



Title

Patient and proxy reports regarding the experience of treatment decision-making in cancer care

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Keywords

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Running Title

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ABSTRACT

Objective: Shared decision-making, including the elicitation of patient preferences regarding treatment decisions, is considered part of high-quality cancer care. However, patients may not be able to self-report due to illness, and therefore proxy reports may be used. We sought to determine the difference between proxy and patient reports about patient decisions and preferences among patients who received or were scheduled for chemotherapy using data from a large, population-based survey of patients with incident lung or colorectal cancer.

Methods: Of 3,573 patients who received or were scheduled for chemotherapy, 3,108 self-reported and 465 had proxies reporting on their behalf about preferred and actual decision roles regarding this treatment. Preferred and actual decision roles were assessed using the Control Preferences Scale, and categorized as shared, patient-controlled, or doctor-controlled. Multivariable logistic regression models were used to assess the association between patient and proxy responses and whether preferences were met. The models adjusted for sociodemographic and clinical variables and patient/proxy-reported health status.

Results: Sixty-three percent of all respondents reported actual roles in decisions that matched their preferred roles (role attainment). Proxies and patients were similarly likely to report role attainment (65% vs 63%). In adjusted analyses, proxies were more likely report role attainment (OR=1.27, 95%CI=1.02-1.59), but this difference was smaller if health variables were excluded from the model (OR=1.14, 95%CI=0.92-1.41).

Conclusion: Most patients' preferences for treatment participation were met. Surveys from proxies appear to yield small differences on the reports of attainment of preferred treatment decision-making roles in cancer care versus surveys from patients.

Keywords

Cancer, oncology, patient experience, proxy, psycho-oncology, shared decision-making, treatment preference

BACKGROUND

The Institute of Medicine defines high-quality cancer care as patient-centric, and specifies that such care includes good communication and shared decision making.¹ Eliciting patient treatment preferences is emphasized as part of high-quality communication.¹ Previous research has indicated that patient preferences for treatment engagement vary, but patients who attained their preferred roles were more satisfied with treatment decisions.² Shared decision-making has been positively associated with perceived care quality,³ while not attaining one's preferred decision-making role is negatively associated with health-related quality of life.⁴

Additionally, surveys assessing how patients experience care are frequent.⁵⁻⁷ This assessment can include an evaluation of shared decision-making; for example, the Consumer Assessment of Health Plans Survey (CAHPS) for Cancer Care includes supplemental items related to shared decision-making.⁸ However, such experience surveys do not solely involve patients. If patients are unable to respond, proxies are asked to report on the patient's behalf. The potential impact of proxy reporting in experience surveys has been evaluated previously.^{5,9} However, information on how proxy reporting may affect estimates of shared decision-making is limited.

Research suggests that proxy reports best approximate patient reports when the outcome of interest is observable.¹⁰ Evaluating treatment decision-making roles requires the assessment of both patient preferences and the actual role in decisions that patients experienced. Furthermore, proxies may project their own preferences on to the patient,¹¹ although this finding is not consistent across studies.¹² The evaluation of proxy-patient concordance using paired data has had mixed results. Concordance with current

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preferences was moderate to good for patients with mild dementia and their spouses and caregivers,^{12,13} but poorer regarding preferences for hypothetical scenarios involving future events.¹³

Importantly, this previous research has primarily emphasized hypothetical or future treatment scenarios. In contrast, experience surveys focus on past or current treatment decisions. Thus, it is unclear how applicable the previous literature is to this context. Paired proxy-patient evaluations are important for assessing concordance, but the generalizability of such results to situations where patients are unable to self-report is unclear. It is important to understand the impact of proxy reporting in such situations.

We therefore sought to understand if including proxy reports was associated with preferred decision roles and role attainment using a large, population-based survey of patients with newly-diagnosed cancer. We focused on treatment decisions relating to chemotherapy as it remains a mainstay of cancer treatment. Additionally, new payment models seeking to improve cancer care in the US such as the Oncology Care Model have focused on practices that administer chemotherapy.¹⁴

METHODS

Patients and Settings

We used data from the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) study, a large, multi-regional, population-based study of patients with newly-diagnosed lung or colorectal cancer during 2003 to 2005 identified using rapid case ascertainment.¹⁵ Briefly, CanCORS participants were drawn from multiple US geographic regions and health systems in the US. Interviewers surveyed participants approximately three to six months after diagnosis using computer-assisted telephone interviews.¹⁵ Patients who were contacted but unable to respond due to illness or other factors nominated a proxy to complete the interview on their behalf. Patients or their proxies reported sociodemographic and

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clinical information, symptoms, health-related quality of life, care experiences, and preferred and actual decision-making roles. American Joint Committee on Cancer stage was abstracted from medical records. If medical record data were not available, stage was obtained from cancer registries (for a small number of patients, only historical stage was available). Additional details about CanCORS recruitment,¹⁶ representativeness,¹⁷ survey instruments¹⁸ and imputation methods¹⁹ have been reported elsewhere. The American Association for Public Opinion Research¹⁷ survey response rate was 51.0% and the cooperation rate (“the proportion of all cases interviewed of all eligible units ever contacted”)^{20(p.6)} was 59.9%. The Dana-Farber Cancer Institute approved the CanCORS study (2002-P-000196), and approvals were obtained for CanCORS Primary Data Collection Research (PDCR) sites. The CanCORS study was approved by human subjects research committees (IRBs) at all participating institutions. Participants at 2 PDCR sites provided written informed consent. The other site IRBs waived this requirement; verbal informed consent was obtained at those sites in lieu of written consent. CanCORS was conducted in agreement with the Declaration of Helsinki.

This analysis used the core (dataset version 1.18) and baseline survey (dataset version 1.12) datasets. Among the 6471 patients or proxies who completed the baseline survey, we focused on the 3573 participants (465 proxies and 3108 patients) who reported receiving or being scheduled to receive chemotherapy and also provided information about their preferred decision-making roles and their decision-making role with regard to chemotherapy. Only n=62 patients were not eligible to be included in the study population (Appendix 1).

Instruments

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Patient decision preferences and actual roles were measured using categories derived from the Control Preferences Scale.²¹ To assess preferences, patients were asked as to the role they would prefer to play in treatment decision-making. Following the question, a series of statements (Table 1) were provided and patients indicated their agreement with one of the statements. Patients were also asked about the role they played regarding the decision about chemotherapy and the same statements were provided, with “prefer to make the decision” changed to “made the decision.” Proxies were asked the same question and provided the same statements, but the question prompt referred to the role the patient preferred to play/played. Following previous studies,^{3, 22} we categorized these roles into three groups, defined as “patient-controlled,” “shared,” and “doctor-controlled” decisions (Table 1). We considered patients to have attained their preferred role if the preferred and actual roles were in the same category (e.g., both shared). As noted above, patient socio-demographic characteristics were collected as part of the CanCORS questionnaire, as was medical history (e.g. comorbid conditions).¹⁸ The health status questions in CanCORS were from the SF-12.¹⁸ For health status questions, patients were asked about how they felt, whereas proxies were asked how they thought the patient was feeling.

Data Analyses

The primary independent variable was the use of a proxy respondent. Using an indicator variable for proxy status is a common method in surveys that collect proxy-reported data.²³ After reviewing the literature, including the CAHPS instruments,^{24, 25} we identified covariates to include in our adjustment models. These included patient age, race, whether the patient had Medicaid/low-income insurance and patient or proxy-reported patient co-morbidities, general health status, and mental health status (operationalized as how often the patient felt calm and peaceful); this covariate has been used in previous CAHPS analyses.²⁶ We also adjusted for CanCORS study site, the language in which the survey was

administered (English, Spanish, and Chinese), cancer type (lung/colorectal), and cancer stage, defined as not advanced (stage I, II, III, local/regional), advanced (stage IV, distant), or unstaged.

Statistical Methods

Descriptive statistics were used to compare proxy and patient reports of preferred and actual roles. Multivariable logistic regression models were used to explore the conditional association of proxy respondent status with role attainment, adjusting for the covariates listed above. To examine the sensitivity of the estimates to the health status covariates, we also explored multivariable logistic regression models that accounted for all characteristics except patient- and proxy-reported patient general and mental health (because poor patient health may lead to proxy responses). We obtained adjusted probabilities of role attainment by respondent status, holding all other variables at their mean values. Finally, among proxies, we examined if their relationship with the patient affected reports of role attainment after adjusting for the aforementioned covariates using a multivariable logistic regression model. Analyses were conducted using SAS (v9.4) and Stata (v15.0).

In our study population, approximately 4% of covariates were missing and were imputed using multiple imputation (MI). MI was implemented centrally with IVEware,¹⁹ resulting in m=5 imputed datasets. Analyses were conducted within each imputed dataset and then pooled using Rubin's rules. The Hosmer-Lemeshow test was used to assess model fit. Because there is no current best practice for evaluating logistic regression models in multiply imputed datasets,²⁷ we examined the Hosmer-Lemeshow test statistic in each imputed dataset.

RESULTS

Sample Characteristics

Among 3,573 patients who received or were going to receive chemotherapy, 465 (13%) had proxies respond to the survey. Of these 465 proxies, 259 (55.7%) were the patient's spouse/partner and overall 440 (95%) were a member of the patient's family. Compared with patients who reported for themselves, those with proxies tended to be older (16% vs. 5% aged ≥ 80 years, Table 2) and to have advanced disease (39% vs 30%). Additionally, reports of health status differed: 20% of patients with proxies had "poor" proxy-reported health compared with 6% of patients who self-reported.

Treatment Preferences and Role Attainment

Few proxies and patients reported a preference for doctor-controlled decision-making (8% and 6%, respectively) (Table 2). Proxies were more likely than patients to report patient preferences for patient-controlled decisions (43% vs 36%), and less likely to report preferences for shared decisions (49% vs 58%). Overall, role attainment (defined as an actual decision role that matched the preferred role) was achieved for 63% of patients regardless of respondent type. Nearly two-thirds of proxies (65%) and patients (63%) were classified as having reported role attainment.

Among patients preferring doctor-controlled decisions (Table 3), only 38% of proxies endorsed role attainment, compared with 48% of patients. Role attainment was reported for 69% of patients with proxies and 67% of patients preferring patient-controlled roles. For patients with preferences for shared decision-making, 65% of patients with proxies reported role attainment versus 62% of patients.

Association of Respondent Type and Role Attainment After Adjustment

In adjusted analyses (Table 4), there was a conditional association between proxy status and role attainment (OR 1.27, 95% CI 1.02-1.59); the adjusted probabilities of role attainment were 75% for proxy report and 70% for patient report (data not shown). If proxy- and patient-reported patient health status

covariates were excluded from the adjusted model, the association was smaller and no longer statistically significant (OR 1.14, 95% CI 0.92-1.41), and the adjusted probabilities for role attainment were 73% for proxies and 71% for patients (data not shown).

Among proxies, the type of relationship with the patient was not significantly associated with reports of role attainment. Compared to spouses, children (OR 0.91, 95% CI 0.54-1.54) and other relatives (OR 0.89, 95% CI 0.41-1.93) were less likely to report role attainment, whereas other non-relatives (OR 1.48, 95% CI 0.54-4.03) were more likely (data not shown).

DISCUSSION

Our evaluation of proxy respondent status for reported attainment of preferred decision-roles among patients receiving chemotherapy in a large, population-based cohort found generally similar rates of decision role attainment among patients whether decision roles were reported by patients themselves or proxies. In fully adjusted analyses, proxy reports were associated with statistically significant greater patient attainment of their preferred treatment decision roles, but this result was not statistically significant when proxy- and patient-reported health status were not included in the model. Furthermore, the proxy-patient relationship was not significantly associated with proxy reports of patient role attainment.

Our findings of overall and by-respondent levels of role attainment are consistent with other studies;²⁸ previous reviews of the cancer literature have reported mismatches between preferred and actual treatment roles.²⁹ However, Colley et al's recent work in patients receiving chemotherapy found higher rates of role attainment (88.7%).³⁰ One possible explanation for this discrepancy may be the patient population. Previous reviews²⁹ and studies³⁰ have indicated that decisional preferences vary across cancer

types. Our study included patients with lung and colorectal cancer, while Colley et al's study included patients with breast, gastrointestinal, gynecological and lung cancer.

The highest levels of role mismatch in our study were seen among patients and proxies reporting patient preferences for doctor-controlled decisions, but this group comprised a small proportion of the population. Additionally, our study reports patient- and proxy-reported preferences collected at one time point. Role preferences can and do change over time,²⁹ however they are often assessed at one time point. Future longitudinal research may be worthwhile.

One possible explanation for the small discrepancy between patient and proxy reports in our study may be that although role preferences are not as observable as other outcomes, it may be easier for proxies to report on preferences and actual roles pertaining to recent treatment decisions. CanCORS participants enrolled within three to six months after diagnosis and thus proxies were asked to report on relatively recent events. Earlier studies of paired proxy-patient concordance relating to preferences frequently describe hypothetical scenarios, rather than past events. However, even with hypothetical scenarios, proxies tend to more accurately predict treatment preferences in scenarios relating to the patient's current versus future health.³¹ This suggests that studies asking proxies to evaluate preferred and recent actual treatment decision roles may be asking for outcomes that are comparatively easier for proxies to report than other decision-making outcomes frequently evaluated in the literature.

Of possible concern is that despite our finding of association between proxy status and role attainment, this association appeared to be stronger in adjusted models, particularly if we included patient- or proxy-reported health status covariates as adjustment variables. In many health surveys, proxies report patient health status and these reports are used as covariates; health status is an important predictor of other

outcomes such as care experience.³² Because proxies tend to report on behalf of sicker patients, it is not clear if this reflects a true difference in experience or if it reflects proxy reporting bias. One possible explanation may be that proxies have greater involvement in the care of sicker patients as such care may be more complex. Additionally, it is unlikely that cancer stage alone may account for burden of disease and thus assessment of health status is important; however, the possibility of proxies inaccurately reporting health status must also be considered. Although health status is likely associated with proxy report, the association of health status and role attainment is less clear. Role attainment and quality of life were not associated in a study of patients with advanced lung cancer.³³ In any case, studies collecting both health status and role preference variables should consider sensitivity analyses to examine the robustness of their results to proxy-reported patient health status covariates and examine possible reasons for discrepancies.

Study Limitations

The strengths of this study include the use of a large, population-based cohort of newly-diagnosed cancer patients with many covariates. Although several studies have evaluated proxy-patient concordance about patient preferences using hypothetical scenarios and vignettes, this is one of the first to evaluate proxy reports of actual and preferred patient decision-making roles relating to patient treatment. Additionally, to the best of our knowledge few studies have compared reports of actual and preferred decision roles in population-based cohorts.

The study also has limitations. The Control Preference Scale may not fit well to all situations and in some contexts patients with cancer may struggle to perceive decisions as truly shared.³⁴ However, this scale is widely used in a variety of settings,^{28, 35} including cancer,^{30, 36, 37} and thus our analysis provides practical insight. Second, the study is subject to nonresponse bias; however, our response rate of 51%

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compares favorably with other general population-based surveys, such as the Behavioral Risk Factor Surveillance System.³⁸ Additionally, although the question prompt for the actual decision role referred to chemotherapy specifically, the question about preferred decision roles did not; a chemotherapy-specific question prompt may have resulted in different answers. Because we do not have paired patient and proxy reports, we cannot be sure if our findings are because proxy respondents report differently than patients or because patients in our study for whom proxies reported had different decision experiences. A further limitation is that we restricted our analysis to the population of patients who received or were scheduled for chemotherapy and asked patients about decisions three to six months after diagnosis. Although this has the benefit of situating our study with current efforts such as the Oncology Care Model which focus on patients who receive chemotherapy, results may differ for patients who do not receive chemotherapy or who are surveyed before beginning chemotherapy. Finally, the CanCORS data were collected in 2003 – 2005, and substantial advances in cancer treatment have occurred since that time, although chemotherapy remains an important component of anti-cancer therapy. However, CanCORS is one of the few population-based studies assessing patient care experience and thus the results may be more informative than analyses from a more recent convenience sample. Additionally, this study has a methodological focus in which the age of the data is less of a concern, as it is unclear how newer therapies would affect proxy reporting.

Clinical Implications

Our findings have implications for population-based or survey-based assessment of SDM in medical oncology, which may occur as part of experience and quality assessment for oncology clinicians. Future work examining this issue in other cancer types or more recent data would be worthwhile, given therapeutic advances as well as complex decision-making, for example for hematologic cancers such as multiple myeloma³⁹ and the acute presentation of acute myeloid leukemia.⁴⁰ Acutely-ill patients (e.g., with

acute leukemia) or those undergoing stem cell therapy, necessitating inpatient hospitalization, may have a greater need for and use of proxies, and thus assessment of this issue in other patient populations is an important next step.

Conclusions

We found relatively small differences between patient and proxy reports of the attainment of preferred treatment decision-making roles in a population-based cohort of patients with lung or colorectal cancer. These data suggest that the use of proxies may have a small impact on reports of attainment of preferred treatment decision-making roles in these tumor groups.

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CONFLICT OF INTEREST STATEMENT

Drs Roydhouse, Keating and Wilson have nothing to declare. Dr Gutman reports personal fees from Johnson & Johnson/Janssen, outside the submitted work. Dr Kehl reports paid consulting for Aetion, outside the submitted work.

DATA AVAILABILITY STATEMENT

The data are not publicly available due to privacy and ethical considerations.

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TABLES

Table 1. Categorization of roles (derived from the Control Preferences Scale)

| Category | Statement |
|--------------------|-------------------------------------------------------------------|
| | You [†] prefer... |
| Patient-controlled | To make the decision with little or no input from your doctor(s) |
| | To make the decision after considering your doctor's opinion |
| Shared | That you and your doctor make the decision together |
| Doctor-controlled | Your doctor to make the decision after considering your opinion |
| | Your doctor to make the decision with little or no input from you |

[†]Proxy version refers to “[the patient’s name]” rather than “you”

Table 2. Selected characteristics of study participants

| Characteristic | Overall(N=3573) | Proxy(N=465) | Patient(N=3108) |
|------------------------------------------|-----------------|--------------|-----------------|
| Respondent type | | | |
| Proxy | 465(13%) | | |
| Patient | 3108(87%) | | |
| Patient age | | | |
| <=59 years | 1420(40%) | 103(22%) | 1317(42%) |
| 60-69 years | 1112(31%) | 138(30%) | 974(31%) |
| 70-79 years | 825(23%) | 151(32%) | 674(22%) |
| 80+ years | 216(6%) | 73(16%) | 143(5%) |
| Patient education | | | |
| <High school | 676(19%) | 172(37%) | 504(16%) |
| Some university | 2049(57%) | 214(46%) | 1835(59%) |
| University degree+ | 833(23%) | 68(15%) | 765(25%) |
| Missing | 15(<1%) | 11(2%) | 4(<1%) |
| Patient general health [†] | | | |
| Poor | 274(8%) | 95(20%) | 179(6%) |
| Fair | 772(22%) | 150(32%) | 622(20%) |
| Good | 1236(35%) | 128(28%) | 1108(36%) |
| Very good | 916(26%) | 66(14%) | 850(27%) |
| Excellent | 358(10%) | 22(5%) | 336(11%) |
| Missing | 17(<1%) | 4(1%) | 13(<1%) |
| Patient feels calm/peaceful [†] | | | |
| None of the time | 104(3%) | 39(8%) | 65(2%) |
| A little of the time | 456(13%) | 105(23%) | 351(11%) |
| Some of the time | 927(26%) | 123(26%) | 804(26%) |
| Most of the time | 1428(40%) | 144(31%) | 1284(41%) |
| All of the time | 648(18%) | 48(10%) | 600(19%) |
| Missing | 10(<1%) | 6(1%) | 4(<1%) |
| Patient insurance | | | |
| Insured (non-Medicaid) | 2967(83%) | 341(73%) | 2626(84%) |
| Uninsured | 263(7%) | 26(6%) | 237(8%) |
| Medicaid/low income insurance | 335(9%) | 94(20%) | 241(8%) |
| Missing | 8(<1%) | 4(1%) | 4(<1%) |
| Survey language | | | |
| English | 3396(95%) | 428(92%) | 2968(96%) |
| Spanish | 112(3%) | 24(5%) | 88(3%) |
| Chinese | 65(2%) | 13(3%) | 52(2%) |
| Cancer type | | | |
| Lung | 1726(48%) | 267(57%) | 1459(47%) |
| Colorectal | 1847(52%) | 198(43%) | 1649(53%) |
| Cancer stage | | | |
| Not advanced | 2287(64%) | 252(54%) | 2035(66%) |
| Advanced | 1109(31%) | 181(39%) | 928(30%) |
| Unstaged | 177(5%) | 32(7%) | 145(5%) |

| Characteristic | Overall(N=3573) | Proxy(N=465) | Patient(N=3108) |
|-----------------------------------|------------------------|---------------------|------------------------|
| CanCORS study site | | | |
| 5 integrated delivery systems | 462(13%) | 24(5%) | 438(14%) |
| 8 counties in Northern CA | 745(21%) | 95(20%) | 650(21%) |
| State of Alabama | 487(14%) | 117(25%) | 370(12%) |
| Los Angeles County | 747(21%) | 109(23%) | 638(21%) |
| State of Iowa | 346(10%) | 40(9%) | 306(10%) |
| 23 counties in North Carolina | 383(11%) | 30(6%) | 353(11%) |
| 15 VA Medical Centers | 403(11%) | 50(11%) | 353(11%) |
| Patient race/ethnicity | | | |
| White | 2358(66%) | 272(58%) | 2086(67%) |
| Latino | 296(8%) | 54(12%) | 242(8%) |
| Black | 506(14%) | 60(13%) | 446(14%) |
| Asian | 226(6%) | 55(12%) | 171(6%) |
| Other | 187(5%) | 24(5%) | 163(5%) |
| Patient chemotherapy treatment | | | |
| Completed | 3470(97%) | 455(98%) | 3015(97%) |
| Ongoing/to start | 103(3%) | 10(2%) | 93(3%) |
| Patient gender | | | |
| Male | 2073(58%) | 356(77%) | 1717(55%) |
| Female | 1500(42%) | 109(23%) | 1391(45%) |
| Preferred decision-making role | | | |
| Doctor-controlled | 225(6%) | 37(8%) | 188(6%) |
| Patient-controlled | 1312(37%) | 202(43%) | 1110(36%) |
| Shared | 2036(57%) | 226(49%) | 1810(58%) |
| Actual chemotherapy decision role | | | |
| Doctor-controlled | 416(12%) | 41(9%) | 375(12%) |
| Patient-controlled | 1508(42%) | 217(47%) | 1291(42%) |
| Shared | 1649(46%) | 207(45%) | 1442(46%) |
| Preferred decision role attained | | | |
| No | 1316(37%) | 165(35%) | 1151(37%) |
| Yes | 2257(63%) | 300(65%) | 1957(63%) |

†Self-reported if patient, proxy-reported if proxy

Table 3. Unadjusted analyses (observed, non-imputed data): Role attainment by preferred role

| Category | Proxy(N=465) | | Patient(N=3108) | | Overall(N=3573) | |
|-----------------------|---------------------|----------|------------------------|-----------|------------------------|-----------|
| <i>Preference</i> | | | | | | |
| Doctor-controlled(n) | 37 | | 188 | | 225 | |
| Attained(n, %) | | 14(38%) | | 90(48%) | | 104(46%) |
| Patient-controlled(n) | 202 | | 1110 | | 1312 | |
| Attained(n, %) | | 139(69%) | | 741(67%) | | 880(67%) |
| Shared(n) | 226 | | 1810 | | 2036 | |
| Attained(n, %) | | 147(65%) | | 1126(62%) | | 1273(63%) |

Table 4. Association of proxy status with role attainment: Logistic regressions

| Characteristic | Adjusted analysis – all covariates [‡] | Adjusted analysis – no health status covariates |
|------------------------------------------|-------------------------------------------------|-------------------------------------------------|
| Respondent status | | |
| Proxy | 1.27(1.02-1.59) | 1.14(0.92-1.41) |
| Patient | Reference | Reference |
| Patient's general health status | | |
| Poor | Reference | |
| Fair | 1.16(0.87-1.54) | |
| Good | 1.26(0.95-1.67) | |
| Very good | 1.30(0.97-1.76) | |
| Excellent | 1.27(0.89 -1.81) | |
| Patient feels calm/peaceful [†] | | |
| None of the time | 0.64(0.41-1.002) | |
| A little of the time | 0.66(0.51-0.87) | |
| Some of the time | 0.80(0.64-0.999) | |
| Most of the time | 0.86(0.70-1.05) | |
| All of the time | Reference | |

[†]Mental health status measure; [‡]All analyses, unless otherwise specified, include adjustment for patient general and mental health status, insurance status, survey language, cancer type and stage, CanCORS site, chemotherapy completion status, and patient co-morbidities