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Justin M Yopp, *University of North Carolina*
Donald L Rosenstein, *University of North Carolina*
Teresa Edwards, *University of North Carolina*
[Mi-Kyung Song](#), *Emory University*

Journal Title: Journal of Pain and Symptom Management

Volume: Volume 55, Number 2

Publisher: Elsevier: 12 months | 2018-02-01, Pages 451-457

Type of Work: Article | Post-print: After Peer Review

Publisher DOI: 10.1016/j.jpainsymman.2017.09.021

Permanent URL: <https://pid.emory.edu/ark:/25593/tng6d>

Final published version: <http://dx.doi.org/10.1016/j.jpainsymman.2017.09.021>

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Accessed February 22, 2024 9:54 PM EST



Published in final edited form as:

J Pain Symptom Manage. 2018 February ; 55(2): 451–457. doi:10.1016/j.jpainsymman.2017.09.021.

Psychometric Analysis of the Parenting Concerns Questionnaire in Women with Metastatic Cancer

Eliza M Park, MD^{1,2}, Xianming Tan, PhD², Elise M Stephenson, MD³, Allison M Deal, MS², Justin M Yopp, PhD¹, Donald L Rosenstein, MD^{1,2,4}, Teresa Edwards, MA⁵, and Mi-Kyung Song, PhD, RN⁶

¹Department of Psychiatry, University of North Carolina, Chapel Hill, NC (USA)

²Lineberger Comprehensive Cancer Center, University of North Carolina, Chapel Hill, NC (USA)

³School of Medicine, University of North Carolina, Chapel Hill, NC (USA)

⁴Department of Medicine, University of North Carolina, Chapel Hill, NC (USA)

⁵H. W. Odum Institute for Research in Social Science, University of North Carolina at Chapel Hill, Chapel Hill, NC (USA)

⁶Center for Nursing Excellence in Palliative Care, Nell Hodgson Woodruff School of Nursing, Emory University, Atlanta, GA (USA)

Abstract

Context—Parenting concerns are a major source of distress for patients with advanced cancer. However, validated tools to measure this construct in advanced cancer patients are lacking.

Objectives—The Parenting Concerns Questionnaire (PCQ) is the only tool available to assess parenting concerns in cancer patients, yet its psychometric properties have not been fully evaluated.

Methods—This cross-sectional web-based survey of the psychosocial concerns included 211 women with stage IV solid tumor malignancy who had at least one minor child in the home. Participants completed a battery of questionnaires assessing parenting concerns, health-related quality of life (HRQOL), depression and anxiety symptoms, and sociodemographic and clinical characteristics. Internal consistency was assessed by computing Cronbach's alpha. Convergent validity was evaluated using correlations of the PCQ with anxiety and depression symptom severity and HRQOL. We examined the PCQ's underlying dimensions with confirmatory factor analysis.

Corresponding author: Eliza M Park, MD, Department of Psychiatry, University of North Carolina, 170 Manning Drive, Campus Box #7305, Chapel Hill, NC 27599, Phone: 919-966-3494, Fax: 919-966-6735, leeza_park@med.unc.edu.

Disclosures: The authors have no conflicts of interest to disclose.

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Results—The mean total PCQ score for the sample was 2.2 (SD, 0.7), corresponding to “a little bit concerned.” Internal consistency was 0.82. The PCQ demonstrated adequate convergent validity with expected correlations with anxiety ($r=0.49$) and depression ($r=0.56$) symptom severity, and HRQOL ($r=-0.61$). The original three-factor structure was not fully supported by confirmatory factor analysis.

Conclusion—The PCQ assesses a unique aspect of psychological distress in cancer patients. It demonstrated adequate reliability and convergent validity, but its original three-factor structure was not supported in a population of patients with metastatic cancer. The PCQ would benefit from further testing and refinement to enhance its representation of parenting concerns in metastatic cancer.

Keywords

Cancer; Neoplasm; Parenting concerns; Parents; Psychometrics

Introduction

Hundreds of thousands of individuals with advanced or incurable cancer are parenting dependent children. Compared to adult cancer patients without dependent children, parents experience more symptoms of worry, are half as likely to be peaceful, and are five times more likely to experience panic disorder.(1) Qualitative research suggests these symptoms may be due to parents’ concerns about the impact of their illness and death on their children as well as grief about their inability to raise their children into adulthood.(2) Other studies have also demonstrated that the intensity of parenting concerns is associated with lower health-related quality of life (HRQOL).(3, 4) Parenting concerns may also be associated with other cancer-related outcomes such as anti-neoplastic treatment intensity or accepting palliative medicine services. In a study of parents with metastatic solid tumor malignancies, nearly 70% of the parents reported that concerns about their children influenced their decisions about anti-neoplastic therapy.(5) Thus, among adult cancer patients with dependent children, parenting concerns are a substantial stressor affecting their illness experience.

The concept of parenting concerns -- broadly defined as parents’ worries about the impact of cancer on their children or ability to parent -- is an under-studied area in oncology and supportive care. The Parenting Concerns Questionnaire (PCQ) developed by Muriel and colleagues is the only existing tool to measure the severity of parenting concerns in cancer. (4) The PCQ is a 15-item scale with five-point response options. The scale includes three five-item subscales: (1) concerns about the practical impact of their illness on children, (2) concerns about the emotional impact of their illness on children, and (3) concerns about the co-parent. The total PCQ and subscale scores are an average of all completed items (1=no concerns, 2=a little bit concerned, 3=somewhat concerned, 4=very concerned, 5=extremely concerned). For the five-item subscale of concerns about the co-parent, if the participant indicates he/she is not currently partnered, then two items do not apply (and are not presented to them) and the subscale score is the mean of three items. If the participant indicates that their children do not have another living parent, then two separate items do not apply (and are not presented to them).

Since the PCQ's initial development, Inhestern, *et al.*(6) confirmed the PCQ's three-factor structure. In this sample of cancer survivors, the PCQ's total and subscale internal consistency (Cronbach's alphas) ranged from 0.84–0.93, and all factors were highly correlated (0.65–0.92).(6) In Inhestern *et al.*'s study and Muriel *et al.*'s original study, the PCQ's construct validity was demonstrated by small to moderate positive correlations ($r=0.3$ – 0.6) with other measures of psychological distress (Distress Thermometer, Hospital Anxiety and Depression Scale).(4, 6)

Inhestern *et al.*'s study using the PCQ have also revealed several important limitations, including a floor effect (when a considerable proportion of participants score the minimum score, limiting the measure's ability to capture variability) and several items that are not applicable to every respondent and thus causing missing data.(6–8) Further, parents with advanced cancer may have particular concerns about the impact of their future health decline and death on their children that are not fully explored in the measure.(2) Qualitative studies of cancer patients(9, 10) suggest that parents with cancer worry about how to discuss their illness with their children, including communication about life-limiting illness and death,(9) but the PCQ does not contain items to assess this communication concern.

Accurate measurement of parenting concerns in patients with advanced cancer is important to patient-centered care, and measures for systematic assessment of parenting concerns like the PCQ are needed. Therefore, the purpose of this study was to conduct a psychometric analysis of the PCQ in a different population of advanced cancer patients by analyzing the PCQ's internal consistency, testing its convergent validity through correlations with other measures of psychosocial distress, and assessing the underlying dimensions and factor structure of the PCQ using confirmatory factor analysis (CFA).

Methods

Study design and sample

We conducted a cross-sectional, web-based survey of adults who had an advanced cancer diagnosis and identified themselves as a parent of a child less than 18 years old. This study used internet-based recruitment to identify potential participants from a geographically diverse population. Participants were contacted through community-based, cancer patient advocacy organizations including the Metastatic Breast Cancer Network, Living Beyond Breast Cancer, MetaCancer, Livestrong, Stupid Cancer, Colon Cancer Alliance, and Melanoma Research Foundation. These organizations distributed the survey to their members through social networking methods including Twitter announcements, Facebook posts, website postings, and email listservs.

Inclusion criteria were adults who were at least 18 years old, had a self-reported diagnosis of advanced or metastatic cancer—defined as stage IV solid tumor or relapsed/refractory hematological cancer, were able to complete a questionnaire in English, and had a dependent child defined as a biological or adopted child younger than 18 years of age. A total of 231 individuals who met eligibility criteria completed the survey. We removed men ($n=7$) from final analyses due to the low number of participating individuals. Of the remaining participants, 211 completed the PCQ.

All data were collected online using Qualtrics software (Qualtrics, LLC, Provo, UT) from December 2014 to September 2015. Before starting the survey, each participant was presented with an informed consent statement; only participants who acknowledged this consent statement were allowed to proceed to the survey. This study was approved by the University of North Carolina-Chapel Hill Institutional Review Board.

Survey

In addition to the PCQ, participants provided information regarding their sociodemographic characteristics and illness history. They also completed the following questionnaires:

Functional status

Functional status was assessed via the Karnofsky Performance Status (KPS) scale, modified for self-report.⁽¹¹⁾ The KPS is a standard way of measuring the ability of cancer patients to perform ordinary tasks. Scores range from 0–100 with higher scores reflecting better ability to carry out daily activities.⁽¹²⁾ Self-reported KPS scores are correlated with survival time and have demonstrated moderate agreement with clinician ratings.⁽¹³⁾

Depression and anxiety

Depression and anxiety symptoms were measured using the National Institute of Health's Patient-Reported Outcomes Measurement Information System (PROMIS®). PROMIS contains standardized metrics for assessing depression and anxiety symptoms (www.nihpromis.org) and has been well-validated among patients across a range of chronic conditions.^(14–16) Cronbach's alphas for the sample were 0.94 for depression and 0.95 for anxiety.

Health-related quality of life (HRQOL)

HRQOL was assessed with the Functional Assessment of Cancer Therapy—General, one of the most commonly used and well-validated self-administered assessments of general HRQOL in cancer patients.^(17–19) Cronbach's alpha for the sample was 0.90.

Data analysis

Responses to PCQ items were assessed by mean, standard deviation, percentage of missing data, and floor and ceiling effects. We computed Cronbach's alpha coefficients to assess internal consistency of the subscales and the 15-item total scale. We also reported corrected item-total correlations.

Pearson correlation coefficients were used to examine the relationships of PCQ with PROMIS Anxiety, PROMIS Depression, and FACT-G scores. We expected moderate positive correlations between PCQ scores and PROMIS Depression and Anxiety scores, and moderate negative correlations between PCQ and FACT-G scores, thereby demonstrating that the PCQ measures a unique aspect of psychosocial distress.

We conducted CFA using SAS/STAT software (SAS 9.4, Cary, NC, SAS Institute) to examine the three-factor structure as proposed in Muriel *et al.*⁽⁴⁾ PCQ factors were assumed to be related and allowed to correlate, based on Inhestern *et al.*'s findings of high

interrelations among PCQ subscales.(6) Several fit indices were calculated to assess model fit, as recommended in factor analysis literature, including: χ^2 statistic, the root mean square error of approximation (RMSEA), Tucker Lewis index (TLI), weighted root mean square residual, and the comparative fit index (CFI).(20, 21) Model fits were also assessed using the Akaike Information Criterion (AIC) and Schwarz Bayesian Criterion (SBC).

Results

Participant and scale characteristics

Table 1 presents participant characteristics. The mean total PCQ score was 2.2 (SD, 0.7) corresponding to “a little bit concerned.” Mean subscale scores were the following: 2.3 (SD, 0.9) for concerns about practical impact; 2.2 (SD, 0.9) for concerns about the emotional impact and 2.1 (SD, 1.1) for the concerns about the co-parent. Descriptive statistics for individual PCQ items are listed in Table 2. Rates of missing items ranged from 5.8% to 20.5% with the highest rates of missing data occurring for items in the co-parent subscale. Floor effects (participants selecting the lowest response option) were 20.4–60.4% with the highest percentage of floor effects also occurring for items in the co-parent subscale. Mean PCQ scores also varied by degree of functional impairment; PCQ scores for the 53 (25%) participants with KPS scores <70 were 0.6 points higher than the 156 (74%) participants with KPS \geq 70 (2.6 vs. 2.0).

Internal consistency

Cronbach’s alphas were 0.86 for total PCQ scale and 0.82–0.83 for subscales. The correlation between the practical and emotional impact subscales were moderate; correlations were substantially lower for the co-parent scale (Figure 1). For all individual items, corrected item total correlations were adequate and ranged from 0.74 to 0.83, suggesting that each item was related to the overall scale.(22)

Convergent validity

Mean PCQ scores were positively correlated with PROMIS Anxiety ($r=0.49$) and PROMIS Depression scores ($r=0.56$) and negatively correlated with FACT-G scores ($r=-0.61$). The practical and emotional impact subscales were similarly correlated with these measures in the expected directions (Table 3). For the co-parent subscale, Pearson’s correlation coefficients were low (PROMIS Anxiety, $r=0.19$; PROMIS Depression $r=0.24$; FACT-G, $r=-0.35$).

Factor validity using the original three-factor model

The CFA revealed moderate to high (standardized) factor loadings for practical impact (0.60–0.79), emotional impact (0.55–0.84), and co-parent subscales (0.49–0.88) (Figure 1). All loadings were statistically significant ($p<0.001$), and all factors were positive and significantly interrelated with correlations of 0.79 ($\text{cor}(F1, F2)$), 0.21 ($\text{cor}(F1, F3)$), and 0.31 ($\text{cor}(F2, F3)$).

The χ^2 -test for discrepancy between sample and fitted covariance matrices indicated misfit of covariances ($\chi^2=255$, $df=87$, $p<0.001$). The RMSEA was 0.108 (95% CI: 0.093–0.123),

indicating suboptimal fit.(23) The TLI score was 0.816, also indicating suboptimal fit. Additional fit indices showed weighted standardized root mean square residual index=0.079, CFI=0.847, AIC=320.91, and SBC=423.80.

Discussion

As a new measure, the PCQ has not been well tested across different cancer types, particularly in patients with advanced or incurable cancer. For new patient-reported outcome measures like the PCQ, measure validity must be continuously evaluated in different populations and settings to define its scope and ultimately, clinical significance.(24)

Our analysis showed that the PCQ has high internal consistency but the original three-factor model demonstrated suboptimal fit as measured by the CFI TLI, and RMSEA. In comparison to the study by Inhestern *et al.*, our results showed poorer fit than their calculated model fit indices. As in prior studies,(3, 4, 6) the PCQ demonstrated moderate correlations in the expected directions with other measures of psychosocial distress.

This study provides evidence that the PCQ would benefit from further refinement. Consistent with previous study findings, nearly all items showed a high floor effect. The mean PCQ score for our sample was 2.2, corresponding to a “little bit” or “somewhat concerned.” The low overall parenting concerns scores are surprising given existing qualitative data suggesting that parenting concerns are a major source of concerns for adult cancer patients with advanced or metastatic cancer.(2, 9) Removing or revising items with high missing or flooring rates would likely improve the ability of the measure to identify the parenting-related distress of this patient population. In addition, studies suggest that expansion of the PCQ’s parenting concerns construct may be needed. Specific domains to include are concerns about communication with children(9) and concerns about the ability to maintain parenting responsibilities (such as being the financial provider for the family).(25) Questions in the original item bank pertained to communication but were not included in the final measure.(4)

We also observed limitations of the co-parent subscale. Two items about partner support do not specifically address parenting and are only applicable to individuals with a partner/spouse. Additionally, parents may share childcare responsibilities with adults who do not have a legal or biological relationship with their children. US family law does not always recognize these individuals as “parents,”(26, 27) and participants’ interpretation of what represents “another living parent” may have led to incomplete responses for two of the items in the subscale. In contrast to the other two subscales, the co-parent subscale demonstrated low correlations with other measures of psychosocial distress, suggesting that it may be measuring a different construct than the other subscales. Removing the items pertaining to partner support and redefining co-parents as “other adults who care for your children” may help improve the performance of this subscale.

There are several limitations of this study. Our sample included primarily married women with breast cancer who are white or Caucasian with above average education and income. These results also reflect the perspectives of patients who are members of cancer advocacy

organizations. We used web-based data collection, which limits the ability of non-internet users to provide their feedback. As of 2016, 13% of US adults report they do not use the internet.(28) Existing literature does suggest that self-reported survey-based internet data collection may be generally equivalent to traditional paper data collection, though their equivalence may vary based on the characteristics of the study population.(29–31) Based on Muriel *et al.*'s original study(4) as well as prior research from our group,(3) we suspect that patients of lower income and less access to online resources would experience higher parenting concerns and more psychological distress than our present sample. Thus, the PCQ requires further testing in more diverse populations including racial/ethnic minorities, parents with lower income, and men. While these populations were not extensively tested in our sample, this limitation points to several important areas of future inquiry.

The assessment of parenting concerns for parents with advanced cancer may be different from the concerns of parents with earlier stage or curable illness. Concerns about the impact of progressive illness and death may be more pertinent for this population than for other parents with cancer. Research on bereaved men raising dependent children suggest that dying mothers experience high rates of worry about their children at the end of life.(32) An expanded parenting concerns measure for parents with advanced cancer might include domains that not only assess the PCQ's concerns about the impact of illness on children and co-parent, but also address concerns about communication and being a good parent.

In summary, parents with advanced cancer have unique concerns about the impact of their illness on their children and parenting abilities.(2, 25) Accurate evaluation of parenting concerns may be a critical step toward identifying patients that would benefit from family-centered psychosocial interventions. Thus, the PCQ may require further refinement to enhance its representation of parenting concerns in advanced cancer.

Acknowledgments

This work was supported by the UNC Junior Faculty Development Award, the Foundation of Hope, the Doris Duke Charitable Foundation [2015213], the National Center for Advancing Translational Sciences (NCATS) [1UL1TR001111, 1KL2TR001109], and the National Institutes of Health [1K07CA218167]. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH. The authors wish to gratefully acknowledge the men and women who participated in this study and who gave their time to share their experiences.

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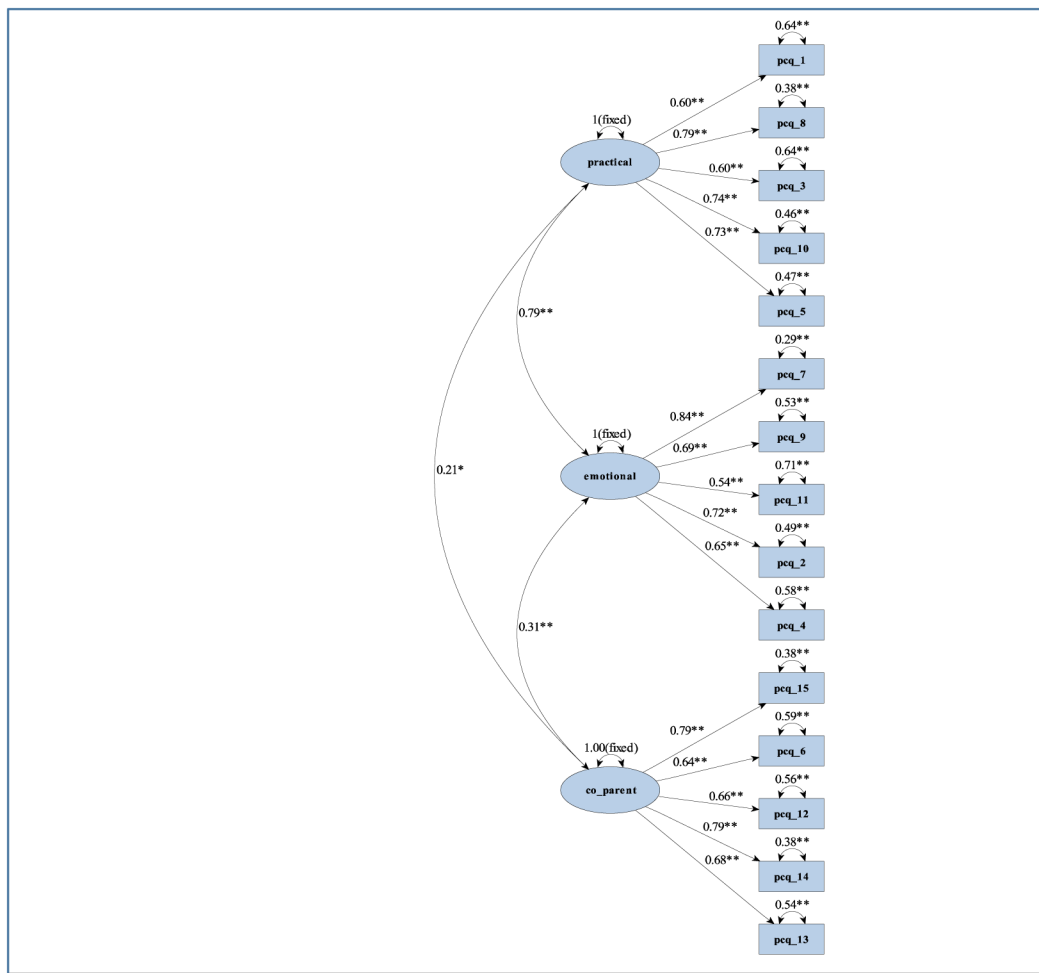


Figure 1. Confirmatory factor analysis of the Parenting Concerns Questionnaire original three-factor model

Note: Factor structure of the original three-factor Parenting Concerns Questionnaire in women with metastatic cancer. All paths with ** were statistically significant at $p < 0.001$.

Table 1

Participant characteristics

Characteristic	Total sample (N = 211)	
	n	%
Socio-demographic		
Age, years, mean (SD)	44.3 (7.1)	
Partnered or married	168	79.6
Caucasian race	193	92.8
College graduate	152	73.1
Annual household income < \$50,000	50	24.2
Employed or homemaker	121	61.7
Religious faith “very important”	79	38.2
Live in United States	184	89.8
Illness-related		
Duration of metastatic cancer, years, mean (SD)	2.5 (2.3)	
De novo metastatic diagnosis	82	40
Cancer site		
Breast	193	91.5
All other	18	8.5
Location of cancer care		
Academically-affiliated hospital	107	51.4
Other *	101	48.6
Functional status (KPS)		
None (100)	27	12.9
Normal activity with effort (80–90)	129	61.7
Cares for most needs or self (60–70)	50	23.9
Severe – disabled (40–50)	3	1.4
Patient-identified goal of cancer treatment		
Cure	32	15.2
Extend life	135	64.0
Improve or maintain quality of life	40	19.0
Other	4	1.9
Prognostic clarity		
Completely or mostly	176	83.4
Not very clear or not clear at all	35	16.6
Parenting-related		
Number of children, mean (SD)	1.8 (1.1)	
Age of children <18 years, mean (SD)	11.3 (4.3)	
Age of youngest child, mean (SD)	10.1 (4.9)	

Characteristic	Total sample (N = 211)	
	n	%
Single parent household	50	23.7
Prognostic communication with children		
Have discussed	84	48.0
Have not discussed	64	36.6
Children not old enough to discuss	27	15.4
Concern about financial impact on children		
Very or extremely worried	109	51.9
A little or not at all worried	101	48.1

* Other include: community and private oncology practices, inpatient or home hospice services, Veterans Affairs Medical Centers, primary care physicians

Abbreviations: KPS=Karnofsky Performance Status Scale

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Table 2

Parenting Concerns Questionnaire item-level statistics

Item	N	Mean (SD)	Median	Missing %	Flooring %	Ceiling %	Corrected item-total correlations (standardized)
Concerns about Practical impact							
my own mood, worries, or emotions are affecting my children (Item 1)	211	2.6 (1.1)	3	5.8	20.4	4.7	0.80
my physical limits or low energy level are affecting my children (Item 8)	211	2.4 (1.2)	2	5.8	28.0	5.2	0.74
I am not able to spend as much time with my children as I would like (Item 10)	211	2.2 (1.3)	2	5.8	41.2	5.7	0.78
My illness is changing my children's routines (Item 5)	210	1.9 (1.0)	2	6.3	43.3	1.0	0.76
changes in my memory and attention are affecting my children (Item 3)	209	2.3 (1.1)	2	6.7	32.1	2.4	0.79
Concerns about Emotional impact							
my children are emotionally upset by my illness (Item 7)	210	2.4 (1.1)	2	6.3	22.9	5.7	0.75
my children are worried that I am going to die (Item 9)	209	2.5 (1.2)	2	6.7	25.4	8.1	0.77
my children get upset when we talk about my illness (Item 2)	209	2.2 (1.1)	2	6.7	32.1	4.3	0.78
my children might be in need of professional mental health care (Item 4)	210	2.1 (1.1)	2	6.3	39.5	4.3	0.81
my children get confused or upset by what others say about my illness (Item 11)	210	1.8 (1.1)	1	6.3	51.4	3.3	0.81
Concerns about the Co-parent							
my children's other parent would not be able to meet their emotional needs if I died (Item 15)*	201	2.6 (1.5)	2	10.3	32.8	18.4	0.79
that there is no one to take good care of my children if I die (Item 6)	211	1.8 (1.2)	1	5.8	57.3	5.2	0.83
my partner is not providing me with enough emotional support (Item 13)**	178	1.8 (1.2)	1	20.5	55.6	6.2	0.79
my partner is not providing me with enough practical support (Item 12)**	177	1.8 (1.2)	1	21.0	57.1	5.6	0.80
my children's other parent would not be a responsible caregiver if I died (item 14)*	202	2.0 (1.4)	1	9.8	60.4	12.4	0.79

* Per the Parenting Concerns Questionnaire instructions, this question was only presented to participants who indicated that their children had another living parent.

** Per the Parenting Concerns Questionnaire instructions, this question was only presented to participants who indicated that they currently have a partner or spouse.

Table 3

PCQ correlations with other measures of psychosocial well-being

Measure	PROMIS Anxiety (Anxiety)	PROMIS Depression (Depression)	FACT-G (HRQOL)
PCQ total	0.4925	0.5550	-0.6144
Practical impact	0.5260	0.5686	-0.6708
Emotional impact	0.4522	0.5064	-0.4218
Co-parent	0.1932	0.2417	-0.3474

* Based on Pearson's correlation coefficients

Abbreviations: PCQ = Parenting Concerns Questionnaire; PROMIS = Patient-Reported Outcomes Measurement Information System; FACT-G=Functional Assessment of Cancer Therapy-General; HRQOL=Health-related quality of life