ORIGINAL ARTICLE

Bereaved Parents and Siblings Offer Advice to Health Care Providers and Researchers

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Objective: To determine how to improve care for families by obtaining their advice to health care providers and researchers after a child's death from cancer.

Design: Families with a surviving sibling (age, 8 to 17 y) were recruited from cancer registries at 3 hospitals in the United States and Canada 3 to 12 months ($M = 10.4$, SD = 3.5) after the child's death.

Setting: Data were collected in the home.

Participants: Participants (N = 99) included 36 mothers, 24 fathers, and 39 siblings from 40 families.

Outcome Measures: Each participant completed a qualitative interview that was audio recorded, transcribed, and coded for thematic content.

Findings: Five major themes included the need for: (a) improved communication with the medical team, (b) more compassionate care, (c) increased access to resources, (d) ongoing research, and (e) offering praise. Interwoven within the 5 themes was a subtheme of continuity of care.

Conclusions: Many participants were pleased with the care the child with cancer received, but others noted areas in need of improvement, particularly medical communication and continuity of care. Additional research is needed to inform interventions to improve services for families of children with life-limiting conditions.

Key Words: pediatric cancer, advice, bereavement, communication

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Nearly 60,000 children die each year in the United States and Canada, and cancer remains the leading cause of death by disease for children aged 1 to 19 years.[1,2] Despite some improvements in symptom management and suffering among children at end-of-life (EOL),[3] progress in pediatric palliative care has been slow.[4] Challenges are multifaceted and include the need to improve communication between families and health care providers,[5,6] train medical providers to accurately assess and manage symptoms at EOL,[7–10] provide continuity of care,[11,12] and increase the availability of effective support services for families.[13]

Quality improvements in EOL care have typically been measured from the perspective of families and health care providers through 1 of the 3 avenues: (a) satisfaction surveys,[8,14] (b) needs-based assessments,[8,15] or (c) qualitative feedback.[16] Research has described parents' perspectives on EOL care,[17–19] the communication of bad news,[12] and decision making,[20,21] with several common issues emerging. Parents report honest, clear, and consistent communication with medical staff is most important to their child's care and overall experience at EOL.[8,19,22,23] Compassionate, skilled care by providers,[11,12,24] access to support and financial resources,[23] and continuity of care are also highly valued.[22,25–27]

Unfortunately, we still know little about how to improve pediatric EOL care and translate these findings into clinical practice. Most research has focused on the perspectives of mothers; few studies have included fathers or siblings. Also, most retrospective reports include interviews obtained over a year after a child's death. Thus, we conducted qualitative interviews with mothers, fathers, and siblings, on an average within the first year after a child's death from cancer, to solicit their advice to health care providers and researchers. Through systematic analysis of subjective, experiential data, we categorized responses based on thematic content. We expect that these data will enhance the ability of health care providers and researchers to better serve the needs of families of children with cancer and other life-threatening conditions.

METHODS

This research was part of a longitudinal study of families after the death of a child from cancer. Data collection in the larger study involved visits to bereaved siblings' schools and homes on average within the first year after the death, followed by another home visit 1 year later. We included cross-sectional, qualitative data from a subset of families at the first home visit.

Procedures and Measures

Institutional Review Board approval was obtained at each of the 3 data collection sites, including Nationwide Children's Hospital in Columbus, OH; Vanderbilt University Medical Center in Nashville, TN; and Hospital for Sick Children in Toronto, ON. Families were sent a letter of

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introduction from the child's attending oncologist and recruited through phone by study staff 3 to 12 months after the child died. Informed consent/assent was obtained from participants. For the larger study, research assistants administered a series of questionnaires and conducted semistructured interviews. Individual interviews with open-ended questions were conducted one-on-one with each family member after questionnaires were completed. Participant responses were audio-taped for transcription and coding. Data for this paper were derived from answers to one of the interview questions:

What advice, if any, do you have for us as health care providers and researchers, who work with children and families?

Participants

At recruitment, eligible families: (a) had a bereaved sibling 8 to 17 years old, (b) were fluent in English, and (c) lived within 100 miles of the hospital. Adopted, half-siblings, and step-siblings were eligible if parents reported that regular ongoing contact had occurred between the sibling and the child who had died. When >1 eligible sibling was available, one was randomly selected to participate from each family.

Of 60 eligible bereaved families who were recruited, 41 (68%) participated in the home visit. Qualitative data were missing from 1 family because of a tape recording malfunction, and 1 sibling was too upset to participate in the interview portion of the assessment. Thus, participants (N = 99) included 36 mothers, 24 fathers, and 39 siblings from 40 families. Mothers averaged 40.5 years of age (SD = 7.4), and 78% (n = 28) were white. Fathers averaged 43.9 years of age (SD = 7.8), and 83% (n = 20) were white. On an average, parents had some college education (*M* = 14.5 y, SD = 2.2), and family socioeconomic status (*M* = 44.2, SD = 25.1) using the revised Duncan[28] reflected clerical, sales, and service occupations. Most siblings were female (64%, n = 25), white (72%, n = 28), with an average of 12.3 years of age (SD = 2.6). Deceased children averaged 12 years of age (SD = 5.3), with approximately 2.7 years (SD = 2.3) from diagnosis until death. Data collection occurred about an average of 10.4 months (SD = 3.5, range 6 to 19 mo) after the child's death.

Analysis

Four researchers independently analyzed the data through content analysis, a qualitative approach for analyzing data from open-ended questions.[29,30] Details on the coding procedures have been reported.[31] In short, researchers repeatedly read the transcripts to gain an overall sense of the data. Similar ideas were clustered from 15 transcripts, and preliminary categories emerged. Researchers reviewed the initial coding scheme, extracted quotes, and repeatedly discussed the rationale for emerging categories after independent analysis of each set of transcripts. Data were reexamined by recoding original transcripts and making mutually agreed upon changes (eg, editing category names, combining/dividing categories). Fifteen new transcripts were added, and new codes were adopted when data did not fit into an existing category. Memos containing questions, possible comparisons, and leads for follow-up were kept throughout the coding process.[32] Researchers repeated this analysis until they reached consensus, and no new categories emerged (ie, saturation). Parent transcripts were coded in their entirety first; transcripts of siblings were coded second.

FINDINGS

After content analysis, 5 major themes emerged representing a range of advice from bereaved family members. Themes included the need for: (a) improved communication with the medical team, (b) more compassionate care, (c) increased access to resources, (d) ongoing research, and (e) offering praise for the medical team, hospital, and research. Interwoven within the 5 themes was a subtheme of continuity of care. Aside from praise, 4 parents stated "nothing" or had no advice, but it was notable that 13 of 39 siblings (33%) had no advice.

Communication

The need for improved communication with the medical team was a major theme for families. Parents and siblings provided advice about what, how, and to whom information should be communicated. One mother shared opinions on the specific information that should be communicated to parents stating, "…when they tell you… 'There's nothing we can do,' then you kind of wonder, 'What is it going to be like? What are the changes?'…It didn't seem like we had a lot of information about what it would be like." Another mother valued having details about what to anticipate: "I always wanted to know…if this happens where do we go, and if this happens where do we go?" While having details were important to these parents, 1 mother emphasized the need for also understanding the big picture: "…at first the doctors tell you the prognosis isn't good, and then after a year or so you kinda tend to forget that. Sometimes you just need to maybe rethink that. You gotta stop and take time to look at the big picture."

With respect to how communication should occur, parents repeatedly emphasized that health care providers should be open and honest. A mother shared, "I wanted to know honestly…are you telling me we have a chance? If we don't have a chance, then tell me that we don't have a chance. Don't sugarcoat it or tell me, 'This is the best thing you should do.' Tell me everything and let me decide what the best thing is to do." Another mother wanted "more honesty from the doctors. 'Cause it seemed like they knew things, and they didn't want to say the whole truth or made it seem a little better than it was." A father stated that he was pleased with the information that was communicated to him: "Her doctors didn't really sugarcoat anything to make us believe that there was still hope when there wasn't. Through some of the therapy, I was hoping that maybe this will work…there were things I would hope for, but they (medical staff) didn't lead me on. They never, never did that I think I was pretty informed."

Parents acknowledged the difficulty in communicating bad news but offered that they need to be heard and a delicate balance must be maintained. One mother felt information should be repeated to families to ensure their understanding: "Keep on keeping on…even when they (the family) just don't want to let the hospice people step in the door…because we will eventually come around." Another mother suggested that parents' perspectives should be acknowledged: "I want them (medical staff) to respect my point of view as much as I was respecting theirs…They were pressuring (me) to make decisions that I knew were not right at that time. We know that they've been taught. We are very grateful for what they are doing. They do their best, but there are those times that they have to listen to parents."

Other parents offered advice about with whom information should be shared. The mother of a teenage patient stated, "Talking more doctor-to-parent because (deceased child) was older, they told her everything that was going on. There was nothing hidden from her. Maybe if it had been discussed with me more, I could have had a more realistic attitude rather than encouraging her to try. I think it would have been better, looking back, if—yes they told her everything—but still took me aside and said more of the bad things." Some parents focused on including the siblings, such as a father of an adolescent sibling: "The communication with the doctors never included (sibling). Never.... We feel like we talked to (sibling)... but I know that it was pretty tough for her, 'cause our focus was so much on (deceased child)."

Siblings provided advice about how medical teams could communicate more effectively with them and noted the need to be included in a developmentally appropriate manner. One 17-year-old sibling stated, "The doctors, they mostly just talked to my parents, but it might have been nice to have been included in stuff like that." Similarly a 14-year-old sibling added, "They (doctors) talked to me, but they kinda talked down to me like I was stupid, "cause I'm younger." "Some people change depending on the situation they're around. Some people get more sophisticated than other kids. So they have more of an adult mind," added a 13-year-old sibling.

Compassionate Care

Family members offered advice to health care professionals about their need to feel supported and cared for throughout the child's illness. A father encouraged health care providers to "realize that (these) are special people that ya'll work with." A mother added, "These kids are dying, and they know they are dying. Some of them (health care providers) need to be more compassionate." A father stated, "You don't want to think that your child is just a patient at a hospital. Treat them more as an individual... rather than just a patient on a clipboard." Another father added that "during some of the more stressful times the (health care providers) were... a little less than compassionate, more of a matter of fact of business. I understand they can't make promises, but I didn't want promises that everything would be okay. But at the same time, I want their promise that we would get through it." Siblings also echoed the statement that their brothers and sisters want to be treated like normal kids. One 16-year-old sibling said, "Treat them (patients) like human beings... not like they're sick." However, one 13-year-old sibling cautioned health care providers not to become too attached to their patients: "You can get close to your patient, but don't get really, really close... just close enough to know their name and what they do. Because if you are really, really, really, close... then you'll be sadder in life, 'cause you'll be treating them like they were your own."

Parents also provided important considerations for health care providers who interact with siblings of patients. One father stated: "Give the siblings a chance to spend some time with the kids that are sick... let them have those last memories of them." Siblings also emphasized the importance of visiting their brother or sister in the hospital. One 15-year-old brother said, "I couldn't go up and see her till I turned 13, 'cause she was in the myelosuppression unit... I couldn't go up there for a really long time and that really bothered me."

Resources

Some parents and siblings requested better access to tangible resources such as financial assistance, respite care, and formal support services. A father offered, "The government needs to help more... I shouldn't have had to work sixty hours a week just to keep this place (house) while she was in (the hospital). I couldn't visit. I wanted to, but I couldn't. There should be more help for parents when they have a sick kid... They should be more helpful for parents, financially." Regarding the use of respite care, one mother stated, "I wish we could have started that (respite) earlier... That support (or)... help for me taking care of her. Like when we had hospice, I had somebody. Not (that I) always needed it, but if I did, then they were there."

One mother discussed the need for support groups close to her home: "I know they offer support groups for parents... I haven't gone to any of those. Mainly, because they're at the hospital, and I just can't seem to step my foot in the hospital again. And maybe if they had something like that for siblings." Another mother stated, "I found that when we left the hospital for the last time, it was really sad knowing that there's no help after this. There's no telling how to get resources and that it was just... it was nothing. After... you're at home, you hit reality and there's no one there to tell you what to do or give you any help, especially in small towns." A mother suggested support groups needed to be specific to cancer: "I was looking for a support group specifically for parents who had lost a child to cancer. ...I did attend a couple of (support group) meetings, and it didn't really... I guess comfort me as much as I thought it would, because I was the only parent there that had lost a child to cancer. Most of them were sudden deaths. I think enduring... a long-term terminal illness is just... the emotions are a lot different..." A 14-year-old sibling noted the need for a "support group for teens... they need to have more people who are trained to deal with teenagers." Another mother emphasized the need for individualized support: "There's one lady... a grief counselor. She incessantly asked, 'Well, how did that make you feel? What did you do when you felt that way?' Everything was that, question and answer. Her tone was very 'feeling sorry for me,' and I didn't need that. I needed somebody to help me to get up and to go somehow. I know not everybody is the same, but it was almost like she was asking the same questions of everybody. So, we didn't see her again."

Research

Families noted the need to continue research in pediatric cancer and grief. One mother stated, "Keep doing studies. Because the more that is done the better things are going to get. You can't just do one and expect it to be complete, because you are going to eventually find other things that you missed in the first study." Another mother explained the importance of continuing research with bereaved siblings: "I would say definitely continue this work, and help the child that deals with the death of a brother or sister... to do what they can to find out what would help them get through the grief process." A father emphasized the importance of participating in research: "You (researchers) should be part of the resources available from the beginning. It gives you a better chance to track (families)... and the questions you ask may give you some answers... and are a nice, subtle way of getting the person to start to deal with all the issues." One father referring to medical research stated, "I mean hopefully they'll find a cure for cancer," and a mother urged, "do more (research) on it (cancer)…'cause children really shouldn't get cancer." Another mother poignantly echoed, "Just find a cure."

Praise for Hospitals, Health Care Providers, and Research

When asked about advice for health care professionals and researchers, many parents and siblings provided praise for the treating institution and staff. Their advice was to "keep up the good work" as one father stated. One mother described the treatment center and health care providers as a source of support: "I love (treating hospital). They're really good with kids and also the parents…If I didn't have them there, I think I wouldn't have done anything or couldn't have survived that. When (deceased child) passed away, all the doctors, the nurses, and everybody, they just came downstairs and they hugged me and they kissed (deceased child) goodbye. I keep that memory that they came for us. They didn't care they were busy at that time. They just came down to say goodbye." Similarly a father praised the medical staff: "Everybody we met was just so willing, and if they didn't know, they would find out, and you always got an answer…Although the end result for us wasn't what we wanted…there's nothing else that you could have done. It was as if we were the only ones there that were being cared for."

A mother praised the caring treatment her child received: "Everybody is super duper nice, and they really made (deceased child) a part of it. Treated him like he was a human, not like somebody, 'God, he's got cancer.' So, that was really, really good." Similarly a father offered, "Keep up the good work. You people are awesome…I don't know how you do it, but I'm thankful that you do." Siblings also offered praise: "(Staff members) were good…they were just friendly and helpful," said one 10-year-old. "The day passes were great. My sister loved them except it was hard for her to go back to the hospital," stated a 13-year-old sibling. A 14-year-old sibling said, "Having things the way they were, like the game room and lounge. That was pretty cool. So, it just made kids feel a bit like nothing was wrong with them. It's not like they were just trapped in their room…they can go chill."

Parents and siblings also offered praise for bereavement research: "I think that your work is often difficult, having to work with people who have lost their sons…You are helping people talk about the death of their child and that helps us to relieve some of the tension, and I think it's good." One father said their involvement in research made their family feel included: "I would say you are doing a good job. Keep up the good work. This is the first time for us to have such a thing, but it's wonderful. We feel we are not left out. That is, we have somebody who thinks about us." Another mother articulated: "It is nice, because people that are in my situation, we really need someone to reach out for and talk about this. I know that you know what to do, but doing this…it's meant a lot to me."

Similarly, an 11-year-old sibling stated the importance of allowing children to have a voice in research: "I think this is really good how they're doing this (research) with kids. It's really nice how kids can express theirself (sic) and show…between the 2 (settings: school and home) how different kids talk in different places about death." Similarly, an 11-year-old sibling praised the data collection in multiple settings: "The other girl (researcher) came to my school, so that's a good way to gather information and…it's nice that you actually go to the family's house, so it's not like, out of the way for families." Other siblings praised the research conditions, such as this 10-year-old sibling: "I like it when you talk to people in private. Sometimes when you talk to people in front of other people, or if you think other people are going to read what you wrote…then you don't really want to put the truth down."

Continuity of Care

A subtheme regarding continuity of care and continuity of communication with the health care team was woven throughout the 5 major themes. Families described continuity as important: (a) for communication between staff members during hospitalizations, (b) when coordinating medical care during transitions between services or hospital units, and (c) in reference to families' desire to remain connected to staff after the death of their child. The importance of continuity of communication among health care providers during transitions between medical services was highlighted by 1 mother: "The ICU is not as stringent on the rules as they should be with the BMT patients. So I think the ICU might need a little bit more training on how to do BMT patients." Similarly, a father recommended that transitions between services could be handled more seamlessly: "There was a certain point of transition in our care…where we were going from patient care to hospice care. It seemed like that transition was very abrupt…It would have worked better if we'd had a meeting with our doctor and the hospice doctor in the same room. Or our nurse and the hospice nurse…you know? Ok, boom! You're in hospice, and you've got new forms and new doctors. Everything's different…you know it's just a hard time to deal with it. The transition could be handled much better, just a simple meeting. It was a little more abrupt than we expected. And for a certain amount of time we felt a little…lost is probably too strong of a word…but it was unsettling." In addition, a mother explained: "All along through our whole process, the only complaint we ever had was communication. Sometimes we thought there was a lack of communication. You have a big facility like this and you have these wonderful nurses and then they leave, and sometimes things don't always get (communicated), especially if there's an issue. The bigger the facility probably the more that is."

A mother described the attachment that families form with health care providers: "It's kind of interesting, because when you've gone through a long illness and everybody is like your family, then when your child passes, there's that whole segment of your life that goes away. And you feel kind of awkward like you've broken up with somebody. Anytime you wanna come back and visit us…it would be probably a good thing to do. You kind of feel like you don't belong there (the hospital) anymore, but then you instinctively just want to go visit like you're gonna find something." A mother urged health care professionals, "Just continue to remember, because I don't think people should put a time frame on a loss…like hospice, they keep in touch with you for two years… I think that's wonderful, because it's not like 'okay, well, their child is gone now. Let's move on to the next family.' Even the doctors and nurses are still asking how we're doing. And that's wonderful to know as a parent, that not only your child, but that you as a parent touched people's lives." One mother discussed the positive and negative aspects of keeping in touch with health care providers: "It's really nice to know that there are people out there that are trying to make things easier. It is probably the worst thing that you could go through. I know that sometimes it's hard to keep in touch with people that remind you of that time, but last night, we, as a family, had our flu shots and one of the nurses doing that was one of (deceased child)'s last nurses, and so it was so great to be able to see her and hug her, and on the other hand, you get all these memories back that weren't so great."

DISCUSSION

Responses from families in our study provide a better understanding of how parents and siblings perceive their experiences in the health care environment after a child's death from cancer. Findings indicate that while there are many things that we as health care providers do well, there are still areas for improvement. Consistent with other studies, families reported that they want open and honest communication,[18,19,23,33] compassionate care from providers,[11,33] and access to tangible resources and emotional support throughout their child's illness and after the death.[13,23] The inclusion of siblings added a unique perspective. Specifically, siblings of children with cancer offered more concrete advice that emphasized the need for child-centered care and the desire to be included in a developmentally appropriate manner.

Both parents and siblings emphasized the importance of communication throughout the care of the ill child. Parents indicated that having a clear understanding of their child's medical status and prognosis throughout the course of their illness allowed them to make more informed decisions on behalf of the child. They recognized the challenge for health care providers to tailor communication to the family's needs, sometimes needing to emphasize the "big picture," other times providing details. Sometimes including all family members then determining when conversations should occur with parents alone. Sometimes letting parents guide the conversation, while other times needing to be persistent and coaxing parents toward a difficult decision. Given the artfulness and skill required for these challenging exchanges, it is not surprising that some families did not perceive open, clear, and consistent communication from staff. Parents may also have a different impression of communication in hindsight relative to their experience in the moment. Recently, interventions and educational initiatives have aimed to improve medical communication,[34–36] but many health care providers still report they do not feel adequately prepared to give bad news, discuss EOL issues, or have conversations about sensitive topics with families.[8,37] Hence, these areas of communication remain important topics for future research and clinical care.

Parents, especially, noted the importance of continuity of care and communication across health care providers, clinical services, and different phases of their child's illness experience. Again, families recognized the challenges to providing continuity, particularly with regard to accessing services after a child's death. Our findings mirror previous work,[38] and a consensus statement suggesting that continuity of information, relationships, and illness management are core aspects of continuity of care.[39] A recent review suggests that continuity of care may be associated with some improved outcomes (eg, better preventive care, fewer hospitalizations, lower costs),[40] but most research has focused on primary care. Additional work is needed to examine the impact of continuity of care on other quality indicators (eg, family satisfaction, psychosocial adjustment) in pediatric oncology.

When considering the unique perspectives of mothers, fathers, and siblings, we found some similarities and differences. Mothers and fathers were relatively consistent in their advice. Siblings' advice also overlapped with their parents, but they tended to value making the hospital and overall care more child-centered. For example, siblings emphasized the need for health care professionals to treat the ill child like a "normal kid," while providing them with high quality, compassionate care. In addition, siblings wanted to be informed throughout their sibling's illness. This concrete advice from siblings is similar to previous findings from parents, who reported the need for siblings to be involved in the care of the ill child at EOL.[22] Although one third of siblings and a few parents did not offer advice, it is difficult to determine why. It is possible that siblings were fatigued at the end of the interview, less able to verbalize their feelings, or simply satisfied with their experiences at the hospital. Regardless, it is important to include siblings in future work, as they are often overlooked, but key members of the family system when a child is ill.[41]

Historically, research with bereaved families has been a sensitive and difficult venture.[42–44] However, families in our study valued the research and seemed grateful for an opportunity to contribute. Families reported participation in research was an important part of their experience after their child's death. They appreciated being remembered, having a connection with the hospital, and the opportunity to express themselves and potentially help others. Despite the sensitivity that must be maintained when recruiting and working with bereaved families, families may use their involvement in research as a way to contribute to their child's legacy or find some sense of meaning in the death of their child.[45] It seems that some families view their participation in this work as a way to give back to other families and/or assist them in processing their loss.[42,45]

There are several methodological issues that should be considered when interpreting our findings. Our sample was primarily white and limited to families who lost a child to cancer. Results may not generalize to families bereaved of other significant relationships or those who experienced a death from other causes.[46] Approximately one third of eligible families declined participation, which could have introduced a self-selection bias. Although each site is a large pediatric tertiary care facility, psychosocial services and resources vary. Further, the degree to which families used these resources either before or after the death was not tracked and may vary within site. Data are also cross-sectional and retrospective, and family perspectives may change over time. Lastly, the interview question came at the end of a long assessment that may have affected the length and content of the open-ended responses. Nearly one third of siblings had no advice, and younger siblings tended to provide shorter, more concrete responses than older siblings. Thus, it is possible that we did not reach saturation for data from siblings.

Despite these limitations, this study is one of the first to obtain advice in an open-ended format from families directed at health care providers and researchers, who work with seriously ill children. Findings provide some insight into areas for continued improvements in the provision of care, and the conduct of research. Our findings highlight the importance of continually assessing the communication preferences of individual family members throughout the illness, and their preference for continuity of care, especially after a child's death. There is also room for hospitals to improve policies and enhance training and communication within and across services, and between families and health care providers. We should include siblings when possible and encourage families to express their wishes and advocate for their needs. Although some health care systems have relied on patient navigators for this purpose, these services have not been rigorously evaluated or widely used in pediatrics.[47,48] It is important to remember that bereaved families are willing to participate in research, if it is conducted in a manner that is sensitive to their situation. Ongoing work is necessary to learn more about the needs of these families, particularly siblings, after a child's death. However, there is always a delicate balance between engaging families in research to gain information and not placing an additional burden on them.

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