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Helping parents prepare for their child's end of life: A retrospective survey of cancer-bereaved parents

Lori Wiener¹, Julia Tager^{1,2}, Jennifer Mack³, Haven Battles¹, Sima Zadeh Bedoya¹, Cynthia A. Gerhardt⁴

¹Pediatric Oncology Branch, National Cancer Institute, Center for Cancer Research, National Institutes of Health, Bethesda, Maryland ²University of Massachusetts Amherst, Amherst, Massachusetts ³Dana Farber Cancer Institute, Boston, Massachusetts ⁴Center for Biobehavioral Health, The Research Institute at Nationwide Children's Hospital, Columbus, Ohio

Abstract

Background: Most parents vividly recall the weeks, days, and moments preceding their child's death for years to come. Dissatisfaction with communication about their child's condition and lack of guidance can contribute to stress prior to a child's death. Based on findings from a study assessing the degree of preparation bereaved parents received and our collective clinical experience, the authors provide suggestions on end-of-life communication and guidance for parents.

Methods: Caregivers of a child who died from cancer were invited to complete a 46-item survey through a closed social media (Facebook) group ("*Parents who lost children to cancer*"). In four months' time, 131 bereaved caregivers completed the survey. Results were analyzed using descriptive statistics, chi-square analyses, and a thematic content analysis framework. The mean age of the child at the time of death was 12.

Results: Approximately 40% of the parents in this study felt unprepared for both the medical problems their child faced and how to respond to their child's emotional needs; fewer than 10% felt very prepared for either. Parents were more likely to feel unprepared when perceived suffering was high, highlighting the critical importance of communication and support from the healthcare team as an adjunct to optimal symptom control.

Conclusions: Through quantitative and open-ended responses, this study identified specific medical and emotional issues about which parents wanted greater preparation. Future research to evaluate guidance strategies to reduce parental suffering prior to the child's death is needed.

Keywords

adolescents; cancer; children; communication; end-of-life; preparedness

Correspondence: Lori Wiener, National Cancer Institute, Pediatric Oncology Branch, National Institutes of Health, 9000 Rockville Pike, Bethesda, MD 20892. wienerl@mail.nih.gov.

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Despite improvements in pediatric cancer care, malignant neoplasms are the leading cause of death by disease, representing 9% of overall deaths among children and adolescents in the United States.¹ Most parents vividly recall the weeks, days, and moments preceding their child's death for years to come. Although the child's medical team assists with the care of the child before death, parents continue to make decisions and serve as their child's primary caregivers through the EoL. However, dissatisfaction with perceived communication from medical staff about their child's condition, conflicting medical information from different sources, uncertainty surrounding expectations, and a lack of privacy can contribute to significant stress prior to a child's death and more severe parental grief.^{2,3}

There is strong evidence supporting the need for children and their family members to receive anticipatory guidance for procedures, symptoms, and common emotional reactions throughout the cancer trajectory, including at the EoL.^{4,5} Bereaved parents report that they would have appreciated honest conversations, in which the possibility of death was mentioned by their child's medical providers, earlier in the treatment process.⁴ Others describe having to make very difficult decisions without being fully informed.⁶ Moreover, higher levels of parental preparation for their child's EoL period is associated with higher parent rankings of physician quality of care, suggesting that the provision of specific information regarding the child's death is valued as a central aspect of care.⁷

Although the importance of parent preparation during EoL care is well understood, there is a dearth of research addressing the particular domains in which this preparation should be given. Even less is reported on how to translate what is known into clinical practice.⁸ Providers need specific guidelines about what type of preparatory information should be given to parents in terms of both anticipated physical changes and the child's emotional care needs. These topics have not been widely researched or addressed in the existing literature. As part of a larger study designed to understand multiple aspects of EoL care from the parent perspective, we aimed to assess the degree to which parents felt prepared to address their child's medical problems and emotional needs at the EoL, as well as the implications from lack of preparation. These findings are discussed in the context of how healthcare providers can better approach EoL discussions with families, thereby better preparing them for their child's EoL.

1 | METHODS

1.1 | Participants

Caregivers who lost a child to cancer were invited to complete a 46-item survey through a closed social media (Facebook) group ("*Parents who lost children to cancer*"). The group included members from all 50 United States, Canada, Australia, the Philippines, and several European countries.

1.2 | Procedures

With permission from the site administrator, a Facebook group member posted a link to the survey along with an explanation about the study, including information regarding its purpose, risks/benefits, and rights as a research participant. Members of the group were

asked not to share the link with other bereaved parents so as to ensure that data remained specific to those who lost a child to cancer. No member of the research team was added to the Facebook group. The survey remained open from March to June 2018. The group member sent three reminders in the form of posts to the Facebook group, with a link to the survey, three weeks apart during the first two months the study was open and once a week during the last month of the study to improve recruitment. Personal identifiers were not collected. Study approval was obtained from the National Institutes of Health Office of Human Subjects Research Protection, who determined that signed informed consent was not required.

1.3 | Measures

1.3.1 | EoL preference survey—A 46-item survey was developed by the authors (LW, SZB, TYS, and CAG), pediatric psychosocial oncology professionals from several institutions (psychologists, nurses, social workers, psychiatrists, and oncologists) with input from bereaved parent advocates. It contained assessments of support services provided throughout the child's EoL care and perceived psychosocial needs of the child and family before, during, and after the child's death from cancer. Participants were also asked separate questions about how prepared they felt to address their child's medical needs and their child's emotional needs at the EoL ("not at all prepared," "a little prepared," "somewhat prepared," or "very prepared"), whether they perceived their child to have suffered at the time of death ("not at all," "somewhat," "very much," or "other"), and suggestions for cancer centers to help families to feel better prepared. The question on suffering was recoded, as several responses in the "other" category could be labeled "don't know" or recoded into the existing categories. Data were reported as "not at all," "somewhat/very much," and "don't know."

The survey was administered through SurveyMonkey with branching logic directing participants to answer questions relevant to their respective experiences. The survey took participants approximately 20 minutes to complete.

1.4 | Data analyses

One hundred and seventy-eight bereaved caregivers of children with cancer (ages 0–39) began the survey. Our analyses focused on the participants whose children were 24 years old or younger at death ($n = 167$), to be inclusive of children, adolescents, and emerging young adults.

Due to survey drop-off, approximately 78% of participants answered the questions pertaining to preparation for their child's medical problems ($n = 131$) and emotional needs ($n = 130$) at EoL; analyses presented below are limited to these respondents. There were no significant differences between those who answered these questions and those who did not in terms of caregiver age, child age at death, child's cancer type, caregiver race, caregiver ethnicity, length of illness, or place of death. Descriptive statistics were used to present the overall findings. Chi-square analyses were used to compare those who were medically prepared, or emotionally prepared for EOL, and those who were not on various categorical outcomes.

As participants also had the option to provide open-ended written responses, a thematic content analysis framework was used to analyze each of these verbatim responses.⁹ Three independent coders reviewed all 79 open-ended responses to obtain an overall understanding of the material. The responses were reread to generate preliminary categories of themes and then together the coders inductively developed coding themes consisting of five categories. A coding dictionary was created. Two coders with experience in qualitative and psychosocial research (LW and JT) independently coded the responses and communicated regularly to review the coding process. Only minor discrepancies were identified; these were discussed until full consensus was obtained.

2 | RESULTS

Demographic characteristics of the final analytic sample are provided in Table 1. Overall, more than three-quarters of participants were female (77.1%, $n = 101$) and the deceased child's mother (74.8%, $n = 98$). Almost all participants were Caucasian (95.4%, $n = 125$) with a mean age of 48.4 years (SD = 7.3 years; range, 29 to 71 years). The mean age of the child at death was 12.1 years (SD = 5.9 years; range, 0.6 to 24 years). Length of illness ranged from under one year (24.4%, $n = 32$) to over five years (11.5%, $n = 15$). Approximately half of the children died at home (47.3%, $n = 62$).

2.1 | Preparation to address child's medical needs at the end of life

Of the 131 total respondents to the question, "Did you feel prepared to address your child's medical needs during the end of life period?" 37.4% ($n = 49$) felt "not at all" prepared. Twenty-eight percent ($n = 36$) felt "a little" prepared, 26.0% ($n = 34$) felt "somewhat" prepared, and 9.2% ($n = 12$) felt "very" prepared.

2.2 | Preparation to address child's emotional needs at the end of life

Of the 130 total respondents to the question, "Did you feel prepared to address your child's emotional needs during the end of life period?" 40.5% ($n = 53$) indicated that they felt "not at all" prepared. Approximately half of respondents felt "somewhat" (28.2%, $n = 37$) or "a little" prepared (21.4%, $n = 28$), and 9.2% ($n = 12$) felt "very" prepared.

2.3 | Perceived suffering at the end of life

Participants were asked, "Do you feel like your child suffered (i.e., pain, shortness of breath, anxiety) at the time of his/her death?" Just over two-thirds of the respondents (66.4%, $n = 87$) reported they perceived their child to suffer "very much" or "somewhat." Approximately one-fifth (19.8%, $n = 26$) responded "not at all," and an additional 9.9% of participants ($n = 13$) responded that they didn't know. Participants who reported feeling not at all prepared for their child's medical problems at EoL were significantly more likely to have perceived that their child suffered somewhat/very much, $\chi^2(6, n = 126) = 16.3, P = 0.01$, relative to those who did not perceive suffering or did not know whether their child suffered. Those who perceived their child suffered somewhat/very much or didn't know how much they suffered were significantly more likely than parents whose children did not suffer to report that they did not feel prepared to meet their child's emotional needs at the EoL, $\chi^2(6, n = 125) = 12.7, P = 0.049$.

2.4 | What would help parents feel better prepared

In response to the open-ended question, “If you didn’t feel prepared for the kind of medical and/or emotional problems your child experienced, what would have been helpful?” 60% of parents (79 of those who answered the preparation questions) provided a written response. Resulting themes from these responses are in Table 2. In parallel to closed-ended items, 43% ($n = 34$) of parents expressed a desire for communication about medical and emotional issues at the EoL, and 10% ($n = 13$) expressed a specific desire for communication regarding their child’s prognosis. In addition to a discussion of prognosis, six subthemes emerged as necessary aspects of communication. Specifically, of the 41% ($n = 34$) parents who described a desire for better communication, several wanted an explanation of symptoms and physical changes (41%, $n = 14$), what to expect when death was near (32%, $n = 11$), and how to address symptoms (24%, $n = 8$). Parents also wished for preparation for potential upcoming medical interventions and what to expect after death.

Participants recognized the need for guidance about emotional topics from the medical team and from other bereaved parents. This included how to both talk with their child about death and prepare siblings. Sixteen percent of parents ($n = 13$) reported that psychological support or counseling would have helped, specifically relating to the mental health of the child, caregiver, and grandparents. In addition, 11% of participants ($n = 9$) commented about a need for more understanding and compassion from providers.

3 | DISCUSSION

Given the rate of pediatric death from cancer, alongside the challenges of parents feeling a loss of control and watching their child suffer at EoL, the importance of providing interventions to reduce complicated or long-term grief is critical. Between 1997 and 2001, Mack et al. surveyed bereaved parents to determine factors associated with high-quality care at the end of their child’s life.⁷ Parents who reported better care were provided clear information on what to expect and felt prepared for circumstances surrounding their child’s death. Although approximately two decades have passed since these data were collected, little has changed. Approximately 40% of the parents in this study felt unprepared for both the medical problems their child faced and how to respond to their child’s emotional needs; fewer than 10% felt very prepared for either issue. Parents were especially likely to feel unprepared when suffering was perceived as high, highlighting the critical importance of quality communication and supportive care as an adjunct to optimal symptom control. Pervasive lack of preparation was identified despite mounting evidence for better outcomes associated with anticipatory guidance at the end of the child’s life.⁵ Although parents may never feel completely prepared, evidence suggests we can do better.

The question then becomes, how can we better serve the children and families we care for? Participants in this study eloquently described how higher quality communication could have improved their child’s EoL experience, especially through honesty, openness, timeliness, and avoiding assumptions, and they raised specific topics of importance. First, several parents reported inadequate communication about prognosis. Although this issue has received significant attention in the literature,^{3,10–13} challenges remain. Parents in our study described critical costs associated with poor preparation for prognosis, including an inability

to surround the child with loving family members at the EoL. Existing guidance for prognosis communication recommends^{14–16} first asking parents about their understanding of their child's future. Clinicians can then offer more conversation about this issue, expanding on the parent's perception when needed and filling in gaps. Of note, these conversations often need to take place more than once over time, given their emotional weight, the potential for an evolving medical picture, and to continue to assess understanding and perhaps changing goals of care.

Second, parents wanted to understand expected physical changes at the EoL. Clinicians may understandably wish to avoid or protect vulnerable parents from this difficult topic, but the parents in our study emphasized its importance. Ongoing, compassionate conversations that describe the symptoms their child may experience, how their appearance might change, how distressing symptoms will be managed, and how to address their child's emotional needs can help them to feel better prepared to be a good parent to their seriously ill child.¹⁷ This in turn can reduce the risk of profound guilt after the death of their child.¹⁸ Clinicians can ask parents if it would be helpful to talk about what may happen to the child physically as death nears, and after death, then offer honest information about what may come.

Third, parents expressed a need for guidance on talking with the child about death. Many are eager to receive assistance with developmentally appropriate words that take into account the family's cultural or religious views, and previous experiences with death. Guidance on ways to elicit worries that the child may be harboring is often appreciated. Prior work has demonstrated the importance of open conversation about dying as a way of best supporting a child.^{19–22} Even when conversations occur late in care, children report benefiting and not being harmed when included in discussion about the end of curative treatments.^{23,24} Yet parents often struggle with the best ways to open these conversations and may wonder whether such a conversation is really in a child's best interests.^{25–27} Parents need to be assured that they are doing everything possible to support and comfort their children and children need to be assured that they will not be alone and that they will be remembered.²⁴ Advance care planning guides for adolescents and young adults and evidence-based interventions provide clinicians with tools for assisting patients with these conversations.^{28–30}

Although clinicians sometimes wait for parents to ask about these topics or look for signals that such a conversation would be welcomed, our findings suggest that these three topics should be offered to all parents in this situation. In this difficult phase, many parents experience a profound sense of isolation and abandonment. Being treated with compassion is a basic underlying need of parents of dying children and can-not be overlooked. Although avoidance of difficult conversations may seem to be one way to show compassion, these parents felt the opposite to be true—wading into these deep waters with them helped them to feel less alone.^{12,31–33}

Quality communication is associated with greater parental peace of mind and trust in the physician.^{12,31} This requires honest and open communication throughout the cancer trajectory. Family-centered communication and care can be achieved from a skilled multidisciplinary healthcare team that adopts a comprehensive and integrative care

approach³³ throughout the cancer trajectory. This approach must be attentive to how differently parents process information,³⁴ particularly when under great stress and the need to allow time for questions to arise³⁵ even when it appears that treatment decisions have been made.

3.1 | Additional considerations for helping families prepare for end of life

Although limited evidence-based data exist about the most appropriate words to use or the exact timing for these difficult conversations, in Table 3, the authors share best practice examples from their collective clinical experiences. No two families are exactly alike and therefore our approach to these conversations must always reflect where a particular family is in terms of their readiness to talk about how to help prepare their child. Timing is critically important. Although we know that conversations about what to expect as the death of the child nears are usually most helpful in the days or weeks before the child's death, some parents may wish to learn about these issues earlier and some may never seem ready. For the latter, consider the 40% of families who recall never being prepared for their child's medical or emotional needs at the EoL. Continue to invite parents to join you in making sure that they feel as prepared as possible to provide the best care for their child. As death nears, it is not only important for us to improve care and the child's quality of life, but to improve outcomes for bereaved parents. This requires us to reduce decisional regret, whenever possible.

For each of these topics, we recommend a general approach of, first, asking parents about their hopes and worries for their child, so that hopes can be supported and worries addressed in conversations and care. Second, we assess readiness to address these topics by asking, for example, "Would it be helpful to hear more about what to expect for your child as his or her illness continues to progress?" If parents are open to these topics, we then explore what aspects of the future would be most helpful to understand. Some parents are most focused on the expected prognosis and timeline; others on physical changes and what will happen after death; and still others on how to help their child feel protected and loved during this impossible time. Some parents need to address all of these topics; others are not ready but may need reassurance that we can return to these topics if and when the time is right. We then provide information about parents' concerns in honest and simple language, emphasizing that our guidance reflects what we have learned from experience with other children, and that we will also work to meet their child's unique needs, with their help and guidance. We sometimes reflect with parents, for example, on things we have noticed about their child as being especially important or bothersome and commit to attend carefully to that experience. Once this information has been shared, we ask parents how they are feeling, and whether there are other concerns that we need to address. Then we commit to next steps in care and to continued conversations in service of best care for the child.

Despite the skill level of the medical team or individual provider or how gently parents are invited to consider their child's impending death, some parents may never be ready for these conversations. We strive for open, honest, and timely communication, but this work is as much an art as it is a science. It can be exceedingly emotionally challenging and also exceptionally rewarding when we can truly partner with families. Less severe parental grief

responses are associated with parents' trust in their providers regarding their child's symptoms,³⁶ as well as having quality communication with their physician.³ The opportunity to walk this path with parents at the most difficult time of their life is an honor. It is also an opportunity to help them go on after their child is gone.

3.2 | Limitations

This study was limited to bereaved parents who had access to social media, were able read and write in English, and were members of this closed Facebook support group. The sample had limited racial/ethnic and gender diversity. The survey also did not ask how recently the death of the child occurred, which may influence responses. Due to the retrospective study design, we do not know whether a parent might have had different responses to what would have been most beneficial if asked while their child was still alive. It was also not possible to determine the response rate from the study, as data on how many members of the Facebook group signed onto the site the days the study was open were unknown. As participants voluntarily joined the Facebook group, selection bias might have resulted in a skewed cohort. Although this study was not designed to assess the impact of a closed internet group on recruitment, online recruitment was a potential strength of the study as it provided an opportunity to learn from and discover new information from bereaved parents from a wide geographic area. We also did not specifically ask if palliative care was part of the overall care at the end of the child's life. Children with cancer who receive formal palliative care services experience improvements in physical and psychological symptoms, and increased number of and earlier discussion about EoL care.^{32,37-40} Improved bereavement outcomes are possible for parents whose children received palliative care services that helped control distressing symptoms and for whom preparation for EoL was provided.⁴¹⁻⁴³

As death approaches, parents are expected to be able to prepare their children for what is to come. Our study identifies specific medical and emotional issues about which parents want greater preparation. They rely on the healthcare team to initiate timely conversations, provide honest information, and guide them in this difficult task. Fortunately, the field of pediatric oncology has begun to embrace earlier integration of palliative and EoL care,^{44,45} which includes quality communication within collaborative care models.^{28,46} It is our hope that in the future, most parents whose child will not survive their cancer will feel better prepared to address their child's needs as the end of his/her life nears. It is the responsibility of the medical team to ensure that patients and their caregivers benefit from open and honest communication before, during, and after the EoL period, as well as supportive counseling, guidance, understanding and compassion from providers, and access to additional services if needed.

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Abbreviations:

EoL end of life

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TABLE 1

Participant characteristics (N= 131)

Characteristic	N	%	Mean	SD
Female sex	101	77.1		
Relationship to child				
Mother	98	74.8		
Father	29	22.1		
Grandparent	2	1.5		
Other	2	1.5		
Has surviving child	121	92.4		
Race				
Caucasian	125	95.4		
Non-Caucasian	5	3.9		
Missing	1	0.8		
Ethnicity				
Hispanic/Latino	4	3.1		
Not Hispanic/Latino	112	85.5		
Unknown	7	5.3		
Missing	8	6.1		
Caregiver age, years ^a			48.4	7.3
Child's diagnosis				
Brain/spinal tumor	42	32.1		
Blood cancer	40	30.5		
Sarcoma	32	24.4		
Neuroblastoma	7	5.3		
Other ^b	10	7.6		
Time period between child's diagnosis and death				
Under 1 year	32	24.4		
1–2 years	51	38.9		
3–5 years	33	25.2		
Over 5 years	15	11.5		
Child in remission prior to death	69	52.7		
Child's age at death, years			12.1	5.9
Child's place of death				
Home	62	47.3		
Hospital	56	42.7		
Hospice facility	5	3.8		
Other	3	2.3		
Missing	5	3.8		

^aN= 130.

^bIncludes metastatic retinoblastoma, rhabdoid tumors, insular thyroid cancer, Wilms tumor, and one primary cancer type unknown.

Themes generated from responses to the question: “If you didn’t feel prepared for the kind of medical and/or emotional problems your child experienced, what would have been helpful?”

TABLE 2

Theme	Example quote	Number of parents using this code ^a n = 79 (%)
Quality communication about prognosis	<p>“More honesty from her doctors. They should give more realistic probable outcomes about treatment not working instead of pushing the child further when it obviously wasn’t working.”</p> <p>“In our case, physicians did not share with us that our son was dying. We learned this from two trusted nurses. Pain, abdomen filling up with fluid, and difficulty breathing were major problems our son faced at the end of his life. More active dialoguing with us about each of these problems could have resulted in better overall management of his traumatic death.”</p>	10 (13%)
Quality communication about medical events and changes to expect at the end of life	<p>“I think the ICU team saw our history (multiple relapses, clinical trials, advanced cancer) and assumed we knew more than we did. Instead we had never experienced intubation or any breathing support and it would have been helpful to have been given more information on what to expect.”</p> <p>“...information about what happens to the child’s body specific real information the things no one wants to talk about, but we face and need to know.”</p> <p>“The option of telling a parent what to expect physically should be given, allowing the parent to ask when they are ready.”</p>	34 (43%)
Understanding and compassion from providers	<p>“We wanted to have family come but didn’t have time because the team didn’t talk with us about what to expect or tell us we should prepare family.”</p> <p>“... I wish that the psychologist and other team members would have spoken to [my child] during his illness to address any concerns that he had.”</p> <p>“More compassion, patience, more questions asked to make sure we knew what was happening.”</p>	23 (29%)
Psychological support/ counseling	<p>“Discussions with others that had experienced loss.”</p> <p>“A [counselor] was made available to my daughter during that process. Her counseling ended shortly before her terminal diagnosis and it was never revisited. Parents are in such an emotional state, it didn’t occur to me to ask.”</p>	13 (16%)
Understanding and compassion from providers	<p>“My child was heavily medicated during his final days. I had to seek them out (psychologist and other team members) to talk to not the other way around.”</p> <p>“We need doctors, nurses and social workers who truly understand what this is like for the child and the family. Too often we were made to feel that we were being too demanding. My son suffered too much and was never treated as the courageous young man he was.”</p>	9 (11%)

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Number of
parents using
this code^a n =
79 (%)

Example quote

Theme

"I don't think the support needs to be clinical. It just needs to be caring people, caring for people, and that's what we received."
"Pain and sedation meds at my home BEFORE she needed them. Waiting for people to answer voicemails and to have time come assess her, is waiting too long."

7 (9%)

Additional services

"For someone to take over the everyday living things so that I could spend more time with her."

^aNumbers in this table reflect the percentage and number of responses to this theme. Parents often reflected more than one theme.

TABLE 3
Key elements of conversations with parents about what to expect at their child’s end of life

Considerations	Goal	Sample conversations
What the family knows/ expects	Understanding the family perspective, identifying any knowledge gaps, and learning where to start the conversation.	It would help me to hear more about what you are expecting may happen to your child because of his or her illness. How do you see his or her future?
What concerns/worries the family the most (may be different than what the provider thinks)	Identify key stressors, areas where intervention is especially important, and areas where preparation can be helpful.	What are you most concerned about for your child? (or, what worries you most as you think about your child’s future?) Can you tell me what else are you worried about?
What the family is hoping for	Identify priorities for life and care.	Is there anything you are especially hoping for as we care for your child? What else are you hoping for?
Readiness to learn about medical aspects	Assess readiness; for parents who are not ready, let them know you can talk about these things whenever they are.	I will always be here to help you make the best decisions about the care of your child. Would it be helpful to hear more about what to expect as your child’s illness continues to progress? (or as the end of life approaches, or over time?) (For parents who are not ready) Sometimes parents who aren’t ready now end up wanting to talk about this later on. I want you to know that we can come back to this in the future if you would find it helpful.
What to expect medically	Provide clear explanations and guidance about potential changes such as symptoms, changes in breathing pattern, secretions, level of consciousness, decreased urine output, changes in perfusion, and any possible information about timing of changes and death. Consider additional information about autopsy and care of the body after death.	We never really know what to expect for any one child. But I can share with you some of what I and others have learned in taking care of other children in this phase of life. Some parents find this helps them make decisions and answer questions for their child
Readiness to address child’s emotional needs	Assess readiness to talk about emotional topics; convey that this topic is important.	Would it be helpful to think about what your child may need emotionally as the illness continues? What are you most worried about for your child’s emotional needs?
What to expect emotionally	Provide guidance and support around emotional concerns, including discussing death and dying with child and siblings, issues around mutual pretense, and potential for heightened emotional isolation when topics are not addressed. Offer help in discussing these topics rather than expecting the parent to do so.	I can share with you some of what we have learned about taking care of children in this phase of life. I know that this must be stressful to think about, but together I’m hoping we can think about what would be most helpful for your child and how to make this less difficult for you.
Assessing emotional responses to this information	Build in additional supports, if needed.	I can see your sadness/anger/worry. I am sorry that this is so hard. Would you feel comfortable sharing a little with me about what you are thinking and feeling?
Summarize, strategize	Help parents identify key points and next steps.	What are the most important next steps for your child’s care? What should the medical team be considering about your family’s wishes right now?