The Association of Proxy Care Engagement with Proxy Reports of Patient Experience and Quality of Life

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Objective. To assess the association of proxy-specific covariates with proxy-reported patient cancer care experience, quality rating, and quality of life.

Data Sources/Study Setting. Secondary analysis of data from the Cancer Care Outcomes Research and Surveillance (CanCORS) study.

Study Design. Cross-sectional observational study. The respondents were proxies for patients with incident colorectal or lung cancer.

Data Collection/Extraction Methods. Analyses used linear regression models and adjusted for patient sociodemographic and clinical characteristics. Outcomes included patients' experiences with medical care, nursing care, and care coordination, overall quality ratings, and physical and mental health, all scored on 0–100 scales (0 = worst, 100 = best). Independent variables included the proxy's relationship with the patient and engagement in patient care.

Principal Findings. Of 1,011 proxies, most were the patient's spouse (50 percent) or child (36 percent). Although most proxies (66 percent) always attended medical visits, 3 percent reported never attending. After adjustment, on average children reported worse experiences and poorer quality care than spouses (4–9 points lower across outcomes). Proxies who never attended medical visits reported significantly worse medical care (–11 points, 95 percent CI = –18 to –3) and care coordination (–13 points, 95 percent CI = –20 to –6).

Conclusions. Collecting data on proxy engagement in care is warranted if proxy responses are used.

Key Words. Caregiver, proxy, experience, quality of life, cancer

Patient-reported outcomes are an increasingly important part of public reporting and payment incentives in health care. Medicare's Value-Based Purchasing Program incorporates patient-reported experiences from the Consumer Assessment of Health Care Plans Survey (CAHPS) (Centers for Medicare and

Medicaid Services 2016a). Additionally, the Center for Medicare and Medicaid Services (CMS) uses patient-reported health status obtained through the Medicare Health Outcomes Survey (MHOS) as part of their calculation for publicly reported star ratings for Medicare Advantage plans (Centers for Medicare and Medicaid Services 2016b). Importantly, these and other surveys such as the Medical Expenditure Panel Survey allow for the use of proxies such as family members to answer on the patient's behalf if needed. In these situations, the proxy is effectively substituting for what would be an otherwise unavailable patient response.

Prior research suggests that it may be important to measure and possibly adjust for characteristics of the proxy-patient relationship (Elliott et al. 2008; Wehby et al. 2016). In paired patient-proxy studies, better patient-proxy agreement has been reported for proxies who live with the patient (Higashi et al. 2005), and for proxies who are spouses/partners (Stricker et al. 2011). At present, the MHOS asks proxies to indicate only whether or not they are a friend, relative, or professional caregiver for the patient (National Committee for Quality Assurance 2016) and CAHPS surveys do not ask about the proxy-patient relationship (Centers for Medicare and Medicaid Services 2014). Other proxy characteristics such as proxy age and gender may affect proxy-patient agreement, although these results are not consistent across studies (Tang and McCorkle 2002; McPherson and Addington-Hall 2003). If these variables are associated with proxy response and can reduce discrepancies between patient and proxy reports, then their collection, use, and reporting become relevant. However, relatively few studies collect information about proxy characteristics (Roydhouse and Wilson 2017), making it difficult to provide informed recommendations regarding data collection. We sought to ascertain the association of proxy characteristics, including experience with and knowledge of patient care, with proxy reports of patient cancer care experience, care quality, and health-related quality of life using a large, nationally representative dataset of patients with incident lung or colorectal cancer.

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METHODS

Data Source and Study Sample

This study used the Cancer Care Outcomes and Research Surveillance Consortium (CanCORS) dataset, a large, nationally representative population-based study of patients with incident lung and colorectal cancer (Catalano et al. 2013). As described previously, patients were identified shortly after diagnosis and trained interviewers collected data using computer-assisted telephone interviews approximately 4–7 months after diagnosis (Ayanian et al. 2010). Previous publications have described the survey instruments (Malin et al. 2006), recruitment approach (Ayanian et al. 2010), and statistical methodology (He et al. 2010). The American Association for Public Opinion Research response and cooperation rates were 51 percent and 60 percent, respectively (Catalano et al. 2013). Additionally, relevant clinical information such as cancer stage was drawn from medical records or cancer registries.

CanCORS administered detailed surveys that covered a wide range of topics (Malin et al. 2006), including patient experience of care and ratings of care quality (Ayanian et al. 2010), symptoms (Walling et al. 2015), health-related quality of life (Kenzik et al. 2015), clinical trial involvement (Kehl et al. 2014), and perception of likelihood of cure (Weeks et al. 2012). Surveys were administered to patients or proxies if patients were too ill or otherwise unable to reply, or had died.

For this analysis, we placed two restrictions on the study sample. We did not evaluate responses from proxies of patients who were deceased at the time of the survey ($N = 1,738$), as these proxies are not substitutes for an otherwise available patient response. Second, we only included proxies who completed the full baseline version of the survey, as only this version contained all items of interest. Our study sample thus consisted of proxies who answered on behalf of living patients and completed the full version of the survey ($N = 1,011$). We did not include respondents who answered on their own behalf because these individuals were sufficiently healthy to complete the lengthy survey and hence reported consistently higher levels of mental and physical health than those with proxy respondents (Table S1).

Study Outcomes and Variables

Study Outcomes. Patient experience of care fell into three domains: (1) medical care, (2) nursing care, and (3) care coordination/responsiveness. For each

item, patients reported Always/Usually/Sometimes/Never (1- to 4-point scale) and items were reverse coded and then used to calculate composite domain scores, which were linearly transformed to a 0–100 scale (Ayanian et al. 2010; Martinez et al. 2015). Item-level responses which did not fall into the prespecified categories, such as “n/a” or “don’t know,” could not be added to the composite, and the score was then missing for that respondent. Rating of overall care quality was assessed through a single item on a 1- to 5-point scale (excellent, very good, good, fair, poor), which was reverse coded and then linearly transformed to a 0–100 scale.

Health-related quality of life was evaluated using the SF-12 (v2), a well-validated and frequently used scale (Gandek et al. 1998). The SF-12 consists of 12 items on 3- or 5-point scales which are then summed, weighted, and normalized to produce two composite scales, the Physical and Mental Component Summaries (PCS, MCS), reflecting the domains of physical and mental health, respectively. Items with responses outside the scale values or non-numeric responses such as “n/a” or “don’t know” could not contribute to the scale score, and the score was missing for the respondent. Both scales range from 0 (worst) to 100 (best), with normalized means of 50 and standard deviations of 10.

For the patient surveys, patients were asked to report on their care experience and quality. For the proxy surveys, the proxies adopted the proxy–patient perspective (Pickard et al. 2009) and reported from the patient’s point of view.

Study Variables. As relatively little information is available as to the importance of different proxy characteristics, we included all proxy-related characteristics that were collected in the CanCORS survey. These items were included based on their potential to provide insight into how well the proxy might understand the patient’s experiences. The variables of interest were proxy characteristics, including relationship with the patient (categorized as spouse/partner, child [including daughter-in-law and son-in-law], other relative [e.g., sibling, parent] or nonrelative), frequency of proxy–patient contact, and how often patients talked to proxies about how they felt. Frequency of proxy–patient contact was ascertained by asking, “In the last week, how many days did you have contact either in person or by telephone with [the patient]?” (1, 2, 3, 4, 5, 6, 7, or Don’t Know). We categorized this as 1–3 days per week, 4–6 days per week, and 7 days per week due to small numbers of proxies answering 1, 2, or 3 days. Proxies were also asked, “How often does [the patient] speak with you about how [he/she] is feeling? Would you say always,

usually, sometimes, or never?" (Always/Usually/Sometimes/Never/Don't Know). We retained this categorization for analysis.

Additional variables reflecting involvement in or knowledge of patient care included how often proxies were present when patients spoke with their doctor ("When [the patient] has a doctor appointment, how often are you present when [he/she] speaks with the doctor? Would you say always, usually, sometimes, or never?") and how often patients talked about important medical treatment decisions regarding their cancer with proxies ("How often does [the patient] speak with you about important medical decisions regarding [his/her] treatment for [his/her] colorectal or lung problem? Would you say always, usually, sometimes, or never?"). We used these categorizations for analysis.

Finally, proxy sociodemographic variables included gender (Male/Female) and level of education, which for simplicity we categorized as follows: Less than a high school diploma (completion of grade school or high school up to 11th grade)/Less than a university degree (including completion of high school and/or receiving a GED, or completing vocational schools, or completing 3 years of university education but not receiving a degree), or completing a university degree (including undergraduate and postgraduate/professional degrees). For all proxy variables, responses of "Don't Know" were treated as missing and excluded; these comprised a very small number of responses (see Table 1 in Results).

As our goal was to understand how proxy-specific variables might contribute, our analyses also included patient-specific variables used in standard case mix models for the outcomes of interest. Our goal in selecting these variables was to emulate frequently used adjustment models, to examine proxy-specific variables after accounting for patient-specific covariates that are likely to be used.

For experiences with care and quality ratings, we included covariates used in analyses of CAHPS data, while also adding cancer-specific covariates due to the focus of the CanCORS study. Specifically, these covariates were cancer type; disease stage (categorized as incurable [stage IV colorectal and stage IIIB/IV lung] or potentially curable); CanCORS study site; patient race/ethnicity; patient age; language of survey administration (English, Spanish or Chinese); patient education; proxy-reported patient general health status; and proxy-reported patient mental health status (operationalized as how frequently the patient felt calm and peaceful).

For the HRQOL outcomes, we included covariates used in analyses of MHOS data, as well as the additional cancer-specific variables described above and patient hospitalization in the past year. Following the approach

used for MHOS data, we also adjusted for whether the patient had specified comorbidities. In this study, the comorbidities were as follows: heart attack and/or bypass, heart failure, stroke, arterial bypass, lung disease, diabetes, kidney problems, depression, previous diagnosis of cancer.

Analyses

Missing Data. In CanCORS, multiple imputation for covariates and outcomes using sequential regression imputation was undertaken using IVEware (He et al. 2010), producing $m = 5$ imputed datasets. The imputation allowed for categories such as “n/a” and/or “don’t know” for covariates, which appeared relatively infrequently in the data ($N = 4$ proxies reported this for proxy-specific covariates). For simplicity, these individuals were excluded. We also restricted the analyses to respondents with complete case mix covariates, resulting in analytic cohorts of $N = 1,003$ for the experience/quality outcomes ($N = 8$ excluded) and $N = 1,001$ for the quality-of-life outcomes ($N = 10$ excluded). All analyses were performed in SAS (v9.4), with calculations undertaken in R Studio (v3.2.2).

Association of Proxy Covariates with Reports of Patients’ Experiences and QOL. We evaluated the association between proxy-specific covariates and proxy-reported outcomes using multivariable linear regression models. Each outcome was modeled separately. The models consisted of the proxy variable of interest (e.g., the proxy–patient relationship), as well as the patient covariates described in the section “Study Variables” above. R^2 was used as a measure of the explanatory power of the covariates and calculated in each imputed dataset and then pooled using Harel’s approach (Harel 2009; Chaurasia and Harel 2015). The multiple partial F-test was used to evaluate the contribution of covariates and estimated for multiply imputed data (Raghuathan and Dong 2011).

RESULTS

Study Population

As Table 1 shows, 50 percent of the proxies were the patient’s partner or spouse, with children comprising the second largest category of proxies (36 percent). Most proxies were in daily contact with the patient (88 percent), and most (66 percent) always accompanied the patients to medical consultations

Table 1: Characteristics of Proxy Study Sample ($N = 1,002$): Observed Data[†]

Category	Overall ($N = 1,002$) [*]	Spouse/Partner ($N = 497$)	Child ($N = 362$)	Other Relative ($N = 85$)	Other Nonrelative ($N = 58$)
Proxy type					
Spouse/partner	497 (50)	497 (100)			
Child (incl. in-laws)	362 (36)		362 (100)		
Other relative	85 (8)			85 (100)	
Other nonrelative	58 (6)				58 (100)
Frequency of proxy/patient contact					
1–3 days/week	58 (6)	3 (1)	36 (10)	13 (15)	6 (10)
4–6 days/week	59 (6)	6 (1)	38 (11)	9 (11)	6 (10)
7 days/week (daily)	879 (88)	485 (98)	286 (79)	63 (74)	45 (78)
Missing	6 (1)	3 (1)	2 (1)	0 (0)	1 (2)
Proxy and patient discuss patients' feelings					
Always	644 (64)	321 (65)	234 (65)	47 (55)	42 (72)
Usually	196 (20)	99 (20)	65 (18)	21 (25)	11 (19)
Sometimes	134 (13)	66 (13)	52 (14)	13 (15)	3 (5)
Never	24 (2)	9 (2)	9 (2)	4 (5)	2 (3)
Missing (unknown, n/a)	4 (<1)	2 (<1)	2 (1)	0 (0)	0 (0)
Proxy attends patient medical visits					
Always	664 (66)	365 (73)	228 (63)	42 (49)	29 (50)
Usually	170 (17)	71 (14)	67 (19)	16 (19)	16 (28)
Sometimes	141 (14)	56 (11)	57 (16)	20 (24)	8 (14)
Never	26 (3)	4 (1)	10 (3)	7 (8)	5 (9)
Missing (n/a)	1 (<1)	1 (<1)	0 (0)	0 (0)	0 (0)
Proxy and patient discuss important treatment decisions					
Always	721 (72)	379 (76)	255 (70)	48 (56)	39 (67)
Usually	104 (10)	43 (9)	41 (11)	14 (16)	6 (10)
Sometimes	117 (12)	50 (10)	40 (11)	18 (21)	9 (16)
Never	55 (5)	23 (5)	23 (6)	5 (6)	4 (7)
Missing (unknown, n/a)	5 (1)	2 (<1)	3 (1)	0 (0)	0 (0)
Proxy gender					
Male	151 (15)	54 (11)	73 (20)	14 (16)	10 (17)
Female	850 (85)	442 (89)	289 (80)	71 (84)	48 (83)
Missing (n/a)	1 (<1)	1 (<1)	0 (0)	0 (0)	0 (0)
Proxy education					
<High school	163 (16)	94 (19)	45 (12)	10 (12)	14 (24)
<University	605 (60)	315 (63)	201 (56)	56 (66)	33 (57)
University [§]	224 (22)	85 (17)	111 (31)	18 (21)	10 (17)
Missing	10 (1)	3 (1)	5 (1)	1 (1)	1 (2)

[†]Observed and not imputed data presented.

[§]Proxies who did not provide an answer as to type ($N = 9$) are not presented here due to small cell sizes.

and always talked with the patient about important medical decisions (72 percent). Most proxies also reported always discussing the patient's feelings with them (64 percent). A minority of proxies reported never talking about medical decisions (5 percent) or attending medical visits (3 percent); in all cases, spouses had the lowest proportion of "never" involvement. Most proxies were women (85 percent), and only a minority had completed a university degree (22 percent).

In terms of patient characteristics, nonspousal proxies were more likely to report on behalf of older patients (Table S2). For example, 19 percent of spousal proxies were reporting for a patient aged 80 or over, compared with 46 percent of child proxies. While most proxies completed English language surveys, 12 percent of child proxies used a non-English language survey, compared with 4 percent of spouses. Patients with spousal proxies were most often white (71 percent vs. 50 percent or less for all other proxy types), and other races/ethnicities were more often represented by nonspousal proxies (e.g., 14 percent Asian for child proxies, vs. <10 percent for all other proxy types).

Association of Proxy Characteristics with Experiences/Ratings and Quality of Life

Care Experiences/Ratings. On average, spouses/partners consistently reported higher experience/quality scores than children, other relatives, or nonrelatives (1–9 points higher, depending on the outcome and the comparator, Table 2). Nursing care experience and care coordination scores decreased as proxy frequency of contact with patients decreased. Variables reflecting proxy engagement in care were also associated with several outcomes, with decreasing attendance associated with increasingly negative reports for medical care experience and care coordination. Proxies who never attended consultations had scores that were 11 points lower (medical care) and 13 points lower (care coordination) on average. Regular attendance at consultations was also associated with higher quality ratings. Proxy gender was not associated with experience or quality ratings. Proxy education level was not significantly associated with most outcomes, although proxies with less education gave higher scores for nursing care experience on average than university graduates (+4 points for high school graduates and +7 points for proxies who did not complete high school).

Quality of Life. For quality-of-life outcomes (Table 3), none of the proxy characteristics were significantly associated with proxy-reported physical health. Spousal-provided mental health scores were higher than those reported by

Table 2: Adjusted Differences in Experiences with Medical Care, Nursing Care, and Care Coordination and Quality Ratings by Proxy-Specific Characteristics

<i>Covariate</i>	<i>Medical Care: 0–100 Scale (N = 1,003)</i>	<i>Nursing Care: 0–100 Scale (N = 1,003)</i>	<i>Care Coordination: 0–100 Scale (N = 972)</i>	<i>Quality Rating: 0–100 Item (N = 1,003)</i>
Proxy–patient relationship				
Child proxy	–3 (–6 to –1)	–9 (–12 to –6)	–7 (–9 to –4)	–7 (–10 to –4)
Other relative	–5 (–9 to –1)	–9 (–13 to –4)	–6 (–11 to –2)	–3 (–9 to 2)
Other nonrelative	–2 (–7 to 3)	–7 (–13 to –2)	–1 (–6 to 4)	–5 (–12 to 1)
Spouse/partner	Referent	Referent	Referent	Referent
Proxy–patient contact frequency				
1–3 days/week	–4 (–9 to 1)	–8 (–14 to –3)	–9 (–14 to –4)	–6 (–12 to <1)
4–6 days/week	–4 (–9 to 1)	–6 (–12 to –1)	–3 (–8 to 2)	1 (–5 to 7)
7 days/week (daily)	Referent	Referent	Referent	Referent
Discussion of patient feelings				
Always	Referent	Referent	Referent	Referent
Usually	–5 (–8 to –2)	–3 (–6 to <1)	–4 (–7 to –1)	1 (–3 to 5)
Sometimes	–5 (–9 to –2)	–2 (–6 to 2)	–4 (–8 to –1)	–6 (–10 to –2)
Never	–8 (–15 to <1)	–2 (–11 to 6)	–4 (–12 to 3)	–8 (–17 to 2)
Proxy attendance at consults				
Always	Referent	Referent	Referent	Referent
Usually	–4 (–7 to –1)	–4 (–8 to –1)	–4 (–7 to –1)	–1 (–5 to 3)
Sometimes	–6 (–9 to –3)	–3 (–7 to <1)	–8 (–11 to –4)	–7 (–11 to –2)
Never	–11 (–18 to –3)	–6 (–15 to 2)	–13 (–20 to –6)	–7 (–17 to 2)
Discussion of medical decisions				
Always	Referent	Referent	Referent	Referent
Usually	–8 (–12 to –5)	–3 (–7 to 1)	–6 (–10 to –2)	–5 (–10 to <0)
Sometimes	–9 (–12 to –5)	–3 (–7 to 1)	–5 (–9 to –2)	–5 (–9 to <0)
Never	–8 (–13 to –3)	–4 (–9 to 2)	–2 (–7 to 4)	–2 (–8 to 5)
Proxy gender				
Male	<1 (–3 to 4)	1 (–2 to 5)	–1 (–4 to 2)	–1 (–5 to 4)
Female	Referent	Referent	Referent	Referent
Proxy education				
Non–high school graduate	2 (–3 to 6)	7 (2 to 11)	5 (1 to 9)	1 (–4 to 7)
High school/ some university	1 (–2 to 4)	4 (<1 to 7)	3 (<0 to 6)	<0 (–4 to 4)
University ^s	Referent	Referent	Referent	Referent

Notes. Adjustment means case mix variables: cancer type, stage, CanCORS site, patient race/ethnicity, patient age, language of survey, patient educational attainment, patient general health status, patient mental health status. Bolded text indicates that this variable's F -statistic has $p < 0.05$ (statistically different from 0). R^2 for models range from 0.06 to 0.20.

Table 3: Adjusted Differences in Physical and Mental Health Quality-of-Life Proxy-Specific Characteristics

<i>Covariate</i>	<i>Physical Health: 0–100 Scale (N = 997)</i>	<i>Mental Health: 0–100 Scale (N = 997)</i>
Proxy–patient relationship		
Child proxy	1 (–1 to 3)	–5 (–7 to –2)
Other relative	–2 (–5 to 1)	–5 (–8 to –1)
Other nonrelative	<1 (–3 to 4)	–3 (–7 to 1)
Spouse/partner	Referent	Referent
Proxy–patient contact frequency		
1–3 days/week	1 (–2 to 4)	1 (–2 to 5)
4–6 days/week	<1 (–3 to 3)	<1 (–3 to 3)
7 days/week (daily)	Referent	Referent
Discussion of patient feelings		
Always	Referent	Referent
Usually	–2 (–3 to <1)	2 (<1 to 4)
Sometimes	<1 (–2 to 2)	2 (<0 to 4)
Never	<1 (–4 to 5)	–6 (–11 to –1)
Proxy attendance at consults		
Always	Referent	Referent
Usually	1 (–1 to 3)	1 (–1 to 4)
Sometimes	2 (<1 to 4)	–1 (–3 to 1)
Never	3 (–1 to 7)	–1 (–6 to 4)
Discussion of medical decisions		
Always	Referent	Referent
Usually	–2 (–5 to <0)	–1 (–3 to 2)
Sometimes	1 (–1 to 3)	–3 (–5 to <0)
Never	1 (–2 to 4)	–6 (–10 to –3)
Proxy gender		
Male	–1 (–3 to 1)	–1 (–3 to 1)
Female	Referent	Referent
Proxy education		
Non–high school graduate	–2 (–4 to 1)	–1 (–4 to 2)
High school/some university	<0 (–2 to 1)	–1 (–3 to 1)
University [§]	Referent	Referent

Notes. Adjustment means case mix variables: cancer type, stage, CanCORS site, patient gender, patient marital status, patient race/ethnicity, patient age, patient educational attainment, hospitalization in past year, history of heart failure, history of stroke, history of arterial bypass, lung disease, diabetes, kidney problems, depression, previous cancer, coronary artery disease (heart attack and/or bypass). Bolded text indicates that this variable’s *F*-statistic has *p* < 0.05 (statistically different from 0). *R*² for models range from 0.15 to 0.19.

child proxies and other relatives. Interestingly, for discussion of patient feelings, average mental health scores were higher for proxies who usually (+2 points) or sometimes (+2 points) discussed feelings, relative to those who

always did; however, scores for proxies who never discussed feelings were lower (−6 points) compared to those that always did. Proxy attendance at consultations was not associated with proxy-reported mental health, but proxies who reported less frequent discussion of treatment decisions also reported lower patient mental health scores. Proxies who never discussed treatment decisions reported patient scores as 6 points lower on average compared with those of proxies who always discussed these decisions. Proxy gender and education were not significantly associated with any quality-of-life outcome.

DISCUSSION

This research has three main findings. First, even after adjustment for patient characteristics, spouse/proxy respondents reported significantly higher scores for nursing care, care coordination, and overall quality compared with child, other relative, or other proxies. Second, measures of the proxy's level of engagement with care were generally significantly associated with experience outcomes, with lower levels of engagement associated with lower scores despite adjustment for patient characteristics. Third, proxy characteristics were not significantly associated with patient physical health outcomes, but they were often associated with mental health outcomes, again with lower levels of engagement associated with worse assessments of patient mental health.

At present, little, if any, information is routinely collected about proxies in either surveys or research on proxies for evaluations of experience and quality. For example, a comparison of proxy and patient responses for hospital experience relied on hospital-provided covariate information (Bjertnaes 2014) and thus contained no information about proxy responders. When proxy-specific characteristics are collected, the proxy–patient relationship (e.g., spouse/partner, child) appears to be the most frequently collected characteristic. For example, an analysis of the impact of proxy reporting and proxy assistance on CAHPS surveys of Medicare fee-for-service beneficiaries was able to look at the impact of proxy type and suggested that spouses may be better proxies (Elliott et al. 2008). Interestingly, a comparison of concordance with health care utilization claims using a survey of elderly respondents found child proxies to be the most claims concordant (Wehby et al. 2016). In any case, for both analyses, proxy type was the only proxy-specific characteristic available, as is the case for analyses of other surveys such as the Medicare Current Beneficiary Survey (Bann, Berkman, and Kuo 2004).

Even in paired proxy–patient experience studies, proxy information is rarely collected. For example, an evaluation of proxy–patient agreement for care satisfaction among nursing home residents only collected the type of proxy–patient relationship, operationalized as family/friend/other (Castle 2005). A comparison of proxy and patient responses for satisfaction with ICU care collected proxy–patient relationship type as well as proxy age, gender, educational attainment, and weekly frequency of visits to the patient (Stricker et al. 2011). In this study, most proxies reported frequently visiting the patient, but 1 percent reported very infrequent visits (1–2 days/week or <1 day/week). This is consistent with our finding that most proxies were in frequent contact with the patient and involved in patient care, but a minority had little to no involvement. Our findings suggest that proxy engagement in care should be collected. Researchers may want to consider excluding proxies who report no engagement in care from their samples, or at least asking further questions of these individuals to better understand how they developed their report of the patient’s experience.

This study had several limitations. First, the possibility of nonresponse bias in the CanCORS study exists, although the response rate was in line with other major population-based studies such as the BRFSS (Schneider et al. 2012). Second, CanCORS, like many other surveys, suffered from missing data; while multiple imputation was used to mitigate this, we cannot definitively test the missing at random assumption which underlies the use of this technique. Third, while we included several proxy-specific covariates, including infrequently collected or discussed covariates, there may be other, unobserved covariates which have explanatory power. Relatedly, the work was exploratory, and we did not select proxy-specific variables based on an a priori conceptual framework but included all items collected in the CanCORS survey. Further research is required to identify other proxy characteristics that may be relevant for data collection, and future studies engaging in this work would benefit from collecting and analyzing variables based on a strong conceptual framework. Fourth, the sample sizes were relatively small for some proxy characteristics, which limits our ability to make strong inferences about these groups. Finally, future research is needed to evaluate the generalizability of these findings to noncancer care.

The study also had several strengths. Few studies have investigated the impact of proxy-specific covariates, particularly for proxy evaluations of care experience and quality. Furthermore, the small number of studies that have addressed this issue has typically only examined a small number of covariates and only infrequently looked at covariates which address different aspects of

the proxy–patient relationship and the extent of the proxy’s involvement in care.

CONCLUSION

Proxy characteristics are associated with proxy reports of patient care experience and quality of life. Proxies that are not the patient’s spouse/partner or are less engaged in patient care tend to provide more negative reports of patient care experience and quality of life. These findings suggest that it may be beneficial to collect proxy-specific characteristics in health research that uses proxy reporting.

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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.

Table S1: Adjusted* Differences in Outcomes by Proxy-Specific Characteristics: Comparison to Patient Self-report for Quality of Life Outcomes.

Table S2: Proxy Study Sample ($N = 1,002$): Characteristics of Patients Requiring Proxies—Observed Data.