

## Original Article

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**Abstract**

**Background.** An estimated 609,820 child-rearing adults in 2023 died from advanced cancer, affecting 153,675 dependent children. Although children are known to suffer significant distress when a parent is diagnosed with cancer, few studies have described parents' views of their adolescent's behavioral response to their advanced cancer or what the parent did to interpret or manage that response.

**Objectives.** To describe patient-reported concerns about their adolescent and how they responded to their adolescent's behavior.

**Methods.** Single occasion interviews were administered to 6 adolescent-rearing parents with Stage IV cancer. Interviews were analyzed using inductive content analysis by trained coders. Trustworthiness of results was protected through peer debriefing, coding to consensus, and maintaining an audit trail.

**Results.** The core construct that explained study data was *Being There without Taking Over*, comprised of 4 domains: Struggling to Read My Child, Attempting to Talk with My Child about My Cancer, Trying to Maintain Optimism, and Understanding My Child.

**Conclusions.** Parents were deeply concerned about the impact of their advanced cancer on their adolescent but were unable to distinguish between cancer-related distress and adolescent angst. They feared initiating cancer-related discussions and struggled with their own feelings of guilt and parental inadequacy but did not turn to professionals for help.

**Significance of results.** Adolescent-rearing patients with advanced disease need to be triaged into services that offer a framework from which parents can interpret their child's behavior and learn ways to have adolescent-appropriate conversations about the cancer. Such services should also help parents gain skills to manage feelings of parental inadequacy and guilt. In the absence of services, parents struggle and do not know how to interpret and respond to their adolescent's cancer-related behavior.

**Introduction**

An estimated 609,820 child-rearing adults died from advanced cancer in 2023, impacting an estimated 153,675 children under the age of 18 (Siegel et al. 2023; Weaver et al. 2010). Parental cancer and parental death are among the 2 most stressful events a child can face (Howell 2015). Twenty-three percent of these children are known to reach clinical levels of anxiety (Rainville et al. 2012; Siegel et al. 1996); 27–40% reach clinical levels of depressed mood (Beernaert et al. 2017; Christ et al. 1994; Rainville et al. 2012; Siegel et al. 1996, 1992); and 17–21% have behavioral adjustment problems reflected in elevated Internalizing or Externalizing scores on a standardized measure of children's behavioral-emotional functioning (Beernaert et al. 2017; Rainville et al. 2012; Siegel et al. 1992). There is some suggestive evidence that adolescents are particularly pressured by parental cancer as they attempt to develop their own self-identity and pull away from the family at a time when the parent's cancer pulls them back into the household (Armsden and Lewis 1993; Compas et al. 1994, 1996; Grabiak et al. 2007; Houldin and Lewis 2006; Phillips 2015; Welch et al. 1996).

Parents with advanced cancer struggle with the reality of their advanced disease, an awareness that they brought the cancer into the family, and a desire to be the best parent they can be even as they face their own death (Zahlis et al. 2020). Despite the numbers affected and the magnitude of adolescents' distress, the experience of parenting adolescent children during

advanced cancer remains substantially understudied (Park et al. 2017).

In the most recent interview study of concerns of parents with advanced cancer, 27 parents were interviewed, 60% of whom had an adolescent 11–17 years of age (Zahlis et al. 2020). Parents reported they were concerned their child was worrying about them, was scared about and had unanswered questions about the cancer, did not know what would happen, and did not understand that their parent's cancer was terminal (Shands and Lewis 2021). Parents wondered if their child was hesitant to talk about the child's sadness or fear about cancer, were holding their feelings inside, or were acting like nothing out of the ordinary was happening. Parents also wondered about how their cancer was interfering with their child's daily activities and their overall sense of safety and normalcy in family life (Shands and Lewis 2021).

The current study builds on prior work and adds to our understanding of parent's concerns and responses to their adolescents while the parent manages their own advanced cancer. The goal of this study is to describe parent-reported concerns about their adolescent that are attributed to the parent's cancer and how the diagnosed parent interpreted and responded to their adolescent's behavior.

## Methods

Prior to study start, the study was reviewed and approved by the Institutional Review Board (IRB) at the National Cancer Institute (NCI) comprehensive cancer center, the study center. Recruitment proceeded in 2 phases under the supervision of a senior medical oncologist on staff at the cancer center. Initially potentially eligible parents were approached by a site intermediary using a pre-approved IRB recruitment script. After the potential parent agreed to discuss the study, a study team member contacted interested parents, answered their questions, and, pending interest, scheduled a face-to-face meeting in the parent's home to obtain signed informed consent and conduct the interview.

Interviews were conducted in the homes of study participants by a Masters prepared nurse (EHZ) trained to conduct elicitation interviews. See Table 1 for the interview schedule. Interviews lasted 45–60 minutes, depending on the extent to which a parent elaborated. Interviews were audio-recorded, transcribed verbatim, and verified 100% for accuracy (EHZ).

Inductive content analysis was used to code the transcribed interview data using methods adapted from Glaser and Strauss (1967), Corbin and Strauss (2008), extended by Lewis and Deal (1995), and refined by Shands and Lewis (2021), Zahlis and Lewis (Zahlis 2001; Zahlis and Lewis 2010, 1998), and Zahlis, Shands, and Lewis (2020). Data were first coded into categories and then organized into larger conceptual domains (TNP, FML). Labels for the categories and domains were drawn from the words of study participants. Two trained coders reviewed the initial domains to further increase the parsimony of coding (MES, EHZ). The core construct was inductively identified after all categories and domains were identified (TNP, FML). This core construct explained the processes through which parents experienced their adolescent's behavior and what parents attempted to do to manage that behavior.

Three methods were used to protect the trustworthiness and credibility of study results: peer debriefing, coding to consensus, and maintaining an audit trail (Shenton 2004). Peer debriefing is a process by which coded data are reviewed by another coder whose goal is to verify the accuracy of the fit of the data with a

**Table 1.** Parent interview schedule

1. What have you told your adolescent about your cancer?
2. What do you think your adolescent understands about your cancer?
3. What do you feel is important or necessary to talk with your adolescent about your cancer?
4. What, if anything, do you not talk about with your adolescent about your cancer?
5. Where do you get stuck in talking to your adolescent about your cancer, if at all?
6. What do you watch for in your adolescent to know s/he is not doing okay with the cancer?
7. How has cancer changed your relationship with your adolescent, if at all?
8. What opportunity have you had to check in with your adolescent about his/her fears, feelings, or worries about your cancer?
9. What, if anything, have you done to help your adolescent get support outside the family for the cancer?
10. What, if anything, is a source of tension between you and your adolescent because of the cancer?
11. What, if anything, have you done to help your adolescent get information about the cancer?
12. Besides talking with your adolescent, what have you done that seems to help him/her with your cancer?
13. What do you watch for in your adolescent to know s/he is doing okay with the cancer?
14. What do you do that seems to help your adolescent with the cancer?
15. What, if anything, have you discovered about your behavior, that seems to make the cancer more difficult for your adolescent?
16. What, if anything, do you do together with your adolescent to help him/her deal with your cancer?
17. What, if anything, do you see your adolescent do or say about the cancer that concerns or upsets you?
18. What behavior in your adolescent do you see that you attribute to the cancer?
19. What changes, if any, have you seen in your adolescent that you think relate to your cancer?
20. Think back over the last few weeks. There may have been times, related to your cancer, that stick in your mind as particularly difficult for your adolescent. (Help focus the parent on the specifics of an event or incident in which the adolescent showed a behavioral or emotional response to some aspect of the cancer.)

category and domain. Peer debriefing also requires constant comparative analysis, a process by which each code is evaluated for its unique fit with a specific category and domain, thus protecting the uniqueness of each category and domain. Peer debriefing was carried out through all phases of coding (FML). Coding to consensus required that any disagreement between the coder or peer debriefer be resolved by discussion and agreement. An audit trail was maintained for each phase of the coding. This required retaining consecutive files so that a third coder was always able to access the documents to check the accuracy of the coding. This audit trail included dated consecutive word documents which were stored during every phase of the coding.

## Results

Four female and two male parents diagnosed with Stage IV cancer participated. Their adolescent children ranged in age from 11 to 15 years (M: 13.6 years, SD: 1.4). Most adolescents were between 13 and 15 years of age. The majority of parents had lived with cancer more than 5 years, were between 43 and 52 years old, and were married with 1–2 children living at home. Five of the six parents

were married and 66.7% had some college or more of education. All parents were Caucasian. Two (33%) were diagnosed with breast cancer; 2 (33%) had colorectal cancer and 2 had carcinoid tumors.

The core construct that organized study results was Being There without Taking Over, consisting of 4 domains: Struggling to Read My Child, Attempting to Talk with My Child about My Cancer about My Cancer, Trying to Maintain Optimism, and Understanding My Child. Recruitment stopped when a new interview failed to yield new information.

### **Domain 1: Struggling to read my child**

Parents struggled to understand and interpret their adolescent's behavior. Parents described their child's moodiness, irritability, and temperamental behavior but did not know if that behavior was in response to the stress of the cancer or to the child's unique developmental trajectory. Some parents felt lost in knowing how to help their children; other parents sought advice from close friends to confirm that their adolescent's behavior was age and developmentally appropriate, that is, teenage stuff.

I don't know if it (my child staying up too late or being temperamental) has anything to do with the cancer, or if it is just part of adolescence ... I know that there are going to be some growing pains. It is just really hard to separate the two I guess. (Parent 007)

Concerned about the potential association of their cancer with their adolescent's behavior, parents monitored their adolescent's everyday lives: details of their children's school schedules, eating and sleeping patterns, extracurricular activities, questions their children raised, time their children spent with friends, the length of time their children spent alone. They noted their children's social interactions toward the parents and others. Parents actively looked for signs that their children might not be coping well with their cancer and asked themselves questions like, "Is he spending time with his friends?" "Is he eating?" "Why is she yelling at her nephew?" "Is she saying that because she thinks I am going to die?"

Some parents noticed changes in their children's behavior when the parent's condition worsened and felt at a loss understanding or acting on those behaviors. One parent said:

Every time I get sicker and sicker, my child's personality starts changing a lot ... I really don't know what to do to help my daughter. And that really bothers me and kills me inside because I didn't even know what to do to try to help my daughter with this I'm going through. I'm lost .... (Parent 003)

When an adolescent demonstrated altered behavior, especially negative behavior, parents were not only confused, they also worried. Parents understood these behaviors were indicators of their children's stress and watched for signs of depression in their child. When parents saw their children acting mature for their age, not displaying anger, or not showing interest in pop culture, they also worried that things were not easy for their children.

Some parents talked to their children about their behavior while some parents only watched, asked indirect questions, and thought about what they were seeing. Parents reported their children were more forgetful, came home late, spent more time alone, had trouble sleeping, and got mad easily. "Well, she get (*sic*) mad real easy. I mean, she's yelling. And she wasn't like that. My child is always yelling when somebody tell (*sic*) her something." (Parent 003) When parents asked their children about the changed behavior, some children gave abrupt answers while others repeatedly said, "I don't know."

He's usually not forthcoming with initiating discussions like that about any kind of serious issues. I'd expect that if I saw something really affecting him, I would bring it up and I will discuss it with him. (Parent 008)

By watching, collecting information, and assessing their children's behaviors and social interactions, parents sensed that things were not easy for their children. One parent suspected that her child was stuffing his anger about her cancer because he behaved too well. Another parent sensed things were not as easy for her child because her child did not have deep friendships and internalized her mother's problem. This parent reported:

... and this ARNP (advanced registered nurse practitioner) um, grabbed my chart out of my hand, I walked into her office one day, it was very upsetting. And, everybody says that she is very controlling, which I agree with, but, when I relayed the story to my husband, my child heard it and she got really enraged, and she was talking to me about what I needed to do, and so if she hears about anything like that, that really upsets her, then she just really internalizes it while I'm not really. She, she takes it on, you know, as her own cloak. (Parent 007)

### **Domain 2: Attempting to talk with my child about my cancer**

Most parents said their children were told their cancer was metastatic while some did not get told. Further, the meaning of metastasis was not explicitly defined for the children. Parents assumed their children discovered on their own the implication of metastatic cancer. One parent said that she did not directly tell her son of her metastatic disease. She claimed her son could infer that from her statement, "I am changing my treatment." Another parent offered,

... I think she understand (*sic*) that this is chronic that you know it's not just gonna go away. Hmmm I honestly don't know how much she understands about life expectancies associated with it because I just haven't been brave enough to go there with her humm myself. Hmm, they have a pretty good idea how the chemotherapy effects because they've seen that first hand and seen (*sic*) how sick I've gotten from the chemo and they probably relate that sickness to the cancer rather than it being a result of the chemo, you know. (Parent 005)

Most parents did not elaborate their cancer prognosis to their child unless asked. Instead, parents talked about cancer treatments, their side effects, surgeries, and their hope of seeing their children grow up.

... what we told them was that umm I had colorectal cancer and that cancer was a sick spot in my body ... I mean we've always talked freely and openly about it with them but the information that we've given to them, we've tried to keep it real ... hmm in simple terms so that they could digest it and understand what we are saying and we've never gone into the scary stuff about you know life expectancy or anything like that. We've never talked with the children about the possibility that I could die from this. (Parent 005)

One parent related "not holding back" his cancer prognosis when his children asked because of his experience in not being told about his mother's cancer until 2 weeks prior to her death. He commented, "Oh, (I) keep them informed (about my cancer). Um, occasionally reminding them that this cancer could take my life a lot sooner than it should." (Parent 006) He went on to specify that "not holding back" included taking his children to the cancer center and letting them see other patients with cancer.

Most parents refrained from confiding in their children when the parent experienced depression, fatigue, or side effects from their cancer treatment. They believed doing so would overly burden their children. Parents also believed that asking their children

too many questions about their feelings about their parents' cancer would create anxiety. Some parents admitted not knowing how to initiate cancer discussions with their children and discussed the topic only when it came up or if their child asked.

I don't walk around saying, 'Hey, let me tell you about this, let me tell you about this,' because I don't want to burden them .... But if they have a question and they want to know about it, I'm more than happy to tell them about it. (Parent 006)

Some parents voiced frustration when their child did not want to share their feeling about the parent's cancer. One mother reported sadness and dismay at being shut out of her daughter's feelings about the mother's metastatic disease. Though the ill mother encouraged and attempted to persuade her daughter to reveal such feelings, her daughter gave her no clue. This mother reported,

I like to know how she feel (*sic*). How she feel (*sic*) right now. How she feel (*sic*) about me having this cancer, but she don't (*sic*). That's what really bother (*sic*) me. Because there's nothing I can do to make her open up to me. Because no matter what I tell her, she will always say, 'Forget it; I don't want to hear.' (Parent 003)

Parents felt shut out when children limited the amount of time they spent with the parent. One parent expressed his disappointment at not being with his children as much as he would like. He recalled the moment in which he realized his daughter did not want to spend as much time with him. He stated, "... I want my daughter to understand that the reason I want to spend more time with her is because of the cancer." (Parent 006)

### Domain 3: Trying to maintain optimism

In living day-to-day with metastatic cancer, parents tried to be optimistic, deal with changes in their bodies, and acknowledge cancer was part of their lives. Parents stressed the importance of having a positive attitude, continuing life as normal, and being hopeful. Some parents expressed hope to witness milestones in their children's lives such as high school graduation.

Well, I was fortunate in that I got what they call a 'good cancer,' it's a cancer that acts benign but is malignant, and so therefore we don't talk about it much. Not because it's not important, but because I think the best defense towards it is a good attitude, a good spirit and to continue life on as if it weren't there. (Parent 006)

Parents stressed the importance of doing things with their children but also letting their children be involved with and get support from others. One mother explained she tried hard to not be a hovering kind of mom and reported that at times she had to remind herself not to hover. Another mother encouraged her daughter to be involved in charity work so that her daughter would be happy with her world and herself.

Um, I'm trying to help her spread her wings a little bit, so she's doing some activities this year that are a stretch for her, and I think that that's great. Um, some charity work, and um, so, because I think that she tends to be really introverted and hard on herself, um and I don't want her to get so focused on herself and what she thinks might be her own problems. (Parent 007)

Parents also tried to improve the quality and quantity of time they spent with their children. They achieved this by watching silly movies, going on trips, or attending church with them. For these parents, having fun and laughing seemed to be the main theme.

But optimism was not always enough. Parents experienced tension with their adolescents when the parent's energy level was low and the parent was fatigued. Parents believed being in bed most of the day and asking their children to do extra household tasks scared their children and sent the message that their children were at fault. Parents stressed the importance of getting back to their prior functioning as a way to gain normality and improve their parent-child relationship.

I think it's helped my child to see, cause, I had a rough time with chemo, and I would be down for about a week and then I would slowly start to feel better again and so all those weeks when I felt better, you know, I would take them to school, and, you know, ramp up on the activities again and I think that helped them to see that yes things will get back to normal. (Parent 005)

For one family, the ill parent felt obligated to wear a wig whenever she was with her son in public or in front of his friends. Another parent shared,

... well, there've been a couple of physical changes hmm, as a result of my cancer, you know, just practical things like uh, you know, like, I am not built the same anymore, so when we do things, I always have to be within twenty yards of a restroom (laughter), so that's kinda (*sic*) of, that's been a real change for us. (Parent 005)

Despite their attempts to maintain optimism, some parents felt their children were not living a normal existence because of the parent's cancer and reported feeling angry at themselves for not being able to give their children more. They felt sad about putting their children through a difficult life experience at a young age. One parent voiced her frustration at not being able to give her child the same physical and emotional resources she was able to offer her before the diagnosis.

Having cancer doesn't mean you're not allowed to whine or complain about it, but, kids are the most important. My kids are the most important thing to me. And I want them to have a happy childhood. (Parent 006)

Parents felt guilty that their children had to live with their cancer even as they realized their cancer was not their fault. One parent described with emotion how his cancer was something over which he had no control but which he was feeding, protecting, and caring for. "Um, I hate that 'my cancer,' it's like this thing I'm nurturing." (Parent 007) One mother expressed anger and frustration at having cancer especially when her stress, lack of energy, endless cancer treatments, anticipated death, and complicated financial standing affected her son. In her own words,

I'm trying to figure my way out of it and I, I definitely think it's (cancer) affected it. You know it's (cancer) affected my child because I've been very tense. Um, and like I said it's really unfair when it's your kid you're like, 'Oh, why, you know, why does his childhood have to be like this?' But, it is, you know. (Parent 001)

### Domain 4: Understanding my child

Parents worked to gauge the level of their children's comprehension, thoughts, coping, and the impact their cancer had on them. Parents were aware of and tried to accommodate issues that were important to their children such as not wanting people to recognize that the parent had lost their hair or wanting time at school to be normal. Several parents allowed, understood, and accommodated their children not wanting to spend as much time with them while others struggled, felt hurt, and frustrated.

When my daughter was 7, and 8, she went to work with me all the time at night and on her summer vacations. And she doesn't do it anymore. And it hurts. That hurts. (Parent 006)

Though parents felt they knew what was important to their children, sometimes they were shocked at how much the children put cancer in the foreground. One parent shared,

A few months ago I would have said it (cancer) was just background to his life and you know, and I've kind of changed my mind this last little bit, but I'm not sure. And so I did tell him that I was changing my treatment and doing chemotherapy and he said, 'I don't know if I can handle that, or I don't know if I can take you going through chemo again.' And I was really kind of shocked because I thought that he'd, you know, that it had been smooth for him. (Parent 001)

Parents were aware that their adolescents had other concerns as well, not just their parent's cancer. One parent reported her daughter had a lot of things on her mind other than her mother's cancer and, as a result, reported that it was not the right time to discuss the ill parent's plans for her daughter after the ill parent died.

But right now is not time; it's not the right time for me to tell my daughter who she's going to stay with. She got (*sic*) a lot of things in her mind about school, about me, about her life. (Parent 003)

Parents were aware of ways their children dealt with their cancer. One parent noted that his child did not dwell on his cancer, just like the ill parent chose to not dwell on it. One mother reported that her daughter was introspective, smart, and told people what they wanted to hear. This mother said,

She is very bright, and I think sometimes she tells people what they want to hear, and, um, maybe, you know, sometimes I'll think that there might be something wrong and she says that there isn't, and maybe there isn't. (Parent 007)

## Discussion

Study results are the first to provide a granular view of the issues and parenting challenges experienced by adolescent-rearing parents with advanced cancer. Although prior studies documented that 33% of parents report difficulty with illness-related communication, current results illustrate the content areas and degree of tension parents experienced in attempting to initiate cancer-related information. Current results told us where and how parents turned to friends, not professionals, to judge their child's behavior (Ernst et al. 2012; Hailey et al. 2018, 2018; Houldin and Lewis 2006; O'Callaghan et al. 2009; Sheehan and Draucker 2011; Turner et al. 2007, 2005). The core construct, *Being There without Taking Over*, illustrated the larger dilemma: parents did not know how, when, about what, or how frequently to communicate with their child. Parents did not want cancer to take over or dominate their adolescent's life but at the same time they wanted to connect with their child about the cancer and its effect on the child. In the absence of conversation, parents played a guessing game on the impact of the cancer on their child. Further, parents did not know how to create a space in which to carry out such conversations. Instead they channeled their behavior into observing details of their child's daily life and were hypervigilant in monitoring their child's behavior, social relationships, and mood. They turned to friends for perspective but not to professionals to help them understand or respond to their adolescent's behavior. Recall that this study sample was White; we do not know if results pertain to families of color.

Even as parents worried that their cancer could be negatively impacting their child, they rarely initiated a conversation with their child and explicitly avoided discussion about prognosis, death, and dying. They feared that cancer-related discussions would add to their child's stress or further distance them from their child. In the few times some of the parents initiated a cancer-related conversation, they were rebuffed or shut down by the child. This behavior hurt them, leaving them wanting more – more connection, more conversation, more clarity.

Parents sought ways to improve the quality of their parent-child relationship and normalize family life. They waited for times when their symptoms were under control and then did things with their child that the adolescent enjoyed. They did this work on their own, guessing what might help their adolescent. Even as the parents appreciated that their child was an adolescent who needed to explore and build social relationships outside the family, some parents felt frustrated while some understood and accommodated the child.

Parents had no conceptual or operational understanding of how to parent their child about the cancer, how to interpret their adolescent's behavior, or when to attribute their child's behavior to adolescent growth and development or to the cancer. All results highlight the need for services to help parents manage these issues, including parents dealing with their own feelings of inadequacy and guilt and their adolescent's rebuff or refusal to talk. There is no known intervention program to date that has addressed the specific areas of the parent's struggle with their adolescent, even parenting- and child-focused programs (Lewis et al. 2017; Lewis et al. 2020; Lewis et al. 2021; O'Callaghan et al. 2009; Phillips and Prezio 2017).

Future programs and services need to engage the adolescent and parent in co-creating an interactional space that is comfortable for both of them. Adolescents have substantial personal agency and parents could benefit from knowing how to engage their adolescent in developing a way to carry out conversations that are emotionally safe and helpful for both. They can decide together when, how frequently, and in what forms the ill parent and adolescent can talk about the cancer. Such a plan is a first step, albeit an important step, to enhance their connection rather than burying or hiding the parent's cancer or what each of them is going through; going through it together could be a goal.

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