

Original Article

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Communicating with families of young people with hard-to-treat cancers: Healthcare professionals' perspectives on challenges, skills, and training

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Abstract

Objectives. Hard-to-treat childhood cancers are those where standard treatment options do not exist and the prognosis is poor. Healthcare professionals (HCPs) are responsible for communicating with families about prognosis and complex experimental treatments. We aimed to identify HCPs' key challenges and skills required when communicating with families about hard-to-treat cancers and their perceptions of communication-related training.

Methods. We interviewed Australian HCPs who had direct responsibilities in managing children/adolescents with hard-to-treat cancer within the past 24 months. Interviews were analyzed using qualitative content analysis.

Results. We interviewed 10 oncologists, 7 nurses, and 3 social workers. HCPs identified several challenges for communication with families including: balancing information provision while maintaining realistic hope; managing their own uncertainty; and nurses and social workers being underutilized during conversations with families, despite widespread preferences for multidisciplinary teamwork. HCPs perceived that making themselves available to families, empowering them to ask questions, and repeating information helped to establish and maintain trusting relationships with families. Half the HCPs reported receiving no formal training for communicating prognosis and treatment options with families of children with hard-to-treat cancers. Nurses, social workers, and less experienced oncologists supported the development of communication training resources, more so than more experienced oncologists.

Significance of results. Resources are needed which support HCPs to communicate with families of children with hard-to-treat cancers. Such resources may be particularly beneficial for junior oncologists and other HCPs during their training, and they should aim to prepare them for common challenges and foster greater multidisciplinary collaboration.

Introduction

There have been significant improvements in treatments for childhood cancer, with 5-year survival rates increasing to over 80% in high-income countries (Youlden *et al.* 2022). However, survival for some cancers, including high-grade gliomas and relapsed sarcomas, has not improved over the past 40 years (Youlden *et al.* 2022). These “hard-to-treat” cancers are the most aggressive of all cancers, and, sadly, available treatments often do not work for most children (Youlden *et al.* 2022). For example, diffuse midline gliomas are the most common childhood high-grade gliomas, and almost all children die within an average of 12 months after receiving this diagnosis (Bartels *et al.* 2011). For diagnoses where there are no standard treatments available, patients may be offered an experimental treatment through an early-phase clinical trial or through precision medicine pathways. However, the primary intent of early-phase clinical trials is not curative. The primary aim of Phase 1 trials, for example, is to assess the safety and maximum-tolerated dose of novel drugs and therapies (Berg 2007; Hazen *et al.* 2015; Robertson *et al.* 2019). While many children with very high-risk cancers will have clinical benefits from precision-guided therapies, ultimately, for most patients, these treatments are not curative in the long term.

Therefore, alongside any experimental treatments, children may also be offered palliative care to address the physical and psychosocial difficulties that occur alongside cancer-directed treatment.

Healthcare professionals (HCPs) working with children with hard-to-treat cancers are responsible for delivering news of the poor prognosis to families and are required to provide unbiased information and support to families when there may be limited evidence available (Mack and Joffe 2014). Communication with the family about prognosis and treatment options is typically led by the oncologist and supported by other HCPs, including nurses and social workers (Jones et al. 2018). Effective communication in oncology requires the exchange of information to enable decision-making, build rapport with families, manage uncertainty, and provide emotional support and validation (Sisk et al. 2020, 2018). However, research suggests that there are often gaps in communication (Sisk et al. 2020), and parents often report insufficient communication about prognosis (Kaye and Mack 2013).

A common struggle for HCPs in this field is in balancing honesty about the child's condition and limited treatment options with parents' eagerness to "try anything" (Robertson et al. 2019). Literature from adult oncology and life-threatening pediatric illnesses shows that clinicians can report reluctance to disclose prognosis because they worry about the emotional impact of this information on families and do not want to diminish their hope (Gordon and Daugherty 2003; Mack and Joffe 2014). However, there is little evidence that limiting the delivery of prognostic information preserves hope (Mack et al. 2007) or decreases distress (Marron et al. 2018). Effective communication between HCPs, patients, and families may increase families' satisfaction with healthcare and improve their peace of mind (Sisk et al. 2018). Furthermore, honest and transparent communication allows families to focus on attainable goals (Sisk and Mack 2018) in partnership with their primary treating team and palliative care team.

Hard-to-treat childhood cancers require numerous decisions to be made regarding complex treatments, all with uncertain outcomes. With families able to easily access medical information online (much of which is unregulated), HCPs' responsibility to effectively communicate with families about their child's prognosis and treatment may be increasingly difficult. As such, the current study explored 3 research questions:

1. What are HCPs' challenges in communicating with families of children with hard-to-treat cancers?
2. What skills have HCPs developed to communicate with families of children with hard-to-treat cancers?
3. Have HCPs undergone previous training, and what are their attitudes toward formal training, to communicate with families about hard-to-treat cancers?

Methods

Participants

Participants were HCPs (e.g., oncologists, nurses, social workers, and any other relevant professionals) who had direct responsibilities for managing children/adolescents with hard-to-treat cancers in Australia within the previous 24 months.

Procedure

We recruited HCPs via exponential snowball sampling, starting with our clinical investigator (D.Z.). D.Z. emailed study invitations to individuals in his network who were employed at

the study site. Participants were then asked to provide other names/email addresses of other potentially eligible participants. We also recruited HCPs via study advertisements on social media. Email invitations and online advertisements contained a link to the information sheet and e-consent form, hosted on REDCap. Once participants provided their e-consent, they were directed to either complete a booking form on REDCap or to email the research team to arrange a time for the interview.

Data collection

We developed a purpose-designed, semi-structured interview schedule that focused on HCPs' perceived challenges in communicating with families, skills or techniques they had developed to aid communication, and knowledge of, and attitudes toward, training to aid communication. The interviews were used for data collection as part of a larger study that also examined HCPs' knowledge and access to experimental therapies. Only the data regarding communication is reported in this paper (see Supplementary Material for the interview guide). Interviews were conducted by 4 female psychosocial researchers (S.M., R.D., B.M., and C.M.), who all had training and experience conducting semi-structured interviews in pediatric medicine. Interviews were conducted one-on-one via Zoom or telephone, audio-recorded, and transcribed verbatim. Interviews lasted 38 min on average. Participants were interviewed once, and transcripts were not returned to participants for comment. Given the small population size, some participants had previously participated in our earlier research and thus had known the interviewers before study commencement.

Data analysis

We used qualitative content analysis and an inductive, iterative approach to analyze the data according to our 3 research questions. We followed Elo and Kyngäs' (2008) 3 phases of qualitative content analysis, which provides a framework to capture participants' perspectives in descriptive yet rich categories (Elo and Kyngäs 2008). In the first phase, *Preparation*, L.K. (first author) became immersed in the data by reading the transcribed interviews multiple times. In the second phase, *Organization*, L.K. used the guidelines of Miles and Huberman (1994) to open-code the transcripts. We used NVivo Release 1.7 (QSR International) to code the data, develop the coding tree, and record the frequency of the codes. S.M. also coded 4 randomly selected transcripts (i.e., 20% of the data) in accordance with accepted recommendations to reduce research bias (Burla et al. 2008; Campbell et al. 2013). L.K. and S.M. then compared coding, discussed and resolved discrepancies, and revised the coding tree. L.K. abstracted the data by organizing the codes into overarching categories and interpreting these categories in a way that accurately captured the original data. L.K., S.M., and E.T. all reread the transcripts, then met to discuss and revise the codes and categories until consensus was reached and to ensure that the themes accurately reflected the data. In the third phase, *Reporting*, we recorded how frequently we had coded each category and chose quotations from the interviews to represent the categories.

Results

Due to our recruitment strategy, we are unable to determine the overall response rate. However, 32 HCPs opted in to the study, and 25 (78.1%) of those participated. Five participants were then excluded from the study as they did not have direct experience

Table 1. Participant characteristics

Participants' profession	Oncologists = 10 Nurses = 7 Social workers = 3
Years of experience in their profession ^a	≤5 years = 5 6–10 years = 3 11–15 years = 4 ≥16 years = 6
Participants' sex	Female = 14 Male = 6

^aTwo participants were not asked this question.

working with patients with hard-to-treat cancers. Participant characteristics are presented in Table 1.

Table 2 shows the frequencies of the categories for the research questions: (1) challenges; (2) skills; and (3) training, alongside representative quotations.

Research question 1: challenges

Information provision vs. family distress and need for hope

The most frequently cited challenge was trying to balance providing families with accurate medical information while also managing family distress and maintaining hope. HCPs felt challenged to provide accurate prognostic information to families while not overstating the potential success of various treatment options and creating false hope. Adding to this challenge was the need to cater to the individual needs of each family and each family member, with HCPs reporting that some wanted as much information as possible, while others were not able to process or accept any “bad news.”

Parents want to censor information provided to their child

A particularly challenging aspect of family communication reported by 11 (55%) HCPs occurred when parents decided, on behalf of their child, that their child would be too distressed to hear the reality of their diagnosis and prognosis and requested that the HCPs censor either all or most of the details regarding their cancer. While HCPs reported that this was not a common occurrence, when it did happen, it was a significant challenge to navigate, especially when the patient was an adolescent and capable of understanding what was happening to them. HCPs typically reported that, while their preference was to provide developmentally appropriate and honest information to the young person, they wanted “to be respectful of parental wishes” (Oncologist). One oncologist, however, reported that they would inform adolescent patients of their prognosis and treatments, regardless of the parents' preferences.

HCPs and families have different expectations of treatment outcomes

Eleven HCPs (55%) reported that a major challenge was having different expectations for treatment outcomes relative to parents. In particular, they shared that HCPs often had “the expectation that it's unlikely or less likely that there will be benefit derived for that patient” (Oncologist). HCPs shared that some parents were “desperate” to enroll their child on a trial and held immense hope and expectations that it would offer an effective cure. Five HCPs specifically reported that when families accessed information about clinical trials and experimental agents online, it could exacerbate their unrealistic expectations for treatment. One of these HCPs reported

that “it's quite easy for a parent to have distrust in the clinician” (Oncologist) if they found information about new agents via international parent/patient forums that were not recommended by the treating team.

Uncertainty

Seven HCPs (35%) noted that one of the major challenges they faced was uncertainty regarding which treatment option was best, when treatment would begin, whether they could get access to new experimental agents, when those agents would arrive in Australia, and what the outcomes would be. This uncertainty then created difficulties when communicating with families as the HCPs were unable to provide definitive answers to parents' questions regarding treatment options and the likely efficacy of different treatment options.

Barriers to multidisciplinary teamwork

HCPs reported that multidisciplinary teamwork was preferred when communicating with families about diagnosis, prognosis, and treatment options and addressing families' resultant information and support needs. Oncologists typically led the conversations with families to deliver “bad news” and noted that ideally nurses and social workers would also be in the room to advocate for families' needs and provide emotional support. However, 6 HCPs (30%) reported that staff shortages, the busy pace of the hospital, and scheduling conflicts were at times a barrier to having nurses and/or social workers be part of these conversations with families. In addition, all 3 social workers reported that they believed their role was not always understood nor “respected” by the rest of the clinical team, and this led to them being left out of some important conversations with families.

Research question 2: skills

Developmentally appropriate communication

Thirteen HCPs (65%) perceived that an important skill they had developed when communicating with young people was being able to adapt their communication style to the maturity level of the young person, as well as the wishes of the parents. HCPs followed the lead of the young person to help them determine the level of detail to provide and individualize their approach to the information needs of the individual.

Being available to the families (repeat information, listen, and empower)

To build trust and rapport, 11 HCPs (55%) reported that they perceived an important skill they had developed was to patiently explain the details of the diagnosis and the treatment options and to empower the families to ask questions. HCPs reported that, given the complex nature of the disease and treatment and families' high distress, it was necessary to patiently repeat information several times to ensure the family is understanding. Similarly, hard-to-treat cancers involve decisions about treatment options where there is a lot of uncertainty around the outcomes and decisions about whether and when to begin palliative care. HCPs reported wanting to empower the families so that they felt like they were “part of the team,” but also ensure that parents were aware that “there's no right or wrong way in what decision is made” so they do not shoulder guilt or blame. (Social worker)

Table 2. Themes and representative quotations (*N* = 20)

Research question Theme	<i>n</i> (%)	
Challenges		
Information provision vs. family distress and need for hope	14 (70%)	"I think the hardest part is trying to deliver information like deliver the facts without scaring or overwhelming them... You can't say, 'No, they're not [going to die]' because you don't know those things and there's a very high risk they would, being a hard-to-treat cancer." (Nurse)
Parents want to censor information provided to their child	11 (55%)	"Some parents choose for their child not to be informed about what's going on- especially for the teenagers, that's very difficult because they do - they already know and yet one wants to be respectful of parental wishes." (Oncologist)
HCPs and families have different expectations for treatment	11 (55%)	"I think the hardest would be when there are limited therapeutic options, and the expectations of the parents or the child, depending on what their age is, is still for cure, and really being able to...prepare them with the concept that treatment may not be successful." (Research fellow) "There's a lot of information online that is accessible to families which isn't exactly accurate and true...There's also lots more forums that [parents] join and groups with social media which can influence their decisions. And I think that has a big impact in being able to talk to families about poor prognosis and their child's illness." (Nurse)
Uncertainty	7 (35%)	"Often there may not be the same body of data and literature that helps you evaluate what current treatment options are regarded as best available standard of care in rare cancers and hard-to-treat cancers, so there's more uncertainty around sometimes treatment options and then it can sometimes also flow through to that there can be also more uncertainty around what the likely outcomes are" (Oncologist)
Barriers to multidisciplinary teamwork	6 (30%)	"If we know it's gonna be bad news or hard to hear news, then we might, if we can, get the social worker to sit in on the consult as well and to do that kind of multidisciplinary team approach, which I find is good. The challenge for that can be just resources and who's available. It can often be a challenge to get everyone in the room that you would like." (Nurse)
Skills		
Developmentally appropriate communication	13 (65%)	"The way I would communicate is by taking the cues from the young person, because one 12-year-old may still be playing with dolls, whereas another 12-year-old may have a lot of insight.. So I think in the very young patient - and what definition of very young is depends on the maturity of the individual rather than their chronological age - I would not necessarily go into a lot of detail about the treatment, but I would be guided, as I say, by the cues they give and by the cues that the parents give." (Oncologist)
Being available to the families (repeat information, listen, empower)	11 (55%)	"I've always spent a fair amount of time with the family early in diagnosis...Even though they may not take in a lot, the fact that you've taken the trouble to speak to them, go through it in detail while you're with them...they feel...reassurance. And then it requires...going back and going over the same information as many times as possible because we don't expect them to take it all in." (Oncologist)
Transparency of processes: Show parents they are trying everything	4 (20%)	"The wait time [for molecular results] can be six, eight, ten weeks sometimes, where families are just like, 'Why is it taking so long?'...And often there's a lot of explanation as to why you can't access it, or we need a washout period, if we stop medication A before we can do medication B...As much as they want things to move quickly...we have to do it in this manner and we can't go any faster than this...So we give them some plan, so they're not just waiting and not understanding...and keeping them up to date as more information comes in." (Nurse)
Training		
Practical and easily accessible resources	10 (50%)	"I think a checklist is helpful to have or a run sheet, and you may not go in that order at all, and you may deviate from it, depending on what comes up, but I do think a checklist or run sheet, if possible, because there will be things with all these conversations that will come out." (Nurse)
Training for junior HCPs	10 (50%)	"We, as paediatric oncologists, try to develop the skill across the years and seeking advice from our more senior colleagues, but it does not have any structure or systematic way to do this...I'm really realising that it's a huge gap because there are certainly strategies and methods that could potentially be followed...We are not certainly experts in how to read a family when receiving this type of traumatic information. And even though we develop skills, because we have to be exposed to this very often, we don't have a formal training or upskilling approach...I think it's challenging because the 'old school' way for us all is you find your way and learn from yourself and at the end, you have your own method." (Oncologist)

HCP = healthcare professionals.

Transparency of processes: show parents they are trying everything

Four HCPs (20%) reported that it was important to show parents that they were trying everything to save their child. HCPs noted that some parents valued knowing that the healthcare team

was "doing something right to the very end" (Nurse). For parents who needed more information, HCPs shared that they explained their decision-making processes to families and described any procedures that were occurring "behind-the-scenes" including, for example, molecular testing that had been "tried and hadn't quite

worked” (Oncologist), their own research into new trials, their investigations of new agents, and their consultations with colleagues overseas. HCPs reported that this was particularly important when there were long delays to starting a trial or receiving molecular results.

Research question 3: training

Ten HCPs (50%) reported that they received no specific training to deliver “bad news” to families and how to communicate with families about hard-to-treat cancers. Of the 10 HCPs (50%) who had received training, 5 were oncologists, 4 were nurses, and 1 was a social worker. These HCPs reported that training was generally undertaken via independent study (e.g., workshops and certificate of bereavement counseling) and not a formal part of their degree or specialist education. The training was also typically about breaking bad news in general.

Practical and easily accessible resources

Ten HCPs (50%) expressed a desire for training to be developed to prepare them and their colleagues for difficult discussions with families of young people with hard-to-treat cancers. HCPs emphasized that training or education resources needed to be easily accessible; “easily readable and easy to follow, not 15 pages of text” (Oncologist). Preference was given to practical training that involved role-play or simulation, or online resources that outlined topics that need to be covered when communicating with families.

Training for junior HCPs

Most HCPs reported that they developed their skills “on the job” by observing their seniors and by receiving feedback from their colleagues and supervisors. However, nurses, social workers, and oncologists with <10 years’ experience reported dissatisfaction with this approach and, more commonly than oncologists with >16 years experience, reported seeing value in the development of training resources for HCPs to assist communication with families. Oncologists with <10 years’ experience wanted training for themselves, whereas nurses and social workers discussed the importance of training both for themselves and for junior oncologists.

Discussion

We qualitatively explored HCPs’ challenges, as well as their skills and training needs for communicating with families of children with hard-to-treat cancers. HCPs commonly reported family- and systems-related challenges. Consistent with previous research, HCPs in this study revealed that they build and maintain trust and rapport with families by spending time with them, answering their questions, and repeating information (Sisk et al. 2020). Half the HCPs had not received any specific training for communication with families about hard-to-treat cancers, and the other half expressed a desire for the development of such training. Nurses, social workers, and less experienced oncologists appeared to be more interested in future training than more experienced oncologists.

HCPs in our study noted challenges in their communication with families, including uncertainty and balancing information provision with families’ distress and need to maintain hope. HCPs also reported that their expectations for treatment outcomes often differed to those of parents, and this was a major challenge in their interactions with families. These findings echo those from other studies, with previous research also showing that parents

can have “unrealistic” expectations for treatment in poor-prognosis childhood cancer (Kaye et al. 2021; Mack et al. 2020). This suggests discrepancies in clinician–parent understanding (Sisk and Kodish 2020). Furthermore, prior research shows that parents’ understanding of poor prognosis may improve when oncologists provide direct statements about incurability, as opposed to indirect or implied prognostic language (Kaye et al. 2021). Honest disclosures of poor prognosis can actually help relieve uncertainty in parents, as it allows them to make fully informed decisions about their child’s treatment (Nyborn et al. 2016). Indeed, parents who find prognostic information to be particularly upsetting still want to receive this information (Mack et al. 2006), which underscores the importance of honesty.

HCPs reported that online information about novel therapies and clinical trials overseas exacerbated the divide in expectations between themselves and parents. Previous literature shows that many parents of children with cancer (though not necessarily hard-to-treat cancers) use social media to source information about treatment options (Gage-Bouchard et al. 2018; Gün and Şenol 2019; Nagelhout et al. 2018), despite the commonly inaccurate, unproven, or irrelevant nature of this information (Domínguez and Sapiña 2015; Gage-Bouchard et al. 2018). Given these findings, it is important that HCPs have the resources and skills to help parents navigate the varying quality of information on social media, which may then help to ensure that parents have realistic expectations for their child’s treatment outcomes.

Another major challenge reported by HCPs occurred when parents wanted to censor the information HCPs provided to the young person with cancer. Most pediatric cancer patients want to be involved in conversations about their cancer care, at least to some extent (Coyne et al. 2014), and adolescents may want to take part in the treatment decision-making process (Blazin et al. 2018; Wakefield et al. 2011; Weaver et al. 2015). Adolescent and young adult (AYA) cancer patients also highly value receiving honest prognostic information from their HCPs (Mack et al. 2018). Indeed, there are legal and ethical implications for communication with AYAs, which are beyond the scope of the current study, and are thoroughly explored in previous research (Sansom-Daly et al. 2020; Sisk et al. 2019a). Furthermore, when parents want to censor information from their child, it conflicts with HCPs’ preference for honest and developmentally appropriate communication with young people as reported by the HCPs in this study as well as in previous studies with pediatric cancer patients (Lin et al. 2020) and HCPs (Larone et al. 2022).

HCPs revealed that social workers, and at times nurses, may be missing from important conversations with families due to staff shortages and a perceived lack of understanding of the social worker role among the rest of the clinical team. This differs from previous research in the United States where pediatric oncology social workers perceived themselves to be well integrated within the treating team (Jones et al. 2018). Social workers are key members of the multidisciplinary pediatric oncology team and help to ensure a holistic approach to care for the child with cancer, their parents, and their siblings (Jones et al. 2018). Furthermore, research shows that early integration of palliative care can help families better adjust when treatments are not working (Rosenberg et al. 2016); a point echoed by the social workers in the current study. Research shows that treating oncologists are typically responsible for deciding when to introduce palliative care to the families, but that social workers can help advocate for early integration of palliative care concepts (Dalberg et al. 2013; Jones et al. 2018).

Implications

HCPs' challenges to communicate with families about hard-to-treat cancers may lead to burnout and communication that does not meet families' needs (Sisk *et al.* 2022). Communication training may help to address some of these challenges (Sisk *et al.* 2019b) if it is feasible to complete. Without systematically provided training, individual HCPs are required to be motivated to actively seek out their own education about communication and the latest research (Hopia *et al.* 2019), and lack of time can be a key barrier to doing so (Ten Bruggencate *et al.* 2009). This may result in inconsistent approaches to communication with families across different HCPs (Kaye *et al.* 2021).

Furthermore, while existing communication training regarding "breaking bad news" may be beneficial for HCPs (Johnson and Panagioti 2018), there are no known evidence-based communication interventions that specifically focus on the pediatric oncology setting (Sisk *et al.* 2019c). Targeted communication training for pediatric oncology HCPs is important given the many differences between standards of care in adult medicine versus pediatric medicine (Hussen 2022), as well as the increasingly complex and difficult to understand treatments for hard-to-treat cancers. Limited evidence suggests that such training may be feasible (Kaye *et al.* 2020). Future research should develop and evaluate resources that are easy to use, support HCPs' communication with families about hard-to-treat cancers and complex treatment schedules, facilitate interdisciplinary communication, and address the many challenges associated with such communication. Education may include strategies to improve families' prognostic understanding such as "seed planting" whereby the poor prognosis is discussed early, and further prognostic information is gradually provided over time (Aglia *et al.* 2023; Kaye *et al.* 2021). Education may also incorporate support for HCPs regarding how to advise parents to navigate information on social media about their child's prognosis and treatments.

Limitations

Recruitment to the study began at one site, and participants were colleagues of our clinical lead investigator, which may have skewed the results and overrepresented HCPs working at the study site. Nevertheless, we used the snowballing method to help overcome this and increase the reach of our data collection beyond the main study site. Furthermore, given the limited pool of eligible participants, there was likely to be minimal sampling bias. Only 3 social workers participated in the interviews. Given the important perspectives regarding multidisciplinary teamwork reported by the social workers in the current study, future research should actively engage social worker perspectives. In addition, our study did not include psychologists, palliative care physicians, child-life therapists, and several other allied HCPs. It is likely that the entire multidisciplinary team would benefit from communication skills training, as emotional support for families (using associated communication skills) could be expected to be provided by any member of the team.

Conclusion

With a growing number of complex treatment options for children's hard-to-treat cancer and easy access to potentially inaccurate or irrelevant treatment information online, resources are needed to support HCPs to communicate with families. Such communication

resources may be particularly beneficial for less experienced oncologists during their training and should aim to prepare them for the typical challenges they will face and the skills they will need, as well as foster greater collaboration with nurses and social workers. This will ensure equitable access for children and families to the best standard of communication across their treatment trajectory.

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Competing interests. The authors declare that they have no conflict of interest.

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