Applied Nursing Research 50 (2019) 151205

Contents lists available at ScienceDirect

Applied Nursing Research

journal homepage: www.elsevier.com/locate/apnr

Bereavement care to minimize bereaved parents' suffering in their lifelong journey towards healing

Christine Denhup (PhD, RN)

Southern Connecticut State University, Department of Nursing, New Haven, CT 06515, United States of America

ARTICLE INFO

Keywords:
Parental bereavement
Child death
Suffering
Palliative care

ABSTRACT

This article presents select findings from an interpretive phenomenological study which aimed to describe the lived experience of parental bereavement. Six parents, each of whom experienced the death of a child due to cancer at least one year prior, participated in conversational interviews to share what it has been like for them since their child's death. Heideggerian (1962) phenomenology provided the philosophical underpinnings of the study, while van Manen's (1997) phenomenological method guided data collection and analysis. From this methodological approach, a structure of the meaning of parental bereavement experience was revealed. Profound suffering emerged as one essential theme. Pertinent findings related to this theme are discussed. Parents share ways others might minimize their suffering and provide support in their lifelong journey towards healing. Findings will enhance nurses' practice of providing bereavement care, which is an expectation of quality palliative care.

1. Introduction

Bereavement care is an important aspect of palliative care, which aims to minimize suffering to optimize quality of life (ANA, 2017). As collaborative interprofessional team members, nurses are responsible for ensuring that bereavement care is provided, either directly or indirectly, to the family for a least 13 months after the death of a patient (NCHPC, 2018). Thus, nurses need to have a command of best practices and a deep understanding of the suffering that bereaved families endure in order to develop, implement, and evaluate a bereavement care plan that minimizes suffering and improves quality outcomes. While the literature offers some insight to inform nursing practice in this area, there is a need to better understand the experience related to the death of a child (Thompson et al., 2011).

The purpose of this paper is to present select findings related to the nature of bereaved parents' suffering, and what others can do to minimize suffering and support parents in their journey towards healing. The research findings that are presented here emerged from an interpretive phenomenological study, which aimed to describe the lived experience of parental bereavement following a child's death due to cancer (Denhup, 2017). This topic merits focused attention in light of current data on childhood cancer-related deaths and bereaved parents' health outcomes.

Despite the upward trend in the overall childhood cancer survivorship rate, which is 85% presently (NCI, 2019), cancer remains the leading cause of disease-related death in children (Xu, Murphy, Kochanek, Bastian, & Arias, 2018) and is responsible for an average of 71 years of life lost per child dying of cancer between 0 and 14 years of age (NCI, 2019). Given that 43 children are diagnosed with cancer every day and that one out of eight children with cancer will not survive (CureSearch, 2018), nurses must be prepared to provide bereavement care for parents whose children do not survive. This is of utmost urgency when one considers that bereaved parents are at high risk for a multitude of poor physical, mental, and social health outcomes (Aho, Tarkka, Åstedt-Kurki, & Kaunonen, 2006; Dias, Brandon, Haase, & Tanabe, 2017; Li, Precht, Mortensen, & Olsen, 2003; Ljungman, Hovén, & Ljungman, 2015; Murphy, Johnson, Lohan, & Tapper, 2002). In order to affect change with these outcomes, nurses must be informed of the current state of the science.

The literature provides beginning insight on bereavement interventions to meet parents' needs. Some studies suggest that maintaining a continuing bond with their deceased child is perceived by parents to be helpful (Barrera et al., 2007, 2009; Dutta, Tan-Ho, Ying Choo, & Hau Yan Ho, 2018; Foster et al., 2009; Klass, Silverman, & Nickman, 1996; Thompson et al., 2011; Wheeler, 2001); while other studies indicate that maintaining such connections exacerbate grief and adjustment difficulties (Boelen, Stroebe, Schut, & Zijerveld, 2006; Hogan & DeSantis, 1994; Neimeyer, Baldwin, & Gillies, 2006). Some studies report that bereaved parents find social support from family and friends to be helpful (Barrera et al., 2007, 2009; Tan, Docherty, Barfield, &

E-mail address: Denhupc1@southernct.edu.

https://doi.org/10.1016/j.apnr.2019.151205
Received 28 December 2018; Received in revised form 17 June 2019; Accepted 18 October 2019

Brandon, 2012; Thompson et al., 2011). Other studies emphasize the importance of meaning-making for bereaved parents (Keesee, Currier, & Neimeyer, 2008; Murphy, Johnson, & Lohan, 2003; Tan et al., 2012; Wu et al., 2008,). Some studies suggest that professionally-led bereavement support groups, which are designed for people who have a similar loss experience and provide an environment that offers non-judgmental listening, are helpful (Backer McCall, 2004; Grinyer, 2012; Picton, Cooper, Close, & Tobin, 2001; Rosentblatt, 2000; Vega, Rivera, & Conzalez, 2014); while other studies advocate for formal peer support programs (Berrett-Abebe, Levin-Russman, Gioiella, & Adams, 2017). Studies also stress that ongoing communication and support from healthcare providers, who cared for the child during illness, is be helpful for bereaved parents (D'Agostino, Berlin-Romalis, Jovcevska, et al., 2008; Garstang, Griffiths, & Sidebotham, 2014; Lichtenthal et al., 2015). Although there is growing literature to guide nurses in providing bereavement care, there is a need for further exploration due to limitations that exist in regards to mixed sample selection, under-representation of fathers, and generalizability of findings especially given the individual nature of the bereavement experience (Thompson et al., 2011). This paper will provide nurses with a deeper understanding of the profound suffering inherent in the lived experience of parental bereavement so that they may advance bereavement care for bereaved parents in the future.

2. Research aim and method

This phenomenological study, grounded in Heideggerian philosophy (Heidegger, 1962), aimed to describe the lived experience of parental bereavement following a child's death due to cancer. A detailed explanation of the study's sample, methodological steps and rigor, and ethical considerations is presented in a prior publication (Denhup, 2017). A brief summary is presented here. Six English-speaking parents of different faiths, including Jewish, Baptist, Episcopal, Evangelical Lutheran, and Roman Catholic, consented to participate in this study. These five mothers and one father were of different families, lived in different regions of the United States, had experienced the death of a child at least one year prior, and were actively participants in bereavement support groups. Additional demographic data are provided in Table 1 below.

van Manen's (1997) method guided data collection and analysis. Two conversational interviews were conducted privately with each parent in his or her choice of setting. Three interviews were conducted in person, and three were done via telephone. The interviews, which lasted three to five hours in length per parent, aggregated to 23 hours in sum. These parents provided rich and thick descriptions of their experience when asked to share what it has been like for them since their child's death. The researcher transcribed the audio-recorded interviews, analyzed each transcribed text using van Manen's (1997) three-fold approach to theme identification, wrote analytic memos, and documented field notes of observations that were made during prolonged engagement in the field. To ensure trustworthiness of findings, the researcher used multiple strategies including a member-checking process in which parents were invited to provide feedback on the interpretive analytic summary. Parents' provided positive feedback, indicating that the interpretive summary resonated with their experience and felt it would be helpful for other families.

3. Findings

From this comprehensive interpretive analysis, the following structure of the meaning of the lived experience of parental bereavement was revealed:

Parental bereavement means to enter a new state of being, in which, after the death of a child, parents endure profound suffering, maintain the parenting relationship in the presence of the child's absence, experience a renaissance of self, and journey towards healing sustained by support and hope. (Denhup, 2017, p. 355).

Notably, profound suffering emerged as an essential theme within this structure of the parental bereavement experience. A discussion of profound suffering, as experienced by the six parents who participated in this study, and applications for nursing practice are discussed below.

3.1. Profound suffering

Following the death of a child, parents are thrust into a new state of being in which they endure profound suffering (Denhup, 2017). Suffering has been conceptualized as “the distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person” (Cassell, 1991, p. 24). Applying this concept to the parental bereavement experience as lived by parents in this study, the child's death is the actual threat and the parent's way of being in the world ceases to exist as it once did. Thus, suffering is brought about by this very real threat to the parent's existence. Findings from this study indicate that suffering is experienced throughout parental bereavement, regardless of the amount of time that passes after a child's death. Evidence of this is found in the fact that all participating parents experienced suffering of similar nature. Their suffering was found to be incomparable, indescribable, and undeserved.

3.1.1. Incomparable suffering

The intensity of these bereaved parents' suffering is incomparable. This finding is consistent with existing literature on the unique nature of child loss (Cacciatore & Bushfield, 2007; Christ, Bonanno, Malkinson, & Rubin, 2003; Hazzard, Weston, & Gutterress, 1992; Janzen, Cadell, & Westhues, 2004; Kazak & Noll, 2004; McCreight, 2008; Milo, 1997; Rando, 1985; Sanders, 1980; Sirkiä, Saarinen-Pihkala, & Hovi, 2000; Wheeler, 2001; Wijngaards-de Meij et al., 2008; Wilson, 1988; Znog & Keller, 2002), and adds to the understanding of the incomparable nature of the parental bereavement experience. Emma, who was 41 years into her parental bereavement experience, explained what it is like to experience suffering following the death of a child, stating:

> [It] is the worst, the very worst thing that can ever happen to you… sometimes different people that I have known have lost a husband and they say, ‘Oh, I can understand’, but they can't! There's no comparison over burying a husband or burying a child… There's no comparison.

Kelly, who was 1 1/2 years into parental bereavement, agreed that no loss compares to that of a child's death, saying, “it's totally different for a parent who's lost a parent to try to compare that to losing a child…

Table 1
Demographic data.

The parents	Child's age at diagnosis	Child's age at death	Time since death
Joan, Joshua's mother	Age 6 – Non-Hodgkin's lymphoma	Age 11	15 years
Sara, Adam's mother	Age 6 – Diffuse intrinsic pontine glioma	Age 8	2.5 years
Kelly, Sam's mother	Age 11 - Medulloblastoma	Age 12	1.5 years
Doris, Cindy's mother	Age 12-Diffuse intrinsic pontine glioma	Age 12	2.5 years
Peter, Robert's father	Age 11-Diffuse intrinsic pontine glioma	Age 11	1 year, 4 months
Emma, Dorothy's mother	Age 2-Acute lymphocytic leukemia	Age 4	41 years

there is no comparison". Joan, who was 15 years into her parental bereavement experience, agreed stating, "It's just such a different feeling to lose a parent than to lose a child". Doris has also found this to be true when considering her own loss experiences, including the deaths of several extended family members and the death of her daughter, Cindy, 2 1/2 years prior.

For Doris, one difference is that she got to a point where she felt a sense of comfort and acceptance with her previous losses. Doris explained:

> There was just a level of acceptance, or comfort, that I got with my previous losses and I had a lot of past familial losses. I've always felt that at some point it stopped hurting quite so bad… this just doesn't feel like that!

Another difference with past losses is that the absences of those people are not omnipresent in Doris's daily life. Doris explained, "I know with all the losses over time...it wasn't just in my face, and it feels now more in my face now more than ever". Doris felt that the lack of a comparable experience to that of a child's death contributes to misunderstandings about parental bereavement. Doris said, "I don't think that you can fully understand just how bad this hurts if you haven't [lost a child]".

Peter, whose son Robert died a little over 1 year prior, echoed the mothers' experience, stating:

> I never understood. There was a kid in school a couple of years before Robert that had leukemia and I'm like, 'Oh my God, those poor parents'. And yeah…you did things and you donate to the cause and all that other good stuff…but…I don't care how genuine your heart is or how much empathy you have as a human being, there is nothing that compares to it.

Peter added:

> There are no words…I read somewhere that 'when a husband dies, she becomes a widow or when a wife dies, he becomes a widower, but what happens when a child dies? It is so horrible there are no words'.

Since suffering in parental bereavement is incomparable, it cannot be fully understood by those who have not experienced the death of a child as these parents explained. Not only is bereaved parents' suffering incomparable, it also is indescribable.

3.1.2. Indescribable suffering

In parental bereavement, suffering is indescribable. Peter explained, "It's an intensity that you can't put into words and can't explain...it's difficult to put into words because it's a constant". Parents tried so hard to describe the intensity of their suffering, using such terms as "locked in the gates of hell", "black hole", "the hole" and "the pit".

For Joan, the first five years after Joshua's death were "absolute… indescribable hell". Joan said she has been on a "horrible journey", explaining "I was in hell…I actually lived in hell…I was locked in the gates of hell". Joan recalled back to the day of Joshua's funeral, saying:

> I would have paid anybody anything to be me. And even if I had millions of dollars to give to somebody they would not have wanted to be me for the day.
> It was just some place that nobody would want to be.

Joan referenced the 2004 novel, *My Sister's Keeper* written by Jodi Picoult, *New York Times* bestselling author, and was adamant that reading this novel would help nurses better understand her experience. In this novel, Picoult (2004) used the analogy of a black hole to describe the experience of a family whose child is diagnosed with cancer. Picoult (2004) wrote, "black holes…are so heavy they absorb everything, even light, right into their center...no matter what you cling to, you wind up being sucked in" (p.11). While this novel is a work of fiction, being pulled into the depth of a black hole is very real for many parents whose child has cancer. Further, as Joan and the other parents in this study tried to convey, the image of a black hole illuminates the depth of suffering in parental bereavement.

Parents used the analogy of a black hole to describe this place of suffering. For Kelly, this hole is a physical, empty, and dark space that she cannot get out of. Kelly explained exactly what this hole is like, stating:

> It's definitely a hole…You want it to be bright up top again and… you can't [get out]. You want everything to stand still, but you are being slowly buried by just sadness, depression, just whatever it is and you feel like you can't get out.

Similarly, Emma described a hole which she calls "the pit". Emma explained, "you feel like sometimes you're down in the pit trying to climb out and you just can never, ever make it…there's nothing to help you". Not only is the intensity of parents' suffering incomparable and indescribable, but it also is undeserved.

3.1.3. Undeserved suffering

These parents' suffering is so intense they would not wish it on anyone. Emma said, "It's something that you don't wish on your worst enemy, it's so horrible". Peter concurred, stating:

Being in prison the rest of my life wouldn't be this bad. It wouldn't be a picnic, but it wouldn't be this bad…nobody should be in my shoes…I wouldn't wish this on Osama bin Laden. That's how bad this is. That's how bad this is.

Joan echoed Peter and Emma's sentiments, stating: "nobody deserves to lose a child, not even the worst person in the world". Joan expressed empathy and sadness for Sajida Talfah Hussein, first wife of Saddam Hussein and mother of Uday and Qusay Hussein who were killed in 2003, because "[to experience a child's death] is the most horrible thing that I can ever imagine".

From these parents' descriptions, it is clear that they experienced profound suffering in parental bereavement. Nurses who care for and interface with bereaved parents must be mindful not only of the depths of parents' suffering, but also need to be aware of how their interactions with bereaved parents can either intensify or minimize that suffering. Parents who participated in this study want others to better understand that things they do or say cause additional suffering. For only by having an increased awareness of what may intensify parents' suffering can nurses minimize additional suffering that parents endure in bereavement. This is important for nurses to understand so they can incorporate findings into their own practice, as well as educate family, friends, and others in their communities who interface with bereaved parents.

3.1.4. Things people say or do cause additional suffering

What people do or say caused added distress for these parents after the death of their child. This added distress increased bereaved parents' suffering. These parents described numerous situations which, at the particular moment in time that the situation occurred and also at future time when reflecting back upon that situation, caused them additional suffering. As shown in Table 2, these situations fall into five categories: a) when people manage or explain; b) when people avoid; c) when people question; d) when people complain; and e) when people compare.

These examples illustrate words and actions that intensified suffering for these bereaved parents. Not only was parents' suffering intensified acutely at the time the situation occurred, but also intensified upon recall years after their child died. These parents want others to be mindful of this, and to be aware of more helpful behaviors that can minimize their suffering.

3.1.5. Things people say or do minimize additional suffering

These parents described situations in which people have said or done things that eased their suffering because it gave them comfort for

Table 2
Things people say or do cause additional suffering.

Situation	What someone said or did to the parent
1. People manage the parent's bereavement experience or explain a reason for the child's death	• God doesn't give you more than you can handle. • God needed an angel. • Everything happens for a reason. • You had 11 good years with him. • You're lucky to have him for as long as you did. • Well, you have your memories. • What a gift he was. • You have three other children. • She doesn't need you to do anything for her. • Time will make it better. • You'll get over it. • When your heart is open, healing will come. • If you had enough faith, you would have been healed. • It's time to move on and get on with your life.
2. People avoid contact with or talking to the bereaved parent	• Walk down a different grocery isle to avoid the parent • Cross to the other side of the street to avoid the parent • Text or email, rather than engage in verbal communication with the parent • Cancel dinner plans made with the parent • Avoid saying the child's name
3.People ask questions of the bereaved parent	• How are you? • How many children do you have? • Do you know if your other children have cancer too?
4. People complain about their own matters	• Complain about their child's performance in school or sports • Complain about general stresses of parenting • Complain about their car being dirty or the limited selection of color options at the automobile dealer • Complain about their clothes becoming soiled in the rain
5. People compare their own loss experience to that of the bereaved parent	• I know how you feel, my grandmother died last year. • I know how you feel, I lost my husband.

Table 3
Things people say or do minimize additional suffering.

Situation	What someone said or did for the parent
1.People listen to and talk with parents	• Say the child's name out loud • Cindy (the child's name) would have really liked that. • What kind of dress do you think Cindy (the child's name) would have worn? • Listen to the parent talk while sitting and watching videos of the child.
2. People carry out acts of kindness	• Unexpected gestures (e.g. household chores, errands, prepare meals, pay bills, send “thinking of you” card) • Honor the child (e.g. name new baby in the family after child, create a school award given to a child in the school who embodies the deceased child's spirit)
3. People acknowledge and include parents	• Ask the parent if he/she would like to participate in an activity that his/her child's best friend is doing (e.g. help dress shop for his/her best friend's eighth grade dance) • Include the parent in birthday and holiday celebrations • Acknowledge the parent in written or verbal communication (e.g. Dorothy's mom)

that moment in time, as well as upon recollection years later. As shown in Table 3, these situations fall into three categories: a) when people listen to and talk with parents; b) when people carry out acts of kindness, and c) when people acknowledge and include parents.

These are but a few examples of how others might minimize suffering that bereaved parents endure. Listening and talking helps parents remember and continue their relationship with their child. Emma stated:

> The thinking is, “Don't bring it up because it will make her sad”. But, the sad thing is…it's always on your mind. They're not reminding you of anything that you don't already know in your mind…she's my daughter. I *want* [emphasis added] to remember!…[Bereaved parents] want people to realize [our deceased children] were and…they *are* [emphasis added] a person. You just don't cut it off after they *die* [emphasis added]!

Further, being kind and including parents helps them to feel less isolated and to know that they and their child are not forgotten. As Sara advises:

> Just say I'm sorry. Just say you are thinking about me. Just tell me what you remember about Adam. Just tell me what you loved about him. Just tell me that you think about him, or that you pray for us… [or] ‘I want you to know that I really care’… just support, just kindness, just caring. (pg 33, lines 5–7; pg 34, lines 3–4).

In addition to things that people do or say that either cause or minimize additional suffering, these parents shared how health care providers' behaviors and care processes can either intensify or minimize suffering in their parental bereavement experience.

3.1.6. Health care providers and care processes cause additional suffering

These bereaved parents remembered the care that they and their child received during their child's illness. Flawed care became a source of distress for these parents not only at the time of occurrence but also after their child's death. Parents' recall of distressing care encounters that occurred during their child's illness intensified suffering in parental bereavement. Hallmarks of distressing care encounters are poor communication, insufficient information, exclusion from child's care, and differences in care goals. Examples are presented in Table 4.

In addition to these hallmark examples, there were isolated reports of other types of distressing care encounters that involved a lack of caregiver continuity, treatment delays, inflexible hospital policy, abandonment by the child's health care providers, and lack of

Table 4
Recall of distressing care encounters during child's illness that intensify bereaved parents' suffering.

Distressing care encounter	Example
1. Poor communication	Doris recalled a physician's insensitive communication at the time her daughter was diagnosed with a brain tumor, saying: • You walk in as a parent and…you're newly diagnosed and so you believe you can still get the miracle. You still believe your child can beat it. You're trying to be realistic, but you believe it and [the doctor] looks at your child and says, 'Hey, you know what this means? You can do whatever you want with school this year! *It doesn't really matter* [emphasis added]!'
2. Insufficient information	Peter recalled the unclear explanation he received from the health care team about his son's symptoms of fatigue and respiratory distress as he neared end-of-life, saying: • We were told that…he should be very tired. He was sleeping 23 h a day! So I said, 'Look, your idea of fatigue is like saying the ocean is deep'…so then they changed to term to 'somnolence'…ah, that's great too…I never heard of 'somnolence' before. • No one told me that respiratory distress was the sign for end of life…I don't know what that information would have done at that time, but I learned a whole lot more after he was dead than before he was dead, which, 'Oh great, good time to know that!' And that's what I put up with, *a big stupid jerk* [emphasis added]!
3. Exclusion from child's care	Joan recalled feeling excluded from her son's care when the health care team was not forthcoming with information about her son's clinical condition, saying: • At that time you couldn't look at anybody's chart…but, I'd go take his chart. They threatened to call security on me. They said they were going to throw me out of the hospital if I took his chart again or if I looked at his chart. *I wanted to see his chart* [emphasis added]!! *I want to see what you're seeing* [emphasis added]!! You don't talk in front of the child and parents and *I wanted to know what was going on* [emphasis added]! I don't think I was well informed during the whole process…I felt like everybody was against me for some reason. I remember that feeling quite clearly in the hospital. It was like them against me.
4. Differences in care goals	Kelly recalled feeling distressed when the health care team's goal of nutrition did not align with her priority goal of spending quality time with her son near his imminent death: • Coming in wanting to know about his nutrition?…*Get out* [emphasis added]! What is the *matter* [emphasis added] with you?! I don't want to know anything about nutrition. My son is in a coma. We're probably not gonna [sic] get to talk to him again and *you're worried about nutrition* [emphasis added]?! *Get out* [emphasis added]!

attentiveness to and understanding of the bereaved parents' experience on the part of the parents' own health care providers.

3.1.7. Health care providers and care processes minimize additional suffering

Recollection of quality care encounters brought these bereaved parents comfort, which in turn minimized additional distress after their child's death. When these parents were comforted from their recollections, their suffering lessened. Hallmarks of comforting care encounters are caring behaviors, partnering in decision-making, maintaining presence, and acts of kindness. Examples are presented in Table 5.

3.1.8. Fostering support

In addition to describing health care provider behaviors and care encounters that minimize suffering, these parents also emphasized their need for support with their lifelong journey towards healing as they learn to live with the loss of a child. These parents conveyed their need for support not just immediately after a child's death, but throughout their lifetime. These parents felt supported within the first year after their child's death; however, they felt that support waned thereafter, even though they continued to be in need of support.

These parents explained what they need in terms of support. They need empathetic reassurance, which Doris explained can come in the form of saying "You are alright. It is ok that you feel so sad and you loved her". They also need realistic encouragement, which as Doris explained "some days, I need somebody to say 'you need to suck it up a little bit and do this'. They need to talk about their experience verbally, not just by email or text message. Emma explained, "just talking about her helps me…you want people to know that she did exist and she was and is *still* [emphasis added] my daughter". They need others to take the initiative in offering parents support, rather than leaving it up to the parents to reach out to others when they are feeling the need for support. They need others to understand that all parents need support after a child's death. Sara recalled receiving a follow-up phone call from the hospital after Adam had died. Upon the realization of Sara being a pastor's wife, the hospital staff member stated, "oh, you're OK then". Sara explained that the hospital staff member erroneously assumed that since Sara often provided bereavement support to others, she was not in need of support herself. This left Sara feeling further isolated and alone.

These parents also expressed a need for support as they engaged in self-care behaviors. The self-care behaviors that these parents utilized included writing, reading grief literature, reading contemporary fiction as a distraction, talking aloud to their child and to others about their child, attending to personal health conditions, discontinuing prescribed medications for grief responses and mood-altering substances, physically releasing grief emotions, exercising, getting a pet, having more children, avoiding other people's children, applying permanent makeup, minimizing exposure to negative situations and news coverage of catastrophic world events, and attending support groups. These parents described varied effectiveness of these self-care behaviors.

These parents also shared the examples of helpful support group activities that could be incorporated into either professional-led or peer support groups, including the following: a) having separate parent and sibling designated support groups, b) doing arts and crafts, c) having a day designated in honor of the child where everyone wears the child's favorite color, d) participating in a balloon release and attaching a written note to the child on the balloon, e) being out in nature, f) having pictures of some support group activities to bring home, g) walking, and h) having a memorial service. These parents' shared that it is helpful if support group attendance can be flexible in nature. Some of the parents wished to attend support groups weekly, while others preferred to attend monthly. These parents also shared that it was helpful for them to read bereavement literature, which they received from their support group if they were not able to attend in person. Some of these parents shared that they found on-line chat support groups to be helpful. Peter explained why flexibility in formal support is helpful, stating, "the reality of it is, this is your own and however you do it is how you do it".

4. Limitations

This study provides one interpretation of the meaning of parental bereavement, and the inherent suffering endured, as it is lived by six parents of different faiths in the United States. It is not the only plausible interpretation, as is true of any phenomenological study (van Manen, 1997). Although the sample was small, it was adequate to

Table 5
Recall of comforting care encounters during child's illness that minimize bereaved parents' suffering.

Comforting care encounter	Example
1. Caring behaviors	Doris recalled the following nurse caring behaviors: • Offering caring gesture of a hug • Skillfully administering medications • Walking to pharmacy to pick up pain medication to avoid unnecessary delays • Maintaining hope • Making her feel safe
2. Continuity of care	Joan recalled how helpful primary nursing was for her and her child: • "They gave us the same nurses all the time…they were familiar with him, they were familiar with me, he knew them, so he was [cared for] by people he felt comfortable with…that was very helpful"
3. Partnering in decision-making	Kelly recalled how the health care team listened to her request to check her child's blood work so they might gain a better sense of his current status even though they consented to DNR status and they knew he was actively dying. Upon recall, Kelly expressed a sense of relief because what she wanted for her child was respected by the health care team.
4. Maintaining presence	Doris expressed a need to maintain a relationship with the nurses who cared for her child: • "There is such a desire on the part of me as a mom…to remain a part of their lives even though I am not…they are my last connection to Cindy. They were the ones that loved her like I loved her or were gentle with her…they make you feel connected to your child as the last people who helped me bathe her and do her hair and make her feel safe and comfortable…so I think it's a very important thing" Emma explained how comforted she is by the fact that her own health care provider maintains a supportive, caring presence: • "On my first meeting with my therapist, she told me 'I'll never leave you' and she meant it even when there was a mix-up with my insurance…she's just always been so wonderful"
5. Acts of kindness	Emma recalled how on the night her nephew died, the nurse let Emma stay on the telephone line for an extended length of time until her brother who was with the chaplain could come to the phone to talk to her • "[The nurse] let me hold on that phone I don't know how long it was until she went…and got my brother and I talked to him. I've often thought about that…that was an extra kind act from her…So, along the way it's been hard and it's been lonesome and it's been horrible, but the people that have gone that extra step, I think that's what has helped me a lot…I thought that was so nice"

achieve data saturation. A greater representation of fathers would have given added strength to the study; however, no additional fathers who met inclusion criteria volunteered to participate. Further research is needed to better understand fathers' bereavement experience. Nurses must take caution not to generalize the study's findings to other bereaved parent populations, such as those who have experienced the death of a young child due to other causes or an adult child. Further research is needed to explore the lived experience of parental bereavement among these populations. Further research is also needed to explore the lived experience of parental bereavement as it is lived by parents in other countries and of different cultures.

5. Applications for nursing practice

This study's findings deepen understanding of the nature of suffering as part of the lived experience of parental bereavement. Nurses can decide if this study's findings resonate with their practice in caring for bereaved parents. The parents who participated in this study shared the nature of their suffering, which they described as being incomparable, indescribable, and undeserved. The parents also explained what they need in terms of support along their lifelong journey towards healing. These parents provided evidence that words, behaviors, and care processes can either intensify or minimize their suffering. These parents want others to better understand this. Emma stated, "I would hope that any parent today that goes through [a child's death] that there would be people there that would try to understand and try to be helpful to them. I really do pray".

There is opportunity for nurses to role model communication and behaviors that can minimize bereaved parents' suffering. There is also opportunity for nurses to educate families, friends, and others within their communities who interface with bereaved parents about what to say or do for a bereaved parent, as well as to role model quality care encounters within the interprofessional team. It is possible that additional suffering might be minimized if comforting words, behaviors, and quality care were maximized in encounters with bereaved parents.

Further, nurses ought to consider the extent to which they support bereaved parents after a child has died. While there may be a natural tendency for pediatric nurses who once cared for the child during illness to separate themselves from the child's parents over time, findings from this study suggest that parents felt supported by ongoing, periodic communication with their child's nurses and other healthcare providers. This finding is consistent with literature that indicates ongoing communication and support from the child's healthcare providers is helpful for parents (D'Agostino et al., 2008; Garstang et al., 2014; Lichtenthal et al., 2015). In a very practical way, pediatric nurses might consider creative ways to organize a unit-based or hospital-based bereavement care program. A nurse-led program such as this could include several components, such as maintaining an up-to-date database of demographic information, planning periodic communication with the child's parents, sending bereavement-related literature, and referring to community-based parental bereavement support groups as appropriate. This would be in alignment with current literature that describes the development of hospital-based bereavement programs (Morris et al., 2016), as well as literature on the helpfulness of professional-led support groups (Backer McCall, 2004; Grinyer, 2012; Picton et al., 2001; Rosentblatt, 2000; Vega et al., 2014) and peer-led support groups (Berrett-Abebe et al., 2017).

Since bereaved parents' journey is lifelong, nurses must consider their role in supporting parents for the long-term. While pediatric nurses who provided direct care for the child may be in an optimal position to support bereaved parents after a child's death, nurses who care for adult patients also have the opportunity to support bereaved parents. However, adult health nurses may not even be aware that the patient for whom they care is a bereaved parent. Assessment of an adult patient's loss history at all points of care across the lifespan could be beneficial for screening purposes. If nurses who practice in adult health identify that the patient for whom they care is a bereaved parent, they would be in a better position to ensure maximum supports are in place not just for the current minimum of 13 months post loss (NCHPC, 2018), but throughout a bereaved parent's lifetime as the participating

parents in this study strongly advocated for. Lastly, pediatric and adult health nurses alike are in a prime position to provide bereaved parents with anticipatory guidance. Sharing what is known about the lived experience of parental bereavement with other bereaved parents can decrease a parents' feeling that they are isolated in their experience, demonstrate the normalcy of their experience, and help them to navigate their new state of being that is parental bereavement.

Declaration of competing interest

None

Acknowledgements

This manuscript presents selected findings from a qualitative research study that was partially funded by a small research grant from Sigma Theta Tau International Honor Society of Nursing, Gamma Nu Chapter.

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