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Meaning Making during Parent-Physician Bereavement Meetings after a Child's Death

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Abstract

Objective—Identify and describe types of meaning-making processes that occur among parents during bereavement meetings with their child's intensive care physician after their child's death in a pediatric intensive care unit.

Methods—Fifty-three parents of 35 deceased children participated in a bereavement meeting with their child's physician 14.5±6.3 weeks after the child's death. One meeting was conducted per family. Meetings were video recorded and transcribed verbatim. Using a directed content analysis, an interdisciplinary team analyzed the transcripts to identify and describe meaning-making processes that support and extend extant meaning-making theory.

Results—Four major meaning-making processes were identified: (1) sense making, (2) benefit finding, (3) continuing bonds, and (4) identity reconstruction. Sense making refers to seeking biomedical explanations for the death, revisiting parents' prior decisions and roles, and assigning

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blame. Benefit finding refers to exploring positive consequences of the death including ways to help others such as giving feedback to the hospital, making donations, participating in research, volunteering, and contributing to new medical knowledge. Continuing bonds refers to parents' ongoing connection with the deceased child manifested by reminiscing about the child, sharing photographs, and discussing personal rituals, linking objects and community events to honor the child. Identity reconstruction refers to changes in parents' sense of self including changes in relationships, work, home, and leisure.

Conclusions—Parent-physician bereavement meetings facilitate several types of meaning-making processes among bereaved parents. Further research should evaluate the extent to which meaning making during bereavement meetings affects parents' health outcomes.

Keywords

Meaning; bereavement; child; parent; physician

Parents who experience the death of a child in a pediatric intensive care unit (PICU) are at high risk for adverse health outcomes including complicated grief (Meert et al., 2010, Meert et al., 2011). Complicated grief is a condition characterized by persistent symptoms of separation distress and traumatic distress (Prigerson et al., 2009; Shear et al., 2011). These symptoms include intense yearning for the deceased, a sense of shock and disbelief, anger and bitterness, intrusive and preoccupying thoughts of the deceased, avoidance of reminders of the loss or excessive proximity seeking, intense loneliness, and feeling that life without the deceased has no purpose or meaning. Many of these symptoms also occur with acute normative grief; however, when complicated grief develops, these symptoms are intense, prolonged and debilitating.

Many bereaved parents struggle to restore a personal sense of meaning after their child's death (Lehman, Wortman, & Williams, 1987; McIntosh, Silver, & Wortman, 1993; Murphy, Johnson, & Lohan, 2003; Uren & Wastell, 2002; Wheeler, 2001). As described by Park's (2010) meaning-making model, people possess orienting systems referred to as global meaning (e.g., beliefs, goals, sense of purpose) through which they interpret life experiences. When faced with a tragic event such as a child's death, people assign meaning to the event, referred to as appraised meaning. The extent of discrepancy between global and appraised meaning determines the extent of distress a person experiences; this distress stimulates meaning making. Through meaning making, people attempt to bring global and appraised meaning into alignment, thereby restoring a sense that the world is meaningful and life worthwhile. Also as described by Park's (2010) model, for those who seek meaning, successful meaning making (i.e., meaning made) leads to better adjustment to the tragic event whereas unsuccessful meaning making leads to continued discrepancy and distress, and ongoing meaning-making attempts.

Discrete types of meaning-making processes that occur among individuals who are bereaved have been described including *sense making, benefit finding, continuing bonds,* and *identity reconstruction* (Gillies & Neimeyer, 2006; MacKinnon et al., 2013). Sense making refers to the bereaved person's attempts to find a benign explanation for the loss (e.g., why it happened) and is often framed in philosophical or spiritual terms (Holland, Currier, &

Neimeyer, 2006; Keesee, Currier, & Neimeyer, 2008; Lichtenthal, Currier, Neimeyer, & Keesee, 2010; Lichtenthal, Neimeyer, Currier, Roberts, & Jordan, 2013). Benefit finding refers to the bereaved person's attempts to identify positive consequences of the loss (e.g., silver lining) such as a greater desire to help others, strengthened relationships, and reordered life priorities (Holland et al., 2006; Keesee et al., 2008; Lichtenthal et al., 2010; Lichtenthal et al., 2013). The extent to which bereaved parents make sense or find benefit in their loss has been shown to be associated with the extent of complicated grief symptoms (Keesee et al., 2008).

Continuing bonds refers to an ongoing attachment to the deceased person (Klass, 2001; Neimeyer, Baldwin, & Gillies, 2006; Stroebe, Schut & Boerner, 2010). Rather than sever the bond with their deceased child, many parents transform the bond in ways that enable them to keep the child an important part of their lives (Klass, 2001). This process is often achieved by interaction with a community that shares and validates the bond. The relationship between continuing bonds and adjustment to loss is complex and may depend on the type of bond expressed, its underlying motivation, and the emotions evoked (Field et al., 2005; Field et al., 2013). Research suggests that continuing bonds are associated with complicated grief only when the bereaved person is unable to make sense of the loss (Neimeyer et al., 2006).

Identity reconstruction refers to a reorganization of one's sense of self after the loss of a loved one (Gillies & Neimeyer, 2006; Neimeyer et al., 2006). Becoming a parent is an important milestone for many individuals and the parental role is often a major part of a parent's identity. Losing a child has been compared to amputation of an extremity; it is a permanent loss of a part of oneself to which one may adjust but which will never return (Klass, 1999). Identity change may be positive (e.g., personal growth) or negative (e.g., reduced sense of self). Higher levels of positive identity change have been associated with less complicated grief symptoms (Neimeyer et al., 2006).

To summarize, research suggests that bereaved parents are at high risk for complicated grief, and that meaning making is associated with a reduction in the severity of these symptoms. In addition, several professional organizations in the United States recommend that physicians meet with family members after a patient's death as part of routine care (American Academy of Pediatrics, 2013; Ferrell et al., 2007). To address the needs of parents whose child died in a PICU, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN) developed and tested a framework for conducting bereavement meetings (Eggly et al., 2011; Meert et al., 2014). Bereavement meetings between parents and intensive care physicians in the weeks to months after a child's death in the PICU provide parents with an opportunity to discuss their child's illness and death and may facilitate parents' meaning making. The CPCCRN framework is a general set of principles intended to guide bereavement meetings and includes processes and content adaptable to the specific context of each family's circumstances. The framework is based on prior research investigating parents' and physicians' perspectives and experiences with follow-up meetings (Meert et al., 2007; Meert et al., 2011) and includes suggestions for extending a meeting invitation, preparing for a meeting, meeting structure and content, communicating effectively, and follow-up after the meeting. Parents are encouraged to set the meeting agenda; suggested discussion topics include the chronology of events leading to PICU admission and death, cause of death, treatments, autopsy, genetic risk, end-of-life decisions, ways to help others, bereavement support, family coping, reassurance, referrals, and feedback to the hospital. Bereavement meetings are novel because traditional intensive care practice consists entirely of in-hospital care of patients and families, and this care ends when the patient is discharged or dies. The objective of this study was to identify and describe types of meaning-making processes that occur among parents during bereavement meetings with their child's intensive care physician after their child's death in a PICU.

Methods

The study was a secondary analysis of bereavement meetings with parents whose child died in a CPCCRN-affiliated PICU. The purpose of the original study was to assess the feasibility of conducting bereavement meetings as described by the CPCCRN framework (Eggly et al., 2011). Detailed information about recruitment and other procedures for the original study is provided elsewhere (Meert et al., 2014). The CPCCRN is a multicenter research network consisting of seven U.S. tertiary care academic pediatric centers and a data coordinating center. The study was approved by the institutional review board at each site and the data coordinating center. Informed consent was obtained from all participants.

Study participants included intensive care physicians, parents, parent support persons, and other health professionals; the current secondary analysis focuses only on the parents. Parents were eligible if their child died in a CPCCRN PICU, if they were English or Spanish speaking, if they were > 18 years of age, and if an intensive care physician trained to use the framework participated in their child's care. Parents were introduced to the study by a mailed letter about one month after their child's death, and recruited by a research coordinator over the telephone 1–2 weeks later. Parents were informed that the purpose of the bereavement meeting was to provide parents with an opportunity to gain information about their child's illness and hospital course, ask questions, and provide feedback on their hospital experiences. Parents were also informed that the physician leading the meeting would be one member of the team of physicians who provided care for the child in the PICU. Parents who agreed to participate in the study invited family or friends to attend the meeting and identified other health professionals whom they wanted to be present. Research coordinators invited health professionals whose presence was requested by the parents or physician.

Fifty-three parents of 35 deceased children participated in a bereavement meeting with their child's intensive care physician. Parents were 37.7+9.8 years of age; 32 (60%) were mothers and 21 (40%) fathers; 39 (74%) were married. Race was self-reported as White for 39 (74%) parents, Black for 7 (13%), other for 6 (11%) and unknown or not reported for one (2%); ethnicity was self-reported as Hispanic for 7 (13%), not Hispanic for 40 (75%), and unknown or not reported for 6 (11%). Deceased children (n=35) of participating parents were 6.9+7.0 years of age at the time of death; 17 (49%) were boys; 10 (29%) died from multiple organ failure, 8 (23%) cardiac causes, 7 (20%) respiratory causes, 4 (11%) neurologic causes, 3 (9%) trauma, 2 (6%) malignancy, and one (3%) gastrointestinal causes.

Bereavement meetings were conducted as described by the CPCCRN framework (Eggly et al., 2011; Meert et al., 2014). One meeting was conducted per family. Each physician conducted 1–3 meetings. Eighteen meetings were attended by the deceased child's mother and father, 14 by the mother only, and 3 by the father only. Thirty-three (94%) meetings were conducted in English and 2 (6%) in Spanish with the assistance of a translator. Bereavement meetings were held in a conference room at the hospital where the child died or at another on-campus location. Meetings occurred 14.5+6.3 weeks after the child's' death and were 1.2+0.6 hours in duration. All meetings were video recorded.

Analysis

Video recordings were transcribed verbatim. Transcripts were imported into a qualitative software program (NVivo 10, QSR International Pty Ltd., Doncaster, Australia) to facilitate analysis. Directed content analysis (Hsieh & Shannon, 2005) was used to identify and describe parents' meaning-making processes that supported and extended extant meaning-making theory. Meaning-making processes included parents' attempts to make meaning and meanings made.

Two investigators from the original study (KM and SE) developed an initial coding dictionary based on extant meaning-making theory and their familiarity with the data. The initial coding dictionary encompassed the four major types of meaning-making processes described above (i.e., sense making, benefit finding, continuing bonds, and identity reconstruction) but also allowed for emergent themes that might reflect additional meaning making processes. Subsequently, an interdisciplinary team of three investigators with backgrounds in intensive care medicine (KM), communication science (SE) and nursing (KK) used an iterative process to code the transcripts using the coding dictionary. The investigators independently read and coded three transcripts at a time, then met to compare and discuss coding, and reach consensus. Subtypes of meaning making for each of the four major types were added to the dictionary and defined during the meetings. To address methodological rigor and trustworthiness (Lincoln & Guba, 1985), the investigators used techniques including peer debriefing during coding meetings and maintaining careful notes as an audit trail of decisions regarding the coding dictionary and process. These techniques were used to assure that the analysis remained true to the participants' narrative descriptions while the investigators were employing preexisting concepts of meaning making during the directed content analysis. These strategies are of particular importance when conducting a secondary data analysis (Thorne, 1994). Data saturation was reached after coding two-thirds of the 35 transcripts (i.e., no new codes were identified). However, all transcripts in the dataset were coded. After consensus was reached for the coding of all transcripts, investigators determined the total number and percent of transcripts that contained at least one instance of each meaning-making process (i.e., code). Exemplars of each meaning-making process were selected from the transcripts for presentation.

Results

The meaning-making processes identified in the transcripts are described below. Tables 1–4 summarize the types and subtypes of meaning-making processes, demonstrate exemplars, and provide relative frequencies with which each process was observed. Each exemplar is labeled with a number representing the meeting from which the exemplar was selected. Although the coding process allowed for emergent themes that might reflect additional meaning making processes, the four main types were those suggested by extant theory: sense making, benefit finding, continuing bonds, and identity reconstruction.

Sense making

Sense-making processes were attempts by parents to comprehend their child’s death (Table 1). Comments such as, “We just really don't know what happened” (#24) demonstrate parents’ need to find explanations for their experiences.

Biomedical explanations were the most commonly occurring sense-making process identified during bereavement meetings. Biomedical explanations included discussing the details, course of illness and cause of death, reviewing autopsy results, and exploring counterfactuals (i.e., what if?). Exploring counterfactuals included posing questions to health professionals about (1) whether a different course of action would have prevented the child’s death, or (2) what the child would be like physically and developmentally if the child had survived.

Parents’ prior decisions were processes through which parents attempted to make sense of their own decisions regarding their child’s treatment and end-of-life care. Some parents discussed their decisions by reweighing the risks and benefits of invasive treatments such as artificial feeding, tracheostomy, chemotherapy, surgery, and organ transplantation. Others revisited their decisions to limit or withdraw life support (e.g., mechanical ventilation) often questioning whether they acted too soon or waited too long. Some reconsidered their decisions about autopsy or organ donation. Parents often explained why they made the decisions they did, and sought reassurance from physicians and other health professionals that the information they based their decisions on was correctly understood, and that the best decisions had been made.

Blame was a process that occurred when parents held physicians and hospital staff accountable for deficiencies in care they perceived as ultimately leading to their child’s death. These included deficiencies in medical care such as lack of attention to signs and symptoms, delayed diagnosis or treatment, medical errors, hospital-acquired infections, and problems with the healthcare system such as delayed transfer from the referring hospital or ward to the PICU, or premature discharge leading to readmission and death. Deficiencies in care also included adverse personal and social experiences related to their child’s hospitalization such as poor communication, missed opportunities to understand the cause of death (e.g., genetic testing), restrictions imposed on parents by hospital policies or the built environment, and inappropriate types of follow-up such as home delivery of hospital satisfaction surveys after the child’s death.

Parents’ role in the death was a process through which parents blamed themselves for their child’s death. Parents held themselves accountable for missing early signs and symptoms, providing ineffective cardiopulmonary resuscitation at home, and not preventing suicide or injuries inflicted by an abusive partner.

Blessings were positive experiences encountered by parents during their child's illness and death. Parents discussed feeling grateful for their parenting experience, time spent with their child, and circumstances that allowed them to fulfill their parental role during the child's illness and death. Parents also expressed gratitude for health professionals who provided compassionate care, and the support of family, friends and community.

Other sense-making processes observed among parents included recognizing the *inevitability of death* in that a predetermined time for the child's death had occurred; making *downward comparisons* with less fortunate others or hypothetical worse case scenarios (e.g., survival with no quality of life); acknowledging *God's will* in that the child was taken by God as part of a divine plan; accepting that health professionals and parents *did everything* possible to help the child; expressing relief that the child was *no longer suffering;* expressing gratitude that the child *exceeded the expected age* of one with that diagnosis; acknowledging the *child's will* to end suffering through death; asking *why me* in that the loss was undeserved; and realizing the *parent was not capable* of providing the necessary care if the child would have survived.

All bereavement meetings in our sample included at least one demonstration of a parent sense-making process. However, some parents also expressed that *no sense could be made*; this expression was often accompanied by reports of frustration or disappointment. Additionally, some parents expressed they had *no need to make sense* of their child's illness and death.

Benefit finding

Benefit-finding processes were parents' attempts to identify positive consequences of their loss (Table 2). Comments such as, "I just feel like good things have to come from it" (#2) demonstrate parents' need for something positive to result from their experiences.

Ways to help others were the most common benefits identified by parents. These included providing feedback to physicians and other health professionals about the hospital experience, making donations, participating in research, volunteering, contributing to new medical knowledge through their child's case, and donating organs. Feedback was both positive and negative and intended by parents to improve the experience of other families who lose a child. Benefits were also found in the impact the child had on promoting *change in parents and others for the better*. These changes included enhanced awareness and appreciation of life, improved relationships, and increased ability to deal with adversity.

Continuing bonds

Continuing bonds were processes through which parents sought ongoing connection with or a continued presence of the deceased child in their *inner lives* and *social worlds* (Table 3). Comments such as "There is no closure - as long as you're alive, that person is part of you" (#7) reflect parents' continuing bonds with their deceased child.

Parents' inner bond with the deceased child was revealed during bereavement meetings as parents reminisced about their child's unique attributes and special life events; discussed personal rituals enacted to remember and honor the child; displayed photographs of the child and family; described artifacts and keepsakes that serve as linking objects; described beliefs about and interactions with their deceased child as a spiritual being (e.g., angel); and imagined what the child would have been, said or done in the present and future if he or she had survived.

Parents also described ways in which their bond with the deceased child was shared by others in their social network. Many parents spoke with pride about large community attendance at the child’s funeral, memorial services, and other events (e.g., balloon releases) to remember and honor the child. Parents recalled actions of health professionals that demonstrated dignity and respect for the child. Parents also recalled ways in which the deceased child was remembered and honored by his or her siblings.

Identity reconstruction

Identity reconstruction was reflected in the personal changes that parents reported had occurred as a result of surviving their child’s death (Table 4). Comments such as, “This took the chunk of me…it took the vital part” (#34) and “You will be starting over” (#29) demonstrate parents’ fragmented sense of self and need to redefine their lives.

Many parents recalled ways in which they fulfilled their parenting roles and responsibilities during their deceased child’s life, and often sought confirmation that they were *good parents*. The good parent role included self sacrifice (e.g., “We always put her first” (#23)), insight into the child’s condition (e.g., “You don’t know her the way I know her” (#30), and a focus on achieving quality of life (e.g., “We made sure life went according to her quality” (#13)) and as normal a childhood as possible (e.g., “We didn't treat him any different” (#1)).

Parents also discussed many *life changes*, both positive and negative, that had occurred since their child’s death. These included changes in their relationships, work, and environment. Parents also discussed upcoming plans such as travel, hobbies, and other activities they could engage in since they no longer were caring for their child. Regarding relationships, parents often struggled with how they should acknowledge their deceased child when asked about the *number of children* in their family.

Discussion

Findings of this study suggest that various types of meaning-making processes occur among bereaved parents during bereavement meetings with their child’s intensive care physician. The meaning-making processes identified were consistent with extant theory (Park, 2010) and included sense making, benefit finding, continuing bonds, and identity reconstruction.

Sense making was the most predominant type of meaning making that occurred during bereavement meetings, and among sense-making processes, biomedical explanations were most common. This finding is in contrast to prior research suggesting that parents who are bereaved are most likely to make sense of their child’s death by reliance on religion and spirituality (Lichtenthal et al., 2010; McIntosh, Silver, & Wortman, 1993; Murphy, Johnson, & Lohan, 2003). The attention to biomedical explanation observed in this study is likely related to the expectations of parents and physicians who are accustomed to discussing biomedical issues pertaining to the child’s care when they interact with each other; physicians remain the preferred and most trusted source of health information (Hesse, Moser, & Rutten, 2010). Also, during study recruitment, parents were told that the meeting would provide them with an opportunity to gain information about their child’s illness, ask questions, and provide feedback. Other types of sense-making processes were observed among parents in this study. These included the cognitive and emotional processing of one’s personal role in the events, attribution to others, and consideration of potential practical, existential and spiritual explanations for the death.

Although all parents demonstrated engaging in some type of sense-making process, we found that some parents also expressed frustration and disappointment in their inability to make overall sense of their child’s death. For example, one parent who painstakingly recounted her child’s course of illness, asked numerous medical questions, and displayed good medical knowledge during the meeting sadly concluded, “You try and figure it out and nothing” (#6). Possibly, these parents were particularly frustrated because the meetings occurred relatively soon after the death, and parents were in the early stages of trying to make sense. However, these expressed emotions are consistent with Park’s (2010) meaning-making model, and suggest that parents who are unable to make sense may experience ongoing distress.

A minority of parents suggested that they had no need to make sense of their child’s death. This was most often exemplified during the meetings by comments such as “I don’t have any questions at all” (#3). Possibly, some of these parents may already have made some degree of sense by the time of the bereavement meeting that they felt less of a need to make sense during the meeting. Other possibilities are that these parents had less of a need to make sense from the beginning or did not feel comfortable discussing their meaning making struggles during a meeting with the hospital team. Parents who expressed having no need to make sense did so with neutral affect suggesting less emotional distress than those unable to make sense. It is also possible that these parents were carefully controlling their emotional expression during the bereavement meetings. Prior research has demonstrated a discrepancy between parents’ positive emotional expression and their self-reported positive affect during discussions with health professionals about their seriously ill child’s condition (Hexem, Miller, Carroll, Faerber, & Feudtner, 2013). Regarding bereavement outcomes, prior research among parents whose children died from sudden infant death syndrome or motor vehicle accidents suggests that parents who never search to make sense and those who search and successfully make sense have better psychological adjustment than those who search without achieving this goal (Davis, Wortman, Lehman, & Silver, 2000).

Benefit finding among parents in this study primarily consisted of seeking ways to help other parents whose children were ill or had died. Parents spoke of being “in the club” (#34) and of their potential to help others as a result of “lessons learned” (#35) from their experiences. Using an anonymous web-based survey completed by parents an average of 6 years after their child’s death (range 0–40 years), Lichtenthal and colleagues (2010) similarly found the most common benefit reported by parents was a newfound ability to help others who experienced loss. Some authors have cautioned that benefit finding may not occur early after a death but rather come about many months or years later (Neimeyer &

Anderson, 2002). However, parents in the current study often discussed their willingness and plans to help others during bereavement meetings which took place about 14 weeks after their child's death. Parents in this study also described taking solace from the value their child's life had for others, and some sought to preserve their child's legacy by living their own life in a way that was worthy of their child.

Bereavement meeting conversations were rich with parents' manifestations of their continuing bonds with their deceased children. Consistent with the observations of Klass (1999, 2001, 2006), the continuing bonds revealed by parents not only reflected their ongoing inner relationship with the deceased child but also the integration of the deceased child into their social networks. Manifestations of parents' inner bond included parents' offering of memories and imaginings during bereavement meetings, photographs and scrapbooks brought to the meetings to share with physicians, and descriptions of personal rituals and linking objects. Klass (1999) described how bereaved parents often perceive their deceased children as "angels, saints, and bodhisattvas (p. 37)" that bridge the gap between transcendent and everyday reality. This concept was exemplified in the current study when parents spoke of their deceased children as spiritual beings who had a sustained presence and influence in their daily lives.

The social nature of parents' continuing bond with their deceased child was evident in parents' descriptions of the ways in which family (e.g., deceased child's siblings) and the larger community (e.g., friends, teachers, coworkers) remembered and honored the child. In particular, health professionals who regarded the child as a unique person, treated the child with dignity and respect before and after death, and participated in events to commemorate the child were deeply appreciated by parents. Prior research suggests that parents who are bereaved have an important need for their children to be recognized as human and as having social worth (Meert, Briller, Schim, Thurston, & Kabel, 2009).

Parents in this study bore witness to the intense pain and suffering associated with losing a child, as well as the need to integrate the loss experience into their personal identity. Signs of identity reconstruction during bereavement meetings included parents' self-evaluation of their past parenting experiences, their descriptions of the many life changes that have taken place since their child's death, and their struggle to acknowledge the deceased child in new relationships.

According to the Dual Process Model of Coping with Bereavement (Stroebe & Schut, 2010), individuals oscillate between dealing with loss-oriented and restoration-oriented stressors during bereavement. For parents, loss-oriented stressors may include dealing with the question of whether they were good parents to the deceased child. Parents often sought reassurance from physicians and other health professionals during bereavement meetings that they were indeed good parents. Hinds and colleagues (2009) and October, Fisher, Feudtner & Hinds (2014) previously described the concept of trying to be a good parent to children with terminal cancer and children with life-threatening conditions in PICUs, respectively. Among parents of children with terminal cancer, "doing right by my child" was the most frequently mentioned aspect of being a good parent (Hinds et al., 2009). Among parents of children in PICUs, "focusing on my child's quality of life," "advocating for my child," and "putting my child's needs above my own" were most frequently mentioned (October et al., 2014). Aspects of being a good parent identified in the current study overlap with these findings and include self-sacrifice, knowledge of the child's condition, and a focus on the child's quality of life. Perceiving oneself as having been a good parent may be a step towards positive identity change after a child's death. Restoration-oriented stressors discussed by parents included adapting to life changes such as new relationships, and changes in work, school, home and leisure as a result of the child's death. Some parents spoke with optimism about their life changes whereas others spoke with more hopelessness and despair.

Limitations of this study include the inability to distinguish between parents' meaning-making attempts and meanings made during bereavement meetings. Meaning-making theory posits that this distinction is important because futile searching without meaning made may contribute to parents' ongoing distress. Another limitation is the self selection of research participants which may bias the findings because parents who agree to participate in a bereavement meeting may be actively searching to make sense of their experiences or desiring to find benefit by contributing to the research process. Also, the design of the original study was appropriate for assessing the feasibility of parent-physician bereavement meetings, but did not allow us to analyze our findings by parent psychological or socio-demographic characteristics, or child diagnostic categories or other clinical characteristics. Future studies conducted with a larger, diverse population may be able to investigate how meaning-making processes occur in special populations, and how individual characteristics influence these processes. Also, physicians' role in the meaning-making process was not analyzed; it is possible that physicians using the CPCCRN framework prompted certain types of meaning making among parents potentially biasing the findings. Finally, the lack of assessment of parents' health outcomes in this study prevents evaluation of relationships between meaning-making processes and health after the loss of a child; this is an important area for future study because a causal relationship between meaning making and better health outcomes has not been empirically demonstrated.

Strengths of this study include the direct observation of parents' spontaneous meaning-making processes and the theory-based analytic approach. Previous studies investigating meaning making among parents who are bereaved have been limited to self reports. These prior studies typically asked parents to rate the extent of meaning making or meaning made using closed-ended items such as "Have you made any sense or found any meaning in your child's death? 1=no, not at all, and 5=yes, a great deal" (Davis et al., 2000; McIntosh et al., 1993). Direct observation of parents during bereavement meetings allows exploration of meaning-making processes as they unfold, provides greater depth to the findings, and reveals the importance that meaning plays in the lives of bereaved parents through the emotions displayed as their stories are told. Meaning-making theory is rich and complex (Park, 2010); however, abstract constructs and processes related to meaning have not been well operationalized through empiric research. The analytic approach used in this study produced findings that support and extend meaning-making theory by demonstrating the need many parents have to make meaning, and by providing real life examples of meaning-making processes utilized by parents during bereavement.

In conclusion, many parents whose children die in a PICU have a need to find meaning in the experience of their child's death. Ways in which parents seek to find meaning include making sense of the experience, finding benefit in the loss, continuing the bond with the deceased child, and restructuring their personal identity. Through bereavement meetings, intensive care physicians and other health professionals may facilitate meaning-making processes by providing information, emotional support and an opportunity for feedback as described by the CPCCRN framework (Eggly et al., 2011). Future research should investigate the relationships between meaning making, meanings made, and future health outcomes among parents who are bereaved.

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Table 1

Sense-making processes observed during follow-up meetings (N=35)

Sense-making process	Example (Follow-up meeting number)	n (%)*
Biomedical explanations	Do you think there’s anything we should be asking as far as from a medical perspective that maybe we’re just not—any information that we should know that we might not already know? (#21)	34 (97)
Details of illness	What about the high blood sugar? … And did his weight have anything to do with it? (#4)	32 (91)
Course of illness	My question was how things happened chronologically. For me it was a blur. (#28)	27 (77)
Counterfactuals	I just have the “what ifs” like what if we waited one day and they would have done surgery. (#23)	23 (66)
Cause of death	Do you know what her cause of death is? Is it blunt force trauma to her head? (#8)	20 (57)
Autopsy	So was there anything in the autopsy that was surprising or significant? (#25)	13 (37)
Parents’ prior decisions	You’re always going to have that question whether or not you made the right decision. (#21)	24 (69)
End-of-life care	One of B-’s main concerns is that we didn’t pull the plug too soon or gave up on her too soon. (#23)	17 (49)
Treatment	The feeding tube, we understand we want to try to feed him…But was it worth it? (#15)	14 (40)
Blame	What happens is a lot of times when you try to get all the answers you’re trying to find somebody to blame. (#30)	18 (51)
For child’s death	You can tell me when my pizza’s going to be here, but you can’t tell me when they’re going to be here to pick up a child who’s dying? It’s just unacceptable. (#14)	9 (26)
For parents’ experience	Why did it take four hours for the nurse to call us? If they’re telling us everything started around 9 pm, we didn’t we get a call until 1:15 am, and we’re a half an hour away. (#16)	16 (46)
Blessings	And every day he lived was a blessing. Every day was better than anybody had ever told me. (#29)	18 (51)
Inevitability of death	Even though he had his ups and downs, he was on a downward cycle. (#25)	18 (51)
Parents’ role in the death	Has smoking ever been connected to any kind of heart problem in pregnancy? I smoked when I was pregnant. (#32)	15 (43)
Downward comparisons	There’s been a couple sudden deaths in our area… In some ways that would be even harder. (#13)	14 (40)
God’s will	Maybe that was her day to be with the Lord. (#11)	13 (37)
Did everything	I do believe you all did everything you could to save my daughter. (#20)	11 (31)
No longer suffering	He’s in a good place, he’s not suffering anymore. (#3)	7 (20)
Exceeded expected age	I had nine months. Nine months that technically I never should have had. (#10)	7 (20)
Child’s will	He (child) told Dr. S-, “I’m not having no more surgery.” He said, “This is my last one.” (#22)	4 (11)
Why me?	It’s unfair, but it’s my life, you know. This is what I was dealt. (#2)	3 (9)
Parent not capable	I know I can’t handle a sick baby… I wouldn’t be able to take care of a sick child forever. (#2)	2 (6)
No sense made	When we got the results back, basically we were told they didn’t find anything wrong. So we’re still left	9 (26)

Sense-making process	**Example (Follow-up meeting number)**	**n (%)**[*]
	without an answer…It’s like getting handed a blank piece of paper. It’s like why? Why did we go through what we went through for no answer? (#16)	
No need to make sense	I believe this stuff happens and that’s just how it was supposed to happen, you know. Left your house an hour early, got in a car accident, that’s just what was supposed to happen. (#2)	9 (26)

[*] n (%) = number and percent of follow-up meetings demonstrating each meaning-making process

Table 2

Benefit-finding processes observed during follow-up meetings (N=35)

Benefit-finding process	Example (Follow-up meeting number)	n (%)
Ways to help others	We're trying to get to the point where we can help other people, instead of them helping us. (#13)	29 (83)
Feedback	It's a lot easier to have repetitive nurses than to keep having new ones take care of your child…To ask the parents if they would rather have that would be nice for other parents. (#3)	15 (43)
Donations	I was lucky that we had this equipment sitting around to donate to them. (#22)	8 (23)
Research	I just didn't want to not participate in the research to help other families. (#21)	8 (23)
Volunteerism	And as far as any sort of parent outreach or anything that you need I would feel — I would always be open and available to helping any way I can. (#33)	5 (14)
New medical knowledge	I know that he was sent here for a reason and like I said, now these doctors know what they need to do for the next baby. (#10)	6 (17)
Organ donation	It comforts us knowing that she would be able to live on through other people. (#17)	2 (6)
Change in others for the better	Even in his slow motion he helped them slow down and smell the roses and think better of what they were doing. (#7)	9 (26)
Change in parents for the better	I feel like she helped me get to a different appreciation and respect things on many different levels way different than I did before. (#21)	7 (20)

[*] n (%) = number and percent of follow-up meetings demonstrating each meaning-making process

Table 3

Continuing bond manifestations observed during follow-up meetings (N=35)

Continuing bond	**Example (Follow-up meeting number)**	**n (%)**
Parents' inner lives	Every time I hear a bird I think of him. (#9)	33 (94)
Child attributes	She had a strong personality, that one. She had the biggest, biggest brown eyes ever. She was so beautiful. (#14)	28 (80)
Child life events	He played baseball, he played soccer. He'd drive the power chair around the bases on his own, stealing bases and everything. (#1)	21 (60)
Personal rituals	We wanted to take our little girl home with us in our way instead of having her sitting in some cold place. (#31)	21 (60)
Photos	Just have a family picture here of all of us. (#5)	18 (51)
Linking objects	So you know it's still sitting there. His diaper pail is, gross as it is, we haven't emptied it. (#15)	17 (49)
Angel	My friend's grandpa was having surgery for cancer… the first thing I did was I looked up and I was like, "J- (deceased child), can you look out for grandpa?" (#8)	8 (23)
Imagine	I can only imagine what she would have said if she was still living… (#13)	3 (9)
Parents' social world	I just have to talk about her. (#20)	26 (74)
Community	The funeral director said he had never seen so many people come out for a baby. They ran out of flags for the cars; that's how many people came out. (#16)	19 (54)
Health professionals	It really meant a lot to me how good they were with R- and how much they treated her like a child and not a series of medical events. (#18)	15 (43)
Siblings	They talk about her a lot. If I say, "C-, who's my favorite daughter?" She's like, "Your favorite daughter on earth is me; your favorite daughter in heaven is her." (#5)	7 (20)

[*] n (%) = number and percent of follow-up meetings demonstrating each meaning-making process

Table 4

Identity reconstruction processes observed during follow-up meetings (N=35)

Identity reconstruction	**Example (Follow-up meeting number)**	**n (%)**
Good parent	I have no doubt that I did a really good job caring for him. (#6)	23 (66)
Life changes	I have to figure out what my purpose is now. (#18)	22 (63)
Relationships	I had another baby. Yeah, L- and everything's well with him. And that's kept me going. (#4)	18 (51)
Work	I am getting ready to go back to school and hopefully going to be up here working soon. (#10)	9 (26)
Environment	She said, "We have to sell the house."… We have another house on the river. We bought it a few years ago for investment… So she said, "Fix that up and we're going to go." (#34)	5 (14)
Travel	We're going on a cruise…getting away, just the two of us …we met on a cruise 22 years ago. (#1)	2 (6)
Hobbies	I'm back to the choir now…I got to do something I like and he liked and so I'll do it in his honor and move on. (#1)	1 (3)
Number of children	There's always that question, how many kids do you have? I hate that question. I have four kids, but … (#2)	2 (6)

[*] n (%) = number and percent of follow-up meetings demonstrating each meaning-making process