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Understanding health-related quality of life in adult women with metastatic cancer who have dependent children

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Abstract

BACKGROUND—Cancer is a leading cause of death among parenting-age women in the United States. Women living with advanced or incurable cancer who have dependent children experience high rates of depression and anxiety as well as unique parenting challenges. Few studies have examined the parenting factors associated with health-related quality of life (HRQOL) in women with advanced cancer.

METHODS—We conducted a cross-sectional, web-based survey of the psychosocial concerns of 224 women with a stage IV solid tumor malignancy who had at least one child aged <18 years. Participants completed validated measures of HRQOL (Functional Assessment of Cancer Therapy–General, FACT-G), depression and anxiety symptom severity, functional status, parenting concerns, and investigator-designed questions to assess demographic, communication, and

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parenting characteristics. Multiple linear regression models were estimated to identify factors associated with FACT-G total and subscale scores.

RESULTS—The mean FACT-G score was 66 (standard deviation, SD, 16). Mean emotional well-being subscale scores were particularly low (13, SD, 5). In multivariable linear regression models, parenting variables explained nearly 40% of the HRQOL model variance. In the fully adjusted model, parenting concerns and absence of parental prognostic communication with children were both significantly associated with HRQOL scores. For each one point increase in parenting concern severity, FACT-G scores decreased by 4 points (p=0.003).

CONCLUSIONS—Women with metastatic cancer who are parents of dependent children are at risk for high psychological distress and low HRQOL. Parenting factors may have a negative influence on HRQOL in this patient population.

Keywords

Quality of life; patient-reported outcomes; cancer; neoplasm; parenting

INTRODUCTION

For American women in their peak parenting years, cancer is a leading cause of death.[1] Advances in antineoplastic therapies are also increasing survival among adults with advanced cancer[2, 3] (defined here as a malignancy with low likelihood of cure or long-term remission). Thus, there is an increasing number of US adults with advanced cancer who are parenting dependent children.

Individuals with advanced cancer who have dependent children experience unique challenges to their health-related quality of life (HRQOL) and psychological functioning. They have parenting concerns about the current and future impact of their illness on their children,[4, 5] uncertainty about optimal illness-related communication with their children,[5] and profound anguish that they may not raise their children into adulthood.[5–7] Cross-sectional studies suggest that parents with advanced cancer have high rates of anxiety and depressive symptoms,[4, 8] and higher rates of mood disorders in comparison to patients without dependent children.[9]

Parenting concerns may also influence cancer treatment decision-making. Among women with early stage breast cancer who completed adjuvant chemotherapy, mothers with dependent children were more likely to view smaller benefits from adjuvant chemotherapy as worthwhile.[10, 11] In a study of parents with metastatic cancer, desire for more time with their children was a strong motivator to pursue antineoplastic therapy despite treatment toxicities and potential reductions in HRQOL.[12] Similarly, a large cohort study of advanced cancer patients found that patients with dependent children are more likely than patients without dependent children to prefer a course of treatment that focused on life extension rather than symptom palliation.[9] Consequently, the presence of dependent children may be particularly salient for the advanced cancer patient when cure is no longer possible and the goals of treatment shift toward life extension, symptom relief and maintenance of acceptable HRQOL.

HRQOL and other patient-reported outcomes are commonly assessed in cancer trials and routine oncology care, yet most HRQOL measures for cancer patients do not specifically assess concerns about children. Bereaved caregivers report that patients with dependent children have worse QOL during the last week of life compared to patients without dependent children.[9] Preliminary evidence suggests that these reductions in HRQOL occur among parents living with advanced cancer even before they reach the terminal stage of illness.[8] However, the relationship between parenting concerns and HRQOL perception are inadequately understood. Therefore, the purpose of this study was to explore the relationship between parenting factors and HRQOL in a sample of women with metastatic cancer with dependent children. We hypothesized that parenting concerns would be independently associated with HRQOL scores after accounting for demographic and clinical factors such as illness severity or degree of mood symptoms.

METHODS

Study Design and Sample

We conducted a cross-sectional, web-based survey of the psychosocial and parenting concerns of English-speaking adults with advanced cancer. We recruited participants from a georgraphically diverse population using internet-based recruitment and data collection methods in collaboration with community cancer organizations. Participants were contacted about the study through 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 information about the survey to their members through social networking methods including Twitter announcements, Facebook posts, website postings, and email listservs.

Eligible individuals were adults who were at least 18 years old, had a self-reported diagnosis of advanced cancer—defined as stage IV solid tumor with distant metastases or relapsed and treatment-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 adults who completed the survey met eligibility criteria. We excluded the seven male respondents (n=7) because the number was too small to provide meaningful results. This left 224 individuals for data analysis.

All data were collected online using Qualtrics software (Qualtrics, LLC, Provo, Utah, USA) from December 2014 to September 2015. Informed consent was obtained from all participants prior to start of the survey which was approved by the University of North Carolina (UNC) at Chapel Hill Institutional Review Board.

Survey overview

The survey, which took a median of 20 minutes to complete, included the following:

Health-related quality of life

The 27-item Functional Assessment of Cancer Therapy—General (FACT-G) is a commonly-used and well-validated self-administered assessment of general HRQOL in cancer patients.[13–15] Response options are given on a five-point ordinal scale (0=not at all, 4=very much). Total scores range from 0 to 108; there are four subscales (physical, social/family, emotional, and functional well-being). For total and subscale scores, higher scores indicating better HRQOL.[13] Cronbach's alpha for the study sample was 0.91.

Parenting concerns

The Parenting Concerns Questionnaire (PCQ) is a 15-item, self-administered assessment of parenting concerns in cancer patients. Each item is answered using a five-point ordinal scale (1=no concerns, 5=extremely concerned). The PCQ produces a total score and three five-item subscales addressing concerns about the emotional (e.g. I have been concerned that my children get upset when we talk about my illness) and practical impact of illness (e.g. I have been concerned that my physical limits or low energy level are affecting my children) on the child and concerns about the co-parent.[4] The total and subscale scores are the mean of the items contributing to it and thus range from 1–5. Participants without a co-parent were not included in the concerns about the co-parent subscale. The PCQ has demonstrated good internal consistency and face validity.[4] Cronbach's alpha for the study sample was 0.86.

Depression and anxiety symptoms

The National Institute of Health's Patient-Reported Outcomes Measurement Information System (PROMIS®) contains standardized metrics for assessing depression and anxiety symptoms (www.nihpromis.org).[16] We used the PROMIS Depression short form and the PROMIS Anxiety short form. Each measure is based on a five-point ordinal scale (1=never, 5=always). Scores for all PROMIS measures are reported on the T-score metric in which the mean=50 and standard deviation (SD)=10 are centered on the general population means. Higher scores represent greater degrees of mood symptoms.[16] Cronbach's alphas for the study sample were 0.92 and 0.95 for the depression and anxiety scales, respectively.

Functional status

A modified self-report version of the Karnofsky Performance Status (KPS) scale was used to assess functional status.[17] The KPS is a standard way of measuring the ability of cancer patients to perform ordinary tasks. Scores range from 0 to 100 with higher scores reflecting better ability to carry out daily activities. Scores for the KPS are frequently used to determine eligibility for clinical trials, to evaluate the impact of antineoplastic therapy on HRQOL, and as an aid in assessing an individual patient's prognosis.[18, 19]

Demographic, illness, and parenting characteristics

Respondents provided information about their socio-demographic characteristics such as age, race/ethnicity, and income. In addition to the PCQ described above, we assessed parenting characteristics via closed and open-ended questions regarding number and age of children, presence of other caregivers for children, role of parental status in cancer treatment decision-making, concerns about the financial impact of illness on children, and whether or not they have communicated with children about cancer. Given the variable nature of pediatric development, we allowed parent's to self-report whether they believed their children were old enough to communicate about their cancer. Relevant illness variables included cancer site and staging, goals of treatment, prognostic understanding, type of cancer treatment center, and duration of illness.

Data Analysis

Relationships between HRQOL scores and participant demographic and illness characteristics were explored using two sample t-tests, one-way analysis of variance, and Pearson's correlations as appropriate. We conducted multiple linear regression models to identify factors associated with participants' HRQOL (FACT-G scores). Independent variables that were significant at $p<0.2$ (two tailed) were entered into the regression models. We first explored associations between demographic characteristics alone on FACT-G scores. We then examined the associations between illness characteristics alone, mood symptoms (PROMIS measures) alone, and then parenting characteristics alone. We also conducted a full multivariable linear regression model to assess the independent contribution of parenting variables to total and subscale FACT-G scores while controlling for clinically important or statistically significant (at the $p<0.2$ level) covariates. All analyses were performed using SAS version 9.3 (SAS Institute, Inc., Cary, NC).

RESULTS

Demographic and clinical characteristics

Women from 40 states and five countries completed the survey, with most (n=185, 82%) respondents living in the United States. Table 1 contains descriptive characteristics for the sample. The majority of respondents had breast cancer (n=206, 92%). The median self-reported KPS score was 80, corresponding to normal activity with effort.

Depression, anxiety and parenting concern severity

Standardized mean depression symptom severity scores (Table 2) were 56 for depression (range 38 to 81) and 56 for anxiety (range 37 to 83); mean depression and anxiety scores were more than 0.5 SD (at least 5 T score units) higher than US general population norms. Mean total PCQ score was 2.3 (range 1 to 5), corresponding to "a little bit concerned." PCQ subscale scores are listed in Table 2.

Factors associated with total HRQOL in mothers with metastatic cancer

The mean FACT-G score for the entire sample was 65.9 (range 25 to 107). Table 2 provides the subscale and total FACT-G scores in comparison to reference values for all adults with cancer and adult women with metastatic breast cancer. Emotional well-being (EWB) subscale scores were a full SD lower than reference values for all adults with cancer and met the threshold to be considered "low."[20]

The association with functional status on HRQOL scores were notable. Among study participants with KPS scores of 80–90 (n=135), indicaticating mild functional impairment, parents' FACT-G scores were 10 points lower than other adult cancer patients with similar levels of functioning.[20] Among participants with KPS scores of 60–70 (n=52), FACT-G scores were nearly 22 points lower than other adult cancer patients with equivalent functional status scores (Table 3).[20]

In unadjusted analyses, HRQOL scores were associated with several participant characteristics including participant age, education, employment status, KPS score, depression and anxiety symptom scores, and physician prognostic clarity (Table 4). HRQOL scores were also associated with several parenting variables. In unadjusted analyses, for each one point increase in PCQ scores (indicating greater concerns), FACT-G scores worsened by nearly 14 points ($p<0.0001$). Lower HRQOL scores were also signficantly associated with parental concerns about the financial impact of illness on children and parental avoidance of prognostic communication with children.

In a model with demographic variables alone, demographic factors predicted only 15% of the variance in the total FACT-G scores, primarily due to participant age. In a model assessing the contribution of only illness-related variables, 45% of the FACT-G score variance was explained and this was almost entirely driven by KPS score. The model assessing the contribution of mood symptoms (depression and anxiety scores) explained 50% of the FACT-G score variance and a model of parenting variables explained 39% of model variance.

Multivariable analyses provided a more nuanced assessment of the association between parental factors and HRQOL assessment. In the fully adjusted multivariable model, parenting concerns scores and absence of parental prognostic communication with children were both significantly associated with HRQOL scores (see Table 5 for variables included in final model). For each one point increase in PCQ scores, FACT-G scores decreased by 3.8 points ($p=0.003$). With the exception of physician prognostic clarity, PCQ scores had the most significant regression weights, indicating that parents with higher PCQ scores were expected to have worse HRQOL (Table 5). Multivariable analysis of FACT-G subscale scores indicated similar statistically significant associations between PCQ scores and each FACT-G subscale. In a multivariable model with FACT-G EWB scores as the dependent variable, several additional parenting characteristics were significantly associated with lower EWB scores, including younger mean age of minor children, lower mean age of youngest child, absence of prognostic communication with children, higher concern about financial impact of illness on children, and belief that parental status influenced anti-neoplastic treatment decision-making.

DISCUSSION

Patient-reported outcomes are important when treating and studying patients with advanced cancer. Among the most pertinent outcomes among cancer patients is HRQOL. In this cross-sectional study of women with metastatic cancer who were the parent of a dependent child, parenting concern severity had a significant and substantial negative association with self-assessment of HRQOL, even when adjusted for powerful predictors of HRQOL such as mood symptoms, functional status, and other clinical factors. These results add to our understanding of how parenting concerns may potentially relate to the advanced cancer experience in two important ways.

First, our findings corroborate evidence that women with metastatic cancer who have dependent children experience poor HRQOL. Many published studies report the HRQOL among adults with metastatic cancer and women with recurrent breast cancer.[13, 20, 21] Although parental status was not systematically reported in these studies, their samples likely include individuals both with and without dependent children. In comparing our results to pooled data from adult cancer patients and adult women with metastatic breast cancer with presumed mixed parental status, our sample had FACT-G scores 13 points (nearly an entire SD) lower and 16 points (a full SD) lower, respectively.[20] Our findings therefore suggest that interventions are needed to reduce psychological morbidity and improve HRQOL in mothers with metastatic cancer.

Second, our study provides additional contextual understanding of why HRQOL may be low in women with advanced cancer who have children. Participants had high psychological symptom burden, with mean PROMIS depression and anxiety symptom burden scores 6 points greater than US adults. Notably, differences of 2.3–3.4 points on these PROMIS measures are clinically meaningful.[22] FACT-G EWB scores were similarly low; mean scores were a full standard deviation lower than reference values for all adult cancer patients and US general adult population.[20] Additionally, parenting-related (including parents' concerns and decisions about communication with their children) and clinical factors contributed nearly equal amounts of variance in FACT-G scores. Women with high functional impairment reported particularly low HRQOL and they represent a patient population at risk for poor psychosocial outcomes. The cross-sectional nature of this study does not allow us to infer causal links and the relationship between high parenting concerns and low HRQOL is likely bidirectional. However, we suspect that reductions in physical functioning and the psychological impact of functional decline precipitate major changes in family routines and responsibilities for parents with advanced cancer, which synergistically influence parenting concern severity and HRQOL. HRQOL measures and HRQOL frameworks typically include items about the impact of illness on family life but most do not specifically address patients' parenting concerns. Yet, across demographic groups in the US, parents of minor children identify their parental status as central to their identity.[23] Thus, inclusion of parenting concerns in HRQOL frameworks may enhance our understanding of HRQOL assessment. Additionally, helping parents with advanced cancer adjust to illness-induced changes in parenting roles is a potential target of intervention to improve their outcomes. Targeting parents prior to reductions in functional status due to treatment toxicity or disease progression may also reduce their risk of developing poor outcomes.

The use of a web-based survey in collaboration with several cancer advocacy organizations represents a novel way to engage this patient population who are young and generally technologically adept. Nearly two-thirds of Americans report using social media and internet usage is nearly ubiquitous (96–99%) among 18–49 year olds.[24] Harnessing the power of web-based data collection is critical for this research because many electronic medical record systems do not systematically identify parental status. The use of an online survey created an opportunity to conduct research in a cost-effective and feasible manner, as well as confirm previous findings on the unique experience and distress of this patient population.

There are several limitations of this study. First, the sample may not be representative of all women with advanced cancer. Respondents were overwhelmingly Caucasian women with breast cancer with above average education and income, which may reflect their being recruited online through cancer advocacy organizations. Second, the study was cross-sectional, which limits our ability to make causal inferences. Third, we could not separate the effects of younger age from parental status. Data from the Cancer Care Outcomes Research and Surveillance Consortium on patients with advanced colorectal or lung cancer suggest that the differences in reported treatment-related worries between young adult versus middle-aged adults are due to the presence of dependent children in the home.[25] Fourth, cancer diagnoses were self-reported and unable to be confirmed for the purpose of the study. While we used several screening questions to identify the target population (e.g. asking about self-reported cancer stage, locations of metastases, etc.), it is possible that some participants reported inaccurate information regarding their diagnosis and thus may not truly reflect the population intended to be captured. Additionally, the PCQ does not distinguish between biological co-parents or other caregivers, therefore we do not know the nature of the patient-co-parent relationship or the extent of co-parent involvement.

Nevertheless, the ability to generate a comprehensive assessment of the psychosocial experiences of a large group of parents outweighs these limitations; these results can inform the development of theoretical models to describe how individual, dyadic (marital communication and satisfaction), family (family-functioning, family communication styles), and illness-related factors interrelate to shape psychosocial outcomes in parents with advanced cancer. Future studies that test these models in a broader demographic population including racial/ethnic minorities and men are needed. Additionally, we know little about how family systems and family role functions (including those by children) are impacted by parents with advanced cancer. The secondary consequences for children due to changes in parental employment and financial burden have not been well-investigated either.

In summary, psychosocial factors such as parenting concerns may play a substantial role in patients' assessment of HRQOL, particularly in the context of metastatic cancer. To reduce suffering and improve HRQOL for parents with advanced cancer, health care providers and researchers must consider the role of parenting concerns in these patients.

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Table 1

Respondent characteristics (N=224)

Characteristic	N (%)	Mean (SD)
Socio-demographic		
Age, years		44.2 (7.2)
Married	171 (80)	
Caucasian race	194 (93)	
College graduate	153 (73)	
Household income >$50,000	157 (68)	
Employed *	122 (62)	
Religious faith “very important”	79 (38)	
Live in United States	185 (82)	
Illness-related		
Duration of metastatic cancer, years		2.5 (2.4)
De novo metastatic diagnosis	87 (40)	
Breast cancer diagnosis	206 (92)	
Treatment center		
Academically-affiliated practice	108 (52)	
Other **	101 (48)	
Karnofsky Performance Status score		
None (100)	29 (13)	
Normal activity with effort (80–90)	136 (61)	
Cares for most needs or self (60–70)	52 (23)	
Severe–disabled (40–50)	5 (2)	
Life extension as goal of cancer treatment	142 (63)	
Prognostic clarity		
Completely or mostly	187 (83)	
Not very clear or not clear at all	37 (17)	
Parenting-related		
Number of children		1.8 (1.1)
Age of children <18 years, † years		11.3 (4.3)
Age of youngest child, years		10.1 (4.9)
Presence of another caregiver for children	173 (77)	
Parental status influences cancer decision-making		
Almost totally or mostly	205 (92)	
Somewhat or not at all	19 (8)	
Prognostic communication with children		
Have discussed	96 (45)	
Have not discussed	80 (37)	

Characteristic	N (%)	Mean (SD)
Children not old enough to discuss	38 (18)	
Concern about financial impact on children		
Very or extremely worried	116 (52)	
A little or not at all worried	107 (48)	

[*] Working full or part-time or full-time stay at home parent

[**] Community practices, hospice services, Veterans Administration Medical Centers

[†] Age of children ≥18 years not included in calculation

Table 2

Means and standard deviations for health-related quality of life and psychological symptom burden measures

Domain	Measure	N	Range	Sample Mean (SD)	Adult cancer patients[†] Mean (SD)	Metastatic breast cancer[‡] Mean (SD)
Health-related quality of life	Functional Assessment of Cancer Therapy-General	223	25–107	65.5 (16.4)	79.3 (17.0)	81.9 (14.3)
	Physical well-being	224	3–28	18.4 (6.1)	21.0 (6.0)	
	Social/family well-being	224	5–28	17.8 (5.4)	22.0 (5.3)	
	Emotional well-being	223	0–23	13.1 (5.0)	18.1 (4.6)	
	Functional well-being	223	2–28	16.1 (5.4)	18.2 (6.6)	
Anxiety symptom severity	PROMIS Anxiety[*]	210	37–83	56.0 (9.8)		
Depression symptom severity	PROMIS Depression[*]	210	38–81	56.0 (8.3)		
Parenting concerns	Parenting Concerns Questionnaire	211	1–5	2.2 (0.7)		
	Practical concerns	211	1–5	2.3 (0.9)		
	Emotional concerns	210	1–5	2.2 (0.9)		
	Concerns about co-parent	206	1–5	2.1 (1.1)		

[*] T score normed to population

[†] Adult cancer patient sample, all disease types, n=4912; Pearman et al, Ambulatory Cancer and US General Population References Values and Cutoff Scores for the Functional Assessment of Cancer Therapy. *Cancer* 2014;(120), p2906.[20]

[‡] Adult metastatic breast cancer patient sample, n=187; Pearman et al, Ambulatory Cancer and US General Population References Values and Cutoff Scores for the Functional Assessment of Cancer Therapy. *Cancer* 2014;(120), online supplement.[20]

Abbreviations: PROMIS=Patient-Reported Outcomes Measurement Information System (range 0–100, higher scores indicate more symptoms, 50=US general population mean);

Table 3

Functional Assessment of Cancer Therapy-General scores by Karnofsky Performance Scale (KPS) status

KPS score	ECOG equivalent	N	Range	Sample Mean (SD)	Adult cancer patients[†] Mean (SD)
100	0	29	45–103	79 (14)	88 (14)
90	1	71	36–107	74 (14)	79 (15)
80	1	64	38–87	65 (11)	
70	2	39	25–74	50 (11)	71 (15)
60	2	13	27–62	47 (11)	
50	3	2	42–48	45 (4)	61 (15)[a]
40	3	3	36–42	40 (3)	

[†] Adult cancer patient sample, all disease types, n=4672; From Pearman et al, Ambulatory Cancer and US General Population References Values and Cutoff Scores for the Functional Assessment of Cancer Therapy. *Cancer* 2014;(120), p2906[20]

[a] Collapsed variable (ECOG levels 3 and 4)

Abbreviations: ECOG=Eastern Cooperative Oncology Group Performance Status Scale (range 0–4, higher scores reflect better functioning)

Table 4

Unadjusted associations between each patient characteristic and health-related quality of life scores

Characteristic	Estimate	SE	P†
Socio-demographic			
Participant age	0.411	0.151	**0.007**
Married	1.436	2.765	0.6
Caucasian race	−0.322	4.381	0.9
College graduate	5.263	2.528	**0.04**
Household income >$50,000	7.055	2.613	**0.008**
Employed	9.148	2.333	**0.0001**
Religious faith “very important”	2.432	2.341	0.3
Live in United States	3.494	3.762	0.4
Illness-related			
Duration of metastatic illness	0.281	0.464	0.5
De novo metastatic cancer	1.314	2.242	0.6
Breast cancer	4.241	4.035	0.3
Academically-affiliated practice	−3.545	2.246	0.1
Karnofsky Performance Status score	0.861	0.069	**<0.0001**
Life extension goal of treatment	0.534	2.291	0.8
Clear prognostic understanding	10.271	2.880	**0.0004**
Mood symptoms			
Depression	−1.307	0.100	**<0.001**
Anxiety	−0.736	0.103	**<0.001**
Parenting-related			
PCQ score	−13.849	1.233	**<0.0001**
Number of children	−0.723	1.023	0.5
Age of children <18 years	0.107	0.264	0.7
Age of youngest child	0.173	0.233	0.5
Presence of another caregiver for children	2.512	2.618	0.3

Characteristic	**Estimate**	**SE**	**P**[†]
Parental status influences treatment	−7.050	3.918	0.0733
Have not discussed prognosis with children	−7.412	2.453	**0.003**
Children not old enough to have discussion	−1.245	3.095	0.7
Concerned about financial impact on children	−5.842	2.179	**0.008**

[†] Age of children ≥18 years not included in calculation

Abbreviations: PCQ=Parenting Concerns Questionnaire (range 1–5, higher scores indicate more concerns)

Table 5

Multivariable regression model for health-related quality of life scores

Domain	Estimate (adjusted)	SE	P
Socio-demographic			
Participant age	0.174	0.108	0.1
College graduate	1.093	1.599	0.5
Household income >$50,000	−2.140	1.728	0.2
Employed [*]	2.900	1.527	0.06
Illness-related			
Academically-affiliated hospital	−0.781	1.385	0.6
Karnofsky Performance Status score	0.533	0.068	**<0.0001**
Clear prognostic understanding	4.054	1.929	**0.04**
Mood symptoms			
Depression	−0.734	0.128	**<0.0001**
Anxiety	−0.160	0.094	0.0897
Parenting-related			
PCQ score	−3.763	1.243	**0.003**
Parental status influences treatment	−0.656	2.508	0.8
Have not discussed prognosis with children	−0.409	1.557	**0.009**
Children not old enough to have discussion	−0.391	2.064	0.9
Concerned about financial impact on children	0.422	1.451	0.8

[*] Employed=Working full or part-time or full-time stay at home parent

Abbreviations: PCQ=Parenting Concerns Questionnaire (range 1–5, higher scores indicate more concerns)