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Concerns Underlying Treatment Preferences of Advanced Cancer Patients with Children

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Abstract

Objective—Decision-making about advanced cancer treatment is complex and may be influenced by patients' family context, including the presence of children.

We explored how parental values and concerns motivate patients' preferences about aggressiveness of advanced cancer treatment as well as preferences for palliative care and hospice services.

Methods—We conducted semi-structured interviews with 42 patients with advanced cancer who had at least one child under 18 years. We created and applied thematic codes. Descriptive analyses were used to report the number of participants who mentioned each code.

Results—The majority of participants (29/42) reported that having children influenced their preferences for advanced cancer care. For most parents, extending life to maximize the time they had left to parent their children was important in guiding treatment preferences. Others prioritized preserving their physical condition and parental functioning and remaining physically close to their children. Many parents discussed life extension and parental functioning preservation as

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competing priorities. Most of the sample expressed interest in palliative care services and hospice, but responses by several participants reflected concerns about dying at home and lack of clarity about the role of early palliative care.

Conclusions—Parents in our sample expressed that maximizing time with their children and preserving parental functioning were important concerns underlying their preferences for advanced cancer care. Future research should assess the palliative and end-of-life care needs and preferences of parents with advanced cancer, which may differ from those of non-parents.

Keywords

Cancer; Oncology; Quality of Life; Treatment Preferences; End-of-Life Care

Introduction

Many patients with advanced cancer are parents of dependent children. Eighteen percent of patients in active cancer treatment have children under 18 years of age [1] and there are over 66,000 deaths each year due to cancer in the United States among adults between the ages of 25 and 54, the prime parenting years. [2] In addition to the distress typically associated with advanced cancer and its treatment, these patients face extraordinary challenges. [3, 4] Parents have concerns about the present effects of their illness on their children as well as worry about how their children will cope with their death.[3] Compared to advanced cancer patients without dependent children, parents report higher levels of depression and anxiety and experience worse quality of life (QOL) prior to death.[5]

Among parents with advanced cancer, severity of parenting concerns has been shown to be associated with increased depression and anxiety symptoms and lower QOL.[6] How parental concerns and challenges inform advanced cancer patients’ treatment preferences is unclear, as previous research on the influence of the parental role on patients’ treatment preferences has largely focused on patients with early-stage disease. Compared to the treatment of many early-stage cancers, decision-making about advanced cancer treatment can be complex due to the incurable nature of illness, limited evidence on the risks and benefits of treatment options, and the difficulty of realistic patient-provider communication about prognosis and treatment benefits.[7]

In early-stage cancer, research has established the importance of the presence of children in choosing between treatment options that differ in expected length of survival and implications for QOL. [8] Regarding the specific influence of the parental role on treatment preferences, one study of early-stage breast cancer patients concluded that parents, compared to non-parents, were more likely to view smaller gains in length of life from chemotherapy as worthwhile despite treatment side effects. [9] Another study including patients with diverse cancer types and stages found that patients with dependent children had an increased willingness to undergo burdensome treatments. [10] Only one study has focused specifically on patients with advanced disease; its results suggest that patients with dependent children were more likely to express a preference for a course of treatment focused on extending life rather than a course of treatment focused on relieving symptoms. [5]

Although prior quantitative research has established a link between cancer patients' parental status and their preferences for aggressiveness of treatment, evidence of this link among advanced cancer patients is sparse, and factors underlying patients' preferences remain unclear. The symptom burden, poorer prognosis, and accumulated toxicity from anti-neoplastic therapies experienced by advanced cancer patients makes formulating clear treatment preferences particularly complex. In addition to understanding parents' preferences for advanced cancer care, it is important for providers to appreciate the motivations underlying parents' preferences in order to support them in making decisions that are consistent with their expressed values. In doing so, cancer and supportive care providers have the potential to improve the mental health and QOL of parents with advanced cancer. The objective of our study was to enhance understanding about how, from the perspective of parents with advanced cancer, the presence of children may influence their preferences for cancer care, beyond serving as motivator for life-extending treatment. To better understand the comprehensive care needs of this population, we asked not only about how having children influenced parents' preferences surrounding anti-neoplastic treatment, but also about the potential impact of parental considerations on preferences for hospice services and palliative care more broadly.

Methods

Participant Sampling

Our study was conducted at the North Carolina Cancer Hospital in Chapel Hill, North Carolina. Potential study participants were identified through review of outpatient and inpatient oncology service rosters or referred by treating providers. Eligible participants were at least 18 years old, English- or Spanish-speaking, had a diagnosis of a stage IV solid tumor malignancy, and had at least one dependent biological or adopted child under 18 years old. Research staff confirmed study eligibility and obtained permission from each patient's attending physician prior to approaching potential participants. Only English-speaking participants were included in this analysis, as data from our interviews with Spanish speakers, whose parenting and cancer care experiences were distinct, were analyzed separately.

Data Collection

After informed consent, participants completed a written survey composed of several quantitative measures followed by a semi-structured interview. Quantitative analyses are reported separately. [6] All participants also completed a demographic questionnaire and Eastern Cooperative Oncology Group (ECOG) performance scale ratings were obtained from all participants.

Following completion of the structured measures, 43 of the 58 English-speaking respondents participated in an interview. The 15 respondents who did not participate included two people who died before interviews could be conducted, one person who withdrew from the study, and twelve individuals with high ECOG status who were enrolled in the study after thematic saturation had been reached for individuals with high performance status (ECOG 0 or 1). At this point, the study protocol was amended to make self-reported ECOG status part of eligibility screening; participants with high performance status were invited to complete the structured measures only, while we continued to invite people with low performance status to complete both the structured measures and interview. 42 of 43 English-speaking interviews are included in this analysis, as one interview was excluded due to poor audio-recording quality.

Two trained interviewers (DKC and EMP) conducted the 42 interviews in private locations. 16 interviews were conducted in the chemotherapy infusion center; 14 were conducted in hospital clinic rooms; 10 were conducted in patients' hospital rooms; and two were conducted by telephone. The interviews focused on coping with advanced cancer, parenting concerns, communication about illness and how parental considerations influenced treatment decision-making. Members of the study team who had clinical experience with this patient population developed the interview guide (EMP, DKM, JMY, DLR, LCH) and a qualitative research consultant then reviewed it. Initial open-ended questions were formulated from an empirical review of the literature and subsequently modified by study team members in an iterative process. Prior to final distribution of the interview guide, key informants (patients and an oncology providers) reviewed the guide for readability, acceptability, and length.

This analysis focuses on parents' responses to our questions about treatment preferences and decision-making, which included: (1) How, if at all, does your role as a parent influence your decisions about treatment? (2) Do you think the age of your children affects how you make decisions about your treatment?" (3) Would you be interested in seeing a specialist who focuses on managing your symptoms and helping you make decisions (i.e., palliative care)? (4) At what point, if ever, would you consider using hospice care? The interviews were digitally recorded and transcribed for analysis using qualitative analysis software (NVivo version 10, QSR International, Victoria, Australia).

Study assessments were conducted between May 2013 and April 2014. Subjects received a hospital parking voucher for completion of the structured measures, and a parking voucher as well as a gift card for completion of both the structured measures and interview. This study was approved by the University of North Carolina (UNC) at Chapel Hill Institutional Review Board and the UNC Lineberger Oncology Protocol Review Committee.

Analysis

First, the four research team members (EPM, DKC, KRH, DKM) reviewed the same seven interview transcripts and developed a coding scheme based on themes that arose from these seven interviews. Next, the coding process began, where three coders (DKC, KRH, DKM) independently coded 10–12 different transcripts, and a fourth coder (EPM) independently coded all of the interviews, so that each interview had two independent coders. During the coding process, the four coders met regularly to modify the coding scheme based on any new themes that emerged. When new codes were developed, the coders went back to re-code earlier transcripts. At the end of the coding process, the coders of each transcript discussed and resolved discrepancies in their coding. [11] Next, for each qualitative code, they created a binary variable based on the presence or absence of that code in a particular interview. t tests (means) and x^2 tests (categorical variables) were used to compare interviewed participants' characteristics to the broader study sample. Descriptive analyses were used to characterize the interview sample and to report the number of participants who mentioned each code.

Results

Interview sample characteristics

Characteristics of interview participants are shown in Table 1. Compared to study participants who did not complete an interview, interview participants were more likely to have low performance status (ECOG of 2, 3, or 4) (p=0.02). Otherwise, there were no differences.

Influence of parental concerns on preferences for advanced cancer treatment

Thirty-nine of 42 participants responded to our questions about treatment preferences. The majority of participants (29/42) reported that having children influenced how they approached decisions about their advanced cancer treatment. Overall, participants wanted to be physically present for their children, namely, by staying alive. For 27/42 participants, this meant that extending life to maximize the time they had left to parent their children was an important priority guiding their preferences for treatment. As one participant explained, “My highest priority is, will it likely give me a chance to be here longer with my girls?” Some participants’ motivation for life extension centered around a particular milestone in their children’s future, for example, graduation from high school. Participants did not always perceive that they had an alternative to pursuing aggressive treatment, because of their children:

> I was reaching the point where it was like, I just can’t do this anymore. I’m sorry, I’m just gonna have to give up on treatment and let the disease take its natural course more quickly cause I can’t do this anymore, and if I didn’t have children, I might be tempted to actually do that, but I know I can’t. The temptation would be really strong otherwise.

Having children influenced participants’ treatment preferences in other ways. Ten participants reported that, in thinking about their treatment options, preserving their physical and parental functioning (stamina, cognitive ability, and wakefulness) was an important consideration. Participants thought about the side effects of both anti-neoplastic treatment for their advanced cancer and palliative treatments, including pain medication:

> My wife works full time now and didn’t before, and so I try to do the support stuff, picking up my son from kindergarten, doing the carpool. If [my doctor] suggested something that would make me unable to help for a while, I would do it, but that would be the apprehension, trying to still help [the family] function.

> I cannot take the pain medication regimen that they’re giving me because I have a family to raise and I have two kids that need to be taxi cabbed around, or else they wouldn’t be normal kids and they wouldn’t do normal kid things. And I can’t possibly ask the neighbors to do all this extra stuff. I sacrifice my comfort and what I really need to make it so my kids can have a normal life.

Seventeen parents discussed quality and quantity of life as competing priorities. As one participant explained, "I'd like to be here for as long as possible, even if it's not in as good of shape as possible." Another participant was more explicit about this tradeoff:

> Do you want to have an extra six months with your son or do you want to have certain number of those months be without nausea all the time so that you can do more [with him]? I shudder to think, but I would rather deal with side effects and feel worse for a longer period of time. I can't imagine answering the other way around – that I would prefer to be here for a shorter time.

Another theme, mentioned by 5/42 participants, was the preference for treatment options that kept them physically close to their families. Parents described forgoing travel for second opinions or clinical trial participation, and avoiding treatment that may require prolonged hospitalization, or frequent visits to the hospital. One parent said, "I think one way [having kids] has affected my thinking is if I didn't have kids and I saw some drug study in Boston or somewhere, I might be willing to get on a plane and go there."

On the other hand, 10/42 participants said having children did not affect their treatment preferences. In other words, these participants did not feel that their treatment preferences would be different if they did not have children, since they would be motivated to live as long as possible no matter what. These participants felt that they had other reasons, including the presence of other loved ones or their own young age, that motivated them to pursue life-extending treatment. For example, one participant said, "If I didn't have kids I would think about my mother and my sister and them, like I'm trying to get back to them, not just my kids, I have more family other than my kids." Another explained that his children are one of many considerations motivating his treatment decisions:

> I want to live as long as I possibly can with the best quality of life. Those will be the things that weigh on my decision. I don't know what else to say. My kids make living much better, I'd be devastated if something happened to them - but they aren't the reason.

Twenty participants believed that the age of children affected participants' treatment considerations. Often, these participants felt that having younger children made them more likely to consider the extent to which treatment side effects would interfere with parenting responsibilities: "Yeah, see if they were older, I would be less concerned about the side effects because they could do [things] for themselves." Having younger children also made some participants more inclined to pursue aggressive treatment:

> I think there's a big difference when you have little kids. If they were already on their way and they were teenagers, you know I think it might be a little different. But I do think I need to stick around as long as I can because they're so little and they deserve a mom and a dad and I just don't understand why they might not be able to have that, you know it's just not fair.

Despite the stated importance of parental identity in participants' formulation of treatment preferences, it was not clear how much this was discussed with providers. Some participants acknowledged that parental considerations were rarely explicit in treatment discussion with their oncologists:

> It’s like the parenting part is the hidden and the ‘not discussed.’ How do you want to change the treatment so that I can continue to mother my son through these very, very important years? Who’s having a big discussion and debate about that?

Influence of parental role on preferences for hospice and palliative care services

We also asked participants whether they would consider using hospice services. We did not specify home hospice versus institutional hospice services. Twenty-two participants said they were interested in receiving hospice care at the end of life. Often, hospice was seen as a way to reduce family members’ caregiving burden, and as a supportive resource:

> I think it helps the patient but I think it helps the family even more because it takes away the burden of physical caring and allows that support for the family and I think that’s huge. It was for us when my mom passed away, it was very important so yes, absolutely.

Some participants saw inpatient hospice as a positive alternative to dying at home, which they worried could have a negative impact on their children:

> I think I would want to die in a facility, I don’t think I want to die in a house that my kids are gonna go back to, and live in. I can’t see that for them. I think that, you know if it comes to that point at the end of the road I would definitely be looking into hospice one way or another, and I think I would want to be on site somewhere.

Concern about dying at home, in front of children, was also a reason for disinterest in hospice services, for participants who focused on home hospice services:

> He had to watch my grandfather go. My grandpa had cancer and he died at home… I don’t want him to see that breakdown, I don’t want him to remember step by step his mom dying. I don’t want him to see me suffer. I don’t want to do it in the house. I don’t want him to deal with that.

Among the 9/42 participants who were explicitly not interested in hospice, most were disinterested due to lack of readiness to discuss end-of-life issues, or for reasons distinct from concerns about the impact on children, for example, participants’ views about using hospice services as a sign of “giving up.”

We also asked parents about preferences for receiving palliative care concurrent with cancer treatment, defined as “seeing a specialist who focuses on managing symptoms and helping make decisions.” Although over half of parents in our sample (24/42) were interested in learning more about palliative care or felt that they were already receiving it, some seemed to misunderstand its purpose or conflate it with EOL care. Specifically, several patients commented that they were unready to consider palliative care at all.

Discussion

The majority of participants in our sample reported that parental considerations influenced their treatment preferences. Most often, having children motivated a preference for life-extending treatment; this was largely due to participants’ desire to maximize the time they had left with their children. Participants who did not think that having children impacted their approach to treatment also described living as long as possible as a goal of care, citing other motivators, for example other family members. Among parents who did see having children as influencing their preferences, several participants described that having children motivated them to consider the impact of treatment side effects on their ability to successfully fulfill their parenting responsibilities. Regarding preferences for palliative care services, although most participants were open to exploring the option of hospice, several parents voiced concerns about the potential negative effect of their death at home on their children. Likewise, most participants expressed openness to seeing a palliative care specialist, however, several participants seemed to conflate palliative care with EOL care.

Our data offer insight into why parents of dependent children may be motivated to pursue aggressive treatment, namely, the desire for more time, often regardless of the quality of that time, with their children. In addition, our research is the first to suggest additional ways in which having dependent children may influence advanced cancer patients’ treatment decisions. These include preservation of parental and family functioning and maintaining proximity to one’s children. Another unique contribution of our study is its focus on parents’ preferences for palliative care services, including hospice. Our findings point to several practical observations.

First, as others have suggested, [12] provider-patient communication about the presence of children may be an important piece of shared decision-making for this population. Our results suggest that parents rarely discussed their parental identity and its influence on their treatment preferences with their oncologists. Lack of communication about family context could be potentially detrimental to patients’ quality of care. For example, a number of parents in our study mentioned that their treatment schedules and/or side effects interfered with their ability to effectively parent. Such disruption of parental responsibilities could lead to treatment non-adherence or severe emotional distress in response to seemingly unresolvable conflicts. The experiences of participants in our study suggest that some parents may be less willing to sacrifice parental functioning for optimal symptom or disease management. Enhanced communication about how anti-neoplastic and supportive therapies may be balanced with important parental responsibilities could lead to helpful modification of treatments or treatment schedules.

Second, our data suggest that parents with advanced cancer may have some difficulty planning for death and dying. Nilsson and colleagues found that parents with advanced cancer, compared to non-nonparents, had lower rates of advanced care planning. Compared to non-parents, parents also experienced more distress and poorer QOL at the end of life. [5] A number of parents in our sample were likewise hesitant to discuss plans for their care at the end of life. Often, this was because parents did not feel ready to discuss this phase of their care. Among parents who were interested as well as those who were uninterested in considering hospice, there was concern about dying at home and exposing children to the dying process. This observation is noteworthy, because of previous research among terminal cancer patients that has identified dying at home as part of a good death. [13, 14] Our results suggest it is possible that this traditional concept of a good death may be a lower priority for parents with children at home, Parents’ preferences for and concerns about place of death and other aspects of EOL care represent a novel area for future research.

Third, some participants seemed unclear about the role of palliative care across the advanced cancer care continuum. This could potentially lead to underuse of early palliative care services, which have been shown to improve survival and QOL. [15] Both of these outcomes were important to the parents in our sample, who wanted to maximize both the time left with their children, and their ability to fulfill their parental responsibilities. Thus, parents with dependent-age children may especially benefit from the early integration of palliative services in their care. Future research should investigate the specific supportive and palliative care needs of parents with cancer, and the impact of supportive and palliative care interventions on patients' parenting-related concerns, which have been linked to depression, anxiety, and overall QOL. [3]

Our study was limited to a single institution, and patients who seek care at academic medical centers like ours may not represent the range of experiences and opinions of all parents with advanced cancer. In addition, although sufficient for qualitative analysis, our sample was small, and thus we were not able to assess the impact of parental characteristics, for example gender or single parent status, on participants' response to our questions. Moreover, we did not specifically ask parents about home-based versus institutional hospice care, which may be an important distinction for this population, given concerns that arose about dying at home in front of children.

Unlike treatment regimens for most early-stage cancers, advanced cancer regimens may be less established, and their clinical benefits may be uncertain. Thus, decisions about advanced cancer treatment may be more nuanced, and social and family factors may play a greater role than in decisions about early-stage cancer treatment, with potentially greater consequences for life expectancy and QOL. Going forward, it will be important to understand whether the treatment preferences voiced in our study translate to differences in care received by parents compared to non-parents with advanced cancer. Further, understanding whether factors amenable to palliative intervention, for example emotional distress, contribute to observed differences in patterns of care will help to inform interventions to maximize parents' QOL during a difficult time for their families.

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Table 1

Characteristics of Interview Participants

Characteristic	Total Sample (N=42)	
	n	%
Patient age, M (SD)	44.21 (9.0)	
Months since metastatic diagnosis, M (SD)	17.12 (17.77)	
Number of children <18, M (SD)	2.23 (1.01)	
Age of children, M (SD)	11.56 (4.08)	
Patient education (years), M (SD)	15.76 (3.6)	
Patient gender		
Male	15	35.71
Female	27	64.29
Race/Ethnicity		
White, non-Hispanic	31	73.81
Black, non-Hispanic	7	16.67
Other	4	9.52
Marital status		
Partnered/married	29	69.05
Single	13	30.95
Income		
< $25,000	12	29.27
$25–50,000	9	21.95
$50–100,000	13	31.71
> $100,000	7	7.07
Metastatic at diagnosis	22	52.38
Cancer site		
Breast	10	23.81
Melanoma	7	16.67
Colon	6	14.29
Other	19	45.24
ECOG[1] Status		
High (0–1)	25	59.52
Low (2–4)	17	40.48
Receiving anti-neoplastic treatment at time of interview	36	85.71

[1] ECOG = Eastern Cooperative Oncology Group Performance Status Scale

Table 2

Structural and Content Codes Related to Treatment Preferences and Decisions

Structural Code	*Content Code*	*Definition*	*Example*
Parental considerations affect preferences - yes			
	Treatment for time	Undergoing treatment with primary goal of having more time to be alive. While this is often so they can be alive to parent their children may also includes desire just to be alive longer. Includes concept that parental status is motivation for treatment. Includes concept of desire to stay alive until the child or children is older.	"Especially with the age of my youngest, I would say that I would be willing to endure whatever treatment…just whatever I could do to be around longer."
	Just Until	A desire to live until a specific milestone or specific event can be reached. High overlap with treatment for time code. There is a specific event that patient describes as motivating reason.	"They need you, at least you feel like they do, and you want to be there for them and you want to see them grow and you want to see them, you know, graduate from college or graduate from high school, in my 10 year old's case."
	No Choice	Patient does not feel he/she has a choice in his/her decisions regarding treatment. They may also describe a choice but then state, that because of the parental role, it is not really a choice.	"When it comes down to the doctors, are you ready for it, I'll have to say yes, cause it might give me a chance of being around longer."
	Quality vs. Quantity	Balancing treatment decisions on quality of life (QOL) versus length of life. Often defined by ability to fulfill parental role. May include shifting frames regarding acceptable trade-offs regarding QOL and time.	"I would dread the imagery of me sitting on the couch, wrapped up in a blanket and I can't go outside and [the kids] are running around. That would not, that would not be a decision I would make very easily. On the flip side, because I'm I fighter, and I'm determined to win, I'll do what I have to do."
Parental considerations affect preferences - no			
Palliative Care - No	Not Now	Statement or belief that it is too soon or not the appropriate time to discuss or confront issues that relate to the end of life	"We're not even that conversation because I really think it's too soon to have that kind of conversation."
Palliative Care - Yes or maybe someday			
Hospice - No	How I want to die	How or where they may or may not want to die. Includes references to whether they believe their child will witness the death and whether the parent feels this is a good or bad thing.	"I don't want him to se that breakdown, I don't want him to remember step by step his mom dying."
Hospice - Yes or maybe someday			