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## Parenting Concerns, Quality of Life, and Psychological Distress in Patients with Advanced Cancer

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### Abstract

**Objective**—Parents with life-limiting illness anticipate the loss of their parental role and the long-term consequences of their illness on their children. The purpose of this study was to examine relationships between parenting concerns, quality of life (QOL), and symptoms of depression and anxiety in parents with advanced cancer who have dependent children.

**Methods**—Sixty-three parents diagnosed with a Stage IV solid malignancy completed the Hospital Anxiety Depression Scale (HADS), Parenting Concerns Questionnaire (PCQ), and Functional Assessment of Cancer Therapy - General (FACT-G). The Medical Outcomes Study Social Support Survey (social support) and Eastern Cooperative Oncology Group (ECOG) performance status were assessed as potential covariates. We performed descriptive statistics and multivariable linear regression models for depression, anxiety, and QOL measures.

**Results**—Mean PCQ score was 2.3 (SD 0.9), reflecting mild to moderate parenting concerns. Average depression and anxiety scores were 6.0 (SD 4.2) and 8.2 (SD 3.9), respectively. PCQ

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### DISCLOSURES

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scores were associated with depressive symptoms ( $r = 0.46, p < 0.001$ ), anxiety symptoms ( $r = 0.52, p < 0.0001$ ) and QOL scores ( $r = -0.60, p < 0.001$ ). The relationship of PCQ scores to anxiety symptoms ( $B = 1.5, p = 0.016$ ) and QOL ( $B = -5.7, p = 0.02$ ) remained significant after controlling for ECOG status, social support, and treatment status.

**Conclusions**—Parenting concerns are associated with anxiety and depressive symptoms and worse QOL in parents diagnosed with advanced cancer. Further studies that evaluate how parental status affects coping and psychological distress in advanced cancer are needed.

### Keywords

Cancer; Oncology; Parents; Quality of life; Adaptation; Psychological

## BACKGROUND

Unlike most other major life-threatening diseases in the United States, cancer causes premature serious illness and death for many parents of dependent children. Excluding traumatic injury, cancer is the leading cause of death for persons aged 25–64 in the United States [1]. In addition to these 170,000 men and women who die of cancer each year [2], there are likely tens of thousands of additional individuals who are living with advanced stage cancer while parenting dependent children.

Parents with advanced cancer experience the usual concerns about the effects of their illness on their own lives, compounded by concerns related to both their children and their ability to function as caregivers [3–6]. These concerns are well-founded; children of seriously ill and dying patients [7, 8] are at higher risk for depression and other long-term psychological effects [9].

While early research describes the psychological distress of parents with cancer, little is known about the consequences of these unique challenges for parents with advanced illness [10, 11]. One study by Muriel et al. demonstrated that parents with recurrent or metastatic cancer endorse more parenting concerns than parents with earlier stage disease [3]. However, the body of literature on parents with advanced cancer primarily consists of qualitative, cross-sectional interview studies. Existing research is consistent with the clinical wisdom that parents with advanced cancer experience additional psychological stress. Parents struggle with adaptation to incurable illness [11, 12], concerns about the impact of their disease on children [12, 13], and the challenges of being a “good parent” [5, 6, 14].

Only one longitudinal study has addressed the relationship between parental status and subsequent clinical outcomes of advanced cancer [15]. This study found that parents with advanced cancer are more likely to be diagnosed with depression and anxiety and experience lower QOL prior to death compared to those without dependent children [15]. No study, however, has explicitly addressed the parenting concerns of patients with advanced cancer or the effects that these concerns may have on their mood and QOL. Details about parenting concerns and their relationships with depression and anxiety symptoms require further examination in order to better understand the unique distress that parents facing a life-limiting illness experience. It is unknown whether and in what ways psychological distress is

related to parenting concerns, social support, and performance status. When patients experience losses in functional status, we expect that they struggle to fulfill parental roles and responsibilities. How differences in physical symptoms and performance status may relate to psychological coping and parenting concerns is unknown. Therefore, the purpose of this descriptive study was to examine the associations of parenting concerns with QOL, performance status, and symptoms of depression and anxiety for parents with advanced cancer. We hypothesized that parents with lower performance status would experience greater mood symptoms, lower QOL, and higher parenting concerns due to their poorer prognosis and reduced ability to perform parental responsibilities.

## METHODS

### Participant identification and recruitment

This was a single-center study of parents with advanced cancer who have dependent children. Patients were eligible if they met the following criteria: (1) diagnosis of a stage IV solid tumor malignancy; (2) parent of at least one child younger than 18 years old; (3) ability to speak and read English or Spanish; (4) adequate stamina to complete an interview and study measures as assessed by the patient's treating oncologist; and (5) participant age of at least 18 years. Patients were excluded if they were unable to complete self-report instruments due to illiteracy or neurologic illness.

Potential study participants were identified through review of outpatient oncology clinic and inpatient oncology service rosters or referred by treating providers. Research staff confirmed study eligibility and obtained permission from patients' attending physician prior to approaching potential participants about the study.

A total of 104 patients were screened for eligibility. Of the 86 eligible patients, 67 (78%) provided written informed consent and enrolled in the study. Participants who declined ( $n = 12$ ) were more likely to be male ( $p = 0.05$ ). Seven participants who enrolled in the study were unable to complete study measures due to scheduling difficulties. Two participants withdrew after consent and two participants were unable to complete study measures due to fatigue, yielding a final sample of 63 participants. This study was conducted between May 2013 and April 2014 and all study procedures were approved by the University of North Carolina – Chapel Hill Institutional Review Board.

### Study measures and data collection

A study team member administered a structured interview inclusive of the following measures in a private room during participant's hospital or clinic visits or at home.

**Parenting concerns**—The Parenting Concerns Questionnaire (PCQ) is a 15-item, self-administered assessment of parenting concerns developed for cancer patients. It is measured on a 5-point ordinal scale and has three subscales addressing concerns about the emotional and practical impact of illness on the child and concerns about the co-parent. Participants in this study without a co-parent were not included in the PCQ subscale about co-parent concerns. Total score range is 1 – 5 and responses are averaged with higher scores indicating

higher parenting concerns. The PCQ has demonstrated good internal consistency and face validity [3]. Cronbach's alpha for the study sample was 0.88.

**Depression and anxiety symptoms:** The Hospital Anxiety and Depression Scale (HADS) is a self-administered rating scale that assesses anxiety and depressive symptoms in populations with medical conditions. The HADS is comprised of 14 items with two 7-item subscales: HADS Depression and HADS Anxiety. Items are rated on a four-point ordinal scale with a range of 0 – 21 for each subscale. Higher scores represent greater degrees of mood symptoms with scores of 8 – 10 considered mild symptoms and 11 – 14 moderate symptoms. Cronbach's alphas for the study sample were 0.82 and 0.81 for the depression and anxiety subscales, respectively.

**Quality of life:** The Functional Assessment of Cancer Therapy – General (FACT-G) is a commonly used and well-validated self-administered assessment of general QOL in cancer patients. It is scored on a five-point ordinal scale and has four subscales addressing emotional, social/family, physical, and functional well-being. Total score range is 0 – 108 with higher scores indicating better QOL [16]. Cronbach's alpha for the study sample was 0.93.

**Performance status:** The ECOG performance scale is one of the most widely used measures of functional status [17]. It has high reliability and validity and is frequently used to estimate prognosis and treatment eligibility in oncology clinical trials [18]. ECOG performance status is scored on a 6-point scale with higher scores representing greater physical restriction due to illness. For this study, ECOG ratings were obtained from the participant report as well as the participant's attending oncologist. When discrepancies between ratings arose, ratings obtained by the participant were used.

**Social support:** The Medical Outcomes Study (MOS) Social Support Survey is a 19-item self-administered multi-dimensional survey of perceived social support and has been used in patients with chronic medical conditions. It is scored on a five-point scale and has four subscales addressing tangible, affectionate, emotional or information support, and positive social interaction. Scores are calculated by averaging items and transforming the mean score to a 100-point scale. Higher scores reflect greater support. The MOS social support survey has good internal consistency and reliability [19, 20] and has been used in oncology populations. Cronbach's alpha for the sample was 0.95.

**Statistical Analysis**—Descriptive statistics (frequencies, means, and standard deviations) were used to characterize the study sample. We explored relationships between the variables of study interest and participant demographic characteristics using Pearson correlation coefficients for continuous variables and Wilcoxon Rank Sum tests for categorical variables. Multiple linear regression models were used to evaluate the relationship of PCQ scores to HADS Anxiety, HADS Depression, and FACT-G scores. We conducted separate multivariable models for each of our main outcomes (HADS Anxiety, HADS Depression, FACT-G) to investigate the relationship of parenting concerns with mood scores and QOL while controlling for important covariates: ECOG performance status, social support, and current receipt of antineoplastic treatment. These were chosen based on

significance in univariable analyses along with clinical relevance. HADS scores and QOL scores were not combined into a single model as the FACT-G includes several questions about mood in its composite score and would therefore measure overlapping constructs. All analyses were performed using SAS version 9.3 (SAS Institute, Inc., Cary, NC).

## RESULTS

**Sample Characteristics**—Table 1 contains the demographic characteristics of the sample. Participants were predominantly female (67%) with a mean age of 43.8 years (range, 21 to 63 years) and had an average of 2 children under the age of 18 years. The most common diagnosis was breast cancer ( $n = 19$ , 30%) and 18 different cancer types were represented in this sample. Nearly half ( $n = 30$ , 47.6%) had an ECOG performance status of 1 and 30% ( $n = 19$ ) had a performance status of 2 or higher. Mean social support scores for the total sample was 76.1 (SD 22.1). Sixty-four percent of the sample scored higher than 70, the mean social support score for the original sample of patients with chronic illness for which this survey was developed [21].

**Parenting Concerns**—The average total PCQ score was 2.3 (SD 0.9) (Table 2), which reflects “somewhat” to “moderate” concerns. However, most participants had substantially higher scores on specific parenting items indicating they were “very” or “extremely” concerned. Participants reported concerns about both the current consequences of their illness on their family (e.g. physical limitations affecting children) as well as anticipated concerns about how their family will cope with future illness and death (e.g. children having long term emotional problems because of their illness). The concern that participants endorsed the most intensely was worrying about how their children would cope with their death (mean 4.0, SD 1.2), corresponding to “very concerned.” The item with the second highest score was worrying about the current emotional impact of their illness on their children (mean 3.3, SD 1.2) and the emotional impact of their illness on their partner (mean 3.1, SD 1.3).

**Depression and anxiety symptoms**—The average score for the HADS Anxiety and HADS Depression subscales were 8.2 (SD 3.9) and 6.0 (SD 4.2), respectively (see Table 2). Thirty-six participants (57.1%, 95% CI, 45%, 70%) scored 8 or higher on HADS Anxiety, of whom 17 participants (27%, 95% CI, 16%, 38%) scored higher than 11, the threshold for moderate anxiety. Twenty participants (31.7%, 95% CI, 21%, 45%) scored 8 or higher on HADS Depression, of whom nine participants (14.3%, 95% CI, 6%, 23%) scored higher than 11, suggesting moderate depression.

**Associations between sample characteristics and study measures**—Demographic characteristics, such as age, race/ethnicity, and income were not significantly associated with HADS, FACT-G, or PCQ scores. Characteristics such as number of children, age of youngest child, or average age of children were also not associated with HADS, FACT-G, or PCQ scores. The only demographic or parental characteristic associated with higher PCQ scores was single marital status ( $p = 0.05$ ). Non-partnered participants had an average PCQ score of 2.74 (SD, 1.06) compared to 2.13 (SD, 0.78) in those who were

partnered. However, marital status was not associated with HADS, FACT-G, or MOS Social Support Survey scores.

ECOG performance status was correlated with all measures. For every single question on the PCQ, participants with poorer performance status (ECOG 2–4) reported greater concerns. The only other clinical characteristic that was associated with HADS Depression and Anxiety scores was concurrent treatment with anti-neoplastic therapy for advanced disease; however, the number of participants who were not receiving these therapies was low ( $n = 7$ ) and disproportionately included participants whose ECOG performance status was poorer (86% had ECOG 2–4).

**Relationships of parenting concerns to anxiety and depressive symptoms and QOL**—HADS Depression, HADS Anxiety, and FACT-G scores were highly correlated with each other (see Table 3). In bivariate analyses, parenting concerns as measured by PCQ scores were significantly associated with the HADS Depression and HADS Anxiety subscales. PCQ scores were also highly correlated with QOL as measured by FACT-G scores.

Multivariable linear regression models were then used to control for the effects of ECOG performance status, social support and current active treatment on these associations. Table 4 lists results from multivariable linear regression models for HADS subscale scores and Table 5 for FACT-G scores. In the multivariable linear regression model, for each 1-point increase in the PCQ, indicating greater concerns, the HADS Anxiety subscale score increased by 1.5 points ( $p = 0.015$ ). The relationship between PCQ and HADS Depression did not remain significant after controlling for ECOG status, social support, and current treatment. ECOG scores and social support seemed to explain the variation in HADS Depression scores.

The multivariable model evaluating the relationship between PCQ and FACT-G showed that PCQ retained its significant association even after controlling for the other covariates ( $p = 0.02$ ).

## CONCLUSIONS

To our knowledge, this is the first study to investigate the associations among psychological symptoms, performance status, QOL, and parenting concerns in patients with advanced cancer. In this sample, parenting concerns were an important aspect of psychosocial distress in parents diagnosed with advanced cancer. PCQ scores were significantly associated with HADS Anxiety and QOL scores even when performance status, treatment status and social support were controlled. Consistent with previous studies [15], these results confirm the importance of parenting concerns and their relationship to mood symptoms and QOL in a diverse cohort of patients diagnosed with advanced cancer who have dependent children. The relationship between parenting concerns and QOL merits special attention. QOL has been recognized as an essential outcome of quality cancer care, particularly in advanced stage disease. Parental roles and responsibilities may influence or be influenced by patients' QOL, though they are rarely assessed by current validated measures.



The relationships among ECOG, PCQ, HADS, and QOL in our study suggest that a decline in performance status may have a complex relationship to psychological distress and QOL that may be related to parenting concerns. However, such relationships warrant a longitudinal investigation to determine if changes in performance status are predictive of parenting concerns and symptoms of depression and anxiety. Our results suggest a relationship between these important domains but the directionality of these complex relationships merits further study.

The mean HADS Anxiety and HADS Depression scores in our study were higher than other published averages of oncology patients [22–24]. Nearly 60% of participants in this study exceeded the screening levels on the HADS Anxiety scale and over 30% for the HADS Depression scale. These results underscore the high level of psychological distress that this patient population experiences. Clinicians caring for parents with advanced cancer must consider the higher likelihood of depressive and anxiety disorders in this population as compared to other oncology patients without dependent children.

The burden of parenting concerns in our sample is notable. The highest endorsed item on the PCQ focused on the impact of participants' future death on their children and the emotional consequences of their illness on family members. Even among those with high performance status, parents endorsed worries about the negative effect of their death on their children. Compared to patient populations with earlier stage disease, we suspect that this worry about anticipated death is particularly burdensome to the advanced cancer population.

Interestingly, single (non-partnered) marital status was associated with parenting concerns but not HADS or FACT-G scores in our sample. Several participants identified as single or non-partnered but they were a heterogeneous group. They included parents without formal or informal adult caregivers who assisted with parenting responsibilities, divorced or separated individuals who shared parenting responsibilities with former spouses, and individuals who identified their own parents as important caregivers for their children. Therefore, we found single parenting status difficult to characterize, though it has been defined as a demographic variable associated with higher parenting concerns in other studies of adult cancer patients [3]. While single parents in our sample reported equivalent levels of social support as measured by the MOS Social Support Survey, we suspect that single parents are at risk of greater parenting concerns due to the increased possibility that their children will lack an identified adult caregiver following the ill parent's death. Future studies of parenting and advanced cancer should specifically and narrowly define single parent caregiving status and the role of parenting support.

This study is limited by the cross-sectional design, small sample size, and single institution recruitment. Due to sample size limitations, we were only able to control for a handful of covariates in our analyses. A larger sample would allow for additional covariates and the evaluation of multiple models to find the one that predicts the outcomes best. Selection bias may have affected the sample as treating oncologists' deemed several eligible patients unsuitable due to concern that they were too ill or that study participation would negatively impact them emotionally. Thus, it is possible that depressive and anxiety symptoms and parenting concerns may be higher in the broader population of interest than in our sample. In





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**Table 1**

## Participant characteristics

| Characteristic                            | Total sample (N=63) |      |
|---|---------------------|------|
|   | n                   | %    |
| Age, M (SD)                               | 43.6 (8.2)          |      |
| Years of education, M (SD)                | 15.0 (4.3)          |      |
| Number of children, M (SD)                | 2.4 (1.0)           |      |
| Age of children < 18, M (SD)              | 11.6 (4.0)          |      |
| Months since metastatic diagnosis, M (SD) | 17 (18)             |      |
| Gender                                    |                     |      |
| Male                                      | 20                  | 31.7 |
| Female                                    | 43                  | 68.3 |
| Race/ethnicity                            |                     |      |
| White, non-Hispanic                       | 47                  | 74.6 |
| Black, non-Hispanic                       | 8                   | 12.7 |
| Hispanic                                  | 6                   | 9.5  |
| Other                                     | 8                   | 12.7 |
| Marital status                            |                     |      |
| Married/partnered                         | 42                  | 66.7 |
| Single                                    | 21                  | 33.3 |
| Income                                    |                     |      |
| < \$25,000                                | 16                  | 26.2 |
| \$25,000 – 50,000                         | 14                  | 23.0 |
| \$50,000 – 100,000                        | 20                  | 32.8 |
| > \$100,000                               | 11                  | 18.0 |
| Antidepressant use *                      |                     |      |
| Yes                                       | 30                  | 48.4 |
| No  | 32                  | 51.6 |
| Metastatic at diagnosis                   |                     |      |
| Yes                                       | 38                  | 42.9 |
| No  | 27                  | 57.1 |
| Cancer site                               |                     |      |
| Breast                                    | 20                  | 31.7 |
| Melanoma                                  | 9                   | 14.3 |
| Colon                                     | 7                   | 11.1 |
| Other gastro-intestinal                   | 7                   | 11.1 |
| Genitourinary                             | 6                   | 9.5  |
| Gynecologic                               | 5                   | 7.9  |
| Other                                     | 9                   | 14.3 |

| Characteristic                                       | Total sample (N=63) |      |
|--|---------------------|------|
|  | n                   | %    |
| ECOG performance status                              |                     |      |
| 0  | 13                  | 20.6 |
| 1  | 30                  | 47.6 |
| 2  | 10                  | 15.9 |
| 3-4  | 9                   | 14.3 |
| Currently receiving treatment for metastatic illness |                     |      |
| Yes  | 56                  | 88.9 |
| No   | 7                   | 11.1 |

Abbreviations: ECOG = Eastern Cooperative Oncology Group Performance Status

\*  
n = 62

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**Table 2**

Means and standard deviations for all measures

| Domain                      | Measure                     | Mean | SD   |
|-----------------------------|-----------------------------|------|------|
| Anxiety symptom severity    | HADS Anxiety                | 8.1  | 3.9  |
| Depression symptom severity | HADS Depression             | 6.0  | 4.2  |
| Quality of life             | FACT-G                      | 65.9 | 20.1 |
|                             | FACT-G Physical             | 15.6 | 7.1  |
|                             | FACT-G Social/family        | 20.5 | 5.8  |
|                             | FACT-G Emotional            | 14.4 | 5.4  |
|                             | FACT-G Functional           | 15.5 | 7.3  |
| Parenting Concerns          | PCQ                         | 2.3  | 0.9  |
|                             | PCQ Co-parent               | 1.8  | 1.0  |
|                             | PCQ Practical               | 2.5  | 1.1  |
|                             | PCQ Emotional               | 2.5  | 1.1  |
| Social Support              | MOS Social Support Survey * | 76.1 | 22.1 |
|                             | SSS Emotional               | 72.0 | 27.1 |
|                             | SSS Tangible                | 78.0 | 25.9 |
|                             | SSS Affection               | 85.1 | 25.7 |
|                             | SSS Positive Interaction    | 76.6 | 23.5 |

Abbreviations: HADS = Hospital Anxiety Depression Scale; FACT-G = Functional Assessment of Cancer Therapy – General; PCQ = Parenting Concerns Questionnaire; MOS = Medical Outcomes Study Social Support Survey

\* n = 61

**Table 3**

Correlations between HADS, PCQ and other study measures

| Variable                   | HADS Anxiety   | HADS Depression | FACT-G  | PCQ      | MOS Social Support Survey* | ECOG               |
|----------------------------|----------------|-----------------|---------|----------|----------------------------|--------------------|
| HADS Anxiety               |                | 0.64**          | -0.71** | 0.52**   | -0.30<br>0.019             | 0.44**             |
| HADS Depression            | 0.64**         |                 | -0.86** | 0.46***  | -0.47**                    | 0.62**             |
| FACT-G                     | -0.71**        | -0.86**         |         | -0.60**  | 0.49**                     | -0.61**            |
| PCQ                        | 0.52**         | 0.46***         | -0.60** |          | -0.35***                   | 0.42**             |
| MOS social support survey* | -0.30<br>0.019 | -0.47**         | 0.49**  | -0.35*** |                            | -0.10<br><i>ns</i> |
| ECOG                       | 0.44**         | 0.62**          | -0.61** | 0.42**   | -0.10<br><i>ns</i>         |                    |

Abbreviations: HADS = Hospital Anxiety Depression Scale; FACT-G = Functional Assessment of Cancer Therapy – General; PCQ = Parenting Concerns Questionnaire; MOS = Medical Outcomes Study; ECOG = Eastern Cooperative Oncology Group Performance Status; ns = non-significant

\* n = 61

\*\* p < 0.001

\*\*\* p < 0.002



**Table 4**

Multivariable regression for depression and anxiety subscale scores

|                                | HADS Anxiety |      |      | HADS Depression |      |        |
|--------------------------------|--------------|------|------|-----------------|------|--------|
|                                | Estimate     | SE   | P    | Estimate        | SE   | P      |
| PCQ                            | 1.48         | 0.59 | 0.02 | 0.76            | 0.57 | 0.19   |
| ECOG                           | 1.11         | 0.53 | 0.04 | 2.38            | 0.51 | <0.001 |
| MOS Social Support Survey      | -0.03        | 0.02 | 0.16 | -0.06           | 0.02 | 0.005  |
| Current treatment <sup>a</sup> | -1.02        | 1.63 | 0.53 | 1.10            | 1.58 | 0.49   |

Abbreviations: HADS = Hospital Anxiety Depression Scale; PCQ = Parenting Concerns Questionnaire; ECOG = Eastern Cooperative Oncology Group Performance Status; MOS = Medical Outcomes Study Social Support Survey

<sup>a</sup>Currently receiving anti-neoplastic treatment for metastatic illness: no/yes

Note: unstandardized estimates are provided. The adjusted R-squared values are 0.33 for HADS Anxiety, and 0.45 for HADS Depression.

**Table 5**

Multivariable regression for quality of life scores

|                                | <i>FACT-G</i>   |           |          |
|--------------------------------|-----------------|-----------|----------|
|                                | <b>Estimate</b> | <b>SE</b> | <b>P</b> |
| PCQ                            | -5.69           | 2.35      | 0.019    |
| ECOG                           | -10.77          | 2.09      | <0.001   |
| MOS Social Support Survey      | 0.33            | 0.08      | 0.001    |
| Current treatment <sup>a</sup> | -0.32           | 6.48      | 0.96     |

Abbreviations: FACT-G = Functional Assessment of Cancer Therapy - General; PCQ = Parenting Concerns Questionnaire; ECOG = Eastern Cooperative Oncology Group Performance Status; MOS = Medical Outcomes Study Social Support Survey

<sup>a</sup>Currently receiving anti-neoplastic treatment for metastatic illness: no/yes

Note: unadjusted estimates are provided. The adjusted R-squared value for the model is 0.61

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