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Parent Perspectives on Information about Late Effects of Childhood Cancer Treatment and their Role in Initial Treatment Decision-Making

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Abstract

Background—Though most childhood cancer survivors experience late effects of treatment, we know little about parent preferences for late effects information during therapy, nor how parents weigh late effects when making treatment decisions. Our objective was to explore how parents of children with cancer consider late effects in initial treatment decision-making and during active cancer treatment.

Methods—Semi-structured interviews were conducted with 12 parents of children with cancer who were actively receiving treatment at Dana-Farber/Boston Children's Cancer and Blood Disorders Center. Interviews were audio recorded, transcribed verbatim, and qualitatively analyzed using thematic analysis.

Results—10/12 parents reported that they had to decide between two or more treatment options for their child's cancer. Of those, 50% (5/10) considered late effects to be an important factor in their decision-making. Most parents wanted early and detailed information about their child's risk of late effects to make treatment decisions and to feel prepared for the future. However, a few parents felt too overwhelmed to focus on late effects at diagnosis. While many recalled extensive late effects information in informed consent discussions, some parents felt these issues were minimally addressed.

Conclusion—Parents desire detailed information about late effects to make informed treatment decisions and prepare for the future. Despite the role of late effects in treatment decision-making, some parents feel that late effects are either inadequately addressed or too overwhelming to process at diagnosis. Parents may benefit from early assessment of their information needs and a return to these issues over time.

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Keywords

Late Effects of Cancer Treatment; Pediatric Oncology; Decision-Making; Communication; Information; Parent

INTRODUCTION

Thanks to iterative cooperative group trials, more than 80% of children diagnosed with cancer will become long-term survivors.¹ However, this cure comes with a cost, as the majority of childhood cancer survivors experience at least one late effect as a result of cancer or its treatment.^{1,2} Historically, clinicians have focused on providing late effects information, and educating survivors about their individual risk of long-term health issues, after treatment completion and in survivorship clinics.³ Though several studies have shown that parents desire information about late effects in initial diagnosis and treatment conversations,^{4–6} potential long-term health implications of treatment receive little attention in informed consent discussions.⁷ Perhaps as a result, childhood cancer survivors and their parents report many unmet information needs about late effects of therapy,^{8–10} and many parents feel sub-optimally prepared for their children's survivorship.¹¹

There is little evidence on how best to provide information about potential late effects of therapy at the time of diagnosis. Studies of survivors and their parents have indicated a preference for personalized, written late effects information.^{8,10,12,13} In disease specific studies, survivors of lymphoma want information continuously offered from diagnosis through survivorship, and want information to be individualized, honest, and offered proactively by their providers prior to a patient's request.¹² However, studies about late effects information preferences have been conducted among survivors and their parents years after the initial diagnostic and treatment conversations,^{8,10,12,14} and perception of information received and desired may differ between diagnosis and survivorship. Furthermore, it is unclear whether and how parents consider late effects information when making treatment decisions. In this study, we interviewed parents of children actively receiving cancer therapy in the months immediately following their child's cancer diagnosis. We used a qualitative approach to explore parent preferences for information and communication about late effects of childhood cancer, and to examine the role that concern for late effects plays in initial treatment decision-making.

METHODS

Participants

Participants were recruited from the Dana-Farber/Boston Children's Cancer and Blood Disorders Center. Parents of children within one year of cancer diagnosis who were actively receiving cancer-directed therapy were eligible. Pediatric oncology visit lists were screened regularly for potential candidates. English-speaking parents of children with cancer under 18 years of age at diagnosis on active treatment were eligible. Purposive sampling was used to ensure diversity of cancer diagnoses, prognoses, and participant sociodemographic factors. Patients' physicians were contacted to confirm eligibility and obtain permission to approach.

Eligible parents were approached in-person by study staff at clinic visits or during inpatient stays. In total 14 parents were approached, and 12 (86%) gave their consent to participate. One parent declined due to time constraints; one found the topic upsetting. Written informed consent was obtained from all participants. Participating parents were interviewed in-person from April to July 2016 and received a \$20 gift card as a token of appreciation. The Institutional Review Board of the Dana-Farber Cancer Institute approved this study.

Procedure

Individual semi-structured interviews were conducted in-person by an interviewer trained in qualitative interview techniques. The interview guide included open-ended questions focusing on parents' recollection of late effects information provided in early treatment discussions, and the role of late effects in their treatment decisions (Table 1). Probing questions were asked for clarification or elaboration. Interviews were audio-recorded and transcribed verbatim. Continuous analysis was performed, and recruitment continued until thematic saturation was achieved.

Data analysis

All transcripts were coded independently by two authors (KAG and AD), using standard comprehensive, directed thematic qualitative analysis methods. A two-stage coding process was utilized for the analysis, with both prefigured and emergent codes.¹⁵ Initial coding used questions from the interview guide as the framework for the prefigured coding structure. We used a framework orientation for the second phase of the analysis; a thematic framework was constructed from topics that emerged from the data, and this framework was then applied to all transcripts.¹⁶ Independent coding, and comparison of coding assured both credibility and dependability of the coding process to accurately elicit main themes. Discrepancies were discussed and resolved through in-person meetings between coders. Data analysis and management were supported by NVivo (QSR International, Version 11, 2012).

RESULTS

Characteristics of participating parents and their children are shown in Table 2. Main themes elicited included: desire for information about late effects, late effects worries, and late effects as a consideration in treatment decision-making. Quotes are annotated with parent number and gender, (Parent X, M/F).

Parent late effect information preferences

All parents wanted to learn about their child's risks of late effects and considered this information important (Table 3). One parent commented, "I wanna know what's gonna happen... What are we really facing down the road? What is her life really gonna be like?" (Parent 10, F).

Of 9 parents who expressed a preference about the timing of late effects information, 7 preferred early information at the time of diagnosis. Some wanted this information to begin preparing for their child's future, others to help them make informed treatment decisions.

“I’d like to know that ahead of time, so we know what to prepare for, what we need to worry about” (Parent 5, M). Another parent said, “It is important to make these decisions, we need to know all of the facts and know what possible outcomes are” (Parent 6, F). However, 2 parents felt too inundated with information at diagnosis to consider late effects and instead felt that they require a separate, later conversation:

It’s hard enough to realize that she has to go through this for 2 years, and this is what’s happening, this is what could happen to her body now, and then... it seems so overwhelming to think about down the road... it’s a whole other diagnosis to think about what could happen down the road. (Parent 4, F)

Several parents expressed ambivalence, simultaneously wanting information while at the same time finding information daunting. “For some people, more information is better. For some people, more information is overwhelming. And for someone like me, both of those things are true” (Parent 10, F).

Parents especially wanted information about actionable late effects, which they could try to prevent or ameliorate. “I wanna do whatever I can to protect my child... [don’t] tell me after the fact” (Parent 10, F). They also wanted to know what was most likely to occur to their child, “They gave us these sheets of paper that had ‘likely,’ ‘unlikely,’ and ‘very unlikely’ side effects; and to be quite frank, I kind of looked at the ‘likely,’ I didn’t really pay much attention to the rest...” (Parent 7, M). Some parents also expressed that it would be helpful to understand how the combination of therapies impacted their child’s likelihood of late effects, instead of learning separately about the late effects associated with each individual treatment or chemotherapeutic.

Many parents were satisfied with the quantity and quality of late effects information provided by their child’s medical team. “My wife and I went through all the paperwork that they gave us, and then, of course there was a lengthy discussion about it, and then there was more discussion, then we signed paperwork, there was more discussion, so I felt like we were very well informed” (Parent 2, M). However, even those who felt they received high quality information found the presentation of information quite daunting, and many still had unanswered questions about likelihoods of specific late effects, or about the risks associated with combinations of treatments. “I felt that I had enough information... but fertility options weren’t discussed before” (Parent 3, F). Meanwhile, 2 parents felt potential long-term health outcomes were inadequately addressed. One parent commented, “I’m still facing this black wall of unknown” (Parent 10, F); another said, “they didn’t tell us anything about what happens after treatment yet” (Parent 5, M).

Role of late effects in treatment decision-making

Of the 12 parents interviewed, 10 felt they faced a decision between 2 or more treatment options, for example enrollment in a clinical trial versus standard of care treatment. Of those who faced such a decision, the majority considered late effects in their decision-making process, and half (5/10) reported that potential late effects played a major role in their deliberation. “I looked very closely at any type of, at the side effects, or long-term effects of anything that was related to a choice or treatment decision, something that might be affected by our actions” (Parent 7, M). Another parent said, “You’re making a decision about putting

all this stuff in him, and, what's it going to be like? How's it going to affect him when he's 30? Or longer, you know, so I thought about that quite a bit and had lots of discussions with the team" (Parent 2, M). Those who considered late effects often spoke about trade-offs – trading one late effect risk for another, or choosing for or against the standard of care due to the risks of late effects. However, 2 parents felt that late effects played no role in their decision-making. "I feel like we haven't given enough thought to the long-term effects, but at the same time I feel like it doesn't impact your decision, because she has to get the treatment and you just have to hope for the best" (Parent 9, F).

In describing the process of making treatment decisions, some parents commented on information presentation formats, or their doctor's approach to decision-making, and how different styles impacted their decision-making process. One parent was appreciative of the way her child's physician engaged her family in decision-making:

He never told us what he would do, and he thought it was so important for our family to make the choice on our own... I really admired him for that... the easy way out is just to have your doctor say, 'this is what you should do,' but he knew that the choice was life-altering, for a family and a person, and he honestly educated us on each one. (Parent 6, F)

Many parents found the pages of potential acute and long-term side effects described in informed consent documents to be comprehensive but overwhelming and difficult to decipher what was most relevant to their children. Parents also spoke of the importance of asking what they would like to know, "I think that parents should be given the option by their physicians - 'How much information do you want?', 'How would you like to be told?', and 'How much?'" (Parent 10, F).

Those parents who wanted early information about late effects, and those who considered late effects in their treatment decision-making, often talked about continuing to worry about them, "I'm generally concerned with his health going forward" (Parent 7, M). Meanwhile, of those who found upfront late effects information overwhelming, some commented on not worrying about them at all during treatment. As one parent said, "I don't really worry about the long-term effects, there hasn't been that much emphasis on it in speaking with the doctors... for us, it's just... can we get rid of this and can we get rid of it for good" (Parent 9, F). However, some parents spoke of deliberately avoiding thoughts of late effects, "I know the short-term side effects from the treatments... I try not to think about or focus on anything long-term" (Parent 12, F). Many parents expressed conflicting sentiments, simultaneously trying not to worry about late effects due to apprehension about them,

When they give you all the paperwork with all the side effects, the truth is, I actually try not to look at those... I glanced because I want to get an idea of what to expect, but I try not to focus too much on it because I feel like, you know, it's still a lot of fear, and there are so many side effects and so many drugs... (Parent 9, F)

Nearly all parents articulated that potential late effects of treatment, while worrisome, were worth the chance of cure; "I'd rather have him alive with a minor fault" (Parent 8, F). Another parent said, "There's so many side effects, but as of right now that's our best alternative, and I never thought that I would ever say that, but you're like thankful for this

powerful, toxic medicine” (Parent 6, F). Many parents commented on the uncertainty surrounding the chance of late effects (“I can’t worry myself about so much unknown” Parent 3, F), and took the approach that they would face late effect challenges as they arose. “I don’t think about the ‘nows’ or the ‘what ifs’, you know, I think of, ‘she’s gonna get better’ and that’s it! And if, you know, treatment does damage something in her, then we’ll deal with it right then and there” (Parent 11, F).

This sentiment was particularly apparent when parents discussed infertility. Potential infertility was mentioned as a late effect concern by every parent interviewed. Some parents considered fertility preservation options prior to initiating treatment, even if they had not discussed these options with their child’s physician. Though infertility was cited as a concern by every parent, most felt this was surmountable, either through modern reproductive technologies or adoption. “There’s so many different options, there’s drugs and treatments and stuff that they’re coming up with every day, and if children [are] an absolute must, there’s adoptions and surrogate people and whatever else” (Parent 2, M). Nearly all commented that potential infertility was worth the trade-off for cure, particularly as many parents did not know if having children would be important to their child when he or she grew up, “Fertility is not a priority, I mean it’s lovely to procreate, but I’d rather a quality of life and a cure... who knows, he might grow up and it might not be a priority for him, I’d rather him be healthy now” (Parent 1, F). While parents discussed many other potential late effects specific to their individual children, parents’ greatest worries were recurrence of their child’s cancer and second malignancies as a result of cancer treatment.

DISCUSSION

While informed consent documents for pediatric cancer treatment contain information on potential late effects, the majority of late effects education has typically occurred after treatment completion, during long-term follow-up care.^{3,17,18} This approach has clear merits – survivorship is when late effects screening is required, and when most late effects occur. This timing also allows education of survivors who may have been too young to participate in discussions at diagnosis.¹⁸ However, this approach neglects the role of late effects information in initial treatment decision-making. Parents in this study valued late effects information from the time of diagnosis, because it helped them to feel prepared for what is ahead and informed the decisions they made about their children’s care.

Parents of seriously ill children view informed medical decision-making to be a primary component of good parenting.^{19,20} Our findings suggest that we should consider conveying more information about possible late effects in an upfront setting to meet parental desire for information and to allow parents to engage in shared decisions about treatment. Waiting to fully discuss potential late effects of treatment until completion of therapy and survivorship may not meet parent information needs, and may hinder informed decision-making.

Providing upfront information about potential late effects of childhood cancer therapy poses many challenges. Early diagnostic and treatment conversations, or Day One talks, are emotional conversations during which a child’s diagnosis, prognosis and proposed treatment are discussed, leaving little time or emotional capacity to also review potential late effects.

4,21,22 Furthermore, the risks of late effects can be challenging to estimate, let alone convey to families. Many providers are uncomfortable providing information about late effects of therapy even after treatment completion as they fear taking away hope.²³ Adult oncology providers worry that information about potential late effects of cancer and its treatment will be emotionally upsetting to cancer survivors as it “could have a negative impact on psychological adjustment to life as a cancer survivor and may actually increase the experience of late effects through autosuggestion.”²³ These concerns are likely magnified in the setting of heightened emotions at diagnosis. However, survivors of childhood cancer with unmet late effects information needs are more likely to experience depression, anxiety and inferior mental and physical health related quality of life,^{8,9,24} and lack of information does not decrease late effect worries,^{10,25} underscoring the potential importance of this information to psychological health.

Disclosure of information about late effects has parallels to conversations about prognosis, where physicians similarly worry about causing distress and loss of hope. Research on prognostic disclosure suggests that providing information, even if upsetting, is critically important to parents of children with cancer, and does not diminish hope.^{26,27} While a subset of parents of children with cancer find prognostic information quite upsetting, parents who are upset by the information find it equally valuable and still desire detailed information.^{27,28} In fact, omission of prognostic information can impede the therapeutic alliance between parents and providers, and negatively impact parental decision-making.²⁸ Just as understanding of prognosis has been shown to result in different treatment choices,²⁹ our findings suggest that parental understanding of late effects risks may impact treatment decision-making. Therefore, even if parents find late effects information upsetting, many still need and desire this information.

A child’s diagnosis, prognosis, and the availability of treatment options may all affect the type and amount of information desired by parents, and whether parents consider late effects when making treatment decisions. The role of these factors in parent information preferences were not explored in this small qualitative study. In our practice, we typically review the late effects information on informed consent documents with parents, focusing on those late effects we think we might be able to prevent, those we need to monitor for, and those we think parents should be prepared for. Further investigation is required to understand how best to provide late effects information in a way that meets individual parent information needs and offers realistic estimations of risk, while simultaneously supporting hope. However, parents in our study offered some guidance. First, parents wanted to be offered information about late effects. Second, they wanted their own information needs and preferences to guide discussions, and desired the opportunity to defer detailed discussions. We would add that clinicians must consider what information is essential for decision-making and informed consent, such that some information may need to be shared regardless of a parent’s desire to avoid it. But, when information can be deferred for the relatively few parents who wish to do so, clinicians can openly discuss this decision and make a commitment to readdress late effects in the future. Finally, many parents commented on the lengthy “paperwork” provided which typically lists late effects by chemotherapeutic agent, and found it difficult to decipher the implications of the comprehensive treatment regimen.

New ways of conveying a more integrated view of a child's future in both our verbal and written communication are needed.

Our study had several limitations. We collected perspectives from 12 parents at a single institution, posing concerns about the generalizability of our findings. However, many children and families receive cancer care at pediatric cancer centers like ours, and through purposive sampling we collected varied parent perspectives. Furthermore, as over 50% of children with cancer are treated on a clinical trial,^{30,31} many parents receive similar informed consent documents which outline potential late effects. We interviewed parents in the months after initial diagnostic and treatment conversations, making it possible that important elements of the communication process were forgotten during the time that elapsed between the day one conversation and our interviews. Despite the time lapse, many parents recalled aspects of these conversations in detail, and this timing was more proximal to treatment discussions than prior studies which have queried parents and survivors years after treatment completion, and after some survivors have experienced late effects. Lastly, the child's voice is missing from this study. We interviewed parents of children who were less than 18 years of age at the time of diagnosis, as parents are the primary decision-makers for their children, but older children may have participated in treatment decision-making. The perspectives of older children and adolescents on late effects information bears further study.

Provision of early information about potential late effects of childhood cancer treatment meets many parents' information and decision-making needs, and may help parents feel prepared for their children's healthcare needs in survivorship. We recommend that pediatric oncology clinicians consider 3 main questions as they prepare for initial treatment conversations. First, what does the parent need to know about late effects to make an informed treatment decision? Second, beyond the most essential information, what does the parent want to know, and when? And third, how does the parent wish to learn about late effects? This third question raises opportunities for future research about how best to convey late effects information in a meaningful way, focusing on the future life of an individual child rather than extensive lists of possibilities associated with discrete treatments. Doing so may help parents to hold their essential roles as stewards to their children, protecting their children's present health and future well-being.

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Table 1

Interview Questions. Parents were prompted to “*Please think back to when you first received your child’s diagnosis and had to make decisions about your child’s treatment.*”

1.	Were you given different treatment options? If so, how did you decide between the options?
2.	What do you remember learning about the long-term risks and benefits of treatment?
3.	When making initial treatment decisions for your child, what things were most important to you?
4.	When you think about your child’s life in the future, what do you worry about? What do you hope for?
5.	When you think about late effects of cancer treatment, what do you think about? Are these issues you worry about?
6.	When making treatment decisions for their children, some parents feel that they have to make trade-offs between the immediate side effects of treatment, the possible late health effects of treatment, and cure. How do you think about balancing these different things?

Table 2

Parent and Child Participant Characteristics

Parent Characteristics	
	N (%)
Gender	
Female	9 (75)
Age at survey completion	
<40 years	7 (58)
Race/Ethnicity	
White, non-Hispanic	10 (83)
Black, non-Hispanic	1 (8)
Hispanic	1 (8)
Highest level of education completed	
College graduate or higher	7 (58)
Child Characteristics	
	N (%)
Gender	
Female	6 (50)
Age at diagnosis in years	
Median, range	7.9 (0.2, 15.7)
Cancer diagnosis	
Hematologic malignancy	5 (42)
Brain tumor	2 (17)
Extracranial solid tumor	5 (42)
Time between diagnosis & interview (mos)	
Median, range	6.1 (3.6, 10.5)

Table 3

Parent Late Effects Information Preferences

Theme	Example Quotation
1. When to inform?	<i>Early, to support treatment decision-making</i> <ul style="list-style-type: none"> “I think for us it seemed like we really wanted to hear all the information upfront so we could make the best decision.” (Parent 7, M)
	<i>Early, to prepare for the future</i> <ul style="list-style-type: none"> “Why in the world would you want to know- hear about the effects after you’ve already started or if you’re done. I’d wanna know... what we’re getting into before we get into it.” (Parent 2, M)
	<i>Too overwhelming to think about upfront, prefer information later (2 parents)</i> <ul style="list-style-type: none"> “When do I want to hear more about it, and um- during treatment? I don’t know if I really want to hear about it. Haha, um, but afterwards, yes I want to know more about it, because I guess, when I made that first initial decision, I’ve made the decision... but then afterwards, kind of revisiting, what could possibly [happen]...” (Parent 6, F)
2. What to include?	<i>Most Likely</i> <ul style="list-style-type: none"> “I mean, I’ve read the protocol, and of course you get horrified, because this is your child, all of the late term effects that could potentially happen. What I really wanna know is statistically... with regard to my child, at her age, you know, what can you tell me about ...what are we really facing down the road?” (Parent 10, F)
	<i>Actionable</i> <ul style="list-style-type: none"> “It would be helpful to know what you could do to better your child’s chances of not getting those other side effects.” (Parent 4, F)
	<i>The impact of the treatment regimen as a whole</i> <ul style="list-style-type: none"> “But I’d like to know... with the cocktail of drugs that she got, with her current ongoing health problems... with the radiation that we’re choosing, what is she facing? What is she gonna have? Tell me what she’s gonna have.” (Parent 10, F)