



# Decision-making in childhood cancer: parents' and adolescents' views and perceptions

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## Abstract

**Purpose** Few studies have addressed the way in which families of children with cancer make treatment decisions, and how we can meet parents' and young peoples' decisional involvement needs. We aimed to explore parents' and adolescents' views and perceptions of making medical decisions in pediatric oncology.

**Methods** We conducted semi-structured interviews with 25 parents of children diagnosed with cancer in the past 12 months, and 5 adolescents diagnosed in the past 12 months. Our interview schedule was underpinned by Elwyn and Miron-Shatz's decision-making model. The model acknowledges the deliberation (process of coming to a decision) and determination (making a choice) phases of decision-making. We conducted a thematic analysis.

**Results** Our findings indicate that information provision is not enough to facilitate parents' decision-making involvement. Many parents sought additional information to meet their individual needs and preferences. While many parents and young people desired decisional involvement, they trusted the doctors to make treatment decisions. Feelings of distress, inadequacy, and lack of choice impacted decision-making participation. Regardless, many parents in our study were satisfied with treatment decisions, but this was largely dependent on positive treatment outcomes.

**Conclusion** Our study contributes to understanding how families of a child with cancer make treatment decisions. Families tend to rely on doctors to make treatment decisions, but often seek additional information to help them feel involved in the decision process. Findings highlight that decision-making in pediatric oncology should focus on involving families in the deliberation phase, rather than just determination of choice.

**Keywords** Decision-making · Pediatric · Experiences · Information · Preferences · Qualitative · Parents

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## Introduction

Families of children with cancer are often presented with more than one clear treatment path. Current guidelines in pediatric oncology recommend that physicians share developmentally relevant medical information to the child and their parent/s, so that the family can actively participate in any medical decisions [1]. Shared decision-making (SDM) involves introducing choice, describing options, and ensuring that decision-makers are well-informed [2]. In childhood cancer, SDM often occurs between healthcare professionals (HCPs) and parents, and may also extend to include the patient.

According to the Decisional Priority Model in pediatric oncology [3], parents have decisional *authority* (i.e., the legal responsibility) for their child's treatment decisions. However, at times, parents may wish to share

or relinquish decisional *priority* (i.e., the lead in the decision) with many families trusting their treating team to make the “right” decision for their child [3, 4]. Some parents may also find making a proxy decision on behalf of their child distressing, and want the HCPs to take decisional priority to alleviate that distress [4]. Based on the Decisional Priority Model, clinicians may be better placed to take decisional priority for treatment decisions that have one best option and a probable chance of cure. Conversely, families take decisional priority for treatment decisions that have no clear best choice. However, Elwyn and Miron-Shatz [5] proposed that quality decision-making comprises both a deliberation and a determination phase. The deliberation phase involves searching for and appraising information, gaining knowledge, and determining preferences. The determination phase involves making a choice based on the findings of the deliberation phase. Regardless of the type of treatment decision or decisional priority preferences, SDM is always possible.

Shared decision-making is preferred by many families and HCPs, but preferences for decision-making involvement can vary between and within families, and across decisions [6–8]. Parents also differ in their preferences for information (in regard to modality and amount), with some parents feeling overwhelmed, and others feeling that they received an insufficient amount [9–11]. Health literacy, which differs between and within families, may impact treatment information comprehension, and thus information needs and preferences [12, 13].

While guidelines encourage the involvement of young people in treatment decisions [1], determining when and how to include a child is complex [1, 3]. Many young people report wanting to be involved in treatment decisions, yet many often rely on their parents to guide the decision process and act as a mediator for information [14–16]. Parents are then responsible for informing their child, whilst balancing the potential distressing nature of disclosure [17].

In the context of cancer, there is growing evidence that involving parents and young people in treatment decision-making may improve decision satisfaction [18], and reduce risk of decisional conflict and regret [19]. However, the literature has largely focused exclusively on either information needs or decision involvement, with little research exploring the interplay between the two. A better understanding of families’ decision-making experiences, exploring both deliberation and determination processes, will inform best-practice decision-making interventions. Through a qualitative interview methodology, we aimed to explore parents’ and adolescents’ views and perceptions of the treatment decision-making process in pediatric oncology.

## Methods

### Participants

After receiving ethics approval from the Sydney Children’s Hospital (SCH) Network, we recruited participants from SCH between July 2016 and March 2018. Both parents were eligible if they had a child < 18 years, diagnosed with cancer < 12 months ago. Adolescents (> 12 years at interview) diagnosed < 12 months ago were also eligible. We identified families through the SCH database and confirmed their eligibility with the treating oncologist. Exclusion criteria included insufficient English, and families who the oncologist deemed inappropriate to contact (e.g., severe psychiatric conditions). We mailed eligible families a study invitation. We conducted three follow-up calls with participants who had not returned a consent form or opt-out card.

### Interview

We developed semi-structured interview schedules using Elwyn and Miron-Shatz’s model of quality decision-making in pediatric oncology (Supplementary Table 1) [5]. We piloted our parent and adolescent interview schedules between two authors (ER, JF), with an observer providing feedback (CW). We adapted our interview schedule until the length was appropriate to minimize burden, and to ensure rich data collection. We asked parents to elaborate on the “most difficult decision” during their child’s treatment (e.g., clinical trial enrolment); however, participants were able to share more than one decision. Adolescents completed a shorter interview addressing similar components. Following the interview, we asked participants basic demographic questions, including four items to determine information modality preferences. Two authors (ER, JF) conducted interviews face-to-face at SCH or by telephone.

### Analysis

We audio-recorded the interviews, then transcribed them verbatim. We analyzed demographic data descriptively using SPSSv23 (IBM Corp., New York). Our deductive thematic analysis, based on Spencer and Ritchie’s Framework analysis method [20], involved six steps:

1. *Familiarization with data*: ER reviewed transcripts several times.
2. *Coding structure*: Three authors (ER, BM, CW) developed an initial coding structure. Parent and adolescent data was analyzed separately.
3. *Line-by-line coding*: ER conducted line-by-line coding of interviews (NVivo, version 11, QSR International, Australia), and continually revised the coding structure

to ensure new themes were captured. BM conducted line-by-line coding on a random 20% of interviews. Given the highly structured coding tree, we had a high level of coding agreement (98.67%, 0.79 Kappa, determined by NVivo).

4. *Analytical memos*: ER wrote memos alongside the line-by-line coding to summarize main ideas and provide reflections of the data.
5. *Development of themes*: We reviewed analytical memos (ER, BM) and coding structure to identify themes. We discussed emergent themes with the authors. Development of themes occurred alongside Step 3 and 4. We used constant comparative methodology and closed recruitment once we had met theoretical data saturation (i.e., when additional data did not lead to any new themes) [21] for parent interviews ( $n = 25$ ). Given the difficulty recruiting adolescents (see limitations) and time constraints, we recruited a convenience sample. We reported the adolescent data descriptively.
6. *Validity*: ER reviewed all transcripts to determine whether the identified themes were representative of the data. ER made minor refinements to themes until they provided a clear representation of the experiences reported by participants.

## Results

We interviewed 25 parents (mean interview length = 54.6 min; SD = 15.1) and 5 adolescents (mean interview length = 17.4 min; SD = 3.5) from 23 families (family response rate = 32.1%; adolescent response rate = 46.15%). Children of participating parents were 6.9 years on average at diagnosis. Participating adolescents were 12.8 years on average at diagnosis. The most common medical decision identified by parents was clinical trial enrolment ( $n = 12$  parents). Four parents and all adolescents reported that they were not confronted with any decisions. These participants were asked to respond generally to the overall cancer experience. See Table 1.

Ten parents (40%) reported that they would have liked to receive a recording of their treatment consultations. However, some felt that the recordings would be unnecessary or would cause distress. No adolescents wanted to receive a recording. Most parents ( $n = 20$ ; 80%) and all adolescents ( $n = 5$ ; 100%) preferred their oncologist/fellow to provide them with treatment information. Parents preferred to receive both verbal and written information ( $n = 15$ ; 60%). 60% of parents ( $n = 15$ ) and adolescents ( $n = 3$ ) preferred hard-copy information rather than online. See Table 2.

**Table 1** Participant demographics

Parent demographics ( $n = 25$ )	
Mothers, $n$ (%)	23 (92%)
Mean age at interview (SD; range)	40.96 (6.98; 30–53 years)
Mean time since diagnosis	6.88 months (2.71; 1–12)
Highest level of education, $n$ (%)	
Year 12 or below	2 (8%)
University of post-graduate	20 (80%)
Other (e.g., TAFE, apprenticeship)	3 (12%)
Employment status, $n$ (%)	
Employed–full-time	7 (28%)
Employed–part-time	5 (20%)
Unemployed/full-time carer	13 (52%)
Mean child age at diagnosis (SD; range)	6.93 years (5.57; 8 months–17 years)
Male child, $n$ (%)	19 (76%)
Cancer diagnosis, $n$ (%)	
Solid	5 (20%)
Blood	13 (52%)
Brain/CNS	7 (28%)
Decision*	
Clinical trial enrolment and randomization	12 (48%)
Portacath insertion/removal	5 (20%)
Treatment commencement	4 (16%)
Fertility preservation	2 (8%)
Commencement of radiotherapy	1 (4%)
No specific decision discussed	4 (16%)
Adolescent demographics ( $n = 5$ )	
Males, $n$ (%)	4 (80%)
Mean age at interview (SD; range)	12.8 years (1.64; 11–15 years)
Mean time since diagnosis	7 months (3.24; 3–12)
Cancer diagnosis	
Solid	3 (60%)
Blood	1 (20%)
Brain/CNS	1 (20%)

For two families, both parents participated. A single asterisk indicates that parents could discuss more than one decision

## Qualitative themes for parents

We identified four main themes: (1) information overload but poor understanding, (2) information provision to meet individual needs/preferences, (3) involvement in treatment decisions, (4) decision satisfaction outcome bias (see Table 3; Fig. 1).

### Information overload but poor understanding

Most participants recalled receiving large amounts of information prior to making treatment decisions, and at times experienced “information overload.” Despite the amount of

**Table 2** Information provision preferences

Parent ( <i>n</i> = 25)		
Best person to deliver information	Oncologist or fellow	20 (80%)
	Clinical nurse consultant	6 (24%)
	Social worker	1 (4%)
	Outreach nurse	1 (4%)
Written or verbal	Both	15 (60%)
	Written	7 (28%)
	Verbal	3 (12%)
Online or hard-copy	Hard-copy	15 (60%)
	Online	5 (20%)
	No preference	5 (20%)
Informed consent consultation recording	Yes	10 (40%)
	No	12 (48%)
	Not sure	4 (16%)
Adolescent ( <i>n</i> = 5)		
Best person to deliver information	Oncologist	5 (100%)
Written or verbal	Verbal	3 (60%)
	Written	1 (20%)
	Both	1 (20%)
Online or hard-copy	Hard-copy	3 (60%)
	Both	1 (20%)
	Missing data	1 (20%)
Informed consent consultation recording	No	5 (100%)

information provided, many parents also reported that they were not well-informed, which resulted in them feeling unqualified for decisional involvement. Many parents reported feeling “quite emotional” or “shutting down” due to the large amounts of information, which meant that they felt unable to apply the information they received in their decision-making. Some parents also felt that they were unable to understand the large amount of information in the time needed to make the decision. This often caused parents to feel pressured to make a decision, resulting in a handover of decisional priority.

### Information provision to meet individual needs/preferences

**Inadequate initial information provision** Some parents reported not receiving preferred levels of information from the treating team. This made parents feel “a bit anxious” and in some cases was “traumatic” (e.g., understanding the procedure after it had been completed). Parents also reported that treatment information was often difficult to understand due to “medical jargon,” although they felt more comfortable with the medical terminology over time.

**Seeking additional information** A perceived lack of understandable information led most families to seek information

in addition to that provided by the hospital. Many families looked for information online, including searching Google™, medical journals, parent forums, and hospital websites. Most parents found additional online searches useful to obtain specific or broad/general information. However, some parents found searching for, and reading online information, distressing which further contributed to information overload. Some parents avoided searching for information online as they felt that their oncologist was available to answer their questions, or were concerned about the relevance of the information.

**Question-asking** All parents emphasized the benefit of being able to ask their treating team questions, and having them answered. Question-asking allowed parents to access more, or clarify information. Some parents acknowledged that the opportunity to ask questions, and the time the treating team provided in answering these questions, made them feel respected and cared for by the treating team. This helped parents feel part of the decision-making team, empowering them to be more involved in treatment discussions. In contrast, other parents found it difficult to ask questions. These parents reported that they did not want to cause offense to the HCPs or waste their time. They reported they “didn’t know what to ask” contributing to ongoing lack of understanding. Some parents would “readily have a list of questions,” which was based on conversations with their family members and other families on the ward. Parents reported that talking with other families of a child undergoing the same treatment was useful to understand “what was going to happen” and also provide daily support with “hospital life” which helped reduce unnecessary stress.

### Involvement in treatment decisions

**Preference for involvement, but satisfied to trust** Most parents reported wanting to be involved in the decision process, but did not elaborate on their level of preferred involvement. However, the majority of parents were satisfied to go ahead with “whatever the doctors [decided] to do” given that they trusted the treating team to do the best for their child. Some parents relied on the doctor to make the final decision because they felt “a lot of pressure” to make the “right” decision. These parents felt that trusting the treating team helped reduce this distress. Parents felt that they trusted the HCPs because they were “upfront and honest” and they took the time to explain information.

**No choice but to trust** While most parents were comfortable to transfer decisional priority, some parents felt that they did not have a choice in treatment as no alternative was presented by the treating team (e.g., a phase III clinical trial), or because they felt what they “think doesn’t really matter.” This led parents to feel that they had no choice but to trust the doctor.

**Table 3** Illustrative quotes

Theme	Illustrative quotes	Participant
Information overload but poor understanding	“We were given a lot of that information in the early days. There was just so much and I could not even think of sitting and reading it... I think sometimes you can have too much and I think - as I said at that stage we did have a lot to go through. For us I think it was probably the right level of information. I think any more would have been too overwhelming and I would not have got to reading it.”	P1: Parent of a 14-year-old
	“It required a little bit of reading... it was a little bit difficult to concentrate on such lengthy documents.”	P2: Parent of a 3-year-old
	“Then she started rattling off these few things about treatment, and whatever. I do not know, I suppose it went a bit over our heads, really, because it all had happened so fast... So really, I mean, while we knew what was happening, we probably did not absorb a lot of the details at that stage.”	P3: Parent of a 17-year-old
	“We were not asked to make a decision, we were told it had to happen. When we were told that it had to happen, I did not even really know what it was. But at that stage too, it was information overload. There was just so much going on. He was having lots of baseline testing. I think we were in a world of hurt. Yeah, maybe we - there was some information that fell through the cracks there, but that’s just how I felt about it at the time.”	P4: Parent of a 16-year-old
Information provision to meet individual needs/preferences	“I have not suppose it went a bit over our heads it... it’s quicker for me to Google, and look up on the internet than what it is to go through one of those novels.”	P5: Parent of a 3-year-old
	“I found that quite stressful, bringing up - asking those questions because I did not want to offend anyone by asking, and that took quite a bit of my courage”	P6: Parent of a 6-year-old
	“Information leads to questions, and questions leads to more information, being more informed, removing more stress and making it easier.”	P7: Parent of a 6-year-old
	“I have got an 11-year-old with brain cancer, you cannot possibly take everything in. It’s not possible, it’s a lot of new information. I remember saying to one of the doctors, I do not want to know about the side effects of chemo yet. Like we are only just up to radiation, I really do not want to know that yet. Yeah, so I did not want to know everything. But at the same time, I think some of the doctors found that a little bit difficult because they needed informed consent...they were very, very, very good at trying to feed me the information that I needed when I was really, really resistant to that.”	P8: Parent of a 12-year-old
	“I tended just to trust more what I was told or do a bit of googling and get specific on just - even if they’d given us a sheet just on the type of tumor Patrick had, rather than a book of every brain tumor that exists in children. Would have been a lot more effective I think.”	P9: Parent of a 1-year-old
Involvement in treatment decisions	“Every decision that we have made along the way, it was a decision made with the help of the doctors and other medical staff. Because we do not have any background, we do not have any knowledge. We were totally relying on them to give us options, but then put forward what the best options is.”	P10: Parent of a 2-year-old
	“I think taking the information in took weeks rather than - and because it was critical to make the decisions about his treatment and stuff, we were led by the team, as opposed to what we were reading.” – P1: Parent of a 14 year old	P1: Parent of a 14-year-old
	“I think small decisions, he should be given options... Every child should be given every opportunity to understand exactly what’s happening to them... In the end that was really hard because I thought he should be told all the things about what was going to happen, and I realized in the end that being told all those things was adding to his distress, at times.”	P6: Parent of a 6-year-old
	“I guess you kind of feel a bit intimidated because it’s not your area of strength and expertise and knowledge. You kind of feel well, I have to go along with what they say because they know. I do not.”	P5: Parent of a 3-year-old
	“I feel a lack of in-depth knowledge, but I do not know that that is required. I think the - no I am not going to say that. I think more education would be helpful, so that would be the only thing. Because I really find often that I have to approach things just with acceptance	P11: Parent of a 12-year-old

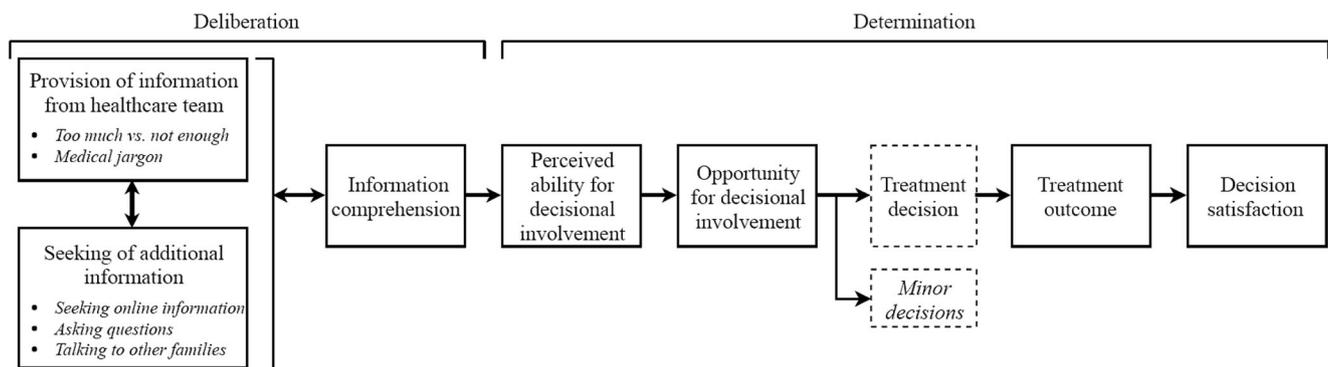
**Table 3** (continued)

Theme	Illustrative quotes	Participant
	rather than - because I really do not have a deep understanding of a lot of these issues. So my questioning is reasonably limited.”	
	“That meeting was lengthy, it was thorough, it was - we had every opportunity to ask questions and we had every opportunity to prepare prior for what questions we wanted to ask. We were provided written information about the drugs and the risks. That was all very thoroughly explained. There were some options - so there were some choices around that, but we were very much guided by our [oncologist] and his recommendations. He went to great lengths to explain why he was recommending that - that we go down that path... I think having that meeting and that conversation - being provided that information, having the opportunity to ask all of those questions, we just felt - we just had a lot of confidence from that point about the fact - we just felt that we were in the right place.”	P4: Parent of a 16-year-old
Decision satisfaction outcome bias	“We were desperately worried that she seemed in such terrible condition that they were starting it [chemotherapy] so early... I suppose thank god we did not have any say in it - but had we had any say we would have asked them to hold off the earlier rounds to try and let her recover from her operation and things. But [oncologist] wanted it going ahead and as it turned out he was right... So I am glad we did not have a choice.”	P12: Parent of a 12-year-old
	“I still firmly believe it was the right decision. In hindsight he responded well and achieved a remission in about 12 days from initiation, so it’s gone really, really well and it looks like that protocol was right.”	P13: Parent of a 3-year-old
	“I feel 90 per cent comfortable. I think, ultimately, you are often faced with situations in life where you have to make very tough decisions. Once you have come to a decision you need to accept it. . . I may feel differently if he had a relapse in two years’ time. I may unwittingly have my mind track back to that decision and think oh, what if, but I try not to think that way.”	P14: Parent of an 8-month-old
	“Well he’s in remission and we cannot ask for any more than that.”	P3: Parent of a 17-year-old

Quotes have been obtained from both mothers and fathers. Parental role/gender has not been specified to ensure quotes are de-identified

Some parents reported not engaging in the decision process (e.g., not listening to conversations) because they felt they had no control over the situation regardless of their views. A few parents expressed frustration with this, but the majority were accepting of not being involved in the decision as the treating team had the “experience and knowledge behind them.”

**Role of minor decisions** Many parents reported that their child had little involvement in their treatment decisions. Parents highlighted that involving their child in minor decisions was a way to give their child some control. Minor decisions were described as those that “had the same outcome but with different, or varying options” (e.g., choosing medication flavor).



\*Distress plays a role throughout each stage of the deliberation and determination phase

**Fig. 1** Overview of study findings

Parents felt that it was “really important that each patient has a voice.” Other parents did not want to involve their child in any discussions or decisions as they felt that their child “just doesn’t have the capacity” to understand or manage the emotional impact of the information. Some parents experienced difficulty in balancing informing their child about their treatment/disease whilst protecting them from distress.

### Decision satisfaction outcome bias

Parents indicated that regardless of their involvement in the decision process, if their child’s treatment outcome was positive (e.g., remission), they were satisfied with their treatment decision. Some parents initially felt “unsure” or “anxious” about the treatment decision, but in hindsight felt “grateful” for the decision that they/the treating team made. A few parents avoided thinking about the decision after it had been made, reporting that it was “better to accept it and move on.”

### Adolescent decision-making experiences

Despite extensive probing, we were unable to obtain rich data from adolescents: ER: “What were your thoughts about the clinical trial?” A1 (12 years old): “I thought it would be pretty cool to try it” (see limitations). Most adolescents reported that they understood content well, but also reported either not remembering details about their treatment or feeling “a bit confused [with] all this scientific language” (A2: 13 years old). As one adolescent said, “I understood what they were doing, but not necessarily what it was for” (A3: 15 years old). In contrast to parents, adolescents did not recall receiving information in written form; however, they were satisfied with the level of information they received and did not tend to seek additional information.

Adolescents stated that they went along with the doctors or their parents: “I just go with the flow. I’m a really - I’ll pay attention here and there, but other than that I’ll just switch off and just let them sort it out with mum” (A4: 15 years old). Adolescents still wanted to be informed about what was happening and appreciated when the doctors talked directly to them: “I reckon it’s better when we talk about it together” (A1). However, they did not report expressing their thoughts to the treating team or their parents regarding treatment. When adolescents had questions, they tended to ask their parents. Adolescents seemed satisfied with treatment decisions mainly because they thought it was the best option for them, or because it helped other people.

## Discussion

We conducted a qualitative analysis of parents’ and adolescents’ experiences of decision-making in pediatric oncology.

Our findings suggest a modified and expanded conceptualization of decision-making, based on Elwyn and Miron-Shatz’s model [5] (Fig. 1). Our model adds to the original by highlighting the interplay between information provision, comprehension, and seeking of additional information. It also acknowledges the importance of both the perceived ability and opportunity to participate in the decision process. While Elwyn and Miron-Shatz hypothesize that decisions cannot be measured by reference to their outcomes [5], our study finds that this is indeed what many parents base their decision satisfaction on. This reliance on positive outcomes for decision satisfaction emphasizes the need to delineate the nuances in the deliberation process for families of a child diagnosed with cancer.

Based on participant responses, information provision is not enough to ensure involvement in the decision process. Previous research has also shown that parents of children with cancer experience dissatisfaction with the quality/amount of information provided by the hospital [9, 22]. Our findings mirror past research which has found that many parents supplement the doctor’s information with online information [23, 24]. Adolescents in our study also experienced difficulties in understanding/recalling treatment information. This may be due to their reported lack of written information provided, also noted in previous research [25]. Access to high-quality information, including evidence-based online resources [26], for both parents and adolescents is necessary to engage in the decision process [27]. Interventions focusing on facilitating adolescent patient knowledge is especially crucial for decisions such as clinical trials, where a lack of understanding is a key challenge to enrolment [28].

Ensuring families are satisfied with the amount of information they receive and their level of decisional involvement is important as dissatisfaction may play a role in decision regret [19], and may be a deterrent for involvement, as suggested by parents in our study. However, there is a lack of evidence-based recommendations for effective delivery of information to families of children diagnosed with cancer [29]. Common across the literature however is the recommendation for information needs to be determined at multiple time points, with information tailored to preferences [10, 30], and balanced with informed consent requirements [10].

Our families reported feeling pressured to make a decision, which contributed to their distress. High levels of distress led to parents feeling incapable of participating in the decision process, which has also been noted in previous research [31]. As outlined by the Yerkes-Dodson law, high arousal (e.g., high distress) may result in poor performance of difficult cognitive tasks (e.g., comprehending complex information) [32]. Without reducing distress, it may not be possible for parents to comprehend information, regardless of the quality or amount that they are provided with. Improved psychosocial support and adequate time to deliberate is necessary to facilitate families’ involvement in decisions.

Parents in our study reported the benefit of question-asking, which has been noted in previous research in early-phase clinical trials [33]. In adult oncology, question prompt lists (QPLs; structured lists of common questions) can increase patient question-asking and facilitate discussions [34]. Providing QPLs for parents may empower families to ask questions and result in fewer misunderstandings [35]. Future research should evaluate the feasibility and efficacy of QPLs in pediatric oncology.

In regard to decision-making determination, our findings indicate that parents want to be involved in their child's treatment decisions, but are satisfied to handover decisional priority as they trust their oncologist. Trust in the oncologist is beneficial when the clinician appropriately assumes decisional priority [3]. Forcing parents to take decisional priority in these scenarios may be unnecessary and result in moral distress for the HCPs—when the clinician is compelled to provide medical care that he/she does not believe is in the patients' best interests [36]. Alternatively, trust in the treating team to make decisions that have no clear best option and are values-based may not be constructive for decision satisfaction [3]. Families who are reluctant to engage in values-based decisions may require further support, but should also be respected if their true preference is for the doctor to take decisional priority. Forcing families to participate in decisions that they do not feel equipped to make may cause distress [37]. Determining individual preferences and capability for decisional involvement, at each major decision point, and supporting families to meet their preferred levels of involvement, is critical to improve quality-of-care [10].

Adolescents in our study tended to rely on their parents and doctor to make decisions, but also want to be informed. Previous research has found similar results [38, 39], but also that many adolescents prefer to take a more active role in decisions [16], including for complex decisions such as clinical trial enrolment [40]. Our findings may differ due to the small sample, and younger average age of participating adolescents. Involving young people in minor decisions may be useful way to facilitate their involvement, as highlighted in our study. Previous literature has acknowledged the role of minor decisions for young people in providing a sense of control [38]. Healthcare professionals and parents should consider providing adolescents with opportunities for minor decisions where possible. The process of obtaining assent for clinical trials may also be beneficial across other cancer treatment/medical decisions to facilitate supportive collaboration with parents [41].

Most parents in our study experienced outcome bias—they were satisfied with the decisions that were made during their child's treatment, but that satisfaction was based on positive treatment outcomes (e.g., remission), rather than any internal certainty it was the “right decision” or the quality of the

decision process (e.g., feeling well-informed). This raises concerns for parents whose child has poor outcomes (e.g., relapse). These parents may be at risk for experiencing high distress, lower quality-of-life and dissatisfaction with the healthcare system as seen with women deciding on early breast cancer treatment [42]. Encouraging parents to make values-concordant decisions in conjunction with being better informed may safeguard families against poor decision satisfaction [43].

## Limitations

The small number of adolescents with cancer at SCH limited the recruitment. It was also difficult to elicit in-depth experiences from the young people, which has been noted in previous research [44]. This may be a reflection of their developmental stage, clarity of questions, feeling uncomfortable to open up, or an indication that they were not typically involved in treatment decisions. Piloting interview schedules with adolescent recently diagnosed with cancer (if this were feasible) may have improved our ability to capture in-depth responses.

We recruited mainly highly educated, English-speaking, mothers, from only one hospital. Decision-making experiences may differ significantly with culturally and linguistically diverse populations. Recruiting mainly mothers is common across psycho-oncology research [45], and may be indicative of mothers being the main decision-maker for their child. We did not differentiate between types of decisions; however, we did not identify any clear thematic differences by decision type in our analysis.

## Conclusion

Our findings suggest that SDM in pediatric oncology should focus on involving parents and young people in the deliberation phase, rather than specifically on determination of choice. Families may need more psychosocial support to manage their distress when making decisions. Both parents and young people may benefit from improved quality of written information (including online), and QPLs to facilitate communication. Future research should also consider the use of values clarification exercises to reduce the risk of poor decision satisfaction.

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## Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Control of the data** The authors have full control of all primary data and agree to allow the journal to review it if requested.

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