COPING WITH CANCER:
LIFE CHANGES REPORTED BY PATIENTS
AND SIGNIFICANT OTHERS DEALING WITH
LEUKEMIA AND LYMPHOMA

Susan H. Davis, Mark A. Chesler,
and Barbara Chesney

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SUSAN H. DAVIS

AND

MARK CHESLER

THE UNIVERSITY OF MICHIGAN

AND

BARBARA CHESNEY

THE UNIVERSITY OF TOLEDO

TABLE OF CONTENTS

I. INTRODUCTION

Cancer strikes the lives of hundreds of thousands of Americans each year, often without any warning. The initial shock of diagnosis, followed by extensive medical treatment, challenges people's pre-existing coping mechanisms, and leaves them vulnerable to a wide variety of stresses and life changes. A diagnosis of cancer is no longer the death sentence it once was, however, and as more people are surviving with the illness, how they deal with it becomes an increasingly important topic of research.

Previous research has established that being diagnosed and living with a chronic illness can have a serious impact on the emotional and psychological functioning of patients and family members (Worchel and Copeland, 1988). Indeed, some researchers and practitioners consider cancer to have such pervasive impact on the family that they discuss it as a "family disease" (Cassileth & Hamilton, 1979). This report examines issues of coping and life changes in patients and families of people experiencing certain forms of cancer - leukemia and lymphoma. What does it mean to "cope" with cancer, and what are the predominant issues that people are coping with during the illness?

The majority of research that addresses the concept of "coping" with cancer relies on standardized psychological testing to measure how well an individual is adjusting to the illness (Burgess et al., 1988; Cella and Tross, 1986; Cohen, 1982; Jenkins and Paragament, 1988; Morrow et al., 1978; Schag et al., 1983). As a result, this literature is heavily biased towards psychological measures of depression, anxiety, and cognitive appraisal. With so much attention focusing on the psychosocial morbidity of cancer, (Fobair and Mages, 1981; Weisman and Worden, 1976), little is reported about the much larger group of patients and families who cope adequately with the disease.

1

Only a minority of patients actually manifest serious coping difficulties (Rainey and Cullen, 1981). The opportunity for social and emotional stability, or even positive transformation, as a result of the cancer experience has been overshadowed by research which emphasizes the negative aspects of patient response. However, some researchers are beginning to identify the positive life changes and personal growth people can make in the context of the cancer experience (Daiter *et al.*, 1988).

This report explores the perplexing and intriguing question of what it means to cope with cancer, from the subjective perspective of the individuals experiencing the disease. Voysey (1975) and Knafl and Deatrick (1987) note that the literature on illness and the family follows one of two general approaches. The first is based on the assumption that having a sick member in a family produces an inherently negative situation which inevitably disrupts the family. Literature which takes this approach tends to rely on objective outcome measures, and it generally views family members as passive victims of the disease. The other approach views family members as active players in the treatment and coping process. It makes no assumptions about the inherent effects of chronic illness and directs its attention to understanding the family's subjective definition of the situation and how the family copes with the illness. This latter approach allows for the possibility of positive growth and change resulting from the illness, and it is this approach which we have most closely adopted. Aaronson and Beckmann (1987) provide additional support for the use of subjective measures over objective measures in evaluating quality of life or potential for life change and growth.

We support the use of subjective measures over objective measures for three main reasons. 1) We believe that an individual is often more capable of assessing the effect of the cancer experience on his/her own life than is an "objective" third party observer who may be fairly removed from the day-to-day experiences of the individual. 2) Unlike the measures used in our questionnaire, standardized psychological tests generally are not designed specifically to look at the unique issues of the cancer experience. 3) Subjective

2

measures allow people who experience the illness to tell about the experience in their own words, as can be seen in the quotes cited in this report.

We might expect people dealing with cancer to report negative changes in their lives, because of the commonly shared conception of cancer as an all-encompassing and life-destroying illness. But as we will show in later portions of this report, many patients and their significant others report coping positively and making positive changes since the beginning of their cancer experience. As one person with cancer so succinctly questioned, "Why did we have to wait till now, till we are riddled with cancer, to learn how to appreciate life?" (Yalom and Greaves, 1977). How else can we explain a positive response to what most of us would consider to be a very traumatic and negative experience? Do people really perceive their lives changing for the better or do they merely report them as such on questionnaires such as we used? If the reported changes do indeed reflect true positive changes, what is it about the experience that contributes to such changes?

If personal growth and positive life changes can and do occur, future services should be directed to both preventing disabling psychosocial sequelae to cancer and encouraging and nurturing positively valued psychosocial outcomes. In the following sections of this report, we look at the coping processes and outcomes, including life changes, reported by people experiencing cancer, and analyze several variables including age, gender, income, treatment status, medical interaction, worries, and counseling services in an attempt to discover the source and nature of people's positive coping patterns and outcomes.

II. METHODS

This section outlines the design and the various measures used in the study. The data come from a 1988 psychosocial needs-assessment study conducted at the University of Michigan for the Children's Leukemia Foundation of Michigan. The project was

designed to gather information from cancer patients and their family members for use in improving programs and services for families experiencing leukemia and lymphoma. In addition, it also was designed to advance the general state of practical and scholarly knowledge about the psychosocial impact of cancer on the family. This document is the fourth in a series of technical reports provided to the Foundation (Chesler and Chesney, 1989; Chesney, Chesler and Abrigo, 1990; Lawther, Chesler and Chesney, 1989).

The study includes four populations: 1) young adults with cancer and 2) their parents, and 3) adults with cancer and 4) their spouses. Table 1 indicates the sample size for each separate population, and Table 2 provides information on the general background characteristics of all informants. In the parent / young adult population pairing there are proportionately more parents than young adults because young adults under 14 years of age were not sampled, whereas their parents were. Comparisons across populations show that parents are approximately 10 years younger than the other two adult populations, namely adult patients and their spouses. Parents and young adults have higher family incomes than do adults and spouses, and parents have the highest level of education.

The data indicates a fairly good representation of cancer patients at various ages, of different gender (except in the parent population which is heavily skewed with females), and from families of differing economic status. However, the racial makeup is badly skewed toward an overrepresentation of whites. According to the American Cancer Society, cancer rates over several decades show that blacks have a higher death rate than whites, and there are many variations in cancer incidence and mortality among the various racial and ethnic groups for which data is available (Cancer Facts and Figures For Minority Americans, 1986). These findings emphasize the limits of this study and the need for additional psychosocial studies of various racial and ethnic groups.

Table 1: Sample Size by Population Status

Patients:

Young adults = 88

Adults = 91

Significant others:

Parents = 161

Spouses = 78

Table 2:   Background Characteristics by Population Groups

Background Characteristics	Young Adult	Parent	Adult	Spouse	Sig.
Age (years)	17.5	40.8	52.3	53.1	*
Age at diagnosis	10.4	n/a	46.2	n/a	*
Education Level (years)	10.9	13.6	11.0	12.8	*
Family Income (thousands)	32.0	29.5	21.6	23.4	*
Marital Status (%)					
Married	2	83	84	94	*
Divorced	0	16	6	3	*

(Never married, separated, and long-term relationship make up the remaining 100%)

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

All four populations were asked to evaluate 11 specific life changes that may have occurred in their lives since the cancer experience. These eleven variables target three major categories of coping outcomes or potential life change including: 1) **mental health, 2) activism**, and 3) **social relations**. These three categories are the **Dependent Variables** in this study. Cronbach alpha statistical tests were run to verify the internal consistency of the items within each of these categories, and scales were constructed accordingly (Cronbach & Meehl, 1955). Alpha values are reported in Appendix A.

The **mental health** scale is designed to measure changes that occurred in a person's sense of his/her overall mental health as a result of the cancer experience. The scale is composed of four items including changes in a person's: 1) sense of general mental health, 2) sense of personal control, 3) sense of who I am, and 4) ability to cope with tragedy.

The **activism scale** is designed to measure changes in how ready and willing people are to take action on their own behalf or for the benefit of others. Another way to think of this scale is a measure of social empowerment. The scale is composed of four items, including changes in a person's : 1) willingness to join up with others to change things, 2) sense of what I as an individual can do, 3) concern for others, and 4) desire to change the medical system. The last item is included on the parent and spouse scales only.

The **social relations** scale is designed to measure changes that may have occurred in a person's social life as a result of the cancer experience. The scale is composed of three items, including changes in a person's: 1) time with friends, 2) relationships with family, and 3) relationships at work. The last item is included on the parent and spouse scales only.

These three scales are all significantly correlated with one another for each of the four populations. This suggests that people often express a general sense of "life change" as a result of their cancer experience. Cancer seems to affect people in a holistic way, meaning that people who experience positive life changes in one aspect of their lives tend to

experience positive life changes in other aspects of their lives. Similarly, people who experience negative life changes in one area are most likely to experience negative life changes in other areas of their lives as well.

On each item and scale, we asked people to assess whether their lives had changed for the better, for the worse, or stayed the same since the cancer experience. **People's responses of changes for the better on each item were coded as a 3, same as a 2, and worse as a 1.** "Positive change" then is defined as any score greater than 2.00, and "negative change" is any score below 2.00. Throughout this report, changes that we refer to as "more positive" and "less positive" are relative changes above 2.00. In other words, a change that is "less positive" is still a change for the better unless specifically noted as a change for the worse (i.e. below 2.00).

Five sets of **Independent Variables** were examined to determine their relationship with each of the three life change scales. The five independent variable categories were selected because they touch upon a wide variety of life-issues including sociodemographic variables, worries and stresses, treatment status, medical involvement, financial status, and use of counseling services. The independent variables are listed in Figure 1. Some items fall into more than one category: therefore, they have been listed under all categories to which the item applies. For example, financial worries is listed under both Worries and Stresses and Financial Status Variables. The arrows in Figure 1 outline the pathway of our analysis: each of the population status groups was run against each of the independent variable sets, which was run against each of the dependent variables.

Figure 1: List of Independent Variables and Analysis Plan

Population Status: -----> Independent Variables: -------> Dependent Variables:

1. Parent
2. Spouse
3. Adult patient
4. Young adult patient

1. Sociodemographic
2. Worries / Stresses
3. Treatment Status
4. Financial Variables
5. Counseling Services

1. Mental health
2. Activism
3. Social relations

INDEPENDENT VARIABLES:

1) Sociodemographic Variables:
- age
- gender
- income

2) Worries and Stresses:
- about the future
- about personal health
- about the medical staff
- about finances
- in general (open-ended)

3) Treatment Status and Medical Involvement Variables:
Treatment Status:
- currently receiving treatment
- being cured
- having visible side effects

Medical Involvement:
- intervening to prevent a medical mistake from happening
- playing an active role in treatment
- attitudes towards the medical staff

4) Financial Status Variables:
- financial worries
- financial outcome resulting from illness
- use of financial services

5) Counseling Services:
- assistance with stress
- counseling during hospitalization
- counseling to learn to cope
- counseling for worries

III. STRESSES: WORRIES AND "DIFFICULT" ISSUES

Cancer is a stressful experience for patients and their family members. Some of these stresses are rooted in the physical experience of the illness and treatments, and others reflect the way this illness affects the psychosocial world of everyone concerned. The cancer experience creates new practical constraints and demands, often disrupts or alters interpersonal relationships, generates intense emotional reactions, and often requires new ways of dealing with work and community organizations. All these issues impact on the patient and family members, creating long-term and often intense concern and anxiety.

This study posed a number of questions to informants regarding their worries and concerns. Table 3 reflects the degree of "worry" each of the four populations expresses with regard to four major concerns: their futures, their assessments of their own health and energy level, their relationships with the medical staff, and their financial situations. The first scale looks at **worries about the future** which includes a person's 1) fear of relapse, 2) fear of death, and 3) fear of complicated future treatments. These questions were asked of the significant others (parents and spouses) in reference to fears about their respective cancer patient's future, while patients (adults and young adults) were asked the same questions in reference to fears about their own future.

The second scale examines **worries about personal health**. This scale is made up of four items, including the extent to which people 1) worry about having headaches, 2) worry about getting tired, 3) worry about getting enough rest, and 4) worry about getting a cold or flu. Significant others were asked to assess the amount of worrying they did in reference to their own personal health for the first three items, while patients were asked to assess how much worrying they did in reference to themselves on items (2) and (4).

The third scale is concerned with **worries about finances**. It includes: 1) worries about finances, 2) worries about obtaining life insurance, and 3) worrying about

9

paying bills. The fourth scale looks at **worries about the medical staff** which
includes: 1) worries about the staff being unhappy with my complaints, and 2) worries
about getting along with the staff. The items in this scale were asked of the significant
other (i.e. parent and spouse) populations only.

Responses for all four scales were coded as to whether people worried **a lot,
some, a little, or none** about each particular item on the two scales. Further
information about these four scales, and their components, are presented in Appendix A.
Table 3 indicates that both sets of significant others - parents of young adults with cancer
and spouses of adults with cancer - report worrying more about the patients' future than do
the patients (young adults or adults with cancer) themselves. Why might this be so?

Perhaps there is a difference in the way patients and significant others perceive the
illness, such that patients take a "one day at a time" approach which permits less concern
with the future, whereas significant others focus on the "final outcome" of the illness which
necessitates more of a concern with the future. A patient who present him/herself to others
in a positive, up-beat, worry-free light may find that other people reciprocate the positive
feelings and are more receptive to spending time with him/her. Expressing low levels of
worry then may represent a patient's way of encouraging the company of people around
him/her. Perhaps patients elect not to express their worries to protect their loved ones. In
some instances, patients have reported just such a protective stance, suggesting that their
family members have enough to worry about and that they do not wish to add further
burdens.

Moreover, perhaps significant others report worrying more because worrying is all
a non-patient family member can do. After all, family members can do little to affect the
actual course of the disease, and this may lead to feelings of helplessness and frustration.
If there is little "real work" to do to help the patient in their direst physical crisis, perhaps all
that is left is to worry.

Table 3:   Worries by Population Status

Worry Scales	Young Adult	Parent	Adult	Spouse	Sig.
Worries about the patient's future • Fear of relapse • Fear of death • Fear of future tx.	2.10	2.73	2.39	2.91	*
Worries about personal health • Getting headaches • Being tired • Getting a cold • Getting enough rest	2.00	2.10	2.42	2.42	*
Worries about finances • Obtaining life insurance • Our finances	2.18	2.45	2.43	2.43	
Worries about the medical staff • Getting along with the staff • The staff being unhappy with my complaints	1.37	1.44	1.36	1.59	

The scores represent means for each population on each scale. The higher the mean score the greater the worry.

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

With regard to worry about their own health and physical energy, (i.e. personal health) both sets of older persons - adult patients and their spouses (mean age 53) - report more concern than do the young adults (age 14-25) or the relatively younger (mean age 41) parents of young adults with cancer. It would appear that age may best account for concerns about physical energy and current health.

All four populations appear to express little concern about their relationships with the medical staff. Although the level of concern about finances is relatively strong, there is not much difference among the four population groups.

WHAT WAS DIFFICULT TO "HANDLE"?

In addition to asking about stress and worries, we sought to discover what people found difficult to deal with in the cancer experience, in their own words. This effort to retrieve the voices of patients and family members provides another window into the cancer experience, a view that more directly reflects their own reality. By asking people "what did you not handle well?" we are able to get another version of what people found stressful and difficult to manage. These responses may help us understand how so many people managed to deal positively with the cancer experience.

Four major sets of responses seem to typify the difficulties people encountered: (1) aspects of the disease, the treatment and interactions with the medical system; (2) management of one's own emotions; (3) management of the emotions of one's significant other; (4) aspects of family life and the external social world. In presenting direct quote material, we indicate each informant's status as a young adult with cancer (YA), adult with cancer (A), parent of a young adult with cancer (P), or spouse of an adult with cancer (S).

Difficulty dealing with the disease and treatment routines

Concerns about the disease and treatment routines focussed on the pain and side-effects of the treatment for cancer, and on interactions with physicians and the hospital

1 2

system. For instance, several adult patients and their spouses expressed difficulty in handling the pain of treatment:

> Physical pain in the joints was bothersome. (A)

> The pain she was in. The tests they put her through. (S)

> How much pain he is in and I can't help. (S)

Several parents also expressed their difficulty dealing with the pain they saw their children experiencing.

> The pain caused from blown IVs and the trouble with getting
> new ones started - 14 tries once! (P)

Closely related to problems dealing with the patient's pain was concern about the side-effects of treatment. As young people and adults with cancer indicates, both short and long term effects were troublesome.

> Side effects can sometimes make you want to give up - nausea,
> weakness, vomiting, mouth scores. (YA)

> It was hard coping with losing my hair at 16. (YA)

> Not being able to drive because of cardiac arrest and brain injury. (YA)

> Weight gain. (A)

> Appearance - due to hair loss and the "rounding" effects of prednisone...
> but it was not enough to stop me from doing the things I wanted to do. (A)

Significant others also reflected on the side-effects of treatment.

> The reaction to the treatment. (S)

> The ideas of what the hospital has done to my child. She ended
> up with chemo inflation of the arm. She has a deformed arm
> along with pain now to the upper arm. (P)

It is of course stressful to experience pain and to find one's life constrained by either the short-term or long-term effects of treatment for cancer. In addition, it obviously is stressful for parents and spouses to see their loved ones in pain. This stress is exacerbated when the pain or limitation observed does not appear to be a necessary component of the disease and treatment, as in the last excerpt where a parent expresses reaction to a medical "error."

Another stressful aspect of the cancer experience is hospitalization. Hospitalization
means time away from family and friends, and the necessity of dealing with a new and
compromising environment. Adult patients expressed their difficulty in handling hospital
stays in the following terms:

Repeated hospitalizations. (A)

The two and three month long hospital stays are very difficult.
And now the worry of having to go back in bothers me a great deal. (A)

Young adults with cancer and their parents also expressed serious concerns about
hospitalization.

Going to the hospital. (YA)

Extended hospital stays. (P)

The long hospital stay. (P)

And an often-overlooked source of stress may exist in the behavior of the medical
staff. Several significant others (but few patients) had difficulty dealing with certain
physicians or aspects of the social service system in the treatment facility.

Professional people not knowing what they are talking about. (S)

Reports of the doctor's insecurity about the treatment program
and deciding whether or not to get a second opinion. (S)

Some doctors' attitudes while my son was in the hospital
receiving chemo. (P)

I was very angry at the lack of help or compassion of the social
work department at our hospital. It took them approximately 6
weeks to respond to us. By the time they had suggested reading
materials I had already had to do that myself. (P)

Relatively little prior research examines patients' (or family members') views of the
attitudes and behaviors of the medical staff. One exception is the report by Chesler and
Barbarin (1984), indicating that parents of children with cancer express considerable
concern about getting adequate and honest medical information, and about creating good
interpersonal relations with staff members. The data above also clearly indicate that the

14

staff's behavior can impact meaningfully on patients' and family members' difficulties and sense of stress.

Difficulty dealing with my own emotions

A second major source of difficulty expressed by informants centered on the management of their own emotions. Shock, fear, uncertainty and loneliness dominated these reports. Especially for significant others, the effort to cope with their loved one's pain often generated intense emotional reactions.

The shock of the diagnosis, and the attempt to come to terms with the disease itself, often was troublesome. No one - no patient or family member - was prepared for the diagnosis of cancer. The serious nature of this disease, plus the sense of mystery and fear often accompanying discussions of cancer, often made the diagnosis shocking.

> When I was first told that I had cancer I thought I would die. (YA)
>
> Accepting that I have cancer. (YA)
>
> The shock of the diagnosis. (P)
>
> The initial shock. (P)

Many of these concerns continued after the early diagnostic period. The continuing threat of death was reported as stressful by a number of informants. Comaroff and McGuire (1981) also indicate that the prolonged period of uncertainty about the future course of the illness was a major source of stress for parents of children with cancer.

Parents, especially, also found it emotionally trying to deal with the pain and distress they saw their children experiencing.

> I couldn't handle him crying when he would get his shots. (P)
>
> Watching my child go through the treatments. (P)
>
> Not being able to help her through this; I just could not handle this. (S)

15

A number of informants referred in general to the high degree of emotional stress they experienced, and their dissatisfaction with the way they had handled this stress.

> My emotional problems. I am not satisfied that I am
> in control. (A)
>
> I did not cry enough. Not being able to totally let myself go in
> private as far as crying and feeling sorry for myself and my
> spouse and children. I was scared that once I started crying
> I would not be able to stop. (S)

Finally, for some, feelings of loneliness and isolation compounded their situation.

> Feeling so emotionally alone during his illness...feeling that
> nobody understands. (S)

The emotions of my significant other

In addition to dealing with one's own emotions, as a patient or a close family member, almost everyone at some point had to deal with the emotions of their significant other. Patients expressed difficulty dealing with their parents' and spouses' emotional reactions, and parents and spouses expressed similar difficulty dealing with patients' emotional responses.

> Dealing with my parents' pain. (YA)
>
> Putting them through all this. (A)
>
> Worry about my wife's health and if it is affected by my affliction. (A)
>
> My husband's denial of his illness. (S)
>
> The withdrawal of my spouse's feelings...he wouldn't
> talk about it. (S)
>
> I don't know what to do or who to talk to. She's going crazy.
> She is not able to work. What should we do? What can I say to her? (P)
>
> The emotional needs of the patient. (P)

These excerpts make it clear that everyone worries about everyone else, in addition to themselves. Parents and spouses worry not only about patients' physical status, but also

about their feelings and emotional responses. Patients, often engulfed in dealing with uncomfortable and anxiety-laden treatments, also worry about their family members' emotional welfare. These excerpts indicate that cancer truly is a "family disease," affecting the emotional and physical welfare of all family members.

Difficulties dealing with family and lifestyle issues

The final category of difficulties informants discussed focused on issues arising explicitly in the context of family life and the external social world. Substantial research indicates that the reactions of others - friends and neighbors and co-workers - is a vital aspect in the life of people with cancer and in their ability (and their significant others') to maintain a "normal" life (Wortman & Dunkel-Schetter, 1979).

Relationships with other family members and the necessity of accomplishing household chores sometimes were difficult to manage.

> The concern for my family was hard. My husband was torn between me, his job, and our children, and the children were constantly with other people...and were very insecure. I felt like a burden to my family and totally helpless. (A)

> I found being away from home hard on all family members... especially being away from my other child. (P)

> There is a great deal of stress in trying to keep the household in a more or less normal pattern. (P)

For some, financial matters occupied a great deal of attention and were a major source of worry.

> Employment and insurance problems. (A)

> Money problems. (A)

> Financial burden of travel and related expenses during hospitalization. (P)

> Pressure from hospital bill collectors. (S)

1 7

Several authors have indicated the tremendous financial burdens that some families face, as they try to cover non-insurable medical of related expenses (Lansky et al, 1979).

Closely related to these financial concerns were work related matters, such as employment, employment discrimination and income maintenance.

> I returned to work too soon and I could not handle it.
> My job is extremely stressful and after consulting with
> my therapist we have concluded that I can no longer do the
> type of work that I have done in the past. This is a severe
> loss to me. (A)

> The extra work load has been very time-consuming and trying.
> We are full-time farmers, and I had to take over my husband's
> job. (S)

Feldman (1980) and Monaco (1984) have detailed some of the discrimination encountered by young people with cancer as they seek employment, and the American Cancer Society recently urged legislation to protect the civil and employment rights of adults with cancer.

For young people with cancer, school is their "work place," and a number of patents expressed concern about the ways in which classmates reacted to the child with cancer.

> How some of the kids at school treated him and made fun
> of him when he lost his hair. (P)

> Sending him to school without his hair and fat from prednisone,
> and having the kids tease him. (P)

A number of other studies have indicated some of the problems children with cancer face when they return to school (Barbarin and Chesler, 1983; Deasy-Spinetta, 1980).

Dealing with friends, neighbors, and other people outside the family often was difficult, whether in the context of work/school or not.

> The fact that some people treat me differently because I have
> cancer. I want to be treated life a normal person. (YA)

> I didn't want anyone to know I was sick or to treat me differently.
> In a way I must have been ashamed of being sick. (YA)

> Dealing with my friends' and associates' reactions to my
> ups and downs. (A)

1 8

> People knowing about my illness and backing off out of fear,
> I feel, because my situation is so overwhelming. (A)

> The lack of understanding from friends. (S)

> Dealing with people who don't understand. (S)

Finally, several patients discussed the difficulty of having to change or delay the pursuit of their life plans or futures.

> At the time I was diagnosed I had graduated and was looking
> forward to a new life and college, and it fell apart and took me
> time...maybe a year or so...to stop looking for the past and to
> start to live again. (YA)

> All the time it took to recover and get back on track. (YA)

> Inability to perform activities I like because of the partial paralysis
> because of the stroke. (A)

> Not being able to work and do everyday things. (A)

These reports indicate the range of worries and stresses accompanying the diagnosis of cancer in a family member. As informants note, these were some of the most difficult issues they had to cope with in dealing with the illness.

IV. COPING AND LIFE CHANGES

In the previous section we examined some of the specific issues people said they had to deal with as part of the cancer experience. Our intention in examining these open-ended responses was to paint a general picture of the issues most commonly faced by people experiencing cancer. By better understanding the common issues people face, we can more fully appreciate what it means to them to "cope" with the illness.

Our interest in individuals' subjective assessment of coping is measured in two ways: 1) by asking people in general how well they handled the illness, and 2) by looking at how people report that their lives have changed since the diagnosis with cancer. The first

measure was phrased in the form of the following question: "Some ways of dealing with problems work better than others. In general, how well have you handled the illness?" Response choices were "very well," "fairly well," or "not well." The second coping measure involved an individual's assessment of his/her life changes as "better," "same" or "worse" since the illness.

When people in the general public are confronted with the question, "how are you doing?" the majority respond with the proverbial, "fine thank you." This same trend towards a generalized statement of well being seems to characterize the populations in this study. When informants were asked to assess how well in general they handled the cancer experience, the overwhelming majority of PARENTS, ADULTS, and YOUNG ADULTS said they handled things "very well," as indicated by 53% of parents, 66% of adults, and 71% of young adults. However, only 41% of the SPOUSES report handling things "very well" which suggests that spouses are not coping as well as the other three populations.

But what does it mean? Does it merely reflect surface-level politeness, or is it rooted in an actual assessment of a person's experiences and life outlooks? The findings suggest that when a person is asked to assess how well he/she handled things in general, he/she formulates a frame of reference comprised of the issues most salient and central to him/herself. By looking at the relationship between the general coping question and people's life changes, we may be able to shed some light on what it means to cope well or not well with the cancer experience.

LIFE CHANGES

This section examines each of the three life change scales separately in the four population status groups. There is an overwhelming consistency among the four populations to report positive life changes (above 2.00) on all three life change scales

(Refer to section II for a discussion of the life change scales, and see Table 4 for mean life change scores by population status). There are no overall negative life change scores (below 2.00) reported by any of the population groups on any of the life change scales. Of course, some negative life change scores occur for subgroups, and such scores will be mentioned as we go through the various sections and examine the outcome variable with the independent variables.

The findings indicate that the cancer experience can and does trigger positive change in people's lives. One explanation might be that cancer pushes people to their furthest limits, and those who live through it gain a sense of empowerment through the struggle. This mentality is consistent with that expressed by Olympia Dukakis in <u>Steel Magnolias</u> when she says, "that which does not kill us will make us stronger." Another explanation for the reported positive changes may be that chronic illness causes people to gain an increased appreciation for life, such that the petty problems which negatively affect most people's lives no longer have a major impact on the lives of the people experiencing cancer.

It may be difficult for the reader to accept the positive changes reported here at face value. It is puzzling for most of us to understand how positive change could result from experiencing cancer, generally considered to be a very negative, devastating experience. We are unable to discern whether people interpreted the life change question to mean how their life changed **since** the illness which would imply a "during illness / after illness" orientation, or whether they interpreted the question to mean how their life changed **as a result of** the illness which would imply a "before illness / after illness" perspective. However we interpret the meaning of the question, people clearly indicate that positive changes have occurred, and occurred consistently.

2 1

TABLE 4.

Life Changes Scales by Population Status

Life Change Scales:	Young Adult	Parent	Adult	Spouse	Sig.
Mental Health:	2.36	2.23	2.15	2.11	*

Mental health
Sense of personal control
Sense of who I am
Ability to cope with tragedy

Activism:	2.42	2.34	2.23	2.21	*

Willingness to join up with others
Sense of what I can do
Concern for others
Desire to change the medical system

Social Relations:	2.32	2.21	2.25	2.08	

Relationships with family
Time with friends
Relationships at work

The scores represent means for each population. The higher the mean score the more positive the life change.

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

<u>Mental Health</u>

YOUNG ADULTS report the most positive mean life changes in their mental health (2.36), followed by the positive changes reported by their PARENTS (2.23). ADULTS and their SPOUSES report less positive life changes, means of 2.15 and 2.11 respectively. The difference between the two patient populations of young adults and adults, as well as the difference between the pair of significant others, is statistically significant.

This finding suggests that mental health is contingent upon more than just a person's status as patient or significant other. In other words, it is would be incorrect to discuss the collective mental health of all patients because there is a significant difference between the mental health report of adult patients and the mental health report of young adult patients. In addition, the same reasoning applies to distinguishing between parents as significant others and spouses as significant others. This is an important finding, because much of the current cancer literature generalizes about patients and significant others without sufficient attention to the different sub-categories among these groups.

The higher mean scores reported by the YOUNG ADULT population may point to denial, resilience, or the general optimism of youth! Young adults have probably experienced fewer of the letdowns and disappointments in life than adults, which may permit them to hold on to their youthful optimism. This does not imply that young adults' optimism is unfounded. Five year survival rates for whites age 0-14 is 65% for all types of cancer combined, whereas the rates for white male and female adults is 51%. Five year rates for children are even higher for specific types of cancer such as Acute Lymphocytic Leukemia (71%) and Hodgkin's Disease (89%). Since the 5 year survival rates are more favorable for the young adult population than for the adult population, the greater optimism we see expressed by the young adults and their parents may be appropriate (<u>Cancer Statistics Review 1973-1986</u>).

<u>Activism</u>

The ordering of population groups seen on the mental health scale with young adults most positive, parents next, and adults and spouses least positive is repeated on the activism scale. Young adults lead the other three populations with regard to mean positive life change scores (2.42), followed by their parents (2.34), adult patients (2.23), and spouses (2.21). Because of the difference in one item on the activism scales for patients and significant others (refer to Appendix A), parents and spouses were analyzed separately from adults and young adults. **Parents reported statistically significantly more positive activism scores than did spouses, while young adults reported statistically significantly more positive activism scores than did adults.**

The difference between parents' and spouses' activism scores may result from the greater opportunity and responsibility that the medical community places on parents for the care of their children. The hospital may be more likely to view childhood cancer as a "family disease" and involve parents in the care-giving system. Parents may also have more energy than spouses partly because of their younger age.

Parents' responsibility, availability, and energy for their child's care may formally or informally bring them together with other parents to share common questions and concerns about their child's illness. Also, because most children are treated together in major children's cancer centers parents may have more of an opportunity to interact with other parents than do spouses of adult patients who are treated in a variety of settings. The feeling of community and empathy generated by parents' interaction with other parents may lead to the more positive activism scores reported by the parent population. These findings especially illuminate the need for more services and support networks for spouses of people who are experiencing cancer.

The finding that young adults report significantly more positive activism score than do adult patients suggests that young adults are more likely and/or more willing to join up with others to affect changes than are adults . As previously discussed, there may be more

effort by the hospital staff and service agencies to bring young adults with cancer together than there is to bring adult cancer patients together. If this is the case, young adults may feel a greater sense of community with other young adults than do adults, which may be reflected in the young adults' more positive activism scores.

Social Relations

Population status does not make a significant difference in life changes on the social relations scale. However, similar trends already discussed for the other scales emerge on this scale as well: young adults again report the most positive life changes (2.32) and spouses report the least positive changes (2.08).

Why doesn't population status affect the social relations scale the way it does the mental health and activism scales? One possibility is that the cancer experience has a more universal impact on peoples' social relations, regardless of age or population status. Perhaps people develop strategies for protecting their social relationships from the cancer experience because of the sanctity they feel for these relationships. Further, the variables which most affect social relationships most directly may be found within peoples' individual life circumstances which were not measured by our study instrument. The social relations scale asks about general changes concerning relationships with family and friends, and perhaps a scale which asks a variety of questions about more diverse or intimate changes in a person's relationship with family and friends could more accurately detect changes in social relations.

Trends Among the Significant Findings

YOUNG ADULTS report the most positive mean life change scores on all the scales, mental health, activism and social relations. On the opposite end, the least optimistic trend is seen in the SPOUSE population: spouses report the least positive change in their mental health, activism and social relations. This signals a genuine need for

increased research and attention to the often overlooked population of spouses and partners of adults with cancer.

THE RELATIONSHIP BETWEEN
COPING AND LIFE CHANGES

The analysis of the coping question and the life change measure verifies that many people report coping well and that many report making positive life changes. The following analysis examines the relationship between these two measures, and indicates that people who report more positive life changes also report coping very well with the illness, and people who report less positive or negative life changes report coping not as well.

YOUNG ADULTS who report coping very well also report more positive life changes than those who report coping not well. This is true across all three life change scales although it is only statistically significant for mental health and activism scales. In general, the social relations scale does not produce the same level of statistical significance seen for the mental health and activism scales.

In the PARENT population, how well people say they cope is related significantly to their scores on all three life change scales. Parents who report handling things very well report more positive life changes than do those parents who report handling things not well.

In the ADULT population, people who say they handle things very well report more positive life changes than those people who say they handle things not well. The trends is consistent across all three life change scales, although it is only significant for the social relations scale. This suggests that coping with relationship issues may be most central for the adult population.

SPOUSES who report handling things very well in general also report significantly better life changes on the mental health and the activism scales. However, they do not differ on the social scale: Spouses who report handling things very well, and those who report handling things not well demonstrate similar scores. This suggests that general coping measures are not an effective way of assessing the specific changes that take place in spouses' social lives as a result of their partner's illness. Perhaps changes in spouses' social lives are not as central for them as are the changes in their mental health and activism.

People who report coping better in general also report more positive life changes overall across all three life change scales. This is generally true for all four population groups, and supports our use of the life change measures as an indication of coping outcomes.

V.   WORRIES AND LIFE CHANGES

Cancer is an anxiety-producing experience for both patients and their significant others. Extensive treatment, changes in lifestyle, and the uncertain prognosis may cause people to experience feelings of apprehension and worry. What impact does worrying have on a person's life? Do people who worry more experience less positive life changes than people who worry less? Table 5 indicates the relationship between a person's degree of worrying and his/her life changes. (Refer back to table 3 for worries by population status.) This section examines the relationship between life changes and worries about the future, personal health, and the medical staff. The relationship between financial worries and life changes are discussed in section VIII.

Table 5: Worries by Life Changes

WORRIES

(Pearson's correlation coefficients r reported)

Population Status	Patient's Future	Personal Health	Finances	Medical Staff
A. Young Adults				
Mental Health	-.34 *	-.12	-.11	n/a
Activism	-.11	.07	-.03	n/a
Social Relations	-.20 *	-.14	.05	n/a
B. Parents				
Mental Health	-.35 *	-.20 *	-.22 *	-.09
Activism	-.03	-.03	.04	-.09
Social Relations	-.06	-.01	-.07	.01
C. Adults				
Mental Health	-.13	.02	.06	n/a
Activism	-.01	.03	.11	n/a
Social Relations	-.02	-.03	-.06	n/a
D. Spouses				
Mental Health	-.06	-.06	-.16	.23 *
Activism	.08	.07	-.08	.12
Social Relations	.27 *	.01	-.18	.10

The values reported in this table represent Pearson's correlation coefficients (r). The Pearson's r can be used as a test of the relationship between variables. Correlations range from -1 to +1, with a -1 reflecting a perfect negative relationship, 0 reflecting no relationship, and +1 reflecting a perfect positive relationship. The higher the correlation, the greater the strength of the relationship.
* represents (r) values which are statistically significant at the .05 level.
n/a indicates that the item was not asked of that population.

Worries About the Future

There is a statistically significant correlation between worrying about the patient's future and life changes in mental health for both parents (r=-.35), and young adults (r=-.34). The negative correlation for both populations means that there is an inverse relationship between worries and positive life changes: parents and young adults who report that they worry a lot about the future show less positive life changes in their mental health than do parents and young adults who do not worry as much. Worrying about the future does not have a significant effect on either ADULTS' or SPOUSES' mental health. However, as Table 3 indicated, this does not mean that adults and spouses worry less than do parents and young adults. Perhaps having more of a future to worry about makes the worrying that young adults and parents do more potent for their mental health.

There is a statistically significant correlation between worrying about the future and life changes in social relations for spouses (r=.27) and young adults (r=-.19). The negative (r) value reported by YOUNG ADULTS indicates that young adults who report that they worry a lot about their future experience less positive changes in their relationships with family and friends than do young adults who worry less. The implication of this finding is that the young adult population appears to be especially vulnerable with regard to social relations. Family members, close friends, and social service providers should be especially supportive of and responsive to the young adult who expresses worry about his/her future. However, since young adults may hide their emotions behind a "everything's ok" facade, it is important for family members and close friends to maintain support relationships **throughout** the young adult's treatment process.

Findings in the SPOUSE population run counter to assumptions about the negative effects brought on by worrying. The positive r-value reported by spouses indicate that spouses who **worry a lot** about the patient's future experience <u>more</u> positive life changes

29

than do spouses who do not worry as much. This implies that worrying is not always a bad thing.

Spouses who only worry **a little** about the future may keep their worries to themselves and deal with them on their own, while spouses who worry **a lot** about the future may be less able to keep their worries to themselves, and they may be more likely to express their worries and ask for or seek assistance or support. The spouse's family and friends may then become more attentive to the spouse's needs and concerns, and this attention may lead to positive changes in the spouse's social relations as diagrammed below.

more worries ---------------> more support ---------------> more positive life changes

Another explanation for the positive changes in social relations reported by spouses who worry more about the future is that spouses who worry more about the future may be spouses whose loved ones are most ill. If this is the case, family and friends may provide additional support to a spouse during times when the adult patient is most critically ill. This increased support for the spouse might then lead to increased positive life changes, as outlined above.

Worries About Personal Health

Worrying about personal health does not have a significant relationship with any life changes, with the exception of parents' mental health (r= -.19).

These findings suggest that most people who worry a lot about their personal health are just as likely to report positive changes in their lives as people who only worry slightly about their health. However, PARENTS who worry a lot about their own health report significantly less positive changes in their mental health than do parents who do not worry as much. This finding may stem from a parent's association between his/her own personal

30

health and the ability to take care of his/her child. The intense level of active involvement in patient care required of parents of children with cancer places high demands on parents' emotional and physical health. Parents may fear that if something -happened to them, no one would be there to take care of their child. The anxiety produced by the notion that their child's health is dependent upon their own health may· account for the less positive changes in mental health reported by parents who worry a lot.

We do not mean to suggest that spouses do not suffer a great deal of anxiety about who would take care of their partner should something happen to them as well, but that parents experience exaggerated worries surrounding such issues because of the unique dependency of children, especially sick children.

Worries about the Medical Staff

Worrying about the medical staff does not have a significant relationship with any life changes, with the exception of spouses' mental health (r= .23).

Significant others are the only two populations who were asked whether they worried about their relationship with the medical staff. The findings suggest that PARENTS who report that they worry a lot about their relationship with the medical are just as likely to report positive changes in their lives as are people who worry only slightly. However, SPOUSES who worry a lot about getting along with the staff, and whether the staff will be unhappy with their complaints, report more positive changes in their mental health than do spouses who do not worry as much. Perhaps spouses who worry a lot may be more actively involved in treatment than spouses who do not worry as much. This involvement may lead to increased support and positive mental changes as discussed and diagrammed for spouses' worries about the future.

Summary

Worries have a negative association with parents' and young adults' mental health and social relations, whereas they have a positive association with spouses' social relations. The latter findings reiterate that worrying may not always be as detrimental to people's lives as commonly believed, and it may in fact propel other people to the aid of the worrying person.

Worrying is not significantly related to a person's activism. In other words, people who worry a lot about the patient's future and/or their own personal health are just as likely to be concerned for others, and willing to join up with others to change things as people who do not worry as much. The force which motivates peoples' activism appears to be driven by something other than their worries about the patient's future and about their personal health. This is a positive message, in that people who are faced with a lot of worries are probably the people who could benefit the most from joining up with others, and it is encouraging to see that their worries do not prevent them from doing so. It is disheartening to find that worrying does not, however, encourage people to join up with others either.

Worrying appears to have its greatest impact on the area of mental health, and parent's mental health seems to be especially vulnerable to the effects of worrying. This suggests that worrying may act as a negative or draining force on the parent's ability to maintain their regular level of mental health, more so than for the other populations. While few people plan ahead for cancer, spouses and adult patients may anticipate future illness as part of the intrinsic nature of "growing old together." However, having a child with a serious illness is not an anticipated part of normal child rearing. The unexpected tragedy of having a child with cancer may destabilize the mental health of parents more than the other three populations. Services must be implemented and/or increased to help parents handle these worries.

VI. THE RELATIONSHIP BETWEEN DEMOGRAPHIC STATUS AND LIFE CHANGES

This section examines the relationship between demographic status and life changes. With few exceptions, variables such as age, gender, and income do not prove to have a significant effect on people's reports of their life changes.

Age

Age has a statistically significant effect on the adult patients' assessment of changes in their mental health and activism. The younger adult patients, those less than 40 years of age, report significantly more positive change in mental health and activism than do adult patients over forty. Our findings suggests that adults who are in their thirties or younger may actually experience cancer differently, or perceive it differently, than do their older counterparts .

One explanation is that the younger adult patients have a greater need to believe that "everything is going to be ok," which may translate into more positive mental health scores. This need may arise from the cancer stigma being more prevalent among younger adults in their workplace and friendship circles than among older adults, for whom the disease, or any illness, is more common. As they try to appear as if everything is ok, there may be a self fulfilling prophecy at work, such that younger adults begin to believe they feel ok. Younger adults also may feel that the illness threatens more years of their life than do the older adult patients, who may already lived relatively full lives by the time of the initial diagnosis. This feeling of being "robbed" of their healthy adult years may instill a fighting instinct and positive mental well being in younger adults. It may also be that younger adults are just more flexible and adaptive than older adults.

As far as the difference in **activism scores** is concerned, it is possible that younger adult patients experience a more positive change in their activism scores because they anticipate several years of productive life ahead after they "beat cancer." This desire

to beat the illness may encourage them to join up with others who are fighting a similar battle. On the other hand, the older adult patient may not be as optimistic about his/her chances of surviving long with the illness, and may wish to spend his/her remaining time in the company of family and close friends rather than with other people who are in a similar situation as themselves. By not joining up with other people to affect a change in things, the older adult patient may score less positively on the activism scale than the younger adult patient

Regardless of the explanations for these reported differences in life change scores, it is important for health care providers to be aware that the older adult patient population is at greater psychological risk, and that they need to address the unique concerns of these patients accordingly.

Gender

Gender is related significantly to life changes in only one instance: to activism for the young adult patients.

Female young adult patients report that they are more concerned about others, and more willing to join with others for change than are male young adult patients. (2.54 v. 2.33). Since substantial research suggests that women are more emotionally expressive and active, it seems likely that women in general are more likely to feel empathy and interest in helping themselves and others change, regardless of the impact of the cancer experience.

Income

Income is related significantly in only one instance to life changes: to activism for the adult patients.

Income has a significant affect on adult patients' activism scores, with adults in the middle income bracket (defined as $20 - $40,000) reporting the greatest degree of

willingness to join up with others for change (2.38). Adults in the highest income bracket (over $40,000) report the next highest activism score (2.22), and adults in the lowest income bracket (less than $20,000) report the lowest activism score (2.12). It is this least wealthy population that is the least likely to join up with others to affect change. This finding may reflect a lack of information about or access to others in a similar situation, or that people in the lowest income bracket are too preoccupied with financial concerns to invest time and energy into joining with others.

Summary

The old adage, "money can't buy happiness" seems applicable in the cancer experience. Cancer touches the lives of patients and significant others in a universally human way which is independent of financial status. This message should serve both the rich and the poor well because it reminds us that all are impacted severely in the cancer experience.

The paucity of significant finding for the demographic status variables suggests that age, gender, and income do not play a powerful role in affecting the way people deal with the psychosocial aspects of their cancer experience. It is an encouraging sign to anyone who works in the health care professions or cancer related service agency to see that the most important issues affecting people's life changes are not "changeless variables" such as age, gender, and income. The discovery that life changes are not predetermined by variables which are nearly impossible to control justifies attention to the psychosocial cancer strategies which may be controllable, such as counseling services, financial assistance, and attitudes and interactions with the medical staff. We will now begin to look at these more controllable variables.

VII. THE RELATION BETWEEN TREATMENT STATUS AND MEDICAL INVOLVEMENT AND LIFE CHANGES

According to the American Cancer Society, cancer touches the lives of three out of every four households in this country. Nearly every American is familiar with the cancer vocabulary, consisting of words such as chemotherapy, radiation, side-effects, and remission. The level of understanding about the disease and treatment may vary according to a person's relationship to the disease, but regardless of status as patient, parent, spouse, friend, neighbor, co-worker, or acquaintance of someone with cancer, the image of painful and extensive medical treatment is universally shared. Two general categories relevant to the medical aspects of the disease are a person's: (1) current treatment status, and (2) medical involvement. This section examines the relationship between each of these categories and a person's reported life changes. As an aside, we found no significant difference in life changes with respect to a person's diagnosis with either leukemia or lymphoma.

Current treatment status utilizes 3 variables, including whether a person is 1) currently receiving treatment, 2) considers him/herself cured, and 3) experienced any visible side effects from therapy. All these items deal with aspects of treatment which are generally believed to be outside of an individual's control, with the exception of "cured", which will be discussed further in its respective section. **Medical involvement** variables deal with an individual's level of participation in the treatment process. These variables are considered to be within an individual's control. They include whether a person 1) played an active role in treatment, 2) intervened to prevent a medical mistake, and 3) is satisfied with the medical staff and facility.

All of the items in both categories were single item measures answered simply as "yes / no", with the exception of the last item. Satisfaction with the staff consisted of a 7

36

item scale coded as "very satisfied," or "not very satisfied" with the medical staff and ·facility. (See Appendix A for more information about the scale) Table 6 shows the percentage of each population reporting "yes" and "very satisfied" for the 6 separate items discussed in this section.

Treatment Status Variables

A person's current treatment status can be thought of as a point along a continuum which ranges from being on treatment to being cured. Being off treatment and being in remission are treatment status points which fall somewhere along the middle of the continuum, however this section only looks at the end points which are 1) receiving treatment, and 2) being cured. YOUNG ADULTS define themselves as cured more often than do parents, spouses, or adults (32%). This finding is consistent with the optimism expressed by the young adults throughout this report and in other literature (Chesler, 1988). It may reflect typically different objective courses of the illness for young adults v. adults as much as it reflects the greater subjective optimism or resilience of young people.

We expect current treatment status, especially the feeling of being cured, to play a significant part in people's views of their life changes. If being cured is considered the desired end point of cancer treatment, then the further along the continuum a person feels she/he is towards being cured, the more positive his/her life changes should be. The diagrams below represents the parallel changes that we expect to find as people move simultaneously along the treatment status continuum and the life change continuum.

```
|-----------------------|-----------------------|-----------------------|-------->
receiving tx.       remission              off all tx.              cured


|----------------------- increasingly positive life changes ----------------------->
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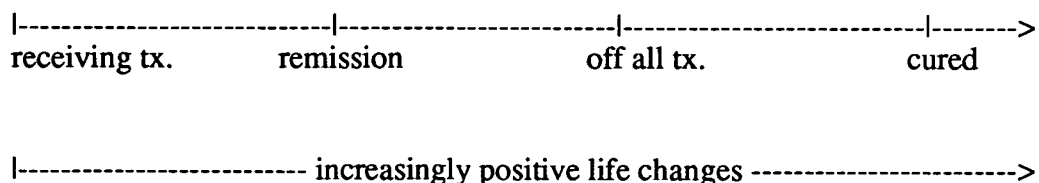
Table 6.

Treatment Status and Medical Involvement Variables

% of respondents answering "yes" to each item

Variables	Young Adult	Parent	Adult	Spouse
Treatment Status:				
• Receiving Treatment	18	27	29	24
• Cured	32	23	15	12
• Visible Side Effects	57	63	62	76
Medical Involvement:				
• Active Role	n/a	95	76	77
• Intervene	n/a	43	24	28
• Attitudes Toward Staff (% answering "very satisfied")	n/a	25	22	n/a

·**n/a** indicates that this question was not asked of this population

38

The feeling of having the experience behind them should allow people to assess the effects of the illness from a more detached and positive perspective. People who believe that they have "beaten cancer" can distance themselves from the pain and suffering of the illness and rationalize, or perhaps clarify, how they have grown since the initial crisis.

On the other hand, people for whom treatment is ongoing face an especially uncertain future, one which does not provide them with the detachment that people who feel they are cured have. As a result, people still on treatment can not "look back" on the cancer experience with any sort of peace of mind or resolution about its outcome, and we would expect people still on treatment to report less positive life changes.

Whether or not a person is currently receiving treatment did not significantly affect any of the life changes in the four populations. There is a consistent trend among PARENTS, ADULTS, and YOUNG ADULTS such that people who are currently on treatment report less positive life change scores than do their counterparts who did not report being on treatment. These findings are what we would expect.

Findings in the SPOUSE population follow an opposite trend. Spouses whose significant others are currently receiving treatment report more positive life changes on the mental health and activism scales than do spouses whose significant others are not currently receiving treatment. This seems to suggest that a spouse's mental health and activism is somehow enhanced when his/her significant other is on treatment. Spouses may experience an increased feeling of responsibility and involvement during the treatment process, which may increase their mental health and activism. They may also receive more support during the active treatment process, and the support and attention may translate into increased feelings of positive mental health and activism.

Since we reported earlier that spouses also report worrying more than the other populations, and that this greater worry was related to more positive life changes, it seems that positive change in the spouse population may be related to circumstances which call to people's attention the ongoing hardship of the cancer experience (i.e. having their loved-

ones currently receiving treatment, or expressing a lot of worry). Such situations may serve as triggers to family members, friends, and the medical system that spouses are an integral part of the experience, and are in need of support just as much as the patients are.

Being cured is a subjective measure, reported by people themselves in accordance with their own assessment of their current medical status. Therefore, being cured may mean different things to different people. Some people may report being cured just months after completing therapy, while others may not report being cured even years after treatment has ended. This does not imply that people can choose for themselves whether or not they are free of the cancer cells; rather, it points to the importance of a personal assessment of treatment status. We believe that the subjective assessment of being cured may be just as significant in affecting life changes as the actual medical prognosis. Defining oneself as cured may be the most empowering, optimistic, and/or denying thing that a person experiencing cancer can do. Feeling cured may not alleviate all of a person's worry and doubt, but it may provide a giant sense of comfort and relief to the person who has lived with uncertainty about his/her prognosis.

Twenty-three percent of all PARENTS define their child as cured. Parents who define their child as cured report more positive life change scores on all three life change scales than do parents who do not report their child as cured. These findings are significant for both the mental health and social relations scales, and they are consistent with our expectations. Parents who feel that their children are cured may have free time and energy to spend with family and friends that previously was spent with their ill child. This increased time and energy may be responsible for the more positive changes in social relations reported by parents. Believing that their child is cured also may inspire a positive mental outlook; in reverse, parents with a more positive mental health may be more inclined to report their child as cured.

Similar trends are reported by the ADULT population. Only 15% of the adults define themselves as cured, but those who do report more positive life changes on all three

40

life change scales than do adults who do not define themselves as cured. However, the findings are only significant for the mental health scale.

YOUNG ADULTS who report being cured show more positive changes on all three life change scales than do young adults who do not report being cured. The findings are significant on both the activism and social relations scales. People (especially younger adults) may not know what to say, or how to interact with a friend who has cancer, so they may wait until the person is cured to resume an active friendship with them. If this is the case, we need to educate people (especially young adults) about the illness, and challenge the stigma that prevents people from maintaining relationships with young adult patients throughout the treatment process.

SPOUSES are the only population group which does not report a significant relationship between the assessment of cure and life changes, although the trends discussed for the other three populations are seen here as well. The lack of significance may be due to the very low number of spouses who report their significant other as cured (n=8, 12%). The discovery that spouses are more hesitant to define their loved one as cured may reflect pessimism, skepticism, or realism. Whichever the case, spouses' life changes do not seem to be as as contingent upon a subjective notion of cure as much as are the life changes of the other three population groups. Since we know that spouses score lower on all three life change scales, it is possible that they are preoccupied with other concerns.

Side Effects

Visible side effects are reported by over half of all informants, but their presence or absence has no significant effect on life changes. This is a positive message to all people who experience devastating hair loss, weight gain, surgical scarring, sustained fatigue, or other side effects from treatment.

Medical Intervention Variables

Whether or not a person plays an active role in treatment, and whether or not he/she has to intervene to prevent a medical mistake, relates to a person's assessment of their participation in the treatment process. What affect does the level of participation have on a person's life changes? Does active participation and intervention in treatment empower a person and contribute to overall positive changes in his/her life? Or does active involvement mentally or physically exhaust the person such that his/her life changes take a turn for the worse?

We expect that people who play an active role in treatment will generally report more positive life changes. Young adults were not asked whether they played an active role in treatment, or whether they had to intervene to prevent a mistake, so this section only includes the reports of parents, spouses, and adult patients..

Active Role

Since 95% of the PARENTS report playing an active role in their child's treatment, we can not make comparisons between active and non-active parents, but the most significant finding is the discovery that nearly every parent played an active role in his/her child's treatment. Because parents are the legal guardians of their minor children, parents are required by law to consent for all medical treatment and procedures performed on their children. This means that physicians often interact directly with the parents, as if they were the patient themselves. Information is presented initially to the parents, and then it is filtered to the patient via parental discretion. For all intents and purposes, then, parents can be thought of as an extension of the young adult patients when it comes to treatment issues. This may explain why they sometimes report life changes more like those reported by patients than those reported by significant others.

In the SPOUSE population, only 77% of the people report playing an active role in their significant other's treatment. This suggests several possibilities: spouses may be less

welcomed into the treatment process by the medical system; they may not have the time or energy that parents have; or they may voluntarily choose to not get actively involved with their partner's treatment process. Any combination of these reasons could account for the lower involvement reported by spouses than by parents. The spouses who are actively involved in treatment do report significantly more positive life changes in mental health than do spouses who are not actively involved in treatment. This suggests that either spouses with more positive mental health are more inclined to be actively involved in treatment, or that active involvement in treatment causes more positive changes in a spouse's mental health. We can not ascertain the causal direction of this relationship. Similar significant trends are not seen on the activism or social relations scales; it is clear that mental health is more significantly related to a person's level of participation than are either of the other two life change scales.

Seventy-six percent of the ADULT population report playing an active role in their own medical treatment. It is surprising that this percentage is not higher, considering that 77% of the spouses reported active involvement . We would expect patients to report active involvement in treatment more often than significant others, but such is evidently not the case here. Playing an active role in treatment does not have a significant relationship with adults' life changes. Adults who choose to be involved in their treatment, may feel equally empowered as those who choose to turn their care over to the health care providers.

Intervention

Forty-three percent of parents, 28% of spouses and 24% of adult patients report having to intervene to prevent a medical mistake. The higher involvement reported among parents may reflect the more intense protective and policing role that parents play in their child's medical treatment.

Regardless of the differences in prevalence reported by parents, spouses, and adults, there is no significant difference in life change scores between people who

intervened and people who did not. Both groups were just as likely to report positive life changes. If there is a sense of empowerment gained by intervening, or if there is fear instilled by knowing that a mistake could have happened, it is not reflected in people's life changes. Perhaps people accept minor medical mistakes as a possibility in complicated medical treatment, and as long as these mistakes do not cause harm, experience them without any significant effect on their lives and outlooks.

Satisfaction with the Staff and Facility

The final medical intervention variable deals with the level of satisfaction a person has regarding the medical staff and facility. Seven variables make up this scale: 1) quality of medical care, 2) relationship between the medical staff and patients, 3) quality of social work services, 4) emotional support for you and your family, 5) information given about the disease and its treatment, 6) coordination among hospital specialists, and 7) communication with patients. (See Appendix A for Cronbach alpha scores.) For each variable, people were asked to assess how satisfied or dissatisfied they were with the particular aspect of treatment and responses were coded on a four-point system, ranging from "very satisfied" to "not satisfied." The questions that make up this scale were asked of the parent and adult populations only; therefore they are the only two populations discussed here.

PARENTS who say they are very satisfied with the staff and facility report more positive life changes on all three scales. This finding is significant for the mental health $r = .13$), and activism scales ($r = .15$). These findings suggest either that a person's satisfaction with the medical staff and facility contributes to his/her positive life changes, or that a person who experience more positive life changes may be more inclined to report satisfaction with the medical staff and facility. We can not determine the direction of causation between these two variables, but we have shown a relationship between positive life changes and satisfaction with staff and facility. The lack of significant findings on the

44

social relations scale suggests that parents' relationships with their family and friends and their attitudes towards the staff and facility change irrespective of one another.

ADULT PATIENTS who report being very satisfied with the the staff and facility also report more positive life changes on all three scales. Significant findings are found on the activism ($r = .19$), and social relations scales ($r = .24$). These relationships are more powerful than those reported for the parent population. The lack of significant findings on the mental health scale suggest that adult patients' mental well being is not contingent upon their satisfaction with the medical staff and facility.

Summary

Medical intervention variables which reflect a person's level of participation (i.e. active role in treatment and intervening to prevent a mistake) generally do not have a significant relationship with a person's life changes. Satisfaction with the staff and facility does demonstrate a significant correlation with two of the three life change scales in the populations for which these questions were asked. Whether or not a person is currently receiving treatment is not statistically related to any life changes in the four populations. Visible side effects do not make a significant difference for any of the populations either. Defining one's self as cured appears to be the chief discriminating treatment status variable when it comes to affecting people's overall life changes, such that people who report being cured also report more positive life changes.

VIII. FINANCIAL STATUS AND LIFE CHANGES

Living with cancer often means living with unexpected bills, exorbitant expenses, and possible financial disaster. Although the majority of hospital experiences may be covered by insurance for many people, this is not true for everyone. Moreover, there are numerous non-reimbursable expenses, such as traveling to and from the hospital for

45

treatment, lodging and meals for out-of-town families, and potential cutback or loss of employment for both patients and primary care providers. The financial burden, combined with the emotional stress of the cancer experience, may produce negative changes in people's lives.

If financial difficulty can create anxiety and worry for otherwise healthy individuals, what does it do to the person who is already under stress from the cancer experience? This section explores the relationship between people's' life changes and three financial variables, namely: 1) worries about finances, 2) assessment of overall financial impact of the illness, and 3) assistance with financial concerns.

Worries about Finances

Financial worries includes worries about finances, worries about obtaining life insurance, and worries about paying bills. **With only one exception, worrying about finances does not correlate significantly with any life changes in the four populations.**

The lack of significant findings suggests that financial worries are not at the heart of what impacts a person's mental health, activism, or social relations. This does not mean that financial concerns are not a real part of the cancer experience, but that these concerns are not linked to these outcome measures. This is encouraging news, because it suggests that people are able to separate their mental health and social relationships from financial worries. It is a positive sign to find that financial worries do not mandate negative life changes!

The exception to the lack of significant correlations occurs on the parents' mental health scale. Parents who worry a lot about finances report less positive changes in their mental health than do parents who do not worry as much ($r = -.22$). This suggest that paying the bills and obtaining life insurance are potent issues for parents of children with cancer, and more potent for them than for others. This may occur because the parent

46

population on average is younger and less financially stable (even though their incomes are higher) than the adult patients and spouses; thus their lives and life changes may be more affected by financial concerns. It may also occur because of the financial dependency between young adult patients and their parents that causes financial concerns to be more threatening to the parent population. Perhaps parents worry that if something would happened to them, their child would be unable to support him/herself, and this realization must take its toll on a parent's mental health.

Financial Impact

Financial impact is defined as a person's subjective assessment of how the illness impacted his/her finances. Responses ranged from serious financial disaster to no financial impact at all. This measure is not intended to assess the total cost of cancer treatment, or people's financial status, but whether a person's personal sense of the financial impact on their lives has any correlation with his/her life changes. Do people who feel they faced complete financial disaster as a result of the illness report less positive life changes than people who report no financial difficulties?

Findings show that people's assessment of the financial impact of the illness has no significant correlation with their life changes. These encouraging findings are consistent with the findings discussed regarding financial worries. People's financial concerns and financial setbacks do not have a significant effect on people's perception of the positive life changes which they report as part of the cancer experience. One possible explanation is that denial allows people to separate financial concerns from other aspects of their life. Or, perhaps the illness changes people's priorities, and alters their perception of the importance of money. People living with the cancer experience evidently feel that personal growth, mental health, relationships with loved ones, and concern for others are not contingent upon financial security.

Financial Assistance

People in all four population groups were asked to indicate whether they 1) used financial assistance, 2) would like to use financial assistance, or 3) had no need to use financial assistance. People in the first and third category are not in need of services, whereas people in the second category are experiencing an unmet need. Unmet need does not distinguish between people who experienced an unsuccessful attempt at obtaining assistance from people who did not even request assistance, but the common denominator of all people who expressed unmet need is the unfulfilled desire for the use of the service.

People who report unmet need are acknowledging that they did not feel equipped to handle the situation alone, and desired the assistance of other people and resources. "Unmet need" is different from "no need", because the later suggests that people may deny what they can and can not handle on their own, may have gotten enough help, or may have a different coping style than the people with unmet need. People who express the need for financial assistance are acknowledging the need for help.

By the time people acknowledge the desire for assistance, they may already be experiencing a great deal of anxiety about not being able to pay their medical bills. Does the inability to find financial assistance add to their pre-existing anxiety? Does unmet need have a negative impact on a person's life changes? Do people who report unmet need report less positive changes in mental health, activism, and social relations than people who do not report unmet need?

People who said they either received financial assistance, or had no need for financial assistance, report more positive changes in mental health compared to people who said they needed for financial assistance. Unmet desire for financial assistance appears to be detrimental to people's mental health, since the people who report such unmet need actually indicate <u>negative</u> changes in their mental health. This trend is not statistically significant, but it is repeated in the parent, spouse, and adult patient populations. There are no significant findings or trends among young adults in

48

regard to issues of financial assistance, probably because young adults often lack accurate information about their parents' financial situation.

In the significant other populations (parents and spouses) there are no significant relationships financial services and the activism or social relations' scales. Why does financial assistance plays a key role in parents' and spouses' mental health, but not in their activism or social lives? The answer to this question may be rooted in the nature of access to and delivery of financial assistance programs. These programs may often be accompanied by counseling which targets issues of self esteem and coping ability, which are closely related to items on the mental health scale, but which do not specifically target the interpersonal skills necessary for positive changes in activism and social relations.

Financial assistance does have a significant relationship with the activism of ADULT PATIENTS, which suggest that financial assistance has a different impact on patients than it does on significant others. Adults who report using financial assistance services report significantly more positive life changes than do adults who report no need for such services, or adults who report an unmet need for services. Adults with unmet need for services report the least positive change in activism.

Summary

Finances are a personal and emotional issue. Many people (especially men) equate their self-worth with the ability to provide for their family and to meet their family's financial needs. As a result, asking for, or admitting a need for, financial assistance may be more difficult than asking for other forms of help. The findings indicate that the financial issue most significantly affecting people's life changes is the availability of financial assistance, not the overall financial impact brought on by the illness, or the amount of financial worries people have. This means that service agencies which provide financial assistance can impact positively on people's lives by providing these resources to people who need it. Preventing the negative life changes which occur as a result of unmet

need for financial assistance may require agencies to increase their visibility in the public sector, or actively seek out people who may not otherwise ask for assistance.

IX. COUNSELING SERVICES

One common approach to dealing with stress is the use of psychological counseling services. This section examines the relationship between patients' and significant others' reports of their life changes and their use (or desire to use) four types of psychological counseling services: 1) counseling to handle stress, 2) counseling during hospitalization, 3) counseling to learn to cope, and 4) counseling for worries. For each type of counseling, people were asked to assess whether they a) had used, b) would like to use, or c) had no need to use that particular service.

As in prior section, we refer to people who indicated they "would like to use the service," as people with **unmet need.** People providing the other responses are considered either to have met their need or not to have such a need for services. In previous sections, we discussed how unmet need for financial assistance was associated with less positive life changes, and based on those findings we expect people with an unmet need for counseling services to report less positive life changes as well.

Assistance Handling Stress

Assistance handling stress is a broad counseling category which includes professional counseling, religious counseling, counseling as part of a support group, peer counseling, etc. Assistance handling stress shows a statistically significant correlation with at least one life change scale in three of our four population groups, namely PARENTS, ADULTS, and YOUNG ADULTS. The broad range of significance reported for this type of counseling may result from the diversity of sources that assist people with stress, or it may result from the wide range of interpretations people have for what it means to receive

50

assistance handling stress. Table 7 indicates the percentage of parents who have used, would like to use, or had no need to use the various counseling services, and the mean scores on each of the three life change scales for people indicating their use (or non-use) of various services. Statistically significant differences between life change scores for different responses to service usage are indicated with an asterisk. Statistically significant findings in the spouse, adult, and young adult populations are more infrequent and therefore we do not provide tables for these populations responses.

In the PARENT population, people who received assistance handling stress report significantly more positive changes in mental health and activism than do people with an unmet need for the service. This is consistent with previous findings which point to the detrimental affects of unmet need.

PARENTS who said they have no need for assistance with stress report life change scores only slightly less positive than the parents who received assistance handling stress. This finding suggests several possibilities. 1) Parents who say they do not need assistance with stress may have received enough support from family, friends, or religious leaders, such that they do not desire additional counseling services. 2) Parents who report no need for the service may be aware of their own stress threshold, and do not require counseling services if that level is not exceeded during the cancer experience. 3) Parents who report no need for services may be in denial about their needs, and this denial may carry over into an inflated assessment of their life changes. There is no way to determine which of these scenarios is most prevalent among the people reporting no need for services, but all three may be represented in some degree. Regardless of people's rationale for reporting no need for assistance with stress, we expect to find that they have positive life changes equal to,

TABLE 7.

USE OF COUNSELING SERVICES BY LIFE CHANGES
FOR THE PARENT POPULATION

TYPE OF COUNSELING	LIFE CHANGES		
	MENTAL HEALTH	ACTIVISM	SOCIAL RELATIONS
ASSISTANCE WITH STRESS			
• Have used (26%)	2.44	2.44	2.25
• Would like to use (38%)	1.97	2.23	2.11
• No need to use (36%)	2.31 *	2.39 *	2.23
DURING HOSPITALIZATION			
• Have used (32%)	2.32	2.41	2.23
• Would like to use (19%)	2.02	2.22	2.19
• No need to use (49%)	2.28 *	2.36	2.20
TO LEARN TO COPE			
• Have used (27%)	2.35	2.44	2.27
• Would like to use (29%)	2.05	2.21	2.13
• No need to use (44%)	2.27 *	2.36 *	2.22
FOR WORRIES			
• Have used (25%)	2.34	2.43	2.28
• Would like to use (30%)	2.02	2.23	2.07
• No need to use (45%)	2.30 *	2.34	2.24

The scores represent means for each population. The higher the mean score the more positive the life change.

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

or very similar to those reported by people who received assistance. This expectation is based on the assumption that assistance promotes positive life changes.

PARENTS with an unmet need for assistance handling stress report less positive changes on all three scales and negative changes in their mental health. This is especially alarming considering the infrequency of negative life changes found in this report. Parents' mental health appears to be highly contingent upon their ability to get help in handling stress.

In the ADULT population, assistance with stress is also statistically significant with activism, but the trends seen for adults are different than the trends seen for parents.

Adults: Assistance Handling Stress

	No need to use (58%)	Would like to use (28%)	Have used (14%)
Activism:	2.10	2.40	2.40

Adults who receive assistance with stress and those with unmet need report equally positive life changes, whereas adults who report no need for the service have the least positive life changes. This contradicts the notion that people with unmet need have the least positive life changes. Instead, these findings suggest that adults with no need for the service may be in denial about their need for assistance, or do not recognize their own need. If this is the case, extending services simply to adults who ask for assistance with handling stress may not be enough to increase the positive life changes in adults' activation potential. It may be important for counseling services to reach out to educate adults who may be unaware of their own need for assistance.

In the YOUNG ADULT population, we find a significant relationship between assistance handling stress and mental health. The findings in this population contradict those found in both the parent and adult patient populations. Young adults with an unmet need for assistance, and young adults with no need for assistance

report equally positive changes in their mental health, whereas young adults who did ~receive assistance with stress report the least positive life change score. See the data below for percentages and mean scores.

Young Adults: Assistance Handling Stress

	No need to use (71%)	Would like to use (22%)	Have used (7%)
Mental health:	2.45	2.38	1.92

The discovery that young adults who have used assistance handling stress report negative life changes is very troubling. It is counter-intuitive to our notion of the therapeutic benefits of counseling. These findings may suggest a sort of self-selection or referral pattern into counseling services such that young adults who have low mental health scores use counseling more frequently than young adults with more positive mental health scores. It also may suggest that people other than the young adults themselves (i.e. parents or health care providers) are making the decision for the young adults to use counseling. If this is the case, the negative life changes we see may reflect young adults' negative reaction to being "forced" to use assistance against their will. Moreover, since this is only a very small percentage of young adults (7%), it may indicate an especially "distressed" sub group, one with serious emotional or behavioral problems.

Assistance handling stress does not correlate significantly with SPOUSES' life change, but spouses who report an unmet need for counseling services report negative life changes in their mental health scores compared to the positive scores reported by both the "have used," and "no need to use" groups. The discovery of negative life changes should once again alert us to the stress experienced by spouses with unmet need regardless of the lack of statistical significance to the finding.

Both populations of significant others (i.e parents and spouses) who were unable to receive desired assistance with handling stress experience detrimental changes in their

mental health. People need skills in stress management in general, and specifically related to illness management; therefore, programs must be targeted to meet these unmet needs if we are to break this vicious cycle of stress producing stress.

Counseling During Hospitalization

Counseling during hospitalization does not target a specific need in the way counseling for stress does. Rather, it addresses the issue of when and in what setting the counseling will be received. Often people's first exposure to the overwhelming stresses associated with cancer, and thus the need for counseling services, comes during hospitalization; therefore, this type of counseling may be considered the first line of defense against later stresses and conflicts.

Counseling during hospitalization does have a statistically significant relationship with PARENTS' and SPOUSES' reports of positive changes in their mental health, but not with adults' or young adults. These findings suggest that significant others benefit more from initial counseling during hospitalization than do patients . Significant others may be especially vulnerable because of feelings of powerlessness and distress during their loved-ones' hospitalization, whereas patients themselves may be preoccupied with the behavioral adjustment to hospitalization and treatment. See the data below for the mean scores for spouses' mental health, considered in relation to their reports of counseling services. Parents' mental health scores are reported in Table 7.

Spouses: Counseling During Hospitalization

	No need to use (60%)	Would like to use (26%)	Have used (14%)
Mental health:	2.09	1.94	2.56

55

In both the PARENT and SPOUSE populations, people who used counseling services report the most positive life changes, while those who have an unmet need for counseling report the least positive life changes. In the SPOUSE population, people who report an unmet need for counseling actually report negative life changes in their mental health.

Since counseling during hospitalization benefits significant others' mental health, it behooves hospitals to increase their outreach to significant others who express the desire for counseling, or who might respond positively to an invitation. Hospitals also should consider integrating stress management services directly into the patients' hospital experience. This would be especially feasible in the parent population, since 95% of parents report taking an active role in their child's treatment. The evidence that counseling during hospitalization did not have a significant relationship with activism or social relations for any population group probably reflects the kind of counseling typically provided: counseling focused solely on intrapersonal issues cannot be expected to improve external aspect of people's lives, however vital these areas are. Hospitals could be encouraged to offer counseling services that incorporate issues related to patient / family activism and social relations.

Counseling to Learn to Cope and Counseling for Worries

Learning how to cope, and how to deal with worries, are specific coping mechanisms vital to the mental health of people experiencing cancer. What happens when a person's feels that his/her desire for these types of assistance has not been met? Do people who report unmet need in these areas report less positive life changes than their counterparts who do not report unmet need?

With the exception of PARENTS' mental health and activism, counseling to learn to cope and counseling for worries do not have significant relationships with people's life changes. In other words, people with unmet need for these services are no more or less likely to report detrimental life changes

than are people without unmet need. The significant findings that do appear in the parent population are consistent across all forms of counseling. The findings reported in Table 6 are consistent with the data on worries, in which we found that parents' worries about the future and about their own personal health were significantly related to their mental health.

Review of Significant Findings

• **All four types of counseling services** have a statistically significant relationship with PARENTS' mental health, such that parents with unmet need for these services always report less positive life changes.

• **Psychological counseling for learning how to cope and assistance with handling stress** have a statistically significant relationship with PARENTS' activism, such that parents with unmet need for these services always report less positive life changes.

• **Counseling during hospitalization** has a statistically significant relationship with both groups of SIGNIFICANT OTHERS' (parents and spouses) mental health, such that significant others with an unmet need for services report less positive life changes.

Parents are the only population who consistently benefits from every type of counseling offered. The implication here is that counseling has more of an impact on parents' life changes than on the life changes of spouses, adults, or young adults. Or parents who self-select for counseling may reap benefits that enable them to report more positive life changes. Parents' mental health appears to be especially dependent upon the assistance they receive in dealing with their stress, and their unmet need is uniformly tied to less positive changes in their mental health scores.

Peoples' changes in their social relations are uniformly unrelated to all the counseling services discussed in this section. This suggests that issues of interpersonal intimacy may not be being addressed in counseling services, or that these relationships are contingent upon conditions outside the realm of counseling services.

57

X. COPING WELL - ADVICE AND SUGGESTIONS FOR OTHERS

As part of our inquiry into coping tasks and strategies, informants in this study were asked, "What did you handle well?" The examples of things they handled well in the experience of cancer can be translated into advice and suggestions that others dealing with cancer could think about adopting. These comments were, strictly speaking, not presented as advice, but we can infer coping suggestions from these reports of positive coping experiences and activities. In general, the positive reflections and suggestions people had can be organized into several categories; (1) dealing with treatments and their painful or lasting side-effects; (2) being accepting and having a positive outlook; (3) dealing with others; (4) "getting on" with one's life; (5) dealing with family matters; (6) dealing with God.

With regard to dealing with the treatments, per se, the following examples of what was handled well were reported:

> Taking the drugs faithfully. (YA)
>
> Participating in my own treatments - such as care of the Hickman, administering IV drugs at home. (A)
>
> Getting myself to doctors and for treatments. (A)
>
> Being with the child during treatments. (P)
>
> Keeping track of the proper medicine schedule. (P)
>
> Go with him to get a checkup. (S)

Especially for parents of children and young adults with cancer, the importance of gathering information from the medical staff was emphasized often.

> Winding my way through the medical world to get the answers I needed. (P)
>
> Knowing what is happening, to be informed...through textbooks, the Cancer Society, etc. (P)

The importance of "accepting" the illness and dealing forthrightly with this new
-reality was addressed in the following ways.

Accept the fact that I myself have leukemia. (YA)

Accepting the fact that my child is ill and has special needs. (P)

Accepting the illness and the treatment of it. (A)

I have accepted the fact that he has a very serious illness. (S)

Knowing that I have cancer and what I have to do to get better. (A)

In addition to acceptance, another personal coping tactic that many people reported was
creating a "positive outlook" and an active posture toward recovery.

Keep a positive attitude. (YA)

Having a will to survive. (A)

Determination to follow doctor's orders and survive as long
as possible. (A)

My outlook on life and a positive attitude and a strong desire
to live. (A)

Maintain a positive and cheerful attitude on chemo days, I found
something special to share on those days with my child. (P)

Not feeling sorry for ourselves. (P)

Attention to family issues often stood out as an important issue.

I feel I maintained a normal home life through all the
turmoil of my illness. Happily, this was accomplished
with little effect on my children. (A)

Tried to keep family life as stable and normal as possible. (P)

Keeping our life together in the mainstream. (S)

Sitting down and talking things over with my husband -
getting positive again. (S)

Dealing with others outside the family in an open way, and with a positive stance, also was suggested as important.

> I handled people who try to feel sorry for me by showing them that I am perfectly fine now. (A)

> I used to share it with people at the appropriate time. I never used it to get ahead. (YA)

> Expressing my feelings with my family and friends. (A)

> We shared our feelings...the good and the bad. (P)

One important aspect of many people's experience with cancer was the determination to <u>maintain as normal a life as possible</u>, including the ability to "get on" with future plans.

> Getting on with other things. (YA)

> Dealing with the fact of leukemia has not changed my life style. (A)

> Getting on with life. (A)

> Went on about life as usual. (A)

A final coping strategy that informants suggested as helping them to deal with the difficulties of the cancer experience was a <u>faith in God</u> and a reliance on prayer. Interestingly, it was primarily the adult portion of the population (adults with cancer, parents of young adults with cancer, and spouses of adults with cancer) that noted the success of this approach.

> I believe there has been a purpose for all this. (A)

> I turned to God for help and strength. (P)

> We prayed a lot and knew that everything was going to be alright. (P)

> I was able to cope and hope with my faith in God. (P)

> Everything was in God's hands. (S)

These positive suggestions could be the cornerstone of peer counseling or support programs. Obviously, "veteran" patients and family members have much wisdom to pass on to others, and many newly diagnosed patients could benefit from learning about these positive coping strategies.

XI. SUMMARY OF MAJOR FINDINGS AND RECOMMENDATIONS

In this report we have examined the perplexing and intriguing question of what it means to cope with cancer, from the subjective perspective of individuals experiencing the disease. We have identified a dozen major findings and they are highlighted below, with a brief discussion of recommendations and policy implications.

1. There is an overwhelming consistency for all four populations to report positive life changes on all three life change scales. YOUNG ADULTS consistently report the most positive life changes, followed by the positive changes reported by their PARENTS. ADULTS and their SPOUSES consistently report less positive life changes, with SPOUSES reporting the least positive changes of all. These findings suggest that all four population groups are experiencing positive life changes since the beginning of the cancer experiences. Whatever the explanation, it is clear that many, perhaps most, people cope quite effectively and are able to live quite positive lives in the face of cancer. However, adult patients and spouses are in need of increased support and assistance, with particular emphasis on research and attention for the spouse population.

2. The majority of YOUNG ADULTS (71%), PARENTS (53%), AND ADULTS (66%) report handling the illness "very well," whereas only 41% of the SPOUSES report similar findings. This again points to the need for increased services and attention targeted to the spouse population.

61

3. Four major sets of issues typify the difficulties people encounter including: 1) aspects of the disease, the treatment and interactions with the medical system; 2) management of one's own emotions; 3) management of the emotions of one's significant other; 4) aspects of family life and the external social world.

4. Both sets of significant others (parents and spouses) report worrying as much or more about the patients' future, their own personal health, finances, and the medical staff than do the patients themselves. This suggests that significant others have a particularly difficult role to play, and that they could benefit from increased services particularly designed to assist with handling their unique worries

5. Worrying generally is related to less positive life changes. PARENTS' mental health appears to be especially vulnerable to the effects of worrying, and services must be implemented to help parents handle the unique difficulties of having a child with cancer.

6. Worrying is not always a bad thing, especially for the spouse population. SPOUSES who report worrying a lot about the future and about their relationship with the medical staff report more positive life changes than do spouses who do not report worrying as much. This suggests that worrying, and sharing worries publicly, may lead to increased support from family, friends, and medical staff, which in turn may lead to more positive life changes in the spouse population.

7. Age, gender, and income do not appear to play a powerful role in affecting the way people deal with the psychosocial aspects of their cancer experience.

8. Defining one's self as "cured" appears to be a chief determinant in affecting overall life changes, such that people who report being cured also report more positive life changes. These findings suggest that a person's subjective outlook on and assessment of his/her current treatment status is very important. It points to the powerful affects of positive thinking which must be cultivated by friends, family, and the medical system.

9. The financial issue most significantly affecting people's life changes is the availability of financial assistance, not the actual financial impact brought on by the illness, or the amount of financial worry people have. This suggests that service

agencies which provide financial assistance can impact most positively on people's lives by reaching out to and providing assistance to people who need it.

10. Counseling services received during hospitalization have a significant relationship with the mental health changes of significant others, more so than for patients themselves. This suggests that when patients are hospitalized is an especially good time to offer / provide psychosocial support and counseling for the entire family.

11. Unmet need for counseling services is generally detrimental to people's life changes. In particular, PARENTS with unmet need for counseling services consistently report less positive life changes than do parents who either report using services or report no need for such services. This suggests that agencies offering various types of counseling services could make a significant impact on positive life changes by increasing their availability to parents.

12. The positive reflections and suggestions people had can be organized into several categories including: 1) dealing with treatments and their painful or lasting side-effects; 2) being accepted and having a positive outlook; 3) dealing with others; "getting on" with one's life; 5) dealing with family matters; and 6) dealing with God.

We conclude on a positive note. Although the majority of current cancer research depicts the illness as a life-destroying experience, the findings of this study strongly suggest that many people report positive growth and positive life changes since the beginning of their cancer experience. As previously mentioned in this report, there are alternative explanations for these positive changes, depending on whether a person interpreted the life change questions to mean changes occurring **since** the illness, or changes occurring **as a result of** the illness

In the first explanation, people who interpreted the question to mean changes occurring since the illness bring a during illness / after illness perspective to the question. In other words, these people may feel that the diagnosis and early treatment was so terrible,

life is better now. Or, the further away they are from the experience, the better they feel. In both cases, the responses reflect a comparison of life <u>during</u> the illness to life <u>after</u> the illness.

Alternatively, people who interpreted the life change question to mean changes occurring as a result of the illness bring a before illness / after illness perspective to the question. These people may feel that the cancer experience is such a challenge that living through it has enabled them to put their lives back together in more meaningful ways. It may also be that these people feel that cancer is a challenge, and that "beating it" feels great! Their responses reflect a comparison of life <u>before</u> the illness to life <u>after</u> the illness.

Whichever the explanation, it is clear that people are reporting positive changes, and we advocate that the future of cancer research and services orient their focus away from the pathology of coping, and instead focus on enhancing the positive changes people can and do make.

Scale Items and Cronbach Alpha Scores

Life Change Scales:	Young Adult	Parent	Adult	Spouse
Mental Health	.70	.66	.47	.70

- Mental health
- Sense of personal control
- Sense of who I am
- Ability to cope with tragedy

Activism	.73	.67	.67	.59

- Willingness to join up with others
- Sense of what I can do
- Concern for others
- Desire to change the medical system

Social Relations	.41	.64	.40	.53

- Relationships with family
- Time with friends
- Relationships at work

An alpha of .4 is generally considered acceptable, and a .6 or greater indicates a coherent scale that is internally reliable.

Worries Scales:	Young Adult	Parent	Adult	Spouse
Patient's Future	.70	.79	.80	.73

- Fear of relapse
- Fear of death
- Fear of future tx.

	Young Adult	Parent	Adult	Spouse
Personal Health	.61	.77	.62	.66

(Items in scale are different for different populations.)

	Young Adult	Parent	Adult	Spouse
Finances	.58	.58	.55	.72

- Obtaining life insurance
- Our finances

	Young Adult	Parent	Adult	Spouse
Medical Staff	n/a	.64	n/a	.77

- Getting along with the staff
- The staff being unhappy with my complaints

Satisfaction With The Medical Staff	Young Adult	Parent	Adult	Spouse
	n/a	.68	.78	n/a

- Quality of medical care
- Quality of social work services
- Relationship between the medical staff and patients
- Emotional support for you and your family
- Information given about the disease and its treatment
- Coordination among hospital specialists
- Communication with patients

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n/a indicated that the items were not asked of that population

An alpha of .4 is generally considered acceptable, and a .6 or greater indicates a coherent scale that is internally reliable.

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