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Addressing Parental Bereavement Support Needs at the End of Life for Infants with Complex Chronic Conditions

Juliet S. Tan, M.D., B.A.,[1,4] Sharron L. Docherty, Ph.D., CPNP,[2,3]
Raymond Barfield, M.D., Ph.D.,[1] and Debra H. Brandon, Ph.D., R.N., CCNS, FAAN[2,3]

Abstract

Introduction: Health care providers' understandings of parental bereavement needs before and in the acute period following the death of an infant with a complex chronic condition are based upon models that outline the process of grief and provide direction for possible points of intervention. These models do not address prospective factors along the illness trajectory that may contribute to the depth and debilitating nature of grief, and fail to clarify the influence of social structures on parents' experience and construct of grief, loss, and mourning. The purpose of this study was to prospectively describe the bereavement experience of parents whose infants die in acute care settings with a complex chronic condition.

Methods: A longitudinal, qualitative, descriptive design was used to explore the process of parental bereavement. Extreme case sampling with variation on race, socioeconomic status, prenatal diagnosis, and multiple gestations was used to select 7 cases represented by over 72 narrative interviews with parents.

Results: Findings are organized into five broad categories: Having Expectations, Continuity of Care, Memory Making, Wide Network of Support, and Altruism. Themes under each category were developed based upon examples given in the parental interviews.

Conclusion: This study provides an exploration of the complex and longitudinal nature of bereavement. Anticipatory support initiated prior to the death of an infant can help parents experience a smoother transition from caring for their very ill child to coping with the actual death event and its aftermath.

Introduction

Coping with the death of an infant is a complex and stressful experience for parents. Despite the universal nature of grief, parental bereavement remains poorly understood.[1–3] Bereavement support can help grieving parents explore the meaning and challenges associated with their experience of a child's death.[4–5] Current support interventions are based on models that focus on stages of grief and on psychological tasks that need to be accomplished during the grieving process.[6–12] While these models describe the process of bereavement they do not address factors along the child's illness trajectory that may have contributed to the depth and debilitating nature of grief. In addition, these models do not clarify the influence of social structures on an individual's experience with grief, loss, and mourning.

Preparation of parents for their ill child's death can have long-reaching consequences. Studies show that caregivers who are less prepared for the death of their loved one may be prone to suffer from depression, anxiety, and complicated grief.[13] However these studies have been retrospective and cross-sectional in design, focusing on the experience following death. The impact of events occurring in the days and weeks prior to death on the bereavement process and nature of grief experience has not been studied. Understanding how providers can identify time points and events earlier in the child's illness trajectory to assess parental support needs may be instrumental in minimizing the negative effects of grief. The purpose of this paper was to identify experiences, interactions, and interventions that occurred over the illness trajectory and at the time of death that may have played a significant role in parents' bereavement process.

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[1]Division of Pediatric Hematology and Oncology, [3]Department of Pediatrics, Duke University Hospital, Durham, North Carolina.
[2]Duke University School of Nursing, Duke University, Durham, North Carolina.
[4]Duke-NUS, Graduate Medical School, Singapore.
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Methods

A longitudinal, prospective design was used to explore the bereavement process of parents with critically ill infants. We identified antecedents, consequences, and the subsequent impact of events and experiences prior to death on the bereavement process. Data for this secondary analysis was collected between 2008 and 2011 as part of a longitudinal, multiple case study exploring parent and health care provider decision making for infants with complex life-threatening conditions (1R01-NR010548). Each case in the principal study included one or more infants, at least one parent, and a minimum of three health care providers (including physicians, nurses, and social workers). Mixed method data sources were used. We analysed 72 narrative interviews from 7 cases (14 parents of 8 infants) of infants who had died.

Participants and setting

A purposive sampling technique was used in the principal study to select infants with three kinds of complex life-threatening conditions (CLTCs): extreme prematurity (<26 weeks gestation), complex congenital heart diseases (e.g., hypoplastic heart), or genetic disorders requiring a hematopoietic stem cell transplant (HSCT) (e.g., metabolic or storage diseases) receiving care at a southeastern U.S. academic medical center. These conditions were chosen because of their complex clinical course and high mortality rates. Sampling continued within each of these diagnostic categories to include infants of various races and socioeconomic status to ensure a population representative of those encountered in this clinical setting. Parents were at least 18 years old, English speaking, and biological parents of the infants. The 7 cases sampled for this secondary analysis (from a subset of 11 cases in which the infant had died) was small enough to allow for intensive study of over 72 interviews while permitting some variation in race and diagnostic groups. Table 1 displays the demographics of the parent sample.

Table 1. Demographics of Parents Participating in Study

Variable	*Number (%)*
Sex	
Male	7 (50%)
Female	7 (50%)
Ethnicity	
Caucasian	10 (71%)
African-American	4 (29%)
Age (range)	23-46
Years of education (range)	9-18
Married	
Yes	10 (71%)
No	4 (29%)
Religious preference	
Christian	13 (93%)
Other	1 (7%)
Income	
\$15,000-\$25,000	2 (14%)
\$26,000-\$50,000	4 (28%)
\$51,000-\$75,000	5 (35%)
\$76,000-\$100,000	3 (21%)
Employed	
Yes	12 (86%)
No	2 (14%)
Infant diagnosis	
Complex congenital heart disease	6 (43%)
Genetic/metabolic disease/HSCT	6 (43%)
Extreme prematurity	2 (14%)
Infant age in weeks (range)	23-108

HSCT, hematopoietic stem cell transplant.

Data collection

Narrative interviews were conducted with parents, beginning with enrollment (at birth or at diagnosis for extreme premature and complex cardiac group or at decision to transplant for genetic disorder group), and continuing monthly until death. Interviews were also conducted within a week following a life-threatening event or significant change in treatment, and at six weeks and six months post-death.

The narrative-style interviews were open-ended and allowed parents to tell their story including how the infant's illness and treatment were progressing. Probe questions were then used to explore topics pertaining to experiences during their child's illness trajectory, such as the decision making process, coping mechanisms, and bereavement. Parents' emotions, anxieties, and grief were explored. Initial interviews focused on understanding their infant's condition, decisional issues, participation in care and comfort, and thought processes regarding decisions made. Post-death interviews focused on the death experience and process of grief. In the bereavement interviews parents were asked to reflect on their entire experience with their infant's condition and treatment. Table 2 includes sample questions from the interview conducted six months post-death.

Procedure

Informed consent was obtained from parents. Interviews were conducted in person or over the phone by an assistant trained in narrative interview techniques. All parents were informed that the information shared would not be disclosed to the other parent or any health care providers involved in their case.

Table 2. Sample Interview Questions

- This must be a very difficult time for you. Talk about how you are coping?
- How is your family (husband/wife) coping?
- Tell me about a very difficult experience for you.
- Are you comfortable with the health care decisions for your infant?
- Tell me about what happened when [name of infant] died.
- Some parents find it helpful to avoid thinking about their infant's illness after he or she has died while others like to focus at this time in order to remember their infant. Tell me how you have been thinking about your infant and his or her illness.
- We talked at the six-week interview about the events surrounding your child's death and how you felt about that. Has anything changed in the way you feel?
- Tell me about one of your best, most positive memories of this time.
- What was the most difficult experience for you?

Data analysis

Interviews were digitally recorded, transcribed, and reviewed to ensure accuracy. All participants' names were changed to preserve anonymity. The analysis presented here was conducted using a content analysis technique applied to parent interviews and field notes.[22] The focus of this analysis was to identify experiences, interactions, and interventions that occurred over the illness trajectory and at death that may have played a significant role in parents' bereavement process.

All interviews were read throughly to obtain an understanding of the parents' story and infants' illness trajectory. A text-based analysis program (ATLAS.ti) was used to view, organize, and apply codes to the data. The coded data were then clustered into themes, and the themes grouped into categories. Detailed analysis process notes were kept, which enabled members of the research team to see how data had been processed and categorized.

Results

The findings are organized into five categories: Having Expectations, Continuity of Care, Memory Making, Wide Network of Support, and Altruism. Within each category we describe themes that represent events or interventions that played a role in the parents' bereavement process. Supporting data samples for each category and theme are listed in Table 3.

1. Having expectations

This category included themes related to the decision making process parents engaged in, the establishment of expectations of the infant's illness and likely progress, and modes by which parents were able to form these expectations.

Entertaining possible outcomes. Parents were generally hopeful that their child would survive their conditions, but those who acknowledged the possibility of negative outcomes earlier in the course of illness described less distress around the time of death and during bereavement. Although contemplating these outcomes was distressing, parents who had anticipated undesirable situations appeared to be coping better following infant death.

Decisions they can live with. Parents described experiencing less distress during bereavement when they had been actively involved in care decisions and had considered all potential interventions that were offered. Understanding the limitations of current medical technology and accepting that not all available options were suitable for their child also helped to lessen their feelings of guilt and blame during bereavement.

Speaking with other families. Though all parents affirmed that communicating with health care providers was essential in dealing with their infant's condition, some believed it was equally useful to speak with other parents and caregivers about their respective experiences. Participants who communicated with parents of other infants with similar conditions said that these conversations helped them anticipate likely courses of illness and helped them to form realistic expectations.

2. Continuity of care

This category included themes related to care provided by a dependable person who had a history of interaction with the child, the parent's positive perceptions of this contact, and the importance that parents placed on continuity of care within the health care system.

Having a personal witness. Though this study was not intended to be interventional, parents expressed that the research interview sessions conducted by a consistent member of the study team was helpful and allowed them to reflect upon their thoughts and reactions to their child's illness. Parents described the importance of having the same person at each interview to listen to their thoughts without passing judgement or offering suggestions, which family members and close friends tended to do. They found it easier to speak with people who had been with them throughout the entire course of the illness, and with whom they had maintained a good relationship.

Provider care. Though parents understood the rotating nature of the health care team, they expressed frustration at the lack of continuity of care. Changes in providers caused some parents to experience a sense of abandonment during their child's illness. This sense of abandonment and accompanying perceived loss of an advocate continued after decisions were made to transition their infants from curative treatment to comfort measures. Some parents also started to doubt the therapeutic motives and integrity of unfamiliar providers.

3. Memory making

This category included themes related to memories of their infant: how memories were created, the physical and emotional nature of these memories, the influence they have on the lives of parents, and how memories continue to be created after death.

Remembering time spent together

Memories of their infant were particularly important to parents during the bereavement period. Parents frequently reminisced about final hours with their child, most particularly the events leading up to and surrounding their infant's death. Parents recounted parenting activities they had participated in (such as holding and dressing) and expressed appreciation at having had the opportunity to create these memories with their child. Time spent together as a family during the course of illness was extremely important.

It was important for parents to know that while their infant had been alive they had provided care and comfort to the best of their abilities. Parents' perception that their infant's suffering was minimized enabled them to contemplate their infant's illness and death with lessened guilt and distress. This knowledge that they had provided love and comfort became a memory that parents could draw upon for support during bereavement.

Physical memory making. Physical items were also valuable to parents and helpful in memorializing their infant. Though most parents had their own collection of items such as photographs and clothing, they appreciated the additional memory boxes and hand prints created by staff at the hospital

Table 3. Results

Category	*Theme*	*Example*
1. Having Expectations	Entertaining Possible Outcomes	"It's alright, it wasn't something that we were expecting, but we knew…this could be the turnout before we came down here, and we were willing to take that option if it happens…I don't want to say we were prepared for it but…We knew that outcome could come and I think we were prepared for that…and I think right now we are at ease with the decision we made [to withdraw care]."
	Decisions They Can Live With	"There really was nothing else we could do.…It was what right now in 2008 what is medically possible…So I can't get mad or you know, fault somebody for…this medicine not being a complete cure. I knew pretty much the outcome of what it was going to be, and there's nobody, there's nobody at fault. We did what we had to do and we knew going down there this could happen, but I would much rather do that than us sit here and just watch it, and just see that something's not right and not do anything about it."
	Speaking with Other Families	"It would be helpful for me…[to have] had somebody that's already been through it to sit down and talk to us. We would've felt so much better about everything, we would've known what to expect, it wouldn't have crept up on us. But, well we didn't have anybody…we didn't have anybody to hear from, so we just had to go with what we went with."
2. Continuity of Care	Having a Personal Witness	"It kind of helps to know that sometimes somebody else had the same feelings as you– not as much had the same feelings as you but understands where you're coming from instead of talking to a total stranger who has no clue what you're talking about."
	Provider Care	"We seem to be the only people that notice the changes. I think everybody else is so used to seeing her all the time and so used to sick babies that they really can't tell if this changed or that changed. I think probably the best way to improve that is to have the same nurse follow the same kid, or the same couple of nurses follow the same kid.…We've gone through [almost] every nurse on the ward and because we're swapping out, that redness that's there today, you know it could've been there yesterday, so they don't bring it up."
3. Memory Making	Remembering Time Spent Together	"We decided, look, let's…make her comfortable…We've done all we can possibly, you know we did everything we could by the book…Everything we could medically…and if nobody in the state…can fix Ally, she's a fighter, you know just let her be…We did all we could."
	Physical Memory Making	"The Child Life people came in and made some really neat like cast things like um like a, stone thing I don't know what it is like a molding of his hands…So I could have handprints and footprints and that kind of thing. So I would be able to have his memory."
4. Wide Network of Support	Support from Strangers	"We had one [memorial event] at the house, where we had almost 500 balloons, and can you imagine that?…And we had almost 25, 30 people just at my house letting them all off. And you know that really means a lot…We even had people show up that I didn't know who they were…Just for them to take out, ten, fifteen minutes and go pick out a pink balloon and take a picture of…letting it go in the air…They didn't have to do that…But that fifteen minutes that they did that it wasn't about them, it wasn't about…me, it was about her and that's what I like…If people can go out of their way like that…it makes me feel better."
	Affirmation of Their Strength and Decisions Made	"It is a very tragic thing but we're very content with the decisions that we made.…We're confronting a lot of people…that came to us, you know what, ya'll are damn strong for doing what you did, you know you're great parents…I've had people come up to me and say…you're one hell of a man for doing what you did. And it means a lot because…getting this from grown people…It's very heartwarming knowing that if I can go through this…I'm going to be ok the rest of my life."
5. Altruism	Helping Others Through Their Experience	"We were definitely more than happy to do it any way to help out…When Logan passed…They um, offered to do an autopsy so maybe we did it for more to get answers for ourselves but you know what…they said it *could* help other kids you know that could be in similar situations…and they…asked if we'd like to donate his brain for research…that was a hard decision to make…but if it's going to help you know one person out then you know we want to help in any way we can."
	Passing on Personal Items	"Every single toy that I had brand new in the box, which was probably half of her toys, I gave to the Happy Place…I told them, don't just give it to [anyone]; give it to a kid that needs it. Give it to a kid that wants to play with this. She never got to play with it, but, give it to a kid that wants to play with it…that's gonna cherish it."

and said these items helped to strengthen their memories of their infant.

4. Wide network of support

This category included themes related to parents drawing support from individuals outside of their immediate family and social networks. Access to this support was both in person and through social media.

Support from strangers. Parents described their surprise at the helpfulness, support, and concern that came from strangers they encountered on internet sites, blogs, and at memorial events. While parents had not personally known these individuals, they experienced a sense of comfort from knowing that their story had a broader impact beyond their immediate social support network. Parents were touched when strangers would attend memorial events and dedicate time to commemorate and remember their infant. Their participation was treasured as a way of honouring their infant's existence.

Affirmation of their strength and decisions made. Parents usually appreciated condolences that were offered, even from people they did not know well. They cherished the knowledge that other people were aware of the plight they had experienced. Having others affirm the difficulty of their situation also made it easier for parents to accept the decisions they had made for their infant.

5. Altruism

This category included the themes of satisfaction and a sense of meaningful purpose when parents were able to reach out to other families in similar situations.

Helping others through their experience. The experience of coping with the illness, treatment, and death of a critically ill infant is one that parents found agonizing. Many parents wanted good to come out of their experience. Helping other parents allowed them to find some positive meaning in their grief and purpose in their infant's life.

Passing on personal items. Even though their infant lived for a short time, most parents had accumulated a number of personal items (such as clothing and toys). Following the death, parents expressed a sense of gratification at passing these items on to other children who were in need of them.

Discussion

Numerous studies have described the overwhelming pain and distress that parents experience following the death of a child.[14–17] The prospective descriptions of infant illness factors and death experiences given by parents in this study provide insight into parental bereavement needs and grief experience.

Parents developed *expectations* of their infant's illness trajectory from discussions with care providers and parents of other children with similar complex conditions. As the infant's illness trajectory changed over time, altered treatment plans were developed. Parents generally pursued all treatment options that were offered out of a desire to lessen regret and feel "we did everything possible." Understanding the limits to modern medicine's ability to cure their infant was critical to moving forward. These findings underscore the importance of evaluating treatment options in the context of the goals of care, rather than availability, before offering them to parents. Together providers and parents should frequently reassess the child's illness trajectory with a goal toward realistic expectations of the likely outcome of the illness.

Parents in this study described the importance of *continuity of care*. Parents of dying children need the support and expertise of a caregiver that has a relationship with their child. Children with complex chronic conditions often require a large number of consultants and specialists over the trajectory of their illness. Identification of a central provider that can assume responsibility for care coordination is one strategy that health care teams can use to achieve continuity of care. In addition, parents need someone to talk with who does not come to the conversation with a caregiver "role" agenda. Therefore, an impartial support person, like a social worker or chaplain that has the time to "just listen" can be a source of significant support for parents.

Consistent with previous work on bereavement support, the importance of *memory making* was central in this study. Parental regret during the grieving process often focused on actions parents took during their limited time with their infant and not on medical decisions.[18] Other retrospective studies have found that parents wished they had engaged in more parenting activities, such as bathing, dressing, and holding to provide more memories to reflect upon during bereavement.[19] Our study prospectively documented the importance of memory making, in which tangible evidence of the infant's life was integrated into future memories. This is particularly important for parents of infants given that they may have never brought their infant home to create family memories.

These findings underscore the importance of early intervention in preparation for the possible death of an infant and establishment of resources to prospectively support parent bereavement, including memory making. Where possible, parents should be actively involved in daily infant care such as feeding and bathing. Encouraging parents to bring personal items such as quilts or toys can give parents a sense of providing love and comfort for their child, an important memory during bereavement. Infant memory boxes or handprints from the providers also provide bereaved parents with physical remembrances of their infant.

Prior studies have validated the importance of *a wider network of individuals in a range of support roles*.[20] In our study, parents not only drew strength from close family, friends, and caregivers, but found avenues of support in social media such as online support groups, websites, and personal blogs. While strangers and peer supporters cannot deal with medical questions pertaining to illness and cause of death, they are an invaluable source of presence, affirmation, and support for grieving parents. Prior studies reported that feelings of extreme isolation in grieving parents is reduced during self-help group attendance; parents derive a sense of acceptance from interacting with others with similar experiences.[21] Communicating with other parents enables them to release pent up feelings and decrease the potential intensity of future emotional and social distress.[21] Providers can assist parents in joining support groups or direct them to appropriate online support resources. Organizing annual memorial events that commemorate the deceased can reach out to bereaved families in a setting of support.

Altruism was important for families: to give to others following the death of their infant. Sharing their stories on social media sites provided comfort to parents as did their ability to share their child's physical belongings with others. While sharing their story may not be useful to all parents, providers should encourage families to explore such options.

Our findings describe experiences and events that occurred prior to and following the death of an infant that parents found helpful in reducing their distress during the grieving period. Parents described these experiences as having lessened their anguish during the bereavement period. Future research that measures the impact of such experiences on parental bereavement outcomes (such as the length of acute bereavement, impact on daily functioning, complicated grief) is needed.

While this study provides guidance for interventions to support parent bereavement, the data was collected for a study on medical decision making and did not specifically focus on bereavement needs. More direct questioning on parental bereavement experience is required to further clarify optimal bereavement support needs of parents. It is hoped that some of the findings and suggestions offered in this study will present health care providers with a wider range of options for improving the delivery of parental care during the acute bereavement period.

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Address correspondence to:
Sharron L. Docherty, Ph.D., CPNP
Duke University School of Nursing
DUMC 3322
Durham, NC 27710

E-mail: sharron.docherty@duke.edu