

Proposal No: 99-03
Topic: Barriers to Long-Term Health Care

Lead CCSS Investigator: Kevin Oeffinger

Collaborators:

Submitted to Publications Committee: 11/1/99

Approved by Publications Committee: 2/1/00

Priority Rating:

CHILDHOOD CANCER SURVIVOR STUDY
Analysis Concept Proposal

1. **TITLE:** Barriers to Long-Term Health Care for Survivors of Childhood Cancer
2. **WORKING GROUP AND INVESTIGATORS:** This proposed study will be within the Epidemiology/Biostatistics Working Group. Proposed investigators will include:

Kevin Oeffinger kevin.oeffinger@email.swmed.edu 214-648-2134

3. **BACKGROUND AND RATIONALE:**

As the population of childhood cancer survivors grows, attention is increasingly being directed to the evaluation and management of late effects or sequelae of treatment. Virtually all organ systems can be affected by either radiation, chemotherapy, or surgery, leading to a wide variety of potential late effects. There is general consensus that survivors of childhood cancer should have long-term follow-up, or as Meadows suggests, "continued surveillance of childhood cancer survivors is good medicine." Ongoing surveillance is considered necessary to optimize the early detection and management of sequelae of treatment and second malignant neoplasms. Bleyer and colleagues recommend lifetime, annual follow-up for all survivors of childhood cancer. In spite of these recommendations, most long-term survivors of childhood cancer are not followed on a regular basis. Preliminary data from the Childhood Cancer Survivor Study show that 51% of about 14,000 responding long-term survivors of childhood cancer had not seen a physician of any type during the previous two years.

Research in non-cancer populations indicates that cultural, sociodemographic, psychosocial, and medical system-related factors may present significant barriers to seeking health and preventive care. Patient, physician, and health care system-related barriers to long-term health care for childhood cancer survivors are poorly understood. Until the potential barriers to regular medical follow-up are defined and understood, strategies for improving the longitudinal care of this population will be inadequate.

Findings of the proposed exploratory study will fill part of this critical gap by developing an explanatory model for predicting characteristics of subgroups of long-term childhood cancer survivors who are not likely to follow-up. The model is based upon research findings of studies investigating the health seeking behavior of general patients and specific subgroups. Additionally, the model examines the independent effects of patient demographic variables and factors unique to the study population.

4. SPECIFIC AIMS/OBJECTIVES/RESEARCH HYPOTHESES:

Specific Aim: Investigate the effect of various factors which may be important barriers to medical follow-up among childhood cancer survivors.

Hypothesis: Survivors from medically underserved populations are less likely to seek medical follow-up.

Hypothesis: Survivors with "highly curable" cancers, such as ALL and Wilms', are less likely to seek cancer related follow-up.

Hypothesis: Survivors living in areas without a long-term survivor program are less likely to seek cancer related follow-up.

5. ANALYSIS FRAMEWORK:

a. Outcome of interest:

Primary outcome: dichotomous variable – medical follow-up within past 2 years

No follow-up = respondents who answered "no" for Question B3

Secondary outcomes:

B4: Follow-up for cancer in past 2 years; dichotomous (yes, no)

B1: See or talk to health care providers in past 2 years; dichotomous (yes, no)

N16: Last time you had a general physical examination (none; <1 year; 1-2; 3-4; ≥ 5 years)

b. Subject population: all CCSS respondents

c. Explanatory variables:

- Age related (age at response to CCSS questionnaire, age at cancer diagnosis, interval between cancer diagnosis and response to CCSS questionnaire)
- Cancer related (cancer type, chemotherapy type/dosage, radiation location and total dosage)
- Gender (A2)
- Race and ethnic group (A4, A4a)
- Religious preference (Q7)
- Marital status (L1-13)
- Medical and life insurance (Q1, Q2, Q3, Q4, Q5, Q6)
- Economic indicators (income [Q8, Q9], current residence [A8, A9])
- Education level (O1, O2, O3, O4)
- Employment history (O5, O6, O7, O8)
- Health and psychosocial measures (self perceived health status [N15], physical activity [N9, N10, N11, N12], pain as a result of cancer [J36], anxiety/fears as a result of cancer [J37])
- Health risk habits (smoking [N1, N2], alcohol use [N3, N4, N5, N6, N7, N8])
- Preventive health behavior (dentist [N17], TSE [N18], BSE [N19])

- Future concerns (future health [R1], ability to have children [R2], developing cancer [R3], ability to get health insurance [R4], ability to get life insurance [R5])
- Presence of long-term survivor program within 100 miles of survivor's residence (available from data from a survey of all POG and CCG institutions [response rate 83%] conducted in January 1997)

d. Specific tables and figures:

- d1. Demographics of CCSS Cohort
- d2. Univariate Analysis: Number/percent of survivors having self-reported medical follow-up within three categories tabulated by each of the explanatory variables listed above.

Categories:

- a. Follow-up with any physician in past 2 years [B2]
 - b. Cancer related follow-up [B4]
 - c. General physical examination [N16]
- d3. Estimate of the Risk: Probability of not seeking medical care (B2, B4, N16) for each explanatory variable determined by unconditional logistic regression. This information will be divided into two to three tables of interest.
 - d4. Explanatory modeling to identify group(s) of variables predictive of lack of general medical follow-up and of cancer related follow-up in specific subpopulations (e.g. sociodemographic, cancer type/treatment, age categories, etc.). This information will be divided into two to three tables based upon subpopulation of interest.

6. **SPECIAL CONSIDERATION**

Resources are available to handle the dataset, analyze the data, and develop the explanatory model at the Division of Cancer Epidemiology and Genetics, National Cancer Institute and UT Southwestern.

PLEASE NOTE: References are available if needed.

THE UNIVERSITY OF TEXAS
SOUTHWESTERN MEDICAL CENTER
AT DALLAS

Department of Family Practice
and Community Medicine

November 1, 1999

Anna Meadows, M.D.
Chair, CCSS Publications Committee
The Children's Hospital of Philadelphia
34th Street and Civic Center Blvd.
Philadelphia, PA 19104

Dear Dr. Meadows,

Enclosed is a proposal for analysis of the CCSS cohort, entitled "Barriers to Long-Term Health Care for Survivors of Childhood Cancer". Thank you for consideration of this proposal.

Best regards,

Kevin C. Oeffinger, M.D.

cc. Les Robison, Ph.D.
CCSS Chair
University of Minnesota
420 Delaware Street SE
Box 422 Mayo
Minneapolis, MN 55455

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