

**Helping parents live with the hole in their heart:
The role of health care providers and institutions in bereaved parents' grief journeys**

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Precis for use in the Table of Contents: Parents of children who die often suffer from significant psychosocial and health sequelae and may benefit from ongoing support and resources throughout their grief journey. In this article, bereaved parents identify the quintessential components of bereavement support that they believe should be provided by individual members of the medical team and by the institution as a whole.

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Abstract

Background: Bereaved parents experience significant psychosocial and health sequelae, suggesting that this population may benefit from ongoing extension of support and resources throughout the grief journey. The interaction of hospital staff with patients and families at the end of a child's life and after death profoundly affects parental grief, offering a unique opportunity for the medical community to positively impact the bereavement experience.

Objective: To explore the role of the health care team and medical institutions in the grief journeys of parents whose child died a cancer-related death.

Design: Eleven bereaved parents participated in 2 focus groups. Responses to each of the 3 main prompts were coded and analyzed independently using semantic content analysis techniques.

Results: Four main concepts were identified within the parental narratives, including the importance of strong and ongoing relationships between providers and bereaved families, the importance of high quality communication, the effect of negative experiences between providers and families on parental grief, and the importance of the institution's role in the grief journeys of bereaved parents.

Conclusion: Bereaved parents consistently identify the critical role played by medical staff and medical institutions throughout the grief journey. Key components of bereavement support identified by parents should serve to guide the actions of providers as well as provide a template for the development of a comprehensive bereavement program within an institution.

Keywords: bereavement, grief, bereaved parent, bereavement program, communication, end of life, palliative care, cancer, pediatric oncology, healthcare provider

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"I often say I have a hole in my heart and I can hear the wind blow through it. Some days I actually hear that wind whistle through my heart. If I don't feel that way I think there's something wrong."

– Bereaved parent

Introduction

The death of a child is an unimaginable and devastating event, resulting in profound grief for surviving parents. Bereaved parents frequently experience debilitating feelings of shock, helplessness, and guilt,¹ and for many parents, the grief journey may be intense and prolonged.² Bereavement can adversely affect interpersonal relationships and societal functioning, leading to negative feedback cycles of compounded isolation and anguish.³ Further exacerbating this cycle, parents with unresolved or complicated grief may suffer from worse psychological and physical health, including increased risk for chronic mental and physical morbidities.^{4,5} The phrase "dying from a broken heart" is often invoked in a figurative sense, and yet the death of a child is literally associated with an overall increase in mortality for bereaved parents.^{6,7}

These significant sequelae experienced by grieving parents highlight the need for ongoing care and resources targeted specifically to this bereaved population,² and a multidisciplinary approach is needed to provide optimal bereavement care to parents.¹ Unfortunately, the bulk of supportive services typically are offered during illness and at the end of life, with limited resources available to families after a child's death and many families may receive little or no bereavement follow-up.⁸ Pediatric palliative care team involvement increases institutional bereavement support, but this continues to be mostly reactive in nature.⁹

Despite this, parents consistently identify a need for improved bereavement support, and they emphasize their deceased child's healthcare providers (HCPs) and medical institutions as integral sources of support throughout the grieving process.^{2, 3, 10} Parents highlight the importance of having institutional services to assist with the difficult transition from primary medical center to the community either before (as in transferring to hospice care) or after the death of a child¹⁰ and recognize a need for improved support at other times, including better anticipatory guidance to prepare for death and bereavement and standardized provision of grief support services following the child's death.¹¹

Further study of bereavement perspectives has been identified as a top research priority in palliative care¹² and efforts are underway to better understand the preferences and needs of bereaved parents. To begin to address this gap, we conducted a focus group-based investigation of bereaved parents of children with cancer to explore the nuances of their grief journeys before and after the death of their child, including ways in which the members of the health care team and institution participated in their grief experience. To our knowledge, this is the first study of bereaved parents of children with cancer to focus on the ongoing role of healthcare providers and institutions in the parental grief journey.

Methods

This study was approved by the St. Jude Children's Research Hospital Institutional Review Board. Eligible participants included parents whose child died during or after receiving medical care at our institution and were recruited from an advisory council at our institution; there were no exclusion criteria. The two audio-recorded focus groups occurred in March and August of

2014 and took place at our institution. A clinical psychology doctoral student with extensive experience working with bereaved parents but without clinical responsibilities at the institution served as facilitator of both focus groups. Two additional members of our investigator group were present, neither were involved in the clinical care of any of the deceased children of participating parents. Audio-recordings were transcribed by an independent group, with all personal identifiers removed.

Analysis

Three main prompts were developed by our investigator group for use during the focus groups based on review of the literature. Transcripts for each prompt were independently analyzed, and responses to each prompt underwent qualitative semantic content analysis¹³ performed using MaxQDA software. Parental replies to each prompt were characterized as a unit of response, and specific phrases were characterized as the unit of analysis within each.

Two study team members (JS and EK) jointly reviewed the transcripts and applied codes to each key phrase to capture meaning. A third team member (JB) reviewed the codes associated with representative quotes to ensure content validity. A fourth study team member (DG) separately analyzed the transcripts and applied previously defined codes to the transcript to demonstrate reliability.

Responses to each prompt were analyzed independently and the frequency of the codes was tallied for each prompt using semantic content analysis techniques.¹³ To compensate for multiple appearances of the codes within a single answer to a prompt, we also tallied the total number and

percentage of parents for whom the code appeared. In this analysis, we focus on the role of HCPs and the institution on the parental grief journey.

Results

Thirteen parents were recruited to participate in the study, 11 (85%) of recruited parents participated in each of the two focus groups included in this analysis; 8 parents participated in both groups. Participants in both groups were predominantly Caucasian (82%) and female (82%). Parents in the first focus group had experienced the death of their child a mean of 6 (range 1.5-14) years prior; participants in the second focus group had lost their child a mean of 4.8 (range 1.5-7.6) years prior to participation. The child of one parent in each focus group died at home with hospice care (total n=2, 15%, with a different parent/child represented in each focus group), the remainder of the children of participating parents died in the hospital. The mean inter-rater reliability between the consensus established by the first 3 investigators and the fourth investigator was greater than 80% for all prompts.

Table 1 comprises the comprehensive summary of codes and themes related to the role of the HCP and institution on the parental grief journey, including example quotations.

Prompt 1. Tell me about your grief journey before your child's death. What are some things that helped you as you went through this?

For the first prompt, a total of 201 segments of text were coded using 31 de novo codes. The code “explaining the medical background,” in which parents explained the clinical situation prior to their child's death, was used 14 times but not included in the final analysis because it did not relate directly to the prompt. The remaining 187 coded segments were grouped into 7 main

themes. The most common theme related to the role of the HCP/institution was “importance in preparing for death” (codes in this theme represented 17.6% of coded segments).

Prompt 2. Tell me about your grief journey/bereavement experience after your child’s death.

What are some things that helped you?

For the second prompt, a total of 301 coded segments encompassed 32 unique codes; codes were then grouped into 7 different themes. Codes under the theme ‘how to help a bereaved parent’ represented 27% of coded segments.

Prompt 3. What services can we offer to bereaved parents that would help them in their grief journey, and what is the appropriate time to offer them?

For the third prompt, a total of 98 text segments were coded using 14 different codes, which were grouped into 3 themes. The 2 most common themes were the “institution memorializing the children” (56% of coded segments), and “institutional bereavement support” (25% of coded segments).

Discussion

In our analysis of responses given by bereaved parents of children who died from cancer, the effect of HCPs and the institution on the bereavement experience permeated the grief narratives. Four prevailing concepts emerged from our analysis of these narratives: 1) the importance of strong and ongoing relationships between HCPs and bereaved families, 2) the importance of high quality communication between HCPs and families, 3) the effect of negative experiences

between HCPs and families on parental grief, and 4) the importance of the institution's role in the grief journeys of bereaved parents.

Strong and ongoing relationships between HCPs and bereaved families

Both around the time of their child's death and during the subsequent bereavement period, parents perceive their relationships with HCPs to be critically important, noting intimacy, close bonds, shared understanding, physical presence, and emotional availability of HCPs as being important components of bereavement support. Parents also identify the importance of maintaining their connections with HCPs well past the death of their child, placing emphasis on the need for structured opportunities to make contact and share future experiences with their child's HCPs:

“For me personally, it's been [a] very important part of my journey to continue those relationships with the people that were on [my son]'s care team that took care of him and to continue to share our family's life with them.”

As evidenced in the literature, collaborative relationships between patients, families, and HCPs are also integral to formation of the therapeutic alliance.¹⁴ A well-fostered bond between patients, families, and HCPs can aid with the process of difficult decision-making around goals of care at the end of life¹⁴ and enable families to maintain hope.¹⁵ Our findings suggest that bereaved parents continue to value this therapeutic alliance well beyond their child's death, identifying it as an important component of support throughout bereavement. Perhaps most notably, bereaved parents particularly valued those actions that centered on presence and understanding, as opposed to those actions focused on cure-based medical interventions or fixing

an identified problem. This finding suggests that an effective provider should be able and willing to flexibly shift his/her identity from a medical provider to a healer who bears witness and walks with parents throughout the grief journey.

High-quality communication between HCPs and parents

The importance of HCPs delivering transparent and empathetic information to parents and families has been previously described.¹⁶ Empathetic delivery of difficult news or discussion of end-of-life topics, including prognostication delivered in the context of a caring relationship, is associated with lower levels of long-term parental grief.^{15, 17} Our findings corroborate that bereaved parents want clear information provided to them in a timely manner, as well as support and assistance in making decisions about care. Parents also acknowledge that transmission of information should be followed by decisional support without judgment, allowing parents to have a degree of control in an otherwise chaotic situation.

Bereaved parents also emphasize that quality communication involves providing anticipatory guidance around the end of life and that bereavement support should begin before the child's death. Parents identify a need for HCPs to assist families and patients in recognizing imminent death and support them in discussions about goals of care with a focus on comfort and amelioration of suffering. Importantly, some parents reflected that their grieving process began at the time of diagnosis, while others noted that it began at the time of disease progression, at the end of life, or after their child's death. Regardless of each individual's timeline for initiating their grieving process, parents unanimously voiced a desire for additional support from HCPs throughout their bereavement journeys.

Bereaved parents also articulated their expectation that HCPs be highly trained and skilled in facilitating and supporting parental discussion around end-of-life issues. Unfortunately, there remain significant deficits in formal communication training for providers, especially as it pertains to difficult decision-making at the end of life.^{18, 19} Bereaved parents recognized the consequences of this gap and offered suggestions for improving HCP communication training, including a willingness to assist with the training process. As a result of these and prior suggestions, our institution has developed communication training sessions for nurses and physician trainees that utilize bereaved parent educators in both interactive role-plays and educational seminars and we have ongoing efforts to determine the effectiveness of these education interventions.

Effect of negative experiences between HCPs and families on parental grief

In this study, bereaved parents identified negative experiences with HCPs as not helpful, including HCPs' avoidance of difficult conversations, failure to provide frank information about illness severity, provision of overly optimistic prognostication or unrealistic treatment options, and suboptimal transitions between medical teams resulting in fragmentation of care and feelings of abandonment. Parents reported that these negative interactions led to decisional regret and self-doubt about care decisions that transpired at the end of life:

“But there’s some things that we regret, and I think it was because of lack of communication.”

These findings suggest that incomplete, inaccurate, abrupt, harsh, or thoughtless communication can have a lasting and detrimental effect on bereaved parents. Even a single negative interaction may leave emotional wounds that do not heal.²⁰ As championed by bereaved parents themselves,

special attention should be taken in training providers to provide clear and complete information including prognostication and anticipatory guidance, with an emphasis on improving communication at times of care transition, evolution of illness severity, and end of life, in an effort to abrogate parental perceptions of abandonment and solidify the therapeutic alliance.

The institution's role in the grief journeys of bereaved parents

In this study, bereaved parents emphasized the importance of HCPs and the institution as a whole in acknowledging and prioritizing formalized grief supports for parents, families, and staff.

Bereaved parents in this study identified 2 deficiencies in particular: the lack of a structured, institutionally-led bereavement program, and the absence of a physical memorial to honor the children who died after receiving care at the institution.

In recognizing the importance of formalized institutional bereavement support, parents proposed 3 concepts integral to the development of an effective institutional bereavement program, which expand on the limited literature addressing the current status of bereavement programs:²¹ 1) bereavement support must be personalized because no two parents experience the same grief journey; 2) bereavement support must be readily available/accessible to parents at any given time along the grief trajectory because different parents might benefit from services at different times; and 3) bereavement support must be tangible, with concrete resources and institutional contacts provided to families. In addition to grief support, parents also suggested that legacy-building and memory-making opportunities should be made available by the institution, both before and after the child's death.

Another particularly important issue for bereaved parents involved institutional acknowledgment of the right of a deceased child to be remembered and memorialized by HCPs and the health care establishment itself:

“I think the hospital has an obligation to recognize this, that not every child that comes here is going to be saved.”

Parents emphasized that they harbored a strong connection with their child’s place of care or location of death, identifying this location as “sacred” and thereby warranting an on-site memorial. The deep connection to the institution and desire for a memorial was noted by parents whose child died at home as well as those that died in the hospital. Parents also felt that, by memorializing the children who died, the institution would be providing a de facto open invitation to bereaved families to return as well as a location to visit upon their return. Institutional memorialization of the children who died also might create an environment that enhanced dialogue about death as a part of life, potentially leading to more frequent and transparent discussions between HCPs and families about goals of care throughout treatment and especially at the end of life. Finally, parents proposed that programs that encourage and support bereaved families’ return to the institution would not only facilitate legacy-building opportunities for the bereaved but might also yield positive effects for providers as well by providing a sense of closure as well as potentially mitigate the high rates of burnout and staff turnover inherent in pediatric oncology:

“And I wonder how would it impact their compassion fatigue, I wonder if it would impact turnover rates, ...all of those things that are hard, to be able to interact with the families whose children die, I think, would be huge in helping them to continue on in what they’re doing...”

We acknowledge that this study has several limitations, including the fact that the analysis involved a small cohort of bereaved parent participants. Recall bias also must be considered, as some parents experienced the death of their child many years prior to participation in these focus groups. Additionally, this study includes parents from a single, oncology-based institution, with primarily Caucasian bereaved parents that self-selected into this study and the focus groups occurred on the grounds of the treating institution. Given evidence that parents may find it difficult to return to the location of death ²² in addition to the previous factors mentioned, participants may not be representative of bereaved parents in either the larger population or the institution.

Conclusion

Bereaved parents consistently identified HCPs and the institution as integral aspects of their grief journeys, with particular emphasis on the importance of developing and continuing strong and ongoing relationships between HCPs and bereaved families, providing high-quality communication throughout the grief trajectory, and preventing negative experiences that may have a lasting effect on parental grief. These findings should serve as a call to arms for all pediatric providers and hospitals to provide formalized bereavement support to parents of children with life-limiting conditions beginning during the child's illness trajectory and extending well beyond the child's death (Figure 1). This study is the first in a series of trials currently underway aimed at augmenting and further developing a comprehensive institutional program to support bereaved families that is based on input and feedback from bereaved parents themselves. We are conducting in-depth interviews with a number of other bereaved parents to further identify bereavement needs and we have ongoing quality improvement and other

quantitative studies to determine the effectiveness and impact of the various program components. Finally, we have a planned prospective cohort trial to more accurately longitudinally assess the grief of parents with a goal to eventually provide interventions aimed at better supporting families throughout their grief journey.

“I’m always going to have this grief, I’m always going to have just, sort of this big, gaping hole in my heart with the wind blowing through but, at the same time, that doesn’t dictate that I can’t be happy, that I can’t have joy and bring others joy. You know? It’s sharing his story, a lot of times, that’s what I’m getting from it, is strength. Strength, he didn’t get from me, I get it from him, it lives on...”

– Bereaved parent

Figure Legend

Figure 1. Bereaved parent directives for grief support to be provided by pediatric providers and healthcare institutions

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Table 1. Overview of the role of the health care provider and institution on the parents' grief journey

Code	Code definition	Prompt/ Theme	# text segments coded, (%)	# parents using code, (%), N=11	Example quote
Relationship between providers and family					
Strong and ongoing relationship with care team	Continued connection between medical team and family; family members sharing future experiences with medical staff	2 RST	12 (3.9)	7 (63)	"Can there really be a deeper relationship than somebody you've taken and said, "here's my child," trusting you with their life? I just don't think there's any deeper relationship than that."
Strong relationship/ support from care team	Intimate relationship between care team and family/patient; HCPs being available and present	1 PE	10 (5.3)	3 (27)	"So the people that were important the most to us in being here was our care team. You know, everyone that had been part of that journey from the very beginning."
Shared understanding between family and HCPs	Value of bonds formed between family and providers; appreciation that medical team fully understands patient and family experience	2 RST	6 (1.9)	4 (36)	"And so, you know, you don't have to even try to make them understand because they were in it with you."
High-quality communication between providers and family					
Anticipatory grief/grief guidance	Start of the grieving process at time prior to imminent death; parents needing guidance from HCPs	1 IPD	9 (4.8)	4 (36)	"It might sound a little bit strange but I guess I would have to say that the grieving process started with the diagnosis...The grieving is there but there's stages that you go through."
Accurate information and decisional support	HCPs giving patient/families clear data to help make decisions; allowing parents to feel control in the situation	1 PE	5 (2.7)	2 (18)	"[The care team] was unbelievably awesome and supportive and giving me all the facts each time there was some decision to make and there were a lot of them. And never judging us or trying to, you know, sway us one way or the other. But they provided good, clear information and compassion..."
Importance of anticipatory grief guidance	Parent's recognition of child's impending death, expression preference for death over continued suffering; asking for bereavement support services prior to death	2 HBP	3 (1.0)	2 (18)	"It's almost like when you know you're at that point, it's almost like they should start talking to you about your transition home and what's it's going to be like and here are our resources for you to have..."
Importance HCP communication training	Parents wanting bereaved parent input on training HCPs on communication around end of life care/issues	3	3 (3.0)	2 (18)	"So you leave a parent or family member not actually getting the communication and partnership that they need. You're not fully engaging them on all levels."
Negative interactions/experiences with health care providers					
Poor communication between HCP and family	Lack of clear information about inevitability of death; parents feeling abandoned; providers avoiding difficult conversations	1 NE	10 (5.3)	3 (27)	"But there's some things that we regret and I think it was because of lack of communication."

Impaired trust between family and HCPs	Parents expressing dissolution of trust in care team	1 NE	9 (4.8)	3 (27)	"So there was a little breach there. And, of course, in certain times, we were in the hands of ICU physicians, people we didn't know... We knew the ones we started with, so how much do you trust these people?"
Team presenting unrealistic options/not giving all options	Parent offered choices that were not clinically appropriate; complicating decision making and grief	1 NE	2 (1.1)	2 (18)	"Well, I never knew that was an option, see, so I don't think I got the total picture."
Institution's/HCP's role in grief journey and bereavement support					
Importance of formalized grief support	Need for professional resources in bereavement journey including sibling support; disappointment at not being offered structured grief support	2 HBP	31 (10.3)	9 (82)	"We always tell our families that come, new, to a group, a bereaving family, try this for 2 or 3 times and if this is not for you, go find something else. Find a grief counselor, read, join some other support group but do something to make yourself better..."
Right of the child to be remembered/ honored by the institution	Importance of equally valuing all parts of child's life, including death; Parents wanting an institutional commitment to remember the child given contribution to research	3 IM	16 (16)	7 (64)	"...they [our children] were there, they lived there, this is their story and they have a right to be heard, too."
Personalizing bereavement support	Utilizing and finding individualized and tangible mechanisms of support	2 HBP	14 (4.7)	6 (55)	"Everybody's different and you cannot let anybody tell you how to grieve, you have to do it on your own."
Individualized opportunities for legacy building/support	Noting that timeframe of grief will be different for all, but resources should be available throughout	3 IBS	7 (7)	4 (36)	"...the timing [of bereavement support] may not be something that could be pinpointed but I think the availability should be out there as soon as possible."
Providing concrete resources	Need for physical bereavement tools	2 HBP	7 (2.3)	5 (45)	"I think having [the bereavement coordinator]'s contact there would have made a big difference. Like this card that says you can call the bereavement coordinator here when you get ready or whatever."
Allowing/making it easy to return to location of care	Reducing barriers or offering a formal invitation to parents visiting care setting after death of child	3 IM	7 (7)	4 (36)	"I don't know if there's ever permission given that you can come back and visit."
Recognition of many ways to honor child's life/legacy	Parents noting that there are a variety of different ways that they/the institution can memorialize the children that died	3 HL	7 (7)	5 (45)	"I think we need to recognize, too, that sometimes just surviving and taking care of your other children or whatever, yourself, your marriage, is honoring your child."
Strong association with last place of care	Feeling tied to location of care/death	2 RST	7 (2.3)	5 (45)	"There's a connection, I just feel connected, my son passed here."
Importance of memorializing place of care and/or death	Recognition of location of treatment and/or death as sacred and worthy of bearing witness	3 IM	4 (4)	3 (27)	"It's not a shrine but yet it's a place where something profound occurred. And for parents who actually lose their child here, that's taken away from them. I mean, shrines are built in New York City, in corn fields in Pennsylvania because people have died and their spots are marked and remembered."

Death providing opportunity to acknowledge reality of mortality	Using the death of the children as a way to allow recognition of this part of humanity	3 IM	4 (4)	3 (27)	"But I think a culture change regarding the life and death is needed...I think part of my mission is to be able to communicate openly that that is a reality that we do have to face, that parents have to face it, that time that you walked in [the hospital's] doors, there's 'hope' but there's also that other side that nobody is showing you."
Recommendations to improve care at EOL	Thoughts on ways to improve communication, care to improve parental bereavement	1	2 (1.1)	2 (18)	"... I would have felt better and I think I would have actually interpreted things better had we been told, when we came to [the hospital] "that we were actually getting the best care we could get for him, that this was the place to get this over and we sought to get it here, that we're going to do everything we can. We're going to try everything we can but please understand that there's not a guarantee."

Abbreviations: HCP, health care provider; RST, role of support team in grief journey; PE, positive experiences with HCPs; IPD, importance of preparing for death; HBP, How to help a bereaved parent; NE, negative experiences with HCPs; IM, institution memorializing the children; IBS, institutional bereavement support; HL, honoring the legacy of the child

Prompt 1: Tell me about your grief journey before your child's death. What are some things that helped you as you went through this?

Total coded segments, N=187

Prompt 2: Tell me about your grief journey/bereavement experience after your child's death? What are some things that helped you?

Total coded segments, N=301

Prompt 3: What services can we offer to bereaved parents that would help them in their grief journey and what is the appropriate time to offer them?

Total coded segments, N=98

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- Communicate with patients and families clearly and honestly, providing accurate and timely information to allow them to participate in shared medical decision-making while taking into account goals of care and working to support decisions made by families.
- Involve bereaved parents in the design and implementation of communication training for health care staff.
- Show empathy as a part of a continuing and strong bond between HCPs and the patient and family. Find ways to continue to be involved with the family after the child's death, working to continue the established therapeutic alliance.
- Acknowledge that the HCP identity may shift from cure-focused medical provider to companion on the parent's grief journey. Do not try to "fix" the hole in the heart of bereaved parents, but rather recognize, acknowledge, and bear witness to its presence.
- Embrace the opportunity and challenge of initiating difficult conversations with patients and families throughout the disease process. Avoid giving false hope or offering unrealistic treatment choices. Enhance efforts at communication and ensure continuity of care around times of transitions of care (e.g., within the hospital, from hospital to the community or to hospice).
- Recognize and support the need of families to return to their child's last place of care and take steps to make this process as easy as possible.
- Memorialize the children that have died as a way to recognize the importance of their lives. Involve bereaved parents in the development of this memorial.
- Allow bereaved parents the opportunity to participate in legacy-building and memory-making activities after their child's death by offering various venues through which to share their child's story, honor their child's legacy, and continue to have ongoing bonds with members of the health care team and hospital/institution.
- Involve bereaved parents in the development of a comprehensive bereavement program to help live with the hole in their hearts, support other parents that have lost a child, and perhaps mitigate compassion fatigue and burnout experiences of health care team members.

Bereaved parent directives for grief support to be provided by pediatric providers and healthcare institutions
24x14mm (600 x 600 DPI)

Accepted