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Parenting While Living with Advanced Cancer: A Qualitative Study

Eliza M Park¹, Devon K Check², Mi-Kyung Song³, Katherine E Reeder-Hayes⁴, Laura C Hanson⁵, Justin M Yopp¹, Donald L Rosenstein^{1,6}, and Deborah K Mayer⁷¹Department of Psychiatry, University of North Carolina, Chapel Hill, NC²Division of Health Policy and Management, University of North Carolina, Chapel Hill, NC³Center for Nursing Excellence in Palliative Care, Nell Hodgson Woodruff School of Nursing, Emory University, Atlanta, GA⁴Department of Medicine, Division of Hematology-Oncology, University of North Carolina, Chapel Hill, NC⁵Department of Medicine, Division of Geriatrics, Palliative Care Program, University of North Carolina, Chapel Hill, NC⁶Department of Medicine, University of North Carolina, Chapel Hill, NC⁷School of Nursing, University of North Carolina, Chapel Hill, NC

Abstract

Background—Patients with advanced cancer who have dependent children are an important population with a life-limiting illness and high levels of psychological distress. Few studies have addressed the experience of being a parent with advanced cancer and their potential palliative needs.

Aim—To describe the experience of living with advanced cancer as a parent, including illness experience, parental concerns, and treatment decision-making and to explore whether these experiences differ by their functional status.

Design—We conducted a cross-sectional, qualitative study using in-depth, semi-structured interviews. Data were analyzed using thematic content analysis.

Setting/participants—42 participants with metastatic cancer and with at least one child under the age of 18 years were recruited from a comprehensive cancer center. 25 participants were rated as having high functional status (the Eastern Cooperative Oncology Group [ECOG] performance status scale = 0–1) and 17 with low functional status (ECOG 2–4).

Results—We identified four themes regarding the experience of being a parent with advanced cancer: (1) parental concerns about the impact of their illness and death on their children; (2)

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

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“missing out” and losses of parental role and responsibilities; (3) maintaining parental responsibilities despite life-limiting illness; (4) and parental identity influencing decision-making about treatment. Parental functional status influenced not only physical responsibilities but also intensified parenting psychological concerns.

Conclusions—Parents with metastatic cancer may have unique palliative care needs as they experience parenting concerns while managing the psychological and physical demands of advanced cancer.

Keywords

Parents; Parenting; Cancer; Neoplasm

INTRODUCTION

Cancer is the leading cause of non-accidental death in the United States for individuals ages 35–54 years¹ and 24% of U.S. adults with cancer are parents with dependent children.² A parental cancer diagnosis changes how families function, such as disruptions to the family’s routine, parenting self-efficacy, role re-organization, and income changes.^{3–6} When the diagnosis is an advanced incurable cancer, the parent and the rest of the family contend with the parent’s progressive symptom burden, end-of-life concerns, and family functioning during illness and after death.^{7–10}

Parents with advanced cancer experience higher levels of depression and anxiety than patients without dependent children.⁸ This may be related to the psychosocial burden of raising dependent children while coping with life-limiting illness, but parenting has not been well studied in palliative care.^{11, 12} While multiple studies have described the experiences of parents with early stage cancer,^{3, 13–15} they primarily focused on the impact of parental illness and death on children’s mental health and functioning.^{16–19} Thus, little is known about the needs of parents with advanced cancer and their experiences in parenting and treatment decision making while simultaneously coping with increasing physical symptom burden. Such an understanding is a necessary first step in order to develop palliative and supportive interventions to meet the care needs that may be unique to parents. Therefore, the purpose of this paper was to describe the experience of being a parent while living with advanced or metastatic cancer and to explore whether these experiences differ by their functional status using qualitative analysis of interview data from a larger study.¹⁰

METHODS

Study design

This study used a qualitative descriptive design²⁰ with semi-structured interviews with parents with advanced cancer who participated in a larger study to examine palliative care and mental health needs in this population.¹⁰ The University of North Carolina at Chapel Hill IRB approved the study.

Participants and setting

Participants were recruited from a southeastern U.S. academic medical center. We used a purposive sampling technique to seek maximum variation^{21, 22} in gender, cancer types and functional status. Functional status was measured by the Eastern Cooperative Oncology Group (ECOG) Performance Status scale (0=fully active to 4=completely disabled). Eligible participants for the larger study were at least 18 years old, English or Spanish speaking, and had at least one child younger than 18 years.

The original study enrolled 67 parents; of those, 46 (69%) participated in the in-depth interview. Due to thematic saturation, not all parents in the broader study were approached for interview. Of the 46 parents' interviews, one could not be used due to malfunction in audio recording, and four interviews with Spanish-speaking participants were not included in this evaluation due to the use of a different interviewer as well as language and cultural differences with these interviews. Thus, a total of 42 interviews were used for this analysis.

Data collection: semi-structured interviews

The first author and a trained qualitative interviewer conducted in-depth interviews with participants using a semi-structured interview guide. Interviews were conducted in-person at the hospital or via telephone if the participant was unable to travel. The investigator developed interview guide included questions about parents' perceptions about how the parental role and parenting concerns affected the cancer experience, the impact of cancer diagnosis and treatment on parenting and their own medical decision-making (Table 1). The interviews lasted 46 (range, 24–107) minutes on average and were audio-recorded.

Data management and analysis

Interviews were transcribed verbatim and checked for accuracy against the original recording by the interviewer. NVivo 10 (QSR International) was used for data management and coding. Qualitative analysis used content and thematic techniques.^{23–25} Four authors (EMP, KRH, DKM, DKC) read interview texts line by line to begin the coding process. Coders independently assigned inductive descriptive codes to text using the participants' own language when possible. At joint meetings, thematic categories were created from groups of related codes, and a final code structure was developed through this process. The final code structure was then independently re-applied to the texts by the four authors followed by joint meetings to discuss differences and resolve them through group consensus.²⁰ The interview codes were condensed into categories and themes were derived from organizing these categories into major themes.

RESULTS

Characteristics of study sample

Table 2 contains the demographic characteristics of the interview participants. The majority were women (n=27; 64%) and the most common cancer diagnosis was breast (n=10, 24%); 22 different cancer types were represented in this sample. Sixty percent (n=25) of the participants had an ECOG status 0–1, suggesting minimal or no functional limitations from

their illness. The remainder of the sample (n=17, 41%) endorsed moderate to severe functional limitations (ECOG status 2–4).

Major themes

We identified four major themes about the experience of parents with advanced cancer: (1) parental concerns about the impact of their illness and death on their children; (2) “missing out” and losses of parental roles and responsibilities; (3) maintaining parental responsibilities despite life-limiting illness; (4) and parental identity influencing decision-making about treatment. Direct quotations from participants are in italics.

1. Parental concerns about the impact of their illness and death on their children—Parents described worry for their children as the most troubling concern when they were diagnosed with advanced cancer, questioning, “what is going to happen to my children?” These concerns included worries about the disruption from their illness on children’s daily routines but far more commonly, they were concerned about the negative effect of their anticipated death on their children. Parents worried about how their death could psychologically harm their children and the quality of the parenting their children would receive in their absence. One participant, a mother with metastatic colorectal cancer with two children remarked:

“I’m going to die and that hit me really hard because my own father died when I was 10, of cancer, so I know what it’s like to grow up without a parent due to cancer...my children are going to go through the same thing I did, and [my father’s death] had a dreadful impact on my life.”

Even parents who felt functionally well or who maintained high hope for cure or extended life, endorsed concern about the possibility of their death and its impact on their children. Parents with poor functional status and awareness of their limited life expectancy reported the greatest anxiety. Several parents expressed concern that their parental responsibilities were irreplaceable. Many mothers, in particular, described their emotional closeness with their children and concern that their co-parent did not share this kind of relationship with the children. One mother with appendiceal carcinoma and two daughters noted,

“I’m a little scared because as a man [my husband] doesn’t have the same emotional thing that women do, and I’m just worried that there’s going to be some of those things missing that I just really want my girls to have.”

The six parents who believed their illness was curable endorsed the lowest degree of worry about death. The remaining 36 parents in the sample acknowledged the incurable or uncertain nature of their illness and/or the possibility of death associated with advanced cancer. Regardless of functional status, most held dualistic beliefs about their cancer – awareness of its fatal nature but hoping that long-term survival until their children were older or potential for cure would occur. Notably, parents reported discussing the incurable nature of their disease with their oncologist at the time of initial metastatic diagnosis but rarely re-visited this topic in subsequent conversations. One mother with metastatic breast cancer described a mutual pattern of avoidance,

“Sometimes when I would ask different questions, she [my oncologist] would just say, it’s not going to make anybody feel any better, or it’s not going to do us any good at this time, so she would just be very upfront with me and say we’re not going to talk about this.... And I’m glad she did that.”

They also expected their oncologist to explicitly inform them when death was imminent or when they should stop cancer-directed therapies, but rarely discussed these communication expectations with their oncologist.

For most parents, the psychological consequences of early parental loss were a greater concern than the potential financial and physical repercussions. Concerns about disruptions in normal development and growing up without a mother or father were particularly distressing for parents. This was amplified if the parent had their own experience and loss of a parental cancer and death. A few worried that their death would lead to long-term mental health problems for their children. Mothers, in particular, also voiced concerns about how their partner would cope with losing a life partner and surviving as a single parent. One mother with metastatic breast cancer noted:

“I worry that he’s going to get lonely, and I worry that he’s not going to be able to take care of the kids, that he’s just going to get really overwhelmed with working and taking care of the kids. And that he wouldn’t be able to do it on his own.”

Patients who were raising their children without involvement from the co-parent voiced worry that their children’s other parent could interfere with their desired custody arrangements.

2. “Missing out” – losses of parental roles and responsibilities—All parents in this sample described how advanced cancer caused losses in their parental role. A major concern was their decreased ability to fully provide physical caregiving responsibilities for their children. Parents with higher functional status described changes in their availability for their children’s activities – often a result of scheduling conflicts with treatment or hospital visits – and reduced stamina. Parents with fewer social supports, particularly those who identified as single parents, endorsed difficulties managing their medical care and their parental responsibilities without a reliable co-parent. Parents with poorer functional status experienced substantial physical changes in their parental duties, with the co-parent or children assuming many parental responsibilities. Several of these parents described themselves as a “bad parent” due to their inability to fulfill previous parental functions. A mother with four children and metastatic breast cancer described:

“I don’t have activities with them anymore the way I used to – playing, watching over them, checking up on what they do...and you feel useless, because you can’t take a single step. You try to get up somehow, but it’s impossible.”

Beyond the physical constraints of illness on parenting responsibilities, a greater source of distress among parents was the concern for “missing out” on their children’s future lives, anticipating their own loss. As expected, parents desired to be present for their children into adulthood and they voiced fear, sadness, and guilt that this would not occur. Parents specifically endorsed fears that they would miss future milestones in their children’s lives

(e.g. graduations) or the ability to shape their children's development (e.g. selecting a college, meeting significant others). Several parents described a sense of guilt for "bringing children" into the world and then "leaving them" before they reached adulthood. This psychological concern was intensified among parents with poor functional status. However, it was notable that even those parents with preserved functional status experienced these anticipatory losses and grief due to their understanding of their illness prognosis.

3. Maintaining parental responsibilities despite life-limiting illness—To counteract the negative impact of advanced cancer on their children, parents utilized a variety of strategies to maintain their parental roles and identity. Parents with lower functional status and greater functional limitations relied on informal support from family and friends. All parents, regardless of functional status, relied upon multiple psychological techniques to manage their parental distress and maintain their parental roles. Only a minority of parents specifically planned custody, financial or other legal documents as a method of mitigating their parental concerns.

To help alleviate fears of missing their children's future, parents deliberately sought to reinforce critical life lessons, enduring memories, or sharing of their personal values with their children. For most parents, these personal values included choosing relationships wisely, the importance of spiritual faith and education, and prioritizing time with loved ones. As one mother with metastatic non-small cell lung carcinoma, poor functional status, and a teenage daughter noted,

“You worry what is going to happen when you're not here, and I've found that I want to teach her everything that I know. I want her to know it now because I don't have time...and I have to teach her what she needs to know to be able to be a successful young adult and person.”

Parents also described how these efforts were an unintended but powerful way to cope with their uncertain future and functional limitations.

Parents of teenage children voiced worry that their children would not appreciate these wisdoms until they matured into young adults. Others expressed a desire to live long enough for their young children to remember them or for their children to grow old enough to maintain more mature memories of the parent. A handful of parents wanted to ensure that their children's enduring memories of them were as a healthy parent and not as an ill cancer patient.

Parents frequently employed additional psychological strategies to cope with their illness and family responsibilities. The second most commonly cited approach specific to parental functioning was maintaining normalcy in the home. Parents recognized that continuing household routines lessened emotional distress for their children, though parents with lower functional status were less able to rely on this strategy. More generally, parents attempted to reduce their individual emotional distress by placing increased faith in their religion or cancer care, avoiding discussion about their illness at home, maintaining hope for cure or prolonged life extension through anti-neoplastic therapies, compartmentalizing their worry, and focusing on short-term goals or future. By limiting their uncontrolled worry about the

future, parents were better able to maintain their routine at home and minimize disruptions due to emotional distress. Maintaining hope in modern cancer care and avoiding discussion about illness also allowed parents to focus on the present and on their families instead of the uncertain future. As a mother with metastatic melanoma and a 10 year old son noted, “*I ignore [the conversation], that’s so bad, I shouldn’t but then it’s really happening. You would be surprised at how much we ignore it. It keeps me going.*” When queried about suggestions for programs to reduce their distress, parents usually suggested parenting-specific cancer support groups, though acknowledged the logistical difficulties in accomplishing this.

4. Parental identity influencing decision-making about cancer treatment—

Being a parent served as a motivator for seeking and continuing cancer treatment for most parents. These participants identified their parental identity as the primary reason why they pursued additional therapies to treat cancer. They described their need to stay alive in order to parent their children into adulthood or as long as possible and cited this reason as the underlying principle behind their decision-making about cancer treatment. As one father with a poor functional status and lung cancer stated,

“I think being a parent is what’s been making me fight to stay alive to begin with. If you didn’t have anybody there, if I didn’t have my kids there, it would almost be too easy just to give up when they said I was terminal.”

Several parents, particularly those with poorer functional status, noted that without children, they would have likely pursued a palliative course of treatment focused on comfort instead of life extension. Others reported that if their children were older they would seek less aggressive care. Most parents, regardless of functional status, simply described a desire to be present in their children’s lives for as long as possible.

Parents also explicitly weighed their need to physically parent their children with their desire for life extension. A smaller number of parents specifically preferred a course of therapy that would allow them to maintain a higher functional status, as opposed to one that would maximally extend life but at a greater functional cost. Regardless of whether the parent prioritized life extension or physical functioning, all parents shared a common goal of choosing a treatment decision-making strategy that they believed would be best for their children.

Despite the stated importance of parental identity in parents’ decision-making about cancer treatment, it was not clear how much this was discussed with their oncology providers. Parents believed that their oncologists “probably” understood the importance of their parental role in decision-making but acknowledged that this consideration was rarely explicit in their treatment discussions. As one mother with pancreatic cancer noted, “*[My oncologist] is a parent herself, so I know she would certainly understand some of it, but it’s not something we’ve talked a lot about, so I don’t know that she knows all my thinking.*”

For a minority of parents in this sample, parental status did not affect decision-making preferences about their cancer care. They noted having other reasons to desire living and that parental status did not play a greater role than these other factors.

DISCUSSION

We identified four major themes relevant to parents, which may have implications for more explicit discussions with their oncologists and for optimizing their supportive and palliative care. Parental status not only generates intense patient distress about the impact of life-limiting illness on children but also influences patients' decision-making about cancer treatment and psychological coping strategies. Parental functional status influenced the experience of each of the domains. Poorer functional status was associated with not only increased limitations in physical responsibilities but also intensified psychological concerns. They also reported more anguish about the current impact of their illness on their families and heightened fear about the effects of their anticipated death for their children.

Similar to the findings from the few qualitative studies of parents with advanced cancer suggesting that parents struggle with adaptation to incurable illness,^{7, 26} concerns about the impact of their disease on children,^{26, 27} and the challenges of being a "good parent,"²⁸ our study participants shared their experiences with psychological distress and strategies to limit their family-related distress. Several parents described themselves as a "bad parent" or struggled with guilt about their inability to fulfill parental responsibilities. Of particular concern to parents in our study was the anticipated effect of their death on their children.

Existing qualitative studies of this population have frequently relied upon a sample of patients who are seeking supportive care services.^{7, 19, 29} Our results demonstrate that serious parental distress exists even among parents who have not sought or received such services. This finding is notable because standard surveys of psychosocial distress such as the Functional Assessment of Cancer Therapy – General³⁰ and the Distress Thermometer,³¹ which may be used by cancer care providers may not fully capture the specific concerns that these parents face despite how strongly this worry contributed to parents' emotional distress. Additionally, some clinicians may not ask specifically about children or parenting concerns unless prompted by the patient. In the absence of explicit discussion, several parents in our sample nonetheless believed that their treating oncologist "probably" understood the influence of parental status on their cancer experience and decision-making. Given this finding, it is important that all health care providers proactively and directly engage with patients about their concerns regarding their parental role in life-limiting illness, including in treatment decision making.

This study included a diverse set of parents, with a variety of cancer types, functional status, and with men and women. Our data suggest that the parental concerns of patients with dependent children may not be specific to gender or individual cancer types but these findings require larger sample sizes to confirm. In addition, our data also suggest that functional status is an important component in parenting-related concerns. The impact of physical symptom burden has not been addressed in previous assessments of this population which have primarily assessed parents with less functional limitations.

Our study was limited to a single institution and patients who seek care at academic medical centers may not accurately represent the opinions and beliefs of all parents with advanced cancer. A related limitation is the relative under-enrollment of fathers in this study. Men

were more likely than women to decline participation and we do not know how the parental experience of these individuals differs from study participants. In addition, the cross-sectional nature of this study did not allow for an evaluation of how parental status influences the advanced cancer experience over time. Future studies that incorporate nuanced assessments of the psychological issues regarding prognostic awareness, and the experiences of the co-parent would provide greater understanding of how the ill parent and the co-parent together address the change in parental roles and responsibilities brought by an advanced cancer diagnosis. Finally, we did not address issues related to parental communication about illness with children as this topic was complex and will be addressed separately in future reports.

Our data suggest several potential pathways of intervention for clinicians working with this patient population. Supportive and palliative care providers are critical in helping parents identify and communicate how parental status may affect their medical decision-making strategies in advanced illness and end-of-life.^{26, 32} Clinicians who encounter patients with dependent children can also directly query them about their parental concerns and focus end-of-life communication to specifically address the impact of parental death on children. Parents can also be encouraged to address their anticipated loss by preparing things for their children for when they are no longer present (such as letters, videos, cards). Clinicians can also ask whether or not ill parents have an available co-parent and who they intend to care for their children during times they are unable.

Despite knowledge of serious illness, many parents in our study had not completed preparatory documents such as standby guardianship to ensure that their children would be physically and financially cared for in the event of parental death.³³ Parents may lack knowledge about how to pursue such measures or defer completion of these advance planning measures due to difficulty accepting the incurable nature of their illness or believing they have more time to do these activities. Advance care planning is an important aspect of palliative care and addressing the barriers to appropriate completion of family legal documents in parents could significantly influence the welfare of their dependent children and their own distress if left unresolved. All providers can adapt their treatments to focus on minimizing the disruption of illness on parents' families (e.g. choosing pain management strategies that limit daytime sedation).

Given the importance of parental concerns among patients with advanced cancer and the significant psychological burden of changes in parental roles, greater attention to this vulnerable population is needed. Results from our study can help inform design of future interventions for the ill parents struggling with the dual role as parent and patient with life-limiting illness.

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Key Statements

What is already known about the topic?

- Parental status in advanced cancer is associated with increased psychological distress but research about the specific contributors to this distress is limited.
- Patients with advanced cancer and dependent children may prefer or prioritize oncology treatment focused on life extension rather than pain and symptom control.

What this paper adds?

- This study demonstrates that parental identity and parenting concerns influence the psychological concerns and decision-making about cancer treatment of parents with advanced cancer.
- Functional status may influence parenting-related distress in parents with advanced cancer.

Implications for practice, theory or policy?

- Findings suggest that parenting concerns are an important aspect of the patient experience in parents with advanced cancer.
- Additional research to tailor existing palliative care interventions for parents with advanced cancer is needed.

Table 1

Relevant Interview Questions

| |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| What is your understanding of your cancer now? |
| At any point, did you have a conversation with your doctor about your prognosis, or what is likely to happen to you because of your cancer? What did your doctor tell you? |
| How does having children impact your thinking about having cancer? |
| While living with metastatic cancer, what are your thoughts or concerns about being a parent? |
| Can you talk about how having metastatic cancer affects you as a parent? |
| What has been the most difficult part of having cancer for you with respect to having your children? |
| What are your biggest worries or concerns now compared to when you were first diagnosed with cancer? |
| How, if at all, do your symptoms from your cancer interfere with your ability to parent these days? |
| Can you tell me what has been helpful to you as a parent these days? |
| How, if at all, does your role as a parent influence your decisions about your treatment? |
| Does being a parent affect your decision about whether to pursue one course of treatment versus another? |
| Do you think the age of your children affects how you make decisions about cancer treatment? |
| How well, if at all, do you think your doctor understands you as a parent? |
| Do your children know that you have advanced cancer? What do you think they understand about that? |
| If you could create a program to meet the needs of other parents of children who have been diagnosed with metastatic cancer what would it be like? |

Table 2

Participant characteristics

| Characteristic | Total sample (N=42) | |
|-------------------------------------------|---------------------|------|
| | N | % |
| Age, M (SD), years | 44.2 (9.0) | |
| Years of education, M (SD) | 15.8 (3.6) | |
| Number of children, M (SD) | 2.2 (1.0) | |
| Age of children < 18, M (SD) | 11.6 (4.1) | |
| Months since metastatic diagnosis, M (SD) | 17.1 (17.8) | |
| Gender | | |
| Male | 15 | 35.7 |
| Female | 27 | 64.3 |
| Race/ethnicity | | |
| White, non-Hispanic | 31 | 73.8 |
| Black, non-Hispanic | 7 | 16.7 |
| Other | 4 | 9.5 |
| Marital status | | |
| Married/partnered | 29 | 69.1 |
| Single | 13 | 31.0 |
| Income | | |
| < \$25,000 | 12 | 29.3 |
| \$25,000 – 50,000 | 9 | 22.0 |
| \$50,000 – 100,000 | 13 | 31.7 |
| > \$100,000 | 7 | 7.1 |
| Metastatic at diagnosis | | |
| Yes | 22 | 52.4 |
| No | 20 | 47.6 |
| Cancer site | | |
| Breast | 10 | 23.8 |
| Melanoma | 7 | 16.7 |
| Colon | 6 | 14.3 |
| Other | 19 | 45.2 |
| ECOG functional status | | |
| High (0–1) | 25 | 59.5 |
| Low (2–4) | 17 | 40.5 |

Abbreviations: ECOG = Eastern Cooperative Oncology Group Performance Status Scale