Tailored Strategies to Enhance Survey Response among Proxies of Deceased Patients

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Objective. To enhance proxy survey responses for deceased cancer patients.

Data Sources. Two waves of surveys about care experiences of cancer chemotherapy patients (used for a value-based purchasing initiative), collected November 2016 through March 2017.

Study Design. Surveys were mailed to deceased patients (for proxy response) in the untailored first survey wave, and using a tailored strategy in the second wave. We compared proxy responses for deceased patients with and without the tailored approach.

Principal Findings. A tailored survey approach improved the proxy response rate from 17.6 percent to 39.0 percent.

Conclusions. Simple tailoring strategies can significantly enhance proxy response rates when surveying patients in a high mortality population. However, we were unable to address the impact of higher proxy response rates on response bias since we surveyed different patients in each wave.

Key Words. Tailored patient survey, deceased patients, proxy response rate, cancer care experience

Surveys about patient care experiences, including experiences at the end of life, can identify opportunities to improve care. Measuring the quality of care provided by specific physicians, hospitals, or other providers is important for value-based purchasing and other innovative payment models. To obtain a complete and unbiased understanding of care experiences of patients served by a specific provider or group, it is important to collect information from both patients who survive and also from the proxy respondents of patients who do not (family member or close friend). This is especially true when measuring care experiences of providers that serve a population with high mortality (e.g., patients with cancer), for whom advance care planning and shared decision making about end-of-life care are important quality

metrics. Surveys such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey gather responses from caregiver proxies only, and the sampling frame often requires a caregiver of record for inclusion in the study (Centers for Medicare and Medicaid Services 2016a). Surveys that seek to include both living patients and proxies for deceased patients—input from the full population served by a physician group or hospital—face several challenges, including sample frames that lack proxy names and contact information, which may lower or bias response as compared with tailored survey approaches (Dillman, Smyth, and Christian 2014).

As evaluators of the Centers for Medicare and Medicaid Services (CMS) Oncology Care Model (OCM), a new Medicare payment model for practices providing chemotherapy to patients with cancer, we are conducting quarterly surveys of patients treated by the nearly 200 physician practices who are participating in OCM voluntarily (Centers for Medicare and Medicaid Services 2016b).

The survey has repeated waves of sampling to measure patients' experiences across practices and to monitor changes over time. The OCM program also uses care experiences as measured by the survey to adjust payments to participating practices. In the first wave, we mailed the paper survey to a sample of Medicare cancer patients treated with chemotherapy by participating oncology practices and asked for a close family member or friend to complete the survey if the sampled patient was deceased. In the tailored second survey wave, we substituted a slightly reworded "alternative" survey for family members of patients who died before we mailed the survey, with a different mailing label and cover letter. This study discusses the difference in proxy response rates between the untailored first survey wave and the tailored second wave. However, we were unable to address the impact of this difference on response bias because we surveyed different patients in each wave.

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METHODS

Participants

We surveyed two separate samples of cancer chemotherapy patients in sequential waves (different patients in each wave). In both waves, we used Medicare claims (after allowing 1 month for claims submission) to identify cancer patients who met the OCM episode definition (Centers for Medicare and Medicaid Services 2016b) and drew a proportionate sample of patients treated by each oncology practice participating in OCM, stratified by patient age, race, and cancer type, information available in the Medicare claims.

Survey Instrument

The survey instrument (included in the Appendix SA2) was adapted from the CAHPS Cancer Care Survey (Agency for Healthcare Research and Quality 2017). It asks about patients' cancer care experiences in several domains: shared decision making, access to oncologists, communication with the cancer care team, patient self-management, information exchange between physicians and patients, symptom management, and understanding of chemotherapy. In Wave 1, all sampled patients received the same survey instrument (the "main" survey), regardless of whether the patient had died by the time of survey mailing. For Wave 2, we implemented a tailored "alternative" survey approach for proxy respondents of deceased patients.

While both surveys ask about similar aspects of care experience, the tailored approach differs in important ways, including different question wording and item skip pattern for proxies, and an alternative cover letter and address label.

The alternative survey omits questions about current health status and activities of daily living, which proxies of decedents were instructed to skip on the main patient survey. The alternative survey has a few additional questions about end-of-life care experiences, which were omitted from the main questionnaire (to avoid discomfort for cancer patients undergoing curative treatment). While the main survey asks questions from the perspective of the patient, referencing "your cancer care experiences," the alternative survey asks about "the patient's cancer care experiences."

A paragraph in the cover letter of the main survey states "If the person to whom this letter is addressed has passed away, we would be most grateful if a close family member or friend would fill out the survey on their behalf. It is important to include the experiences of all cancer patients in this survey." The

tailored alternative survey had an alternative cover letter for proxy respondents of deceased patients that stated, “Medicare records show that [beneficiary name] was treated for cancer and recently passed away. My condolences to you and your family for your loss. I am writing to ask for your help with a voluntary research survey about experiences with cancer care, and care at the end of life. We would be most grateful if a close family member or friend would fill out the survey on behalf of [beneficiary name]. It is important to include the experiences of all cancer patients in this survey. We understand you may not know the answers to all survey questions; please feel free to skip any items for which you don’t know the answer.” The main survey was addressed to the patient, while the alternative survey was addressed to “Family of” the deceased patient. Both were mailed to the patient’s home addresses, as identified in Medicare administrative records, because we lacked addresses for next of kin.

Both survey instruments were 12 pages long and included about 80 questions in total. In pilot testing, cancer patients completed each survey in an average of 30 minutes.

Survey Administration

Both the Wave 1 and Wave 2 surveys were administered by mail, following a CAHPS protocol with an initial survey, a thank-you/reminder postcard 1 week later, and a second survey mailing to nonrespondents 3 weeks after the first. The survey packets included an invitation cover letter, the 12-page paper questionnaire, and a prepaid envelope to return the survey. Wave 1 was mailed in early November 2016 and Wave 2 was mailed in early January 2017, and each wave was in the field for 8 weeks. Both survey waves were mailed to the patient’s address (from Medicare administrative records), as we lacked names or addresses for next of kin.

In Wave 2 (tailored approach), we sent the main survey instrument to patients who were alive at the time of mailing and sent the alternative survey instrument to the attention of the family of patients who had died. To identify the patients who had died, we extracted the latest validated Social Security death records for patients in our sample, just before mailing the survey. We did not extract the death records for the patients in Wave 1 because all patients received the main survey instrument, but we retrospectively identified all who had died before the mailing date for that survey—a population comparable to those that received the alternative survey in Wave 2.

Statistical Analyses

We used the Pearson chi-square tests to assess whether the deceased cancer patients surveyed in Waves 1 and 2 were similar on several key characteristics, because different patient characteristics could affect response rates in the two waves, irrespective of survey techniques. Patient characteristics included age (<65, 65–74, 75–84, ≥85), sex, race (White, non-White), and Medicare-Medicaid dual eligibility (fully/partially eligible, noneligible). We also characterized cancer type (three mutually exclusive cancer groups: breast or prostate cancer with hormonal therapy only, hematologic cancers, and solid tumors with non-hormonal therapy) because these groups may differ in the goals of treatment, and in mortality.

We compared the overall response rate, and response rate stratified by patient characteristics, between the untailored Wave 1 and tailored Wave 2 survey approaches. Additionally, we calculated an adjusted overall response rate for each approach (wave), adjusting for the patient characteristics described above using logistic regression. Response rate was defined as the number of returned surveys with at least one question answered, divided by the number of patients (or proxies) in the sample (The American Association for Public Opinion Research 2016). We also compared responses to 42 individual survey questions to assess differences in item nonresponse by survey approach.

We analyzed data using *Stata* statistical software, release 14 (StataCorp LP, College Station, TX). All statistical tests were two-sided and used a statistical significance level of .05.

RESULTS

Study Population

There were 2,403 and 1,849 patients who died before the survey was mailed, in Waves 1 (untailored approach) and 2 (tailored approach), respectively. Deceased patients in the two waves were similar in age, race, and cancer type (Table 1). Overall, 45 percent of the deceased patients were aged 65 to 74 years old and 32 percent were aged 75 to 84 years old. Fifty-two percent of the deceased patients were male; 16 percent were non-white; and 18 percent were Medicare and Medicaid dually eligible. About 7 percent of the deceased patients had breast or prostate cancer treated with hormonal therapy only, 15 percent had hematologic cancers, and the remaining 78 percent had solid

tumors treated with nonhormonal oncolytics. The sample of deceased patients in Wave 2 had a larger share of male patients (53.9 vs. 50.4 percent) and a smaller share of dual-eligible patients (16.6 vs. 19.2 percent) than the sample of deceased patients in Wave 1. The magnitude of these two differences was small, despite their statistical significance. Table 1 shows that the nondeceased patients receiving the main survey in the two waves were also similar in most of the patient characteristics described above, with a statistically significant but small difference in dual eligibility and cancer type.

Table 1: Characteristics of Cancer Patients in the Survey Sample

Characteristic	Decedents in the Sample			Nondecedents in the Sample		
	Wave 1	Wave 2	<i>p</i> Value	Wave 1	Wave 2	<i>p</i> Value
	(<i>N</i> = 2,403) <i>N</i> (%)	(<i>N</i> = 1,849) <i>N</i> (%)		(<i>N</i> = 21,658) <i>N</i> (%)	(<i>N</i> = 22,105) <i>N</i> (%)	
Age						
Under 65	257 (10.7)	186 (10.1)	.84	2,289 (10.6)	2,336 (10.6)	.61
65–74	1,097 (45.7)	834 (45.1)		10,623 (49.1)	10,973 (49.6)	
75–84	768 (32.0)	610 (33.0)		6,771 (31.3)	6,792 (30.7)	
85 and older	281 (11.7)	219 (11.8)		1,975 (9.1)	2,004 (9.1)	
Sex						
Male	1,210 (50.4)	997 (53.9)	.02	9,096 (42.0)	9,162 (41.5)	.24
Female	1,193 (49.7)	852 (46.1)		12,562 (58.0)	12,943 (58.6)	
Race						
White	2,002 (83.8)	1,550 (84.7)	.43	17,628 (82.4)	18,083 (82.8)	.30
Non-white	387 (16.2)	280 (15.3)		3,773 (17.6)	3,770 (17.3)	
Dual eligibility						
Dual eligible	441 (19.2)	300 (16.6)	.03	3,529 (17.3)	3,539 (16.5)	.03
Nondual eligible	1,851 (80.8)	1,512 (83.4)		16,912 (82.7)	17,930 (83.5)	
Cancer type						
Breast/Prostate cancer with hormonal therapy only	154 (6.4)	139 (7.5)	.21	6,385 (29.5)	7,586 (34.3)	<.001
Hematologic cancers	377 (15.7)	265 (14.3)		4,543 (21.0)	4,092 (18.5)	
Solid tumor with nonhormonal therapy	1,872 (77.9)	1,445 (78.2)		10,730 (49.5)	10,427 (47.2)	

Notes. *p* Values calculated using Pearson chi-square test. 14 decedents/257 nondecedents in Wave 1 and 19 decedents/252 nondecedents in Wave 2 had unknown race. A total of 111 decedents/1,217 nondecedents in Wave 1 and 37 decedent/636 nondecedents in Wave 2 had unknown dual eligibility.

Respondents

The overall response rate for proxies of deceased patients increased from 17.6 percent in Wave 1 to 39.0 percent in Wave 2 ($p < .001$; Table 2). This large increase in response rate was true for all patient subgroups defined by age, sex, race, dual eligibility, and cancer type. All increases in response rate were

Table 2: Response Rate of Cancer Patients in the Survey Sample

<i>Characteristic</i>	<i>Decedents in the Sample</i>				<i>Nondecedents in the Sample</i>			
	<i>Wave 1 Response Rate (%)</i>	<i>Wave 2 Response Rate (%)</i>	<i>Difference (%)</i>	<i>p Value</i>	<i>Wave 1 Response Rate (%)</i>	<i>Wave 2 Response Rate (%)</i>	<i>Difference (%)</i>	<i>p Value</i>
Overall								
Unadjusted	17.6	39.0	21.4	<.001	46.0	48.3	2.3	<.001
Adjusted	17.8	38.5	20.7	<.001	45.9	48.4	2.5	<.001
Age								
Under 65	7.4	24.2	16.8	<.001	34.7	34.5	-0.2	.92
65-74	17.0	39.4	22.4	<.001	47.7	50.9	3.2	<.001
75-84	21.6	41.0	19.4	<.001	48.8	50.6	1.8	.04
85 and older	17.8	44.3	26.5	<.001	39.8	42.1	2.3	.15
Sex								
Male	19.6	41.6	22.0	<.001	47.5	49.1	1.6	.03
Female	15.5	35.9	20.4	<.001	44.9	47.7	2.8	<.001
Race								
White	19.4	41.9	22.5	<.001	48.8	50.8	2.0	<.001
Non-white	8.5	22.1	13.6	<.001	33.2	36.3	3.1	.004
Dual eligibility								
Dual eligible	6.6	17.7	11.1	<.001	30.1	30.2	0.1	.94
Nondual eligible	20.5	43.3	22.8	<.001	49.3	51.7	2.4	<.001
Cancer type								
Breast/ Prostate cancer with hormonal therapy only	17.5	23.7	6.2	.19	42.2	45.4	3.2	<.001
Hematologic cancers	18.0	44.5	26.5	<.001	50.7	53.9	3.2	.003
Solid tumor with nonhormonal therapy	17.5	39.4	21.9	<.001	46.3	48.2	1.9	.005

Notes. p Values calculated using two-sample proportion test. Adjusted overall rate controlled for patient age, sex, race, dual eligibility, and cancer type. A total of 14 decedents/257 nondecedents in Wave 1 and 19 decedents/252 nondecedents in Wave 2 had unknown race. A total of 111 decedents/1,217 nondecedents in Wave 1 and 37 decedent/636 nondecedents in Wave 2 had unknown dual eligibility.

statistically significant except for breast or prostate cancer patients treated with hormonal therapy only. For this small group (154 deceased patients in Wave 1 and 139 in Wave 2), an increase in response rate from 17.5 percent to 23.7 percent was not statistically significant. The difference in overall response rate for proxies of decedents between the two waves remained large (17.8 vs. 38.5 percent) and statistically significant after adjusting for patient characteristics ($p < .001$).

The Wave 1 survey was mailed in early November 2016 and the Wave 2 survey was mailed in early January 2017; thus, our comparisons could be subject to bias if there were differences in likelihood of responding in these different time periods. To test for this, we also compared response rates for patients who were alive at the time of the survey (Table 2) and saw only a minimal increase (46.0 vs. 48.3 percent), suggesting that time trends do not completely explain our findings.

We compared the rate of nonmissing item responses among the deceased patients for whom proxies returned the survey, on 42 individual survey questions, and found no statistically significant differences between the two waves in the nonmissing rate on 16 of the 42 questions (data not shown). For the other 26 questions, the nonmissing rate was 3 to 7 percentage points higher in Wave 2 than Wave 1, and this difference was statistically significant.

DISCUSSION

We designed a tailored survey approach to increase response rates among proxies of deceased patients as compared with an untailored approach. The response rate for proxy respondents of deceased patients was substantially higher with the tailored approach compared with the untailored approach. Mail survey response is a multipart process, requiring respondents to open the mail, decide to respond, and complete their response. In addressing each of these steps, the tailored approach likely improved proxy respondents' progression through this multipart process.

First, the tailored approach sought to connect directly with the proxy respondent rather than with the patient. In the tailored approach, families received a packet addressed to the "Family of" the decedent; a more specific address label that may have been noticed by family members who felt motivated to respond compared with addressing the survey packet to the decedent as in the untailored approach. Survey research indicates that surveys addressed to a specific person, when accurate, yield a higher response rate

than surveys directed at “Resident” or another generic label (Dillman et al. 2007). In addition, bereaved family members face many logistical challenges after a loved one’s death, and mail directed to the patient may be set aside while mail directed to the family may elicit a more timely response.

Second, the tailored approach used a more personalized cover letter. Dillman and colleagues emphasize the importance of personalizing survey correspondence and conveying the relevance of the survey to the respondent early and often (Dillman et al. 2007). In the untailored approach, proxy respondents who did open the survey packet saw a cover letter addressed to their deceased relative, which only mentioned the family member in the fourth paragraph. In the tailored approach, proxy respondents saw a cover letter that immediately recognized their loss and invited them to respond, to help improve care for people like their deceased loved one. Proxy respondents who started to read the tailored survey cover letter may have viewed the survey as more relevant for them than did those who read the untailored survey cover letter, contributing to the improved response rate.

Third, the tailored approach included a survey instrument that was modified for the proxy of the decedent. Respondent burden, which can incorporate not only questionnaire length but also respondent effort and stress (Bradburn 1978), is widely thought to reduce survey response (National Research Council 2013). Proxy respondents in the untailored approach received a survey that asked them to respond on behalf of their loved one, but with questions worded from the perspective of the patient (i.e., “your cancer care”), and proxy respondents to the untailored survey were instructed to skip questions about current health status and quality of life. In the tailored approach, proxy respondents received a survey reworded from the perspective of a proxy answering on behalf of their deceased loved one, and the current health status section was replaced by a section on end-of-life care. By rewording from the proxy perspective and removing irrelevant sections, the alternative survey may have reduced respondent burden and increased the likelihood of completion.

CONCLUSION

When survey data are used for quality ratings and/or payment adjustment, the care experiences of patients who survive and of those who do not are both important and together provide a more comprehensive picture of the care provided. When surveying patients in a high mortality population, especially

when the next of kin name and address are unknown, it is possible to significantly enhance proxy response rates through simple tailoring strategies like those employed here. However, we were unable to address the impact of higher proxy response rates on response bias. Even though characteristics of patients surveyed in the two waves were similar, they were different patients in each wave.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the supporting information section at the end of the article:

Appendix SA1: Author Matrix.

Appendix SA2: Untailored Survey Questionnaire (Used in Wave 1); Tailored Survey Questionnaire (Used in Wave 2).