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Measuring Psychosocial Distress and Parenting Concerns among Adults with Cancer: The Parenting Concerns Questionnaire

Anna C. Muriel, MD, MPH⁽¹⁾, Cynthia W. Moore, PhD⁽²⁾, Lee Baer, PhD⁽²⁾, Elyse R. Park, PhD, MPH⁽²⁾, Alice B. Kornblith, PhD⁽¹⁾, William Pirl, MD, MPH⁽²⁾, Holly Prigerson, PhD⁽¹⁾, Jennifer Ing, BA⁽¹⁾, and Paula K. Rauch, MD⁽²⁾

⁽¹⁾Dana-Farber Cancer Institute

⁽²⁾Massachusetts General Hospital Cancer Center

Abstract

PURPOSE—We conducted a two phase, mixed methods study to develop a Parenting Concerns Questionnaire (PCQ) for adults with cancer. Limited information about this area of psychosocial distress highlights the need for a measurement tool that can identify adult oncology patients with heightened parenting concerns who could benefit from additional intervention.

PATIENTS AND METHODS—Telephone focus groups were conducted with 16 oncology patients who had children 18 years old and younger. Group interview transcripts were analyzed to generate qualitative themes and candidate items for the PCQ. A 38-item version of the questionnaire was completed by 173 oncology outpatients with children 18 years old and under. Participants also completed the Distress Thermometer, HADS, and FACT-G. Exploratory factor analyses revealed the emergence of 3 subscales of 5 items each, yielding a 15 item questionnaire. Associations between total PCQ scores, standardized measures of distress, depression, anxiety, quality of life, and demographic and illness characteristics were examined.

RESULTS—The 15 item PCQ demonstrates good internal consistency (Cronbach's $\alpha = .83$). PCQ scores were significantly associated ($p < .01$) with standardized measures of psychosocial distress (Distress Thermometer, HADS, and FACT-G) in the expected directions. Higher PCQ scores were associated with female gender, single parenthood, metastatic or recurrent cancer, subjective understanding of incurable disease, co-morbid chronic health condition, and current mental health treatment.

CONCLUSIONS—The Parenting Concerns Questionnaire proved a reliable and valid measure of parenting distress among cancer patients meriting further study.

Keywords

psychosocial aspects; quality of life; psychometrics; parenting

Corresponding Authors: Anna C. Muriel, MD, MPH, Dana-Farber Cancer Institute, 450 Brookline Avenue, Dana 312, Boston, MA 02215, amuriel@partners.org. Cynthia W. Moore, PhD, Massachusetts General Hospital Cancer Center, 55 Fruit Street, YAW 6900, Boston, MA 02114, cmoore8@partners.org.

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INTRODUCTION

Approximately 22% of incident cases of cancer occur in adults between 20 and 55 years of age¹, during a time of intense social and vocational activity. For many of these adults, parenting is a primary role, and this essential activity and aspect of identity is often unattended to by multidisciplinary oncology clinical and research teams². Recent epidemiological data estimate that 18% of adults within 2 years of initial diagnosis, and 14% of a large sample of survivors (N= 13,385, mean years since diagnosis = 7.9 years) are parenting minor children, and an estimated 1.6 million adults and 2.85 million children are affected by parental cancer³. Because parenting status is not routinely documented in cancer epidemiology, research, or clinical care, we have no actual prevalence data, and the above epidemiological data are acknowledged to be underestimates. Commonly used Quality of Life research instruments may ask about general family concerns, and only rarely about children in particular⁴. Instruments that do ask about children use a single general item, limiting capacity to assess psychosocial needs, the impact of having cancer on parenting, or the role of parenting status on oncology treatment decisions. There is no published measure that identifies concerns about the impact of parental cancer on children. The paucity of existing data highlights the need for a tool that could be used in research and clinical settings to identify patients who are struggling with parenting concerns.

Parenting status is known to affect medical decision-making in both early stage and advanced illness. Having children living at home predicts willingness to accept more aggressive treatment in patients with a range of disease stages⁵. Women with early stage breast cancer and dependent children required smaller benefits in life expectancy or survival rate to make adjuvant chemotherapy worthwhile, than women without dependent children^{6,7}. Among patients with advanced cancer, those with dependent children had higher rates of panic and worry than those without dependent children. These subjects were more likely to prefer more aggressive treatment, and to be less likely to engage in advanced care planning. This same population of patients with dependent children was also judged by their caregivers to have worse quality of life in the last week of life⁸.

The impact of parental cancer on children is also significant; latency-age boys and adolescent girls are specifically at higher risk of psychosocial problems such as anxiety, depression and aggression than norms⁹. Consistent with other populations¹⁰, risk for child internalizing disorders is higher among children whose parents not only have cancer, but are also depressed. Importantly, rates of depression among parents with cancer are high (up to 35%), and are associated with impaired family function as well as child externalizing disorders¹¹. The extent to which parental depression is attributable to parenting concerns is unknown.

In an initial effort to fill the information gap regarding patient concerns about their children, this study used qualitative and quantitative methods to develop a parenting concerns measure that could be used for clinical and research purposes. We evaluated the psychometric properties of the resulting scale, and examined the correlations between parenting concern scores, other psychometrically sound measures of psychological distress and quality of life, and demographic and illness variables. We hypothesized that higher parenting concern scale scores would be positively associated with more psychological distress and worse quality of life.

PATIENTS AND METHODS

After approval from institutional review boards at the Massachusetts General and Dana Farber Cancer Centers, instrument development proceeded in two phases: qualitative focus

groups and quantitative analyses to reveal emergent factors and items to retain. The resulting 15 item pilot instrument then underwent cognitive testing.

Qualitative Focus Groups

Adults with cancer who had children 18 years old or younger were recruited using flyers posted in outpatient oncology clinics, and participated in telephone focus groups between January and April 2008. To engage parents in discussion of developmentally informed issues, participants were divided into groups of 3 to 5 participants by the age of their children: under 4 years, 4–8 years, 9–12 years, and 13–18 years old. Focus groups were recorded and transcribed. Interviewers used a semi-structured script with questions about the impact of cancer on the family, concerns about children, and changes in interactions with children since diagnosis. Three independent raters manually coded transcripts using an iterative, multi-step process of content analysis to develop major themes and subthemes. Coding disagreements were resolved by consensus and comparison to the raw data. Themes were then used to create scale items.

Quantitative Phase

Introductory letters and survey packets were placed in outpatient clinic waiting rooms at two large urban cancer centers. Self-selected adult oncology outpatients with children 18 years old and younger anonymously completed the packet of self-report assessments described below and returned them during clinic visits between October 2008 and August 2009.

MEASURES FOR QUANTATIVE PHASE

Socio-demographic and Illness Characteristics

Participants were asked to provide information regarding: age, sex, race/ ethnicity, marital status, income, education, cancer diagnosis and stage, recurrence and metastases, time since diagnosis, treatment modalities and frequency, mental health diagnoses and treatment. They were also asked to subjectively rate their current health status and goal of cancer therapy.

Parenting Concerns

Participants completed the 38 candidate questionnaire items that were derived from focus group themes. Items were scored on a 5 point Likert Scale where 1= “not at all concerned and 5= “extremely concerned.”

Quality of Life

Participants completed the Functional Assessment of Cancer Therapy – General (FACT-G), a 27 item questionnaire with four subscales assessing physical, social/family, emotional, and functional well-being on a 5 point Likert scale where 1= “not at all” and 5= “very much”. The total FACT-G has a coefficient alpha of .89, with 51% of variance accounted for.¹² The general adult population norm is a mean total score of 80.1 (SD=18.1)¹³

Depression and Anxiety

The Hospital and Anxiety Depression Scale (HADS) is a 14 item self-report measure that has been well tested in cancer populations. It has two 7-item subscales assessing depression and anxiety¹⁴. An overall cutoff score of 15 or greater results in 80% sensitivity, 76% specificity and a positive predictive value of 41%¹⁵

Overall Distress

The Distress Thermometer uses a single item rating of distress from 0–10 over the past week, and participants checked off current concerns on 32-item problem list, that includes

“dealing with children”¹⁶. This measure compared favorably with the HADS and BSI-18, and was found to have optimal sensitivity and specificity at a cutoff score of 4.¹⁷

Statistical Methods

In this first phase of scale development, we had no apriori hypotheses about the nature of the measure’s underlying factor structure. We conducted an exploratory factor analysis to assess the relationships between the items and identify underlying factors. Factor extraction assists in developing reliable factors from populations of questionnaire items. Alpha factor analysis with Varimax rotation was employed to facilitate item reduction¹⁸. The 5:1 subject to item ratio falls within current practice standards in factor analysis¹⁹. The SPSS PASW Statistics 17.0 statistical software package was used for all statistical analyses.

Cognitive Testing of 15 item Questionnaire

10 additional subjects in active cancer treatment were interviewed to explore their comprehension, interpretation and level of comfort with each of the final 15 items.

RESULTS

Qualitative Phase

16 adults (13 female) with a range of cancer diagnoses participated in qualitative focus groups. Qualitative analyses resulted in 5 major and 4 sub themes, which were reflected in the first version of the PCQ instrument.

Themes included 1) communication with children, 2) children’s current and future coping or behavior, 3) parenting identity and evaluation of own parenting, 4) partner’s ability to support patient and children, and 5) changes in parenting. The last theme included the relational impact of the ill parent’s emotional, physical and cognitive changes, as well as practical changes in social support and daily routines.

From these themes, coders created a pool of 38 candidate items, scored on a 5 point Likert-scale with the prompt “In the past month, I have been concerned that...”.

Quantitative Phase

194 subjects responded to the survey, and 175 completed at least 34 out of the 38 candidate parenting concerns items (< 10% missing items); 90% completion rate. 173 subjects completed these parenting items and all of the standardized instruments, and were included in the analyses of external validity. Median age was 46 years (range 26–65 years). Sample characteristics are described in Table 1. Illness characteristics and subjective assessments of health status are listed in Table 2.

Factor Analysis and Item Reduction

Following recommendations for exploratory factor analysis best practices (18), the scree test guided the decision about how many factors to retain. The scree plot suggested a 3-factor solution; eigenvalues for the first five factors were 9.29, 3.49, 2.90, 1.88, and 1.72. Examination of the item loading tables for 2, 3 and 4 factor solutions suggested that the three factor solution had the cleanest factor structure. These factors were: 1) Practical impact of the illness on children, 2) Emotional impact of the illness on children, 3) Concerns about co-parent. The three factor solution accounted for 41.3% of the item variance, and was used for all subsequent analyses of individual items.

Three items did not have factor loadings $\geq .32$ on any of the three factors and were dropped, to ensure adequate overlapping variance among items on each factor¹⁸. Also dropped were

12 items with variance not well explained by the three factors (communality $<.40$). Six items with borderline communalities were retained for content. Five items cross-loaded on two factors (factor loadings $\geq .32$); 4 were dropped, and one was retained for content.

Inter-item correlations among the remaining items were examined. Three items had high correlations with other retained items ($r \geq .60$). Two were dropped to minimize redundancy, and one was retained for content. Two other items were dropped for redundant content. The final PCQ scale has 15 items loading on 3 factors, with 5 items on each factor. These items represented all of the themes yielded by the qualitative analyses of focus group transcripts supporting face validity. Item means and standard deviations are shown in Table 3.

Cognitive Testing

Individually interviewed subjects demonstrated good comprehension and accurate interpretation of each of the 15 questions. They felt that items represented important areas of concern. Some subjects expressed mild discomfort with the question about the possibility of death, but all recognized the importance of asking about this concern and did not endorse deleting it.

Scale reliability

Cronbach's alpha for the 15-item PCQ scale = .83, $n=141$. Cronbach's alpha for each subscale are as follows: 1) practical impact of the illness on children was .79, $n=185$, 2) emotional impact of illness on children was .79, $n=171$, 3) concerns about co-parent was .85, $n=157$.

Scale validity

The Distress Thermometer, FACT-G and HADS data were tabulated and scored according to instrument directions.

Table 4 lists mean total scores for the 15 item PCQ, the 3 subscales and the HADS, FACT and Distress Thermometer. Mean scores fall in the mild to moderate range of clinical severity. The mean Distress Thermometer score 4.31 just crosses the threshold for clinical intervention ($=4$), and HADS Anxiety scale mean of 7.6 was just over the clinically significant cutoff score ($=7$).

There were moderate correlations²⁰ in expected directions between PCQ total scores and these standardized measures (r 's $.30-.59$, p 's $<.05$) (Table 5). This suggests that being concerned about parenting issues is related to anxiety, depression, functioning and overall distress. However, the correlations also indicate that the PCQ captured a unique aspect of participants' concerns, and support the discriminant validity of this new measure. The PCQ is expected to measure specific aspects of patient distress related to parenting, and so scores may be similar to other areas of emotional distress such as anxiety or depression, but not identical, therefore capturing previously unmeasured forms of distress among adult cancer patients.

Total PCQ scores were normally distributed and t-tests were used to compare scores between different groups of patients. Patients who were female, single, had metastatic or recurrent disease, had another chronic health condition, and were in current mental health treatment, had significantly higher mean PCQ scores. Patients who described the goal of their treatment as living as long as possible with the disease, versus being cured, also had significantly higher levels of parenting concern (Table 6).

A one-way, between subjects ANOVA examined the relationship between reported income level as a categorical variable, and parenting distress. Total PCQ scores had homogenous variance across income levels as demonstrated by Levene's test. There was a significant overall effect [$F(4, 173) = 3.38, p=.011$], with lower income associated with higher levels of parenting concerns, especially at below \$20,000 ($M=2.95, SD=.86$).

DISCUSSION

This study is a first comprehensive approach to measuring parenting concerns among adults with cancer, and is an initial step in identifying and addressing the specific needs of millions of parents with cancer and their families. The PCQ demonstrates good internal consistency and face validity, and PCQ scores had significant but moderate correlations with standardized measures of distress, suggesting that parenting issues may be a unique contributor to psychological distress associated with cancer. The utility of a new parenting concerns instrument may be to capture the psychological distress specifically associated with parenting that is not fully identified by standardized tools for general distress, anxiety or depression.

This study is limited by the sample demographics being predominantly female, Caucasian, well-educated and married. Research with more diverse subject populations might reveal different patterns of overall distress and parenting concern, additional psychometric data, as well as more specific associations with standardized measures of psychosocial distress or parenting stress.

Our three-factor solution explained 41.3% of the total variance in the original pool of 38 items. There often remains much unexplained variance in the original correlation matrix following exploratory factor analysis. A weakness of the present study is that the ratio of subjects to items was 4.6:1, which is toward the lower end of recommended ratios²⁰, and may result in errors in eigenvalues and factor loadings. Replication of this exploratory factor analysis in other populations is needed to determine the stability of the factors identified here, followed by testing with confirmatory factor analysis. Exploration of the PCQ relative to other measures of parenting distress, such as the Parenting Stress Index²¹, might provide specific criterion validity, although this measure asks more about inherent child issues, rather than specific stressors such as parental illness.

This study assesses parenting concerns, an unaddressed area of distress among adults with cancer that may be related to parental depression and anxiety, as well as medical decision-making in this population. This focus on subjective parental concern is distinct from examination of the children's distress and yet is pertinent to the need for intervention around the experience of the children living with adults with cancer²². Interactions between parental distress and child distress have been noted and bear further exploration.²³ Challenges in communication between parents and children about the illness are also cited as a source of distress and misconceptions for children.²⁴⁻²⁶ Several of the original 38 candidate PCQ items about communication were in the borderline range of factor loadings. Factor loadings for the current 3 factors demonstrates simple structure, yet additional items in the areas of communication, children's misconceptions, and parental attributions about child distress bear further exploration. In research populations, a more comprehensive Parenting Concerns Questionnaire may eventually be useful to specifically assess the role of parenting in quality of life and medical decision-making.

This largely well-educated, married, self-selected sample indicated mild-to moderate concerns about their children, and slightly increased levels of depression and anxiety, and quality of life concerns. However, there is a subset of patients with elevated PCQ scores,

potentially signaling a higher risk population of women with advanced illness, or co-morbid health and mental health diagnoses who are most concerned about their children. Parents with a subjective understanding of their disease being incurable also had higher levels of concern. Single parenthood and low income may be additional risk factors and may confound one another in these analyses. These populations with increased levels of parenting concern may benefit from further assessment and intervention.

Interventions for families coping with medical illness have utilized cognitive behavioral strategies²⁷, psycho-education and parent guidance to support child coping^{26, 28}, with the premise that communication with children about parental illness may reduce child anxiety²⁴. Parental end-of life is known to be particularly stressful for children^{29, 30}, and literature on bereaved children^{31, 32} emphasizes the important role of family functioning and the surviving parent.

Clinical experience²⁶, and data in early stage treatment decisions^{6, 7} and end-of life decision-making⁸ indicate that having dependent children is a primary mediator for the cancer experience. Studies showing high rates of parental depression during cancer, and its impact on family and child function^{11, 23, 33} further support the need for specific intervention for these patients. It is possible that directly asking about parenting concerns may facilitate discussions about medical decision-making, end-of-life care, and quality of life for patients and their families.

In quality of life research, the refined PCQ may eventually identify parenting issues as mediators of distress and decision-making in oncology populations. As a subjective measure of parental concern, such an instrument may also become helpful in clinical screening to help oncology clinicians initiate discussions about family with patients, and guide intervention around parenting, or help with pre and post evaluation of such interventions. Evidence-based clinical interventions could ultimately improve outcomes for adult oncology patients and their families by mediating parent and child distress, and clarifying medical decision-making in this patient population.

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Table 1

Sample Characteristics

Variable	N (Percent)
Gender (female)	141 (73)
Race:	
American Indian	2 (1)
Asian	3 (2)
Native Hawaiian/Pacific Islander	1 (1)
Black/African American	6 (3)
White	184 (95)
Ethnicity:	
Hispanic/Latino	3 (1.5)
Living with spouse or partner	172 (89)
Education	
Less than high school	1 (0.5)
High school grad/GED	25 (13)
2–4 yr college	111 (57)
Graduate degree	56 (29)
Household income	
< \$20,000	9 (5)
\$20,000 – \$49,999	21 (11)
\$50,000 – \$74,999	34 (18)
\$75,000 – \$100,000	41 (21)
>\$100,000	83 (43)

Table 2

Illness characteristics

Variable	N (Percent)
Cancer type:	
Breast	66 (34)
Leukemia/lymphoma	33 (17)
GI	29 (15)
Gynecological	15 (8)
Other	51 (26)
Metastatic	82 (42)
Recurrence	65 (34)
Tx in past month:	
IV chemotherapy	100 (52)
Oral chemotherapy	28 (14)
Radiation	20 (10)
Surgery	19 (10)
Hormonal therapy	13 (7)
Current health:	
Relatively healthy and not likely to die within 6 months	166 (86)
Relatively healthy and likely to die within 6 months	2 (1)
Seriously ill but not likely to die within 6 months	16 (8)
Seriously ill and likely to die within 6 months	1 (0.5)
Goal of treatment:	
Cure so no cancer in body	107 (55)
Treatment to live as long as possible with illness	72 (37)
Palliative treatment	3 (2)
Cure and treatment	7 (4)
Has another chronic health problem	88 (45)
Ever treated for mental health problem	100 (52)
Currently receiving treatment for mental health problem	65 (34)

Table 3

Descriptive statistics for PCQ 15 items.

Factor/Variable	Mean	SD	N	Factor loadings		
				1	2	3
Factor 1: Practical impact of illness on child						
my own mood, worries or emotions are affecting my children	2.92	1.08	192	.64	.08	.03
my physical limits or low energy are affecting my children	2.88	1.19	193	.53	.00	.29
I am not able to spend as much time with my children as I'd like	2.86	1.41	190	.72	.16	-.09
my illness is changing my children's routine	2.34	1.21	190	.65	.17	.19
changes in my memory or attention are affecting my children	2.16	1.13	188	.63	.27	.14
Factor 2: Emotional impact of illness on child						
my children are emotionally upset by my illness	3.12	1.18	190	.33	.65	-.09
my children are worried that I am going to die	2.63	1.33	185	.20	.55	.07
my children get upset when we talk about the illness	2.12	1.07	187	.12	.55	.17
my children might be in need of professional mental health care	2.10	1.11	188	.05	.78	.11
my children get confused or upset by what others say about my illness	1.86	.93	183	.13	.47	.15
Factor 3: Concerns about co-parent						
my children's other parent would not be able to meet their emotional needs if I die	2.45	1.40	183	.15	.15	.70
there is no one to take good care of my children if I die	1.89	1.21	190	.01	.15	.60
my partner is not providing me with enough practical support	1.88	1.23	178	-.03	.19	.53
my partner is not providing me with enough emotional support	1.83	1.24	173	-.14	.19	.62
my children's other parent would not be a responsible caregiver if I die	1.72	1.25	185	.14	.01	.67

Range for all variables 1–5.

Table 4

Descriptive statistics for measures of distress.

Variable	Mean	SD	N	Min	Max
PCQ Total score	2.33	.68	182	1.00	4.57
PCQ Subscale 1: Practical impact	2.64	.89	189	1.00	4.80
PCQ Subscale 2: Emotional impact	2.38	.82	185	1.00	4.40
PCQ Subscale 3: Co-parent	1.95	1.03	179	1.00	5.00
Distress thermometer	4.31	2.80	156	0	10
Physical well-being	18.34	6.65	176	0	28.00
Social well-being	20.56	5.17	174	5.00	28.00
Emotional well-being	15.16	5.44	173	2.00	24.00
Functional well-being	16.91	6.21	174	1.00	28.00
FACT-G total score	70.29	18.94	176	0	108.00
HADS Depression	5.60	3.77	161	0	15
HADS Anxiety	7.60	4.25	162	0	20

Table 5

Correlations between PCQ scores and standardized measures.

Variable	PCQ total score	Subscale 1 Practical	Subscale 2 Emotional	Subscale 3 Coparent
Distress thermometer	.49**	.52**	.32**	.23**
Physical well- being	-.46**	-.61**	-.36**	-.08
Social well-being	-.54**	-.40**	-.32**	-.49**
Emotional well- being	-.50**	-.45**	-.43**	-.25**
Functional well- being	-.39**	-.48**	-.34**	-.05
FACT-G total score	-.59**	-.64**	-.44**	-.24**
HADS Anxiety	.31**	.30**	.22*	.15
HADS Depression	.48**	.55**	.32**	.17*

* $p < .05$ ** $p < .01$

Table 6

Means and standard deviations of PCQ scores.

Variable	M	SD	n	t (df)
Gender				-2.87 (180)**
Male	2.10	.66	49	
Female	2.42	.67	133	
Metastatic disease				-3.83 (166)***
No	2.14	.62	92	
Yes	2.53	.71	76	
Cancer recurred				-2.69 (162)**
No	2.21	.60	105	
Yes	2.50	.75	59	
Receiving mental health tx				-2.38 (166)*
No	2.23	.67	103	
Yes	2.49	.69	65	
Other chronic health problems				2.66 (180)**
No	2.21	.62	97	
Yes	2.47	.71	85	
Single parent				-3.52 (179)***
No	2.27	.64	164	
Yes	2.86	.80	17	
Active tx in past month				-1.96 (180) T
No	2.16	.69	47	
Yes	2.39	.66	135	
Goal of treatment				-3.85 (168)***
Cure (no cancer left in body)	2.16	.56	101	
To live as long as possible with illness	2.54	.71	69	

*
 $p < .05$ **
 $p < .01$ ***
 $p < .001$ T: $p = .052$