AN EXPERIMENT IN DATA COLLECTION MODE PREFERENCE OF LONG-TERM CANCER SURVIVORS

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Abstract

The American Cancer Society Behavioral Research Center is planning a nationwide, population based study of quality of life among 2-, 5- and 10-year cancer survivors. Because the median age at diagnosis for the 6 cancers included in the study is 55-65, the expected median age of 10-year survivors would be 65-75. The mode of data collection (telephone interview, mailed survey or a combination of these) was, therefore, carefully considered. Arguments for the different modes included age-related problems in survey completion specific to each mode, data completeness and quality, and respondent convenience. In the study's pilot phase, survivors were randomly assigned to one of three experimental arms: study presented as phone interview, study presented as mailed questionnaire, and mode selected by each participant at the time of informed consent. The survey requires about 30 minutes to complete in either format. Follow-up of non-respondents was to include the option to complete the survey via the other collection mode, although this information was not communicated to the sampled survivors in advance. The 3 arms will be compared on consent rate (i.e., rate of obtaining informed consent to participate in the study) and on interview completion rate (i.e., rate of completing either the phone interview or the mail survey, given that consent was obtained). Mode response patterns within each arm will also be investigated. The information obtained will be used in planning the implementation of the main study.

Background

Due to advances in detection and treatment, more people are surviving cancer today and facing problems in continuing with their "normal" lives. It has been estimated that close to 8.4 million Americans alive today have a history of cancer[1] and that there are over 7 million who are at least 5-year survivors[2]. Despite the large and ever increasing numbers of people who are surviving cancer today, relatively little is known about their needs and the factors that determine good survivorship and quality of life. Only recently have researchers begun to devote attention to the issue of cancer survivorship. Data from the few studies that have been conducted in this area are limited as they have generally focused only on the period shortly after treatment and have used small convenience samples of survivors. No study currently exists which includes a nationwide, representative sample of adult cancer survivors who are assessed at different time points after diagnosis.

To address this lack of data on quality of life in long-term survivors, the American Cancer Society (ACS) Behavioral Research Center (BRC) is currently planning and piloting a nationwide, population-based study of quality of life among long-term cancer survivors. The study will include persons diagnosed with either primary female breast, prostate, colorectal, urinary bladder, skin melanoma, or uterine cancer 2, 5, or 10 years prior to the survey, who were at least 18 years of age at the time of diagnosis. This study is designed to provide information about the needs of cancer survivors as well as to be an important resource to the American Cancer Society in planning and evaluating programs intended to help cancer survivors and their families.

Because there is currently no national population based registry of cancer survivors, a group of state, SEER and regional cancer registries that have been in operation long enough to have data on 10-year survivors, will be contracted to perform the following functions:

(1) identify and sample eligible survivors from their registry,
(2) obtain consent from each selected survivor's physician of record to contact his/her patient(s) regarding participation in the study,
(3) obtain informed consent for study participation from each selected survivor for whom physician consent to contact the survivor has been obtained and
(4) send the names and contact information of consented survivors to the ACS and a designated survey research contractor.

The survey research contractor will be responsible for data collection and the ACS BRC will be responsible for data analysis and publication of study results.

One risk factor for cancer is increasing age; nearly 80% of all cancers are diagnosed at age 55 or older[1]. Because the median age at diagnosis for the 6 cancers included in the study (except skin melanoma) is 65 or older, the expected median age of the majority of 5-year and 10-year survivors eligible for the study would be 70 or older and 75 or older respectively. Due to this anticipated advanced age of potential study subjects, much attention was given to mode of data collection when planning the study. Three data collection modes were considered: telephone interview, mailed questionnaire and mixed-mode data collection which would allow each participant to choose between telephone interview or mailed questionnaire as part of the informed consent process. Arguments for the different modes included age-related problems in survey completion specific to each mode, data completeness and quality, and respondent convenience. For example, decreased vision in older adults would seem to favor telephone administration but poorer hearing that may be encountered in older participants would seem to favor the use of written questionnaires. On the other hand, not all participants will be older and not all older participants will be hearing or vision impaired, and some may prefer filling out a written questionnaire at a time that is convenient for them rather than completing a telephone interview. It was decided to conduct an experiment as part of the study pilot to investigate the effects of presented data collection mode on study participation consent rates and the effects of the actual data collection mode employed on survey completion rates. This information would then be used to plan implement of the main study.

Methods

The study was piloted in Iowa through the Iowa Cancer Registry at the University of Iowa and in New Jersey through the Cancer Epidemiology Services in the State of New Jersey Department of Health and Senior Services. In New Jersey, sampled cases were allocated equally among Hispanics, African Americans and all other races (the latter group being predominately White non-Hispanic); in Iowa cases were not stratified on race/ethnicity for sampling. In both states, sampled cases were divided equally between 2, 5, and 10 year survivors; within each survival cohort the sampled cases were ¼ female breast, ¼ colorectal and ¼ prostate cancers, with the remaining cases being equally divided among urinary bladder, skin melanoma and uterine cancers. Sample selection was performed in January 2000 using 3 sampling frames in each state (i.e., cases diagnosed in the 1998, 1995 and 1990 calendar years who were state residents and at least 18 years of age at the time of diagnosis and who were not known to be deceased at the time of sampling). Each of the 2 pilot states initially selected a total of 720 cases, of which it was hoped that at least half would consent to participate in the study (i.e., at least 720 names would be sent to the survey research contractor for data collection).

For the data collection mode experiment, sampled survivors were randomly assigned to one of three experimental arms: (1) study presented as telephone interview, arm T; (2) study presented as mailed questionnaire, arm Q and (3) telephone interview or mailed questionnaire selected by each participant during the informed consent process, arm C. The survey was designed to require about 30 minutes to complete in either format and follow-up of survey non-respondents was to include the option to complete the survey via the other collection mode, although the latter fact was not communicated to the sampled cases in advance. Comparison of the 3 experimental arms was planned on consent rate (CR - i.e., rate of obtaining informed consent from survivors to participate in the study), interview rate (IR - i.e., rate of completing either the telephone interview or the mail questionnaire, given consent was obtained) and overall survey response rate (SRR = CR x IR). Mode choice patterns for arm C and mode response patterns (e.g., the proportion in each arm who complete the survey in the originally presented or selected mode versus the alternate mode) also would be determined.

Consenting of physicians and survivors was performed over the next several months following sample selection. In both states the physician consent process was passive. In passive consent, the cancer registry sends each selected survivor's physician of record (at diagnosis) information on the study and a list of his/her patients who have been selected for the study. If the physician does not notify the registry within 2 (IA) or 3 (NJ) weeks that a particular patient or patients should not be contacted regarding study participation, then permission to contact the patient is assumed. The physician consent process also provided an opportunity to discover that a patient was deceased or not study eligible. Because the study involved long-term survivors, it was possible that the physician of record at the time of diagnosis might not feel he or she could give consent to contact the patients at this time; in addition the physician might not currently be in practice. In cases where a physician could not be located to give consent to contact a patient, study recruitment materials were

sent to the survivor without obtaining physician consent. Once passive consent from the physician had been obtained (or efforts to locate a physician to grant consent were exhausted), the survivor was sent a letter from the registry introducing the study, a letter from the ACS BRC emphasizing the importance of the study, 2 copies of an informed consent form and a self-addressed postage paid return envelope in which to return the consent form. In New Jersey, the materials were bilingual, with one side of each page printed in English and the other side printed in Spanish. The registry's study introduction outlined what study participation would involve, any potential risks and benefits of study participation and instructions to return the informed consent form indicating whether or not they wished to take part in the study. If no response was received to the initial mailing within 3 weeks, a second mailing containing the introductory letter and consent forms was sent. If there was still no response 3 weeks after the second mailing, the survivor was contacted by telephone to obtain informed consent or to determine the reason for declining to participate in the study. Names, contact information and study arm assignments of consented survivors were forwarded monthly to the survey research contractor performing data collection.

Results

Consent dispositions for all sampled survivors by state and experimental arm are shown in Table 1. As of October 13, 2000, the consent process was completed for 97.5% (702/720) of selected Iowa survivors and for 66.0% (475/720) of selected New Jersey survivors. Of the 702 survivors for whom the consent process was completed in Iowa, 28 (4.0%) were discovered after sampling to be deceased, 12 (1.7%) stated that they had not been diagnosed with cancer (i.e., were ineligible), physician consent to contact was denied for 23 (3.3%), 13 (1.9%) could not be reached for telephone follow-up after the maximum number of four call attempts had been made and 32 (4.6%) could not be located. Of the 475 New Jersey cases for whom the consent process was completed, 69 (14.5%) were discovered after sampling to be deceased, 41 (8.6%) did not meet study eligibility criteria, physician consent to contact was denied for 12 (2.5%) and 5 (1.1%) could not be located. The following formulas were used to calculate the interim proportion for which physician consent was obtained and the interim proportion for which patient consent was obtained (given physician consent), based on the dispositions listed in Table 1:

$$\text{Interim physician consent rate} = \frac{(\text{denominator} - \#\text{ for whom physician refusal to contact patient was received})}{\#\text{ selected} - (\#\text{ ineligible} + \#\text{ pending} + \#\text{ deceased before/at physician consent})}$$

$$\text{Interim patient consent rate given physician consent} = \frac{\#\text{ with patient consent and physician consent obtained}}{\#\text{ with physician consent} - (\#\text{ deceased at patient consent})}.$$

Note that the formula for interim physician consent rate assumes physician consent for all eligible patients unless the physician specifically requested that the patient not be contacted regarding study participation. Because the consent process in New Jersey has not been completed for one-third of the selected survivors, only the data for Iowa will be analyzed further. The interim rates of obtaining physician consent in Iowa were: arm T, 96.5%; arm Q, 96.6%; and arm C, 96.8%. The interim rates for obtaining patient consent, given physician consent was obtained, were: arm T, 50.7%; arm Q, 58.2%; and arm C, 55.1%. Chi-square testing found that the interim rates of obtaining physician consent and of obtaining patient consent, given physician consent obtained, did not differ across arms of the study in Iowa (all $p > 0.05$).

Choice of data collection mode for those assigned to arm C is also shown in Table 1. In both Iowa and New Jersey, those given the opportunity to choose between the telephone interview and mailed questionnaire overwhelmingly chose the mailed questionnaire option (75.4% in IA and 79.6% in NJ) at the time that informed consent was obtained. This preference for mailed questionnaire was mirrored in Iowa by a somewhat, but not significantly ($p = 0.12$), higher study participation consent rate (58.2% vs. 50.7%) for arm Q in which the study was presented as a mailed questionnaire as compared to arm T in which the study was presented as a telephone interview.

To evaluate the effectiveness of the randomization of selected survivors to the 3 study arms, chi-square tests were preformed for gender, race and cancer type by state and study arm and t-tests were performed to compare mean age across study arms in each state. The results are shown in Table 2. None of the comparisons were statistically significant (all $p > 0.05$).

Some initial data on telephone interview and questionnaire completion is also available, although the number of participants who have been placed in final dispositions for the data collection process is small because data collection did not start as early in the pilot as originally planned. The results are shown in Table 3 for each state. The initial completion rate is defined as the number of completed telephone surveys and/or completed questionnaires divided by the number of survivors from whom patient consent was obtained, given physician consent was obtained. Chi-square testing found no significant difference in initial survey completion rates across the 3 study arms for Iowa and the chi-square for comparing the initial overall mail and the initial overall telephone completion rates was also not significant. In addition, the initial completion rates for arm T and arm C telephone interviews and for arm Q and arm C mailed questionnaires were not significantly different in Iowa. The data for New Jersey were not analyzed due to the large proportion of selected survivors in that state for whom the consent process has not been completed.

Discussion

In order to maximize both study participation and the quality of the data collected, a data collection mode preference experiment was performed as part of the pilot for a study of long-term cancer survivors. It was anticipated that the results of this experiment in the pilot would help with selection of the optimal data collection mode to be used in implementing the main study.

The overall interim rate of obtaining physician passive consent to contact their patients regarding the study was very high (greater than 96%) in Iowa. This was as expected, because the only disposition counted against the consent rate is a request from a physician not to contact a particular patient. The physician rate of consent to contact patients did not vary significantly based on the study arm to which the survivors had been assigned. This latter result also was as expected, because the same information about the study was sent to physicians by the registry regardless of the study arm to which their patient(s) had been assigned.

In Iowa, no statistically significant difference based on the data collection mode that was presented during the informed consent process was found in the interim rates of obtaining patient consent to participate in the study, given physician consent was obtained. The interim consent rate for survivors assigned to telephone interviews (arm T) was lower than that for survivors assigned to either the mailed questionnaire (7.5% lower than for arm Q) or to the choice arm (4.4% lower than for arm C). Although these differences were not large enough to be statistically significant, an increase of 4.5% to 7.5% in consent rate would certainly be of practical significance. In both states however, those given the opportunity to choose between the telephone interview and mailed questionnaire overwhelmingly preferred the mailed questionnaire option. This may be a reflection of the general decline in telephone interview rates. Perhaps it also reflects the fact that the initial contact with survivors regarding the study was made via mail.

Data collection did not start as early as anticipated, but some initial data on survey completion rates were available. In Iowa, there was a 9.4% greater initial completion rate for mailed questionnaires for arm Q vs. arm C mail questionnaire participants and a 5.9% greater initial completion rate for telephone interviews for arm T vs. arm C telephone participants. For both modes, the initial rate of survey completion for the choice arm (arm C) was also higher than for the other 2 arms. In addition, the initial overall completion rate for mail questionnaires was 3.0% higher than the initial overall completion rate for telephone interviews, irrespective of experimental arm. None of these differences, however, were statistically significant at the $\alpha = 0.05$ level.

These results, even if not statistically significant, suggest that all patients selected for the study should be given a choice of telephone interview or mail questionnaire as part of the informed consent process. Because the interim results are different in some respects for the 2 states, we are reluctant to make the decision to present the study solely as a mail questionnaire study, even though the initial mail questionnaire completion rate is somewhat higher than the initial telephone interview completion rate in Iowa. When our data are more complete, it will be possible to investigate differences in both consent and completion rates by survivor group and race/ethnicity. At that time we will also be able to calculate and compare overall survey response rates. Additionally, it will be possible to investigate the effect on overall completion rates of non-respondent follow-up using the other mode of data collection. This follow-up is

just now beginning and no data are available at this time. Once all this information is obtained, a final decision on data collection mode to be employed in the main study will be finalized.

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References

1. *Cancer Facts & Figures - 2000.* American Cancer Society, Atlanta, GA, 2000.
2. *Cancer Facts & Figures - 1996.* American Cancer Society, Atlanta, GA, 1996.

Table 1. Consent Process Dispositions for All Selected Cases by State and Experimental Arm

	Iowa			New Jersey		
Outcome	**Arm T (Phone)**	**Arm Q (Mail)**	**Arm C Choice**	**Arm T (Phone)**	**Arm Q (Mail)**	**Arm C Choice**
Physician & Patient consented	108	128	114	78	88	98
Phone			22			20
Mail			86			78
Either/Neither*			6			0
Patient refused consent	85	77	82	27	30	27
Physician refused consent	8	8	7	7	3	2
Unable to locate patient	15	10	7	2	0	3
Maximum calls to patient	5	4	4			
Deceased patients						
At or before MD consent	3	2	7	13	12	7
At patient consent	6	6	4	10	16	11
Ineligible patients	3	5	4	15	15	11
Pending	7	1	10	88	76	81
Total	240	241	239	240	240	240

* Those indicating that either mode was acceptable and those who did not indicate a choice of mode will be contacted by telephone to determine mode choice

Table 2. Demographic and Medical Characteristics of All Selected Cases By State and Experimental Arm

	Iowa			New Jersey		
Characteristic	**Arm T (Phone)**	**Arm Q (Mail)**	**Arm C Choice**	**Arm T (Phone)**	**Arm Q (Mail)**	**Arm C Choice**
Female (%)	54.2	51.9	52.1	51.2	59.2	54.2
Race (%)						
White non-Hispanic and other				37.5	29.6	32.9
Black non-Hispanic				35.4	30.4	34.2
Hispanic				27.1	40.0	32.9
White	98.8	95.9	98.3			
All other	1.2	4.1	1.7			
Cancer type (%)						
Female Breast	25.0	24.9	25.1	22.5	27.1	25.4
Colorectal	25.0	24.9	25.1	22.1	28.3	24.6
Prostate	25.0	24.9	25.1	29.6	22.9	22.5
Other 3*	25.0	25.3	24.7	25.8	21.7	27.5
Mean age, years (SD)	66.6 (13.2)	65.2 (12.5)	67.5 (12.7)	62.2 (12.7)	62.2 (13.8)	62.9 (13.0)

* Bladder, skin melanoma and uterine cancers

Table 3. Interim Interview/Questionnaire Completion Outcomes* by State, Experimental Arm and Data Collection Mode

Outcome	Arm T Phone	Arm Q Mail	Arm C Phone	Arm C mail	Arm C all modes	All phone	All Mail	All modes
Iowa								
Total	97	113	21	78	99	118	191	309
# completes	59	69	14	55	69	73	124	197
% completes	60.8	61.1	66.7	70.5	69.7	61.9	64.9	63.8
New Jersey								
Total	82	73	25	29	54	107	102	209
# completes	38	43	4	11	15	42	54	96

* Table includes data only for those from whom patient consent, given physician consent, was obtained and for whom data collection has started.