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Exploratory Factor Analysis of a Patient-Centered Cancer Care Measure to Support Improved Assessment of Patients' Experiences

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Abstract

Objective: To increase the understanding of patient-centered care (PCC) and address the need for cross-cutting quality cancer care measures that are relevant to both patients and providers.

Study Design: An exploratory factor analysis (EFA) was performed on a short version of the Patients and the Cancer Care Experience Survey, a patient-reported measure of perceived importance of social, emotional, physical, and informational aspects of care, administered to adult patients (n=104) at a National Cancer Institute-designated comprehensive cancer center. Relationships between PCC dimensions and patient characteristics were also assessed.

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Methods: Principal axis factoring was applied and bivariate analyses were performed using Wilcoxon rank-sum tests.

Results: Most of our sample was over 60 years old (63.4%), female (57.4%), and white (74.2%), with either breast (41.2%) or prostate cancer (27.5%). A five-factor model was identified: (1) quality of life ($\alpha = .91$), (2) provider social support ($\alpha = .83$), (3) psychosocial needs ($\alpha = .91$), (4) non-provider social support ($\alpha = .79$), and (5) health information and decision-making support ($\alpha = .88$). No statistically significant associations were found between these factors and patients' characteristics.

Conclusions: A preliminary factor structure for a cancer PCC measure was identified. Our findings reinforce the interrelated nature of PCC dimensions. The lessons learned from this study may be used to develop a single PCC measure that identifies patient priorities across the cancer care continuum. Data collected from such a measure can be used to support patient engagement in treatment planning and decision-making.

Précis:

The measurement of patient-centered cancer care may be improved by utilizing and refining existing conceptual models and incorporating the assessment of individual-level factors.

Keywords

patient-centered care; cancer; instrument development; factor analysis

Introduction

Cancer care involves distressing physical, psychological, and financial burdens for patients and their families; and requires key stakeholders to make timely decisions that may have life-changing consequences [1–3]. There is a growing number of treatment options with relative advantages that depend on patient-specific characteristics (e.g. tumor characteristics, employment and financial status, and familial roles) [4, 5]. For example, a breast cancer patient with young children may prefer a double mastectomy over a lumpectomy to avoid the possibility of a second surgery in the case of a recurrence. Having multiple surgeries may require more time away from work or more assistance with childcare, causing additional distress. She may also feel conflicted about this preference because she may consider her breasts to be a major aspect of her identity. Alternatively, her provider may recommend a lumpectomy given the genetic make-up of the tumor and past patients' outcomes. Cancer care treatment decision-making can become quite complex. Understanding what matters most to patients and incorporating that information into existing evidence-based practices is critical to improving their care experiences. While delivering patient-centered care (PCC) is an established priority particularly in cancer care, determining how to define, measure, and implement PCC has proven challenging [6, 7].

Evidence Supporting PCC & Measurement Gaps

The 2001 Institute of Medicine (IOM) report, “Crossing the Quality Chasm: A New Health System For The 21st Century,” describes PCC as “care that is respectful of and responsive to

individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions,” and as a critical aspect of high quality healthcare [8](p.6). The IOM PCC model has six dimensions: 1) respect for patients’ values, preferences, and expressed needs; 2) coordination and integration of care; 3) information, communication, and education; 4) physical comfort; 5) emotional support and alleviation of fear and anxiety; and 6) involvement of family and friends [8]. Several studies report statistically significant relationships between PCC measures and various care outcomes (e.g. improved health status and medication adherence; and lower blood pressure, HbA1c levels and decreased mortality) [9–12]. Other published analyses report null or statistically weak relationships between PCC and these outcomes [9, 13]. Lack of conceptual clarity, poor operationalization and the inherent complexity of the concept are often cited as reasons for the mixed findings in the literature [9, 13–18].

In 2013, the IOM identified gaps in cancer care quality measurement and translation into practice [3] that are supported by results from other studies [19, 20]. They include: 1) issues with measure development [19, 20]; 2) the need for greater patient-engagement in measure development and reporting [19, 20]; and 3) data that allow for meaningful and timely action [19, 20]. Most major cancer care providers have not adopted one standardized process for measure development. There is a tendency to focus on process-oriented measures, and overlook key elements of the cancer care experience (e.g., patient and family engagement, care coordination, access, advanced care planning, and management of comorbidities and psychosocial needs) [3, 7, 21, 22]. Measures that apply to several different cancers are also needed [3]. Current measures reflect what has been historically most convenient to capture versus what most accurately depicts the overall quality of care. There is a specific need for more comprehensive quality measures in cancer care including those that assess patient perceptions of care [3, 23].

Patient-reported outcome measures (PROMs) have emerged to support more PCC [24]. The National Cancer Institute has created a patient-reported outcome measurement system called the Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE™). A groundbreaking study by Basch et al. showed statistically positive associations between symptom monitoring using PROMs and health-related quality of life (QOL) and overall survival among cancer patients [25]. It is important to note, however, that these PROMs assessed the symptom experience during treatment versus overall care experienced from a specific healthcare provider or system. For instance, these PROMs did not assess whether patients’ care aligned with patient-defined values, needs, or preferences as recommended by the IOM. There may be critical opportunities for advances in care being missed by not routinely collecting and reviewing individual-level patient data on key aspects of the overall cancer care experience. To address this need, researchers at a National Cancer Institute (NCI)-designated comprehensive cancer center developed and piloted the Patients and the Cancer Care Experience (PCCE) survey. This survey study was the second of three related studies designed to examine patients’ priorities and perceptions of their cancer care experience in 2014. The primary aims of this secondary analysis of the PCCE pilot survey were to: 1) examine the latent factor structure of a short version of the PCCE survey that reflects patient needs and values, and test the internal consistency of the

resulting scales; and 2) assess the associations between the perceived importance of patient needs and values identified by the EFA, and patient characteristics.

Methods

PCCE Survey Development

The findings from the thematic content analysis of a 2013 focus group study informed the PCCE survey development as recommended by the ISPOR PRO Good Research Practices Task Force Report [26]. The aim of the focus group study was to explore what patients perceived as important outcomes and aspects of their cancer care experience (see the focus group discussion guide in Appendix 1). This focus group study was IRB approved and included participants over the age of 18 with a diagnosis in one of the following cancer sites: brain, breast, colon, head & neck, lung, melanoma, ovary, prostate, and soft tissue sarcoma. Researchers found two main domains of outcomes that were important among participants: 1) the physiologic experience, which included physical, psychological, and emotional health; and 2) the treatment experience, which comprised treatment decision-making, treatment effectiveness, patient-provider communication, and obtaining health information. Key stakeholders within the institution met to discuss the identified conceptual framework and develop a survey reflective of these concepts.

The PCCE has 70 items, of those, 54 ask participants how important an aspect of care was or how concerned they were about an aspect of care on a 5-point Likert scale with responses ranging from 1=Very Important to 5=Unimportant or 1=Very Concerned to 5=Unconcerned, respectively. Participants had the option to select 6=Don't Know/Not Applicable. The data from the "Don't Know/Not Applicable" category were merged with data from the "Unimportant" category because these categories were qualitatively similar. Patients may have considered an aspect of care unimportant if they did not experience it. The remaining items included eight pertaining to patient characteristics (e.g. cancer site, age, race, ethnicity and sex), four focused on health information, and four feedback questions (Appendix 2).

PCCE Survey Pilot Study

The pilot study included individuals aged 18 years who had a mailing address in one of the 48 contiguous United States. Patients with more than one primary cancer site were excluded. A listing of all eligible patients registered in our institution's tumor registry before October 31, 2013 and last contacted on or before May 1, 2013 was created. All patients with non-gender related cancer sites were stratified by race/ethnicity and gender prior to systematic random sampling for 300 potential participants. We sent the survey to the identified sample of 300 patients via mail and e-mail using Qualtrics software [27] from January 2015 to March 2015. A letter explaining the purpose of the study and the informed consent accompanied each survey. The institution's IRB approved the parent study and the secondary analysis.

Study Design – Secondary Analysis

This study was a secondary analysis of the PCCE pilot survey data. The IOM's PCC definition informed the selection of a subset of PCCE questions to conduct an EFA. Several

PCC models exist [8, 15, 19, 28–35]; however, the IOM model of PCC is arguably the most widely recognized PCC model in the literature. The IOM’s PCC definition and the first dimension of its PCC model (respect for patients’ values, preferences, and expressed needs) incorporates three distinct constructs: values, preferences, and expressed needs [8]. We excluded preferences from the EFA because they were under-represented in the survey items [8]. After reviewing the literature, we selected conceptual definitions for the needs and values constructs in the IOM’s PCC model (Table 1). We selected these definitions based on: 1) relevance to patient care, and 2) recurring themes in the empirical and theoretical literature. A total of 54 PCCE survey items were evaluated using these conceptual definitions of values and needs to identify which items could be conceptualized as a value or need. After the evaluation, 37 items were included in the EFA. A summary of the selected items that reflect the original conceptual framework of the PCCE in the form of needs and values is provided in Table 2.

Data Analysis

Principal axis factoring was applied for factor extraction in the EFA to minimize the impact of non-normal distributions [36]. The ability to detect a latent factor structure for a dataset depends on: 1) sample size, 2) communalities (the variance of an item predicted by common factors and shared with other items), and 3) the ratio of measures per factor [37, 38]. While a participant-to-item ratio of at least 3 to 1 is recommended, there is no minimum sample size required for EFA, and our sample exceeded 50 subjects which is strongly suggested [37, 39]. We expected the participant-to-item ratio to improve during the model identification process. The Kaiser-Meyer-Olkin statistic for the data was .83 and indicated suitability for factor analysis [40, 41].

We examined the eigenvalues and scree plot to identify where the bend in the data occurred and considered the conceptual meanings of the factors to determine factor retention [38, 39]. We used an oblique factor rotation technique, promax, in anticipation of interrelationships between the latent factors in the model, and to generate a more realistic approximation of the true relationships between items [36]. We determined the internal consistency of the derived scales using Cronbach’s alpha (α). We obtained the descriptive statistics for all study variables. The Wilcoxon rank-sum test was used to test for any statistically significant associations between factor scores and patient characteristics (age, race, ethnicity, sex, and cancer site) at $\alpha = .05$. We performed Wilcoxon rank-sum tests to assess associations between cancer sites and patient demographics at $\alpha = .05$. All statistical procedures were performed using Stata 15 software (StataCorp, College Station, TX) [42].

Results

Data Screening

Data screening showed that 17 of the 37 items selected from the PCCE had positively skewed distributions. Of the 135 participants who completed the survey, 31 participants were excluded because of incomplete data, resulting in 104 participants being included in the EFA. Chi-square analyses of the missing data, patient characteristics, and PCCE variables showed that race, male sex, and concerns about “changes in physical health,” “vomiting,”

“fatigue,” “nausea,” and “chemo-brain” were associated with missing data at $\alpha < .05$. The majority of the EFA sample was over 60 years old (63.4%), female (57.4%), and white (74.2%). In addition, most participants had either breast (41.2%) or prostate cancer (27.5%). Participant characteristics are listed in Table 3.

EFA

An initial examination of the eigenvalues and the scree plot suggested a five-factor model. All factors had eigenvalues > 1 . We retained items with factor loadings > 0.30 , which is standard practice for EFAs and theoretically appropriate for this dataset [36, 39]. A four-factor and six-factor model were also reviewed, but the five-factor model was the most parsimonious, having the least number of cross-loadings and being the most conceptually logical given the relevant literature. Six items were systematically removed based on factor loading, impact on model stability, and item content; this left 31 items in the final model. The EFA results are presented in Table 4. The percentage of participants that identified each variable as being very important or very concerning is listed next to each survey item in the table to provide some context for the EFA results. The items within each of the five identified factors tended to overlap with the initial patient values and need categories, with a few variations.

The first factor in the model, QOL (Cronbach's $\alpha = .91$), had 10 items corresponding to three of the existing categories: 1) physical needs (needs associated with changes in physical health, comfort, and functioning, including, but not limited to, treatment side effects, symptoms, pain, impacts on mobility, memory, cognitive function, and sexual function); 2) general QOL values (including individuals' positive and negative subjective evaluations of life experiences); and 3) family-related QOL values (including individuals' positive and negative subjective evaluations of family-related experiences). The second factor, provider social support (Cronbach's $\alpha = .83$), had six items corresponding to three values and needs categories: 1) value for provider social support (the importance patients placed on different forms of assistance provided by providers during their cancer care experience); 2) value for non-provider social support (the importance patients placed on different forms of assistance provided by family, friends, or peers or others involved in the cancer care experience but who were not members of their healthcare teams); and 3) psychosocial needs (needs associated with psychological and emotional components of the cancer care experience). The third factor, psychosocial needs (Cronbach's $\alpha = .91$) and the fourth factor, non-provider social support (Cronbach's $\alpha = .79$), both had items that came from the same respective patient value or need category without overlap. The fifth factor, health information and decision-making support (Cronbach's $\alpha = .88$), had seven items from four categories: 1) health information values (the importance placed on health information sources and content regarding diagnosis, treatment options, preparation for treatment, and possible side effects or complications); 2) decision making values (the importance patients attributed to different aspects of providers' assistance as it related to treatment decision-making); 3) general QOL values; and 4) physical needs. The cumulative eigenvalue was .85, indicating that the 5-factor model accounted for 85% of the variance in the final set of items. There were three items cross-loadings onto more than one factor. Each factor demonstrated

adequate to high internal consistency and reliability with Cronbach's α values ranging from .79 to .91.

Factors and their Associations with Patient Characteristics

Table 5 includes the results of the Wilcoxon rank-sum tests for the associations between participants' factor scores and patient characteristics. Female sex ($p = .036$) and an age of 60 years old and under ($p = .036$) were associated with greater concern for QOL. Prostate cancer site was associated with a greater concern for social support from providers ($p = .035$) and psychosocial needs ($p = .002$), while lung cancer site was associated with less concern for psychosocial needs than other cancer sites ($p = .029$). After a Bonferroni adjustment to $p < .005$, only the association between psychosocial needs and prostate cancer site remained statistically significant. After a more conservative adjustment ($p < .001$), none of the associations were statistically significant.

Discussion

We identified a five-factor model for the shortened PCCE survey, indicating a preliminary underlying structure of cancer patients needs and values: 1) QOL, 2) provider social support, 3) psychosocial needs, 4) non-provider social support, and 5) health information and decision-making support. While needs and values are theoretically distinct, our analysis found that they were grouped together under broader concepts within PCC. All the identified factors showed good internal consistency. The identified factors aligned with PCC dimensions from the IOM's model and two other cancer PCC models with a few exceptions. PCC dimensions absent from the PCCE latent factor structure but present in the other PCC frameworks were: access [21], coordination and integration of care [8, 21, 43], and follow-up [21, 43]. These domains reflect the coordination aspect of care. This concept emerged in the focus group study that informed the development of the PCCE but it did not appear as its own domain in the EFA.

The results of the EFA revealed that some of the survey items appeared to address multiple concepts. The QOL factor included items that addressed several patient concerns including symptom experience but also how symptoms affected aspects of patients' daily lives. For example, concerns about changes in the ability to perform normal work responsibilities (Question 14E) or increased burden on family members (Question 46). These are two distinct categories within QOL and their relationship is documented in the qualitative literature [44–47] but they are in the same category in this study. When it came to provider support, community assistance and services were grouped with provider support which may reflect the perception that these groups work together to support patients or that they comprise their own category such as non-familial support or professional support. In the health information and decision-making support factor, the overlap between the two concepts is supported by the idea that health information can influence patient engagement in decision-making [48, 49]. Due to the small sample size of this study, however, the results should be interpreted with caution. Despite this, our findings offer insights on how to further refine and restructure PCC measures and improve their validity and reliability for use in oncology practice.

These examples provide additional evidence of how the interrelatedness of PCC concepts can hinder their operationalization and measurement. These complexities make it difficult to determine how to categorize concepts to develop measures that accurately reflect important aspects of the cancer care experience that: 1) vary; and 2) can be modified by providers to improve cancer patients' care experiences. This may also indicate that it is not appropriate to conduct an EFA with very broad concepts. This study reinforced that PCC incorporates several significant healthcare concepts that are interrelated. Perhaps, a set of sub-concepts within each of these larger concepts that encompass prevalent cancer patient values and needs could be identified and combined to create one overarching measure. Several validated measures already exist for symptom experience, QOL, and patient experience, respectively. Perhaps existing measures of these relevant concepts should be reviewed and streamlined into one standard PCC measure for oncology practice.

Strengths and Limitations of the Study

The small study sample size, multiple tests, and high ratings of importance and concern on several survey items restricted our ability to detect possible variations in the importance of the identified PCC dimensions with patients' characteristics. Sampling patients from an NCI-designated comprehensive cancer center may have affected our ability to apply this study's findings to individuals receiving cancer care in other settings. Study participants were predominantly white and over the age of 60 years, which limits the generalizability of the findings to younger and more ethnically diverse cancer patient populations. Another limitation was our inability to establish causality between patient characteristics and different dimensions of cancer PCC because the study was cross-sectional. Lastly, some of the PCCE survey items incorporated more than one concept which affected the ability to identify a stronger factor model.

Strengths of the study included a patient sample with different cancer diagnoses and an instrument developed based on the results of a prior qualitative research study. The use of conceptual definitions for needs and values provided structure to this study and supports the ability to compare our findings to the findings of other studies. Hopefully, this will contribute to a better understanding of PCC in the cancer context and inform more sophisticated study designs to assess PCC and advance patient-centered approaches in oncology practice.

Conclusions

This study provides initial evidence of a latent factor structure for patients' values and needs during their cancer care experience. Patients define their own needs and values but may experience difficulty expressing them; and providers often find it challenging to discern them on an individual basis [50–53]. It may be helpful to focus on values and needs separately in future studies, rather than simultaneously, as grouping them can further obscure PCC operationalization and measurement. For example, focusing on what patients' value may help with advancing the concept of PCC by simplifying research questions and producing research findings that can be more easily communicated and incorporated into clinical workflows [54]. Patients and providers could use the data obtained from a single

PCC measure to efficiently identify areas for improvement and direct action to address them across the cancer care trajectory. This study's outcomes provide a framework that incorporates both symptom and care experience factors, and this study's challenges offer insights on how to advance the development of a more comprehensive and simplified PCC measure to support improved care quality across a variety of cancer care settings.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Highlights

What is already known about the topic?

- Cross-cutting quality measures developed with strong psychometric properties and patient input are needed to assess and achieve high quality patient-centered cancer care.

What does the paper add to existing knowledge?

- A latent factor structure for PCC among cancer patients was identified that included symptom and care experiences; representing a core set of concepts for simplified evaluation.

What insights does the paper provide for informing health care-related decision-making?

- These findings may inform future validation of a PCC measure that informs providers of patient concerns that influence care decision-making.

Table 1:

Conceptual Definitions of Needs and Values

Construct	Definition
Needs	Conditions considered necessary for human well-being, which may be influenced by individual values and perceptions [55, 56]. Needs may be categorized as follows: 1) normative need –determined by expert or professional 2) felt need – determined by perception of individual; may be equated to a want 3) expressed need – felt need that is communicated 4) comparative need – obtained by observation or study of individual or group to determine gaps in the provision of a service or between current and desired states [55, 57].
Values	Beliefs that represent an individual’s interests (individualistic, collectivist, or both) and are motivated by human needs (e.g. enjoyment, security, self-direction, etc.) this may be evaluated on a scale of importance (e.g. from very important to unimportant) as a guiding principle in someone’s life.” [58] (p.10).

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Table 2:

Definitions of Patient Needs and Values from the Patients and the Cancer Care Experience Survey

Construct	Definition	# of items	Item Examples	Item scale
Physical Needs	Refers to needs associated with changes in physical health, comfort, and functioning related to the cancer experience, including, but not limited to, treatment side effects, symptoms, pain, impacts on mobility, memory, cognitive function, sexual function, and the efforts to return to a normal lifestyle [3, 7, 59, 60].	5	How concerned were you about changes to your physical health in general? How concerned were you about: d. Ability to move freely	(1=Very Concerned, 5=Unconcerned)
Psychosocial Needs	Refers to needs associated with the psychological and emotional components of the cancer care experience [61–64].	6	How concerned were you about the following issues related to emotional health: b. Anxiety c. Depression	(1=Very Concerned, 5=Unconcerned)
Value for Non-Provider Social Support	Refers to the support received by individuals in the context of their cancer care and to cancer's impact on previously existing social interactions, roles, and relationships with family, friends, and peers [65].	6	How important was your family's involvement in your treatment (e.g., the acceptance of family members at appointments, having them included in your care)?	(1=Very Important, 5=Unimportant)
Value for Provider Social Support	Encompasses the importance patients placed on different forms of assistance from providers during the patients' cancer care experiences [48, 64, 66, 67].	4	How important was it for you to have social support from other current or previous patients?	(1=Very Important, 5=Unimportant)
Decision Making Involvement Values	Refers to the importance patients placed on different aspects of providers' assistance as it related to treatment-related decision-making [68–70].	4	How important was the health care team's recommendation in making treatment decisions?	(1=Very Important, 5=Unimportant)
Health Information Values	Refers to the sources and content of health information patients sought and received. Health information included information about patients' diagnoses, treatment options and other cancer care components, preparation for treatment, side effects, complications, and expectations [66, 67, 71–73].	4	How important was understanding your treatment plan? How important was receiving an explanation of the available options in making treatment decisions?	(1=Very Important, 5=Unimportant)
General QOL Values	Values related to individuals' positive and negative subjective evaluations of life experiences [66, 74–78].	5	How important was quality of life in making treatment decisions (e.g., ability to participate in daily activities, returning to work)? Other patients have stated that their cancer experience can make them feel "not like a normal person". How important was it for your health care team to address or understand your need to have a sense of normalcy?	(1=Very Important, 5=Unimportant)
Family-related QOL Values	Values related to individuals' positive and negative subjective evaluations of family-related experiences [75, 76].	3	How concerned were you about possible changes in your ability to manage family responsibilities? How concerned were you about being a burden on family?	(1=Very Concerned, 5=Unconcerned)

Note: A 5-point Likert scale was used for all of the survey items above.

Table 3:

Characteristics of Adult Cancer Patients (n = 104) Included in the EFA of a Subset of the Patients and the Cancer Care Experience Survey Items

Variable	Category	n (%)
Age	Over 60 yrs old	64 (63.4)
	60 yrs old and under	37 (36.6)
Sex	Female	58 (57.4)
	Male	43 (42.6)
Race	White	72 (74.2)
	Non-white	25 (25.8)
Ethnicity	Not Hispanic	82 (82.0)
	Hispanic	18 (18.0)
Cancer Site	Breast	42 (41.2)
	Prostate	28 (27.5)
	Lung	8 (7.8)
	Colon	4 (3.9)
	Melanoma	5 (4.9)
	Head and Neck	4 (3.9)
	Other	11 (10.8)
State	Texas	82 (78.8)
	Louisiana	11 (10.6)
	Florida	3 (2.9)
	Oklahoma	2 (1.9)
	California	1 (.9)
	Colorado	1 (.9)
	Georgia	1 (.9)
	South Carolina	1 (.9)

Note: EFA included participants with complete data for the non-demographic data. All items were optional; therefore, there were some missing data for the demographic variables.

Exploratory Factor Analysis of a Subset of the PCCCE Survey Items among Adult Cancer Patients (n= 104) and Analyzed using Principal Factor Extraction with Promax Rotation.

Table 4.

Items	Factor Name Item Description (% of participants rating item as very important or very concerning)	Patient Need or Value Category	1	2	3	4	5	Communalities
1: Quality of Life								
Q14_E	Ability to perform normal work responsibilities (38.2)	Phys	0.898					0.743
Q14_D	Ability to move freely (36.4)	Phys	0.866					0.743
Q07	Efficient use of time during treatment (36.4)	GQOL	0.673					0.453
Q45	Possible changes in ability to manage family responsibilities (29.0)	FQOL	0.634					0.737
Q47	Changes in family roles (24.4)	FQOL	0.589					0.702
Q08	Scheduling conflicts between work and hospital visits (23.6)	GQOL	0.582					0.293
Q46	Being a burden on family (34.4)	FQOL	0.523					0.717
Q14_B	Returning to pre-cancer health status (47.7)	Phys	0.475					0.489
Q49	Other people's perception of health status (19.1)	GQOL	0.475					0.473
Q14_A	Pain management (36.9)	Phys	0.451					0.479
Factor 2: Provider Social Support								
Q27	Healthcare team recognizing changes in priorities or outlook on life as a result of illness (46.2)	PSS	0.852					0.828
Q26	Support from healthcare team following treatment (54.2)	PSS	0.814					0.698
Q34*	Healthcare team recognizing or being sensitive to any feelings of isolation (26.5)	Psy	0.698	.304				0.734
Q35	Healthcare team recognizing or being sensitive to a need for hope (43.9)	Psy	0.616					0.642
Q54	Having access to community assistance and/or services (16.8)	NPSS	0.473					0.540
Q01	Support of the hospital staff (70.2)	PSS	0.418					0.154
Factor 3: Psychosocial Needs								
Q13_C	Depression (23.1)	Psy	0.923					0.816
Q13_D	Feelings of uncertainty and/or loss of control (29.7)	Psy	0.883					0.746
Q13_B	Anxiety (28.5)	Psy	0.873					0.771

Items	Factor Name Item Description (% of participants rating item as very important or very concerning)	Patient Need or Value Category	Rotated Factor Loadings				
Factor 4: Value for Non-Provider Social Support							
Q51	Having social support from friends (39.2)	NPSS	0.9039				0.754
Q50*	Having social support from family members (67.2)	NPSS	0.796	.304			0.659
Q53	Having social support from religious or faith-based groups (40.8)	NPSS	0.629				0.553
Q52	Having social support from other current or previous patients (18.3)	NPSS	0.552				0.409
Q02	Family involvement in treatment (79.4)	NPSS	0.395				0.166
Factor 5: Health Information and Decision-Making Support							
Q19*	Receiving an explanation of the available options for making treatment decisions (78.0)	HI	.310	0.686			0.548
Q24	Feeling supported by healthcare team members when making decisions (80.2)	DM		0.676			0.520
Q21	Healthcare team's recommendation in making treatment decisions (76.5)	DM		0.557			0.499
Q09_A	Knowing about side-effects, symptoms, or complications before treatment (79.2)	HI		0.541			0.368
Q18	Quality of life in making treatment decisions (62.9)	GQOL		0.504			0.481
Q11	Changes to physical health in general (60.0)	Phys		0.478			0.630
Q04	Understanding treatment plan (90.8%)	HI		0.355			0.198
			Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Eigenvalues			10.689	2.141	1.752	1.562	1.397
% of variance			52.05	10.43	8.53	7.60	6.8
Cumulative variance			62.48	71.01	78.61	85.42	
Cronbach's α			0.91	0.83	0.91	0.79	0.88

Abbreviations: DM, decision making; FQOL, family-related quality of life values; GQOL, general quality of life values; HI, health information values; NPSS, non-provider social support values; PSS, provider social support values; Phys, physical needs; Psy, psychosocial needs.

* Item cross-loaded onto more than one factor.

Table 5.

Wilcoxon Rank Sum Tests of Association Between Adult Cancer Patients' PCCE Factor Scores and Demographic Characteristics and Cancer Sites

Factor	Demographic Variable or Cancer Site	n	Rank-Sum	Expected	p (1st group > 2nd group)	P-Value
1: Quality of Life	Age* 60 yrs and under	37	1590	1887	.374	.036*
	Over 60 yrs	64	3562	3264		
	Sex* Female	58	2653	2958	.378	.036*
	Male	43	2498	2193		
	Race Non-white	25	1044	1225	.399	.134
	White	72	3710	3528		
	Hispanic Ethnicity Yes	18	695	909	.355	.055
	No	82	4355	4141		
	Breast vs. Other Cancers Breast Cancer	42	2109	2163	.478	.711
	Other Cancers	60	3145	3090		
	Colon vs. Other Cancers Colon Cancer	4	170	206	.408	.535
	Other Cancers	98	5083	5047		
	Head and Neck vs. Other Cancers Head and Neck Cancer	4	138	206	.325	.238
	Other Cancers	98	5116	5047		
	Lung vs. Other Cancers Lung Cancer	8	404	412	.489	.921
	Other Cancers	94	4849	4841		
Melanoma vs. Other Cancers Melanoma	5	371	258	.734	.079	
Other Cancers	97	4882	4996			
Prostate vs. Other Cancers Prostate Cancer	28	1317	1442	.561	.347	
Other Cancers	74	3937	3811			
2: Provider Social Support	Age 60 yrs and under	37	1668	1887	.407	.122
	Over 60 yrs	64	3484	3264		
	Sex Female	58	3095	2958	.555	.347
	Male	43	2056	2193		
	Race Non-white	25	1236	1225	.506	.931
	White	72	3516	3528		
	Hispanic Ethnicity Yes	18	876	909	.478	.767
	No	82	4174	4141		

Factor	Demographic Variable or Cancer Site	n	Rank-Sum	Expected	p (1st group > 2nd group)	P-Value
	Breast vs. Other Cancers Breast Cancer	42	2229	2163	.526	.656
	Other Cancers	60	3025	3090		
	Colon vs. Other Cancers Colon Cancer	4	195	206	.472	.850
	Other Cancers	98	5058	5047		
	Head and Neck vs. Other Cancers Head and Neck Cancer	4	251	206	.614	.443
	Other Cancers	98	5003	5047		
	Lung vs. Other Cancers Lung Cancer	8	441	412	.539	.718
	Other Cancers	94	4812	4841		
	Melanoma vs. Other Cancers Melanoma	5	261	258	.507	.957
	Other Cancers	97	4992	4996		
	Prostate vs. Other Cancers * Prostate Cancer	28	1162	1442	.365	.035 *
	Other Cancers	74	4092	3811		
3: Psychosocial Needs	Age 60 yrs and under	37	1885	1887	.499	.986
	Over 60 yrs	64	3267	3264		
	Sex Female	58	3149	2958	.577	.190
	Male	43	2002	2193		
	Race Non-white	25	1045	1225	.400	.137
	White	72	3709	3528		
	Hispanic Ethnicity Yes	18	1081	909	.617	.123
	No	82	3969	4141		
	Breast vs. Other Cancers Breast Cancer	42	2247	2163	.533	.570
	Other Cancers	60	3007	3090		
	Colon vs. Other Cancers Colon Cancer	4	279	206	.686	.208
	Other Cancers	98	4974	5047		
	Head and Neck vs. Other Cancers Head and Neck Cancer	4	259	206	.634	.365
	Other Cancers	98	4995	5047		
	Lung vs. Other Cancers * Lung Cancer	8	587	412	.733	.029 *
	Other Cancers	94	4666	4841		
	Melanoma vs. Other Cancers Melanoma	5	281	258	.548	.716
	Other Cancers	97	4972	4996		
	Prostate vs. Other Cancers *	28	1030	1442	.301	.002 *

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Factor	Demographic Variable or Cancer Site	n	Rank-Sum	Expected	p (1st group > 2nd group)	P-Value
	Prostate Cancer					
	Other Cancers	74	4224	3811		
4: Value for Non-Provider Social Support	Age 60 yrs and under	37	2038	1887	.436	.288
	Over 60 yrs	64	3114	3264		
	Sex Female	58	2916	2958	.483	.773
	Male	43	2235	2193		
	Race Non-white	25	1187	1225	.479	.751
	White	72	3567	3528		
	Hispanic Ethnicity Yes	18	903	909	.496	.957
	No	82	4147	4141		
	Breast vs. Other Cancers Breast Cancer	42	2314	2263	.560	.306
	Other Cancers	60	2940	3090		
	Colon vs. Other Cancers Colon Cancer	4	150	206	.357	.334
	Other Cancers	98	513	5047		
	Head and Neck vs. Other Cancers Head and Neck Cancer	4	145	206	.343	.289
	Other Cancers	98	5109	5047		
	Lung vs. Other Cancers Lung Cancer	8	418	412	.508	.941
	Other Cancers	94	4835	4841		
	Melanoma vs. Other Cancers Melanoma	5	235	258	.454	.727
	Other Cancers	97	5018	4996		
	Prostate vs. Other Cancers Prostate Cancer	28	1582	1442	.567	.296
	Other Cancers	74	3672	3811		
5: Health Information and Decision-Making Support	Age 60 yrs and under	37	1908	1887	.509	.885
	Over 60 yrs	64	3244	3264		
	Sex Female	58	2783	2958	.430	.229
	Male	43	2368	2193		
	Race Non-white	25	1351	1225	.570	.301
	White	72	3403	3528		
	Hispanic Ethnicity Yes	18	920	909	.507	.921
	No	82	4130	4141		
	Breast vs. Other Cancers	42	2081	2163	.467	.575

Factor	Demographic Variable or Cancer Site	n	Rank-Sum	Expected	p (1st group > 2nd group)	P-Value
	Breast Cancer					
	Other Cancers	60	3173	3090		
	Colon vs. Other Cancers Colon Cancer	4	191	206	.462	.796
	Other Cancers	98	5062	5047		
	Head and Neck vs. Other Cancers Head and Neck Cancer	4	286	206	.703	.171
	Other Cancers	98	4968	5047		
	Lung vs. Other Cancers Lung Cancer	8	267	412	.307	.071
	Other Cancers	94	4986	4841		
	Melanoma vs. Other Cancers Melanoma	5	252	258	.489	.932
	Other Cancers	97	5001	4996		
	Prostate vs. Other Cancers Prostate Cancer	28	1606	1442	.579	.220
	Other Cancers	74	3648	3811		

* Statistically significant association at the p < .05 level

Notes: Items were reverse-ordered. Lower values indicate greater importance/concern.

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