

Parental experiences with a hospital-based bereavement program following the loss of a child to cancer

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ABSTRACT

Objective: The death of a child from cancer is an intense and life-changing loss for a parent. Guided by the principles of patient- and family-centered care, hospital-based caregivers developed a program to provide bereavement support for parents through phone calls and mailings. The aim of the present qualitative phenomenological study was to understand how parents experienced participating in this bereavement program.

Method: A total of eight parents from six families participated in a focus-group evaluation of the two-year hospital-based bereavement program. Two social work clinicians/researchers independently analyzed the transcript of the focus group to define themes.

Results: Four themes were identified: (1) lived experience of grief, (2) importance of relationships with the hospital-based team, (3) bereavement support from hospital-based providers, and (4) extending bereavement care.

Significance of Results: Participants indicated the value of ongoing communication and connection with members of the healthcare team, who were often central to a family's life for years during their child's cancer treatment. Parents also provided suggestions for extending bereavement support through continued contact with providers and informal annual gatherings, as well as through a peer (parent-to-parent) support program.

KEYWORDS: Bereavement, Pediatric oncology, Hospital-based bereavement program, Qualitative research, Patient- and family-centered care

INTRODUCTION

With advances in research and treatments, pediatric cancer mortality rates in the United States have been declining since the 1970s (NCI, 2014). Nonetheless, in 2014 there were more than 3,200 childhood cancer deaths the U.S. (CureSearch, 2015). The families of these children are left to grieve over what has often

been described as one of the most traumatic experiences a family can endure (Johnson et al., 1993; Kazak & Noll, 2004; Thompson et al., 2011). Compared to other losses, a parent's grief process is often longer, more intense, and life-changing (Rando, 1985). Bereaved parents experience a host of negative outcomes in comparison to parents who have not lost a child: more depressive symptoms (Kreicbergs et al., 2004; Rogers et al., 2008), increased anxiety (Kreicbergs et al., 2004), a greater risk of psychiatric hospitalization and posttraumatic stress disorder (Li et al.,

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2005; Ljungman et al., 2015), marital difficulties (Rogers et al., 2008), and poor health-related quality of life (Song et al., 2010). They have even been shown to experience an increased risk of mortality within the first three years after the child's death (Li et al., 2003). Furthermore, research suggests that many children with cancer experience protracted emotional and physical suffering at the end of life, which may add to parents' distress even as they adapt to their grief (Wolfe et al., 2000).

Social support is widely acknowledged to impact an individual's mental and physical health (Holt-Lunstad et al., 2010). Adequate social support is associated with more positive outcomes. Satisfaction with available social support has been identified as a possible predictor of complicated grief (Villaceros et al., 2014). Other studies have suggested that good marital relationships serve as a buffer for parental grief (Martinson et al., 1994; Song et al., 2010) and that one of the utilities of bereavement support groups for parents lies in development of additional social support (Umpfrey & Cacciatore, 2011). A recent study of parents who had experienced the sudden loss of a child indicated that they valued the emotional support that came from ongoing communication with healthcare providers (Garstang et al., 2014). Similarly, our clinical experience also speaks to the importance of supportive relationships between hospital providers and the families of children who have died from cancer, and parents have expressed the desire to maintain contact with those who knew them and their child best during the trauma of illness.

However, many studies suggest that, despite the call for a standard of care of one meaningful bereavement contact between hospital providers and families, bereavement follow-up practices after the death of a child vary widely among hospital centers (Borasino et al., 2008; Agnew et al., 2011; Lichtenthal et al., 2015b; Thrane & Jones, 2012). Some organizations identify their follow-up practices as occurring informally and would no doubt benefit from structured time and practices for bereavement follow-up (Granek et al., 2015). Similarly, it has been suggested that healthcare providers may believe that there are benefits in ongoing communication with a family, but they sometimes do not have enough time to follow up with families, given such competing demands as clinic time and paperwork (Billings & Kolton, 1999; Borasino et al., 2008).

Johnston and coworkers (2008) surveyed Children's Oncology Group institutions and found that 59% reported having a bereavement program, though the specifics of the programs were not given. Likewise, a survey of nine pediatric oncology programs in Australia and New Zealand revealed that

the majority provided some kind of bereavement support for one year after the death, although there was considerable variation in terms of the services offered. Programs included bereavement groups, counseling, remembrance services, and financial assistance (deCinque et al., 2004). However, there is limited literature that evaluates pediatric oncology bereavement programs and, further, their theoretical underpinnings (deCinque et al., 2006). The limited literature in this area reports telephone follow-up bereavement programs (Darbyshire et al., 2012; Russo & Wong, 2005), with qualitative evaluation indicating that parents preferred telephone follow-up to coming back to the hospital, and appreciated contact with a nurse who knew them (Darbyshire et al., 2012). Other research describes home visits by treatment providers as the best practice following the loss of a child to cancer in Israel (Stein et al., 2006) and as desired by the majority of families in a small survey of New England families (Welch et al., 2012).

Hospital-based bereavement support is also in line with family-centered care. Patient- and family-centered care, which promotes collaborative relationships between providers and patients/families with respect to patient preferences, has recently gained increasing momentum as a model for clinical practice (IPFCC, 2015) and has been further supported by the nonprofit Institute for Patient- and Family-Centered Care (IPFCC) and the 2001 Institute of Medicine report, "Crossing the Quality Chasm" (IOM, 2001). Pediatric oncology providers have historically embraced the value of their longstanding relationships with patients and their families. Continuing to support a family after a child's death would be an obvious extension of the care provided during the child's treatment. Extending bereavement support from hospital-based providers has also been called for by parents in a qualitative focus-group study of bereaved parents' perspectives on their needs (D'Agostino et al., 2008), as well as by a cross-sectional study of 120 bereaved parents in which unmet emotional needs were found to be prevalent (Lichtenthal et al., 2015a). In D'Agostino et al. (2008), parents asked for flexible and ongoing support from hospital-based providers with whom they have had close relationships. They also identified the value of written information about bereavement and social support from other bereaved parents (D'Agostino et al., 2008).

Based upon these concepts and extending the call of the IPFCC (2015) and the 2001 Institute of Medicine recommendations for continuity-focused hospital-based family-centered care, a hospital-based bereavement program was created at the Massachusetts General Hospital for Children to support families after the loss of their child to cancer. The

present article reports the findings of a focus-group evaluation of this bereavement program.

PEDIATRIC BEREAVEMENT PROGRAM AT MASSACHUSETTS GENERAL HOSPITAL FOR CHILDREN

Massachusetts General Hospital (MGH) is a large tertiary care center in Boston, Massachusetts. Care of children with cancer is delivered in the pediatric hematology/oncology practice, a subspecialty practice of the Massachusetts General Hospital for Children (MGH/C). The practice, which cares for children through its outpatient clinic and on inpatient pediatric units, sees about 60 newly diagnosed cancer patients every year.

In 2007, the multidisciplinary pediatric oncology team (which included a clinical social worker, child psychiatrist, medical oncologist, pediatric chaplain, and two nurses) undertook an initiative to develop a comprehensive bereavement support program for parents who had lost a child to cancer at the MGH/C. The clinical social worker and child psychiatrist led two focus groups of parents whose children had died within the previous six years to elicit suggestions for program development. Families were receptive to the idea of follow-up by both phone and mail, and they spoke of the importance of continued contacts from the members of their care team with whom they had established relationships.

Following feedback from the focus groups, a working group comprised of a clinical social worker, pediatric chaplain, and nurse developed specific bereavement materials and a timeline for their distribution. This work was guided by input from the families during the focus-group meetings, and based on clinical knowledge of families' grief and the stress and coping social support theory, which suggests that social support helps individuals manage stressful situations by improving coping responses (Lazarus & Folkman, 1984; Folkman & Moskowitz, 2004). In this case, hospital-based providers were identified as important sources of social support, which is in keeping with previous literature on social support in bereavement (Gear, 2014).

Additionally, the working group realistically considered the time that an already busy clinical staff would have to devote to implementing a new program. A two-year follow-up bereavement program was ultimately established (see Table 1 for the program components). While the clinical staff recognized that grief is a lifelong process for bereaved parents, the resources of the staff could not support formalized follow-up for very many years. The clinical social worker served as the coordinator of the bereavement program and assigned a clinician who had

Table 1. Components of the MGH/C bereavement follow-up program

Intervention	Time following death	Content/special considerations
Phone call	2 weeks	Initial contact with family after death
Comfort basket	3–4 weeks	Items of remembrance, grief books
Phone call	1 month	Invite parents to review child's care
Phone call	2 months	Ongoing supportive check-in
Letter #1	3 months	Info sheets about grief, helping siblings
Letter #2	5–6 months	Include opportunity to opt out of program
Letter #3	9–10 months	Info sheet about self-care and grief
Letter #4	12 months	Info about first anniversary
Letter #5	18 months	Pack of seeds: forget me not
Letter #6	24 months	Include anniversary card signed by team
Phone call or note	Child's birthday	Continued acknowledgment of grief process
Phone call or note	Anniversary of death	Signed card from treatment team
		Acknowledgment end of program
		Annually for 2 years
		Annually for 2 years

been directly involved with the family to facilitate bereavement follow-up.

METHODS

Research Design

This qualitative phenomenological study sought to understand parents' experiences with participation in a hospital-based bereavement support program following the loss of a child to cancer. A phenomenological approach is often employed in nursing and related healthcare disciplines when there is interest in obtaining participants' descriptions and interpretations of their own experiences (Dowling, 2007; Van der Zalm & Bergum, 2000). Our study was approved by the institutional review board of Partners Healthcare. Made up of parents who had participated in the bereavement program, the focus group met in November of 2014. Since the inception of the bereavement program, 35 children who had received care

in the clinic had died. Although no families opted out of the bereavement program, eight were not included in the program for various reasons: three lived out of the country, three were primarily followed by other hospital care teams and/or treatment centers, one had no surviving parents, and one family had an incarcerated parent. All families who participated for at least 12 months of the 24-month-long MGH Bereavement Program were contacted by mail and invited to participate in a focus group ($N = 27$). The inclusion criteria were as follows: that the participant be the parent of a child who died from a pediatric cancer and that the participant had completed at least 12 months of the 24-month MGH Bereavement Program. Letters were mailed to the deceased child's family; where parents had divorced or separated, individual letters were sent to each one. A phone call followed the letter, inviting participation and screening to confirm study eligibility. If parents met the criteria and expressed interest, they were then enrolled and scheduled for the focus group.

The focus group was conducted by a doctoral candidate (researcher 1), who was an experienced oncology social worker. Researcher 1 was an employee of the Social Service Department at MGH and had not previously delivered care to the study families. Verbal informed consent was received from each participant prior to initiation of the focus group. The focus group lasted for about two hours and was digitally recorded and transcribed verbatim. Participants received dinner, parking validation, and a small gift card as remuneration for participating. Focus-group participants responded to a series of open-ended questions, including:

Please share some impressions about your experiences with the treatment team at Mass General during your child's illness.

Thinking back to the time after your child's death, what was that like for you? What helped? What didn't help?

What was your experience with the bereavement follow-up from the MGH (i.e., comfort basket, letters, phone call from nurses, doctors, social worker?)

Was there anything else Mass General/staff could have done for you or your family after the death of your child? Memorial service? Meeting with team after death?

Where else did you turn for support in your grief (e.g., religious community/faith, friends, support group, therapist, extended family)?

Follow-up questions or prompts were asked as needed to clarify comments or elicit additional information, as well as to keep the group on topic.

Participants were also invited to contact the researcher after the group with any additional thoughts or comments, and one participant did so to offer further reflections.

Sample Demographics

Eight parents from six families (out of invited 27 families) participated in the focus group, for a response rate of 22%. Two parents stated that they were unable to attend the focus group, but they requested individual telephone interviews with the researcher prior to the group, as they wished to share feedback about the program, which helped the researchers to refine the interview guide. In total, six women and two men participated in the focus group. Please see Table 2 for demographic information about the parents and deceased children. Four of the participants were married, two were single, and two were divorced. All participants identified as white and were well educated, with 75% reporting having a bachelor's degree or above. The average age of the parents was 51, with a range from 33 to 62, while the average age of the children who had died was 13 years, with a range from 4 to 30. Participants' children had passed away on average three years prior to the focus group, with a range from one to six years.

Table 2. Demographic information

Demographics	$M \pm SD$ or frequency (%)
Participants ($N = 8$)	
Age (years)	51 \pm 10
Gender	
Female	75%
Male	25%
Race	
White (non-Hispanic)	100%
Highest education level	
High school/some college	25%
Bachelors	37.5%
Masters/doctoral	37.5%
Relationship status	
Married/partnered	50%
Single	25%
Divorced	25%
Deceased children ($N = 6$)	
Age of child at death (years)	13 \pm 10.4
Time since child's death (years)	3.1 \pm 1.7
Time between diagnosis and death (years)	4.4 \pm 3.4
Cancer diagnosis	
Acute lymphoblastic leukemia	16.7%
Brain tumor	33.3%
Rhabdomyosarcoma	33.3%
Spinal cord tumor	16.7%

M = mean; SD = standard deviation.

Data Analysis

Two social work clinicians/researchers independently analyzed the data for themes using the principles of Moustakas's (1994) phenomenological data analysis (see Table 3). The steps in this analysis process included: identifying significant statements in the transcript; creating meaning units from the statements; and clustering meaning units into themes. The independent analyses were then compared and discussed until a consensus was reached on themes. To improve validity, several different methods of triangulation were employed (Briller et al., 2008), including: investigator and interdisciplinary triangulation (a doctoral-trained nursing researcher reviewed the themes for validation); and collaborative triangulation (in which individuals with different perspectives and philosophies came together on the research team to analyze the data). The credibility of the data was also enhanced by using quotes verbatim from the interviews and comparing themes to both participants' original statements as well as to the previous research literature.

RESULTS

The analysis revealed results that can be grouped into four main themes: (1) lived experience of grief, (2) importance of relationships with hospital-based teams, (3) bereavement support from hospital-based providers, and (4) extending bereavement care.

Lived Experience of Grief

Grieving the Loss of a Child Differs from Any Other Grief

Throughout the discussion of the bereavement program, participants spoke about their singular experiences of grieving the loss of their children to cancer, as compared to other losses: "It's not less tragic or more tragic . . . just a whole different animal." One parent noted, "You know, it's different. It's a long war." Parents experienced their child's disease and treatment as a protracted illness with uncertainty and despair but with intermittent hope and optimism. The emotional roller coaster described by parents leading up to their child's death separates their experiences from that of other parents mourning the loss of a child. As one parent described her experience in a group for bereaved parents,

I couldn't compare a woman who lost a 35 year old to a heroin overdose with losing my 11 year old to cancer. . . . It's different.

Everyone Grieves Differently

Participants acknowledged that "we all grieve differently" and engaged in conversation about the unique experiences of grieving fathers. Men spoke about being "treated differently" than grieving mothers. There was considerable discussion about men managing grief in the workplace and "expecting because

Table 3. Themes identified through focus group

Theme	Operational definition	Examples
Lived experience of grief	Exquisitely painful experience of grief when a parent loses a child to cancer; grief is also individual and unique.	"There's not one day that I don't have a moment of complete shock that she's gone. . . . There are times when it takes my breath away." "We all grieve differently."
Importance of relationships with hospital-based team	Team included patient, family, and providers from different disciplines. The relationships were close and emotionally supportive.	"Everyone knew her, everyone knew us, and everyone worked together. . . . It didn't feel like a machine here." "They would embrace you . . . they would treat you like you were family."
Bereavement support from hospital-based providers	The current two-year hospital-based bereavement program was positively evaluated by parents.	"So, getting these letters from someone who knew her, remembered her. . . . It's something that's very touching." "I adore it, every communication that I get . . . the basket was so beautiful."
Extending bereavement care	Parents shared preference for longer-term bereavement care; possibility of peer support program was also raised.	"Grieving isn't over in two years. Grieving isn't over in five years. It doesn't have to be as much of a contact, but even just a yearly letter or a yearly gathering of parents that have lost just to be able to get together and see how much is changed and see where you're at."

you're back to work, you're back to normal." As one father commented,

I'm certainly well aware of the notion that ... you're not supposed to show, or you're supposed to be strong for the rest of the family.

One mother spoke of the unique response of her father to her son's death:

It was really hard for him ... because he fixes things. He's like, "How do I fix this?"

Parents also spoke of the ways in which relationships could become very strained or the most comforting source of support after the death of a child. One mother acknowledged considerable frustration about her own mother's responses and "never saying the right thing." She reflected that she came to realize that her mother was "grieving for my suffering" as well as for the loss of her grandson. Marital relationships could offer the most intimate of comfort as parents grieved for their mutual loss. However, as parents may also grieve in different ways, this can cause considerable tension in a relationship. Parents often spoke of finding support in relationships where they might have least expected it. One mother reported how touched she was when a friend whom she had not seen for a long time shared the experience of her own daughter's death after only three days of life. While the friend was hesitant to compare their experiences, this mother found this unexpected connection to be very helpful. Participants expressed appreciation for the opportunity to connect with one another in the focus group and in other places in their lives:

I think it's good to be able to have connection, see faces, and realize that you're not alone.

Grief Is Intense and Longlasting

The conversation was marked by tears and nodding heads as participants described a grief that was intense and longlasting:

There's not one day that I don't have a moment of complete shock that she's gone. ... There are times when it takes my breath away.

Grief Varies Day by Day

Grief is also marked by its ups and downs: "some days I just package up the grief and put it right over there, because I just don't want to go there." Bereaved parents often have the responsibility of caring for other children and have to put away their grief to remain

available to grieving siblings. They spoke of the challenges in being able to continue to lovingly parent their other children. As one mother put it, "We have to continue our lives even though it's hard to figure out how to do that." Some spoke of their ability to better cope with grief over time and expressed appreciation for support from the MGH Bereavement Program (as detailed in the next section):

The outreach is so important. So much thought goes into what it is that they're reaching out with. It's just so humanizing to know that these people are knowing you well enough to reach out in the correct way. It was very sensitive."

Importance of Relationships with Hospital-Based Team

Treat You Like You Were Family

Participants spoke at length about the importance of relationships with their children's medical team, often using the word "family" to describe their feelings of care and connectedness:

And they literally, they will embrace you. If you walked up there tomorrow, they would not forget who you were, they would not forget who your child was, even though you haven't been in there in three years, and they would treat you like you were family.

In speaking about the healthcare team (including physicians, nurses, social workers, administrative staff, volunteers, and even the employees who delivered meals on inpatient units), participants specifically noted that "everyone knew her, everyone knew us, and everyone worked together... It didn't feel like a machine here."

Human Connection During a Terrifying Time

Participants described feeling touched by expressions of human connectedness and compassion in the midst of a terrifying experience:

I never expected them to show up at my son's wake and funeral. I would've never in a million years expected that. And it was awesome to see.

Parents acknowledged the intensity of their feelings and how they could be expressed to the medical team. Some acknowledged their anger and directed that anger at their child's oncologist: "You've got to have someone to be mad at, especially when you're losing the battle." These feelings were countered by parents who expressed a considerable amount of gratitude for the care and support they and their child received:

“There’s a great sense of indebtedness.” Parents who shared negative interactions with certain team members stated that, on the whole, their experiences with providers were positive and that they appreciated having an ongoing relationship with providers in the form of bereavement support (see below).

Bereavement Support from Hospital-Based Providers

The Bereavement Program Is Beneficial

Overwhelmingly, participants shared positive feedback about the hospital-based bereavement program under evaluation. Many expressed appreciation for receiving letters and phone calls, even when they didn’t return the communication:

To me, it’s more like we’re receiving something, and I like receiving it. Sometimes we open it and recycle it, and sometimes we just keep it.

For some parents, just knowing that they and their children weren’t forgotten was the most important thing. For others, the contents of the letters and basket, including educational materials about grief, were also important. This from one mother:

There was a book for grandparents. After reading [that book], I realized that my mother was suffering from watching me in pain, and I didn’t get that until I read that book. So, I think they think of everything when they make that basket, you know.

And from another parent:

I adore it, every communication that I get. . . . The basket was so beautiful. I still have a little museum [with my child’s belongings] in my house, and the little candle is in there, and the picture frames, and I never threw [away] any of the letters.

Many participants reflected on the value of receiving the comfort basket weeks after the child’s death: the items included became important, tangible reminders of a connection with the treatment team.

Ongoing Connection with Hospital-Based Providers Is Important

Several participants commented specifically on the importance of hearing from providers who had known and cared for their children:

So, getting these letters from someone who knew her, remembered her . . . It’s something that’s very touching.

Parents also commented on how isolated they often felt in their grief and how much they appreciated speaking with providers who weren’t afraid to talk about their traumatic experiences and the lives of their children:

The day after my son passed away, no one came over. No one comes to check on you. No one, and a lot of people, like, “I don’t know what to say.” Well, that’s why I like coming back here, because they know what to say.

The focus-group facilitator specifically asked about critical feedback/negative experiences with the MGH Bereavement Program, but no group participants identified any such experiences.

Extending Bereavement Care

Bereavement Support from the Hospital Should Be Ongoing and Flexible

In keeping with the positive experiences with the current MGH Bereavement Program, participants clearly stated that they wanted the support to continue—to “never end!” While they were sensitive to the demands of bereavement support on busy clinical providers, they expressed a desire for longer-term support and ongoing relationships:

Grieving isn’t over in two years. Grieving isn’t over in five years. It doesn’t have to be as much of a contact, but even just a yearly letter or a yearly gathering of parents that have lost, just to be able to get together and see how much is changed and see where you’re at.

When the group facilitator asked directly about a formal annual memorial service, the majority of participants stated that they would not be interested in attending. Most of the group noted that they did not attend the already-established hospital’s annual pediatric memorial service. Rather, they expressed an interest in an informal gathering where they could reconnect with hospital-based providers and other parents:

Seeing the teams that you worked with, and cookies, coffee, you know. I don’t think it needs to be elaborate. . . . And you can come or not come, you know, like this thing [referring to the focus group].

Interest in a Peer-Support Program

The majority of participants expressed interest in more formalized peer support, given their unique experiences of loss. Participants described their experiences receiving support in other venues

(Compassionate Friends support groups, Facebook groups, individual counseling, friends/acquaintances), but all indicated that there was something different about losing a child to cancer and that they would appreciate being with people “you can relate to and who can relate to you.” Several volunteered to be peer “matches” for other parents who had recently lost a child:

[The child] was our only child . . . so to talk to someone who lost their only child . . . [or] someone whose partnership broke up. Like, you know, a little bit of matchmaking would be good.

Participants also acknowledged the benefit of being able to both receive and give support:

So, to be able to do that for somebody else is huge. You know, it's almost like holding their hand, and letting them know that things may be okay. They may not be okay. You're not alone. . . . I think it would help me, too. . . . It has its own reward.

However, some in the group sounded a note of caution about a peer-support program, suggesting that it should be closely managed by a mental health professional and that mentors should be trained to offer support and “not to shift the focus back to their own experiences.”

DISCUSSION

Our study provided a qualitative focus-group evaluation of a two-year hospital-based bereavement program for parents who had lost a child to cancer at the MGH/C. The program was grounded in professional expertise about bereavement, the theory of social support, feedback from parents, and the guiding principles of patient- and family-centered care. Overall, focus-group findings were consistent with the literature, although they add to the body of our knowledge as they suggest that parent/participants have some distinctive preferences for long-term bereavement support. Congruent with previous descriptions of bereavement after the death of a child (Grinyer, 2012; Thompson et al., 2011), parents reported intense and unique experiences of loss. They shared feelings of isolation and stated that the hospital-based bereavement program met their needs in ways that other forms of support had not.

While parents spoke about the value of bereavement support over the two-year period, they consistently noted that the comfort basket sent about three weeks after the child's death was particularly meaningful. Personalized for each particular family, the basket provides gifts of remembrance and com-

fort, educational items, and a letter reflecting on the relationship among the care providers, the child, and their family. Families noted the power in those words and the kindness shown to their family. It was also a tangible offering that demonstrated the continuity of the relationship between the family and their child's care providers. Research has suggested that one meaningful contact between medical care providers and a bereaved family should be the standard of care (Lichtenthal et al., 2015b). For programs where resources are limited and it is not feasible to maintain longitudinal contact with bereaved parents, our participant feedback suggested that a comfort basket would be a meaningful one-time intervention.

For those programs with the capability to provide longitudinal support, parents also provided suggestions for extending bereavement support beyond the length and scope of the current program. A formalized peer-support program was one suggestion. Peer support has been positively evaluated in previous studies (Grinyer, 2012; Nikkola et al., 2013) and has been found to be synergistic with provider support (Nikkola et al., 2013). Participants in our study expressed interest in giving and receiving emotional support from peers.

Participants highlighted their appreciation for strong and supportive relationships with their children's medical care team, both during their children's cancer treatments and after their children's death. Some commented specifically on their positive experiences of being active participants in their children's care, often partnering with the healthcare team to develop a plan of care. These comments suggest that the pediatric oncology clinic's efforts to operationalize patient- and family-centered care have been successful. As an extension of patient- and family-centered care, parents noted their appreciation for receiving bereavement support from providers who had treated their children and with whom they had meaningful relationships. The idea that healthcare providers are an important and unique source of social support is congruent with the theory of social support that underlies the program. Provision of bereavement support by professionals to whom families are known has also been evaluated positively in studies by Darbyshire et al. (2013) and D'Agostino et al. (2008), who found that parents highly desired ongoing and flexible bereavement support from those hospital-based providers with whom they had had close relationships.

Unlike several other recent studies that indicated parental support for home visits following the loss of a child to cancer (Stein et al., 2006; Welch et al., 2012), our participants did not express interest in home visits. Rather, they advocated for informal

opportunities to gather on an annual or biannual basis to connect with hospital providers as well as with other bereaved parents. This approach may offer increased flexibility and control to bereaved parents, who could choose whether or not to attend depending on their own needs. As group participants indicated, they sometimes felt a need to be with others “you can relate to,” while at other times they needed to “package away” their grief. An approach that respects the variable needs of bereaved parents would truly embody patient- and family-centered care.

Our study highlighted the importance of continued psychosocial support after the loss of a child to cancer and the opportunity for the institution with a connection to the family to provide that care. While parents acknowledged their profound grief and feelings of isolation after their loss, they were not only receptive but often eager for continued support from those healthcare providers through individual contacts, group programs, and communication with other bereaved parents. These opportunities also came with challenges. As the success of the program is in part based on delivery of services by the existing healthcare team, those providers have clinical responsibilities to the patients receiving treatment. Additional staffing becomes necessary to expand programming and services to parents. In today’s healthcare environment, where cost containment is necessary, it is difficult to advocate for additional staffing to provide services not reimbursable by insurance companies. Programs focusing on quality of life are left to be absorbed by existing staff or funded through philanthropy.

LIMITATIONS OF THE STUDY

Although everyone who had completed at least one year of the bereavement program was invited to participate in the focus group, eight parents self-selected to attend the group. This was a fairly small percentage of invitees. Several families had moved out of state, and several others commented that it was too emotionally difficult to return for a focus group to the hospital where their children were treated. Research supports the idea that for some bereaved parents a barrier to accessing services is that it is too difficult to speak about the loss (Lichtenthal et al., 2015a). It is possible that those parents need a different or more intensive form of outreach or intervention. However, the experiences of parents who did not participate in our study are not known, apart from the two parents who requested individual telephone interviews prior to the focus group. It is possible that the parents who chose to participate in the study found the bereavement support to be more helpful than other parents did, although they also

identified suggestions for extending and improving the program. This is a preliminary evaluation study conducted at one major medical center within the United States. Our results cannot be generalized and are not necessarily applicable to other pediatric cancer programs. However, the study does provide rich data about parents’ experiences of grief and with bereavement services and can provide a framework with which to design and adapt bereavement services in other care-delivery settings.

CONCLUSIONS

This qualitative study, grounded in the theory of social support and the clinical model of patient-centered care, contributes to the growing body of literature about the evaluation of bereavement support programs for parents after the loss of a child to cancer. The analysis of the focus-group data provides poignant and rich descriptions of parents’ lived experiences of grief. It highlights the importance of incorporating the family’s voices and preferences in developing programs to support bereaved parents. Participants indicated the value of ongoing communication and connection with the members of the healthcare team, who were often so central to a family’s life for years during the child’s cancer treatment. While parents found the content of the bereavement follow-up materials to be helpful, what was equally as important was that what was sent reflected the relationship the care team had with their child and the family. Parents spoke about the individually chosen items in the comfort basket and the personalization in the letters throughout the program as providing a unique and meaningful remembrance of their children. Parents also provided suggestions for extending bereavement support through continued contact with providers and informal annual gatherings, as well as through a peer (parent-to-parent) support program.

As healthcare continues to recognize the importance of patient- and family-centered care, ensuring that parents are central to defining their needs for bereavement support is critical. Incorporating the parent’s voice in creating programs and supports to address the unique needs of bereaved parents coping with the death of their child from cancer will enhance success in meeting these families’ ongoing needs.

DISCLOSURES

The authors hereby state that they have no conflicts of interest to declare.

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