Proposal No: 98-10
Topic: Marriage in Survivors

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Submitted to Publications Committee:	3/15/98
Approved by Publications Committee:	9/23/98
Priority Rating:	2.0

Rizvi, 1998

99-10

TITLE: Marriage in the survivors of childhood cancer: results from the Childhood Cancer Survivor Study.

WORKING GROUP AND INVESTIGATORS:

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BACKGROUND AND RATIONALE:

Marriage in childhood cancer survivors is the culmination of achieving a biologic cure, psychological adaptation to the disease and treatment (1), accomplishment of normal adolescent developmental milestones, and achieving a level of social functioning.

Advances in treatments push the biologic cure of pediatric cancer patients to high levels. The overall five-year survival of children with all malignancies is 72%, with several diagnoses now having survivals of over 90% (2).

As successful therapies emerged so did the long-term physical and physiologic side effects of treatment including growth impairment, neurologic and endocrine dysfunction, cardiac problems, infertility, and the development of secondary malignancies (3-9). These findings continue to emerge (10), and influence psychosocial adaptation (11).

Recognition of the psychological impact of surviving cancer was noted very early (12). Attention to the long term manifestations of childhood cancer and therapy expanded to include the study of psychologic and neuropsychologic effects of these diseases and their therapies (3,4,5,7,11,13-17). These sequelae and the therapies they are related to i.e. CNS irradiation, impact subsequent psychosocial function.

The patient's ability to establish identity and functional independence, separate from parents and to form intimate relationships assure a successful transition from adolescence to adulthood (15,18,19,20-22). Kokkonen described delayed development of adolescent sexual identity/esteem and delayed separation from parents in survivors of childhood cancers. The survivors report their disease made it difficult to meet people (7). Compared to healthy adolescents, childhood cancer survivors showed no difference in social competence, frequency of problem behaviors, or school achievement. They do have more overall distress (15). Transition through adolescent milestones and cancer survivorship was better if the adolescent was in a "balanced" family with good communication between child and parent (16). Some studies suggest that cancer survivors delay marriage (20) and demonstrate less satisfaction with their close personal contacts including partners, family and friends (21) .

Finally, childhood cancer survivors must integrate into society as a participating members attaining educational goals and employment. Assessment of the long-term social functioning in childhood cancer survivors has focused on global adaptation or specific issues such as vocation and insurabilty. (17,23-30).

There are few studies that specifically focus on marriage. The earliest was by Holmes and Holmes published in 1975. They found in patients diagnosed from 1944 to 1963 (median follow-up of 16 years) 60 out of 124 were at one time married. They concluded these survivors adjusted to their diagnoses and treatments and many lived "normal" lives (32). In 1979, Gogan found no significant differences in psychiatric adjustment between childhood cancer survivors that had married and those that did not. Women with physical limitations or visually obvious disabilities married less frequently (33). Other series also noted similar marriage frequency in cancer survivors and control populations (34). Rodrigue demonstrated single adult childhood cancer survivors and those who reported low marital quality, especially males, had more general adjustment and illness-specific adjustment problems than married survivors (35). Green showed marriage rates in cancer survivors were below population norms in both men and women, but similar divorce/separation rates. Age at follow-up was the only variable distinguishing married from unmarried survivors. Age at diagnosis, gender, and diagnosis did not impact marital status, although women may delay marriage. Fifteen percent of the never married survivors stated their disease influenced their decisions regarding marriage, as did eighteen percent of the married survivors. Twenty percent of the divorced survivors cited disease as a factor in their divorce (31). The largest study specifically of marriage was published by Byrne in 1989. It showed that older patients were more likely to be married. Males less than 10 years of age at diagnosis were less likely to be married. Patients, especially males, with brain tumors and Hodgkin's disease were less likely to marry. No specific disease diagnoses had any impact on the marriage rates of the women studied. Men were also found to divorce at a higher rate and to have specific disease associations with CNS tumors and retinoblastoma (36).

Many studies are limited by: (1) small numbers of patients, (2) pre-chemotherapy era time of treatment, (3) over and under-representation of diagnoses depending on the time the study was done and survival of children with these diseases, (4) institutional bias with respect to diagnoses or treatment, (5) exclusion of CNS tumors, deceased patients, or patients who are not in active follow-up, and (6) lack of ethnic diversity.

4. SPECIFIC AIMS/OBJECTIVES/RESEARCH HYPOTHESES.

The goal of this study is to examine the effect of age at diagnosis, age at study, diagnosis, treatment, gender, and ethnic background on marital status in a large number of childhood cancer survivors. The control groups are gender-matched siblings, and the general United States population .

The specific hypotheses are: Childhood cancer survivors in the treatment era from 1970 to 1986, marry, divorce, separate, and are widowed at the same rates as the control populations.

Marriage frequency in patients diagnosed at a young age, when age-adjusted, is not

different from control populations. Marriage frequency of male and female survivors, when age-adjusted, is not different from the control populations. Marriage frequency in different ethnic groups is the same as for ethnic-matched controls.

There will be subpopulations who have more marriage problems, i.e. marry less frequently and divorce or separate more.

Patients with CNS tumors are less likely to be married; those treated with irradiation, having supratentorial tumors, and being younger at diagnosis will have the lowest marriage frequency.

Patients who received very intensive treatment,i.e. bone marrow transplantation are less likely to be married than controls; allogeneic BMT and BMT using TBI, or in patients with prior CNS irradiation will have lower marriage frequency

Patients who have undergone amputations or major pelvic surgeries are less likely to be married.

Patients who received radiation therapy other than CNS are less likely to be married.

(5) Patients with leukemia who received CNS irradiation are less likely to be married than those who were treated without CNS irradiation.

5. ANALYSIS FRAMEWORK:

Outcome of interest (M=married, LAM= living as married,D=divorced, W=widowed, S=separated)
Current marital status add married and living together as married
add divorced and separated together
For analyses in graphs 6-18, use ever married(if you think appropriate)
M+LAM+D+W+S

Subject population
Entire CCSS cohort
Exclude patient with current age < 15 years, for analyses based on current age
Exclude patients married prior to diagnosis of cancer
Exclude patients whose marital status is unknown
Include patients deceased
Gender-matched sibling controls
US age specific population controls
US ethnic specific/age specific population controls

Explanatory variables
Age at diagnosis
Age at study

Diagnosis
Gender
Ethnic group
All CNS tumors do all by AGE AT DX, BY CURRENT AGE AND BY GENDER
CNS tumors - treatment surgery only
CNS tumors - treatment radiation only
CNS tumors - treatment surgery plus radiation
CNS tumors - treatment chemotherapy plus radiation
CNS tumors - treatment chemotherapy plus surgery plus radiation
CNS tumors- treatment chemotherapy alone
CNS tumors- treatment chemotherapy plus surgery
CNS tumors- supratentorial
CNS tumors- infratentorial
CNS tumors- other location
BMT- all by AGE AT DX ,BY CURRENT AGE AND BY GENDER
BMT - TBI
BMT - no-TBI
BMT - allogeneic, plus TBI
BMT - allogeneic, no TBI
BMT - auto, plus TBI
BMT - auto, no TBI
BMT - 20,21,22,23 above, prior CNS radiation
BMT - 20,21,22,23 above, no prior CNS radiation
Amputation present, by current age and gender
Amputation absent, by current age and gender
Major pelvic surgery present, by current age and gender
Major pelvic surgery absent, by current age and gender
ALL-plus CNS irradiation by age at diagnosis, current age and gender
ALL- no CNS irradiation by age at diagnosis, current age and gender

6. SPECIFIC GRAPHS/TABLES:

Also need median ages for categories in each table 1-5

1. Table Marital status at follow-up by age at follow-up

Cohort	:% M+ LAM	%D+S	%W	Sib cntrl:	US pop:
15-17					
18-19					
20-24					
25-29					
30-34					
35-39					
40+					

2. Table Marital status by disease all ages (at follow-up)

Amputation +/-, pelvic surgery +/- by current age and by gender