



Parenting Surviving Children After the Death of a Child from Cancer: An Interpretative Phenomenological Analysis

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Abstract

The death of a child is a tragic, devastating event with enormous emotional and relational impact on the family unit. Parental changes are significant, encompassing the psychological, physical, spiritual, and interpersonal realms. Little bereavement research has focused on the crucial familial role of parenting or the relationship between bereaved parents and their surviving children after another child's death. A noteworthy gap likewise exists in current literature regarding the experience of parenting within families who suffered the death of a child due to an extended, life-limiting illness such as cancer. This interpretative phenomenological analysis addresses the gap by exploring the lived experience of those who parent surviving children after their child's cancer death. Seven mothers and four fathers ($n = 11$) across the United States participated in video or face-to-face semi-structured individual interviews. Parents had a range of 1–2 surviving children whose ages spanned 23 months–18 years ($M = 8.27$; $SD = 5.07$) at the time of their sibling's death ($M = 5.43$ years earlier; $SD = 3.17$). Data analysis revealed two primary themes. "A New Mind" denotes bereaved parents' new, contrasting mindsets regarding self-view, daily motivators, perceived locus of control, perspective, boundaries for children, direction of focus, and outside relationships. "Be Beside Me" highlights parents' deep desire that others come alongside them by validating their emotions and experience and providing opportunities for family renewal. Clinicians working with bereaved families should have awareness of and consider parents' changed perspectives, challenges, and supportive needs in order to deliver family-centered care and enrich existing services and support programs.

Keywords Bereavement · Parenting · Surviving · Pediatric cancer · Interpretative phenomenological analysis

Highlights

- The death of a child portends enormous emotional and relational impact on families and significantly changes parents.
- Bereaved parenting involves concurrent roles of continuing to parent surviving children while grieving the deceased child.
- Parents bereaved by pediatric cancer cope with seven new and contrasting mindsets regarding self, family, and others.
- They deeply desire validation, others' presence, and family renewal throughout their journey of parenting in bereavement.

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For parents, the death of a child is tragic, devastating, and represents loss on many levels: the physical loss of the child; loss of an emotional and psychological closeness within the parent–child relationship; a diminishing of the family; a loss of growth and future hopes; and a loss of the familiar, assumptive world (Buckle & Fleming, 2011). Due to the unique, affectional parent–child bond, the grief resulting from these losses has been described as prolonged, complex, nonlinear, and profound regardless of the type of death, age of the child, or the passage of time (Arnold & Gemma, 2008; Gilmer et al., 2012; McCarthy et al., 2010).

As such, grief may cause significant changes in parents, particularly in their emotions, priorities, and personal relationships (Gilmer et al., 2012). The death of a child also defies the natural order of life and may affect parents' self-perception as protector of their children (Gilmer et al., 2012; O'Connor & Barrera, 2014). Bereaved parents must therefore cope with changed identity and purpose both as individuals and within the family unit (Riley et al., 2007) and often construct for themselves and their families a new and different reality or state of being (Denhup, 2017) that involves living, yet with profound loss and grief (Arnold & Gemma, 2008; Davies, 2004).

Bereaved parenting — which involves the simultaneous roles of continuing to parent other, surviving children while grieving and ceasing to parent the deceased child (Buckle & Fleming, 2011) — is an important area of focus within bereavement research. Knowledge gleaned from such research may provide insight into bereaved parents' adaptive behaviors and their subsequent efforts to create new self- and familial identities (Crossno, 2011). The very basic, foundational role of parenting within the family cannot be ignored, nor can the importance of the parent-surviving child relationship to the ability of families to adapt and function in an effective manner (Morris et al., 2016; Rossetto, 2015). Individuals do not experience loss or grieve in isolation. Rather, bereavement affects the family as well as its individual members (Stroebe & Schut, 2015) and must be viewed with a systems perspective that acknowledges the influence of loss on the family unit (Buckle & Fleming, 2011; Morris et al., 2016; Shankar et al., 2017; Walsh & McGoldrick, 2013). Literature reveals that coping with bereavement is complex and entails significant changes in relational dynamics, communication patterns, and roles within the family (Bonanno, 2009; Rossetto, 2015). Families are vulnerable to adjustment difficulties (Morris et al., 2016) and may struggle to remain cohesive as a result (Rossetto, 2015). In order to better understand bereaved families' transitions to their post-death realities, it is important to give focus to the role of parenting within that evolution.

An integrative review of literature was undertaken to determine the current state of science regarding bereaved parenting (Haylett & Tilley, 2018). Results revealed its relational context, which was characterized by periodic conflict between personal and children's needs, emotional fluctuation, challenges with levels of protectiveness and control, and an appreciation and heightened sense of responsibility for the parental role. Gender differences were noted in that mothers had more intense grief reactions and openly communicated their grief at an earlier timepoint than did fathers. Reviewed studies focused on child death due to causes such as illness and accidents (Buckle & Fleming, 2011; Rossetto, 2015) including suicide (Rosenblatt, 2000;

Shankar et al., 2017); birth complications, perinatal causes, and sudden infant death syndrome (O'Leary & Warland, 2012; Warland et al., 2011); and military action (Hamama-Raz et al., 2010). However, these studies did not differentiate child death due to an extended and life-limiting illness such as cancer, which differs from sudden, unexpected events (Murphy, 2008). With extended illnesses such as cancer, parents navigate several forces to include adjustments to roles and responsibilities and changes in identity during often lengthy treatment courses and prolonged caregiving periods (O'Connor & Barrera, 2014), a subsequent upheaval of family dynamics (Stroebe & Boerner, 2015), disconnection from other children during caregiving periods, siblings' potential feelings of neglect (Walsh & McGoldrick, 2013), and relinquishment of both the caregiving/parenting role and hope that the illness or cancer could be cured over time and survived (Bergstraesser et al., 2015; Hunt & Greeff, 2011). The manner in which these factors associated with extended illness impact parenting in bereavement is unknown; exploration in such a population merits attention.

Therefore, the aim of this study was to describe the nature and interpret the meaning of bereaved parents' experiences of parenting their surviving children after the death of their child from cancer. Such research can broaden the current knowledge base of parental and family bereavement and reveal commonalities and variations of experience among similarly affected parents (Crowe, 2006). This knowledge can in turn inform pediatric psychosocial services in the areas of family-centered education and resources such as bereavement support programs. An increased understanding of bereaved parenting, including parents' desired supports post-death and beyond, can be used in the development or augmentation of such programs in pediatric oncology settings so they are made highly relevant to families' experiences. Palliative care and hospice nurses and those working in ancillary services such as social work, pastoral care, or with support groups will be better equipped to guide families during bereavement (Foster et al., 2012), particularly in the early stages when families are most vulnerable (Harper et al., 2011; Rosenblatt, 2000).

Methods

Study Design

Conceptualized by Smith in 1996, the qualitative research approach of interpretative phenomenological analysis (IPA) contains three foundational theoretical concepts: the philosophy of phenomenology, the study of phenomena and experience; hermeneutics, the theory of interpretation; and idiography, an inductive technique of focusing on particular

cases before moving to general statements (Smith et al., 2009). Researchers who use IPA aim to examine how individuals make sense of significant life experiences and maintain that knowledge of an experience cannot be had without personal interpretation of one's being or self in the context of things, relationships, language, and culture within the world. This worldly-focused mode of awareness as a "person in context" (Smith et al., 2009, p. 17) renders experience an inherently interpretive event through which meaning is created and from which the essence of a phenomenon may be identified (Creswell, 2013).

Participants

Bereaved parents across the United States were purposefully recruited via criterion sampling and snowball sampling, targeting those who experienced the phenomenon under examination and met specific criteria. Individuals were included if they were a biological, adoptive, step, or foster parent; experienced the death of a child due to cancer at least 13 months before the date of informed consent; and had at least one surviving child who was in the home at the time of death. Incorporating a timeframe of at least 13 months post-death precluded participation of parents during an extremely sensitive and vulnerable time, including the first anniversary of their child's death. Recruitment, which began in February 2018, occurred via posting of study advertisements in local and national bereaved parent newsletters and websites (e.g., The Compassionate Friends) as well as through informal networks for bereaved parents. In total, 16 parents expressed interest in the study. Of those, 11 met criteria for inclusion. Of the five who did not meet inclusion criteria, two fathers and two mothers had surviving children who were young adults and out of the home at the time of their sibling's death. Another mother inquired about the study but did not pursue further contact. The final sample size of 11 participants aligns with prior phenomenological research regarding bereaved parenting, in which samples ranged from 8 (Essakow & Miller, 2013), to 13 (Harper et al., 2011), and up to 17 (Hamama-Raz et al., 2010). For IPA studies, Smith et al. (2009) suggest approximate sample sizes of 3–10, although the authors acknowledge that IPA can be used appropriately with a single case as well as with a sample of up to approximately 15 participants.

Between March and October 2018, the 11 parents (seven mothers and four fathers) participated in individual, semi-structured, in-depth interviews and shared their experiences of parenting during bereavement. Three fathers and three mothers represented married couples though all were interviewed separately and the contents of spouses' interviews were not discussed. Characteristics of the parent sample and their deceased and surviving children are provided in Table 1.

Table 1 Characteristics of bereaved parents, deceased children, and surviving children

Bereaved Parents (<i>n</i> = 11)		
	Mean (<i>SD</i>)	Range
	<i>n</i>	%
Age in years	45.82 (11.09)	33–71
Gender		
Male	4	36.4
Female	7	63.6
Ethnicity		
Asian	1	9.1
Black/African American	1	9.1
Hispanic	1	9.1
White/Caucasian	8	72.7
Educational Level		
Some college/Associate's degree/specialized training	4	36.4
Bachelor's degree	3	27.3
Graduate/professional degree	4	36.4
Employment status		
Full-time	3	27.3
Part-time	2	18.2
Unemployed/stay-at-home parent	4	36.4
Retired	1	9.1
Self-employed	1	9.1
U.S. Region		
East South Central	4	36.4
West South Central	4	36.4
Mountain	1	9.1
Pacific	2	18.2
Faith or Religious Affiliation		
Yes (Christian)	8	72.7
Yes (LDS/Mormon)	2	18.2
No	1	9.1
Spiritual Beliefs		
Yes	10	90.9
Somewhat	1	9.1
Annual household income		
\$40,000 - 59,999	2	18.2
\$60,000 - 79,999	4	36.4
\$80,000 - 99,000	2	18.2
\$100,000+	3	27.3
Current marital/relationship status		
Widowed	1	9.1
Married [range 12–31 years; <i>M</i> (<i>SD</i>) = 19.4 (7.5)]	10	90.9
Marital/relationship status at time of child's death		
Married	11	100
Relationship to child		
Biological parent	10	90.9

Table 1 (continued)

Bereaved Parents (<i>n</i> = 11)		
	Mean (<i>SD</i>)	Range
Adoptive parent	1	9.1
Deceased Children (<i>n</i> = 8)		
Years since death	5.43 (3.17)	2.83–11.33
Age in years	9.25 (6.14)	2–17
	<i>n</i>	%
Gender		
Male	5	62.5
Female	3	37.5
Cancer type		
Leukemia or lymphoma	4	50
Brain tumor	3	37.5
Ewing's sarcoma	1	12.5
Surviving Children (<i>n</i> = 11)^a		
Age in years at time of death	8.27 (5.07)	1.92–18
	<i>n</i>	%
Gender		
Male	6	54.5
Female	5	45.5

Some percentages may not total 100 due to rounding

^aFour other children born or adopted since (currently 9 months – 2 years in age)

Data Collection and Analysis

Before recruitment and data collection began, study approval was granted by a university Institutional Review Board. Audio-recorded interviews ranging from 51–133 min ($M = 80$) were then conducted by the first author via Skype or FaceTime from her home office ($n = 10$) or in person ($n = 1$). The latter interview took place in a private meeting room at a local church of which the participant was a member. Before the interviews started, all participants provided written consent and were encouraged to take time for reflection throughout due to the sensitive subject matter. The interviews were broad, allowing space for the parent to share as he or she desired, and included the primary questions of *Please tell me what it has been like for you to parent ___ after ___'s death* and *What parenting supports do you wish you had, either after the time of ___'s death or now?* At the end of each interview, the first author reflected back the participant's main points for correction of any misconceptions or inclusion of additional insights. Observation notes outlining setting details and participants' body language and demeanor were taken throughout and immediately after each interview. The first author then transcribed each interview verbatim and, to preserve participant anonymity, assigned a number to each set of interview documents.

The analytic process started with immersion in the data by reading, re-reading, and reflecting upon interview transcripts, observation notes, and reflective notes, otherwise known as conceptual comments (Smith et al., 2009). These latter notes, taken during and after transcription and throughout the analytic process, represented reflections about participants' comments, areas of divergence and convergence of data, emerging questions, theme development, and ongoing analysis. Methodologic notes about the data collection process and personal notes regarding the interviews were kept in a reflexive journal. These notes informed the conduct of subsequent interviews and assisted in identifying personal feelings and detecting their influence on data interpretation.

The first author then identified noteworthy or explanatory participant phrases and sentences within each transcript; these were indicative of how the participant understood and talked about their lived experiences of bereaved parenting. The phrases and sentences were condensed as needed and labeled with a code, a concise word or short phrase that represented both the participant's words and the researcher's interpretation. The codes echoed particularity as well as abstraction of the concept and were reviewed by the second author. This iterative process occurred for each transcript, one at a time, and involved identification of new or substantiation of existing codes as they emerged from the data. After the first author coded and made additional reflective notes on each transcript, the second author reviewed the transcript containing the coding and notations and provided any potential areas for further focus or analysis. The 607 codes that emerged across all transcripts were then grouped by the first author into 28 categories and sub-categories and were further reviewed for cohesion and interpretive stance by the second author. The categories were then clustered into two primary themes that express commonalities across categories and present an essence of the phenomenon of bereaved parenting. The following narrative represents participants' distinct voices and interpreted experiences as well as the authors' interpretation of the shared, collective experience (Smith et al., 2009).

Findings

Theme 1: A New Mind

The first theme denotes bereaved parents' new, contrasting mindsets of: (a) desiring to maintain one's old self and needing to become a new, changed person; (b) wanting to attend to one's own grief (internal needs) and needing to care for one's surviving children (external duties); (c)

realizing one's own powerlessness and choosing intentionality in parenting; (d) fearing tomorrow and cherishing the present; (e) being protective of and permissive with one's children; (f) hanging on to what was and bridging into life again; and (g) disconnecting from those who cannot understand and connecting with those who can.

Old self and new, changed self

This subtheme reflects the contrasting mindset of desiring to maintain one's old self and yet needing to become a new, changed person. Seven (63.6%) parents shared comments related to this subtheme, mourning the loss of their prior selves and/or recognizing and accepting the inevitable changes to themselves and their parenting. One father shared the contrast he feels about wanting to be seen as himself — not as a grieving parent — and yet needing to grieve:

I never wanted to be a person — then or even now — who lost a young daughter... I just want to be myself - that's who I want people to see me as. And so, I...I try to compartmentalize, you know, and save it [grieving] for a time when I can.

A mother echoed a similar sentiment about the difficulty she felt transitioning to the grieving parent role, stating, “I don't want to be the grieving mom, I want to be who I was! And why can't, just because he's gone, why does that have to change?” Another mother explained how she has been so drastically changed:

The surviving sibling not only has lost their sibling, but they've also lost the only parents they've ever known, because their parents are different...I believe that the loss of a child *changes* a parent. I say it changed me at the cellular level. I mean, it changed *everything about me*: my body, my mind, my perspective, everything, everything has changed.... And really, in a cancer situation, that starts at the cancer diagnosis because that parent changes right then. I know I started to change right then.

Internal grief needs and external parenting duties

This second subtheme highlights the contrasting mindset of wanting to attend to one's own grief (internal needs) and yet needing to care for one's surviving children (external duties). Ten (90.9%) parents shared related comments, reporting difficulty parenting particularly in early bereavement due to intense grief and/or at the same time,

recognizing the importance of continuing to be present and care for their surviving children. One mother explained how her son became her motivation to function each day despite her feelings directing her otherwise:

I think that parenting has been, um, almost a *lifeline* in a sense because on days when I didn't want to get out of bed or I just wanted to crawl into a hole or just didn't have the will to live anymore, at the beginning...on those days, I had to get up because I had a kid that needed to eat breakfast, that had activities to do, and needed me to turn on the TV at least. He wasn't just gonna lay in bed with me all day. And so, having him — in that sense — need me was a *huge* help because I wasn't able to do what my feelings were telling me to do. And that was a good thing.

Powerlessness and intentionality

This subtheme emphasizes the contrasting mindset bereaved parents have of realizing their own powerlessness and yet choosing intentionality in parenting. Ten (90.9%) parents reported feeling powerless in light of their child's cancer diagnosis and death and/or making conscious decisions to parent their surviving children with intentionality. Realizing the risk of harm the outside world poses to their surviving children, they acknowledge their lack of control over their children's safety. One father shared:

Parenting is different in every way. I mean, for one, you know, your sense of, your assumption that life is safe and that the world is a safe place is really just kind of thrown out the window. And so, um, you know, I think it's hard to not be hypervigilant just with anything that is a threat, not even just health things, but *all* things. Life is scarier, if that makes sense. And so, that's definitely affected it.

While parents revealed a greater understanding of their lack of control over life, they also communicated a choice to intentionally parent their surviving children through actions such as listening, communicating, and affirming. Parents reported often being absent - physically and emotionally - from their other children while focusing on cancer treatment decisions and their ill child's health. This 'shadow child' dynamic resulted for many of the parents in an increased intentionality about giving attention to their surviving children in bereavement. A father shared he now has much different communication with his son and is no longer dismissive of his requests:

Everything goes with the tone, the voice you tell, and the eyes you give to them. Now, my son [says], ‘Hey Daddy, do you see my grades?’ Before, I look and say, ‘Keep going, let’s go eat.’ Now, what do I do? I say, ‘I wanna see them!’...Before, hey, can we go and do this? No. Why? I’m tired, I put excuses. But now, when I lose my son, there’s a reason — I’m telling you — I don’t want to lose everything I’ve got right now.

Fear of tomorrow and cherishing of the present

This subtheme illustrates the contrasting mindset bereaved parents have of fearing tomorrow and yet cherishing the present. All 11 parents (100%) shared comments related to these changes of perspective, revealing their fears about an unknown tomorrow and/or the manner in which they cherish the present day. A mother acknowledged the potential for future loss and understandably fears any threat to or loss of her surviving children:

We hung on to our kids, kept them very close, but now since we’ve lost him, we’ve kept them *even closer*. It kinda hampers them because we hang on so tight. Especially me...*I hang on, I hang on...*it’s what we have left now...we can’t lose another one, absolutely not.

In contrast, parents also shared how their perspectives now include a greater cherishing of the time they have with their children and families. Communicating how precious the quality time with and milestones for her daughter became, one mother commented:

In a way, you would think that losing a child would make you more protective over your second child... but we had more of a desire to celebrate her growing up and her accomplishments and things like that. She got to do all the things our other daughter didn’t get to do...Those [milestones] are not things to be sad about, those are things to be celebrated! We were able to do that more with her than we ever would have otherwise because we knew that those are gifts and opportunities that not everyone has.

Protective and permissive parenting

This subtheme emphasizes the contrasting mindset bereaved parents have of desiring to fiercely protect their surviving children from harm and yet be permissive with and allow

their children freedom. All 11 parents (100%) reported a range of physically or emotionally protective and/or permissive parenting actions. One mother shared about her fluctuating levels of protection over her young children:

It’s a weird combination because you’re like that obsessive parent who’s like, everybody has to wear their seatbelt, everybody has to wear their bike helmet, whatever, because you know that your kid can die. But you’re also that parent that’s kind of just like, oh well, there’s nothing I can do to keep them here... So, it’s a weird combination and it kind of ebbs and flows. Sometimes, I’m overprotective and sometimes I’m less overprotective because I feel like I have an understanding that what I’m doing isn’t what keeps my kids safe, healthy, or here.

Parents revealed that since so much was focused on the ill child, siblings are frequently overlooked even into the bereavement phase. As a result, some parents found it difficult to reemphasize their parental role with their surviving children, balancing newfound time and attention with appropriate boundaries.

A hanging on and a bridging into life

This subtheme reflects the contrasting mindset of hanging on to what was and bridging into life again. All 11 parents (100%) shared comments related to this subtheme, communicating the importance of hanging on to the past with its memories and/or needing and attempting to again bridge or re-enter into life, primarily within their families. “When you’re grieving the loss of your child, it’s *so* big and *so* long and it doesn’t really go away...so now, how do we live as a typical family, how do you bridge into that?” one mother asked. With respect to their surviving children, parents embrace the opportunity to once again have time with them and are well aware of their need for support, yet they are concerned their children must deal with a unique and different loss - that of a sibling. Parents also mentioned their need to bridge into others and daily life again. They do so by helping other families experiencing cancer, continuing to live and give to others, and refusing to be stuck in grief. These actions and beliefs enable them to make meaning—to some degree—of their child’s death. One father shared his newfound purpose:

I want to honor her going forward in the way I live. I don’t want to waste that experience, I don’t want to waste that storm, I want to use it for good. And that’s why if my wife and I can get a chance to...use our story to help other people, we’re all in....*We need* to

testify to our stories, the hope, and the peace...the Philippians 4:7 peace.

Disconnection from and connection with others

This final subtheme emphasizes the contrasting mindset bereaved parents have with respect to personal relationships. Seven (63.6%) parents revealed tendencies to disconnect from those who cannot understand their experience and/or connect with those who can. One mother articulated her sense of separateness:

Something else I wanted to mention is...how I relate to other parents. We were sitting at a football game two weeks ago and I saw several groups of mothers talking and laughing and thought how different I am. I can't 'un-know' what I know and they can't know or understand what I have been through and it makes it hard to be carefree or relate to non-bereaved parents. Beyond that, I sometimes feel like I wear a sign that says 'she couldn't save her son' and people treat me differently because of that.

These parents also have an innate sense of what one mother termed a "grief allowance":

One thing is that nobody wants to hear about it especially after a certain point. You've burned out your grief allowance... I went past the grief allowance - it was four years in July... At three years, I really felt strongly, I actually felt *grief* that I was - I don't know how I knew - but I felt like I'm not allowed to talk about it anymore...and really struggled actually at that point. Like I was past where people are like, oh, you're sad, and on to the point where people are like, you're just being dramatic or getting attention or something.

Theme 2: Be Beside Me

"Be Beside Me" exemplifies parents' desires for validation and family renewal. There is a sense within this theme that parents place enormous value on others coming alongside and being beside them, acts which are demonstrated through others' validation of their emotions and experience as well as the provision of opportunities for family renewal.

Desire for validation

This subtheme reflects bereaved parents' desire for comfort, belonging, and understanding from (a) their child's care team into the bereavement phase, (b) other bereaved parents

immediately and continuously, and (c) others in the community on an ongoing basis. All 11 parents (100%) shared comments related to this desire.

Some parents indicated a desire for ongoing connection with their child's care team. They mentioned receiving condolence cards from the hospital or hospice staff at significant anniversaries yet longed for a more personal touch. One mother expressed her deep desire to continue relationships with her son's treating team, including his hospice nurse:

We get attached to these healthcare providers and then when the child dies, you don't really have any reason to be in contact with that person anymore. And it's *devastating*, because you feel like a person that had *such* a big part of your child's life is suddenly gone and you want *so bad* to be able to talk to them about your kid. You *want* to continue those relationships, and suddenly there's no reason to... I remember those first few months, being *devastated* that I felt it was against policy to reach out to them...I think that having that open door would have been awesome, or even having the people that were involved in his life medically reach out a couple of times would have been amazing, just offering to come chat for a few minutes or sending me an email or something.

Parents also expressed the desire to receive comfort from other bereaved parents, which enables them to feel understood and known, as one mother commented:

I mean, I got something I guess from going to the therapists I went to, but *nothing* like sitting in a room and - and none of them have a degree or anything else - but I *know* even when there is absolute silence, they get me. They get everything at the core of what I'm saying. So that, that is my big thing that I think *absolutely* saved me...

Receiving this immediate understanding and camaraderie from others was and is a continuous sustainer and source of encouragement for parents bereaved by cancer. In addition, parents expressed their need for ongoing community support, which indicates to them that their families mattered then and continue to matter even now. Some mentioned specific needs for practical support such as meals and activities or childcare for their other children, and others noted how special the opportunities are to still share their families' stories.

Desire for family renewal

This final subtheme, which eight (72.7%) parents discussed, illustrates parents' desire for resources and programs which

give their children and families opportunities for renewal. They recognize the often-negative impact of a lengthy caregiving period on family dynamics and desire to empower their parenting. They covet tools and informal and formal resources to support their grieving children, both early and later in bereavement. Parents also expressed the need for beneficial bereavement programs to empower their families' adjustment and parenting, as one mother noted:

I see a lot of parents struggling [when] they don't know how to help their kids...and so I don't know that there's really resources for helping parents who don't know what to say to their kids...they just can't handle their own grief and the kids' issues at the same time.

Another mother acknowledged the difficulty of establishing bereavement programs yet emphasized giving parents the opportunity to identify their individual needs:

There have to be hospitals who are doing this [bereavement] well. And there's no perfect way to handle grief. I think there just isn't and that's why it's *always* a topic because it's *so* painful and *so* different for each individual. You can't really create a formula that just fits - it's a difficult area. But you can research, observe, find patterns, and kind of find that scale and then give the opportunity for the parent to plug themselves into that scale.

Discussion

Theme 1: A New Mind

As an extended and life-limiting illness, cancer presents distinct challenges for families (O'Connor & Barrera, 2014). The unique effects of a child's cancer death on parenting surviving children are revealed in the findings. The seven subthemes suggest that parents experience, respectively, fluctuations with regard to their (a) view of self; (b) daily motivators, whether internal or external; (c) perceived locus of control; (d) daily perspective; (e) boundaries for their children; (f) direction of focus, whether past or present/future; and (g) outside relationships. It is understandable that bereaved parents would face contrasting mindsets concerning these foundational issues. Indeed, the findings indicate that parents who experienced the death of a child are explicitly changed and have gone through a crucible that grants them a rare and unique outlook on life. These changes give rise to significant questions about themselves and the world. Bereaved parents may ask

themselves questions such as *Who am I? How am I in the world (e.g., less safe, wiser, more skeptical, fearful)? What is now important to me? How do I relate to others? (How) do I fit and where?* and also pertinent to this research study, *How do I now parent?* The internal working through of these questions and their myriad answers are illuminated within the themes and provide an understanding of bereaved parents' new minds and ways of being. Existing literature similarly recognizes the foundational changes bereaved parents undergo with respect to their emotions, relationships, self-identities (Arnold & Gemma, 2008; Denhup, 2017; Nuss, 2014; O'Connor & Barrera, 2014; Riley et al., 2007), perspectives, coping and behaviors, and spiritual beliefs (Gilmer et al., 2012). The manner in which parents change and cope affects their relationships with and parenting of their surviving children (Buckle & Fleming, 2011; Shankar et al., 2017), and they impact in large part both their children's ability to adapt in bereavement and the family's overall grief experience (Rossetto, 2015).

View of self and daily motivators

The significant shifting of outlook related to the view of self underscores the foundational questions a bereaved parent asks about his or her new identity and way of being, a state similarly described by Denhup (2017) and Nuss (2014). Likewise, parents were motivated to attend to their internal grief needs yet were also motivated by the pull of their external duties to parent their surviving children, a result similar to that of Buckle and Fleming (2011), Harper et al. (2011), and Shankar et al. (2017). Particularly early in bereavement, parents grieve intensely and therefore feel limited in their caretaking abilities and role. However, many credit that very role as the central reason for their ability to function, albeit at a lower level. Essakow and Miller (2013) found comparable results in their study of bereaved parents, who cited the need to function and provide care for the family as a primary reason to carry on despite intense grief.

Both of these mindsets—the view of self and daily motivators—indicate the internal and external duality within which bereaved parents must exist. They experience a contrast or conflict between what they feel internally and what they think they should do externally. Versus existing solely within one or the other (e.g., old or new self), parents find their mindsets fluctuating across a continuum, which denotes the contrasting nature of these and the other mindsets.

Perceived locus of control, daily perspective, and boundaries for children

A contrast in perceived locus of control was evidenced by parents' feelings of powerlessness over their child's death and

choosing to parent with intentionality. Despite acknowledging a sense of powerlessness, the fathers in particular carried a personal burden to be vigilant over their families. They could no longer be oblivious or indifferent to any potentially threatening situation and revealed a subsequent loss of assumption of safety for the family and control over life. At the same time, parents connected their inability to foresee or control the future to their refusal to take for granted anything in the present. They became more immediate, today-focused, appreciative, and intentional in their parenting as a result. This tendency toward intentionality echoes previous research that found parents bereaved of their infants viewed parenting as a gift and chose to be intentional about their behaviors toward surviving or subsequent children (O’Leary & Warland, 2012; Warland et al., 2011).

Participants also exhibited a duality of daily perspective about the precious nature of life, which was manifested as a fear of tomorrow or a cherishing of the present. This duality of perspective indicates a shifting of focus between loss and restoration, a contrast depicted in the Dual Process Model-Revised (Stroebe & Schut, 2015). Parents who tend to fear tomorrow may focus more so on their loss and potential for further hurt, whereas parents who tend to cherish the present may instead focus on restoration and renewal. Prior research has revealed tendencies for bereaved parents to feel fear and anxiety in relation to the potential for further loss (Hamama-Raz et al., 2010; Hunt & Greeff, 2011; Walsh & McGoldrick, 2013; Warland et al., 2011) as well as feel a unique cherishing of their children that might not otherwise have been (O’Leary & Warland, 2012; Shankar et al., 2017).

Regarding boundaries, parents demonstrated a desire to fiercely protect their children from harm yet be permissive with and allow them freedom. This finding aligns closely with Rosenblatt (2000), whose study revealed bereaved parents’ concern for and struggles with levels of protectiveness over their surviving children. In the current study, parents expressed vigilance—often hypervigilance—and an increased readiness to intervene in matters concerning their children. Although parents recognized their parenting actions or inactions were unrelated to their child’s death, providing physical protection over their surviving children was of paramount importance. Yet, parents also desired to avoid additional hurt for their children and thus were more hesitant to discipline and less rigid with boundaries, a finding consistent with the permissive parenting style noted by Lee and Khang (2018).

A novel connection of the findings, there are interrelationships to be noted among these three areas. Feeling powerless and having one’s assumptions of safety irrevocably altered likely results in a fear of the unknown future. Parents may experience this fear if they perceive an inability to control the environment in order to protect their surviving children. In addition, parents’ boundaries for their children

are likely borne out of their perceived locus of control and daily perspective, both of which can fluctuate across time. Parents who at times experience a fear of tomorrow may be more protective of their children. At other times, parents may feel and experience a cherishing of the present and as a result, may be more permissive in their parenting.

Direction of focus and outside relationships

The direction of parents’ focus, whether past- or present/future-oriented, was characterized by hanging on to the past with its memories yet needing and attempting to bridge into life again. For some, trying to hang on or remain connected to something might provide a sense of control in a world in which they feel upended. Several studies have highlighted bereaved parents’ exertion of control in response to the uncontrollable event of their child’s death (Hamama-Raz et al., 2010; O’Leary & Warland, 2012; Warland et al., 2011). Conversely, bridging into others and life again was fueled by their emphasis on adjusting as a family, making meaning of their loss, making a difference for others, and/or having an increased faith in God, findings consistent with existing parental bereavement research (Arnold & Gemma, 2008; Essakow & Miller, 2013; Hunt & Greeff, 2011; Nuss, 2014). The death of a child is so formative that parents cannot simply go back or un-know what is now known; hence, there is something different into which parents and families must bridge and adjust. A transition of this type is indeed challenging since a bereaved parent’s desire to hang on to their deceased child, things, memories, prior roles, and even their surviving children may contribute to a feeling of separateness from others. A piece of them, such as their identity as a parent, caregiver, or cancer parent, is gone or different.

In that vein, parents found themselves changing in terms of the outside relationships they nurture and maintain, a finding consistent with research by Nuss (2014). Parents tended to disconnect from those who could not understand their experience of loss and bereaved parenting while deeply connecting with those who could, the latter echoing existing literature (Berrett-Abebe et al., 2017; deCinque et al., 2006). The philosophical questions bereaved parents often ask themselves simply could not be grasped by others. This explains in part why each parent emphasized the immense value of being in relationship with other bereaved parents, as only they can fully understand.

Theme 2: Be Beside Me

Desire for validation

Although participants recognized that non-bereaved parents did not grasp the experience of the death of a child and

continuing to parent other children, the findings suggest they deeply desired others' presence with them throughout their journey. Often-close relationships built with the healthcare team during cancer treatment were a starting point of comfort and support. Many parents in fact needed to grieve with the care team, also noted in existing literature (D'Agostino et al., 2008; Darbyshire et al., 2013; Snaman et al., 2016). Moreover, the connections forged create within some parents the desire to remain connected, a result consistent with reviews by Donovan et al. (2015) and Foster et al. (2010) of hospital-based bereavement services and pediatric palliative care services in oncology, respectively. Thus, as other studies have also discussed (Berrett-Abebe et al., 2017; Darbyshire et al., 2013; Snaman et al., 2016; Steele et al., 2013; Thrane & Jones, 2012; Wiener et al., 2018), a mechanism by which teams can continue contact with interested parents is vital.

As parents also shared, there was no substitute for other bereaved parents having an innate knowledge and understanding of the experience of losing a child and continuing to parent. This type of comfort and emotional support was needed by parents very soon after their child's death—immediately after, for some—as well as continuously. Similar to other research (D'Agostino et al., 2008), emotional support can take many forms, including grief or bereavement groups, informal meetings, or simple social connections with each other.

Finally, bereaved parents desired ongoing support from others in their communities. Particularly early in bereavement, parents were attending to their own intense grief and functioning at a much lower level, similar to previous research (Buckle & Fleming, 2011; Essakow & Miller, 2013; Shankar et al., 2017). Early bereavement is therefore the time period when the need for practical help such as care and activities for surviving children, transportation, meals, and general acts of service may be greatest. Also expressed in existing literature (Darbyshire et al., 2013; Lichtenthal et al., 2015), parents reported a natural falling away of support and encouragement after a period of time of one to a few years, however. While their practical needs may lessen, parents desired that their communities continue to provide emotional support, a place of belonging, and most importantly, remember their children. This finding is consistent with research by Nuss (2014) which has recognized parents' desire to continue talking about their child and their family's story despite others' discomfort, disinterest, or avoidance.

Desire for family renewal

Parents coveted resources and programs focused on their children's and families' healthy coping and adjustment. Needed and accessed resources include developmentally-

appropriate play therapy for their grieving children, informal family meetings and social events, faith-based or church-related support, family and sibling bereavement camps, and individual and family counseling. These results align with Rossetto (2015) who found that parents greatly value outside support to aid the coping process of their children in particular.

In addition, parents recognized the value of institutional bereavement support programs for empowerment of their parenting and their families' adjustment, a result also discussed by deCinque et al. (2006) and Donovan et al. (2015). The *Standards for the Psychosocial Care of Children With Cancer and Their Families*, evidence- and consensus-based benchmarks developed by the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC, United States), contain two standards related to care in the bereavement phase, including contact from the health care team for assessment of needs, continuity of care, and provision of bereavement support resources (Wiener et al., 2015). Implementing bereavement support programs has been many institutions' answer to these standards as well as parents' expressed need for support and continued contact with the healthcare team. Donovan et al. (2015) ascertained the following psychosocial outcomes for families participating in hospital-based bereavement services: (a) feelings of being cared for and supported, (b) lessened feelings of isolation, and (c) improved coping and personal growth. Parents in the current study felt it vital that institutions continue working to establish bereavement programs that facilitate connections with the healthcare team and other parents, provide education and assistance with parenting and family functioning, and support families at varying stages of bereavement, findings consistent with research by Lichtenthal et al. (2015), Snaman et al. (2016), and Wiener et al. (2018).

Implications for Practice

The findings of this study provide a better understanding of parents' experiences for healthcare professionals who strive to support parenting and healthy families near the end of life and throughout bereavement. Unlike previous research which has revealed the impact of bereaved parenting on their physical and psychological health, this study revealed parents' relational outlook with respect to their surviving children. Palliative care and hospice nurses as well as other professionals working with families in the end of life care period can provide education about bereaved parents' experiences to families who may seek such information or reassurance. Intuiting each family's capacity and readiness for such information is crucial and part of the "art" of being present at the end of life and into early bereavement. Into the bereavement phase, professionals and lay persons alike

such as pastors, grief counselors and therapists, nurses, bereavement coordinators, social workers, and community members can better equip themselves to guide and support families as they cope and adapt to bereavement. Finally, instructors who teach palliative and end of life care concepts in academic programs or curricula such as the US-based End-of-Life Nursing Education Consortium - Pediatric Palliative Care (ELNEC-PPC) training program may implement these findings into education about loss, grief, and bereavement for nurses who care for terminally ill pediatric patients and their families.

Findings also suggest that many parents desire continued connection with their team of nurses and healthcare professionals after their child's death. As previously discussed, many institutions and organizations have established bereavement support programs to meet this need. Within such programs, nurses should assess interested families' adaptation to bereavement and continue to assist them with adaptation and coping, decision-making, and referral to support groups or counseling services. Nurses affiliated with such programs can also serve as families' primary point of contact for matters related to their child and maintain connections with families well into the bereavement phase. These functions support long-term goals of family-centered care in bereavement, which include the improvement of family functioning and the promotion of adaptive grieving (Kissane & Lichtenthal, 2008). Regardless of affiliation with formal programs, however, nurses and healthcare professionals should have an understanding of parents' need for connection in bereavement and if needed, investigate feasible and effective methods for doing so within their individual organizations.

Finally, one can conclude that bereaved parents deeply desire support from other parents as well as their communities. As demonstrated in this study, being in relationship with other bereaved parents is integral to adaptation to parenting in bereavement. The parent participants in this study shared that only others who have experienced the death of a child can know the challenges of the "new" parenting role, the reasons for certain parenting decisions, and the feeling of separateness from society and other parents. To support bereaved parents in this way, nurses and healthcare professionals should continue to facilitate contact with other individual parents or parent groups. There may also be a potential role for nurses or bereavement coordinators in the deceased child's community. As the child's school or community groups attempt to cope and extend care to the family, they could perhaps benefit from education about bereavement effects to minimize potential misunderstanding (O'Leary & Warland, 2012) or unawareness about how to approach or best support bereaved families (O'Connor & Barrera, 2014). The development of such outreach to affected community groups positions nurses to

provide relevant education regarding the impact of grief and bereavement on the family.

Implications for Research

Additional research related to bereaved parenting may focus on siblings' experiences of being parented after their sibling's death. This information, in conjunction with findings from the current study, would provide a broader picture of family adaptation and functioning after a child's death from cancer. It would also give voice to the unique bereaved sibling perspective and could potentially identify areas of convergence and divergence between parent and sibling reports. Future studies could examine bereaved parenting based on varying age groups of surviving children such as infants/toddlers/preschoolers (ages 0–4), school-aged children (ages 5–11), and pre-teen/teenager (ages 12–18) at the time of the child's death based on practical, emotional, and relational differences in parenting a teenager versus a young child, for example. Researchers could also investigate other vulnerable populations' experiences with personal or familial disease, crisis, or other such hardship; determining whether and how a similar sense of separateness might be manifested within other vulnerable populations who experience crises could serve as an area for further investigation and potential intervention. A final area for future research could involve the investigation of emotional wellbeing, resilience, or appropriate professional boundaries for healthcare professionals who provide parents and families long-term bereavement services. Identifying strategies for maintaining wellbeing and avoiding professional burnout in an emotionally-intense environment is vital to preserving a responsive, compassionate workforce over time.

Limitations and Strengths

Limitations of the study with regard to methodology and sample characteristics are acknowledged. There is a potential limitation related to the use of one coder (i.e., the first author) during data analysis. To moderate this, the second author provided close oversight, review, and guidance to ensure validity of coding, cohesion of categories, and an appropriate interpretive analytic stance. Second, two of the three bereaved parents' networks through which recruitment occurred were faith-affiliated. This fact may have disproportionately identified parents who rely on a personal faith or religion, although faith is not a requirement for group participation, nor did all 10 affiliated parents refer to it. Except for explicit connections made by participants, the impact of personal faith or lack thereof on the findings is unknown.

Study strengths involve adherence to evaluative criteria for qualitative research, including sensitivity to context, commitment and rigor, and transparency and coherence (Yardley, 2000). These criteria were fulfilled through

orientation of the study within a current gap in literature; appropriate sampling and thorough data collection; systematic analysis of data; relation of findings to relevant literature; and adherence to the principles of phenomenology, hermeneutics, and idiography (Smith et al., 2009; Yardley, 2000). In addition, a declaration of professional research interest and presuppositions regarding bereaved parents' perspectives as well as the use of a reflexive journal aided the first author in establishing self-awareness and helped to promote the study's rigor and trustworthiness (Berger, 2015; Roberts, 2013).

Conclusion

Findings from this interpretative phenomenological analysis reveal the unique nature of parenting after a child's cancer death and contribute to the current understanding of family functioning in bereavement. Collectively, parents' experiences were depicted by two primary themes of "A New Mind" and "Be Beside Me". Bereaved parenting is interpreted to be characterized by new, contrasting mindsets regarding self-view, daily motivators, perceived locus of control, perspective, boundaries for children, direction of focus, and outside relationships. Bereaved parents also deeply desire that others come alongside them by validating their emotions and experience and providing opportunities for family renewal. Clinicians working with bereaved families should have awareness of and consider these changed perspectives, challenges, and supportive needs in order to deliver family-centered care and enrich existing services and support programs.

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Compliance with Ethical Standards

Conflict of Interest The authors declare no competing interests.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the Institutional Review Board of Texas Woman's University (No. 19950).

Informed Consent Informed consent was obtained from all individual participants included in the study.

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