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A Comparison of Cancer Survivors from the PROMIS Study Selecting Telephone Versus Online Questionnaires

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Keywords

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Introduction

In response to steadily growing Internet use among a broad array of demographic groups in the United States [1], investigators are increasingly employing online surveys to collect self-reported data.[2, 3] Compared to mail and telephone survey administration, online technology provides options for survey administration that may be more convenient for subjects and more cost-effective for study personnel.[2, 4] However, online-only surveys may result in lower participant response rates, especially among individuals who are older, and of minority and lower socio-economic status.[5-7] Increased anonymity provided by online surveys has been shown to convey a sense of privacy to the respondent, who then may feel more comfortable answering sensitive questions,[6, 8] but online surveys limit the ability to clarify survey questions and limits communication with participants. The resulting increase in missing data inserts an unknown amount of bias into final survey estimates which can threaten the generalizability and validity of results.[9]

Research Questions

The primary aim of this study was to compare the demographic profiles of cancer survivors who self-selected telephone vs. on-line survey administration as they participated in the Patient-Reported Outcomes Measurement Information System (PROMIS) surveys.[10]

Secondly, we sought to evaluate the efficiency of online and telephone questionnaire based on the number of reminders required for completion. Our final aim was to assess completion rates between the two modes of survey administration.

Materials and Methods

Subjects

The PROMIS Network is developing valid and reliable patient-reported outcome measures for use across chronic conditions. The data in this manuscript are from the cancer supplement to PROMIS, an effort to ensure PROMIS applicability to cancer survivors. More detailed descriptions of the PROMIS studies have been published previously.[10] Much of the Cancer PROMIS supplement (CaPS) sample was recruited via a comprehensive cancer center registry (n=683). Inclusion criteria were set at greater than 6 months post diagnosis for breast, colorectal, lung, prostate and “other” cancers. With physician approval, recruitment letters were mailed to potential subjects, and interested survivors were instructed to call or email the study team. Study team members screened participants via telephone or email to assure they met the study criteria (diagnosed with cancer, over the age of 18 and able to read and understand English), and gave participants the option to either complete the survey online or on the telephone with a study team member.

Participants were assigned to one of four functional domains assessed by the survey (Sexual Functioning, Sleep/Wake Functioning, Perceived Cognitive Functioning, or Illness Impact) based on their race, gender and cancer type. The university health system Institutional Review Board approved the study, and participants were compensated \$25 for study participation. A stratified recruitment plan was implemented to ensure sufficient numbers for subgroup analysis. We subdivided the overall recruitment goal into “bins,” (e.g., female, non-white lung cancer survivors in the “cognitive functioning” domain); potential participants were enrolled in the study until the recruitment goal for each “bin” was met. To be included in item-testing analysis, surveys were required to be 95% complete.

Since most survey questions referred to a specific recall period of either the past 7 days or the past 30 days, surveys needed to be started and completed within a 24-hour time period to be considered valid. Reminder calls were placed to on-line participants who had either not begun or had partially completed the survey to encourage completion within the required timeframe.

Measures

Each study participant completed 120-156 questions total, including 11 socio-demographic items, 5-10 cancer-specific items, 10 general health status items, and 80-100 items selected from one of the four Cancer PROMIS Supplemental Item Banks. All survey items were programmed into Assessment Center (<https://www.assessmentcenter.net>), a secure, web-based data collection tool. Study participants who chose online survey completion were mailed access instructions, and those who chose the telephone survey were guided through the survey as a member of the study team recorded their responses in Assessment Center.

Statistical Analyses

We explored sources of non-observational errors such as participant non-response, item response rate, domain completion rates and sampling bias. Participant non-response was defined as the proportion of cancer survivors who agreed to participate and received the information necessary to complete the questionnaire, but did not subsequently complete it. We had no a priori expectations about the direction of differences, as research in this area is limited and results are ambiguous. Overall, the general spirit of this study was descriptive in

nature; therefore, bivariate analyses were conducted to address both of the objectives of the study. The key classification variables, mode of administration (online vs. telephone) and reminder status (yes vs. no) are dichotomous, and Chi-square tests were used to evaluate their association with other dichotomous variables (e.g., gender, race, marital status, etc.). Omnibus *Cochran-Mantel-Haenszel* tests were used for extended tests for variables with multiple nominal levels (cancer type and domain). For the single continuous variable (age), the t-test was used. Significance was assessed at the $p < .05$ threshold. All analyses were conducted using SAS® software, version 9.2 (SAS Institute, Inc., Cary, NC).

Results

From May 2008 through April 2009, a total of 728 survivors responded with interest, which comprised a 23% response rate after letters mailed to bad addresses and deceased individuals were removed from the number of recruitment letters mailed. Of these, 683 survivors agreed to participate in the study, and 640 completed the survey.

Telephone survey administration was chosen by 28% of our subjects, and 72% chose to complete the survey online. Those who selected telephone administration were significantly older (69.1 vs. 61.1 years of age), had lower levels of income and education, and were more likely to be unmarried and non-white than those who chose online administration (see Table 1). While a higher proportion of phone respondents were female (56% versus 44% male), that association fell short of statistical significance ($p = .08$). Overall survey completion rates differed little by mode of survey administration; completion rates of 95% or more of the survey questions were achieved in 93% of telephone respondents compared with 92% of the online survey respondents ($p = .78$). Moreover, no significant completion rate differences were observed between men and women by mode of administration for the four domains. Women who chose the phone survey had higher completion rates for the sexual functioning category (88% versus 78% completion rate online); the reverse was true with male participants in the sexual functioning survey who had slightly lower completion rate on the phone (84% versus 88% completion rate online), but these differences were not significant.

Study participants who chose to complete their survey online were much more likely to need a reminder (see Table 2). These respondents were younger, of higher income, and more likely to be employed than those who completed the survey without a reminder.

Discussion

This is one of the first studies to our knowledge comparing the characteristics of cancer survivors who prefer online vs. telephone survey administration. We observed demographic differences between these groups similar to those found in previously-conducted studies with other populations. [5-7]

The sexual function domain contained many sensitive questions that were private in nature (e.g., “In the past seven days, how easy has it been for you to have an orgasm”), but contrary to our expectations, we did not observe greater skip rates for questions in this domain administered on the telephone. Differences in the overall completion rates by gender and mode were observed for this domain, but results were mixed and not significant. These findings contrast with previous research that found that survey respondents were more likely to share sensitive information online than over the telephone. [6, 8]

Although the majority of our sample elected to complete the survey online, one-third of these respondents required at least one email or telephone reminder to complete the survey, (with 11% and 4% needing two and three reminders, respectively), resulting in additional staff time and cost. Interestingly, 8% ($n = 42$) of study participants who initially chose the

online survey option ultimately decided to switch to telephone administration due to technical difficulties or perceived expedience of telephone completion.

The lack of randomization in this study reduces the certainty with which it can be determined that the outcomes observed in our sample were due to questionnaire mode alone. We are unable to determine how many respondents who chose telephone survey completion would have completed the survey online if that was the only option provided. However, the approach that was used approximates a real-world situation and thereby increases the external validity of the results.

Since Internet usage is increasing among the older age groups who are also more likely to be affected by cancer, online survey completion for cancer survivors can be a viable option. However, in light of the potential sampling and response bias created by participants who self-select to complete online questionnaires, investigators who are planning online surveys as a sole means of data collection should consider the limitations of this approach and offer telephone survey backup.

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Key Points

- Researchers increasingly rely upon online data collection methods as internet use becomes more widespread.
- In our study, 72% of participants chose online survey administration and 28% chose to complete the survey on the telephone.
- The cancer survivors choosing to complete the survey online were younger, less racially diverse, had higher incomes, and were more educated than those who completed the survey by telephone.
- We observed no differences in the completion rate of sensitive survey questions online versus on the telephone.
- One third of online survey respondents needed at least one reminder from study staff before completing the survey.

Table 1
Characteristics of survivors choosing telephone and online surveys

Characteristic	Telephone (n=194)	Online (n=489)	p-value
<u>Age</u>			
- Mean (sd)	69.1 (11.7)	61.1 (11.2)	<.0001
- Range	31 - 94	21 - 90	
<u>Gender - % (n)</u>			
- Male	44% (85)	51% (250)	0.08
<u>Race - % (n)</u>			
- White	72% (139)	90% (438)	<.0001
<u>Cancer type % (n)</u>			
- Breast	26% (50)	31% (154)	0.16
- Colorectal	11% (22)	9% (43)	
- Lung	11% (22)	10% (48)	
- Prostate	26% (51)	31% (152)	
- Other	25% (49)	19% (92)	
<u>Domain % (n)</u>			
- Illness Impact	26% (51)	24% (119)	.14
- Perceived Cognitive Functioning	28% (55)	24% (119)	
- Sexual Functioning	26% (51)	24% (116)	
- Sleep/Wake Functioning	19% (37)	28% (135)	
<u>Marital Status - % (n) (*N = 660)</u>			
- Married/Partnered/Widowed	79% (153)	84% (412)	0.18
<u>Education Level - % (n)</u>			
- High School Graduate or Less	31% (61)	11% (55)	<.0001
<u>Income % (n)</u>			
- \$49,999 or less	51% (99)	24% (115)	<.0001
<u>Employment Status - % (n)</u>			
- Employed	13% (26)	41% (200)	<.0001
<u>Survey Completion - % (n)</u>			
- Completed 95% of the survey	93% (181)	95% (459)	0.78

Table 2
Characteristics of survivors' survey completion

Characteristic	Entire Sample (n=683)	Needed reminder to complete (n=187)	p-value
<u>Mode of Survey</u>			
- Online	72% (489)	34% (167)	<.0001
- Telephone	28% (194)	10% (20)	
<u>Gender - % (n)</u>			
- Male	49% (335)	26% (88)	0.52
- Female	51% (348)	28% (99)	
<u>Age</u>			
- Mean (sd)	64.4 (11.9)	60.5 (11.7)	0.0005
- <65	53% (322)	37% (119)	
- >65	47% (361)	19% (68)	
<u>Race - % (n)</u>			
- White	84% (577)	29% (165)	0.1
- Non-White	16% (106)	21% (22)	
<u>Cancer type % (n)</u>			
- Breast	30% (204)	30% (62)	0.68
- Colorectal	10% (65)	22% (14)	
- Lung	10% (70)	27% (19)	
- Prostate	30% (203)	28% (56)	
- Other	21% (141)	26% (36)	
<u>Domain % (n)</u>			
- Illness Impact	25% (170)	24% (41)	0.14
- Perceived Cognitive Functioning	25% (174)	27% (47)	
- Sexual Functioning	24% (167)	33% (55)	
- Sleep/Wake Functioning	25% (172)	26% (44)	
<u>Marital Status - (n=660) *</u>			
- Married/Partnered/Widowed	86% (565)	27% (151)	0.61
- Other	14% (95)	24% (23)	
<u>Education Level – (n=659)*</u>			
- High School Graduate or Less	18% (116)	16% (19)	0.0078
- Some College/College Graduate or Higher	82% (543)	28% (154)	
<u>Income (n=645)*</u>			
- \$49,999 or less	33% (214)	19% (40)	0.0003
- \$50,000 or more	67% (431)	30% (128)	
<u>Employment Status - (n=659)*</u>			
- Employed	36% (226)	32% (72)	0.02
- Unemployed/Retired/on Disability	64% (433)	24% (102)	

* Data available only from participants completing the pertinent survey question.