

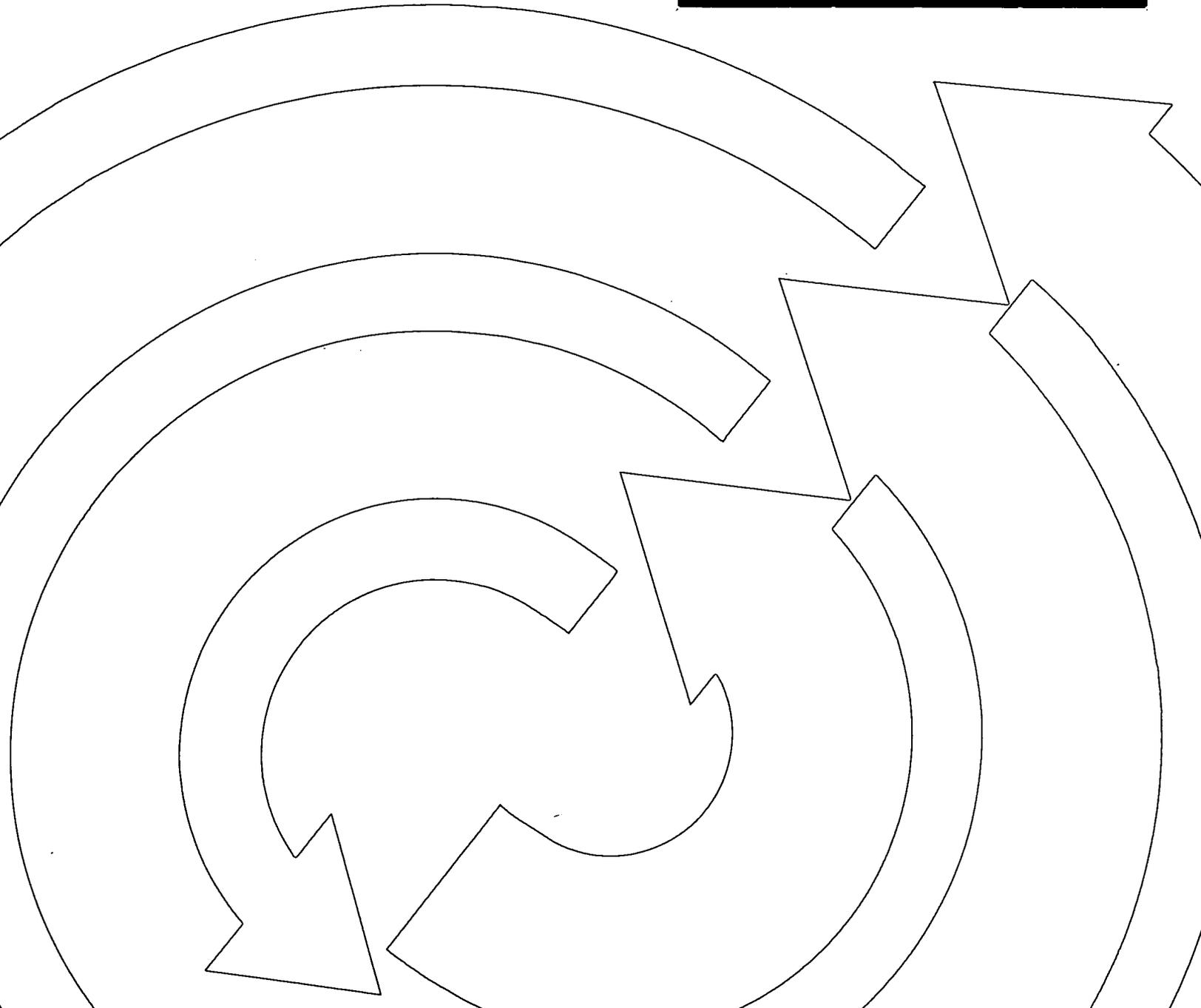
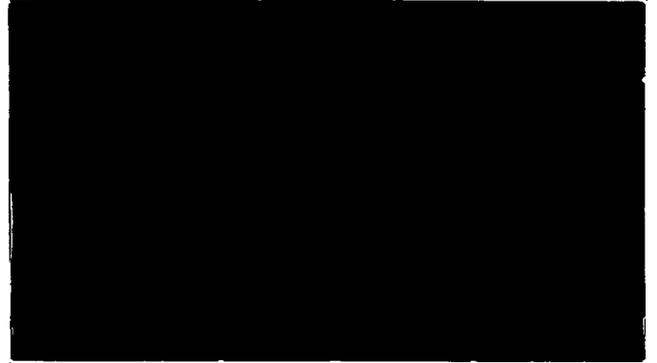


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HOW AM I DIFFERENT?
CHILDHOOD CANCER SURVIVORS'
PERSPECTIVES ON CHANGE AND GROWTH

Mark A. Chesler, Margaret Weigers,
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HOW AM I DIFFERENT?

CHILDHOOD CANCER SURVIVORS' PERSPECTIVES ON CHANGE AND GROWTH

Mark A. Chesler, Margaret Weigers & Timothy Lawther
Center for Research on Social Organization
& The Candlelighters Childhood Cancer Foundation
University of Michigan
Ann Arbor, MI 48109

Advances in the diagnosis and treatment of childhood cancer have greatly extended the life spans of youngsters diagnosed with various forms of this disease. For many, it has led to the real possibility of a long-term "cure". With these advances has come a corollary shift in the nature of psychosocial research on the life experiences and outlooks of children with cancer. Early work focusing on their adaptation to a terminal illness and anticipation of death has given way, over time, to a focus on the processes of coping with a chronic and serious illness, one with an increasing chance of long-term survival. Most recently, some research has begun to focus on the survivors themselves, attempting to understand the ways in these young people dealt with their diagnosis and treatment, how they approach their present and future life experiences, and what may (or may not) distinguish them from other young people without a history of cancer.

Since the prospect of long-term survival from childhood cancer is still a relatively recent phenomenon, few large scale and systematic studies have been undertaken. Those that have examined this population, and the issues they experience, have done so from a variety of

approaches: some with small samples and a clinical psychological (perhaps psychopathological) perspective and others with a large sample and a social adaptational (or normal/healthy coping) perspective; some with standardized psychometric measures and others with uniquely devised questions or instruments; some with young people all being treated at the same institution and others with a population drawn from several centers in a given geographic area; some with survivors of one type of childhood cancer and others with young people with different types of cancer; some conducted (and controlled) by a treatment institution and others conducted outside of these centers; some with random (or sibling) control groups and others without such comparisons; some with a desire to test or impose theories generated in advance and others with a desire to describe and conceptualize the life experiences and perspectives of the young people studied; some attempting to speak for this population and others seeking to discover and reflect the voices of this population themselves. With a (sub)field of inquiry in such an early stage of development, this variety is to be expected, perhaps even to be cherished.

One item in contention in the studies that have been done involves the very definition of a "survivor". In truth, any young person who is diagnosed with cancer is (and should be treated as) a survivor from the moment of diagnosis on... he or she is surviving immediately. This orientation suggests that survival be considered a process rather than a state of being. However, most research saves the term to describe young people with a cancer history who are successfully off treatment (off treatment in remission rather than in relapse and terminally ill), or who have been off treatment for several years, etc. In this paper we utilize the term to describe young people with a history of cancer who have successfully completed treatment.

Our own research and action projects with long-term survivors of childhood cancer stem from a decade of psychosocial work with families of children with cancer, and with the self-help groups these families have formed. In addition to conducting research on these issues, we have been involved in education and peer counselling activities with families, organizing self-help groups and training group leaders, consulting with medical care providers, and attempting to influence the

voluntary and public agencies that make policy and deliver psychosocial and community services to these groups, families and individuals.

Methods

The Candlelighters Childhood Cancer Foundation recently sponsored a study of the experiences and issues faced by long-term survivors of childhood cancer. A 4-page self-report questionnaire was distributed in the Foundation's YOUTH NEWSLETTER (CCCF, 1988),* requesting young people with cancer who were over 14 years of age and off all treatment to respond. Almost 300 long-term survivors of childhood cancer between the ages of 14 and 29, from all parts of the United States, responded. In addition to these questionnaires, several group discussions ("focus groups") were held with small groups of long-term survivors in different parts of the nation.

One limitation of this procedure is that we have almost no knowledge of who or how many young people did not respond to the questionnaire, or why. Without such response rate data, and without good sample control, generalizations must be made cautiously. On the other hand, the responses to the questionnaire and group interviews are so rich and detailed that they provide a level of information and meaning that often offers a suitable basis for broader interpretation. Finally, we distributed a slightly altered version of the questionnaire to a sample of high school and college-age young people without a history of childhood cancer, and responses from this population provide us with vital comparisons with the long-term survivor population on many variables.

One of the closed-ended questions asked on the long-term survivor questionnaire was whether informants agreed/disagreed that "Having cancer has made me different from others my age." In addition, informants were asked to indicate, in answer to an open-ended question, "In what ways are you different from other young people your age?" This paper presents preliminary

* Candlelighters Childhood Cancer Foundation Youth Newsletter, 1988, IX (2), 4-8.

results of our analyses of the answers to these questions, and explores the relationship between these items and other demographic, medical status and attitudinal variables.

Our research staff combines the expertise of trained social scientists and people directly involved with the experience of childhood cancer. The senior staff member is a parent of a long-term survivor of childhood cancer, and two younger staff members are themselves long-term survivors. All these and other colleagues are trained in techniques of social science inquiry. In addition to this research staff, the collaboration between the University of Michigan and The Candlelighters Childhood Cancer Foundation generates a constant dialogue between insiders and outsiders, between more objective and more subjective inquiry modes, and among survivors and their parents and scholars. Our action-research approach means that we are constantly designing research with members of the population under inquiry, sharing preliminary results with them (in attempts at "member verification") and involving them in the design of service programs or policy changes based on the knowledge generated. It has been our experience that this participatory mode of inquiry has numerous benefits, not the least of which is an increased ability to untangle the many knotty problems (data gathering problems and interpretation problems) involved in research on sensitive and complex psychosocial matters, ones that are fraught with subjective meaning and concern.

Findings

Forty-six percent of the long-term survivor informants "strongly agreed" that they were different from others their age, and 77% "agreed" with this closed-ended statement overall. On the open-ended question, 76% indicated that they felt different from other young people their age; 13% said they were not different and 11% did not answer this question. Thus, the distribution of responses on the closed and open-ended items is quite comparable.

Of those young people who indicated, on the open-ended question, that they did feel different from other young people their age, 69% mentioned differences that were positive and

31% mentioned differences that were negative. This is the first clear finding: most of the ways in which these survivors feel different from their peers are positive.

Table 1 categorizes the different kinds of statements informants provided in the open-ended elaborations of their sense of difference.

The most common difference reported (30%), a positive one, was the survivors' feeling that they are more advanced or mature in their personality or psychological development than are their peers. Consider some of their statements:

I grew up faster. I value life a lot more. I'm a happy person being me and I don't need alcohol or drugs.

I strive hard in life. Chemotherapy was a hard struggle and I fought the battle and won. Therefore, I feel stronger than others mentally.

I think I grew up faster, although I didn't have a choice. My illness has allowed me to put things in perspective. Trivial things affect me less now (in school, grades, sports).

While these statements reflect a positive perspective, they are not naive or "pollyannish" in tone. They convey a realistic sense of struggle and at least some of its specific effects.

A second common difference noted (18%), also a positive one, focused on an outlook on life in general or an "existential perspective". Many young people who are off-treatment indicated that they feel they know more about life and their purpose in life than do their peers.

I realize what is important in life and I don't take everything for granted. I want to live life to the fullest.

Having faced the idea of dying has made me look at life in a different way -- to respect life and what I have each day.

I think the most important thing is -- I live life for today because no one promised me tomorrow.

We each have our favorite existential perspective and outlook on the meaning of life; we each make decisions about what it means to have a meaningful life. These survivors' responses focus

on finding meaning in and placing emphasis on everyday encounters and activities. At the same time, other comments indicate that this focus includes long range planning for the future.

The third most common difference long-term survivors reported seeing between themselves and others their age (16%) was a negative one: their physical health status and abilities. They often feel less healthy and less physically able than their peers who do not have a history of cancer.

I can't play contact sports and I have a central line.

I lack physical stamina.

I can't run that fast. I can't tie shoes that good. I can't remember that good.

Table 1 also lists some other categories on which survivors indicate differences between themselves and their peers: positive health differences, positive social/relationship differences, negative personality/developmental differences, and negative social/relationship differences. However, the numbers and percents of responses in these categories are too small to warrant serious attention.

Not all young people with a history of cancer reported that they feel different from others their age, but a majority of those who answered this questionnaire item did (76%). And for the most part the differences they reported are positive; more than twice as many young people said that they are different in good and positive ways as said that they are different in negative ways (69% vs. 31%).

Characteristics of survivors who "feel different"

Several forms of analysis were used to compare those young people who indicated they felt different from their peers with those who reported they felt no difference, and to make comparisons among those who reported positive differences, negative differences or no difference.

For instance, both age and gender distinguished informants: a significantly higher proportion of young women reported feeling different than did young men, and a significantly

higher proportion of older survivors reported feeling different than did younger ones. Moreover, in both instances the females and the older survivors reported more negative differences than did their male and/or younger counterparts. Perhaps women and older adolescents (or older young adults) are involved in a social environment that requires them to be more aware of their status and personal history, and that treats these histories as more important (and more negative).

Most of the medically relevant characteristics we assessed (diagnosis, time since diagnosis, relapse) were not related to reports of difference. However, those survivors who reported having visible side-effects of their treatment (67% of the population) were somewhat more likely to report feeling different, and to report that these differences were positive. Indeed, other research has reported that it may be "easier" to adapt to an illness whose side-effects are visible (to oneself and others) than to one whose markers are invisible. Acknowledging differences, even "negative" ones, may reflect an element of realistic self-appraisal, and thus be a positive coping strategy and evidence of positive self-esteem. To the extent that a "visible" side-effect is undeniable, it may be easier to acknowledge and deal with than an invisible (internal physical or emotional) scar.

The potential relationship between acknowledged differences and positive self-esteem is not simple: facing differences squarely also may mean admitting to certain worries or concerns. Informants who reported feeling different from others also reported more often worrying about a number of issues: their reproductive and genetic capability, their medical futures, and their ability to maintain friendships with peers. On the other hand, they did not report worrying more often about their general health, their looks, their finances or having a relapse.

Informants who reported feeling different from others reported less open and honest relationships with the medical staff, and less support from their family members (parents, grandparents and siblings). While multivariate analysis is yet to be undertaken with these data, the latter two findings may well be a function of the increased age of those who most often reported feeling different: age itself may be associated with more complex and less naive interpersonal relationships, and therefore less open medical interactions and decreased family support.

Finally, those informants who reported feeling different also reported a significantly greater desire to have access to psychological counselling services. There is no indication that this reflects impending psychopathology or severe disturbance; rather it appears to be part of a positive and assertive desire to deal realistically and openly with past and present stress and to make use of potentially helpful psychosocial resources. Many survivors also report a desire for more information about "late-effects", assistance in gaining health and life insurance, and assistance in finding oncologically-sensitive physicians when they leave their family homes (and clinics of original treatment) for advanced educational or employment opportunities.

Informants who reported positive differences or negative differences were not distinguished from one another as strongly or as systematically as they both were from informants who reported not feeling different. Thus, the recognition/feeling/public acknowledgement of difference may be the critical factor in reports of greater worries, poorer relationships with the staff and less support. Perhaps less denial, or greater openness in confronting their situation, has led to greater openness in reporting and dealing with various concerns and dissatisfactions. Perhaps, too, the acknowledgement of difference accelerates recognition of other psychosocial needs and gaps in the support or service system.

This set of findings presents an image of young people in the midst of a struggle to (re)identify themselves in their social world, given the nature of their unique medical experience. For the most part, the psychosocial outcomes of this struggle appear to be positive, with most young survivors feeling good about most of the ways in which they have changed and grown. Many report feeling more mature than their peers, and having a clearer sense of their meaning and purpose in life. At the same time, many continue to worry about their health and their futures, and to express a need for greater psychological assistance and support from people close to them. Despite the relatively positive messages they send, they do not seem to overlook troublesome issues and needs.

How do we explain the prevalence of these positive feelings and positive self-assessments in this sample of long-term survivors? It could be that only those survivors who do feel positive

and upbeat chose to respond to the questionnaire, and therefore this potential sample bias so clouds the findings as to render the question moot. Perhaps sustained denial is at work. Indeed, some scholars and clinical practitioners have argued that denial of bad feelings, of bad outcomes (and in this case of negative differences), is a common and relatively healthy coping mechanism for children with cancer. Perhaps these young people are deliberately "lying" about their feelings, or "falsifying" their outlooks on life for their own or our benefit. Some research suggests that young people with cancer often hide their true distress or negative feelings from their physicians and parents, the better to protect themselves from intrusive procedures and their parents from further pain and burden. The fact that the same young people who report feeling positive (and positively different) also report substantial worries about their futures, alerts us to the complex and realistic struggle in which they feel they are engaged, and to the probable truthfulness of their responses. If they had denied all sense of worry and struggle we might have less trust in the veracity of their positive responses.

Perhaps these young people wish to present themselves to the world in a positive and upbeat manner, regardless of the "true" mix of their feelings. By presenting themselves positively they may help create a set of social expectations and interactions that are positive and accepting. In this way they may pro-actively counter negative expectations and a cycle of pity, stigma and prejudice. Moreover, by constructing a positive social environment, and positive reactions from others, they can help reinforce a positive personal outlook. If they say they are doing well, and can convince others that they are doing well, perhaps they can make and keep themselves (psychologically if not physically) well. The interaction between physical and mental health is too mysterious for us to dismiss this option out of hand.

It also is possible for us to take these reports at face value, as reflecting the fact that these survivors of childhood cancer just feel very positive about themselves, perhaps as an outgrowth of an inner transformation that we do not yet have access to or understand. We all search for meaning and confidence in our lives, and sometimes for benchmarks of our struggles and achievements with the forces of fate or other difficult tasks. These young people may feel they

have engaged in, and mastered, just such a test, qualifying them for a special status. Thus, they may now root a part of their identity and sense of meaning in their achievement of victory in the struggle against cancer -- surely a symbol of great danger, mystery and travail. Such a sense of accomplishment reasonably would lead to reports of lessons learned, confidence gained, positive outlooks, specialness, etc. Even while these young people own their physical and emotional scars, they often do sound and feel like victors rather than victims.

Others' feelings of difference

"Feeling different" and seeking individuation is common for people in our society, especially in the late adolescent age group from which these data were gathered. Just as common and potent, of course, is the desire to appear (and feel) normal and like others in one's peer network. In order to explore the universality of these issues further, we asked the comparison sample of high school and college-age young people without a history of childhood cancer whether they felt different from others their age. Forty-four percent of this comparison sample agreed or strongly agreed on the closed-ended question that they were different, and 44% mentioned differences on the open-ended question. Seventy-nine percent of those informants who reported that they felt different mentioned positive differences. The differences noted most often by this population included positive personality/developmental attributes (20%) and positive social skills/experiences (8%).

Comparisons between survivors' and others' feelings of difference

In response to the closed-ended question, 77% of the survivor sample and 44% of the comparison sample agreed that they were different from others their age. In response to the open-ended question, 76% of the survivor sample and 44% of the comparison sample listed ways in which they were different from other young people. Although the survivor and comparison samples both reported "no difference" on the open-ended question in approximately equal proportions (13% vs. 14%), the comparison sample much more often did not answer this question.

If we assume that non-response is a covert way of indicating no difference, the total "no difference" response ("no difference" plus "no response") is much higher in the comparison sample (42 + 14 = 56%) than in the survivor sample (11 + 13 = 24%).

The survivor sample much more often reported positive existential differences than did the comparison sample (18% vs. 2%). They also much more often reported positive personality/developmental differences (30% vs. 20%). In contrast, the survivor sample much more often reported negative health differences (16% vs. 3%) and somewhat less often reported positive social differences (2% vs. 8%) than did the comparison sample.

The survivor sample reported significantly more worries about their reproductive and genetic capacities, less worries about their looks and general health, more problems in schooling and in getting insurance, and more open and honest relationships with their physicians than did the comparison sample. Finally, the survivor sample reported life habits which included significantly less exercise, less smoking and less use of alcohol and recreational drugs than did the comparison sample.

With the exception of the survivor sample's report of less worry about general health issues, these findings all make immediate sense. Whether the report about general health is a straightforward example of denial, or a reflection of more complex dynamics in the life experience (or questionnaire responses) of this population, awaits further analysis. As noted previously, this report utilizes a preliminary analysis of a rich data set that will have to be analyzed further before these answers can be fully understood (if at all). Part of this analysis will include continuing discussions with long-term survivors of childhood cancer about these and other finding themselves. We will want to know how they explain these results!

Conclusions

We all struggle with the developmental tasks of establishing our individuality and of achieving a sense of commonality with others of comparable age and status. In that general struggle, long-term survivors of childhood cancer are no different from other adolescents, other

young adults, or the rest of us. But in their struggle survivors do face some unique issues.

Children with cancer experience a particularly significant status change, as they encounter a frightening diagnosis, complicated and often painful treatments, a new identity as a patient, a new or tenuous family status, and stigmatizing reactions from associates. Many studies have reported the prejudice and discrimination young people with cancer face with their peers, in school, and in gaining access to educational, employment and community services. All these experiences may cause them to mark themselves personally as different; certainly the environment marks them as socially different. Their social, economic and psychological, as well as medical, experiences may have lasting influence on their self-concepts and self-esteem, in positive and/or in negative ways.

Even these young people who successfully complete treatment and enter the ranks of long-term survivors carry with them a sense of being different from others. In fact, one key task involved in being a long-term survivor of childhood cancer, an ex-patient rather than a patient, is precisely the renegotiation of one's sense of individuality as well as commonality with others. These data make it clear that many of the differentiations survivors make are positive in nature, and reflect their feeling that they have been able to grow and develop positively from their medical experience. To be sure, most young people who are surviving childhood cancer not only argue that they are different from others; they also suggest that they are in many ways quite normal and quite like others their age. To feel or be different is not necessarily bad; it does not mean being abnormal! It may even represent a realistic attitude, and a view of one's specialness, that aids survivors' ability to cope with a difficult history and environment.

The emphasis on positive differences reflected here is not without qualification. Survivors of childhood cancer also report a variety of worries and problems they experience in adapting to their world. These considerations suggest that informants are not presenting mindlessly or defensively positive messages, but considered judgements about their present and future situations. At the very least, these outlooks are one major part of the self-concepts and self-presentational strategies of long-term survivors of childhood cancer. Different observers may yet make different sense out of the positive outlooks reported here. As we have indicated, several

different interpretations are possible, and their relative validity or utility remain to be investigated...and argued...by researchers, by clinicians and by survivors themselves. But much of this data clearly challenges some prior (and older) reports that predict a substantial incidence of depression and serious psychological problems in this population.

The struggle to serve the "truly cured child" requires careful attention to these issues of psychosocial adaptation and outlook. Psychosocial support services need to be designed and provided explicitly for this population, not out of a concern to prevent or cure psychopathology, but out of a respect for the struggle to negotiate (and renegotiate) a stable and realistic personal and social identity. To design and provide services on the assumption of imminent psychopathology or maladjustment is not only wrong -- given these data -- but dangerous: it reinitiates a cycle of negative expectations that may disable or discriminate against these survivors in their struggle to define and assert themselves. To be sure, psychological support services, both of a formal programmatic character and of an informal family-friendship network nature, are a necessity. Of course we cannot afford to trivialize the psychological struggle or distress that long-term survivors of childhood cancer experience, nor to burden them with the status of being supernormal or "heroes", but neither can we afford to "re-medicalize" this recovered and recovering population.

Finally, we note that many of these long-term survivors wish to have the opportunity to share and compare their experiences and reactions with those of other young people with cancer. Over 75% of these informants report the desire to meet with other survivors, and 64% are willing to educate and advocate on their behalf to medical and community groups. This public form of self-presentation is a welcome addition to the armament of resources at our disposal in the effort to educate the general public about childhood cancer and to gain greater resources with which to sustain medical advances.

While young people, parents and service providers may not always know, or agree, how young people "should" cope with their experience, or how they "should" (re)view their illness and life outlooks, attention to these issues of difference and adaptation must be part of a coordinated

treatment program. Then, perhaps, we will be able to help survivors achieve the psychological and social growth for which they clearly strive.

Table 1

Long-term survivors' reports of how they are different from other young people

Differences	n	%
Positive health differences	7	3
Positive developmental/personality differences	81	30
Positive social differences	5	2
Positive existential differences	49	18
No differences	34	13
Negative health/physical differences	43	16
Negative developmental/personality differences	11	4
Negative social differences	11	4
No answer	30	11
<hr/>		
Total positive statements	142	52
Total negative statements	65	24
Total no response/no difference	64	24
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TOTAL RESPONSES	271	101/100

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