

AN UPDATED REPORT ON OUR STUDIES OF  
LONG-TERM SURVIVORSHIP OF CHILDHOOD  
CANCER AND A BRIEF REVIEW OF THE  
PSYCHOSOCIAL LITERATURE

by

Mark A. Chesler and Bradley Zebrack

#531

updated December 1997

CENTER FOR RESEARCH ON SOCIAL ORGANIZATION  
WORKING PAPER SERIES

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Updated report on our studies of long-term survivorship of childhood cancer and a brief review of the psychosocial literature

Mark A. Chesler & Bradley Zebrack  
December, 1997

This addendum brings readers up to date on our ongoing studies of long-term survivorship of childhood cancer. We welcome inquiries and comments.

Since the publication of Working Paper #531 (June 1996) we have made progress on several fronts, some of which were anticipated in the original report.

1. The in-depth personal interviews with 25 long-term survivors of childhood cancer who filled out mailed questionnaires has been completed, and we are currently conducting qualitative analyses of these interviews (see paragraph 3 on page 9 of the original report).

2. The collection of medical records data on the approximately 500 long-term survivors who were in the original study pool (those who responded to the questionnaire and those who did not) has been completed, these data are coded, and they are part of our continuing quantitative analysis (see paragraph 3 on page 9 of the original report). These data will permit us to add the UMMCH data on respondents and non-respondents to table 3 of the original report.

3. The collection of questionnaire data from a comparison sample of approximately 300 adolescents and young adults without a history of childhood cancer has been completed and these data are being prepared for quantitative and comparative analysis (see paragraph 3 on page 9 of the original report). These data, together with the responses from the 300 long-term survivors themselves, will permit us to add the 1996-UMMCH and 1997-Comparison data to tables 1 and 2 of the original report.

In addition, we have gathered questionnaire data from approximately 200 of the parents of the long-term survivors in the UMMCH sample. This is the first step in the effort to gather information from other family members, a limitation of the original studies that was lamented in paragraph 2 of page 12 of the original report. Attached is a copy of the parental questionnaire in use.

With assistance from the Office of Cancer Survivorship of the NCI (and the collegueship of Professor Bernadine Cimprich, School of Nursing, UM), we plan to undertake several further inquiries into the "quality of life" and "service needs" of cancer survivors in the next 2 years:

1. We will conduct in-depth personal interviews with approximately 25 parents of the long-term survivors who responded to the above parent questionnaire (in the winter of 1998).

2. We will conduct in-depth personal interviews with approximately 25 siblings of these long-term survivors (in the winter of 1998).

3. We will re-survey the 300 long-term survivors in the original (1996) UMMCH sample in the winter of 1999 (3 years post original data collection) and follow that with in-

depth interviews with a sub-sample of approximately 25 of these informants. This will permit us to continue assessing the psychosocial impact of childhood cancer in terms of potential late effects, quality of life and positive/negative growth/change. It will also allow us to explore in greater depth issues discovered in the 1993 UCMC and 1996 UMMCH studies.

4. We will extend the methods and findings from the above studies to inquiries with two new populations of long-term survivors of cancer: (1) Re-investigation of informants in a (1987-88) study of 170 young adult and adult survivors of leukemias and lymphomas (and their parents or spouses/partners) throughout the state of Michigan. Questionnaires with the entire original sample and in-depth interviews with selected sub-samples will be utilized. (2) A pilot study with 100 adult survivors of breast cancer (once again using questionnaires and follow-up interviews). These additional studies, with measurement and conceptual comparability, should "test" and increase the applicability of the findings from our earlier and current work with long-term survivors of childhood cancer.

Finally, we continue to be interested in international comparative studies of these populations and these phenomena, and seek interested colleagues to work with in these endeavors.

QUESTIONNAIRE FORM FOR USE WITH PARENTS OF LONG-TERM  
SURVIVORS OF CHILDHOOD CANCER



Hi! Thanks for filling out this questionnaire.

There are no "right" or "wrong" answers, so just answer the questions as best you can.



**FIRST WE HAVE SOME QUESTIONS ABOUT YOUR SON/DAUGHTER WHO WAS DIAGNOSED WITH CANCER. YOUR KNOWLEDGE AND VIEWS OF YOUR CHILD'S EXPERIENCE ARE VERY IMPORTANT.**

1. a. What was your child's diagnosis? \_\_\_\_\_
- b. When was he/she diagnosed? month \_\_\_\_\_ year \_\_\_\_\_
2. a. **Right now** does he/she have any permanent after effects from treatment? no yes
- b. If you checked YES, what are they? \_\_\_\_\_
- c. If you checked YES, how much do the after effects **still** interfere with her/his daily activities?
  - a lot some a little none

3. Everyone has worries, but some young people who have had cancer sometimes have special worries. Please check the box that best expresses **how often your child who had cancer currently worries** about **each** of these things. (This question asks you to rate your child's level of worry, not your own; we will ask you about your own worries later.) Please check one box for each row.

My child who had cancer worries about...	A lot	Some	A little	Never
a. having a relapse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. getting a cold or the flu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. doing well in school (or at work)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. having another cancer when she/he is older	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. dying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. whether he/she can have children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. her/his children getting cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. losing friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. getting medical or life insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. the effects of the illness on her/his brothers/sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. if he/she is as healthy as other people his/her age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. my own health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. a. Some ways of dealing with problems work better than others. In general, how well has your son/daughter handled his/her illness? very well fairly well not well

b. What has he/she handled **well**? \_\_\_\_\_

c. What has he/she handled **less well**? \_\_\_\_\_

5. Some parents feel that their son/daughter is different from other young people their age as a result of their experience with cancer. Other parents feel that their child with cancer is no different from other young people his/her age.

a. Do you feel your son/daughter is different from other young people because of her/his experience with cancer?

yes no

b. If YES, in what ways is he/she different from other young people his/her age? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**NOW WE HAVE SOME QUESTIONS ABOUT YOUR OWN VIEWS AND EXPERIENCES**

6. Please check the box that best expresses YOUR views or feelings about your child who had cancer.

	Strongly agree	Agree	Disagree	Strongly disagree
a. He/she is angry that his/her life was disrupted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Having cancer made him/her different from others his/her age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. He/she is a happy person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. He/she feels lonely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. He/she feels comfortable dating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. He/she expects to have a good and full life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. He/she knows what is important in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. He/she doesn't want others to know about his/her cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. He/she doesn't fit in with his/her old friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. He/she feels good about himself/herself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. There are things about his/her illness he/she does not tell me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. He/she is behind former classmates in school	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. The school system helped him/her a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. a. Many parents report that their son's/daughter's cancer has affected family finances. As a result of the illness have you had to make adjustments in your standard of living? yes no

If YES, for instance, how: \_\_\_\_\_

b. Has your son/daughter's cancer negatively affected your job possibilities? yes no

c. Have you ever been refused a job or promotion because of your son/daughter's cancer history? yes no

If YES, were you told directly that your child's cancer history was the reason, or did you just figure it out?

told directly figured it out myself

8. a. Since your son's/daughter's diagnosis have you ever had difficulty getting or keeping health insurance for your entire family? yes no

b. If YES, what kind of difficulty? \_\_\_\_\_

c. Does your entire family have health insurance now? yes no

If YES, what kind of insurance? group individual HMO/managed care Medicaid/Medicare

9. Have you ever had difficulty getting life insurance for your child who was diagnosed with cancer?

yes no never tried

10. Parents of young people who have had cancer sometimes have special worries about their child. Please check the box that best expresses how much YOU currently worry about each of these things about your child who had cancer. Check one box for each row.

I worry about...	A lot	Some	A little	Never
a. my son/daughter having a relapse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. my son/daughter doing well in school (or at work)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. my child having another cancer when she/he is older	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. my child dying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. whether my son/daughter can have children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. my son/daughter's children getting cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. how my child's body looks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. my son/daughter getting medical or life insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. the effects of the illness on my other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. if my child is as healthy as other people his/her age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. whether my son/daughter will be well adjusted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. my son/daughter's self-esteem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**NOW WE HAVE SOME QUESTIONS ABOUT YOUR OWN VIEWS AND EXPERIENCES**

6. Please check the box that best expresses YOUR views or feelings about your child who had cancer.

	Strongly agree	Agree	Disagree	Strongly disagree
a. He/she is angry that his/her life was disrupted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Having cancer made him/her different from others his/her age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. He/she is a happy person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. He/she feels lonely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. He/she feels comfortable dating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. He/she expects to have a good and full life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. He/she knows what is important in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. He/she doesn't want others to know about his/her cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. He/she doesn't fit in with his/her old friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. He/she feels good about himself/herself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. There are things about his/her illness he/she does not tell me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. He/she is behind former classmates in school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. The school system helped him/her a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. a. Many parents report that their son's/daughter's cancer has affected family finances. As a result of the illness have you had to make adjustments in your standard of living? yes no

If YES, for instance, how: \_\_\_\_\_

b. Has your son/daughter's cancer negatively affected your job possibilities? yes no

c. Have you ever been refused a job or promotion because of your son/daughter's cancer history? yes no

If YES, were you told directly that your child's cancer history was the reason, or did you just figure it out?

told directly figured it out myself

8. a. Since your son's/daughter's diagnosis have you ever had difficulty getting or keeping health insurance for your entire family? yes no

b. If YES, what kind of difficulty? \_\_\_\_\_

c. Does your entire family have health insurance now? yes no

If YES, what kind of insurance? group individual HMO/managed care Medicaid/Medicare

9. Have you ever had difficulty getting life insurance for your child who was diagnosed with cancer?

yes no never tried

10. Parents of young people who have had cancer sometimes have special worries about their child. Please check the box that best expresses how much YOU currently worry about each of these things about your child who had cancer. Check one box for each row.

I worry about...	A lot	Some	A little	Never
a. my son/daughter having a relapse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. my son/daughter doing well in school (or at work)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. my child having another cancer when she/he is older	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. my child dying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. whether my son/daughter can have children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. my son/daughter's children getting cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. how my child's body looks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. my son/daughter getting medical or life insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. the effects of the illness on my other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. if my child is as healthy as other people his/her age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. whether my son/daughter will be well adjusted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. my son/daughter's self-esteem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. Please check the box that best expresses your own views or feelings about things in your own life.

	Strongly agree	Agree	Disagree	Strongly disagree
a. I am angry that my life was disrupted by my child's cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I think I know what is important in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I don't want others to know about my child's cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. There are things about my child's illness that I did not tell him/her	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I feel uncertain about the future of my child who had cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I treat my child who had cancer differently than my other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I am sad that my son/daughter had to go through this	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. I worry about my own health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Having a child with cancer has had a negative impact on my relationship with my spouse/partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. My relationships with my old friends have changed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. My spouse/partner deals with my child differently than I do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. Think back to the time your son/daughter went off treatment:

- a. At that time how worried were you about the cancer returning?  
very worried      a little worried      not worried
- b. What was the hardest part of his/her going off treatment?

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13. Some people say that their experience with their child's illness left them with a sense of growth or positive change in their lives, while others report a sense of loss or negative change. Please check the appropriate column to indicate whether each aspect of your life has gotten worse since before your child was diagnosed, stayed about the same, or has gotten better.

	Worse	Same	Better
a. my physical health compared with others my age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. my mental health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. my spiritual well being	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. my sense of personal control over my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. my willingness to join with others to change things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. my concern for others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. my sense of what I as an individual can do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. my sense of who I am.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. my family relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. my relationships with friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. my ability to cope with tragedy/crisis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. my relationship with my spouse/partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. my belief in God	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. my involvement in community activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. Did any of the following things happen to you since your child was diagnosed with cancer? Please check YES or NO for each item.

	Yes	No
a. Loss of my job	<input type="checkbox"/>	<input type="checkbox"/>
b. Major change in my job	<input type="checkbox"/>	<input type="checkbox"/>
c. Birth of another child	<input type="checkbox"/>	<input type="checkbox"/>
d. Birth of a grandchild	<input type="checkbox"/>	<input type="checkbox"/>
e. Serious illness of another family member	<input type="checkbox"/>	<input type="checkbox"/>
f. Death of an immediate family member	<input type="checkbox"/>	<input type="checkbox"/>
g. Death of one of my parents	<input type="checkbox"/>	<input type="checkbox"/>
h. Problems with the behavior of my other children	<input type="checkbox"/>	<input type="checkbox"/>
i. Separation or divorce from my spouse/partner	<input type="checkbox"/>	<input type="checkbox"/>



15. a. How would you rate your own health currently?  
 Excellent     Very Good     Fair     Poor

b. And how would you rate your spouse's/partner's health currently?  
 Excellent     Very Good     Fair     Poor     Not applicable

16. We are interested in what kinds of information and counseling services you have used, and if you would like to use more of those services (or others) in the future. Please check the appropriate boxes below to indicate which services you have used, and which you would like to use in the future. Check only one column for each item.

	Have used & have no further need	Have used & would like to use more	Have not used but would like to	Have not used & have no need
a. Advice about my child's education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Career information for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Information on my child's illness/treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Information about health insurance for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Counseling for my son/daughter who had cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Legal advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Psychological counseling for myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Information about diet and nutrition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Financial assistance for our family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Meet with other parents of young people with cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Counseling for my worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Assistance in handling my own stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Counseling for my other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Information on the Americans with Disabilities Act	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Information about the chances of my other children getting cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. a. How old are you? \_\_\_\_\_  
 b. What is your gender?     female     male  
 c. Did you complete high school?     yes     no  
 d. How many years (if any) of college did you complete? \_\_\_\_\_

18. a. What kind of job do you have? (Be specific about the kind of work you do.) \_\_\_\_\_  
 \_\_\_\_\_  
 Is your job full-time or part-time?     Full-time     Part-time  
 b. What kind of job does your spouse/partner have? (Be specific about the kind of work she/he does.) \_\_\_\_\_  
 \_\_\_\_\_  
 Is this job full-time or part-time?     Full-time     Part-time

19. What is your family's approximate yearly income?  
 less than \$15,000     between \$25,001 and \$40,000     between \$60,001 and \$80,000  
 between \$15,000 and \$25,000     between \$40,001 and \$60,000     over \$80,000

20. How many children do you have? \_\_\_\_\_  
 Please list their ages \_\_\_\_\_

21. What is your relationship to the child with cancer?     Parent     Step-parent  
 Other relation (Please explain: \_\_\_\_\_)

15. a. How would you rate your own health currently?  
 Excellent     Very Good     Fair     Poor

b. And how would you rate your spouse's/partner's health currently?  
 Excellent     Very Good     Fair     Poor     Not applicable

16. We are interested in what kinds of information and counseling services you have used, and if you would like to use more of those services (or others) in the future. Please check the appropriate boxes below to indicate which services you have used, and which you would like to use in the future. Check only one column for each item.

	Have used & have no further need	Have used & would like to use more	Have not used but would like to	Have not used & have no need
a. Advice about my child's education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Career information for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Information on my child's illness/treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Information about health insurance for my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Counseling for my son/daughter who had cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Legal advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Psychological counseling for myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Information about diet and nutrition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Financial assistance for our family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Meet with other parents of young people with cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Counseling for my worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Assistance in handling my own stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Counseling for my other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Information on the Americans with Disabilities Act	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Information about the chances of my other children getting cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. a. How old are you? \_\_\_\_\_  
 b. What is your gender?     female     male  
 c. Did you complete high school?     yes     no  
 d. How many years (if any) of college did you complete? \_\_\_\_\_

18. a. What kind of job do you have? (Be specific about the kind of work you do.) \_\_\_\_\_  
 \_\_\_\_\_  
 Is your job full-time or part-time?     Full-time     Part-time  
 b. What kind of job does your spouse/partner have? (Be specific about the kind of work she/he does.) \_\_\_\_\_  
 \_\_\_\_\_  
 Is this job full-time or part-time?     Full-time     Part-time

19. What is your family's approximate yearly income?  
 less than \$15,000     between \$25,001 and \$40,000     between \$60,001 and \$80,000  
 between \$15,000 and \$25,000     between \$40,001 and \$60,000     over \$80,000

20. How many children do you have? \_\_\_\_\_  
 Please list their ages \_\_\_\_\_

21. What is your relationship to the child with cancer?     Parent     Step-parent  
 Other relation (Please explain: \_\_\_\_\_)

22. a. What is your current marital status?  
 married                       never married                       divorced and remarried  
 in a long-term relationship                       separated or divorced and now single
- b. Is your current spouse/partner the mother/father of the child who had cancer?                       yes                       no

23. a. What is your religious preference? \_\_\_\_\_
- b. How often do you attend religious services?  
 more than once a week                       about once a month                       never  
 once a week                       less than once a month

24. What is your race or ethnic background?  
 White                       Asian American  
 Black / African American                       Native American  
 Hispanic / Latino                       Other (please specify) \_\_\_\_\_

25. a. Are you interested in meeting other parents of young people with cancer who are off treatment?  
 yes                       no
- b. As part of this research project, some of the parents who return this questionnaire will also have an opportunity to be interviewed. Would you like to be contacted to hear more about these interviews, and perhaps participate in one?  
 yes                       no
- c. Would you like to receive a brief summary of the results of this study?  
 yes                       no

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**IF YOU ANSWERED "YES" TO ANY PART OF QUESTION 25, PLEASE PRINT YOUR NAME, CURRENT ADDRESS, AND TELEPHONE NUMBER SO WE CAN CONTACT YOU. YOUR RESPONSES ON THIS QUESTIONNAIRE WILL STILL REMAIN CONFIDENTIAL.**

Name: \_\_\_\_\_ Address: \_\_\_\_\_  
 Phone: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

 **THANKS SO MUCH FOR YOUR HELP IN FILLING OUT THIS QUESTIONNAIRE!** 

Use the enclosed self-addressed stamped envelope to return your completed questionnaire OR mail it to:

Professor Mark Chesler  
 Center for Research on Social Organization  
 University of Michigan  
 500 S. State Street  
 Ann Arbor, MI 48109-1382

A BRIEF REVIEW OF THE PSYCHOSOCIAL LITERATURE AND OUR RESEARCH  
PLANS/PROGRESS WITH ADOLESCENT/YOUNG ADULT SURVIVORS OF  
CHILDHOOD CANCER\*

Mark A. Chesler  
Margaret Weigers  
Bradley Zebrack  
Kim Trever  
(University of Michigan, USA)  
6/96

Childhood cancer increasingly is a treatable and even curable disease. In terms of years of productive life saved, it is one of the most remarkable examples of the advance of modern high-technology medicine. Now large numbers of long-term survivors of childhood cancer are entering adulthood, with full involvement in workplaces, careers and generative family lives.

Treatment for childhood cancer often is physically painful and debilitating, and frequently produces lasting physical and emotional side effects and late effects. Unfortunately, attention to and improvements in the psychological and social treatment of these long-term survivors has lagged behind advances in biochemical treatment. Partly as a result, teenage and young adult survivors face a variety of psychosocial adjustment problems, ranging from loss of self-esteem and difficulty in peer relationships to discrimination in insurance and employment situations. At the same time, most recent research indicates that, despite these problems, the population of long-term survivors is generally mentally healthy and socially productive. But they are in need of continuing medical monitoring, psychosocial support and information, and social advocacy. Because childhood cancer still is a relatively rare disease (despite being the number one disease-related killer of children under 14 years of age) it has been hard to marshal and provide psychosocial information and support to such a relatively small (relative to survivors of adult cancers), diverse (in medical and demographic terms), widely dispersed and mobile population.

Background and literature

Three decades ago childhood cancer was a largely fatal disease. Childhood cancers are still chronic and life-threatening, but now with substantial chances for cure. Whereas survivorship was once a medical miracle, it is now increasingly commonplace, and this success has changed both the medical and psychosocial meanings of cancer survivorship for young people and their families. Moreover, as the likelihood and period of survival increases, the long-term physical and psychosocial consequences of childhood cancer and its treatment become increasingly important to address.

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\* In conducting this research we appreciate the collaboration of the Candlelighters Childhood Cancer Foundation, Dr. Stewart Goldman and his colleagues at the UCMC, Dr. Lawrence Boxer and Ms. Marcia Leonard and their colleagues at UMMCH, Ms. Sheryl Sullivan and numerous students, other colleagues, friends and survivors.

By the year 2000, there will be an estimated 200,000 childhood cancer survivors in the United States, and they will include one of every 900 people between the ages of 16 and 44 years (Bleyer, 1990; Rogers, 1992). Each year, of the estimated 7,500 children younger than 15 years of age diagnosed with a malignancy, more than 4,800 will be long-term survivors (Robison, 1993). Survivors of childhood cancer are second only to survivors of breast cancer with respect to the number of years of potential and productive life saved (Bleyer, 1990).

The coordinated use of surgery, radiation therapy, and combination chemotherapy has also produced a significant number of long-term physical and psychosocial side effects that affect long-term survivors' quality of life (Neglia & Nesbit, 1993). The need to identify risk factors for the potential occurrence of relapses and second cancers, and to develop biomedical and psychosocial interventions to reduce side effects and improve quality of life, are important objectives for patient care and monitoring of cancer survivors.

#### Physical late/side effects and risks for second cancers

Research on the physical side effects and late effects of childhood cancer and its treatment has exploded within the past 5 years, with small studies emanating from most major childhood cancer treatment centers as well as large studies from multi-site coordinating research operations (a number of these studies are collected and synthesized in Green, 1989; Green & D'Angio, 1992). One of the lingering effects of childhood cancer and its treatment, even beyond the 5-year survival mark, is an increased risk of death at an early age (Nicholson et al., 1994). In a study of 2,319 adults who had survived childhood cancer for at least five years, 292 deaths occurred (13%). The greatest number of these deaths were caused by illnesses resulting directly from the primary malignancy or from acute complications of therapy (Nicholson et al., 1994). The second most common cause of death for this group included second cancers, and many other deaths were related to cancer therapies, especially radiation and alkylating agents (Meadows et al., 1989; Nicholson et al., 1994). Childhood cancer survivors have a much greater likelihood of developing another cancer compared with individuals their age who have not had cancer (Rogers, 1992), and the risk of second cancers 20 years after surviving childhood cancer has been estimated to be approximately 8-9% (Tucker et al., 1984).

Childhood cancer is, of course, a broad family of specific diseases, and markedly different risks exist when the primary diagnosis and treatment are considered: among children with hereditary retinoblastoma, for example, approximately 30% or more will have a second malignancy during adolescence or adult life (Tucker et al., 1987), whereas the cumulative risk of a second malignancy is estimated at 2.5-8% at 15 years after diagnosis for survivors of acute lymphocytic leukemia (Neglia et al., 1991; Pratt et al., 1988). Many other studies identify the impact of treatments on late physical and biomedical sequelae involving: (1) numerous organ systems (Neglia and Nesbit, 1993), (2) fertility and reproductive systems (Byrne et al., 1987; Byrne et al., 1992), (3) neuro-psychologic problems (Brouwers et al., 1985; Copeland, 1992), (4) cognitive/educational deficits (Bleyer et al., 1990; Jankovic et al., 1994; Meadows et al., 1981; Peckham, 1989; Peckham, 1991), and (5) visible physical impairments (O'Malley et al., 1980; Tebbi and Mallon, 1988).

All these studies suggest the need for long-term follow-up, checkups, monitoring and education of these individuals in order to define and respond to the physical risks and benefits of life-saving therapy.

### Psychosocial effects

Much less research, with much less multi-site coordination, has been undertaken with regard to the psychosocial impact of childhood cancer on survivors and on their life experiences and outlooks. Koocher and O'Malley's (1981) seminal work was the first to document clearly and empirically that survivors of childhood cancer were at increased risk for maladaptive psychosocial sequelae. However, until the 1990s, most of the published medical and psychosocial literature on childhood cancer concentrated on parents and families, and on children in treatment, not on those successfully off-treatment and surviving. With rare exceptions (van Eys, 1977; Koocher & O'Malley, 1981), only recently have clinicians, social scientists, parents and educators begun to focus on the lifetime potentials and problems of the "truly cured child" (see the anthologies edited by Bearison & Mulhern, 1994; Christ & Flomenhaft, 1984). And the current context of survivorship in childhood cancer has changed; what were singular "miracles" in the 1960s, in the 1990s are increasingly commonplace (although none the less miraculous for individual children and their families). Now most children diagnosed with cancer expect to survive, and long-term survivors can see, and exchange experiences with, peers who also have survived this illness.

Recent descriptive studies or commentaries about childhood cancer survivors (Chesler, 1990; Koocher, 1984b; Lansky et al., 1986; Meadows et al., 1993; Ruccione, 1991; van Dongen-Melman et al., 1996a; Zeltzer, 1993) delineate issues still faced by these young people, including worries about physical health status, psychological esteem and identity, welfare of one's immediate family, relating with the social world and being "different", re-integrating with the school system, possibilities for the future (including access to life and health insurance, job and career options, and understanding genetic compromises stemming from treatment), and continued care from a skilled and attentive medical system. A few studies have suggested that younger age at diagnosis, greater elapsed time since diagnosis, and higher socio-economic status are predictors of better psychosocial adjustment (Koocher & O'Malley, 1981; Koocher, 1984a); and van Dongen-Melman and her colleagues suggest that girls also show better adjustment than do boys (1996a).

However, the literature regarding the psychosocial effects of childhood cancer for long-term survivors is fraught with contradictions. For example, whereas one study relying on psychometric measures of psychological adjustment reported that 33% of survivors exhibited clinical evidence of at least a moderate degree of emotional difficulty (Chang et al., 1987; see also Sloper et al., 1994; van Dongen-Melman & Sanders-Woudstra, 1986; van Dongen-Melman et al., 1996a; Zeltzer, 1993), another study utilizing psychometric measures confirmed survivors to be psychologically well-adjusted overall (Gray et al., 1992; see also Arnholt et al., 1993; Fritz et al., 1988; Kazak, 1994; Noll et al., 1993). Indeed, in a comprehensive review of the literature, Kazak (1994) concludes that most LTS function well psychologically and do not have significant problems (see also Li, 1977; Holmes & Holmes, 1979), and that some even have quite positive psychological outcomes -- a statement to their coping abilities and emotional resiliency.

In general, the psychosocial literature on survivors of pediatric cancer suggests that cancer universally alters the way survivors view themselves and that these alterations can be positive or negative and both positive and negative (Smith et al., 1991). Adolescents, in particular, have reported a sense of relief upon completion of therapy but also ambivalence related to perceived loss of social ties (i.e., with other adolescents with cancer, with health care providers who have come to know them, with the health care system), and fears of life without the protective "crutch" of effective treatment (Christ & Adams, 1984; Weeks & Kagan, 1994). The literature also

reflects a general theme wherein survivors report that they feel different from others their own age, in some ways that are negative and in some ways that are positive. For instance, balancing a sense of loss in some physical capacities and interpersonal relationships is an oft-noted feeling of psychological growth and the experience of a "maturing influence of the cancer experience" (Chesler et al., 1992; Moore et al., 1987). Related empirical and epidemiological evidence in the last 30 years indicates that a variety of psychosocial factors that can be manipulated may be associated with positive health outcomes and positive adjustment during and after treatment for long-term survivors of childhood cancer, including: adequate information (Moore et al., 1987), social support (Broadhead et al., 1983; Chesler & Barbarin, 1984; Morrow et al., 1984; Tebbi et al., 1982), open family communication (Barbarin et al., 1985; Chesler & Barbarin, 1987; Spinetta, 1984), empowerment (Price, 1988), and coping style (Barbarin, 1987; Baum & Baum, 1989), and regular medical follow-ups and checkups.

We argue that neither the pessimistic nor the optimistic findings and conclusions in the literature about the psychosocial status and experience of long-term survivors are adequate by themselves. These very disparate findings are products of different scholars' divergent ideologies or theories, research methods, and research foci -- and sometimes their sampling procedures. The story of these young people's lives and adaptations cannot be captured by the simple statement that they experience "higher levels of psychological distress" than a "physically normal" population, or even than their siblings. Moreover, the story is not as simple as saying that this population of survivors is "just the same psychologically" as everyone else, or even that they are "psychologically more healthy or sophisticated" than young people without a cancer history. The reality of this phenomenon is more complex, and this reality is affected by many factors, such as: research methods utilized, sample criteria and inclusiveness, questions asked and not asked, initial diagnosis, treatment plan, age at diagnosis, time of diagnosis (time in the sequence of increasingly successful treatments for childhood cancer in general) and time since diagnosis, as well as personal coping styles, family support, medical support, peer contacts, educational and career opportunities, etc. In all likelihood, then, several stories are grossly true: in comparison to others some long-term survivors probably are more psychologically distressed when assessed by standardized instruments, and a small number are distressed enough to require professional care; when asked for details about themselves and their lives some long-term survivors report being no different from their peers, and especially in intensive interview studies, some survivors even indicate experiencing richer and deeper psychological meaning and direction in their lives. In fact, depending upon the particular aspect of their lives and experiences being queried, any individual survivor may fit within all three groups.

The existence of long-term psychosocial effects suggests the need for: (1) systematic follow-up and study of adult survivors of childhood cancer and (2) development of interventions to reduce the possibility of long-term negative psychosocial effects.

### Social stigma and discrimination

Recent studies have reported LTS' experiences with prior peer groups and social institutions that have received them with less than open arms. Several studies have focused on the difficulties in peer relationships experienced by children with cancer; many of their former peers appear awkward, fearful and distant in the face of myths about cancer survivorship (Katz et al., 1988; Noll et al., 1991). Some early studies discussed the "school phobias" that some children with cancer experienced (Lansky et al., 1975), but later research focuses on the ways in which the

educational system fails to adapt to the special needs of some children with cancer (Barbarin & Chesler, 1983; Deasy-Spinetta, 1993; Deasy-Spinetta & Tarr, 1985). In addition, Hays (1993) documents problems LTS report with regard to employment discrimination and difficulties in gaining health and life insurance (see also Feldman, 1980; Hays et al., 1992; Holmes et al., 1986).

The existence of social stigma and discrimination suggests the need to: (1) inform survivors of childhood cancer about their rights, aid them in combating discrimination, and suggest ways in which they may build more successful peer, school and socio-economic lives and (2) inform educational, employment and insurance agencies about the real productive status of this population, as well as of their legal rights.

### Service needs

In order to continue and complete the care provided to survivors of childhood cancer the service base must be expanded to include the needs and concerns reported by these long-term survivors and the health care providers who see and treat them. Data suggest that survivors indicate several basic kinds of service needs: medical information, supportive counseling, peer support systems, community education and legal advocacy, and linkage to continuing medical services (Chesler, 1990; Christ & Adams, 1984; Hays et al., 1992; Hays, 1993; Meadows et al., 1993; Ruccione, 1991).

These data suggest the need to provide such services in the interest of reducing the impact of late/side effects and improving the psychosocial quality life of long-term survivors (thereby enabling them -- and our society -- to realize their full productive potential).

### A note about research methods and foci

Major distinctions and debates have arisen about the methods used to study long-term survivors' quality of life, life experiences and psychosocial status and outlooks (Spinetta, 1982). Some of the research uses very small sample studies (n=30-50) of psychosocial issues (e.g., Fritz et al., 1988; and see Eiser & Havermans, 1994), and others are large studies commissioned and performed by medical staffs using medical and psychometric data (Zeltzer et al., 1995). Different assessment approaches include the use of psychometric instruments standardized on a "physically normal" population (e.g., Carpenter, 1991; van Dongen-Melman et al., 1996; Zeltzer, 1993) and unique instruments designed explicitly for the survivor population (e.g., Feeney et al., 1992; Goodwin et al., 1994). In addition, most studies gather data via responses to highly structured instruments and questions that only minimally attend to the actual psychosocial experiences and feelings of young survivors, while others utilize both closed and open-ended questions or face-to-face and group interviews that permit/encourage survivors to express their experiences in their own words. More useful and comprehensive research approaches will have to deal directly with some if not all of these methodological debates and distinctions.

Finally, despite a growing literature on the psychosocial experiences of long-term survivors of childhood cancer, relatively few substantial studies exist regarding the families of these young people. Fox (1984), Peck (1979) and Wallace et al. (1987), in small sample studies, and van Dongen-Melman and her colleagues in a unique larger-scale study in The Netherlands (van-Dongen-Melman et al., 1995; 1996a) report continuing parental anxiety and tension about symptoms of relapse -- and these anxieties undoubtedly are communicated to their children. In apparent contrast, Kupst & Schulman (1988) and Spinetta et al. (1988) report generally positive parental coping. Obviously these two sets of findings are not mutually exclusive: greater anxiety



and positive coping may occur at the same time and within the same person or family. But even these few studies draw our attention to the significant and lasting impact that childhood cancer has on parents (Adams & Deveau, 1984; Chesler & Barbarin, 1987; Kristjansen & Ashcroft, 1994; Spinetta & Deasy-Spinetta, 1981), siblings (Carpenter & Levant, 1994; Chesler, Allswede & Barbarin, 1991), and the entire "family system." However, most of the work on families has focused on children and families in treatment, not on what has happened or is happening to them long after treatment has been completed. This is a gap that needs further exploration and response.

### Our prior work and history

In 1978 Chesler and his colleagues began a program of research into the psychosocial aspects of childhood cancer. Our first book on this topic is one of the very few monograph-length empirical studies of the impact of childhood cancer on the family (Chesler & Barbarin, 1987; and see related articles). Our later empirical study exploring the organization, operation and outcomes of self-help and mutual support groups organized by these families is the first research monograph on this topic (Chesler & Chesney, 1995; and see related articles). Our attention turned to long-term survivors when, in 1988, the Candlelighters Childhood Cancer Foundation (CCCF) invited us to conduct a pilot study of the psychosocial experiences and needs of long-term survivors of childhood cancer. We developed a self-report questionnaire to assess this population's experiences, attitudes and service needs. In this initial effort, as in later work, we defined a long-term survivor of childhood cancer as a young person who has successfully completed treatment for this disease (thus off treatment for one day or more, a definition agreed to by Smith et al., 1991; other investigators have used longer post-treatment time periods for their definitions of survivorship). This questionnaire was enclosed in the Foundation's YOUTH NEWSLETTER. Approximately 300 young survivors of childhood cancer (adolescents and young adults between the ages of 14 and 29) responded, constituting at that time one of the largest studies of the psychosocial aspects of long-term survivorship. As part of that study we also administered a slightly modified questionnaire to a comparison sample of 300 high school and college-age young people who did not have a history of childhood cancer.

In contrast to much of the early and prevailing literature predicting widespread incidence of severe psychological problems, the preliminary findings of this study suggested that LTS of childhood cancer, in contrast to the comparison sample: (1) felt they were more often "different from their peers", (2) were more mature psychologically, (3) understood more about what was important to them in life in existential or spiritual terms, and (4) were less afraid of death or minor illnesses. The findings also indicated that long-term survivors experienced a series of special problems (such as discrimination in employment, education and insurance availability), worries (such as fear of recurrence, concerns about fertility, about their children getting cancer, and about their parents' health and finances), as well as a series of resultant service needs.

Table 1 contrasts the responses of these LTS and comparison populations with regard to a series of these "worries." Substantially lesser percentages of the LTS population reported worrying "a lot" or "some" about "dying", "how my body looks", "keeping up in school" and "getting tired" than did the comparison group. But when it came to worries about cancer-specific

issues, such as those in section B of this table, substantially more LTS reported worrying about these issues than did the comparison group.

Table 1: Future Health Concerns/Worries

Worries	CCCF long-term survivors (% "a lot" or "some")	Comparison group (% "a lot" or "some")
<b>A. General Health Worries</b>		
I worry about dying	24	38
I worry about getting a cold or flu	16	21
I worry about how my body looks	57	73
I worry about fitting in with my old friends	26	35
I worry about keeping up in school	52	66
I worry about getting tired	22	36
<b>B. Cancer Specific Worries</b>		
I worry about getting (another) cancer	47	39
I worry about whether I can have children	50	32
I worry about whether my children will get cancer	44	21

Table 2: How I Am Different From Others My Age

Differences	CCCF long-term survivors (%)	Comparison group (%)
Physically healthier	2	5
More mature	28	20
Better social relations	2	8
Clearer existential sense	17	2
I am not different	13	14
No answer	12	42
Physically less healthy	19	3
Less mature	4	3
Poorer social relations	4	4

In addition, seventy seven percent of this LTS population indicated that they felt they were different from their peers (44% strongly agreed with this item) compared with fifty four percent of the comparison population (in which 15% strongly agreed). Table 2 presents a coded tabulation of the open-ended responses wherein members of both populations described the ways in which they were different. Not only did LTS often cite their differences as "more mature", "clearer existential sense" and "physically less healthy", these are the three areas where they in fact did

differ most from the reports of young people without a cancer history. Moreover, the fact that a "negative" difference ("physically less healthy") was reported substantially, as well as the two positive differences, should increase our trust in these self-reports.

These results were so provocative that we sent a brief report of them to a panel of 20 long-term survivors and asked them to help interpret the results. Essentially we asked them whether they thought these results reflected: (a) the reality of their feelings; (b) the denial of uncomfortable feelings; (c) the unconscious suppression of feelings; or (d) the desire to self-present in positive ways, perhaps to avoid stigma. (One example of a positive self-presentation occurred in the case of a young woman who said she always put a lot of rouge on her cheeks whenever she went for a checkup; she felt that if she "looked healthy" her physician would think she was healthy and the test results would confirm it!) Most young people in this panel responded to these inquiries with long and thoughtful essays, in which the overwhelming majority (but not all) said that these results should be believed on their face, that they did represent the reality of LTS' experiences and outlooks. As several survivors suggested:

A cold or flu is nothing compared to how you feel after having chemotherapy.

Because the experience of dealing with cancer can be so profound, the more superficial things in life, such as appearance and fatigue, become less important. However, those things such as procreation and recurrence of illness, which are directly affected by the original diagnosis, would quite naturally take on a more substantial role.

I believe that when people encounter the possibility of death, their focus of concerns begins to narrow in order to deal with the issues which might impact their lives the most.

Not all panelists recommended that we believe the data at face value; one took strong issue with the findings, stating that he "worried about all these things all the time", and several others cautioned against overly simplistic and unidirectional interpretations. Overall, however, it seems clear that a large proportion of LTS have managed to create meaning out of their cancer experience that makes them feel more mature, more psychologically centered, and surer of their life experiences and outlooks than their peers who did not have this experience. This procedure of deriving interpretations of the meaning of informants' reports with their own sense of what is being said, or checking our interpretations with theirs, is called "local theory generation" or "member validation" (Lincoln & Guba, 1985); it does not substitute for scholarly interpretation and theorizing, but enriches that process, and is a very useful technique in social scientific inquiry. It also moves us closer to being able to understand the ways in which informants "make sense" out of their own life experiences, and complements more objective forms of data analysis with these critical subjective (and informant-based rather than solely researcher-based) perspectives.

In spite of the exciting nature of these results, this pilot study had serious limitations. Since the questionnaire was distributed through the CCCF YOUTH NEWSLETTER, there was no way of knowing how many young people between the ages of 14 and 29 had received the questionnaire (thus, no clarity about response rate) and no way of knowing who had decided to return the questionnaire and who had not (thus, no clarity about potential response bias and

representativeness of this sample). As a result, aside from two brief and informal reports (Chesler & Lozowski, 1988; Chesler, Weigers & Lawther, 1992), we have held off publishing the results of this study until we could confirm or disconfirm them with more inclusive and determinative samples. Indeed, given the historic and continuing contradictory findings in the literature, this evidence of the positive self-esteem and mental health of childhood cancer survivors seemed very important to pursue carefully.

In 1993, again with the assistance of the Candlelighters Foundation, we followed up this work with a study conducted with the University of Chicago Medical Center's Wyler Children's Hospital (UCMC). A questionnaire was distributed to their list of long-term survivors of childhood cancer between the ages of 14 and 25, and we received 137 responses (approximately a 70% response rate, excluding deceased and unreachable informants who moved without traceable address or telephone). In addition, the hospital staff provided medical records data on the entire population. Analysis of the medical records data comparing the respondent to the nonrespondent samples, reported in Table 3, indicates that survivors who returned their questionnaires were more likely to have had a more difficult course of treatment than those who did not respond. The respondents also were older, were more likely to have been treated relatively recently, and were less likely to be people of color. Thus, whatever response bias may be present in the UCMC data, it is not a bias toward a more positive and easier time with treatments (except, as noted, for the exclusion of young people diagnosed with brain tumors). We also conducted 20 in-depth personal interviews with a select sample of respondents, and as a result have an extensive set of personal reflections and commentaries which enrich the survey data.

With funding from the Children's Leukemia Foundation of Michigan (CLF-M) we began, in the fall of 1995, a replication of the Chicago study in collaboration with the Pediatric Oncology division of Mott Children's Hospital, the University of Michigan (UMMCH). We drew a random stratified (by diagnosis and socioeconomic and ethnic status) sample of 500 long-term survivors of childhood cancer between the ages of 14 and 25 and mailed a self-report questionnaire to them (oversampling for central nervous system tumors and survivors from zip code areas primarily populated with people of lower incomes and racial minority backgrounds). The effective response rate (again excluding deceased and unreachable/untraceable informants) is above 80%. In addition, the hospital staff is providing medical records data on the entire sample of 500, so we will once again be able to make respondent-nonrespondent comparisons. This spring and summer we will conduct approximately 30 personal face-to-face interviews with selected respondents. Finally, in the fall of 1996 we will generate another "comparison population" by administering a similar but slightly modified questionnaire to a Michigan sample of young people between the ages of 14 and 25 who have not had a history of childhood cancer.

The responses of the UCMC and UMMCH samples to the questionnaire items about "health worries" and "differences", presented in Table 4, are in many ways quite similar to those from the CCCF sample reported above in Tables 1 and 2. (However, the percentages of LTS in the UCMC and UMMCH samples reporting their worries and stating the ways that they "differ from others my age" are in several respects closer to the original comparison group than to the CCCF group: whether this is a function of the time periods involved -- 1988 vs. 1993 and 1995, the demographic structures of the different samples, or some other factor is currently under investigation). Since the respondents in the UCMC study (compared to the non-respondents) were older and treated more recently, and since prior studies have suggested that young people diagnosed at an earlier age and those farthest from treatment date were more likely to be better

adjusted, the positive sense of self indicated in these results probably reflects this population's subjective realities, and does not appear to represent a response bias in favor of those most likely to feel well-adjusted.

Table 3: Selected Comparisons Between Respondents and Non-Respondents in the UCMC Sample of Long-Term Survivors\*

Characteristics	Respondents (n=137, %=100)	Non-respondents (n=114, %=100)
<b>Gender</b>		
Male	49	63
Female	51	37
<b>Age now</b>		
14-19	28	42
19-24	42	33
25-29	21	19
Over 29	9	6
<b>Years off treatment</b>		
Less than 4	24	12
5-9	32	34
10-14	29	39
More than 14	12	9
<b>Prognosis at diagnosis</b>		
Good	69	69
Poor	29	27
<b>Treatment intensity</b>		
Easier than typical	7	12
Typical	53	59
Harder than typical	39	28
<b>Physical difficulties during treatment</b>		
Better than typical	9	7
Typical	47	59
Typical with problems	24	11
Worse than typical	19	4
<b>Lasting physical residua of treatment</b>		
Yes	52	42
No	48	57

\*The organization of the Pediatric Hematology/Oncology service at UCMC resulted in very few children diagnosed with cancers of the brain or central nervous system being treated in that service or included in this sample.

Table 4: "Worries" and "Differences" Reported by the Three Samples of Long-Term Survivors

	CCCF	UCMC	UMMCH
<b>A. General health worries (% "a lot" or "some")</b>			
I worry about dying	24	25	29
I worry about getting a cold or flu	16	17	14
I worry about how my body looks	57	50	58
I worry about fitting in with my old friends	26	23	19
I worry about keeping up in school	52	43	60
I worry about getting tired	22	26	30
<b>B. Cancer-specific worries (% "a lot" or "some")</b>			
I worry about getting (another) cancer	47	45	42
I worry about whether I can have children	50	43	43
I worry about whether my children will get cancer	44	47	44
<b>C. How I am different from others my age (%)</b>			
Physically healthier	2	3	1
More mature	28	19	22
Better social relations	2	2	1
Clearer existential sense	17	12	10
I am not different	13	8	3
No answer	12	26	52
Physically less healthy	19	23	9
Less mature	4	5	1
Poorer social relations	4	2	1

In addition, Table 5 presents some results from the CCCF, UCMC and UMMCH studies about the service needs reported by these long-term survivor populations. The representativeness of all these samples is somewhat limited, but the clear and repeated evidence of specific needs for information -- both medical and lifestyle -- and for psychosocial support is compelling.

The general analytic frame we are using in these studies is presented in Figure A. This frame will permit us to examine differences and similarities between populations of adolescent and young adult long-term survivors of childhood cancer and populations of similar-age young people without such a disease history. It also will permit us to examine a variety of factors that potentially distinguish among various segments of the long-term survivor population: age, gender, socio-economic status, diagnosis, time since diagnosis and treatment cessation, side effects, etc. In addition, we are analyzing the personal interviews using inductive techniques consistent with the principles of grounded theory development (Charmaz, 1983; Chesler, 1987; Glaser & Strauss,

Table 5: Services I Would Like To Use

	CCCF (%)	UCMC (%)	UMMCH (%)
1. Information about illness and treatment	21	37	44
Information about diet and nutrition	24	35	43
2. Information about family planning	35	28	18
Information about genetics	42	29	x
3. Counseling to help me cope	21	20	15
Counseling to deal with worries	24	28	21
4. Assistance with career planning	42	49	58
Assistance with school decisions	14	30	29
5. Information about health insurance	x	43	41
Help with job problems	x	22	x
Legal advice	x	22	17
6. Meet other young cancer survivors	46	41	43

x = Items not included in this version of the questionnaire.

1967). This second approach uses a different analytic frame, one focused on discovery and interpretation of the meaning systems employed by long-term survivors as they report on and contemplate their experiences, concerns, advice and future plans. The triangulation of findings from these different types of data and methods of analysis should provide a rich base for theory development and service recommendations.

Unfortunately, the resources available to us do not permit inquiry into a vital and obvious set of related issues: how do family members (especially parents and siblings) of long-term survivors experience and respond to this situation. Van Dongen-Melman and her colleagues have made an impressive start on this broader agenda (van Dongen-Melman, 1995; 1996b, 1996c).

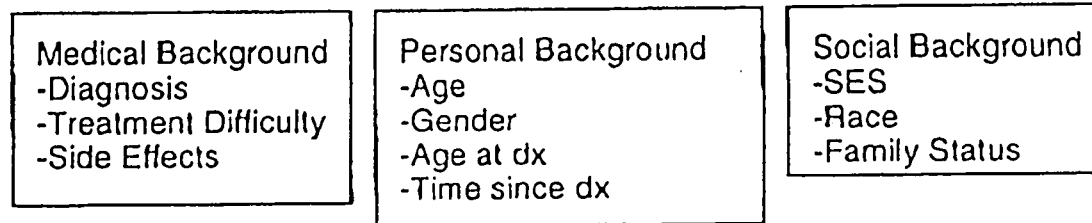
The complete analysis of the UMMCH study, buttressed by the Chicago-UCMC data and the Candlelighters pilot study, will provide us with extensive data on the experiences, outlooks and psychosocial needs of long-term survivors of childhood cancer. They set the stage for interventions that may help these survivors continue to adapt to their lives, attain their life goals, meet their psychosocial and service needs, engage in positive (anti-cancer) health behaviors, and take steps to prevent (to the extent possible) second malignancies. They can be used, especially, by the Candlelighters Childhood Cancer Foundation and other agencies to better serve this population, and to encourage other medical, governmental and private agencies to respond more emphatically to the need for preventive, follow-up and ameliorative care.

As in our prior research (Chesler & Barbarin, 1986; Chesler & Chesney, 1995), to the extent logistically possible our studies have a participatory cast; we involve representatives of the informant population (and advocacy groups formed by/for them) in the design of the research and the interpretation of the findings. They also have an action research orientation; our goals and personal roles extend beyond the production of knowledge to its use in improving services or information available to young people and their families, and in reforming and improving relevant medical care and social policies/programs.

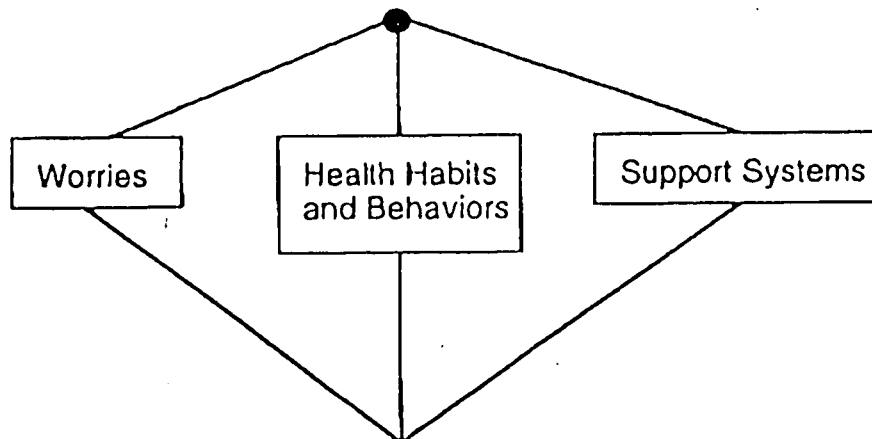
# FIGURE A

## NEEDS ASSESSMENT ANALYTIC PATHS

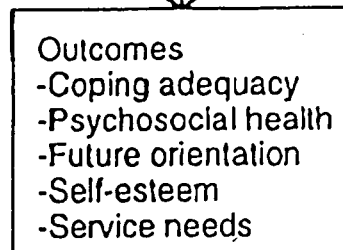
**Independent Variables**



**Intervening Variables**



**Dependent Variables**





### A note about the research staff

It is important to emphasize the unique "insider" status of some of the staff on this work. Chesler is a parent of a long-term survivor of childhood cancer (as well as the parent of a sibling of this survivor) and Brad Zebrack is a survivor of cancer as a young adult. And all these research efforts have had the assistance of undergraduate or graduate students in sociology or psychology who themselves are long-term survivors of childhood cancer (Tim Lawther, Sheryl Lozowski, Jessica Roberts and Brad Zebrack), as well as others who have not had this experience. This combination of "insider" as well as "outsider" perspectives does not guarantee the validity of this work, any more than does a more distant observer status, but it does help in guiding questions and interpretations, and gaining rapport for follow-up work, communication with, the delivery of services to, and collaboration in advocacy with the long-term survivor population.

## References

- Adams, D., & Deveau, E. **COPING WITH CHILDHOOD CANCER**. Reston, VA., Reston Publishing, 1984.
- Arnholt, U., Fritz, G., Keener, M. Self-concept in survivors of childhood and adolescent cancer. **JOURNAL OF PSYCHOSOCIAL ONCOLOGY**. 1993, 11 (1), 1-16.
- Barbarin, O. Psychosocial risks and invulnerability. **JOURNAL OF PSYCHOSOCIAL ONCOLOGY**. 1987, 5 (4), 25-39.
- Barbarin, O., & Chesler, M. **CHILDREN WITH CANCER: SCHOOL EXPERIENCES AND VIEWS OF PARENTS, EDUCATORS, ADOLESCENTS AND PHYSICIANS**. Oakwood, IL., Eterna Press, 1983.
- Barbarin, O., Hughes, D., Chesler, M. Stress, coping and marital functioning among parents of children with cancer. **JOURNAL OF MARRIAGE AND THE FAMILY**. 1985, 47 (2), 473-480.
- Baum, B., & Baum, E. Psychosocial challenges of childhood cancer. **JOURNAL OF PSYCHOSOCIAL ONCOLOGY**. 1989, 7 (4), 119-130.
- Bearison, D., & Mulhern, R. (Eds.) **PEDIATRIC PSYCHOONCOLOGY**. New York, Oxford University Press, 1994.
- Bleyer, W. The impact of childhood cancer on the United States and the world. **CA**. 1990, 40 (6), 355-367.
- Bleyer, W., Fallovolita, J., Robison, L., et al. Influence of age, sex and concurrent intrathecal methotrexate therapy on intellectual function after cranial radiation during childhood. **PEDIATRIC HEMATOLOGY ONCOLOGY**. 1990, 7, 329-338.
- Broadhead, W., Kaplan, B., James, S. The epidemiologic evidence for a relationship between social support and health. **JOURNAL OF EPIDEMIOLOGY**. 1983, 117 (5), 521-537.
- Brouwers, P., Riccardi, R., Fedio, R., et al. Long-term neuropsychologic sequelae of childhood leukemia. **JOURNAL OF PEDIATRICS**. 1985, 106, 723-728.
- Bryne, J., Fears, T., Gail, M., Pee, D., Connelly, R., Austin, D., Holmes, G., Holmes, F., Latourette, H., Meigs, J., Strong, L., Myers, M., Mulvihill, J. Early menopause in long-term survivors of cancer during adolescence. **AMERICAN JOURNAL OF OBSTETRIC GYNECOLOGY**. 1992, 166, 788-793.
- Bryne, J., Mulvihill, J., Myers, M., Connelly, R., Naughton, M., Krauss, M., et al. Effects of treatment on fertility in long-term survivors of childhood or adolescent cancer. **NEW ENGLAND JOURNAL OF MEDICINE**. 1987, 317, 1315-1321.
- Carpenter, P. Scientific inquiry in childhood cancer psychosocial research. **CANCER**. 1991, 67 (3), 833-838.
- Carpenter, P., & Levant, C. Sibling adaptation to the family crisis of childhood cancer. In Bearison & Mulhern (Eds.) **PEDIATRIC PSYCHOONCOLOGY**. New York, Oxford University Press, 1994.
- Chang, P., Nesbit, M., Youngren, N., Robison, L. Personality characteristics and psychosocial adjustment of long-term survivors of childhood cancer. **JOURNAL OF PSYCHOSOCIAL ONCOLOGY**. 1987, 5 (4), 43-58.
- Charmaz, K. The grounded theory method. In Emerson (Ed.) **CONTEMPORARY FIELD RESEARCH**. Boston, Little Brown, 1983.

- Chesler, M. Surviving childhood cancer. *JOURNAL OF PEDIATRIC ONCOLOGY NURSING*. 1990, 7 (2), 57-59.
- Chesler, M. Professionals' views of the 'dangers' of self-help groups. CRSO Working Paper #345. Ann Arbor, University of Michigan.
- Chesler, M., Allswede, J., Barbarin, O. Voices from the margin. *JOURNAL OF PSYCHOSOCIAL ONCOLOGY*. 1991, 9 (4), 19-42.
- Chesler, M., & Barbarin, O. *CHILDHOOD CANCER AND THE FAMILY*. New York, Brunner/Mazel, 1987.
- Chesler, M., & Barbarin, O. Difficulties of providing help in a crisis. *JOURNAL OF SOCIAL ISSUES*. 1984, 40 (4), 113-134.
- Chesler, M., & Chesney, B. *CANCER & SELF-HELP; BRIDGING THE TROUBLED WATERS OF CHILDHOOD ILLNESS*. Madison, University of Wisconsin Press, 1995.
- Chesler, M., & Lozowski, S. What was hard about going off treatment? *CCCF QUARTERLY NEWSLETTER*. 1988, XII (Summer 2/3) 1-2.
- Chesler, M., Weigers, M., Lawther, T. How am I different? Perspectives of childhood cancer survivors. In Green & D'Angio (Eds.) *LATE EFFECTS OF TREATMENT FOR CHILDHOOD CANCER*. New York, Wiley-Liss, 1992.
- Christ, A., & Flomenhaft, K. (Eds.) *CHILDHOOD CANCER: IMPACT ON THE FAMILY*. New York, Plenum, 1984.
- Christ, G., & Adams, M. Therapeutic strategies at psychosocial crisis points in the treatment of childhood cancer. In Christ & Flomenhaft (Eds.) *CHILDHOOD CANCER: IMPACT ON THE FAMILY*. New York, Plenum, 1984.
- Copeland, D. Neuropsychological and psychosocial effects of childhood leukemia and its treatment. *CA*. 1992, 42, 283-295.
- Deasy-Spinetta, P. School issues and the child with cancer. *CANCER*. 1993, 71 (10), 3261-3264.
- Deasy-Spinetta, P., & Tarr, D. The student with cancer and PL 94-142. *JOURNAL OF PSYCHOSOCIAL ONCOLOGY*. 1985, 3, 97-105.
- Eiser, C., & Havermans, T. Long term social adjustment after treatment for childhood cancer. *ARCHIVES OF DISEASES IN CHILDHOOD*. 1994, 70, 66-70.
- Feeney, D., Furlong, W., Barr, R., Torrance, G., Rosenbaum, P., Weitzman, S. A comprehensive multiattribute system for classifying the health status of survivors of childhood cancer. *JOURNAL OF CLINICAL ONCOLOGY*. 1992, 10 (6), 923-928.
- Feldman, F. *WORK AND CANCER HEALTH HISTORIES*. Oakland, CA., American Cancer Society, 1980.
- Fox, B. Discussion: Not easily forgotten. In Christ & Flomenhaft (Eds.) *CHILDHOOD CANCER: IMPACT ON THE FAMILY*. New York, Plenum, 1984.
- Fritz, G., Williams, J., Amylon, M. After treatment ends: Psychosocial sequelae in pediatric oncology. *AMERICAN JOURNAL OF ORTHOPSYCHIATRY*. 1988, 58, 552-561.
- Glaser, B., & Strauss, A. *THE DISCOVERY OF GROUNDED THEORY*. Chicago, Aldine, 1967.
- Goodwin, D., Boggs, S., Graham-Poole, J. Development and validation of the pediatric oncology quality of life scale. *PSYCHOLOGICAL ASSESSMENT*. 1994, 6, 321-328.
- Gray, R., Doan, B., Shermer, P., Fitzgerald, A., Berry, M., Jenkin, D., Doherty, M. Psychologic adaptation of survivors of childhood cancer. *CANCER*. 1992, 70 (11), 2713-2721.

- Green, D. (Ed.) **LONG-TERM COMPLICATIONS OF THERAPY FOR CANCER IN CHILDHOOD AND ADOLESCENCE**. Baltimore, Johns Hopkins University Press, 1989.
- Green, D., & D'Angio, G. (Eds.) **LATE EFFECTS OF TREATMENT FOR CHILDHOOD CANCER**. New York, John Wiley & Sons, 1992.
- Hays, D. Adult survivors of childhood cancer. *CANCER*. 1993, 71, 3306-3309.
- Hays, D., Landsverk, J., Ruccione, K., Schoonover, D., Zilber, S., Siegel, S. Employment problems and workplace experiences of childhood cancer survivors. In Green & D'Angio (Eds.) **LATE EFFECTS OF TREATMENT FOR CHILDHOOD CANCER**. New York, John Wiley & Sons, 1992.
- Holmes, G., Baker, A., Hassanein, R., Bovee, E., Mulvihill, J., Myers, H. The availability of insurance to long-term survivors of childhood cancer. *CANCER*. 1986, 57, 190-193.
- Holmes, H., & Holmes, F. After ten years what are the handicaps and life style of children treated for cancer. *CLINICAL PEDIATRICS*. 1979, 14, 819-823.
- Jankovic, M., Bouwers, P., Valsecchi, M., van Veldhuizen, A., Huisman, J., Kamphuis, R., Kingma, A., Mor, W., van Dongen-Melman, J., Verronato, L., et al. Association of 1800 cGy cranial irradiation with intellectual function on children with acute lymphoblastic leukemia. *LANCET*. 1994, 344 (8917), 224-227.
- Katz, E., Rubinstein, C., Hubert, C., Blew, A. School and social reintegration of children with cancer. *JOURNAL OF PSYCHOSOCIAL ONCOLOGY*. 1988, 6, 123-140.
- Kazak, A. Implications of survival: Pediatric oncology patients and their families. In Bearison & Mulhern (Eds.) **PEDIATRIC PSYCHOONCOLOGY**. New York, Oxford University Press, 1994.
- Koocher, G. Coping with survivorship in childhood cancer: Family problems. In Christ & Flomenhaft (Eds.) **CHILDHOOD CANCER: IMPACT ON THE FAMILY**. New York, Plenum, 1984a.
- Koocher, G. Discussion: The crises of survival. In Christ & Flomenhaft (Eds.) **CHILDHOOD CANCER: IMPACT ON THE FAMILY**. New York, Plenum, 1984b.
- Koocher, G., & O'Malley, J. **THE DAMOCLES SYNDROME**. New York, McGraw Hill, 1981.
- Kristjansen, L., & Ashcroft, T. The family's cancer journey. *CANCER NURSING*. 1994, 17 (1), 1-17.
- Kupst, M., & Schulman, J. Long-term coping with pediatric leukemia. *JOURNAL OF PEDIATRIC PSYCHOLOGY*. 1988, 13, 7-22.
- Lansky, S., List, M., Retter-Setter, C. Psychosocial consequences of cure. *CANCER*. 1986, 58, 529-533.
- Lansky, S., Lowman, J., Vats, T., Gulay, J. School phobia in children with malignancies. *AMERICAN JOURNAL OF DISABLED CHILDREN*. 1975, 129, 42-48.
- Li, F. Follow up of survivors of childhood cancer. *CANCER*. 1977, 39, 1776-1778.
- Meadows, A., Black, B., Nesbit, M., Strong, L., Nicholson, S., Green, D., Hays, D., Lozowski, S. Long-term survival: clinical care, research and education. *CANCER*. 1993, 71 (10), 3213-3215.
- Meadows, A., Gordon, J., Massari, D., Littman, P., Fergusson, J., Moss, K. Declines in IQ scores and cognitive dysfunctions in children with acute leukemia treated with cranial irradiation. *LANCET*. 1981, 2, 1015-1018.
- Meadows, A., Obringer, A., Marrero, O., Oberlin, O., Robison, L., Fossati-Bellani, F., Green, D., Voute, P., Morris-Jones, P., Greenberg, M., Baum, E., Ruymann, F. Second malignant

- neoplasms following childhood Hodgkins' disease. *MEDICAL PEDIATRIC ONCOLOGY*. 1989, 17, 477-484.
- Moore, I., Glasser, M., Ablin, A. Late psychosocial consequences of childhood cancer. *JOURNAL OF PEDIATRIC NURSING*. 1987, 3 (3), 150-158.
- Morrow, G., Carpenter, P., Hoagland, A. The role of social support in parental adjustment to pediatric cancer. *JOURNAL OF PEDIATRIC PSYCHOLOGY*. 1984, 9 (3), 317-329.
- Neglia, J., Meadows, A., Robison, L., Kim, T., Newton, W., Ruymann, F., Sather, H., Hammond, D. Second neoplasms after acute lymphoblastic leukemia in childhood. *NEW ENGLAND JOURNAL OF MEDICINE*. 1991, 325, 1330-1336.
- Neglia, J., & Nesbit, M. Care and treatment of long-term survivors of childhood cancer. *CANCER*. 1993, 71, 3386-3391.
- Nicholson, S., Fears, T., Bryne, J. Effects of cancer therapy must be followed beyond five-year survival. *CANCER*. 1994, 73, 3094-3102.
- Noll, R., Bukowski, W., Davies, W., Koontz, K., Kulkarni, R. Adjustment in the peer system of adolescents with cancer. *JOURNAL OF PEDIATRIC PSYCHOLOGY*. 1993, 18 (3), 351-364.
- Noll, R., LeRoy, S., Bukowski, W., Rogosch, F., Kulkarni, R. Peer relationships and adjustment of children with cancer. *JOURNAL OF PEDIATRIC PSYCHOLOGY*. 1991, 16, 307-326.
- O'Malley, J., Foster, D., Koocher, G., Slavin, L. Visible physical impairment and psychological adjustment among pediatric cancer survivors. *AMERICAN JOURNAL OF PSYCHIATRY*. 1980, 137, 94-96.
- Peck, B. Effects of childhood cancer on long-term survivors and their families. *BRITISH MEDICAL JOURNAL*. 1979, 1, 1327-1329.
- Peckham, V. Educational deficits in survivors of childhood cancer. *PEDIATRICIAN*. 1991, 18, 25-31.
- Peckham, V. Learning disabilities in long-term survivors of childhood cancer. *INTERNATIONAL DISABILITY STUDIES*. 1989, 5, 313-325.
- Pratt, C., George, S., Haddock, M., Hustu, O., Kun, L., Ochs, J. Second malignant neoplasms in survivors of childhood acute lymphoblastic leukemia. *PEDIATRIC RESEARCH*. 1988, 23, 345A.
- Price, K. Empowering preadolescent and adolescent leukemia patients. *SOCIAL WORK*. 1988, May-June, 275-276.
- Robison, L. Issues in the consideration of intervention strategies in long-term survivors of childhood cancer. *CANCER*. 1993, 71 (10), 3406-3410.
- Rogers, P. Late effects in childhood cancer survivors. *JOURNAL OF PEDIATRIC NURSING*. 1992, 7 (5), 364-365.
- Ruccione, K. Survivorship needs and issues after treatment for childhood cancer. Sixth National Conference on Cancer Nursing, Seattle, 1991.
- Sloper, T., Larcombe, I., Charlton, A. Psychosocial adjustment of five-year survivors of childhood cancer. *JOURNAL OF CANCER EDUCATION*. 1994, 9 (3), 163-169.
- Smith, K., Ostroff, J., Tan, C., Lesko, L. Alterations in self-perceptions among adolescent cancer survivors. *CANCER INVESTIGATION*. 1991, 9 (5), 581-588.
- Spinetta, J. Measurement of family function, communication and cultural effects. *CANCER*. 1984, 53 (supplement), 2330-2337.

- Spinetta, J. Behavioral and psychological research in childhood cancer. *CANCER*. 1982, 50 (9), 1939-1943.
- Spinetta, J., & Deasy-Spinetta, P. (Eds.) *LIVING WITH CHILDHOOD CANCER*. St. Louis, C.V. Mosby, 1981.
- Spinetta, J., Murphy, J., Vik, P., Day, J., Mott, M. Long-term adjustment in families of children with cancer. *JOURNAL OF PSYCHOSOCIAL ONCOLOGY*. 1988, 6, 179-191.
- Tebbi, C., Duberstein, P., Mallon, J. Depression in adolescent cancer patients. *PSYCHOSOCIAL ABSTRACTS*. 1982, 6, 259.
- Tebbi, C., & Mallon, J. Long-term psychosocial outcome among cancer amputees in adolescence and early adulthood. *JOURNAL OF PSYCHOSOCIAL ONCOLOGY*. 1988, 5, 69-82.
- Tucker, M., D'Angio, G., Boice, J., Strong, L., Li, F., Stovall, M. Bone sarcomas linked to radiotherapy and chemotherapy in children. *NEW ENGLAND JOURNAL OF MEDICINE*. 1987, 317, 588-593.
- Tucker, M., Meadows, A., Boice, J., Hoover, R., Fraumeni, J. Cancer risk following treatment of childhood cancer. In Boice & Fraumeni (Eds.) *RADIATION CARCINOGENESIS: EPIDEMIOLOGY AND BIOLOGICAL SIGNIFICANCE*. New York, Raven Press, 1984.
- van Dongen-Melman, J., Pruyn, J., DeGroot, A., Koot, H., Hahlan, K., Verhulst, F. Late psychosocial consequences for parents of children who survived cancer. *JOURNAL OF PEDIATRIC PSYCHOLOGY*. 1995, 20, 567-586.
- van Dongen-Melman, J., Sanders-Woudstra, J. Psychosocial aspects of childhood cancer. *JOURNAL OF CHILD PSYCHOLOGY AND PSYCHIATRY*. 1986, 27 (2), 145-180.
- van Dongen-Melman, J., DeGroot, A., Hahlen, K., Verhulst, F. Potential pitfalls in using illness-specific instruments. *JOURNAL OF PEDIATRIC PSYCHOLOGY*. 1996, 21.
- van Dongen-Melman, J., DeGroot, A., Hahlen, K., Pluijima, E., Verhulst, F. Psychosocial functioning of children surviving cancer during middle childhood. 1996a. (Under review).
- van Dongen-Melman, J., DeGroot, A., Hahlen, K., Verhulst, F. Siblings of childhood cancer survivors: How does this forgotten group of children adapt after cessation of successful cancer therapy? *EUROPEAN JOURNAL OF CANCER*. 1996b.
- van Dongen-Melman, J., van Zuiven, F., Verhulst, F. Experiences of parents of childhood cancer survivors: A qualitative analysis. 1996c (Under review)
- van Eys, J. (Ed.) *THE TRULY CURED CHILD*. Baltimore, University Park Press, 1977.
- Wallace, M., Reiter, P., Pendergrass, T. Parents of long-term survivors of childhood cancer. *ONCOLOGY NURSING FORUM*. 1987, 14, 39-43.
- Weeks, D., & Kagan, S. Adolescents completing cancer therapy. *ONCOLOGY NURSING FORUM*. 1994, 21 (4), 663-670.
- Zeltzer, L. Cancer in adolescents and young adults. *CANCER*. 1993, 71 (10), 3463-3468.
- Zeltzer, L., Weiss, R., Bryne, J., Mills, A., Meadows, A. Psychological outcome in adult survivors of childhood cancer. Presented at XXVII SIOP Meetings, Montevideo, Uruguay. 1995.

## APPENDICES: INSTRUMENTS

(These versions of instruments used in the UMMCH study are slight variations on instruments used in the CCCF and UCMC studies.)

1. Mail survey questionnaire
2. Interview form used for individual and small group interviews
3. Form used to extract data from medical records



# Meeting the Needs of Survivors of Childhood Cancer







Hi! Thanks for filling out this questionnaire.

There are no "right" or "wrong" answers, so just answer the questions as best you can.



1.
  - a. What was your diagnosis? \_\_\_\_\_
  - b. When were you diagnosed? month \_\_\_\_\_ year \_\_\_\_\_
  
2.
  - a. What is your current medical situation? (Check the one box that best describes your situation)
 

<input type="checkbox"/> receiving therapy	<input type="checkbox"/> in remission	<input type="checkbox"/> not sure of situation
<input type="checkbox"/> off all therapy	<input type="checkbox"/> cured	
  - b. When did your treatments stop? Month \_\_\_\_\_ Year \_\_\_\_\_
  
3.
  - a. Right now do you have any permanent after effects from treatment? no yes
  - b. If you checked YES, what are they? \_\_\_\_\_
  - c. If you checked YES, how much do the after effects you still have interfere with your daily activities?
 

<input type="checkbox"/> a lot	<input type="checkbox"/> some	<input type="checkbox"/> a little	<input type="checkbox"/> none
--------------------------------	-------------------------------	-----------------------------------	-------------------------------
  
4. How often do you go to an oncologist or cancer specialist for a checkup?
 

<input type="checkbox"/> more often than once a year	<input type="checkbox"/> once a year	<input type="checkbox"/> less than one time a year	<input type="checkbox"/> never
--	--------------------------------------	--	--------------------------------
  
5. Everyone has worries, but young people who have had cancer sometimes have special worries. Please check the box that best expresses how often you currently worry about each of these things. Check one box for each row.

	A lot	Some	A little	Never
a. having a relapse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. getting a cold or the flu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. doing well in school (or at work)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. how my body looks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. having headaches	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. getting tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. having another cancer when I am older	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. my parents' health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. dying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. whether I can have children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. my children getting cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. losing friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. getting or changing a job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. getting medical or life insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. my parents' finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. having to get more treatments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. the effects of my illness on my brothers/sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. if I am as healthy as other people my age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**QUESTIONS ABOUT THE TIME YOU WERE IN TREATMENT FOR CANCER**

6. Below are things that happened in school to some young people while they were in treatment for cancer. Please check the box that indicates the extent to which each thing happened to you. Check one box for each row.

	A lot	Some	A Little	Never
a. I missed school when I was sick	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I was behind in schoolwork	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I had learning disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I needed extra tutoring or help with my assignments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. my grades were lower than my classmates' grades	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Think about the medical staff at the institution where you received most of your treatment. While you were in treatment how often did you feel the following things? Check one box for each row.

	A lot	Some	A Little	Never
a. I enjoyed seeing the staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. the staff answered all of my questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I made treatment decisions with the staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I wanted more information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I wanted more contact with patients my age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I had to correct "mistakes" the staff made	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. While in treatment, many people seek out support and help from others. Below is a list of people who might have been sources of help. Please check the box that represents how helpful each of these people were for you while you were in treatment. If you had no contact with some of them, check that box.

	Very helpful	Somewhat helpful	A little helpful	Not helpful	No contact
a. my sisters and/or brothers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. social workers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. close friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. my mother	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. my father	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. my grandparents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. classmates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. religious leaders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. school teachers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. psychologist/psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. other young people with cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. While you were in treatment, what did your friends do that was the most helpful? (Please give examples)

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10. While you were in treatment, what did your friends do that was the least helpful? (Please give examples)

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#### QUESTIONS ABOUT GOING OFF TREATMENT

11. Think back to the time you went off treatment:

a. At that time how worried were you about the cancer returning?  
 very worried       a little worried       not worried

b. What was the hardest part of going off treatment?

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**QUESTIONS ABOUT YOUR CURRENT SCHOOL, WORK, AND INSURANCE SITUATION**

12. If you are in school or college **now**, are you at the same grade level or year in school as other people your age?  
yes      no      not in school or college
13. Compared to your participation **before** you got ill, how much do you **now** participate in social activities like clubs, teams, parties, or dances?  
more      the same      less
14. Do you currently have a job?      yes      no  
 If YES, what is your job? (Be specific about the kind of work you do in that job.) \_\_\_\_\_  
 Do you work:      part time      full time
15. a. What kind of job would you like to have in the future? (Be specific about the kind of work you want to do in that job.) \_\_\_\_\_  
 \_\_\_\_\_  
 b. Has your experience with cancer influenced the kind of job you would like to have?    yes      no  
 If YES, how? \_\_\_\_\_  
 \_\_\_\_\_
16. a. Has your cancer **negatively** affected your job possibilities?      yes      no  
 b. Have you ever been refused a job or promotion because of your cancer history?    yes      no  
 If YES, were you told directly that your cancer history was the reason, or did you just figure it out?  
told directly      figured it out myself
17. a. Have you ever had difficulty getting **health** insurance?    yes      no  
 b. Do you have **health** insurance **now**?      yes      no  
 If YES, what kind of insurance?    group      individual      HMO/managed care      Medicaid/Medicare  
 If YES, does it cover a check up by an oncologist?    yes      no      don't know
18. Have you ever had difficulty getting **life** insurance?      yes      no      never tried

**QUESTIONS THAT LOOK BACK OVER YOUR EXPERIENCES**

19. a. Some ways of dealing with problems work better than others. In general, how well have you handled your illness?  
very well      fairly well      not well
- b. What have you handled **well**? \_\_\_\_\_  
 \_\_\_\_\_
- c. What have you handled **less well**? \_\_\_\_\_  
 \_\_\_\_\_
20. Some young people feel that they are different from others their age as a result of their experience with cancer. Other young people feel that they are no different from other young people their age.
- a. Do you feel you are different from other young people your age because of your experience with cancer?  
yes      no
- b. If YES, in what ways are you different from other young people your age? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

21. We are interested in what kinds of information and counseling services you have used, and if you would like to use more of those services (or others) in the future. Please check the appropriate boxes below to indicate which services you have used, and which you would like to use in the future. Check only one column for each item.

	Have used & have no further need	Have used & would like to use more	Have not used but would like to	Have not used & have no need
a. school advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. career information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. information on my illness/treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. legal advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. psychological counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. information about birth control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. information about diet and nutrition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. financial assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. meetings with other young people with cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. counseling for my worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. information about health insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. information on whether I can have children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. assistance in handling stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. counseling for my parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. counseling for my brothers/sisters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. information on the Americans with Disabilities Act	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. information about the chances of my children getting cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

22. Some people say that their experience with an illness left them with a sense of growth or positive change in their lives, while others report a sense of loss or negative change. Please check the appropriate column to indicate whether each aspect of your life has gotten worse since your illness, stayed about the same, or has gotten better.

	Worse	Same	Better
a. my physical health compared with others my age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. my mental health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. my spiritual well being	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. my sense of personal control over my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. my willingness to join with others to change things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. my concern for others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. my sense of what I as an individual can do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. my sense of who I am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. my family relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. my time with friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. my ability to cope with tragedy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23. As a result of cancer and its treatment do you currently have any of the following things? Check all that apply.

- |   |   |
|---|---|
| <input type="checkbox"/> scars or marks on arms or hands (not amputation) | <input type="checkbox"/> limb salvage                               |
| <input type="checkbox"/> scars or marks on torso                          | <input type="checkbox"/> skeletal growth retardation                |
| <input type="checkbox"/> scars or marks on legs or feet (not amputation)  | <input type="checkbox"/> weight gain/loss                           |
| <input type="checkbox"/> scars or marks on face or neck                   | <input type="checkbox"/> energy loss/chronic fatigue                |
| <input type="checkbox"/> facial deformity/asymmetry                       | <input type="checkbox"/> internal organ damage (non-reproductive)   |
| <input type="checkbox"/> permanent hair loss                              | <input type="checkbox"/> reproductive organ damage and/or sterility |
| <input type="checkbox"/> blindness and/or loss of eye                     | <input type="checkbox"/> OTHER _____                                |
| <input type="checkbox"/> amputation of limb                               | <input type="checkbox"/> NONE                                       |
| <input type="checkbox"/> limp and/or irregular gait                       |   |

**QUESTIONS ABOUT YOUR VIEWS ABOUT LIFE**

24. Think about your lifestyle and personal habits and place a check in the appropriate column:

- |  | Yes                      | No                       |
|--|--------------------------|--------------------------|
| a. Do you attend religious services regularly?           | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Do you smoke?   | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Do you drink alcoholic beverages?                     | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Do you exercise regularly?                            | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Do you play competitive sports?                       | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Are your smoking habits different from your friends'? | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Do you take special care to eat a healthy diet?       | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Do you take special care not to get a cold or flu?    | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Do see a doctor on a regular basis?                   | <input type="checkbox"/> | <input type="checkbox"/> |

25. Please check the box that best expresses your views or feelings.

- |  | Strongly agree           | Agree                    | Disagree                 | Strongly disagree        |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| a. I am angry that my life was disrupted                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Having cancer has made me different from others my age      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. I am a happy person   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. I try harder than most of my friends                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. I feel lonely   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. I feel comfortable dating                                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. I believe more in God now than before my illness            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. I often have no interest in things                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. I am in a hurry to get on with my life                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. I expect to have a good and full life                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k. I think I know what is important in life                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l. I am popular  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m. I enjoy taking physical risks                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| n. I am more relaxed than most of my friends                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| o. I feel hopeless about the future                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| p. I don't want others to know about my cancer                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| q. Other young people with cancer make especially good friends | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| r. I don't fit in with my old friends                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| s. I feel good about myself                                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| t. There are things about my illness I do not tell my parents  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**QUESTIONS ABOUT YOU AND YOUR FAMILY**

26. a. How old are you? \_\_\_\_\_
- b. What is your gender? female male
- c. How many years of school have you completed? \_\_\_\_\_ years
- If you have completed high school, what year did you graduate? \_\_\_\_\_
- If you have completed college, what year did you graduate? \_\_\_\_\_
27. a. What kind of job does your father have? (Be specific about the kind of work he does in that job.) \_\_\_\_\_
- \_\_\_\_\_
- b. What kind of job does your mother have? (Be specific about the kind of work she does in that job.) \_\_\_\_\_
- \_\_\_\_\_

28. What is your parents' approximate yearly income?  
 less than \$15,000       between \$26,000 and \$40,000       between \$61,000 and \$80,000  
 between \$16,000 and \$25,000       between \$41,000 and \$60,000       over \$80,000

29. Do you have any brothers or sisters?       yes       no  
If YES, please list their ages \_\_\_\_\_

30. Who do you currently live with? Check all that apply.  
 alone       with parent(s) or step parent(s)  
 with spouse or intimate partner       with brothers/sisters  
 with friend(s) or roommate(s)       other (please specify) \_\_\_\_\_

31. a. What is your current marital status?  
 single       married  
 in a long-term relationship       separated or divorced

b. Do you have any children?       yes       no

32. What is your religious preference? \_\_\_\_\_

33. What is your race or ethnic background?  
 White       Asian American  
 Black / African American       Native American  
 Hispanic / Latino       other (please specify) \_\_\_\_\_

34. a. Are you interested in meeting other young people with cancer who are off treatment?  
 yes       no

b. Shall we add your name to the mailing list for THE PHOENIX (a newsletter for long term survivors of childhood cancer which is published by Candlelighters Childhood Cancer Foundation)?  
 yes       no

c. As part of this research project, some of the young people who return this questionnaire will also have an opportunity to be part of an interview. Would you like to be contacted to hear more about these interviews, and perhaps participate in one?  
 yes       no

d. Would you like to receive a brief summary of the results of this study?  
 yes       no

**IF YOU ANSWERED "YES" TO ANY PART OF QUESTION 34, PLEASE PRINT YOUR NAME, CURRENT ADDRESS, AND TELEPHONE NUMBER SO WE CAN CONTACT YOU. YOUR RESPONSES ON THIS QUESTIONNAIRE WILL STILL REMAIN CONFIDENTIAL.**

Name: \_\_\_\_\_ Address: \_\_\_\_\_  
Phone: \_\_\_\_\_

 **THANKS SO MUCH FOR YOUR HELP IN FILLING OUT THIS QUESTIONNAIRE!** 

Use the enclosed self-addressed stamped envelope to return your completed questionnaire OR mail it to:



Professor Mark Chesler  
Center for Research on Social Organization  
University of Michigan  
500 S. State Street  
Ann Arbor, MI 48109-1382

Interviewer Name: \_\_\_\_\_

Respondent No. \_\_\_\_\_

## **LONG-TERM SURVIVOR STUDY: INDIVIDUAL INTERVIEW**

**PRELIMINARY WORK: INTRODUCE YOURSELF, EXPLAIN THE PURPOSE OF THE INTERVIEW (BETTER SUPPORT FOR YOUNG PEOPLE IN TREATMENT AND FOR LONG TERM SURVIVORS LIKE THEM), GO OVER THE CONSENT FORM (EXPLAINING CONFIDENTIALITY-NOTHING THEY SAY WILL EVER BE LINKED BACK TO THEM, NO ONE AT THE HOSPITAL, OR ANYWHERE ELSE, WILL EVER BE ABLE TO LINK THEIR WORDS BACK TO THEM).**

**1. I'd like to start out by asking you to tell me the story of how you found out you had cancer, as best as you can remember.**

- a. When was that?
- b. What made you go to the doctor in the first place? (What were your first symptoms?)
- c. Who told you the diagnosis?
- d. What kind of cancer was it?
- e. How did you react at the time? (what were you thinking, how did you feel?)
- f. [If they were quite young at the time of dx, or tx]Do most of these stories come from your own memory, or are they stories that you remember from other people telling you about them?

**2. What were the treatments like?**

- a. What was the hardest part of dealing with the treatments? Why?
- b. Were there some parts of treatment that weren't as hard? Why?
- c. Have you ever had a relapse or return of the cancer?
- d. [IF YES]Did that occur while you were on treatments? What did you think when that happened?

**3. What do you remember about going off treatment?**

- a. When was that?
- b. How did you feel at the time? (Relieved, Worried, Thrilled, Scared?)
- c. Did you do anything special when you went off treatment? (Have a party, go bungee-jumping?)

**4. Since you've been off-treatment, have you ever worried that the cancer might come back?**

- a. When do you worry? (or was there one time in particular that you got worried?)
- b. Do you ever worry when you get a cold or the flu?
- c. What about around the anniversary of your diagnosis, or before you go see the doctor? or maybe around special events like holidays or family weddings?
- d. Do you feel that you are cured? Why or why not?
- e. Is your experience with cancer over?

**5. Do you have any side-effects or late-effects of treatment?**

IF "NO" USE PROBE: Well, some people have noticed things that they think might be side effects, but they aren't sure. Have you noticed anything that made you wonder if it could be a side effect? Like what?

- a. Do they interfere with your daily activities? How?
- b. When you are at school, or at work, are they visible to others? How do you feel about that?
- c. How about if you are swimming, or showering in the gym, are they visible to others? [IF YES] Does that bother you?
- d. Have any of your ways of dealing with these side effects changed over time?
- e. Do you go back to the doctor for follow-up check-ups or for treatment of late effects or side effects?

**6. Do your parents still worry about the cancer?**

- a. What exactly do they worry about? (The cancer returning, or the side effects, or what?)
- b. What is it that they do or say about it that lets you know they worry?
- c. How do you feel about that?
- d. Do you have any brothers or sisters? Do they treat you any differently than your siblings?

**7. Are there things you never told your parents about your illness, your experiences with cancer, or your feelings?**

- a. For instance? Why didn't you want to tell them about that?

**8. Were you treated while you were in school?**

- a. Are you in school now?
- b. Are there any special services you receive at school? or are there any special services you feel you need?



**9. Do the people who are your close friends now know about your cancer history?**

- a. At what point in a new friendship do you share your cancer history - if you do?
- b. How has that worked in dating relationships?
- c. Has your cancer history raised problems when dating? **IF RESPONDENT IS MARRIED OR PARTNERED, ASK ABOUT THEIR EXPERIENCES WHEN THEY WERE STILL DATING.**

**10. Cancer presents a lot of challenges and problems for anyone. And often people feel that they handle some of the problems cancer presents better than others.**

- a. In general, what issues or problems have you handled well?
- b. And what issues or problems have you handled not so well?

**11. What kinds of things do you worry about nowadays regarding your cancer history?**

PROBE: (late effects, recurrence, psychological or social problems)

- a. What do you do about them?

**12. With regard to your cancer, what information would you like to know about now?**

**(IF RESPONDENT MENTIONS ANY WORRIES, PROBLEMS OR INFORMATION NEEDS IN #11 OR #12):**

**13. Would you have liked any information, support, or help in dealing with these problems, either in the past or the present?**

- a. [IF YES] What kinds of things [would have been helpful then OR might be helpful now] in dealing with these problems, worries or concerns?

**14. Do you think that you are different from other people your age?**

- a. In what ways?
- b. Are any of these differences related to your experience with cancer? [IF YES] How? Why?
- c. Is there anything else? (for example, socially, or emotionally?)
- d. **BE SURE TO PROBE BOTH POSITIVE AND NEGATIVE DIFFERENCES**

- 15. In an earlier study we did, we asked two groups of young people a series of questions about their worries. In one group were long-term survivors of childhood cancer, and in the other group were young people who did not have a history of childhood cancer. We found that these two groups of young people answered some of the questions about their worries quite differently.**

SHOW CARD WITH RESULTS--READ THE FIRST LINE COMPLETELY, WITH THE PERCENTAGES, AND THEN SAY "SO THE LONG-TERM SURVIVORS SAY THEY WORRY LESS ABOUT DYING." THEN READ THE SECOND AND THIRD LINES IN THE SAME MANNER. THEN SUMMARIZE THE LAST THREE LINES SAYING "AND WHEN WE LOOK AT THESE OTHER QUESTIONS ABOUT FITTING IN WITH OLD FRIENDS KEEPING UP IN SCHOOL, OR GETTING TIRED, THE LONG-TERM SURVIVORS SAY THEY WORRY LESS.

- a. What do you think about these results?
- b. Do you believe what the long term survivors told us? Or could it be that they were denying their real feelings, or maybe just telling us what they think we wanted to hear?

- 16. Here are some other interesting differences in the things long term survivors and young people who had never had cancer told us about their worries.**

SHOW CARD WITH RESULTS AND READ IN SAME MANNER AS PREVIOUS QUESTION

- a. So what do you think about these results?

- 17. Is cancer part of who you are today--part of your identity--or something in the past, something that is not part of who you are today?**

- a. How is your life affected by the fact that cancer (IS OR IS NOT) part of your current identity? Or to ask it another way, what do you do because cancer (IS OR IS NOT) part of your identity that you wouldn't do otherwise?

- 18. With regard to cancer, do you take any kind of special care of yourself? For example, do you eat a special preventative diet, or take care to avoid the sun, or avoid smoking, or anything else?**

- a. Do you think any of these supposedly "good health habits" make a difference? Why or why not?

- 19. Have you ever experienced discrimination or unfair treatment at school or work because of your cancer history?**

- a. [IF YES] Tell me what happened.
- b. What made you think this was because of your cancer history? (Were you told directly, or did you figure it out on your own?)
- c. How did that make you feel?

**20. What about health insurance or life insurance--have you ever had difficulty getting covered?**

- a. Have you or your family ever made a big decision--like whether to move or change jobs--based on how it might affect your health insurance or life insurance?
- b. Can you tell me about that?

**21. If you were asked to give some advice to other young people who have cancer, what would you tell them?**

- a. Any special advice with regard to their parents or families?
- b. Any special advice with regard to doctors or the medical staff?
- c. Any special advice with regard to their friends?

**22. Would you like to meet other long-term survivors of childhood cancer?**

NOTE: IF THEIR CURRENT WORK/SCHOOL SITUATION HAS NOT ALREADY COME OUT IN THE CONVERSATION, ASK NOW, THEN ASK:

**23. So what are your plans for the future?**

- a. Anything else?
- b. What about work? marriage? having kids?

IS THERE ANYTHING ELSE THAT WE SHOULD KNOW?

THEN THANK YOU VERY MUCH. I REALLY APPRECIATE YOU TAKING THE TIME TO TALK WITH ME AND DO THIS INTERVIEW. PLEASE FEEL FREE TO GO BACK TO THE BOARD ROOM WHERE WE MET AND GET YOURSELF SOMETHING ELSE TO EAT OR DRINK, AND BE SURE TO PICK UP YOUR CANDLELIGHTERS T-SHIRT WHILE YOU ARE THERE.

# MEDICAL RECORD DATA REPORTING FORM

Name of person filling out this form: \_\_\_\_\_ Date: \_\_\_\_\_

1. NAME OF PATIENT: \_\_\_\_\_

2. PARENTS' ZIP CODE: \_\_\_\_\_

3. PARENTS' OCCUPATION:

FATHER \_\_\_\_\_

MOTHER \_\_\_\_\_

4. FAMILY INCOME:

<\$10,000

\$11-20,000

\$21-40,000

\$40-60,000

>\$60,000

5. INSURANCE STATUS WHILE IN TREATMENT (check all that apply):

private insurance

Medicaid

Medicare

Crippled Children's

none

6. RACE:

White

Black

Latino

Asian

Native Am.

other \_\_\_\_\_

7. BIRTHDATE: \_\_\_\_\_

8. GENDER:

female

male

9. DATE OF DIAGNOSIS: Month \_\_\_\_\_ Year \_\_\_\_\_

10. DIAGNOSIS: \_\_\_\_\_

STAGE (IF AVAILABLE): \_\_\_\_\_

11. PROGNOSIS FOR THIS DISEASE, AT THIS STAGE, FOR THIS PATIENT:

high risk

intermediate

low risk

12. TREATMENT PROTOCOL:  CCSG  POG NUMBER: \_\_\_\_\_

13. WAS RADIATION INCLUDED IN THIS PROTOCOL?  no  yes

IF "YES", WHAT PART OF BODY WAS IRRADIATED? \_\_\_\_\_

14. WAS SURGERY INCLUDED IN THIS PROTOCOL?  no  yes

IF "YES", WHAT SURGICAL PROCEDURE WAS DONE? \_\_\_\_\_

15. WERE THERE DEPARTURES FROM THE PROTOCOL?  no  yes

IF "YES", WHY WERE DEPARTURES MADE?

\_\_\_\_\_  
\_\_\_\_\_

16. DID THE PATIENT RECEIVE A BONE MARROW TRANSPLANT?  no  yes  
 IF "YES", WHAT WAS THE DATE OF THE BMT? Month \_\_\_\_\_ Year \_\_\_\_\_
17. PATIENT'S DEGREE OF PHYSICAL DIFFICULTY WITH TREATMENT (compared to others with same tx)  
 better than usual  usual  worse than usual
18. DATE OF MOST RECENT APPOINTMENT (for long term check up or other) AT PED. ONCOLOGY :  
 Month \_\_\_\_\_ Year \_\_\_\_\_
19. PERMANENT PHYSICAL RESIDUA POST-CESSATION OF TREATMENT (check all that apply)
- |   |   |
|---|---|
| <input type="checkbox"/> scars or marks on arms or hands (not amputation) | <input type="checkbox"/> limb salvage                               |
| <input type="checkbox"/> scars or marks on torso                          | <input type="checkbox"/> skeletal growth retardation                |
| <input type="checkbox"/> scars or marks on legs or feet (not amputation)  | <input type="checkbox"/> weight gain/loss                           |
| <input type="checkbox"/> scars or marks on face or neck                   | <input type="checkbox"/> energy loss/chronic fatigue                |
| <input type="checkbox"/> facial deformity/asymmetry                       | <input type="checkbox"/> internal organ damage (non-reproductive)   |
| <input type="checkbox"/> permanent hair loss                              | <input type="checkbox"/> reproductive organ damage and/or sterility |
| <input type="checkbox"/> blindness and/or loss of eye                     | <input type="checkbox"/> OTHER _____                                |
| <input type="checkbox"/> amputation of limb                               | <input type="checkbox"/> NONE                                       |
| <input type="checkbox"/> limp and/or irregular gait                       |   |
20. KINDS OF HINDRANCES FOR SCHOOL/WORK CREATED BY PERMANENT PHYSICAL RESIDUA:
- |   |  |
|---|--|
| <input type="checkbox"/> cannot stand for long periods                  | <input type="checkbox"/> needs to use medical equipment outside home |
| <input type="checkbox"/> cannot sit for long periods                    | specify kind of equipment: _____                                     |
| <input type="checkbox"/> lack of fine dexterity (e.g. typing difficult) | _____  |
| <input type="checkbox"/> heavy physical labor/play not possible         | <input type="checkbox"/> OTHER _____                                 |
| <input type="checkbox"/> unable to attend school or work                | <input type="checkbox"/> NO HINDRENCE                                |
21. LONG-TERM COGNITIVE RESIDUA FROM TREATMENT
- has severe learning disabilities (may not reach cognitive capacity of normal adult)  
 has minor learning disabilities (may learn more slowly, or have minor limitations in some cognitive skills)  
 NONE
22. IS THERE ANY EVIDENCE OF LONG TERM POST-TREATMENT EMOTIONAL RESIDUA?  
 no  yes  
 IF "YES", PLEASE EXPLAIN \_\_\_\_\_  
 \_\_\_\_\_
23. HAVE THERE BEEN ANY RELAPSES/REOCCURANCES?  
 no  one relapse/reoccurrence only  more than one relapse/reoccurrence
24. WHAT WAS THE TOTAL NUMBER OF HOSPITAL ADMISSION DURING TREATMENT? \_\_\_\_\_
25. DATE OFF TREATMENT: Month \_\_\_\_\_ Year \_\_\_\_\_