



Parental psychological distress and cancer stage: a comparison of adults with metastatic and non-metastatic cancer

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Abstract

Purpose Parents with cancer have unique and often under-recognized psychological distress about the impact of their illness on their children. Relatively little is known about how parenting concerns may differ among patients by cancer stage.

Methods This is a secondary data analysis of 203 adults with cancer who had children < 18 years old from two geographically distinct areas. We used an analysis of covariance to estimate the mean differences in PCQ, depression symptom severity and anxiety symptom severity (Hospital Anxiety and Depression Scale, HADS) scores between participants with metastatic and non-metastatic disease, and Pearson's correlation coefficients to assess associations between HADS and PCQ scores by cancer stage.

Results Seventy-two percent of participants ($n = 146$) had metastatic solid tumor cancer. In adjusted analyses, mean PCQ scores did not significantly differ between parents with metastatic and non-metastatic disease (2.0 vs. 2.2, $p = 0.06$). Differences in mean PCQ scores were driven by a single question concerning the impact of death on children (2.3 vs. 2.9, $p = 0.004$). Mean HADS scores did not significantly differ between groups, although PCQ scores explained a greater amount of variance in HADS scores for the metastatic group as compared to the non-metastatic group.

Conclusions With the exception of concerns about death, intensity of parenting concerns, as measured by the PCQ, was similar between parents with metastatic and non-metastatic cancer. However, parenting concerns may be more strongly linked to overall psychological distress in patients with metastatic disease. Further research is needed to clarify how parenting concerns uniquely relate to advanced stage illness.

Keywords Cancer · Oncology · Parents · Parenting concerns · Psychological distress

Background

In the USA, nearly one in five cancer patients in active treatment are parenting children younger than 18 years, and more than a million families with minor children are affected by parental cancer [1]. Among US adults between the ages of 20 and 49—prime parenting years, age-adjusted incidence rates of cancer have increased from 138 cases per 100,000 population in 1975 to 157 cases per 100,000 population in 2013 [2]. Thus, having children while undergoing cancer treatment is increasingly prevalent.

Adult cancer patients with minor children have concerns about the impact of their illness on their families including concerns about disruptions to family routines, communication with children, and their ability to maintain parental roles and responsibilities despite illness [3–5]. Qualitative data suggest that parents struggle to balance their own need for care with the needs of their children [6–8]. Many parents with cancer, particularly those with advanced or metastatic disease, may particularly struggle with concerns related to premature mortality and the impact of early parental death on their children [9–11]. Parents' concerns are well founded; many families perceive a

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parental cancer diagnosis as a major disruption [12, 13], and children of cancer patients are more likely to experience negative psychosocial outcomes [14]. Adolescent daughters and latency-aged sons (age 4–10 years) of cancer patients are particularly at risk [14, 15].

Understanding cancer patients' parenting concerns is critically important to patient-centered care in oncology. The overwhelming majority of US adults consider their parenting role to be extremely or very important to their identity [16], and this parenting role is greatly impacted by a cancer diagnosis and its treatment. Among cancer patients more broadly, younger individuals, many of whom are raising children, exhibit higher levels of psychological distress than older patients [17], and previous studies have identified positive correlations between the severity of general psychological distress and parenting concerns among adults with minor children [18, 19]. The impact of parental distress is important not only for the individual with cancer but their family members as well. Across studies of parental cancer, a robust predictor of child adjustment is the ill parent's psychological well-being. For either mothers or fathers with cancer, comorbid depression is linked with worse outcomes for their children [15, 20].

There is limited evidence regarding the relationships between psychosocial distress and cancer stage among parents with cancer. Assessments of parenting-specific distress largely utilize qualitative methodology and reflect the experiences of women with breast cancer or patients with curable disease; these reports have described the challenges to the parental role due to cancer and patients' perceptions of how these stressors are linked to emotional well-being [3]. While data from survey-based studies reflect the experiences of both mother and fathers, few include parents of varied cancer stage [21]. Among the studies that do incorporate parents with advanced stage disease, the representation of individuals with incurable cancer is typically low. From these studies, data is mixed regarding the impact of cancer stage on parents' report of general psychological distress; perceptions of illness severity were more strongly linked to distress than objective characteristics of the disease such as cancer stage [14]. Other data suggest that having a cancer with poorer survival rate or the presence of metastases may be associated with higher psychosocial distress [14, 22, 23].

Given the importance of parental status and thus, parenting concerns, for adults with cancer, Muriel et al. developed the Parenting Concerns Questionnaire (PCQ) to assess levels of parenting concerns in adults with cancer who have children younger than 18 years old [22]. The PCQ addresses several domains of concern that parents may have about the impact of their illness on their children such as changes in home routines and how children respond to parental physical changes. Developed in 2012, the PCQ is a relatively new measure and currently, the only known measure of parenting-related distress in cancer; thus, quantitative evidence on how cancer-specific parenting concerns may differ among cancer patients is lacking.

The extant literature suggests that parents with advanced or incurable cancer may be a psychologically vulnerable group. As compared to similarly ill cancer patients without children, parents are more likely to experience clinically significant anxiety and depression [24]. Other studies have demonstrated that these affective symptoms are linked to severity of parenting concerns [19, 25]. Qualitative reports suggest that parents with advanced cancer can struggle with concerns about the impact of anticipated death on their children, distress with respect to communicating prognosis, and coping with the desire to be available to their children in the setting of a contracted future and expected functional decline [9, 11]. Given these known relationships, the current study sought to (1) explore the associations between cancer stage and parenting concern severity by evaluating differences in parenting concerns (as measured by the PCQ) between patients with metastatic cancer and patients with non-metastatic disease and (2) examine differences in symptoms of depression and anxiety among parents with metastatic and non-metastatic disease. We hypothesized that parents with metastatic cancer would endorse higher parenting concerns as measured on the PCQ than parents with non-metastatic cancer.

Methods

Overview

This is a secondary data analysis from two independently conducted studies on parents with cancer. This study focuses on the 203 patients with solid tumor cancers who had at least one child < 18 years old.

Participants

Data from the Fathers and Mothers with Cancer study was collected between May 2013 and April 2014. Participants were English- or Spanish-speaking adults with stage IV solid tumor malignancy receiving care at an academic comprehensive cancer center in the Southeast who had at least one biologic or adopted child younger than 18 years old. Potential study participants were identified through review of outpatient and inpatient oncology service rosters. Research staff approached all patients whose oncologist permitted contact and who met study criteria. Seventy-eight percent ($n = 67$) of eligible patients consented to enroll in the study.

Eligible patients for the Measuring Parenting Concerns Study were adult oncology patients with at least one child younger than 18 years, with any stage cancer diagnosis receiving ambulatory care at two large academic comprehensive cancer centers in the Northeast. Survey data from the Measuring Parenting Concerns Study was collected between October 2008 and August 2009. A total of 149 participants returned completed study measures and were included in this analysis.

For this study, parents who had stage IV solid tumor malignancies with distant metastases were considered “metastatic.” Parents with stage 0–III solid tumor malignancies were classified as “non-metastatic.” Participants with hematologic malignancies and those who did not provide enough information to identify cancer stage were not included in analyses ($n = 39$).

Data collection

Participants in the Fathers and Mothers with Cancer study completed a demographic questionnaire and validated measures of psychological distress and HRQOL and an in-depth semi-structured interview of their experiences as a parent. Study procedure details have been described previously [19]. Only the survey data is utilized for this study.

Participants in the Measuring Parenting Concerns Study anonymously completed demographic and psychosocial self-report assessments, which were made available to them in waiting rooms of all outpatient oncology clinics including breast, gynecologic, gastro-intestinal, urologic, and hematologic malignancies.

Both studies collected data on self-reported patients’ and their children’s demographic characteristics. Information on patient’s illness and treatment history was collected from the medical record for the Fathers and Mothers with Cancer study and via self-report for the Measuring Parenting Concerns Study. Participants in both studies also completed the PCQ, the Hospital Anxiety and Depression Scale (HADS), and the Functional Assessment of Cancer Therapy–General (FACT-G)—a measure of HRQOL with four dimensions (physical well-being, PWB; social well-being, SWB; emotional well-being, EWB; and functional well-being, FWB). To assess the extent of medical comorbidity, participants were scored via the Charlson comorbidity index (CCI), the most widely used index of disease comorbidity [26]. The Internal Review Board Committees of all participating sites approved all recruitment, consent, and interviewing procedures. Informed consent was obtained from all individual participants included in the study.

Parenting Concerns Questionnaire

The PCQ is a 15-item, self-administered assessment of parenting concerns developed for adults with cancer. The PCQ has three subscales addressing concerns about the practical impact of illness on children, the emotional impact on children, and the co-parent. Each item is rated on a 5-point scale (1, no concerns; 5, extremely concerned). The total and subscale scores are calculated by taking the mean of the items contributing to it, thus ranging from 1 to 5. If a patient indicates not currently partnered, two items do not apply, and the subscale score is the mean of three items. If the patient indicates not having a living co-parent, then an additional two items do not apply. The PCQ has demonstrated good internal consistency and face validity [3].

Hospital anxiety and depression scale

General anxiety and depression symptom severity were evaluated with the Hospital Anxiety and Depression Scale (HADS). The HADS is a 14-item scale with two 7-item subscales that evaluates the severity of depression and anxiety in patient population with medical conditions. Each item is scored on a 4-point Likert type scale with a range of 0–21 for each subscale. Scores 8–10 are considered mild symptoms and scores 11–14 moderate symptoms [27]. The HADS is one of the most widely used and validated measures of depression and anxiety in oncology populations [28].

Statistical analyses

We used descriptive statistics to characterize the sample and each group. The primary outcome variables were PCQ total subscale scores and HADS depression and anxiety scores. Our main independent variable was cancer stage, dichotomized as metastatic or non-metastatic. We included additional variables in our analyses that were known or suspected risk factors for higher psychological distress scores and could potentially confound the cancer stage/parenting concerns relationship. These factors included age, gender, race/ethnicity, education and income, number and age of children, marital status, cancer type, time since diagnosis (duration of illness), physical symptom burden (FACT-G PWB subscale), and prior mental health diagnosis or treatment.

We evaluated the unadjusted relationship between each of the independent variables and the outcome scores using Pearson’s correlation for continuous variables and t tests or one-way analysis of variance for categorical variables. Independent variables that were significant in bivariable analyses at $p < 0.2$ (two-tailed) were entered into the regression models. This threshold was chosen to guide purposeful selection of covariates in the regression modeling since more traditional levels such as 0.05 can fail to identify important adjustment variables [29]. We then used analysis of covariance to estimate the mean PCQ or HADS score for metastatic and non-metastatic cancer groups after adjusting for covariates. In the final model, to reduce the risk of collinearity among conceptually similar variables with high correlations, neither mean age of children and age of youngest child were included together nor were single parent status and married/partnered status. For analyses in which HADS scores were the outcome, formal tests for interactions between cancer stage and PCQ scores were conducted and were not included in the model as they were not significant. After fitting a model that included PCQ or HADS score and all covariates, we used change-in-effect to remove any variables from the model that did not meaningfully change the adjusted cancer stage mean estimates for PCQ or HADS score ($> 10\%$), and thus were not confounders of the relationship. We used the beta estimates from the final model to calculate adjusted mean PCQ or HADS scores for each group.

Pearson's product-moment correlations were also conducted to assess the relationship between HADS depression and anxiety subscale scores and PCQ scores by group.

All analyses were performed using Stata 14 (College Station, TX).

Results

Table 1 contains the demographic characteristics of the sample and for each group. On average, participants were 45.5 years old (standard deviation, SD, 7.6) and had 1.9 (SD, 0.9) children. Seventy-two percent ($n = 146$) had metastatic solid tumor cancer. As expected, there were several differences between the non-metastatic and metastatic groups. Notably, compared to patients with non-metastatic cancers, individuals in the metastatic group were less likely to have breast cancer and more likely to be male, unemployed, identify as ethnic/racial minority, have less education, report lower household income, have higher medical comorbidity and higher physical symptom burden, and have shorter duration of illness. Many of these differences

also occurred with geographic location as only two of the three sites recruited patients with non-metastatic cancer.

Parenting concerns and cancer stage

Table 2 lists the bivariable associations between total PCQ scores and clinical or demographic characteristics. In unadjusted analyses, having metastatic cancer was associated with higher total PCQ scores (2.21 vs. 2.00, $p = 0.04$) and emotional impact PCQ subscale scores (2.52 vs. 2.17, $p = 0.01$). Having metastatic cancer was not associated with statistically significant differences in practical impact concerns or concerns about co-parent subscale scores. Participants who were unemployed, with higher comorbidity, with lower income, and receiving care at the Massachusetts General Hospital (MGH) were more likely to report higher emotional concerns. Participants who were unemployed, reported having prior mental health diagnosis or treatment, and receiving care at MGH were more likely to endorse higher practical concerns. Participants with the highest concerns about their co-parent were more likely to be female,

Table 1 Participant characteristics, overall and by cancer stage*

Characteristic	Overall ($n = 212$)		Non-metastatic ($n = 62$)		Metastatic ($n = 150$)		p value
	n	Mean or %	n	Mean or %	n	Mean or %	
Age, mean (SD)	209	46 (8)	60	45 (7)	149	46 (8)	0.8
Female gender	157	74	50	81	107	71	0.2
Caucasian	185	87	57	92	128	85	0.2
Married or partnered	178	84	55	89	123	83	0.3
College graduate	134	63	44	71	90	60	0.1
Employed ^a	114	54	46	75	68	45	< 0.0001
Annual household income > \$50,000	150	71	50	86	100	68	0.01
Number of children ≤ 18 , mean (SD)	210	2 (1)	61	2 (1)	149	2 (1)	0.7
Age of children ≤ 18 , mean (SD)	210	11 (4)	61	10 (5)	149	12 (4)	0.02
Age of youngest child ≤ 18 , mean (SD)	210	10 (5)	61	9 (5)	149	10 (5)	0.1
Location cancer care							
UNC	63	30	0	0.0	63	42	< 0.0001
MGH	35	17	15	24	20	13	
DFCI	114	54	47	76	67	45	
Breast cancer	84	40	36	59	48	32	< 0.0001
Receiving anti-neoplastic treatment	180	85	51	82	129	86	0.5
CCI score, mean (SD)	210	5 (2)	62	2 (0)	149	6 (1)	< 0.0001
Duration of illness, months, mean (SD)	209	49 (135)	61	73 (238)	145	39 (42)	0.1
Prior mental health diagnosis or treatment	94	44	25	40	69	47	0.4
FACT-G PWB score, mean (SD)	199	12 (7)	59	9 (6)	140	13 (7)	< 0.0001

UNC, University of North Carolina–Chapel Hill; MGH, Massachusetts General Hospital; DFCI, Dana Farber Cancer Institute; CCI, Charlson comorbidity index (higher scores indicate more comorbidity); FACT-G PWB, functional assessment of cancer therapy–general physical well-being subscale (higher scores indicate worse physical well-being)

*Based on means \pm SD for continuous variables and percents for categorical variables

^a Full-time, part-time, or home-maker

Table 2 Unadjusted associations between each patient characteristic and total PCQ score

Characteristic	<i>n</i>	PCQ score mean or correlation	<i>p</i> value*
Age	249	$r = 0.0710$	0.26
Patient gender			
Male	71	1.85	0.0001
Female	180	2.22	
Patient race			
White	223	2.10	0.13
Non-white	28	2.30	
Marital status			
Married or partnered	177	2.2	0.006
Single or divorced or widowed	33	2.5	
Education			
College graduate	155	2.11	0.71
Non-college graduate	95	2.14	
Employment status			
Working	135	2.00	0.0031
Not working	114	2.25	
Household income			
Less than \$50,000	61	2.30	0.0195
More than \$50,000	183	2.07	
Number of children ≤ 18	250	$r = -0.0423$	0.10
Mean age of children ≤ 18	250	$r = 0.0881$	0.17
Youngest child ≤ 18	250	$r = 0.1013$	0.11
Oldest child ≤ 18	250	$r = 0.0750$	0.23
Location cancer care			
UNC	63	2.10	0.018
MGH	40	2.29	
DFCI	148	2.08	
Cancer type			
Breast	84	2.10	0.8225
Non-breast	165	2.12	
Receiving anti-neoplastic treatment			
Yes	195	2.22	0.85
No	56	2.13	
CCI score	250	$r = 0.1661$	0.0085
Duration of illness, months	244	$r = 0.0385$	0.56
Prior mental health diagnosis or treatment			
Yes	114	2.28	0.0001
No	135	1.97	
FACT-G PWB score	235	$r = 0.1099$	0.09
Metastatic cancer			
Yes	149	2.21	0.0402
No	62	2.00	

PCQ, parenting Concerns Questionnaire (higher scores indicate more severe parenting concerns); *UNC*, University of North Carolina–Chapel Hill; *MGH*, Massachusetts General Hospital; *DFCI*, Dana Farber Cancer Institute; *CCI*, Charlson comorbidity index (higher scores indicate more comorbidity); *FACT-G PWB*, functional assessment of cancer therapy–general physical well-being subscale (higher scores indicate worse physical well-being)

*Means and *p* values based on 2-sample *t* tests or one-way analysis of variance for variables with more than two categories; correlations and *p* values based on Pearson's correlation. Variables with *p* values < 0.20 were included in subsequent linear regression model

Table 3 Unadjusted and adjusted associations between parental cancer stage and measures of psychological distress

Characteristic	<i>n</i>	PCQ	<i>p</i> value	HADS depression	<i>p</i> value	HADS anxiety	<i>p</i> value
Unadjusted							
Metastatic	149	2.21	0.0402	5.28	0.4	7.48	0.9
Non-metastatic	62	2.00		4.77		7.37	
Adjusted*							
Metastatic	136	2.23	0.062	5.4	0.9	7.9	0.8
Non-metastatic	57	2.20		5.5		8.0	

PCQ, Parenting Concerns Questionnaire (higher scores indicate more severe parenting concerns); HADS, hospital anxiety and depression scale (higher scores indicate more symptoms)

*Based on the beta estimates from a multiple linear regression model, adjusted for employment status, duration of illness, study site, and the Functional Assessment of Cancer Therapy–General, Physical Well-Being subscale score

have a prior mental health diagnosis or treatment, and report lower income. Number of children, mean age of all dependent children, and mean age of youngest child were not associated with total or subscale PCQ scores.

In the final multivariable model, adjusted for all other variables that were either significant in bivariable analyses or hypothesized to be clinically relevant, characteristics associated with higher total PCQ scores included employment status, study site, duration of illness, and FACT-G PWB scores (Table 3). After adjusting for these variables, having metastatic cancer was no longer significantly associated with higher total PCQ scores (2.2 vs. 2.0, $p = 0.06$).

Table 4 shows the mean and SD for each item on the PCQ and by cancer stage. Differences in PCQ scores between the two groups were driven by the single question about concerns about the impact of death on children (2.3 vs. 2.9, $p = 0.004$).

For all other questions, there were no statistically significant differences between the two groups. Similarly, the proportion of participants in each group who reported “no concerns” for each question item did not significantly differ between groups with exception of concerns about the impact of death.

Anxiety and depression symptom severity

Table 3 lists the unadjusted and adjusted mean HADS depression and anxiety subscale scores by group. Among both groups, mean anxiety scores were higher than mean depression scores. The unadjusted mean scores in both groups did not exceed the screening threshold for anxiety or depression (scores > 8), and differences between groups were not statistically significant. Similarly, the percentage of participants with moderate-high (scores > 11) anxiety or depression scores

Table 4 Parenting Concerns Questionnaire (PCQ) item scores by group

PCQ question: “In the past month, I have been concerned that…”	Non-metastatic		Metastatic		<i>p</i> value*
	<i>n</i>	Mean (SD)	<i>n</i>	Mean (SD)	
Practical impact					
...my own mood, worries, or emotions are affecting my children	61	2.80 (1.09)	148	2.97 (1.09)	0.34
...my physical limits or low energy level are affecting my children	62	2.65 (1.15)	149	2.87 (1.24)	0.20
...I am not able to spend as much time with my children as I would like	59	2.95 (1.42)	149	2.79 (1.48)	0.48
...my illness is changing my children’s routines	60	2.25 (1.19)	149	2.31 (1.24)	0.81
...changes in my memory and attention are affecting my children	60	1.98 (1.00)	146	2.19 (1.00)	0.42
Emotional impact					
...my children are emotionally upset by my illness	60	3.02 (1.16)	148	3.24 (1.13)	0.20
...my children are worried that I am going to die	59	2.32 (1.31)	146	2.94 (1.37)	0.0036
...my children get upset when we talk about my illness	58	1.97 (0.92)	148	2.23 (1.20)	0.26
...my children might be in need of professional mental health care	60	1.93 (0.97)	147	2.20 (1.32)	0.43
...my children get upset or confused by what others say about my illness	59	1.68 (0.80)	147	1.99 (1.13)	0.13
Concerns about co-parent					
...there is no one to take good care of my children if I die	61	1.84 (1.13)	147	1.92 (1.26)	0.87
...my partner is not providing me with enough emotional support	55	1.71 (1.12)	136	1.82 (1.28)	0.89
...my partner is not providing me with enough practical support	57	1.68 (1.09)	133	1.86 (1.25)	0.62
...my children’s other parent would not be a responsible caregiver if I died	58	1.66 (1.18)	145	1.85 (1.41)	0.69
...my children’s other parent would not be able to meet their emotional needs if I died	57	2.32 (1.40)	145	2.55 (1.48)	0.35

*Based on Pearson’s correlations for items with normal distribution and Wilcoxon Rank-Sum tests for items with non-normal distribution

did not similarly differ between groups. In adjusted analyses, mean depression and anxiety scores did not differ by cancer stage, although adjusted mean anxiety scores in both groups met the screening threshold for anxiety.

Correlations between mood symptoms and parenting concerns by cancer stage

Key differences emerged between the metastatic and non-metastatic groups in the correlations between PCQ scores and HADS depression and anxiety scores. Among the metastatic group, there was a moderate positive correlation between PCQ scores and depression scores, $r = 0.453$, $p < 0.001$ with PCQ scores explaining 21% of the variation in HADS depression scores. A similar relationship existed between PCQ scores and HADS anxiety scores, $r = 0.399$, $p < 0.001$, with PCQ scores explaining 16% of the variance in anxiety scores. In contrast, PCQ scores only explained 12% of the variance in HADS depression scores in the non-metastatic group ($r = 0.350$, $p = 0.008$), and 9% of the variance for HADS anxiety scores ($r = 0.2953$, $p = 0.03$).

Conclusions

This study provides important insights into how cancer stage did not influence the severity and scope of patients' parenting concerns among a large sample of patients with cancer. With the exception of concerns about death, the intensity of parenting concerns, as measured by the PCQ, did not significantly differ between adults with metastatic and non-metastatic cancers. Similarly, the number of concerns (as measured by the number of PCQ items endorsed as any level of concern) and mean depression and mean anxiety symptom severity scores did not differ between groups.

The results of this study contradict our hypothesis that parents with metastatic cancer would endorse greater parenting concerns than parents with earlier stage disease. Nevertheless, there were stronger correlations between PCQ scores and HADS scores among parents with metastatic disease as compared to parents with non-metastatic illness. Taken together, these results suggest that the experience of generalized psychosocial distress may be more strongly associated with parenting-related concerns among parents with metastatic disease as compared to parents with early stage cancer, even when the severity of measured parental distress is similar between groups. The non-significant differences in concern intensity between parents with metastatic and non-metastatic cancer may also be due to limitations of using a single measure to reflect a complex experience. For example, concerns about the impact of death on children or the availability of a responsible co-parent if the parent died may be far more

important to ill parents than concerns about changes in routine, but these items are given equal weight in the measure.

Our data suggest that cancer stage alone does not independently determine levels or scope of parenting concerns on the PCQ, rather concern severity must be considered in the context of other demographic, clinical, and psychological factors. In addition, our research is the first to explicitly measure differences in parenting concerns—a more specific construct than psychological distress or anxiety—by cancer stage while also controlling for potential confounders, thus a stricter test of the association. Our findings provide several practical observations that may be relevant in the care of these patients.

First, parents' subjective distress about the impact of illness on children may be independent of stage. Hence, parenting concerns in cancer must be understood in context of the overall patient experience. In our study, parents who were female, unemployed, single, with lower income, and higher comorbidity were more likely to report higher parenting concerns in bivariable analyses. Additionally, parents with pre-existing mental health diagnoses or treatment (prior to or during their cancer treatment) were more likely to endorse greater level of concerns about their children. Having metastatic cancer was not a risk factor for greater parenting concerns in this sample when contextualized by the many other variables that also influence parenting concern severity. These data support prior research by Compas et al. who found that stress response symptoms, depression scores, and anxiety scores were more strongly associated with appraisals of illness severity rather than objective characteristics of their disease [14]. Although not formally assessed in our study, parental assessment of their disease prognosis may serve as an important link between cancer stage and parenting concern severity.

Second, our data highlight a specific area in which parenting concern severity differs between parents with metastatic and non-metastatic cancer. Parents with metastatic cancer understandably struggle with concerns about the potential impact of their death on their children and experience elevated distress about the possibility of leaving their children [9]. Research from bereaved fathers due to cancer indicates that dying mothers' concern about their children is ubiquitous at the end of life [30]. Thus, our study points to an ongoing need to help address end-of-life parenting concerns in this patient population earlier in the disease course. This is particularly relevant because cancer remains the leading disease-specific cause of death in most parenting-age individuals in the US despite dramatic improvements in anti-neoplastic therapies [31].

For oncologists and supportive oncology clinicians working with cancer patients who have dependent children, our results also reflect the need to take a broad and comprehensive approach to assessing parenting concerns. Parents at all stages of illness endorsed concerns about the emotional and practical impact of their illness on dependent children; thus, assessing these concerns from time of first diagnosis through all stages

of treatment may help identify individuals in need of additional support. Single mothers in particular may benefit from more frequent conversations about the impact of cancer on family life, and from support in accessing appropriate resources.

This study is limited by the cross-sectional design and representativeness of the sample. While participants were recruited from three institutions, one of which was geographically distinct from the others, data from this study represents the experiences of patients seeking care at academic tertiary care comprehensive cancer centers. Individuals who seek cancer treatment from these institutions may not be representative of all parents with cancer. Indeed, data from the National Cancer Institute cooperative trials group indicate that patients who enroll in clinical trials at academic medical centers are younger and reside in more affluent neighborhoods than patients enrolled from non-academic settings [32]. The differences in mean PCQ scores by site could additionally represent not only geographic variation but also differences due to gender and other socio-economic factors or differences in recruitment practices that were not formally tested in this study. Finally, parenting concerns about communication are not captured in this study as the PCQ does not contain items concerning concerns about communication about disease trajectory or prognosis. This specific concern merits further investigation; qualitative studies suggest that communication challenges may be particularly difficult for parents with incurable or terminal cancer [5, 11, 33]. Despite these limitations, this study is the first study to objectively measure differences in parenting concern severity by cancer stage in a geographically diverse population with a high proportion of patients with metastatic illness.

Adult cancer patients who are parents represent a sizable and likely growing population of cancer patients. Results of this study help inform patient-centered oncology and supportive oncology services that can address parental concerns throughout the disease trajectory.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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