

CHILDHOOD CANCER SURVIVOR STUDY
Analysis Concept Form

Title: Communicating with childhood cancer survivors: An analysis of receiver characteristics and communication content, timing and effects

Working Group and Investigators: The study will be within the Cancer Control/Intervention Working Group. Proposed investigators are:

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Background and Rationale:

One of CCSS' major goals is to help childhood cancer survivors lead active, healthy lives. To do so, survivors must be educated about their cancer diagnosis and treatment, their associated health risks, and methods to reduce cancer-related health risks. In other words, adults who have survived childhood cancer need to know their personal health history, the health risks they may face because of the cancer treatment they received, and what kinds of preventative measures they can take to stay healthy or identify impending health problems. In addition, they need to know how to be strong advocates for their own health and well-being. Achieving these objectives requires effective communication between the CCSS Coordinating Center and cohort members.

Since the beginning of the CCSS project, care has been taken to keep cohort members (or a parent or guardian) involved in the project, aware of Long Term Follow-Up Study progress, and informed about issues potentially of interest to childhood cancer survivors. Periodic newsletters have served as the primary educational tool for the cohort; however, letters from principal investigators, survey questionnaires and the LTFU study Web site—as well as cancer-related content in the mass media--also provide health-related information for study participants. In addition, a 1-800 number, interactive e-mail and space for "Additional Comments" in most LTFU surveys provide cohort members with opportunities for two-way communication with Coordinating Center staff and other individuals connected with the study.

Thirteen newsletters have been published to date: one per year from 1996-2000; two per year from 2001-2004; and one issue so far this year. Decisions about content and the timing of newsletters are made by CCSS Project Director Dr. Ann Mertens with input from the CCSS Education Committee, chaired by Dr. Melissa Hudson, members of the Steering Committee, and the project social worker. Catherine Moen serves as newsletter editor. A list of topics covered in the newsletter can be found in Appendix A.

The LTFU 1-800 number, along with the LTFU Web site, allows cohort members to call the study office free of charge with questions or to request information. These calls are handled by a trained social worker (Christine Jacox), who either provides the information requested or assists survivors in identifying resources to address health issues. Calls to this number increase after LTFU mailings, i.e., surveys and newsletters. A call record has been maintained since 2,000.

The LTFU Web site (www.cancer.umn.edu/ltfu) gives visitors on-line access to all of the newsletters, the Children Oncology Group's LTFU Guidelines, COG's Health Links for survivors, other Web sites of interest, and the University of Minnesota Cancer Center site. It also features an interactive address update function and an e-mail link to the Coordinating Center office. Comprehensive reports that track not just site hits, but page visits, downloads, referring domains, and so on, are generated monthly by the Cancer Center webmaster.

Most LTFU questionnaires provide space for "Additional Comments" to which Coordinating Center staff respond. Comments recorded on returned survey forms are transcribed and saved as computerized text files. Other inquiries, comments and exchanges with cohort members can be tracked through chronological telephone logs, handwritten notes, and files maintained by Ms. Jacox.

Despite these varied communication initiatives, Kadan-Lottick and her colleagues (2002) found that many members of the CCSS cohort lack important knowledge about their diagnosis and treatment. A supplemental telephone interview (n=635) conducted in conjunction with the first five-year follow-up survey found that only 74% of respondents could provide an "accurate general summary" of all of the elements of their cancer history. Notably, not one of the subjects could give an accurate "detailed summary" of diagnosis and treatment therapies. Without such knowledge, it is reasonable to infer that many childhood cancer survivors are unaware of their personal risk for treatment effects as they age. In view of these knowledge deficits, it's not surprising that Yeazel et al. (2004) found that the cancer screening practices of cohort members—even those at high risk for secondary malignancies—were below optimal levels recommended for the general population. The combination of gaps in knowledge and lack of appropriate screening pose a serious challenge for both health care practitioners and patients because they preclude anticipatory, preventive follow-up care.

Coordinating Committee members have incorporated communication-related questions in several LTFU questionnaires to learn more about survivors' information needs, preferences, attitudes and behaviors, but no one has undertaken a systematic analysis of these data. Dr. Mertens and Dr. Hudson designed a feasibility study in 2001 to compare

the effectiveness of two communication approaches—LTFU newsletter alone and newsletter plus insert—to motivate survivors at high-risk for breast cancer, cardiovascular disease and osteoporosis to pursue medical screening. The quasi-experiment involved three high risk groups of survivors, identified by their exposure to specific cancer treatment modalities. Within each group, subjects were randomly assigned to receive either a newsletter that talked about risk factors for all three medical conditions, i.e., breast cancer, heart disease and osteoporosis, or the newsletter plus an insert that provided more comprehensive information about risk factors and recommended behaviors specific to the recipient's diagnosis and treatment. Approximately 12 months later, the sample, along with all cohort members, received the Follow-Up 2 survey which included questions that measured knowledge, attitudes, behaviors and medical follow-up related to the three targeted conditions. The Follow-2 survey also included a series of questions (T.1 – T. 11) specifically related to newsletter readership.

Now, more than 10 years after the CCSS baseline survey, many members of the cohort are young-bordering-on-middle-aged adults whose lives have evolved in countless ways. Whereas little was known about late effects when the LTFU study began, much more is known now. In addition to what they learn from their physicians and CCSS communications, cohort members have access to a steadily-increasing range of media sources (cable television, talk radio, Internet Web sites, etc.) that provide an almost unimaginable amount of information—some of it accurate, some not—about cancer, health insurance and other topics in which they may be interested. The challenge, for LTFU investigators, is to be clear about communication objectives and determine the best ways to achieve them. This study should help inform those judgments.

Specific Aims/Objectives/Research Hypotheses

The proposed study is primarily exploratory and will involve both quantitative and qualitative analysis of existing data sources. Its primary goal is to increase our understanding of what works when it comes to educating and motivating cohort members to take actions that promote their good health and well-being. The study will focus on the following communication-related variables:

- Cohort members' information needs (*what they want to know more about*) and information-seeking behavior (*deliberate action to access information*);
- Format/media channel preferences of cohort members;
- Survivors' reactions and responses to CCSS-initiated communications;
- Associations (cognitive, behavioral, psychological and temporal) between outgoing CCSS communications and incoming cohort communications;
- Efficacy of targeted (*information directed toward entire cohort*) vs. tailored risk communications (*information directed toward specific subgroups of survivors*, e.g., Mertens/Hudson quasi-experiment).

Data sources will include:

- Survey data related to survivors' information needs, late effects knowledge, and preferred ways of receiving information.
- Qualitative data recording cohort members' inquiries and comments via telephone, letter, e-mail and survey comment blocks.

- Mini-readership survey in Follow-2.

Information needs & preferences

- Baseline questionnaire:
 - Q. R. 7: *For our future planning, what type of information or help do you think should be available to survivors of childhood cancer, leukemia, tumor or similar illness?*
- Follow-Up 1 questionnaire/Q. 26-28.
 - Q. 26: *For future planning, if you were given a choice, what are your preferred format(s) for receiving information relating to childhood cancer or similar illnesses?*
 - Q. 27: *Have you gone on-line looking for information about your cancer or similar illness?*
 - Q. 28: *Do you have an e-mail address?*

Qualitative Data

- 1-800 call records.
- Comments recorded in the “additional comments” space on Baseline, F-U 1 and F-U 2 questionnaires.

Readership survey/Mertens & Hudson feasibility study

- Follow-Up 2 questionnaire—Questions T.1 – T. 11) and questions related to Medical Care (A. 7 – A.10).
 - T. 1: *In the past 2 years, did you read a newsletter from the LTFU study?*
 - T. 2: *Did any of the information reported in the newsletter make you feel anxious about your chances of developing health problems related to your treatment for cancer or a similar disease?*
 - T. 3: *Did the newsletter make you seek more information about health problems after treatment for childhood cancer or similar illness?*
 - T. 4: *If yes, what resources did you use to find out more information about health problems after childhood cancer or similar illness?*
 - T.5: *What specific health problems featured in the newsletter were of interest to you?*
 - T. 6: *If you spoke with a doctor or other health care professional, did you share a copy of the newsletter with your doctor at the check-up?*
 - T. 7-11: *Knowledge questions*
 - Related questions, A7-A10:
 - *A7—R’s belief about primary care doctor’s familiarity w. late effects*
 - *A8—PCD’s response/advice*
 - *A9—R has treatment summary or copy of medical records*
 - *A10—PCD has treatment summary/copy of medical records*

Hypotheses:

1. Cohort members who report more information-seeking behaviors related to their cancer are more likely to have their treatment summary and/or a copy of their medical records.
Rationale: Information-seeking suggests motivation which in turn suggests a readiness to change.
2. Cohort members who report more information-seeking behaviors related to their cancer are less likely to think that their primary health care provider is knowledgeable about late effects. *Rationale: People's perceptions/judgments are shaped by knowledge and experience. Several studies have found that PHCPs don't feel knowledgeable about late effects; consequently, if a cohort member asked his/her primary care doctor about a late effect issue, it's quite possible the physician would express a lack of knowledge. Also, the active information-seeker may well be more knowledgeable than his/her doctor.*
3. In the newsletter/newsletter-plus subsample, medical screening test experience will be similar between intervention and control groups. *Rationale: An unscientific review of content suggests there was not enough difference in the newsletter alone content vs. the newsletter-plus content to trigger significantly different changes in behavior.*
4. Childhood cancer survivors who are more knowledgeable about their diagnosis, treatment and late effects will report less anxiety related to their illness (*Follow-Up 2 questions K1-K17*). *Rationale: Fear of the unknown produces more worry and anxiety than knowledge about what to expect.*
5. Childhood cancer survivors with high anxiety levels are less likely to follow cancer screening recommendations. *Rationale: Fear feeds resistance.*
6. Childhood cancer survivors who feel healthiest (*Follow-Up 2 questions E1, E2, F10-F14, and G19—pain*) are less likely to read the newsletter (T1) or seek other information about their childhood cancer. *Rationale: Information-seeking, i.e., reading the newsletter, is a motivated behavior. Among all the other media competing for cohort members' attention, the newsletter probably does not rank high unless the recipient has an immediate concern about his/her health.*

These hypotheses are just some of my expectations about what we will find. Since this is an exploratory study, it is not guided by a tightly-focused research question.

Analysis Framework:

- a) Outcomes of interest: Possession of cancer treatment records; sharing of newsletter/cancer treatment records with primary care physician; adherence to cancer screening guidelines; treatment-related information seeking; the association between the number, timing, and content of e-mails, letters and phone calls and communications received, e.g., newsletters and surveys; newsletter readership satisfaction; information interests and format preferences; effect of a targeted (newsletter alone) vs. tailored (newsletter plus) risk communication intervention.

- b) Subject population: all members of the CCSS cohort, including the intervention and control sub-samples drawn for the *Newsletter-Plus* study that preceded the Follow-Up 2 questionnaire.
- c) Explanatory variables:
- a. Diagnosis and age at diagnosis
 - b. Time since diagnosis
 - c. Current age
 - d. Sex
 - e. Race/ethnicity
 - f. SES
 - g. Health insurance coverage
 - h. Perceptions about primary care physician's knowledge about and responses to information about late effects
 - i. Self-assessment of health status
 - j. Cancer-related anxiety
 - k. Cancer screening practices at baseline (N18-N22) and Follow-2
 - l. Readership/media use measures: Follow-2: T1-T6); Baseline: R7; Follow-1: Q26-Q28
 - m. Outcome measures: Follow-2: T7-T11; A9-A10
- d) Types of analysis: Both quantitative and qualitative analysis will be conducted. Initial quantitative analysis will be descriptive, emphasizing information that can inform future communications with cohort members. Subsequent analysis will focus on the association between potentially explanatory variables (*a* through *j* above, plus content of newsletter and survey questionnaires) and outcomes of interest, i.e., knowledge about treatment and potential effects; information seeking behavior and desire for specific kinds of information; cancer screening behavior/self-examination for testicular and breast cancer; sharing of newsletters and treatment history with primary care physician. Trend analysis will be conducted to evaluate the temporal relationship between information coming into the CC by phone and e-mail and information going out via newsletters, surveys, and letters.

Qualitative analysis of communications initiated by cohort members, family members, physicians and anyone else connected with the study will be conducted using HyperResearch or a comparable computer-assisted software application for computerized text files. Such software streamlines the central task of qualitative analysis—namely, making sense of texts—by making it possible to code text and generate reports that track coded patterns and themes electronically. In addition, qualitative software allows the researcher to link potential or emerging interpretations to text blocks that later will be used as evidence to support the interpretation (See Udo Kelle's *Computer-aided Qualitative Data Analysis: Theory, Methods and Practice*, 1995, for more).

When only longhand notes of inquiry/resolution are available, data will be extracted from subject files. (See Appendix B for preliminary data extraction codes and coding protocol.) Textual analysis will focus on identifying key themes, concerns, and topical patterns and their relationship with explanatory variables. For example, does coverage of “x” topic in the newsletter trigger anxious phone calls from cohort members with the same diagnosis, treatment or symptoms?

Although the data will not support any causal assertions, the study should allow for data-driven observations about the effectiveness of CCSS communication initiatives to date and point to options that should be considered for the future.