to questions about types of measures and their standardization, debates also occur about the relevance of mail questionnaires, face-to-face interviews, projective tests, records' analysis, information from significant others, as appropriate or reliable/ valid or preferred forms of data. Discomfort with self-report data, and with others' reports, are simultaneously raised.

Given the nature of the phenomena under study, it is quite difficult to utilize tight pre-post study designs, and hard to resolve questions of controls (at all), or appropriate control and comparison groups for studies of off-treatment survivors. For instance, is the most appropriate comparison with a group of not-off-treatment children with cancer, siblings of off-treatment survivors, an age-similar population that has not had this illness, etc.? Are any of these control or comparison groups really vital or even useful, or can effective research utilize solely or primarily internal comparisons, procedures that inquire into and reflect off-treatment survivors' realities in their own unique terms? (See Spinetta, 1984, for a discussion of these options.)

All studies referred to in this paper, including our own, encounter one or more of these methodological concerns (Dobkin and Morrow, 1985-86). As a result, there are as yet few or no "definitive" findings or studies with regard to the psychosocial needs and relevant services/programs for off-treatment survivors. Indeed, we should not expect such studies in the near future, if at all. In the psychological and social sciences there seldom are definitive studies. The social world never stands still, and even when it appears to come to a temporary standstill, psychic or social conditions quickly change (sometimes even as a result of research). Moreover, no one person's work, let alone single study, stands alone in science. The cumulative process of knowledge development requires reliable or "definitive" findings to be the product or amalgam and synthesis of many scholars' work.

The state of the service system also is fragmented and uncoordinated with major innovations occurring in some health care centers and shocking service gaps in many others. The recent advent and growth of the long-term survivor population, and its small numbers at any one

institution, certainly compound the problems caused by a lack of systematic research. Despite these problems, some significant needs and related service suggestions stand out. They should be acted upon -- experimented with and implemented -- while we conduct research to better identify them. To "wait for better data" condemns another generation of survivors to added psychological "late effects," potential social disability and continuing discrimination. Moreover, while the costs of waiting are relatively high, the risks of premature or inappropriate service implementation are really quite low; not many dangerous suggestions have been made.

In dealing with these issues it should be clear that childrens' successful adaptation to the social world, and the social world's successful adjustment to children with cancer, occur long before children are off treatment and labelled long-term survivors. Survivorship starts immediately after diagnosis, and terminating treatment is just one more (late) stage in long-term survival. "Re-entry" is immediate and continuous; personal and family adjustment, peer relationships, school performance and other issues all must be dealt with during treatment. To wait to deal with these issues until after treatment has ended undoubtedly permits major problems to develop. However, it is increasingly obvious that "off-treatment survival" is quite different from "living with cancer," and it is this stage of long-term survivorship that is of primary concern in this paper.

## II. METHODS

One of the methods utilized in preparing this paper involves a review of other studies of survivors of childhood cancer. Prior research into childhood cancer began with a focus upon physical factors in illness and treatment. Over time, a concern with the impact of treatment led to studies of physical "side-effects" of treatment or even of "late effects." Initial inquiries were defined in neuropsychological or psychophysical terms, focussed primarily on mental functioning, intelligence test scores, learning difficulties and sometimes "stress." More recently, a psychiatric or clinical psychological focus has approached issues of emotional stress, mental health and psychological adjustment (most notably with Koocher and O'Malley's groundbreaking 1981 study). And in recent years a concern with social and environmental issues has arisen, prompting attention to insurance, employment, schooling, and the like (the most promising example of which is Teta et al.'s 1986 report of their omnibus work). Lansky, List and Ritter-Sterr (1986), among others, have noted this developmental sequence in research foci. Our primary focus in this paper is upon the last of these, the social world of the off-treatment survivor. To set the stage, however, we do discuss some of the more recent psychological studies.

Although our primary concern is with issues specifically of concern to off-treatment, long-term survivors, and we do review psychosocial studies conducted with this specific population, the lack of systematic psychosocial research in this area occasionally requires us to extrapolate from studies with children with cancer who are still in treatment. We also utilize new data obtained from a large group of off-treatment survivors themselves, gathered through the use of a four-page questionnaire inserted in the quarterly edition of the YOUTH NEWSLETTER, published by the Candlelighters Childhood Cancer Foundation (1987, IX [#2], 4-8). Over 275 informants responded to the questionnaire, with the greatest percentage of those responses coming within the first three months of distribution.

We recently extended this study in several ways: (1) with roughly comparable data from samples of college and high school-age students who have not had a history of childhood cancer. The use of this comparison group sheds additional light on those aspects of the data that are and

are not unique to survivors of childhood cancer, as compared with survivors of childhood in general; (2) with personal stories and anecdotes from some of these survivors of childhood cancer in the context of a series of follow-up personal conversations and semi-structured small group interviews. Many informants indicated, on the questionnaire, that they would be willing/interested in sharing their feelings and experiences further, and we have met and will continue to meet with geographically accessible small groups of them in order to gather in-depth information and perspectives on issues raised in the structured questionnaire. In addition, many informants wrote lengthy comments in the margins of the questionnaire, included poems and articles they had written, and otherwise shared meaningful aspects of their personal lives with us. These responses, in addition to the formal data, justify the importance and relevance of this project. They also require us to plan ways of feeding back information to this pool of survivors and aiding them in their effort to meet with one another, share their experiences with one another and the general public, make meaningful and informed decisions about their lives and place their experience with childhood cancer in meaningful and useful contexts. As noted later in this report, the Candlelighters Childhood Cancer Foundation has embarked on a networking and information dissemination program that should help accomplish these objectives.

Since participation in this study was voluntary, we have no way of knowing how and why some persons responded and others did not, nor how representative these informants are of the entire off-treatment population. We may guess, at the outset, that their willingness to respond marks them as somewhat unique, probably more out-going, more willing to be public about their illness history, and perhaps even better adjusted psychologically and in better shape physically than others in this populaton. Thus, there may be a positive or upbeat bias to the data reported herein. Such potential skews in the study sample demand caution in interpreting and generalizing the results of this study to the larger population of off-treatment survivors of childhood cancer. By the same token, these data from a substantial number of informants should create many good guesses and leads that can be followed up with more extensive or tightly controlled samples.

The questionnaire specified that it was directed at "young people with cancer who are off-treatment and over 14 years of age." The distribution of the ages of informants now and at the time of their diagnosis, and the time elapsed since their original diagnosis, are provided in Table 1. The bulk of this sample is between 14 and 18 years of age, was diagnosed in their early teens, and is 2-5 years post diagnosis. These concentrations further define and limit the representativeness of the informant sample.

The staff and officers of the Candlelighters Childhood Cancer Foundation have been engaged over the past year in an ongoing telephone outreach project designed to assess the state of services available to off-treatment survivors at treatment centers across the nation. Such information is being collected through discussions with local parent self-help groups, local physicians and nurses and social workers, hospital administrative personnel, leading researchers, and major research and service agencies (ACS, NCI, NIH). While this information has not been gathered in a way that constitutes a full picture of the range of institutions and service delivery patterns, it does reflect a growing compendium of what is happening where.

Table 1

AGE, AGE AT DIAGNOSIS, AND TIME SINCE DIAGNOSIS OF SAMPLE OF CHILDREN WITH CANCER
WHO ARE OFF-TREATMENT

| A. Age | | | B. Age at Diagnosis | | | C. Years Since Diagnosis | | |
|---|---|---|---|---|---|---|---|---|
| | N (254) | % (100) | | N (254) | % (100) | | N (254) | % (100) |
| Under 15 | 29 | 11.4 | Under 5 | 18 | 7.2 | Under 2 | 21 | 8.4 |
| 15 | 27 | 10.7 | 5 | 8 | 3.1 | 2 | 31 | 12.2 |
| 16 | 37 | 14.7 | 6 | 9 | 3.5 | 3 | 30 | 11.8 |
| 17 | 25 | 9.9 | 7 | 4 | 1.6 | 4 | 27 | 10.6 |
| 18 | 37 | 14.6 | 8 | 5 | 2.0 | 5 | 30 | 11.8 |
| 19 | 20 | 7.9 | 9 | 11 | 4.3 | 6 | 23 | 9.1 |
| 20 | 18 | 7.1 | 10 | 14 | 5.5 | 7 | 16 | 6.3 |
| 21 | 17 | 6.7 | 11 | 21 | 8.3 | 8 | 11 | 4.3 |
| 22 | 14 | 5.5 | 12 | 25 | 9.8 | 9 | 11 | 4.3 |
| 23 | 8 | 3.2 | 13 | 33 | 13.0 | 10 | 12 | 4.7 |
| 24 | 4 | 1.6 | 14 | 23 | 9.1 | 11 | 8 | 3.2 |
| Over 25 | 18 | 6.7 | 15 | 33 | 13.0 | 12 | 6 | 2.4 |
| | | | 16 | 19 | 7.5 | Over 13 | 28 | 11.0 |
| | | | Over 17 | 31 | 12.2 | | | |

### III.  KEY ISSUES:  CONCERNS AND SERVICE NEEDS OF THE OFF-TREATMENT SURVIVOR POPULATION

I briefly address eight areas of social experience in which survivors may encounter problems and may require services.  The source of these problems sometimes is disabilities (physical, intellectual or emotional) within the child or young adult; often the primary source is discomfort, prejudice, stigma and discrimination emanating from actors and institutions in the social world.  At the very least, the social world escalates and exacerbates vulnerabilities the child or young adult may have.  Inquiries into the root and nature of these social patterns is another crucial research agenda, one that has received considerably less attention than the child and her capacities.  The patient-oriented and intrapersonal focus that has dominated the research agenda is another reflection of the medical and psychological biases evident in research on these issues.

The areas I address include:  (1) physical illness effects, (2) general psychological health and self-esteem, (3) family, (4) friends, (5) school, (6) insurance, (7) employment and (8) continuing medical care.  Table 2 indicates the extent to which off-treatment survivors in the Candlelighters Childhood Cancer Foundation study reported worrying about some of these issues.

We arbitrarily categorize the questions relating to one's own ability to have children (and children free of cancer) under friends rather than family, because they concern one's own future family, an outgrowth of continued successful "friendships."  We retain the family category to refer to one's family of origin -- including one's parents.

These concerns/worries were investigated further as we asked off-treatment survivors to indicate whether they "have used" and/or "would like to use" a variety of information and counselling services.  The percent of informants responding positively to some actual or possible programs is presented in Table 3.  A substantial portion of the services survivors "have used" were available to them while in treatment, not specifically when they were off-treatment; this fact inappropriately escalates the number of services "used" by off-treatment survivors.  Obviously substantial desires for services still exist in several areas.

Table 2

CONCERNS OF OFF-TREATMENT SURVIVORS OF CHILDHOOD CANCER

| Concern | % Worry A Lot | % Worry Some |
|---|---|---|
| 1. Physical Illness | | |
| a. Having a relapse | 16 | 28 |
| b. Getting another cancer | 16 | 31 |
| c. If I am as healthy as others my age | 13 | 23 |
| 2. Self esteem | | |
| a. How my body looks | 39 | 18 |
| 3. Family | | |
| a. My parents' health | 28 | 31 |
| b. My parents' finances | 21 | 27 |
| 4. Friends | | |
| a. Losing friends | 30 | 16 |
| b. Whether I can have children | 29 | 20 |
| c. My children getting cancer | 23 | 20 |
| 5. School | | |
| a. Keeping up in school | 32 | 23 |
| 6. Insurance | | |
| a. Getting medical insurance | 12 | 11 |
| b. Getting life insurance | 17 | 12 |

Table 3

SERVICES USED/DESIRED BY OFF-TREATMENT SURVIVORS OF CHILDHOOD CANCER

| Service | % Have Used | % Would Like to Use | % Not Used and Would Not Like to Use |
|---|---|---|---|
| 1. Physical Illness | | | |
| a. Information about my illness | 67 | 17 | 16 |
| 2. Self-esteem | | | |
| a. Counselling for my worries | 31 | 18 | 51 |
| b. Counselling for learning to cope | 35 | 15 | 50 |
| 3. Family | | | |
| a. Counselling for my family | 28 | 17 | 55 |
| 4. Friends | | | |
| a. Meeting with other young people with cancer | 35 | 35 | 30 |
| b. Family planning information | 14 | 30 | 46 |
| c. Genetic counselling | 7 | 35 | 58 |
| 5. School | | | |
| a. School counselling | 55 | 13 | 32 |
| 6. Insurance | | | |
| a. Financial assistance | 20 | 22 | 58 |
| 7. Employment | | | |
| a. Career information | 42 | 35 | 23 |
| b. Legal advice on getting a job | 8 | 35 | 57 |

General descriptive data may provide an overall picture of the concerns and service preferences of this population, but they also may mask some important differences. For instance, Lansky et al. (1986), and Koocher and O'Malley (1981) suggest that off-treatment survivors who are diagnosed at an older age, or for whom termination of treatment is more recent, may report more psychological difficulties. What about young people who have visible disfigurements and substantial "side-effects"; will they report more worries and less positive interpretations or orientations regarding their illness experience? (Koocher and O'Malley's data indicate no.) It is crucial to explore these and other factors affecting survivors' diverse outlooks, because only then can we develop and implement programs that respond to different groups of survivors' very different psychological and social statuses and needs. We begin such a differentiated inquiry in section IV of this paper, but most of it represents a later step in our analysis.

## Physical Illness Effects

The long-term physical complications or sequallae of childhood cancer are the best researched of all issues affecting off-treatment survivors. This does not mean that we know all there is to know. or even enough, by any means. But the research community's concerns have followed the clinical priorities of physicians, and problems of relapse or second cancers, of "late-effects" of treatment, and of physical, neurophysiologic or psychophysical sequallae have received the most direct attention to date. Several good reviews of the literature on "late-effects" discuss the probabilities of a relapse or of the ocurrence of second cancers in this survivor population (see, for example, Jaffee, 1984; Oliff and Levine, 1982; Packer et al., 1987; Waskerwitz and Fergusson, 1986). Most students of these issues use the term "cure" only after a period of several years subsequent to termination of treatment; after that period of time a return of cancer is seen as a "second cancer" rather than as a "relapse" of the original disease. Obviously, one's personal and subjective concept of being "cured" may not be the same as a medical definition (Hammond, 1986; Van Eys, 1977). Podrasky (1986) provides an insightful first person perspective on just how difficult it is for off-treatment survivors and their parents to come to terms with this concept.

In the following interview excerpts, off-treatment survivors reflect how ambivalent they are about using the term.

> I am getting to the point where I can say that I had it, but I really can't say that yet because I am scared it is going to come back. So I can't say I'm fully cured.

> You don't want to get too cocky about it. I'm always watching what I say. "Oh, I'm better. I'm fine."

The physical illness and treatment, and their long-term effects, create a variety of intrapersonal and interpersonal concerns or psychosocial needs for survivors. Mullan (1989) notes that one prominent concern of "ex"-cancer patients, adults and children alike, is a fear of recurrence of the disease (note the 16% who worry a lot about a relapse or getting another cancer, and 28% and 31%, respectively, who worry some in the CCCF study -- Table 2). That there is not even more worry may be explained by Koocher and O'Malley (1981) and Lazarus (1981), among others, who have noted the use of denial as a healthy and effective coping mechanism in the face of such fears. Two young women reflect such a pattern in the following interview excerpts.

> I am not one to ask a lot of questions. They tell me whatever I want to know and they tell me things I don't want to know. People would come up to me and say, "Do you want to know... Do you have questions?" I would say, "No." I don't really want to know. I don't care.

> I try not to think about it. For years I wouldn't talk about it because I would not come out and want to discuss it. Like five years ago you couldn't get me to do this interview.

Beyond encouraging or supporting denial, per se, Lewis and LaBarbera (1983) and Hobbie (1986) suggest that physicians and nurses help (ex)patients respond to these "normal fears" by reassuring them of the low probability of recurrence. Such reassurance may have to be repeated several times, so that gaps in information and in emotional processing are both dealt with.

In addition to possible relapse or return of the disease, other "late effects" have been discussed in the literature. Several researchers have demonstrated the impact of treatment on neuropsychological functioning (usually with the use of IQ test scores and school performance data) of recovered leukemia patients (see, for example, Copeland et al., 1985; Copeland et al., 1988; Lansky et al., 1984; Meadows et al., 1981; Robison et al., 1984; Rowland et al., 1984). Most of this work indicates some problems for survivors in certain aspects of abstract reasoning

and non-language skills, especially for those treated with cranial radiation at a young age. This is a fast-growing body of literature, with many new studies underway.

Visible or noticeable side-effects are also discussed in the literature, most often as consequences of surgery (amputation, limb salvage procedures, or scars) or disabilities resulting from tumors or chemotherapeutic or radiologic regimens. Boyle et al. (1982) and Tebbi et al. (1985), as well as some prior cites, discuss some of the psychological impacts of such long-term effects. Sixty-nine percent of informants in the CCCF study reported "noticeable side-effects" of their illness and treatment, ranging from temporary to permanent conditions, and from internal organ damage to visible deformities. Mullan (1984) suggests that this concern with side-effects or bodily limitations, including any changes in function or abilities, is a prominent concern for off-treatment survivors of cancer, regardless of age. Indeed, part of the definition of "good coping" or "positive psychological adjustment" may rest on the adoption of a realistic perspective on these issues.

In a similar vein, Fobair et al. (1986) and Cella and Tross (1986) indicate that off-treatment survivors of lymphoma often struggle with their feelings of attractiveness (note the 39% of the CCCF sample who worry a lot about "how my body looks"). Although there is considerable objective difference between side-effects that consitute a functional change or loss and those that primarily have cosmetic impact, the psychological feelings involved may be quite similar. We deal with this issue in the section on general psychological adjustment, rather than physical illness, since this concern appears as relevant to psychological as to physical factors.

One of the implications of all this work, and a suggestion made by many researchers, is that medical staffs should pay attention to early identification of physical problems and/or disabilties, in the hope that adequate information and proper planning can help youngsters and their families, and the educational agencies that serve them, deal with these issues forthrightly. Although 67% of the informants in the CCCF study indicated that they had received and used "information about my illness," 17% noted that they wanted more information, presumably about just such issues (see also Fobair et al., 1986). Assistance in applying for special educational

programs, planning for complementary skill development programs that help compensate for some disabilities, and proper diagnosis of learning difficulties all are essential services.

## General Psychological Concerns -- Self Esteem and Adjustment

The overwhelming trend of the literatures indicates that off-treatment survivors of childhood cancer are adjusting well to their illness and to recovery, off-treatment status or cure. Most appear to be living "normal" lives. Their self-esteem and psychological capacities generally appear to be well within the normal range. Holmes & Holmes (1975) come to this conclusion with a sample of 124 youngsters, Meadows et al. (1983) with 93, Li & Stone (1976) with 142, Obetz et al. (1980) with 18, Boyle et al. (1982) with 27, Jamison, Lewis and Burish (1986) with 31, and Teta et al. (1986) with 450.

All these researchers do indicate that some percentage of young adults studied are psychologically very vulnerable, need some intervention or are not functioning well, but the numbers so depicted generally are small and the dysfunctions or vulnerabilities minimal. O'Malley et al. (1979) and Koocher and O'Malley (1981), studying 117 long-term survivors, present a somewhat different picture, arguing that a majority (59%) was "psychologically impaired," although only 23% had moderate-to-severe symptom formation that might affect their functioning. Lansky et al. (1986) also report a higher incidence of depression among off-treatment survivors than in a control sample of siblings.

Various scholars examining this mix of studies (or others that depict similar trends) come to different conclusions regarding the adjustment of off-treatment survivors. Some argue that most of this population appears to be well within the "normal" range, with an unclear percentage vulnerable or at some risk, and a rather small population quite distressed. Others see this glass of water half empty rather than half full; they see the substantial proportion of this population doing well, another sizable portion marginally distressed, depressed or at risk, and a smaller portion psychologically endangered and dysfunctional. The different conclusions often come from different data, but may even arise from similar data. They may reflect different clinics'

emphases, different professional orientations, or seriously different ideological preferences and convictions. Only time and continued study will put these studies into perspective and tell us just how much and what kinds of psychological risk and dysfunction are likely to occur in what percentage of the off-treatment population.

One significant issue this research raises is what we should consider as a working definition or assumption regarding "normality" or "normal behavior" or "adjustment" (Chesler and Barbarin, 1987; Van Eys, 1977). Our assumptions directly affect professionals', parents' and ex-patients' expectations of youngsters' and young adults' behaviors and their subsequent reactions to and interactions with them -- including service suggestions. Young people off-treatment often report they "feel normal;" not quite like everyone else but not necessarily strange or disabled. Is that a working definition of normality we can use? Or does normal mean "like everyone else" in some statistical sense? Surviving children with cancer are not like everyone else, and it is inappropriate to suggest that they should be -- for treatment purposes or for measurement purposes. Moreover, normality certainly does not mean "like before diagnosis;" the diagnosis and treatment are such life-changing events that any non-changed return to that prior status is inconceivable (Botcky and Cohen, 1985; Moore, Holton and Martens, 1969).

In my view, concepts of normality must be made pluralistic and tied to the reality of the person and situation at hand. In the CCCF study, for instance, 44% strongly agree and 32% agree with the statement that "having cancer has made me different from others my age." When asked how, or in what ways, one young survivor captured her "different outlook" in the following terms:

> You're more careful after you have cancer. You're afraid of dying so you wear your seatbelt, you don't drive fast, and you don't do drugs. You have this experience where you think you're going to die and you want to live so badly, so what's the sense of doing this stuff and then dying anyways? Live life to the fullest, and don't do all this stuff that's going to make you die any earlier.

Overall, some comments (less than 20%) emphasize negative issues, such as "more worries about my health," "unclarity about who are my friends," "less outgoing" and "too serious." However, the overwhelming majority (80%) of comments note positive factors, such as "more serious or

determined," "more appreciation of life," "more mature," "able to deal with sickness and death," "more sensitive," and "more interest in helping others." These all may be statements of "non-normality," but certainly we would not regard them all as negative; we might, in fact, wish for more of some of them for ourselves. Moreover, 57% strongly agree (and 38% agree, equaling 95% overall) that "I expect to have a good and full life," and 32% strongly agree (and 55% agree, equalling 87% overall) that "I feel good about myself."

We indicated earlier that it is common for off-treatment survivors to struggle with their feelings of attractiveness (note the 39% who worry a lot about "how my body looks"). Such feelings are not rooted simply in physical body-image (Blotcky and Cohen, 1985; Zeltzer, 1978), nor limited to those young people who bear visible and long-term side-effects of treatment, such as amputations or surgical scars. Rather, such feelings also are connected to weight loss or gain, hair loss, and emotional reactions to a body that has contracted a dread disease and has undergone various forms of treatment-related assaults. These concerns are likely to be escalated for adolescents; even those without cancer typically struggle with issues of attractiveness and difference.

All these issues reflect the struggle with a new sense of self and a new psychological identity. Attempts to integrate social differences and similarities, and an uncertain physical history and future, all lead off-treatment survivors to struggle to understand their true capacities adn future potential. This is reflected especially in seeing oneself as "cured" and as a "survivor." For some, especially those diagnosed when young, their special status as a cancer patient may be the only identity they have known. They may build their careers and future lives off this identity, seeking future roles as medical professionals, cancer volunteers or informal helpers and counsellors to others. In this way they can make use of their special expertise and compassion, as well as explore a social identity rooted in their unique experience (indeed, 41% of the CCCF study informants report thinking somewhat or a lot about "wanting to work in a medical field").

In attempting to deal with these general psychological stresses of childhood cancer, youngsters cope in a variety of ways. Koocher and O'Malley (1981) and Zeltzer (1978) indicate

that seeking information (reading and thinking) and denying major problems (not thinking much about the illness) are the most common coping patterns. We asked youngsters what advice they would give other young people with cancer with regard to coping with the illness, and some of their advice is presented in Figure 1. Although the result is quite a mix of ideas, the life experience and wisdom reflected here is quite powerful. They suggest an active fighting and hoping posture, cooperation and compliance -- but not docility -- with regard to the medical staff, outreach and connection to other people, realistic attempts to deal with feelings, and a non-selfish compassion for others in their lives.

A number of these issues begin to be crystallized when children with cancer begin to become "off-treatment survivors." Lewis and LaBarbera (1983) and Ross (1982) note that youngsters coming off treatment often feel anxious about their future without the continued protection of life-saving chemotherapy. Koocher and O'Malley (1981) highlight the continuation of concern and worry with their use of the powerful metaphor of "The Damocles Syndrome" to entitle their study of long-term survivors. Survivors talk about the feeling of "sitting on a time bomb," "throwing away a crutch," and "waiting for the other shoe to drop." Hockenberry (1986) also includes an excellent discussion of the problems parents and children face in this regard by labelling "discontinuation of therapy" as one of the major crisis points in childhood cancer. It is at this point that a new identity begins to be forged and the (ex)patient engages in the transition to a self-concept of oneself as a "survivor," as "cured," as "healthy" and as "less special" than before. All these welcome changes carry their own psychic risk.

In an extraordinarily insightful commentary, Koocher (1984) discusses several post-treatment crisis points in the life of the child and family surviving childhood cancer: anniversaries of key events, such as diagnosis; symptom consciousness or concern about relapse as a result of minor illness reminiscent of pre-diagnostic symptoms; realization of the loss of special forms of support several months after treatment has terminated; and "normal" development crises that highlight important past or future events, such as graduation, marriage, major birthdays. These normal developmental events or crises carry special meaning for the child and family of the child

Figure 1

SOME WORDS OF ADVICE:  FROM YOUNGSTERS WITH CANCER
TO OTHER YOUNGSTERS WITH CANCER


Don't give up and don't take advantage.  When you're not doing anything you feel more helpless, and that's why I have a garden.

Don't think bad thoughts alone.  The worst thing I ever did was cry by myself and keep it all to myself.

The only way you are going to make it is if you fight.  If you fight back it is going to go away.  Take your chemo as it comes and do things to stop yourself from being sick.  Most of the people you meet will be nice.  It's going to be hard to handle what's happening to you, but that's when your mom and dad and other people have to come in.  You can handle it.

You have to be considerate of other people and not take advantage of the situation.

Keep up your hope and all isn't lost.  You have a long way to go, but keep fighting and you're going to win.  Do what the doctor says to do.  If you don't want to do it, do it anyway.  It's all to help you.

You have to say to yourself, "I have it and I'm going to live with it."  You have to take the treatments and medicines as well as the pain of treatments.  You will soon overcome the pain, and when the pain dies, so do many of the feelings of death and dying.  In its place comes stronger feelings of hope, courage and a feeling for others who are struggling.

I'd like to tell little kids that funny feelings are normal, like wanting to kill yourself.  It doesn't mean you're crazy.  I went from that feeling to, "darn it, this isn't going to get me."

You can't let the staff intimidate you with all their importance; you're a person.

I think you really gotta speak up.  There's this one girl here, when you say, "How are you doing, Mary?" her mom will say, "Oh, she's doing pretty good today."  I don't know how she can get through to the doctors that way.  You gotta speak up.  You can't sit back and let them run over you.

with cancer, because they represent life markers whose cahievement were in doubt, as was the very life of the child. They often are times of great emotion, relief and stress. In like fashion, many of the normal rites of passage in adolescence and young adulthood are escalated and fraught with deep emotion for the off-treatment survivor and family. Independence and autonomy, for instance, a typical issue faced by all adolescents, seems to be a greater challenge for the young person surviving cancer. Since the disease and treatment usually require an unexpected period of enforced dependency upon the medical staff and family, release from the disease may announce a renewed struggle for independence.

The responses of informants in the CCCF study to the question of what was hard about going off treatment are presented in Figure 2. The concern about leaving "life-saving" chemotherapy, and the implicit fear of a relapse is obvious. But we also see a concern about getting on with the rest of one's life, with adjusting to "common pressures" and "where I left off." Despite a commitment to early "re-entry" and "normalization" of the life of the child with cancer, it is important to consider the possibility that real normalization may only be possible after treatment ceases -- at least for some youngsters. At the very least, a concern for "living one day at a time" must be transformed into "living for the longer term." Many off-treatment survivors express a sadness about leaving their "friends" on the medical staff, people with whom they have developed an intimate relationship over the course of several years. It takes only a casual inquiry into staff members' feelings about off-treatment survivors to realize this generally is more than a unilaterally dependent relationship. It often is an interdependent and mutually caring association and its potential ending is nothing to take lightly -- nor need it happen as a matter of course. Finally, of course, many young people note that there is nothing hard about going off-treatment, it is an eagerly awaited, celebrated and (perhaps) unambiguous event.

Both parents and children must re-orient their expectations and psychological coping patterns, must think anew about the long-term future, and must manage their anxiety about reduced reliance on treatment, per se. Their anxieties about the transition are probably quite realistic; after all, the treatments have been life-saving, the disease could return, new late-effects

Figure 2

OFF-TREATMENT SURVIVORS' COMMENTS ABOUT
"WHAT WAS HARD ABOUT GOING OFF-TREATMENT"


Being worried that your body won't be able to kill all the bad cells without the aid of the
        chemotherapy.
Coping with the fear that it might return.
Wondering if I was really cured, if all the cancer was gone.
Wondering if the doctor stopped too early.
Not knowing whether or not I should continue for just a little longer. Was this enought treatment?
        So far so good...
Being scared of not knowing if something is wrong again.
Knowing that you would soon find out the TRUTH, not percentages, about if you were cured.
Not having the crutch of knowing chemo was killing the cancer cells. If there were cancer cells in
        my body still, I wasn't on drugs to kill them. Also I no longer had the excuse of chemo to
        get out of things.
The treatment and staff had started to become a security blanket.

Readjusting to the common pressures of everyday life.
Trying to figure out where I left off.
The next five years waiting period.

Missing the patients and the other staff.
Knowing that I wasn't going to spend as much time as usual with the medical staff.
Not getting to see my friends quite as often.
Not being able to see my nurse friends.

Nothing was hard. After several years it was a welcome event.
Nothing!
Nothing, I was glad.
There was no hard part about going off treatment.
Glad to get it over with.
There was none.

may be discovered, basic health may be somewhat compromised, etc. For off-treatment youngsters to experience no anxiety -- to be like children who have not had cancer -- would be abnormal and a cause for concern. Is it normal for off-treatment survivors to be more attentive to their health and minor physical symptoms than youngsters without a disease history? No in comparison to a non-ill control sample, but yes in terms of a population of survivors. Such attentiveness not only is normal, but probably quite functional.

Off-treamtent, it is less legitimate to "worry" about the cancer. After all, as far as most of the social world is concerned, it means one is cured and can get on with life! But worries remain, as the data clearly indicate. Without the legitimacy of a social role as an ill person, a patient, a person under treatment for cancer, worries become more subtle and secretive. Worries may be denied and repressed intrapersonally, and avoided or not discussed interpersonally. They continue to exist, however, and like other buried concerns may burst forth during times of stress and strain (e.g. during school exams, family arguments, on anniversaries, etc. -- see Koocher above). A major dilemna at this stage is just how much worry is fruitful or realistic, and about what.

Clearly it is appropriate to respond proactively to these issues (and to pass on the advice in Figure 1 and the reflections in Figure 2) by offering psychological counselling and support to long-term survivors of childhood cancer. A considerable number of survivors indicate (in Table 3) that they have used such counselling services -- over 30% (typically during treatment) -- or would like to use them -- 15-18% (after treatment). One major question regarding this sort of invitation, or intervention, is whether it should be based primarily upon a health promotion model of counselling or a health deficit model (Spinetta et al., 1982). If we plan and initiate such a program because we expect many off-treatment survivors to have psychological disabilities, we may help stereotype and disable them further. If we plan such a program because we assume many psychologically healthy young people need assistance to deal with a major and continuing crisis in their lives, we may help promote more mental health. Most programs will attempt to serve populations with both sets of needs, but our going-in assumptions have potent implications.

Although some clinics offer individual psychological counselling to youngsters, few have developed support groups for children on or off treatment for cancer, settings where young people are encouraged to talk with others their same age and medical status (Bryne et al., 1984; Heiney et al., 1988; Lewis, 1984; Sachs, 1980; Thomas, 1980). Clinics which do offer such services within a psychological deficit model generally talk about "group therapy," while those pursuing a psychological health model generally talk about "support groups." Sometimes professional practitioners fail to make this important distinction: for instance, Heiney et al. (1988) appear to use the terms "group therapy" and "support group" interchangeably, and Byrne et al. (1984, p.36) state that they "review the use of group therapy... [in order to] ...describe an experience with adolescent support groups." From either vantage point, such group settings provide an arena for off-treatment youngsters to share feelings, gather and exchange information, learn and teach coping skills, and explore new ways of solving personal and social problems.

In an increasing number of states and cities, special "camps" for children with cancer are attempting to provide a similar service (Buttino, 1983; Camps for children with cancer and their siblings, 1983), and older off-treamtent survivors often are utilized as counsellors or mentors to younger patients.

For some young people, a peer (fellow patient and survivor) support system may even be more successful than professional services, and peers leery of psychological manipulation or more "treatment" may be more receptive to it (Panke, 1978). Note, in this regard, the large number of survivors (35%) who indicate in Table 3 that they would like to meet with other young people with cancer. As we discuss later, many more informants are willing and interested in being of assistance to other young people with cancer. This is not always a universal desire, of course; some survivors would prefer no help, or professional help, to a peer counselor; some would prefer to cope privately and not refer to their cancer history "in public." Many alternative forms of psychological and social support should be made available in order to deal with the broad range of adjustment levels and problems faced by off-treatment survivors, and with their varied individual preferences.

The Candlelighters Childhood Cancer Foundation represents those parents, researchers and clinicians who encourage the development of peer support and self-help groups for survivors of childhood cancer (Youth Board Member..., 1983). Such groups clearly are an alternative to professional counselling and professionally-led support groups; they are a form of lay-support, peer counselling or mutual sharing and experiental exchange of wisdom. Very few reports discuss the problems professionals, parents or youth leaders face in creating and leading support groups for children with cancer (one exception is a refreshingly honest and insightful piece by Lewis, 1984), and there is little sound research on this program option for youngsters off-treatment, whether run by professionals or guided by young people themselves. This is an area where we could benefit from an expanded series of anecdotal or descriptive reports by professionals and/or parents or off-treatment survivors who have tried to create such groups.

### Family

There is now beginning to be a substantial body of research concerning psychosocial issues in the lives of families of children with cancer. Some of this work focusses upon the issues children with cancer face as they relate to other family members: how parents deal with child-rearing and discipline issues; how they relate with siblings; whether the ill child's chores and tasks are re-allocated; and the like. Other research focusses upon the reactions of other family members; how parents cope and what changes they make in their own lives; how parents relate with one another; what role grandparents play; how siblings deal with the threat to their sister or brother's life, as well as their own feelings of jealousy, need for special attention, etc. Above all, it is clear that childhood cancer is a "family illness"; it affects all family members and creates psychosocial issues, worries and coping tasks that all family members must face (see Chesler & Barbarin, 1987, chapters 5,6,7,12). It also creates needs for services that can and should be delivered to various family members.

The family dynamics of childhood cancer continue to be relevant when the child is off-treatment, although there is almost no research available on this period in the family's struggle.

Table 2 reflects some of the concerns about family issues expressed by the CCCF study informants. Approximately one-fourth worry a lot about their parents' health (and financial situation as well, a topic we return to in a discussion of insurance). In the following interview excerpts three young survivors discuss with great understanding and compassion some of the special pain they know their parents experienced.

> When I first got diagnosed my father didn't come to the hospital, but he would drive everybody crazy because he didn't know what to do. He didn't know how to deal with it. He would start to straighten things up in my room and straighten them up again. He was just really nervous to be around. He would stand over my bed right above my bed and just stand there. And I'd be like, "Dad, sit down and watch TV." He just didn't know what to do, he wanted to make everything all right.

> I think it's really hard for a man to see his child very sick and hurting. I think a man is supposed to control everything, or so they think. When they see something that is out of their control and can't do anything about it, it's just like, "Oh my God, I'm losing control. I'm not in control and it's my own child." I saw that a lot with my dad. You know, he went to the hospital all the time, but you could see something was defeating him inside and he couldn't fight back. It's pretty bad to see that especially in a man who has always been your mentor.

> It's not like I've hurt her, but I have put her through a lot. I feel okay about what I've done, but I feel guilty that I've made everyone go through this. I feel that I have made my mother put her life on hold too for years, and I feel bad about that.

Although the research suggests that some families are in serious danger of dysfunction or disintegration during these stressful times (Kaplan et al., 1973), most families seem to cope quite well (Chesler and Barbarin, 1987; Cook, 1984; Kalnins, 1983; Koocher and O'Malley, 1981; Kupst et al., 1982; Kupst et al., 1984; Lansky et al., 1987). As noted in our discussion of concepts of normality, "coping quite well" does not mean "the same as before" or "like other people"; it typically means "doing alright under these (dreadful) circumstances."

The fact that most individuals and families may feel they are coping well does not mean that services to assist in the process of family coping are not relevant or not needed. To the contrary, in Table 3, 28% of the CCCF study informants indicate having used counselling services for family issues, and 17% would like to use such services if they were available.

On the basis of prior research, as well as these expressions of needed/desired services, various forms of psychological counselling or support are suggested for families (Ross, 1982). Two

reasons stand out as justification: (1) intervention may improve the psychological functioning of individual family members and thus the entire family unit; (2) improving the functioning of the family unit may help create a less stressful and more supportive environment for the child. As in the prior discussion of psychological counselling and support for the child with cancer, debates focus on whether such services should primarily be focussed on "therapy" or "support," led by professionals or peers, occur in groups or singly, etc. In many locales parents themselves have created mutual support or self-help groups for families of children with cancer, (e.g. local and national Candlelighter groups), and scholars or parent organizers have described these efforts (Bogue and Chesney, 1987; Chesler and Barbarin, 1987; Monaco, 1988; Nathanson, 1986; Yoak and Chesler, 1985). Social workers or psychologists also have described their efforts to organize and lead therapy/support sessions for families of children with cancer, either in individual or group formats (Adams, 1978; Belle-Isle and Conradt, 1979; Heffron, 1975; Ross, 1980).

Even more prominently than in studies of individual children with cancer, almost all the research on the family is focussed on families of children in treatment. The little work that has been done on the issues facing the family of a child (or the child in the family) who is off-treatment and a survivor suggests that major family stress continues after the child with cancer has completed treatment. Indeed, the cessation of treatment may itself be a major stressful event, creating feelings of considerable confusion and re-adjustment as well as anxiety (Hobbie, 1986; Hockenberry, 1986; Lewis and LaBarbera, 1983). Escalated anxiety may accompany key incidents in the lives of survivors, such as the anniversaries and special events noted earlier. Moreover, over time previously unprocessed issues may rise to the surface, hidden worries may burst forth under stress, family members who resented special attention given to the ill child may demand their due, friends who are tired of providing extra help may drift away now that it is "not needed," etc. A family prepared for these eventualities, and experiencing them as normal, can deal with them and their impact on the child with greater skill and aplomb. A child and family unprepared is a family at risk! Since living with a survivor of childhood cancer may call for coping patterns quite different than those utilized while a child is in treatment, additional

information, psychological counselling and social support is appropriate. Support and specific coping aids may be provided by expert clinicians and/or by experienced parents and family members.

Friends

Consideration of the friendship system as a problem area for young people surviving cancer must include both old friends and new friends. Concerns about old friends relate to the ongoing peer support system that children and young adults came from and need to return to and stay enmeshed in. Concerns about new friends involve perspectives on the future, the ability to continue to establish new relationships and solving the problems of "when do I tell her/him about my cancer". Several survivors discuss this "telling" issue in the interviews, as follows:

> I will sometimes tell a few close friends that I have cancer. One guy that I am very close to knows and he is always still worrying about me. I feel maybe he should know in case something should happen, and they would wonder why I was in the hospital. If I am real sick, or if I went out of remission, it would be helpful for them to know.

> I told one person and I trust him because he is my special friend and won't go around spreading it around to everyone. There are very few at school that I tell.

> I don't need to share this with anyone. I don't have a boyfriend. If I ever do get engaged or am really close to someone then I will tell them. But nobody needs to know because it's gone. It's nothing I need to share because it doesn't need to be part of my life. I'm not going to be sick on anybody and I'm not even going to lose hair on them. To them I am a normal person.

Friendships often set the stage for the creation of loving and intimate partnerships. In the actual or potential establishment of families of the future, concerns about marriage and child-bearing become relevant and potent.

Several researchers speculate about or report patients' or survivors' fears of loss of old friends and peer support, or even the actual loss of such support (Orr et al., 1984; Zeltzer et al., 1980). Table 2 indicates that 30% of the informants in the CCCF study worry a lot about this issue. Survivors' own fears about their attractiveness, their awkwardness in discussing or not discussing their experience, combine with peers/friends' fears and/or ignorance about cancer to

form a potent set of barriers.  As a result, many authors discuss the importance of relocating survivors in an effective peer network as an essential component of full care.

Cella and Tross (1986) and Fobair et al. (1986) report that many off-treatment survivors of whatever age also raise questions about their reproductive capacities, thus confirming the experiences of the 29% of CCCF informants who worry a lot about "whether I can have children" and the 23% who worry a lot about "my children getting cancer."  Moreover, a considerable percentage of these young people express a desire (see Table 3) for family planning and genetic counselling services.  One young woman expressed her concern, and her lack of ability to get adequat information, as follows:

> There are no neuroblastoma people living who I know of who have kids, so I can't talk to them and see if things went well and are going well.  Maybe I have to be the first to do it, I don't know.

Recent research (Fobair et al., 1986; Li et al., 1987; Meadows and Hobbie, 1986; Mulvihill and Byrne, 1985; Mulvihill et al., 1987) suggests there are still uncertainties about this issue. Youngsters who have experienced internal organ surgery, abdominal radiation, certain forms of multi-modal chemotherapy, or rare hereditary cancers, may indeed be at risk for compromise of fertility.  The vast majority of survivors of childhood cancer, however, appear to be free of such risk.  It is especially important to confront these fears with programs that provide survivors with up-to-date and personalized genetic counselling and reproductive information.  Part of the service agenda should deal with typical adolescent and post-adolescent concern with sexual activity and birth control, but it must also address concern about eventual reproductive capacity.

The Candlelighters Childhood Cancer Foundation data speak clearly to off-treatment survivors' needs and desires to meet, talk with and help one another -- as new friends.  Two off-treatment survivors report, below, part of what is "special" about meeting and talking with other young people who have had cancer.

> I mean I feel closer to other kids with cancer instantly, whereas with people who didn't have it, it would take longer to become friends with them.  We have an understanding that we don't have to talk about.  It's just there.  I understand something about her and she understands something about me that doesn't need explaining.  That's why I think I get attached to them more quickly.

> You don't "counsel" other kids, you just say what you had and talk about topics of common interest. I just talk about it with others because sometimes you can't talk to your parents because they have their own problems with the bills and with watching you go through it. Parents understand it, but not on the same level like other kids do.

In Table 3, thirty-five percent of the informants reported having used such meetings and another 35% reported they would like to use such meetings. In addition, 46% of informants reported that they "could have used more contact with other patients my age." Finally, 81% stated they are interested in meeting other young people with cancer who are off treatment, 70% stated they are willing to be a local contact for a childhood cancer survivors' network, 77% stated they are interested in being a pen pal to a young person with cancer and 64% are willing to be part of a speakers' bureau to talk with educators, medical staffs and employers about childhood cancer. We must find ways to meet these needs and to utilize this incredible resource; these informants can enrich our life and work as well as advance their own ability to confront the issues facing themselves and their peers!

The CANDLELIGHTERS YOUTH NEWSLETTER puts young people with cancer -- youngsters off-treatment and on-treatment -- in touch with one another across the nation, provides them with experiential information, and establishes an avenue for sharing coping skills. Local peer support groups and a national network of off-treatment survivors of childhood cancer are crucial parts of the Candlelighters Foundation's service agenda in the years to come (and are underway in other nations as well; see Carr-Gregg and Hampson, 1986).

Four service agendas flow from these needs or concerns: (1) efforts to educate survivors regarding these potential peer problems and opportunities and to equip them to deal straightforwardly and assertively with their peers; (2) efforts to educate peers and the social network of each survivor, perhaps with physician-led or family-led sessions that deal with the intact peer network on a pro-active basis (in schools, hospitals, homes, neighborhood centers, etc.); (3) public information/education campaigns in schools, colleges and other sites of peer gathering; and (4) efforts to build networks among off-treatment survivors.

School

Schooling issues are among the best researched areas in the social life of children with cancer. Although this focus has not systematically been extended to the educational lives of long-term survivors, the existing research does permit us to extrapolate cautiously to the issues facing off-treatment survivors. Table 2 indicates that 32% of the informants in the CCCF study worried a lot about "keeping up in school." This general concern covers a number of different issues, some focused on attendance in or access to school, some on academic performance, some on peer relations, etc. For instance, 67% of the informants indicated that they missed a lot of school when they were sick, 30% said they were behind a lot in their schoolwork and 22% reported that they needed extra tutoring a lot. On the other hand, 85% reported that they are now at the same grade level as other young people their age, and only 5% reported having a lot of learning disabilities. School is the central social institution (outside of the family) for youngsters between the ages of 6 and 18, and it is natural that it should become the focus for a number of personal and social concerns -- both positive and negative.

The research literature on schooling for children with cancer has focused on several different categories of issues: (1) medical influences on school performance; (2) possible school phobia; (3) problems in peer relations; (4) teacher behavior that diminishes youngsters' capacities, efforts or opportunities for effective learning; (5) institutional discrimination or channelling of students into dead ends.

Studies of physical influences on school performance include the long-term impact of treatment on youngsters' physical and cognitive capacities. Children with amputations need to learn how to be mobile within the constraints of their disability, and to cope with peers' reactions to their appearance and ability. As noted earlier, youngsters who have received cranial radiation or brain surgery may encounter learning disabilities or deficits, sometimes minor and sometimes quite major. There is a substantial body of literature now available on neuropsychological deficits, and much of it is concerned explicitly with long-term survivors.

School phobia was one of the earliest educational concerns raised in the literature, and it often stood as a catchall for the other issues noted in this section. Over time, it has faded as a major concern, as medical staff members have helped parents, children and educators face the issue, and as related issues (peer relations, staff discrimination) were differentiated, identified and dealt with. While phobias may have disappeared from the research agenda, school absenteeism, whatever its causes, has not. Chesler and Barbarin (1987), Deasy-Spinetta (1980), Lansky et al. (1983) and Stehbens et al. (1983) verify the CCCF informants' report of considerable school absence. By the time children with cancer reach the stage of being off-treatment survivors, we may expect school attendance to approach normal rates. However, unless special measures are undertaken by children, families, and school staffs early in the game, absenteeism while in-treatment can have disastrous effects on later academic performance and social relations.

Problems with school peers are often noted in the literature, but less systematically researched than the prior concerns, and this is one more reflection of the trend that research into psychosocial issues are less adequately funded and addressed than are biomedical and neuropsychological ones. However, it is clear that most of our society harbors many myths and fantasies about cancer, and young people are no strangers to this culture. As they express their concerns in instrusive curiosity, awkwardness, withdrawal or rejection of the child with cancer, this causes pain and discomfort for the child seeking re-entry and normalization (Katz et al., 1977; Moore and Triplett, 1980).

Several researchers also have reported stereotypes and fears among teachers of children with cancer (Cyphert, 1973; Deasy-Spinetta and Spinetta, 1980). Persons in positions of authority with regard to the formal schooling system, and the informal relationships that undergird classroom and school life, play a vital role in setting a tone conducive or constraining of positive academic performance and good peer relationships for childhood cancer survivors.

Finally, several observers have noted the ways in which schools may inappropriately "track" children with cancer into special classrooms, into programs for children with learning disabilities, or onto the garbage heap of minimal expectations (Deasy-Spinetta and Tarr, 1985).

Such discriminatory actions and programs have been challenged by local medical staffs and parent groups, sometimes drawing on special services mandated by legislative action (e.g. public law 94-142) and sometimes escalating to formal litigation. Unfortunately, the catchall approach of federal agencies often overlooks the special problems faced by children with cancer (or other specific diseases or disabilities).

Several treatment institutions have developed innovative services to ameliorate these problems. They generally take one or more of several forms: (1) counselling youngsters and their families to be vigorous advocates of their rights to an equal and minimally restrictive education; (2) providing seminars and workshops for educators regarding the real needs and abilities of youngsters with cancer (Barberin and Chesler, 1981; Deasy-Spinetta, 1980; Ross, 1984); (3) outreach efforts whereby the medical center links to the school system which a child with cancer is attending, delivering specific case-relevant information and support to child, family and educators (McCormick, 1986). That some services of this sort are already being provided is evident in the report that 55% of the CCCF informants have used school counselling programs; indeed, next to medical information this is the second most widely available and utilized service effort. Another 13% indicate that they would like to use such services. The widespread use of services does not indicate what kind of services are being provided, however; in all likelihood the primary focus is upon the first three areas noted above, with less focus on treating positive peer relationships and advocating for change in discriminatory school processes. Moreover, unless the treatment center or the school system is pro-active, the burden for intervention remains with often overburdened children and their families. A preventive and aggressive public health campaign is needed.

To what extent can we generalize from these research findings on school issues for children with cancer in treatment to those youngsters off treatment, to long-term survivors? Medical influences on school performance will still exist. Although most survivors may be expected to adapt well to amputations and physical changes (Mullan, 1984), those experiencing major intellectual changes or learning disabilities may continue to face problems in academic performance. They will continue to need special educational supports and services that help them

achieve their highest potential in the context of their different abilities. Deliberate and active attention to peer relations also is crucial, and there is no reason not to attend to positive peer relations and student respect for individual differences (in abilities, as in race and gender and ethnicity) as a serious academic issue, involving regular instruction, readings and assignments. Teacher behaviors that depress student motivation to perform are less likely to continue for survivors than for children in treatment, because later teachers will know less about the surviving child's unique history. As with other forms of prejudice, when potential victims are unknown or invisible it is hard to discriminate against them.

### Insurance discrimination -- medical and life

As more survivors of childhood cancer enter adulthood, and begin to achieve fiscal independence from their parents, they have begun to encounter difficulties in getting adequate health and life insurance (Holmes and Baker, 1986; Monaco, 1988; Teta et al., 1986). The CCCF data indicate that 23% of off-treatment survivors report "worrying about trouble getting medical insurance" and 29% report "having trouble getting life insurance." Since 47% of this sample of off-treatment survivors is under 18 years of age (and 77% under 21), the relatively low level of "worry" about insurance probably reflects the fact that many of these informants have not yet encountered a need for insurance, not that it is not a concern of survivors in general.

In some cases, difficulty with health insurance was encountered long before survivorhood, as some families were not originally covered by insurance and other families covered only minimally. This is not a problem unique to families of children with cancer, of course. According to the Family Support Bulletin (of the United Cerebral Palsy Association), in 1985, "11 million children age 18 or younger were uninsured." Lansky, Black and Cairns (1983) and Bloom, Knorr and Evans (1985) document the high cost of medical treatment for childhood cancer, and these costs have escalated tremendously since the time of their research. Moreover, Lansky et al. (1979) and Bloom et al. (1985) document that extensive out-of-pocket expenses (not reimbursable by most insurance policies) are usually incurred by the family of the child with cancer. Chesler

and Barbarin (1987) indicate that 38% of the families they studied reported the financial impact of childhood cancer as "serious" or "somewhat serious."

Some families have been unable to maintain insurance coverage as the illness progressed and treatment costs escalated. And, as Monaco (1988) points out, insurance systems often do not cover some treatments (e.g. some bone marrow transplants) because they are considered "experimental." Despite the willingness of hospitals and medical centers to take on "charity" cases (even the word is a stigma deriving from societal unwillingness to provide protection to its most vulnerable members as a right) there are limits to the economic carrying capacity of most medical centers. What are children and families to do in these circumstances, except appeal to the mercy and charitable processes of community fund-raising efforts? In addition to affecting the possibility of surviving, per se, we expect these issues to affect survivors' own social and economic status and the personal psychological and material resources available for pursuing future educational and career goals.

Koocher and O'Malley (1981), Teta et al. (1986), Mullan (1984) and Monaco (1988) point out some of the difficulties off-treatment survivors encounter in getting independent health insurance. It often is difficult for them to get policies of their own; they may be forced to pay exorbitant rates for single coverage policies; they may have to wait several years to join a pool; or they may be "forced" to join a large employer/organization in order to be covered by a group plan. Two survivors report their experience with these difficulties as follows:

> I had to go on a high risk insurance program and pay higher rates.

> The thing is, I'm on my parents' insurance and the only other way I'll get my own insurance is if I get married and my husband's company fixes it up, or if I get a job in a big company that has a good group program. But that's going to be difficult enough, getting a job, if in fact people are going to say, "We don't want to hire anyone in that condition."

At the least, these problems may coerce survivors into selective employment patterns; at its worst, some young adult survivors may remain uncovered.

Monaco (1988) and Teta et al. (1986) point out similar problems off-treatment survivors face in purchasing life insurance. For the survivor who elects to live a single and lone life this

may not represent a problem. But for a survivor with plans to raise a family, and to live a life interdependent with others, life insurance is an important part of building a safe future for one's partner and progeny. The inability to obtain such security jeopardizes normal family life. In addition to the hard fiscal reality contained in both these examples, off-treatment survivors who encounter such difficulties find it a stressful reminder of their special and stigmatized status in this society.

Although it is clear that there are important needs or problems in these areas, we do not have much good data on their actual extent. Since many negative encounters go unreported, the extent of these problems may be much more severe than would appear at the outset. There also is little research data available that informs us as to the actual perspectives and reasoning of executives and planners in health and life insurance agencies. Without a coherent understanding of the basis for the discriminatory treatment of survivors, we are in poor shape to devise plans for changing policies and programs. Educational efforts (directed at insurance agencies and executives, and at public policy-makers), public education programs, litigation and legislative action are all reasonable courses of action (Adams-Greeley, 1986; Koocher and O'Malley, 1981).

## Employment discrimination

Advocates of children with cancer (Monaco, 1984) and recent research studies, have begun to document problems off-treatment survivors face in the employment arena. In some ways young adults' problems may be even greater than those of older adults: as persons thinking about the job market, rather than having much experience in it, they are more vulnerable than adults to subtle tracking and channeling messages; as young persons with minimal work experience, their expectations are more likely to be molded by stereotypes; without union backing, they are more likely to have to switch jobs and careers than fight discrimination.

Mullan (1984) and Burke (1988) emphasize the particularly devastating impact employment discrimination can have on survivors who have fought their way back from a life-threatening disease, only to find themselves facing socially-threatening environments. Koocher

and O'Malley (1981) report that 50% of the survivors they studied who were over 18 years of age, and who were employed, had experienced job discrimination. In the Candlelighters Childhood Cancer Foundation data, 29% of those off-treatment survivors who are employed report that the cancer affected their job possibilities, although not all the effects are negative. Twenty-three informants reported that they were refused a job because of their career history, with 6 of these noting that they "were told directly that was the reason." Feldman (1980) has begun to document the extent of this problem for the California Division of the ACS, and Boyle et al. (1982) and McCalla (1987) also have noted it prominently. Teta and colleagues (1986) have documented the extent of this problem in their studies of a representative sample of childhood cancer survivors in Connecticut. They also note that male survivors are much more likely to experience employment refusal than are females. The Teta et al. study begins to help us understand the true statewide incidence rates of this social problem, but we need much better evidence nationwide.

The effects of discrimination, or anticipated discrimination, are often quite subtle. When adolescents and young adults are also confused about their career plans and functional abilities, either because they are young or because they are cancer victims, the problems of career preparation and choice are compounded. Feldman (1980) reported that 47% of the 38 young people who had been treated for cancer in her study had made changes in their career goals. Many of these survivors said they changed for reasons unrelated to their illness, typical of adolescents with or without cancer, but the need for assistance remains nonetheless. It is important that off-treatment survivors receive some form of personal career counselling, so as to bolster their self-esteem in making educational and career choices, to help them think realistically about the job market and career paths, and to prepare them to withstand potential employment discrimination. It is in this context that we can understand survivors' reports (in Table 3) of a high need for career counselling, information, and perhaps even legal assistance.

In addition, actions should be taken to reduce or eliminate the existence of employment discrimination, whatever its motivation. The American Cancer Society has embarked on major public education programs designed to sensitize the nation, and public and private sector

employers, to employment discrimination problems facing adult cancer patients -- whether in treatment or off-treatment. Several states are considering explicit anti-cancer-discrimination provisions in their human rights' codifications, and increasing pressure for executive or legislative action at the national (Congress) or state (see examples of new initiatives in New York and California) levels is undoubtedly required. These initiatives should be expanded to highlight the issues faced by young people who are surviving childhood cancer, but who may not survive adult discrimination.

Employers and insurance companies and community agencies all represent potential targets of concerted public education campaigns, influence efforts, and political pressure. Action will have to be taken in many ways, in all these institutional arenas, to improve the psychosocial services and environment available to off-treatment survivors. Efforts to alter insurance and employment practices, for instance, probably will not be successful without "expert testimony" from physicians regarding the real medical risks involved. However, such information is not likely to be effective unless it is accompanied by political pressure, whether applied by the American Cancer Society, insurance and employer associations, arms of the local/state/federal government, or the public relations presence of off-treatment survivors themselves. Action in these public and community arenas clearly represents a form of social change; it will require skills and commitments not generally expected of medical practitioners and the staffs of most health care agencies.

## The medical system

One very potent institution in the lives of children with cancer -- on-treatment and off-treatment -- is the medical system itself. The operating styles of clinics/hospitals and their staffs may socialize young patients in ways that help or hinder their preparation for off-treatment success. Most research (including the Candlelighters Childhood Cancer Foundation data) indicates that children with cancer and their families have very positive views of their physicians and of the hospitals in which they were treated. But Chesler and Anderson (1987), Orr et al. (1984),

Pendleton (1980), and Zeltzer (1978) discuss some of the staff behaviors young patients found objectionable, and their fears of irritation or retaliation from the medical staff should they ask too many questions, criticize procedures or otherwise be too assertive or non-compliant.

Pfefferbaum and Levenson (1982) report on some of the ways in which adolescent cancer patients and their physicians differ on the informational concerns or issues that they see as most important. For instance, adolescents significantly more often than their physicians felt it was important to have information on the potential spread of the disease, statistics about recurrence, new facts about treatment, an understanding of the causes of cancer and suggestions about prevention. Physicians thought that other issues would be more important than the adolescents themselves did, including advice on how to talk with family members and friends, information on the effects of treatment on their appearance, hearing about the experiences of other young cancer patients, how to help with treatment plans, and the potential of physical therapy and activity limitations. These data are from physicians and from adolescents in treatment, not long-term survivors, but they nevertheless point to some important gaps in communication and mutual understanding between young patients and their medical staff. These gaps are potentially quite problematic if not addressed by sensitive staff members committed to being in close touch with patients' concerns.

Informants in the CCCF study provided advice for the medical staff in the form of "dos" and "don'ts"; some examples are listed in Figure 3. The desire for honest information, for room to share fears and feelings, for a lack of patronizing or minimizing of issues, and for a meaningful relationship with the staff are evident in these comments. Interestingly, parents often raise quite similar issues in discussing positive and negative aspects of their relations with staff members (Chesler and Barbarin, 1984).

In addition to these social and interpersonal factors that may affect treatment relationships and adaptions to the hospital or clinic, the growing number and age of survivors creates a new problem of care for their special needs. Some institutions have developed "late-effects teams," "off-treatment clinics," and the like (see for example, McCalla, 1987); we know of

Figure 3

## OFF-TREATMENT SURVIVORS' SUGGESTIONS REGARDING WHAT THE STAFF SHOULD AND SHOULD NOT DO

Should Do

Cry with us, laugh with us, be honest with us, visit us away from our parents.

Encourage young people to express their fears and concerns about treatment, finances, the future, etc.

More than anything I feel the doctor should be honest with teens and tell them the effects of treatment, before the treatments.

Have the staff sit down with them and ask them how they feel or what they're thinking, so the patient can express her/his feelings about something.

Be honest; encourage patients to ask questions and explain answers so patients will understand. Allow patients to express emotions, like anger. It is important to let these emotions out.

Always be straightforward and honest with the patient. LISTEN to the comments and concerns of the patient and don't doubt what they say. They know and understand just about as much (if not more, sometimes) about their disease and treatment as some staff do.

Depending upon their age be completely honest, explain things clearly WITHOUT patronizing, being gentle and supportive. Remember kids understand more than adults give them credit for.

Always be honest and don't hide your emotions; when we sense something is being hidden it scares us. So much of our lives is uncertain, we need belief in the people around us.

Supply an outlet for the patient to deal with his problems. Do not assume that just because he is young that he is not contemplating his mortality or other problems. The young cancer patient is being forced to deal with issues that most young people don't have to deal with. They can't do it alone.


Should Not Do

Never ignore the question of a patient.

Never minimize the fears and concerns, especially concerns about the future.

Don't tell them everything is going to be OK if it is not...be frank, with an air of hope.

Don't leave their smiles at home. Everyone needs a pleasant staff when going through such an ordeal.

Never lie or cover up the truth. Never treat the person like an object. Remember that you're treating a PERSON, not just a cancerous leg, blood cell, etc.

They should never underestimate the patient's intelligence by making a comment like "it won't hurt" or other things along that line. Tell the truth!

Don't act like normal procedures aren't a big deal compared with cancer. We are kids with cancer, but always "kids" first.

Never talk about us outside the room where we can tell they are talking about us but can't hear what they are saying.

Don't let an intern do a bone marrow test when a doctor goes on vacation.

such specialty clinics at NCI, Children's Hospital of Philadelphia, M.D. Anderson, Texas Children's Hospital, Rochester's Strong Memorial Hospital and Cincinnati Children's Hospital, and there undoubtably are others. However, not all pediatric oncology clinics apparently see this as a priority. Some lack the funding to support such a program; others are so overburdened treating children with active disease that they do not have (or make) the time and resources available for these clinics. Some don't have the right staff: if many off-treatment survivors' issues are more psychosocial than medical, that requires an unusual and different staff mix; if dealing with off-treatment survivors' primary concerns requires community outreach and political organizing or lobbying as well as psychological counselling, that requires a skill base not often available in major medical care institutions. Currently we have very little research that illuminates the problems faced by staffs who care for children with cancer as they consider or plan innovative services/ programs for off-treatment survivors. Without better evidence on the problems of making such changes in these medical bureaucracies, we are not in a good position to offer advice or support to medical staffs who wish to implement the suggestions detailed in this report.

When young survivors grow up and leave their families of origin they often leave their hometowns as well, transferring to new medical systems. They then encounter problems that are similar, in some ways, to those involved in coordinating pediatric oncology care between major medical centers and local pediatricians or community physicians (Miller and Miller, 1984; Shah, 1986). In the case of young people who go away to college or work, however, they also must create a relationship with a new physician and new medical system. Many young people report difficulty in creating an effective and caring relationship with a new physician, especially one who may not be sophisticated about childhood cancer (and its long-term promise and problems). Some of their reflections on this issue are reported as follows:

> At that health center at where I go to college I stick with one doctor. I make sure
> to go in and get one doctor, a good doctor and tell him the whole story and
> background and then make sure to stick with that doctor. Otherwise it's
> impossible to get anything done; some of them get scared treating a person who
> had cancer and others don't know how to act.

After I left home to go to college they sent all my records.  Or, I guess they sent a letter saying such and such, and giving a brief history.  But I don't think they got all my records, anyway.

I tend to stick with people who know my situation, including dentists.  My dentist was there from the beginning and we talk about it when I go in there.  It makes it a better experience that they know.  You don't have to go through the whole thing all over again.  I have to go through that all again with a new doctor anyway.  Even if they have all the records, they ask you all these questions fifty times.  But it's better than doing it without the records, by myself.

I don't know.  The town I live in now there is nothing.  I could go to the next city, they have a big Children's Hospital there and they're very good.  I think I might check it out.  But if anything was wrong I would definitely go home.  I like the doctors who first treated me; they know me, they know my past, the stuff I took; they won't miss anything.

If an effective connection is not made between the clinic that treated the young patient and the college medical system or local physician who continues care, additional stress accompanies health care and medical choices.  Then the off-treatment survivor who encounters normal fears of recurrence, or normal concerns about minor health symptoms, must enter a strange system and socialize an unfamiliar physician regarding her/his history...and perhaps the appropriate stance toward an off-treatment survivor.  In the extreme, local physicians unsophisticated about childhood cancer, its treatment and long-term effects, may not be prepared to offer optimal treatment (D'Angio, 1984).  If the new local care system also is not particularly sophisticated about psychosocial issues in childhood cancer, the stresses or problems noted throughout this paper may become more severe.  A compassionate and effective medical care system should help patients make the linkage between initial systems of care and later systems.

Clinicians and  researchers (and especially their organized associations) and the American Cancer Society can help by gathering data on the medical service options available to off-treatment survivors, especially those who leave their hometowns.  Is it best that they link to another pediatric cancer center or to an adult clinic?  Should they go to an oncology clinic or simply to a competent pediatrician and/or internist?  How can pediatric oncology clinics be encouraged and supported to aggressively assist (ex)patients to link with physicians/clinics who are "known quantities" in far-away places?  How can a nationally linked network of childhood cancer survivors assist in this process?

# IV. DIFFERENTIATING WORRIES/CONCERNS AND NEEDS/DESIRES FOR SERVICES

## FOR DIFFERENT GROUPS OF SURVIVORS

We indicated earlier that although overall data on this sample of off-treatment survivors is interesting and instructive, it also is important to distinguish among sub-groups of these survivors, and to examine the different views and life experiences of young people who are following very different paths to survivorship. In this section we present cross-tabs or bivariate analyses on several major screening variables related to informants' concerns/worries and needs/desires for services. In some cases we present non-significant findings as well as significant ones; the challenge to our conventional wisdom or expectations is sometimes even more interesting than its substantiation.

What follows is only an early sampling of the results that can be obtained from this study. In later papers we will incorporate other variables and derive indices from unitary variables; we also will later undertake more complex multivariate analyses of the interactions among these variables.

Gender

Sixty-five percent of the CCCF informant sample is female and 35% is male. We have no information on the gender ratio of young people who received the questionnaire, which would permit comment on potentially different response rates, but general experience in psychosocial surveys support the expectation that females are more willing than males to respond to questionnaires and to report and discuss their feelings. Even of those young people responding to the questionnaire, for instance, women are far more willing to be part of a speakers bureau, and thus to "go public" with their feelings and experiences, than are young men (70% vs. 54%).

Table 4 presents some comparisons of the extent to which males and females worry differently about various issues. A quick comparison with Table 2 indicates the great number of issues about which there are no gender differences. On the other hand, there is strong evidence that females worry more than males about their ability to have children, about their parents'

ability to pay their accumulated medical bills, and about losing friends. Interestingly, although young women are more concerned than are young men about their ability to have children, they are relatively equally concerned (or at least not very differently concerned) about the children they do have getting cancer. Perhaps the general concern about having children is more prominent for young women than for young men, since it is the women who actually "have" the children. Indeed, women also report that they "have used" and "would like to use" genetic counselling services more often than men report this service use or need. The lack of difference in worry about children getting cancer also may be due, in part, to the fact that for many informants at this stage of their lives that is still a relatively abstract problem; when they are older and it becomes more concrete more differences may appear.

Young women also worry more than do young men about their parents' payment of their medical bills, and about their parents' finances in general, although the latter item demonstrates only a weak relationship.

Young women worry more than do young men about losing their friends, perhaps reflecting their greater level of sociability or alertness to variations in their social world. But women, expected in this society to hold a corner on vanity, do not appear to worry more than men about how they look.

Koocher and O'Malley (1981) anticipate some of these concerns, even though their data do not show substantial gender differences. They suggest a special need for counselling and psychological intervention for female survivors of childhood cancer. Since women in this sample express more concerns related to child-bearing, genetic effects and difficulties in interpersonal relations, this would appear to be a good idea. However, despite the lack of significant gender differences, the 40% or so of young men who also worry about parenthood, generational transmission of cancer, losing friends, and how they look, cry out for similar attention.

Table 4

GENDER AND WORRIES OF OFF-TREATMENT SURVIVORS

| Worries | | Male (N=90) | Female (N=164) | $X^2$ | P |
|---|---|---|---|---|---|
| Worry about having children | lot/some | 39% | 54% | 5.4 | <.05 |
| | little/none | 61 | 45 | | |
| Worry about children getting cancer | lot/some | 38 | 45 | 1.1 | NS |
| | little/none | 62 | 55 | | |
| Worry about parents' finances | lot/some | 41 | 52 | 2.7 | <.10 |
| | little/none | 59 | 48 | | |
| Worry about parents paying medical bills | lot/some | 25 | 48 | 12.8 | <.01 |
| | little/none | 75 | 52 | | |
| Worry about losing friends | lot/some | 35 | 52 | 6.6 | <.01 |
| | little/none | 65 | 48 | | |
| Worry about how I look | lot/some | 51 | 60 | 2.3 | NS |
| | little/none | 49 | 40 | | |

## Age and Age at Diagnosis

Table 1 presented the age structure of the sample. Since age is rather highly correlated with age at diagnosis (.35) we do not explore the latter variable here, except when the results differ substantially from those of age itself. In later analyses we plan further examination of age at diagnosis and careful attention to the relative explanatory power of each variable. For now, we can assume that most of what is reported about age is roughly true of age at diagnosis as well.

Koocher and O'Malley (1981) report that survivors of childhood cancer who were diagnosed at a younger age showed better psychological adjustment. Their explanation is tied to the probable diagnosis and treatment of childhood cancers that are most prominent at different ages. Since neuroblastoma and Wilms' Tumor, those cancers most common at a very young age, are relatively easily treatable if diagnosed early -- in a short time period and with minimal side effects -- it is this underlying dynamic that Koocher and O'Malley rely upon to explain later adjustment. In prior work reporting that parents of children diagnosed at a later age experienced more problems in their relationships with the medical staff, Chesler and Barbarin (1984) also suggest that the fact that older children are at a higher level of conscious awareness of their illness and its meaning, are more likely to be active and assertive patients, and may already be entangled with authority struggles (with parents and medical staffs), may also explain this trend.

Table 5 indicates that, at least for this sample of off-treatment survivors of childhood cancer, older youngsters worry more about having children and somewhat more about the loss of friends and their ability to get life insurance. Age effects rather directly seem to explain these findings; older young people are closer than younger people to actually facing child-bearing decisions, to negotiating an intimate relationship and to needing independent life insurance. Section B of Table 5 indicates that patients diagnosed at an older age report greater worry about relapse, but it is unclear whether this is a function of age at diagnosis or time since diagnosis, or both (see later discussion).

Table 5

## A. AGE AND WORRIES OF OFF-TREATMENT SURVIVORS

| Worries | | Age 14-17 (N=104) | 18-20 (N=75) | 21+ (N=59) | $X^2$ | P |
|---|---|---|---|---|---|---|
| Worry about relapse | lot/some | 38% | 43% | 53% | 3.4 | NS |
| | little/none | 62 | 57 | 47 | | |
| Worry about having children | lot/some | 33 | 62 | 63 | 20.9 | <.01 |
| | little/none | 67 | 38 | 37 | | |
| Worry about losing friends | lot/some | 38 | 55 | 51 | 5.7 | <.10 |
| | little/none | 62 | 45 | 49 | | |
| Worry about life insurance | lot/some | 30 | 37 | 49 | 4.6 | <.10 |
| | little/none | 70 | 63 | 51 | | |
| Worry about parents' finances | lot/some | 47 | 51 | 47 | -- | NS |
| | little/none | 53 | 49 | 53 | | |
| Medical Concerns | | | | | | |
| Could have used more info | lot/some | 26 | 38 | 47 | 8.0 | <.05 |
| | little/none | 74 | 62 | 53 | | |
| Could have used more contact with patients (my age) | lot/some | 39 | 41 | 62 | 9.3 | <.01 |
| | little/none | 61 | 59 | 38 | | |

## B. AGE AT DIAGNOSIS AND WORRIES OF OFF-TREATMENT SURVIVORS

| Worries | | Age at Diagnosis 1-11 (N=90) | 12-14 (N=81) | 15+ (N=78) | $X^2$ | P |
|---|---|---|---|---|---|---|
| Worry about relapse | lot/some | 28 | 48 | 59 | 17.3 | <.01 |
| | little/none | 72 | 52 | 41 | | |
| Worry about having children | lot/some | 37 | 58 | 51 | 8.2 | <.05 |
| | little/none | 63 | 42 | 49 | | |
| Medical Concerns | | | | | | |
| I made treatment decisions with the staff | lot/some | 38 | 64 | 56 | 12.2 | <.01 |
| | little/none | 62 | 36 | 44 | | |

Some similarly interesting findings are derived from off-treatment survivors comments about their relations with the medical staff. Older informants indicate that they could have used more information significantly more often than do younger informants; they also indicate that they would have liked more contact with patients their own age. Youngsters diagnosed at an older age also indicate that they more often made treatment decisions with the staff than did persons diagnosed at a younger age. These findings suggest that older youngsters may utilize denial less frequently than younger patients and may want more information on which to base their actions and reactions. Older patients expected to be involved and asserted themselves more in the treatment process. The data also probably reflect the ways in which the medical staff differentially communicates with and invites or permits participation in treatment as a function of age.

Younger survivors report that they would like career counselling, school counselling and family planning counselling more often than do older survivors. Indeed, the 14-17 year old group (and to a certain extent the 18-20 group) are more likely to be currently enmeshed in making preliminary (if not actual) decisions about schooling, careers and sexuality. Older informants are more likely to have resolved, temporarily or more or less, their choices on these issues by the time they are 21 or older.

## Time Since Diagnosis (and Time Since Treatment)

Table 1 also presents the distribution of this sample of off-treatment survivors in terms of its years since diagnosis. Time since diagnosis is correlated highly (.51) with time since treatment ceased, so we limt our report here just to time since diagnosis.

Koocher and O'Malley (1981) report that those long-term survivors who are further from time of diagnosis appear to have a better psychological adjustment. The evidence in Table 6 bears out this finding, at least with regard to the strong association between greater elapsed time since diagnosis and less worry about relapse.

Table 6

TIME SINCE DIAGNOSIS AND WORRIES OF OFF-TREATMENT SURVIVORS

| Worries | | Time Since Diagnosis | | | $X^2$ | P |
| | | 3 years or less (N=81) | 4-8 years (N=96) | More than 8 years (N=71) | | |
| --- | --- | --- | --- | --- | --- | --- |
| Worry about relapse | lot/some | 56% | 46% | 28% | 12.3 | <.01 |
| | little/none | 44 | 54 | 72 | | |
| Worry about parents' finances | lot/some | 56 | 52 | 30 | 13.0 | <.01 |
| | little/none | 44 | 48 | 70 | | |
| Worry about medical insurance | lot/some | 23 | 24 | 21 | -- | NS |
| | little/none | 77 | 76 | 79 | | |
| Worry about life insurance | lot/some | 27 | 21 | 44 | 8.8 | <.05 |
| | little/none | 73 | 79 | 56 | | |

The data in Table 6 also indicate that young people further from the time of their diagnosis worry less about their parents' finances but more about their own ability to get life insurance (although not medical insurance). These findings, and the relations between the two variables, reflect the transition of older off-treatment survivors from dependency on their parents' financial situation into independent lifestyles and finances. Persons with a shorter elapsed time since diagnosis report having used more genetic counselling and a desire for more career counselling, but since similar service needs were reported by younger informants, we do not yet know whether this finding is primarily a function of age (or age at diagnosis) or time since diagnosis. We will have to wait for future multivariate analysis to untangle some of these puzzles.

Visible Side-Effects

Several observers have suggested that the "psychological adjustment problems" and general orientation to life of off-treatment survivors should be impacted by the degree to which they have visible side-effects or impairments from the disease and its treatment. in the best done study to date, however, Koocher and O'Malley report that "neither the degree of physical impairment nor the degree of visible physical impairment related to long-term psychological adjustment among the childhood cancer survivors in our study" (1981, p.128). What a challenge to our conventional wisdom and normal expectations! Despite this optimistic report, however, we note that these comments relate to actual impairment (visible or not); a person's subjective sense of their impaired abilities may indeed have an effect on psychological health.

In the CCCF study, 69% of the informants indicated that they "have noticeable side-effects from treatment." Those off-treatment survivors reporting noticeable side effects are slightly more likely than those others to indicate more worry about a relapse, more worry about getting another cancer, and more worry about how they look. These are not strong associations, however, and they do not strongly contradict the Koocher and O'Malley findings. However, upon closer examination, a substantial number of these informants do not indicate, in a follow-up question, side-effects that are truly visible. They may be noticeable to oneself, of course, but not necessarily

visible to others. For instance, several informants list "fatigue," "loss of energy," "lots of colds," and "damage to my immune system" as examples of noticeable side-effects. Future analyses will recode these responses into a scale of minor vs. severe and covert vs. overt side-effects. At that point we will be able to pursue this issue further.

## Cured?

Forty-eight percent of the sample of off-treatment survivors of childhood cancer checked the item indicating that their "current medical situation" is that of cured. We indicated earlier in this report that calling oneself (or calling anyone) cured is a major step in the processs of recovering from (childhood) cancer.

Those who reported themselves "cured" were also more likely to be further away (in years) from the time of diagnosis. There was no relationship between reporting oneself as cured and age, gender, or the report of noticeable side-effects. Table 7 presents contradictory evidence regarding the concerns/worries of informants who do/do not report themselves as "cured," and raises questions in our mind regarding the actual meaning of the term. Persons reporting themselves as cured less often report worrying about a relapse, which seems quite reasonable. However, they also report themselves worrying slightly (although not significantly) more about having children than persons not reporting themselves as cured, more worry about losing friends and less worry about schooling. Why should informants who feel they are cured also worry more about friends and less about school? One possibility is that being cured is closely associated with age and time since diagnosis, and is more a reflection of those objective realities than of a subjective sense of being fully free from cancer. Older young people do report more worry about losing friends and less worry about schooling issues. Interestingly, young persons who report themselves as being cured also are more likely to be employed currently, a further indication of an (older) age effect.

Table 7

SELF-REPORTED CURED STATUS AND WORRIES OF OFF-TREATMENT SURVIVORS

| Worries | | "Cured" Status | | $X^2$ | P |
| --- | --- | --- | --- | --- | --- |
| | | Cured Checked (N=122) | Cured Not Checked (N=134) | | |
| Worry about relapse | lot/some | 35% | 52% | 7.9 | <.01 |
| | little/none | 65 | 48 | | |
| Worry about having children | lot/some | 53 | 44 | 1.8 | NS |
| | little/none | 47 | 56 | | |
| Worry about losing friends | lot/some | 54 | 38 | 6.6 | <.01 |
| | little/none | 46 | 62 | | |
| Worry about school | lot/some | 47 | 63 | 5.9 | <.01 |
| | little/none | 53 | 37 | | |

These twists and turns in the data cannot be unravelled at the moment; they will have to await future analysis. Indeed, a number of important questions that have been raised throughout this section of the report will only be answered (if at all) by further analyses.

## A Note About Services

Table 3 presented informants' reports of their use of and desires for various services relevant to the concerns/worries they experienced. These service options are not completely independent of one another; many of them occur or could occur together. For instance, there is a .52 correlation between the use or desire for school counselling and for career counselling, indicating that needs for or access to these programs generally occur together. Moreover, there is a .38 correlation between use/desire for family planning services and for genetic counseling services, a .33 correlation between family planning services and family counselling, and a .28 correlation between genetic counselling and family counselling services. These patterns may help us think about programs that encourage the integration of a full range of services for off-treatment survivors, rather than a piecemeal set of presentations and choices.

## V. A SUMMARY OF SERVICE/PROGRAM RECOMMENDATIONS

In this section I review and synthesize the findings of this and prior studies in terms of the services and programs that should be made accessible and available to young people who are surviving childhood cancer and to their families. The central objective of such programs is to help young people who are off-treatment, who have successfully survived the physical illness and treatment of childhood cancer, attain the highest quality of life they and their families can imagine and strive for. It is to aim for what van Eys (1977) called a "truly cured child," one who is able to take his or her place as an active and potent citizen of our society and the world. Nothing less will satisfy us.

Survivorship starts immediately after diagnosis, to be sure; the child with cancer who is in treatment is already a (potential) survivor and should be treated as such from the beginning. Such a conceptualization helps to establish a health-oriented framework that permits the child and family to think about and plan for a positive future. But off-treatment survivorship is a different matter, and does require different types of thinking and planning. For off-treatment survivors the future has arrived, and those uncertain dreams of a disease-free life are considerably more real. In fact, the data on off-treatment survivors indicates substantial health and a bright future, in physical and emotional terms, for most of these children and their families. They also suggest the existence of physical, personal and social dilemmas and problems that may plague the child and family, and that means they will have difficult struggles ahead. In order for services and programs to be freeing rather than limiting, they will have to help prepare young people to face these dilemas or struggles in an assertive and self-directed fashion from a stance of strength not weakness. We must help empower them and their families to exert their own will and direction on the opportunities and problems ahead of them. Since no one can be empowered in isolation, services must address the social world in which the off-treatment survivor lives, as well as the internal psychological world of the child and family.

In designing programs and services on the basis of information about off-treatment survivor's needs, we must remember that needs and service availability often are reciprocal --

each may create the other. For instance, we are accustomed to thinking that needs determine services that should be made available. But the availability of services sometimes permits previously unstated needs to be recognized and articulated. As we develop new programs, we may expect much greater usage than previously anticipated on the basis of available evidence. Moreover, many of the needs/concerns/worries expressed in this study by off-treatment survivors are related to one another; they are not disparite issues. Therefore, services to meet these needs must be integrated and delivered in a coherent and multidisciplinary character. It will serve little purpose to greatly separate the delivery of medical information and psychological or lifestyle information, since both speak to similar concerns for a single human being. In fact, one of the major difficulties facing the effective long-term treatment of children and families of children with cancer is the current lack of integration of services and medical facilities. Proprietary medical interests, based on professional, institutional and/or economic competition, often stands in the way of cooperative delivery of a full range of services. Various services must be linked with one another into an integrative and patient-centric pattern that overcomes the isolation and competition among staff members, professional disciplines, and hospitals.

The mobile character of off-treatment survivors means that the service and treatment system increasingly will have to be diversified, and can no longer be concentrated in major medical centers. Many survivors will not be clustered around a major treatment center and, since their effective treatment may not require high-technology medical services, will be less willing to travel long distances for relevant services. Just as Miller and Miller (1984) and Shah (1986) addressed the relevance of coordinated planning between major medical centers and community physicians during active treatment of the child with cancer, so must we invent new forms of cooperation among practitioners with regard to the delivery of services to off-treatment survivors.

The call for integration not only cuts across medical or health disciplines; it requires medical staffs to join with local commuity agencies and national organizations such as ACS and CCCF, for professionals to join with laypeople, and for practioners to join with (ex)patients. Only

by working together and utilizing the different resources and expertise of all these people, groups, and agencies can the full range of needed services and programs be provided effectively.

While we can specify hear some of the needs/worries that are "typical" of off-treatment survivors of childhood cancer, and on that basis identify services that are appropriate, the population of survivors is quite diverse -- by gender, by race, by ethnicity, by economic class, by location, by age, by disease, by treatment, by time since treatment stopped, by side-effects, by psychological health, by social environment, etc. As the prior section indicated, their needs differ. Thus, all service suggestions must be taken in a flexible vein, and a diverse and varied service system will be most useful.

We also must think more clearly about what institutional changes must be made in order for these services to be designed, placed on line and delivered. Stating what is needed is that first step, of course, but it is the easiet step. Finding the expertise and energy to design particular service programs, and making sure they are implemented, often requires a sustained process of social and organizational change in the medical system. Not only will we require new funds, but alterations in staffing patterns and roles/relationships between staff members and consumers. For instance, Spinetta and Deasy-Spinetta argue that staff members will need to be trained to deliver resources, "not as a superior to an inferior, not as an adult to a child -- but as equal partners in life's struggles" (1986, p. 515). It is one thing for staffs to relate directly with "patients," with "sick persons;" the standard model of medical and social relations follows a compliance and control pattern that concentrates expertise and power in the hands of professionals. But off-treatment survivors, especially, are no longer obviously "patients"; they are "well persons"; they have substantial expertise about their condition and primarily need supportive care and monitoring. Thus, more egalitarian and mutually respectful models of professional care are required (see, for example Szasz and Hollander, 1956). Such redefinitions of professionals' roles clearly call for new ways of thinking as well as behaving, and new organizational structures and patterns in the delivery of medical and psychosocial services.

Finally, as will be clear from the following suggestions, those of us concerned with the futures of children with cancer need to focus on changing the world around them. It is not sufficient to prepare children to "adjust" to a society that will stigmatize and discriminate against them, or that will fail to deliver appropriate services. We must help change these aspects of the society that have negative impact on these young people, thereby increasing their future opportunities. Ninety-five percent of them expect to have a "good and full life," and it is our responsibility to reduce the barriers to the realization of these expectations. Education and political pressure will be required to alter the discriminatory and stigmatizing stances that characterize too many persons' and agencies' approaches to people with cancer -- young or old, in-treatment or off-treatment. Failure to accept this broader social challenge, as difficult as it may be, is the ultimate failure to treat the off-treatment survivor of childhood cancer in the world.

It is of little value to state here service needs, unless we can design their eventual shape; it will avail us little to design them well without changing the prevailing ideologies and orientations that so heavily characterize professionals' status and pwer vis-a-vis patients and their families; and it will avail us little to do any of the above unless we can find ways to fund and implement these programs in concrete and specific terms in institutions and communities around the nation.

Services/programs particularly relevant to each of the areas of concern addressed earlier in this paper are summarized in Figure 4. Here we suggest that some services are likely to be more relevant to different concerns or issues faced by children with cancer who are off-treatment. Given the current state of invention (and non-evaluation) of such services, this discussion is somewhat speculative, but it is guided by the literature, the findings of the CCCF study, the experiences of many families and reports from institutions across the country.

Figure 4

## PSYCHOSOCIAL SERVICES RELEVANT TO PARTICULAR ISSUES FACED BY CHILDREN WITH CANCER WHO ARE OFF-TREATMENT

Services

| Issues | LTS Clinics Multi-Disc. Teams | Information | Psychological Counselling | Peer Support and Self-Help Groups | Social Networks | Public Education | Political Action/Pressure |
|---|---|---|---|---|---|---|---|
| 1. Physical Effects | X | X | | | | | |
| 2. Psychological Health | X | X | X | X | X | | |
| 3. Family | | | X | X | | | |
| 4. Friends | | X | X | X | X | X | |
| 5. School | X | | X | X | X | X | |
| 6. Insurance | | | | | | X | X |
| 7. Employment/ Career | | X | | | | X | X |
| 8. Medical Care | ?X? | X | | | | | |

## Long-Term Survivor Clinics -- Special Multi-Disciplinary Teams

The literature on "late effects," both physical and psychological, necessitates some sort of specialized and continuing attention to and monitoring of the life and status of off-treatment survivors. The range of issues involved almost call for a new set of specialists -- persons who are experts in the life problems and opportunities of off-treatment survivors of childhood cancer. As noted previously, some clinics and hospitals have already established "late effect teams" or multi-disciplinary units (oncologists, internists, rehabilitation specialists, school counselors, etc.) that focus explicitly on the issues (social, environmental and psychological, as well as physical and medical) facing survivors (McCalla, 1987). Such teams generate specialized knowledge, unique programs and some even hold speical clinic days for returning survivors. The existence of focussed clinics also permits the staff to design special events that may draw together a large number of survivors treated at a particular institution, or in a particular community. This helps to build a network of survivors that can generate a peer information, support and co-counselling system.

Speciality clinics that focus on the unique issues facing survivors also may help solve the difficult problems of medical transitions that older survivors must undertake. They can help link off-treatment survivors who are leaving their community to competent and caring medical practitioners (and counselors and other networks of survivors) in other communities. If these activities can be conducted in ways that involve young patients and their families as active co-participants in the direction and operation of such a program, it should carry over into effective preparation for an active and assertive role in managing their own medical affairs. Certainly it should speak to youngsters' information needs, and perhaps their future sense of themselves as competent and empowered medical consumers.

## Information

Information is a key to empowerment, and to the wisdom with which to make good decisions about the future. Young people and their families need up-to-date and honest

information about the long-term effects of disease and treatment that are known (obvious physical or neuropsychologic damage, social discrimination), and that may be suspected (potential neuropsychologic deficit, anniversary anxiety, special school needs). Some of this information is true for a specific child and family, other information is true of children and families in general, and some is uncertain in the specific case (for instance, the way a specific child may encounter discrimination). Even so, general information is helpful as a way of alerting the child and family to the future they may face together. One way of providing such information involves handing each youngster who is going off-treatment a checklist of potential concerns (such as in the long list of "potential side-effects" of chemotherapy), and a parallel list of available services (such as those noted in Figure 4). Another procedure might involve the interview-format suggested by Blotcky and Cohen (1985).

Some of this information is best delivered by professional staff members; other information may best be shared by other off-treatment survivors (e.g. how to find new friends, when to tell peers about one's cancer history); provisions should be made for both sets of personnel to play a role in the informational program. In addition, careful attention must be paid to the actual informational needs of young adults, and not just to adult medcial staffs' assumptions about what is important to share with survivors (see Pfefferbaum and Levenson, 1982, and discussion on pages 37-38).

The recent CCCF data indicate that off-treatment survivors are in particular need of family planning and genetic information, and information about careers. Potential insurance and employment discrimination, and the steps one can take if they suspect they have encountered such discrimination, is a vital part of the post-treatment socialization of the survivor into an active and assertive social role. Monaco (1986) list some informational resources especially relevant to these concerns in the life of off-treatement survivors.

The American Cancer Society has created information and support programs for adults living with cancer, the "I Can Cope" and "Cansurmount" programs. The Candlelighters Childhood Cancer Foundation is currently embarking upon the design and pilot test of a roughly similar

program for survivors of childhood cancer. With different versions designed for different age groups, and with computerized as well as face-to-face versions available, this effort should increase the informational, coping and sharing options available for offf-treatment survivors.

Psychological Counseling

We indicated earlier some of the differing interpretations of the extent of psychological dysfunction or disability that may exist among off-treatment survivors. General psychological health appears to be the rule, although special needs do exist. Regardless of the interpretation, it is imperative that formal counselling be made available to the young (ex)patient and family if and when they face a need for its use. We can be relatively certain that most off-treatment survivors will worry about a relapse or recurrence, about integration with friends and family members, and with how they are the same or different from their peers. Those of an older age probably will face issues such as anniversary anxiety, concern about reproductive adequacy, employment-related concerns, long-term life goals, and the like. While some of these concerns can be met and alleviated with adequate information alone, others will be aided by the availability of skilled and sensitive counselling.

Our assumption is that the great majority of off-treatment survivors will not experience substantial psychological dysfunction, but that many could profit from counselling and skilled psychological support. Such supportive counselling should be directed at life-adjustment rather than pathology, at health-maintenance rather than sickness-cure, and easily accessible to young people who have a concern but not necessarily a "psychological problem" (see Lauria et al., 1987).

Psychological counselling service also will be relevant to the adjustment problems faced by family members other than the off-treatment child, since all family members are now survivors of childhood cancer. Just as many aspects family life were altered when the child was diagnosed (division of labor in the home, job/career plans, attention to siblings, etc.), many more may require re-alteration as the child and family attain this new off-treatment status. Issues that "piled up" while the child was in treatment may now burst forth in ways that require attention. Like the

child, the family may need psychological support and counselling, and needs to be able to get it without announcing sickness or pathology.

Informants in the CCCF study, especially those still in school, also indicate a desire for school counselling, aid in keeping up with schoolwork and help in thinking through their school options. While a number of clinics now have special school-related programs, many do not. And some of those that do exist are not sustained over time, past the immediate crisis of the early stages of treatment. While many programs seek to help the child re-adjust to the school environment, too few plan effectively for changes in the delivery of educational services, in the skill and compassion of school staffs, in the organization of peer relationships, or in the establishment of school-community support systems.

## Organized Peer-Support and Self-Help Groups

Not all information and supportive counselling can be provided best by professionals; the growth and development of peer/mutual support and self-help groups testifies to the enormous power of help provided by laypeople who are in similar situations. Monaco (1988) and Yoak and Chesler (1985) summarize some of these helpful resources, in terms of the informational, social, psychological and practical issues that families of children with cancer face while the child is undergoing treatment. Many of these issues continue after treatment has ceased, albeit in somewhat differrent form and potency.

Informants in the CCCF study indicate quite emphatically their desire to be linked to peers and for meetings with other young people with cancer like themselves. They often want to compare notes on issues such as "Do you called yourself cured?", "When do you tell new friends?", "How do you convince your parents not to worry?", and "What do you do when you get a bad day and start worrying about it coming back?" Part of the data-gathering process for the CCCF study of off-treatment survivors involved bringing some young people together for small group interviews. Almost universally, participants in such small group sessions express a desire to meet again and to share more information, feelings, experiences and advice with one another.

Obviously such meetings are a very attractive option for many off-treatment survivors, especially since their off-treatment status separates them from other young people with cancer with whom they used to meet and talk in clinic sessions.

In addition to the assistance such groups can provide with the medical and social questions that plague young people, they may also play an important role in educating the larger community to the issues faced by off-treatment survivors. Indeed, Mullan's (1987) discussion of primarily adult survivor groups, and Chesler and Chesney's (1988) discussion of parent groups, highlight their potential for taking action to alter current medical practices, legislative programs and community or agency operations. Peer support systems can provide several types of assistance: information, expertise, and emotional support to the off-treatment survivors and family directly; information and education to the medical staff, the public community and targeted insurance or employment executives; and advocacy of change in the community, in the medical system, or in legislative councils. In all these areas, peer support groups can help social workers, nurses and physicians do their own jobs, and can add to the meager resources now available for these extensive tasks.

In order for such peer support groups to be an effective force in communities or medical centers across the nation, three components appear to be essential: (1) the creation of networks of young people interested and skilled in forming, leading and participating in such groups; (2) the availability of parent advocates who can aid the development and maintenance of such systems; and (3) the availability of professionals who can make referrals, identify local lists of off-treatment survivors, prepare young people for their leadership roles, and advocate the legitimacy of such groups. Parents and professionals, while important soruces of support, must learn how to encourage and assist such groups without trying to control or manage them, and many professionals must learn to overcome their fears of independently (or semi-independently) organized groups of (ex)patients (see, for instance, Chesler, 1987, and self-reports by professionals in Heiney et al., 1988, and Lewis, 1984).

<u>Social Networks</u>

Not all off-treatment survivors wish to avail themselves of psychological counselling; nor do all wish to be part of an organized suport or self-help group. And some of those who wish to be part of an organized group cannot do so because of a lack of time, access or geographic propinquity. But a great many wish to be and and can be part of some sort of social network. The Candlelighters Childhood Cancer Foundation is taking leadership in the development of such networks, on a regional and national basis, in several ways.

First, many young people, including a substantial number of those participating in the CCCF study reported here, wish to establish writing or phone relationships with young people who are not geographically close to them. The Spring 1988 issue of the CANDLELIGHTERS YOUTH NEWSLETTER lists a page of names of potential pen pals, and invites people to write to one another.

Second, thousands of young people with cancer, on-treatment and off-treatment, receive the CANDLELIGHTERS YOUTH NEWSLETTER. These young people are already part of a national network, even if they do not elect to write to each other or get any closer than receiving their newsletter. Many contribute articles that appear in this forum.

Third, the Candlelighters Foundation currently is trying to help establish networks of off-treatment survivors of childhood cancer at treatment centers and communities across the nation. This venture is part of the overall concern and program for long-term survivors developed by Candlelighters, and is undertaken in collaboration with local health care professionals, ACS staffs and parent activists.

The value of established networks lies partly in the assistance and support its very existence gives to people who are a part of it. In addition, however, it has added potential as a force for social and political change, when such mobilization seems appropriate. The willingness of many off-treatment survivors to be public spokespersons (64%; see p. 29) begins to suggest the special power of this resource.

## Public Education and Political Action

Does the professional obligation and commitment to "curing" childhood cancer cease when biomedical treatment and even psychological counselling for the disease and its effects has been successful? We think not. Adams-Greeley argues quite explicitly that at the stage of survivorship, "advocacy in the community, or through the media, is an important intervention we can make to alter society's attitudes, change discriminatory laws and policies, and assure our patients of equal opportunities" (1986, p.450; see also Hobbie, 1986). All of us involved in the life of off-treatment survivors -- professionals and parents, children and adults, (ex)patients and friends and family members -- must plan to alter the institutions and social environments within which survivors seek to survive. Schools, the medical system, employers, insurance companies and community agencies all represent potential targets of concerted public education campaigns, influence efforts, and political pressure.

Action will have to be taken in many ways, in all these institutional arenas, to improve the quality of life of survivors. Efforts to alter insurance and employment practices, for instance, probably will not be sucessful without "expert testimony" from physicians regarding the real medical risks involved. However, such information is not likely to be effective unless it is accompanied by political pressure, whether applied by the Candlelighters Foundation, the American Cancer Society, insurance and employer associations, arms of the local/state/federal government, or the public relations presence of off-treatment survivors themselves. Action in these public and community arenas clearly represents a form of social change; it will require skills and commitments not generally expected of medical practitioners and the staffs of most agencies.

We have indicated in this paper our assessment of the current state of knowledge regarding off-treatment survivors' psychosocial needs, and of relevant programs and services that may meet some of these needs. Although the research base of this (CCCF) study is somewhat problematic, and the sample skewed in ways that may promote an optimistic bias, many lessons

are clear and compelling -- even at this preliminary stage of data analysis. More research is needed to examine these concerns and to evaluate these programs. More aggressive planning and action are needed by all medical and social service agencies to design and implement such programs. More innovative leadership is needed by teams of clinicians to experiment with new services/programs. More inventive ways of involving off-treatment survivors are needed to use their expertise to define needs, establish programs, help each other and educate the public and professionals. More funds are needed to support the development and expansion of service programs, and of those agencies that are taking the lead in service provision (specific clinics/hospitals, individual practitioners, the Candlelighters Childhood Cancer Foundation).

In the long run, the quality of life of off-treatment survivors will be in part determined by how well we do our job of providing support to them and of altering the socio-environmental conditions within which they seek full and meaningful lives. In the long run, the quality of our society will be in part judged by how well we can help these young people achieve their fullest potential. Their off-treatment status itself is an indication that advances in medical technology work. Can we now design, implement and deliver the improvements in human and social technology that can guarantee their success?

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