Parent Perspectives on Information-seeking, Trustworthiness, and Decision-making in High-risk Neuroblastoma

Katherine Brown, BASc,† Shelly Benjaminy, PhD,‡§ Judy Illes, PhD,†‖ and Rebecca J. Deyell, MD, FRCPC¶#*

Background: This study explores how parents of children with high-risk neuroblastoma incorporate information from multiple sources into treatment decision-making for their children as they evaluate the trustworthiness of the sources.

Methods: Following ethics board approval, parents of children with high-risk neuroblastoma were recruited through purposive sampling from a tertiary care pediatric oncology program in Vancouver, BC, Canada. Participants completed an in-depth, semistructured interview with a study member. The qualitative descriptive methodology was utilized to code interview transcripts and identify emergent themes.

Results: Nine parents of children with high-risk neuroblastoma during upfront therapy (n = 4) or treatment of refractory disease (n = 5) were included. Despite almost universal access of web-based information, parents acknowledged distrust in the reliability and consistency of these sources. Open communication between parents and physicians about sources of information outside the clinic and access to regulated, accurate information is highly valued. The impact on the quality of life and the costs, both financial and personal, of travel are key factors in decision-making.

Discussion: Health care providers shoulder an immense responsibility to augment and contextualize information available about high-risk neuroblastoma for parents to maximize benefit in decision-making. Health care providers should guide access to accurate, evidence-based resources that can be monitored and continuously updated.

Key Words: neuroblastoma, decision-making, trust, information sources

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Neuroblastoma is the most common extracranial solid tumor of infancy and remains among the most frequent causes of cancer-related death in children.[1] Despite an intensive and multimodal upfront approach to therapy, overall survival for high-risk neuroblastoma remains ~50%, and cure is unlikely following relapse.[2,3] Initial therapy for high-risk neuroblastoma is challenging for families and patients as it involves multiple rounds of cytotoxic chemotherapy, surgery, tandem myeloablative chemotherapy with autologous stem cell rescue, radiation therapy, and anti-GD2 immunotherapy in maintenance.[3–6] Despite this, a group of children have primary refractory disease and alternative approaches to therapy are considered early in the disease trajectory. Similarly, at relapse, there is no standard roadmap that is recommended for all children and providers may consider the availability of a variety of options, which include anti-GD2 chemo-immunotherapy regimens, targeted iodine-131 meta-iodobenzylguanidine therapy, conventional chemotherapy relapse regimens, early phase clinical trials, supportive care approaches or alternative medicine.[7,8] Each option carries differing risks of toxicity, efficacy, and availability depending on the primary treatment site and health care system. Some children and adolescents have an indolent postrelapse course, allowing parents, patients, and providers to explore multiple second-line therapies with the hope of achieving disease control and improving quality of life.

Parents seek information on both the complex, standard upfront approach to high-risk neuroblastoma therapy in addition to alternative approaches if upfront therapies fail. Treatment decisions at relapse, progression, or for the primary refractory disease are even more complex and may include a variety of early phase trials offered through a range of consortia, including the New Approaches to Neuroblastoma Therapy consortium, along with others. The goal of early phase trials is to determine the safe pediatric dose of a regimen, assess for toxicity, and to get the first signals of efficacy. In addition, participation may not be covered by health insurers and may require participants to relocate to a treatment center, further complicating the challenges in the choice of care.[9]

Shared decision-making is a common practice within pediatric oncology. Allowing parents to take on the role they prefer throughout the decision-making process can lead to decreased anxiety, although parents who take on an overly active role are at higher risk of developing decisional regret later in their child's treatment.[10] With ever-evolving therapeutic and investigational opportunities, parents of children with cancer engage in a wide range of information-seeking activities to make health care decisions and gain a sense of control over the illness.[11] However, the complexity, heterogeneity, and variable quality of available information can be overwhelming.[12] To further complicate matters, parents of children with neuroblastoma must often act quickly after their child's diagnosis or following news of a relapse.

These challenges exist in the face of widely accessible but unregulated information resources that may confuse or

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From the *School of Population and Public Health; †Neuroethics Canada; ‖Department of Medicine, Division of Neurology; ¶Department of Pediatrics, Division of Pediatric Hematology/Oncology/BMT, University of British Columbia; #British Columbia Children's Hospital and Research Institute, Vancouver, BC, Canada; ‡Shirley Ryan AbilityLab; and §Feinberg School of Medicine, Northwestern University, Chicago, IL.

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Reprints: Rebecca J. Deyell, MD, FRCPC, Division of Pediatric Hematology Oncology, BC Children's Hospital, University of British Columbia, B315—4480 Oak Street, Vancouver, BC, Canada V6H 3V4 (e-mail: rdeyell@cw.bc.ca).

mislead parents about therapy options that carry risks without the possibility of reasonable hope of direct medical benefits.[13–17] It is a well-known phenomenon that information on the Internet is of highly variable quality.[18–20] Trustworthiness incorporates a belief in the reliability, accuracy, and truthfulness of information sources and also comes into play as parents of children evaluate the sources of information that they find and integrate them into their decision-making analyses.[12] In addition, for treatment decisions that are associated with uncertain outcomes, such as in treatment for high-risk neuroblastoma, "trust requires a leap of faith leaving decision-makers particularly vulnerable."[20] To our knowledge, while researchers have explored the end-of-life treatment decisions for children with neuroblastoma,[21] no prior study has examined how families of children with neuroblastoma utilize and integrate information from providers, the media, and other sources for the care of their children.

METHODS

Recruitment

Participants were recruited through purposive sampling from a pediatric oncology program at British Columbia Children's Hospital (BCCH) in Vancouver, BC, Canada, during the 4-year period between 2014 and 2018. This is the only tertiary care pediatric center in the province and providers assess and diagnose ~140 to 150 new oncology patients annually, of which there are an estimated 4 to 5 new diagnoses of high-risk neuroblastoma. The program also follows patients with relapsed or refractory neuroblastoma and manages their care. As a medium-sized Canadian center, several early phase clinical trials are available locally, but the care of this patient group may include out-of-province or out-of-country referral for high-dose iodine-131 metaiodobenzylguanidine therapy, proton radiotherapy, and certain early phase clinical trials.

Parents were eligible for an interview if they were English speaking adults (19 y and above) whose child had been diagnosed with high-risk neuroblastoma for at least 1 month, was alive in follow-up, had received therapy within the past 3 years, and had either (1) only received high-risk upfront therapy since diagnosis (upfront therapy) or (2) had received therapy for relapsed, progressive or refractory disease (relapsed/refractory). Both parents were eligible to participate.

Following ethics approval from the University of British Columbia Research Ethics Board (H13-02659), patients treated for high-risk neuroblastoma within the prior 3 years at BCCH were identified. Parents were approached either by hardcopy letter or in-person at the clinic following approval from their treating oncologist.

Interviews

Individual study team members conducted a series of in-depth semistructured interviews with research participants. Interviews were completed individually between a parent and a researcher over the phone or in-person and audio recorded. The interview guide was constructed to address 3 overarching questions:

(1) What information sources do parents draw upon to make treatment decisions for their children (media, specific Internet sites, health care providers, parent support groups)?
(2) How do parents gauge the trustworthiness of information and information sources?
(3) How do parents integrate information into their decision-making for treatment options?

Data Analysis

A third-party transcription company transcribed recordings verbatim, and team members verified for accuracy and made transcripts software-ready for analysis in NVIVO 12 (QSR International). Using qualitative descriptive methods, we developed an initial codebook that reflected emerging trends and themes throughout the data set.[22] One study member conducted all initial coding. Primary coding was done line by line and then reviewed across transcripts using the constant comparative approached to identify emergent phenomena.[23] Authors then organized the primary codes into major themes and subthemes to form a codebook that reflected the hierarchy of themes in the narrative. The coders identified major themes based on frequency and relevance to the research questions. Coding was completed concurrently with data collection, which allowed researchers to ensure theoretical saturation was reached before closing recruitment.[23] The final codebook consisted of 4 major themes and 13 subthemes. To ensure the dependability of the codebook, the 2 trained study members independently coded 20% of the interviews. Statistical analysis of intercoder reliability yielded a Cohen κ coefficient of 0.86, indicating substantial intercoder agreement.[24]

RESULTS

Nine parents of 9 children agreed to take part in the study, of which 4 were in the upfront therapy group and 5 had the primary refractory disease (Tables 1, 2). Interviews were 20 to 140 minutes long. A total of 6 hours of audio data were recorded. None of the parents interviewed had a child who had experienced a relapse following a period of remission.

Following an iterative analysis, 4 dominant themes emerged from the data based both on the frequency of occurrence and presence over multiple interviews: (1) information-seeking motivators and deterrents; (2) information sources; (3) trustworthiness; (4) other considerations (Table 3).

TABLE 1. Characteristics of Children Whose Parent Participated in the Study

Characteristics	No. Participants, n (%)
Sex	
Male	8 (89)
Female	1 (11)
Age at diagnosis (y)	
4-18 mo	2 (22)
19 mo to 5 y	3 (33)
> 5 y	4 (44)
Age at interview	
4-18 mo	2 (22)
19 mo to 5 y	3 (33)
> 5 y	4 (44)
Diagnosis	
New diagnosis	4 (44)
Refractory	5 (56)
Length of treatment at the time of interview	
4-8 mo	4 (44)
9 mo to 1 y	2 (22)
> 1 y	3 (33)
Received treatment at > 1 institution	
Yes	4 (44)
No	4 (44)
Undisclosed	1 (11)

TABLE 2. Participant Characteristics (N = 9)

Characteristics	No. Participants, n (%)
Age (y)	
20-30	1 (11)
31-40	5 (56)
41-50	2 (22)
Undisclosed	1 (11)
Sex	
Female	5 (56)
Male	4 (44)
Marital status	
Married	7 (78)
Common law	1 (11)
Separated	1 (11)
Highest level of education completed	
High school	4 (44)
College	1 (11)
University	2 (22)
Postgraduate	2 (22)

Information-seeking Motivators and Deterrents

Participants spoke of the need to understand treatment options for high-risk neuroblastoma as well as the importance of understanding the treatment recommended for their child. To achieve this goal, parents engaged in research during critical time points during their child's course of treatment, including before or after a child's medical appointments or when treatment was not effective.

I always wanted to know, okay if it's stable then we do this. If it's worse, we would do that. If it's … improved, obviously we continue. So, for that, then it was more frequent, the research because at every point I wanted to make sure I was either a step ahead or with the doctors, I knew what to ask….

—Participant 1

While many parents reported that they wanted to stay informed about their child's care, others reported that they did not seek information outside of the oncology clinic in an effort to avoid negative or conflicting information. This included strategically avoiding information on the web as well as interactions with other parents of children with poor prognoses. Multiple families mentioned awareness of online parent groups, but also that they avoided reading specific stories of children with similar diagnoses because it was too emotionally challenging.

But emotionally, it was too much for me to look at it, and I didn't want to know about these kids that had been going with treatment for years of chemo that weren't responding: I didn't want to hear—I didn't want to know the bad side of it. And I like to stay on the positive … so I don't look [at information outside the clinic] because I don't want to know it.

—Participant 8

Information Sources

Participants described the use of online resources such as returns from Google searches or popular disease-specific websites in their search for information. Other parents reported turning to their child's oncologist for information about disease progression and treatment options. Of the parents who used the Internet to find information about their child's treatment, many parents discussed their findings with their child's oncologist.

… if we come across something and we try and dig into it … try to do as much work as we can to educate ourselves about what may be worth bringing up with our oncologist. And the next time we see her, we would bring it up and just for her opinion on it, if she had come across it or whatnot.

—Participant 6

Trustworthiness

While almost all participants stated that they used the Internet in some capacity while searching for information, parents also reported a deep distrust of the information they found online. Participants explained that while online information is accessible, it is often inconsistent and unreliable. Others based their trust in the reputation of the information provider.

Because you can get into different pages, different research. They always change a little bit and sometimes the change is big for me. So, I don't think they have stable information.

—Participant 2

I mean you can Google and a ton of stuff comes up but unless it's from a well-known organization … you kind of read it and file it away.

—Participant 8

Many of the parents who reported that their oncologist was their main source of information grounded trust in their qualifications.

We agree mostly with the fact that the doctors are experts in this situation, and we let them … guide us in the right direction.

—Participant 8

Other Considerations—Cost

Parents must not only consider the trustworthiness of the information they found, but they must also account for the cost of travel, the cost of various treatments, as well as access to and the potential risks and side effects of the medications or trials, offered:

[…] everything's sort of … clinical trial when it comes to kids, which is unfortunate right? And there's not really much in Canada compared to the States, right? So that's sort of frustrating….

—Participant 5

Despite the cost of travel and treatment, many parents spoke of an ongoing determination to be able to provide an opportunity that would promote their child's best chance at survival.

I think that there are always going to be financial issues there. But nothing will stop us to follow the treatment. I think if I have to walk from here to there, I will do it, if I have to cross the border, I have to do it, right? So, I'm focused on doing what I have to do every day with him.

—Participant 2

It was seven weeks away from home, so it was difficult—we have two other children so that was complicated as well, and my husband getting time off work at the right time and just scheduling it and organizing ourselves to be away for that long.

—Participant 9

TABLE 3. Emergent Themes

Themes and Subthemes	Description	Quotations
Information-seeking	Factors that influence information-seeking behaviors	
Clarification/understanding		"Most times I look for information after the visits with the doctor." —Participant 4
Decision-making		"When they told us that it wasn't responding to chemo … that's when I really start doing research …." —Participant 3
Avoiding bad news/avoiding other stories of others		"Most of the information on the internet about the neuroblastoma, especially stage four, is very scary. … I just try not to read them, or if I read by accident, I try not to believe them." —Participant 6
Information sources	Resources used	
Health care provider		"… we do talk with our oncologist and … about different options and stuff, because she's in touch with other oncologists across Canada and the U.S." —Participant 2
Hospital		"In the beginning, there was [sic] some resources that the hospital suggested and some other stuff that we had looked at the beginning…." —Participant 6
Internet		"… health sites… I try to look … the doctors and nurses gave us other sites that you can look at." —Participant 4
Trustworthiness	Factors that influence trust in information sources	
Health care provider		"… mostly we go with whatever she [oncologist] says is the best option. If we came to a point where even, you know if 'doctor' said these are your options, you need to decide kind of a thing, we would still ask for 'doctors' input on what was best." —Participant 4
Hospital		"… the major hospitals and the major research centers … those I trust more." —Participant 9
Internet		"I don't think that the internet is the most reliable …." —Participant 7
Other considerations	Factors that parents consider for treatment decisions for their child	
Financial barriers to care		"… you're giving me a glimmer of hope, but that's basically going to cost me $300,000 …." —Participant 5
Geographical barriers to care		"I wish it was all available close by, but obviously, that's not possible for everything." —Participant 9
Child's quality of life		"… I would say that the type of decision that would be very difficult as a parent to make for a treatment that could significantly compromise the quality of life … we've tried to focus on that quality of life but recognizing there may also need to be an element of risk, let's call it, that needs to be taken to try and help get him to where he needs to be." —Participant 6
Side effects of medication/ treatment		"… when I'm looking at the side effects, that's a big thing for me. I remember being so upset thinking they might not be able to have kids after some chemo. And now that matters a little less to me when I think about just keeping them." —Participant 1

[…] it definitely sucks being away from home for that long because my husband was at home working, my husband had to work, I had to stop working and pretty much just base my life around the hospital. We were only able to come home once a week so I was by myself in Vancouver for that time. It's hard, but you just have to do it, I mean there's no other—there's nothing around here to do treatments or anything right, like the closest place was Vancouver so we had to make it work.

—Participant 7

DISCUSSION

The results of the present study largely reaffirm that parents engage in information-seeking behaviors with the hope of understanding the options for their child's treatment, allowing them to take on an active role in the decision-making process.[25] This is consistent with previous reports reflecting the complex nature of decisions that health care providers and parents must confront during neuroblastoma treatment.[26] Past research surrounding parents' decision-making in pediatric oncology has shown

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the importance of access to trustworthy information for these decisions.[27–29]

Stewart et al,[29] for example, found that the level of trust a parent placed on their child's physician played a significant role in determining how involved the parent wanted to be in the treatment decision-making process. Mack et al[21] underscored the importance of the parent role in decision-making when they discovered that parents who had a more passive role than they wanted were less likely to trust their physician's decision. The results of the current study indicate that parents value a trusting relationship with their health care providers, and this relationship enables them to bring up information they found from other information sources, including the Internet.[11,18–20,30,31] This result stands in contrast with the scholarship that demonstrated variable practices about discussing information found online with health care professionals.[32]

While participants noted the accessibility and ease of online information gathering, many in the present study also spoke of deep distrust of the information they found on the Internet. Indeed, parents were discerning about the quality of online information. As such, they weighed the quality of the information against their own experiences, the information provided by their health care provider, and evaluated the reputation of sources of information found on the web. These critical perspectives about the rigor and quality of health information online are reported by others.[33,34]

While some participants described a need to immerse themselves in online information-seeking to cultivate the necessary expertise to make medical decisions for their children with neuroblastoma, others were deterred from seeking information as they did not want to be reminded of the high rates of a fatal outcome for children with neuroblastoma. The phenomenon of "fear-based information filtering" is described by Gage and Panagakis,[12] and serves as a protective mechanism for parents who wish to remain positive about their child's prognosis. Indeed, Gage and Panagakis found that the majority of parents who describe avoiding online information gathering report that their oncologists recommended that they do not conduct Internet searches about their child's diagnosis. In the future, exploration of what drives parents to seek information through multiple sources and to self-educate, including new possibilities through online support groups, will lead to the improvement of resources that are even more beneficial than those available today.

Finally, this study also sheds light on the trade-offs that parents of children with cancer must weigh as they integrate information from diverse sources into their decision-making analyses about treatment. Many spoke of the personal and financial costs associated with traveling for treatment, while simultaneously expressing a willingness to sacrifice whatever necessary to obtain the best care.

This was a study with a small sample size that took place over a 4-year period of time over which there was some evolution in standard and innovative approaches to high-risk neuroblastoma therapy. Of note, tandem high-dose myeloablative chemotherapy and autologous stem cell rescue became a standard approach in North America, as did the use of anti-GD2 chemoimmunotherapy in the relapsed or refractory setting.[5,8] Both of these therapies are intensive, require additional inpatient time, and carry significant risks of toxicity. It is likely that information sources found online varied over the time period of the study in conjunction with the evolution of therapy and new trial options. The data did not segregate by participant characteristics including whether participants' children were newly diagnosed or had refractory disease. Such trends may be masked by the limited sample. It is also important to consider that this study only included participants from 1 Canadian center where access to information and treatment options may have been similar.

The interview venue and external scheduling constraints may have contributed to the variability of interview lengths. To accommodate participant preferences and schedules, study interviews were offered in-person at the oncology clinic or remotely by telephone. Some interviews were limited in length as they were conducted between children's busy schedules at the clinic. A number of telephone interviews that were scheduled in the evenings offered a greater time window for discussion. In the qualitative analysis, we took this variability into account by assuring that themes repeated by one person were only accounted for as a single occurrence. The results, therefore, are cross-cutting and not dominated by any one participant.

Both the small sample and long study timeframe speak to the difficulty of recruiting for psychosocial studies in oncology such as this one, particularly as parents carry the burden of care for their children with cancer and are actively engaged with critical treatment decisions.[35,36] Interestingly, all patients in our relapsed/refractory cohort had primary refractory disease, possibly due to the small sample size. These patients underwent a range of second-line and third-line treatment strategies and although their experiences navigating treatment were rich, they may differ from those of a patient who first achieves response and later relapses. Though children with neuroblastoma are often young, it is also important to recognize that children as young as 2 years may also be important participants in decision-making in relation to their care.[37] As in most qualitative studies, the methods here aimed to explore for depth rather than breadth of perspective. We recognize that while studies such as this cannot be said to be generalizable, results hold value through their transferability and confirmability.[22]

Pediatric oncologists and nurse clinicians are uniquely positioned and trusted to help parents access information about treatment decisions for their children with neuroblastoma. Although pediatric oncologists, nurses, and others on the child's care team routinely provide families with cancer-care handbooks and trustworthy information sources including web-based resources, families also obtain additional information from a vast array of other variable-quality resources, including social media. These extended online resources, often characterized by testimonies and personal stories, may have a strong influence that conflates the information provided in the clinical encounter and recommended resources. In the face of the extreme burden that high-risk neuroblastoma places on the affected patients and families, access to trusted, evidence-based resources are essential. Future prospective parent/patient and health care provider evaluation of available information resources should inform the development of accessible, accurate, and comprehensive tools that address therapeutics, clinical trials, and patient-centered supports within a health care setting. Collaborations between patient and parent advocacy groups and health care professionals are uniquely positioned to inform and create trusted information sources that must be kept up to date in the rapidly evolving world of pediatric oncology care.

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