Lived Experience of a Child's Chronic Illness and Death:

A Qualitative Systematic Review of the Parental Bereavement Trajectory

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Abstract

To understand the lived experience of parents who have lost their child to a chronic life-limiting condition, six major databases were searched by adhering to the PRISMA guidelines. Articles were screened for appropriateness using the SPIDER tool, and relevant qualitative studies were selected for full-text data analysis using Thematic Synthesis. Findings were categorized into 13 themes that were further organized into a four-phase trajectory of parental bereavement experience of child loss, namely: Liminal Margin, Holding Space, Navigating Losses, and Reconstructing Lives. The findings are discussed in the light of existing literature with practical recommendations for enhancing parental bereavement support services.

Keywords: *qualitative systematic review; death in families; parental bereavement; child loss; grief; chronic illness*

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Contrary to the popular belief that deaths occur in later life, recent global statistics show

that 8.8 million children die annually before their fifth birthday (You, Wardlaw, Salama, & Jones,

2010) and 2.6 million youth between the ages of 10 to 24 die every year (Patton et al., 2009).

The untimely death of a child can deny parents their role as a caregiver, resulting in a shattered

concept of self, massive invalidation of worldviews, ongoing existential suffering due to

unresolved grief, and fear for the safety of surviving family members (Janoff-Bulman, 2010). A

child's death can also result in disenfranchised grief, wherein the magnitude of loss that

mourning parents experience is not fully recognized and appreciated (Attig, 2004). The death of

a child is indeed regarded as 'the worst loss' and is associated with a wide range of physical,

psychological, emotional, social, and existential sufferings (Barrera et al., 2009; Dias, Docherty,

& Brandon, 2017).

Families of children with chronic life-limiting illness are often faced with great

caregiving burdens, made heavier with the addition of many practical and financial demands

(Doka, 2005). Many marital relationships can become strained because of the stress brought on

by a child's illness and death, particularly due to gender differences in coping with grief

(Bergstraesser, Inglin, Hornung, & Landolt, 2015; Schwab, 1992). The chaotic cycle of treatment

and relapse that parents tend to fall into as they care for their chronically sick child can result in

neglect of their other surviving children (Barrera et al., 2007; Jordan, Price, & Prior, 2015).

Furthermore, caring for a chronically ill child involves close liaison with medical professionals,

but such interactions are not necessarily smooth or pleasant and can in fact heighten distress for

caregiving parents (Jordan et al., 2015; Meert et al., 2008). With the myriad of seemingly

unending challenges, it is then no doubt that the process of caring for a chronically ill child has been described in literature as "battling the dragon" (Davies et al., 2004).

The experience of highly challenging life events can bring about positive change in individuals, also termed posttraumatic growth (Tedeschi & Calhoun, 2004). Although there is evidence to support such positive transformation in parents who have lost their child to a chronic illness (Foster et al., 2009, 2011; Hynson, Aroni, Bauld, & Sawyer, 2006; Reilly, Huws, Hastings, & Vaughan, 2008), it would be unwise to deem any study of parental experience of a child's chronic illness and death as universally applicable because of limitations in the study scope and sample.

The present authors believe that a consolidated investigation, which summarizes findings from various studies, would provide a stronger foundation to understand the experience of parental bereavement due to chronic illness and death of one's child, the typical challenges and the potential for growth following this trauma. Particularly, a systematic review would draw attention to gaps in researched literature, inform practitioners of the advancement in empirical evidence, and serve as a starting point for recommending practical guidelines (Swingler, Volmink, & Ioannidis, 2003). A review of qualitative literature would extract concepts from primary studies to develop a line of argument that pulls together corroborating concepts and moves beyond the primary studies to offer novel interpretations of the data, by critically examining all the research reports as a whole (Thomas & Harden, 2008).

Methodology

A systematic search of literature was performed in February 2017 and updated in February 2018. The review was guided by the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA;(Liberati et al., 2009). The SPIDER (Sample, Phenomenon of

Interest, Design, Evaluation, Research type) tool was used to design a search strategy because of its established efficacy with qualitative research methods (Cooke, Smith, & Booth, 2012). According to Cooke et al. (2012), the reliability of other tools such as PICO/ PICOS is limited to systematic reviews with quantitative research questions.

Search Strategy and Inclusion Criteria

Six major databases (MEDLINE, PsycInfo, CINAHL, ERIC (EBSCO), ProQuest and Social Science Citation Index) were searched using the following key words: bereaved parents, parental grief, child mortality, end of life (EoL), child death, and chronic illness. Minor adjustments were made to the search string depending on the requirements of each database.

Identified articles were included in the review if: (1) the sample comprised parents whose child lived with and died due to a chronic life-limiting condition, (2) the phenomenon of interest was the lived experience of these parents as they moved from caregiving to anticipating death to finally bereavement, and (3) the study design involved use of face-to-face or telephonic verbal interviews and the research was either qualitative in nature or mixed methods research with a strong qualitative base. For the purpose of this review, a parent was defined as any adult who is the primary caregiver of the child. It was required that the age of the child at the time of death was between 1 to 18 years. Studies with parents whose children had died within the first year of their lives were excluded since the focus of this review is on parental experience due to child loss rather than loss of a newborn or infant. Only original research journal articles published in the English language during the period from 2000 until 2017 were included, since the authors agreed that contemporary findings would offer more insight to academic and clinical work in the present context. Publications were excluded if they employed a quantitative or case study method of research. A case study focuses solely on a single individual case. In qualitative studies that use

thematic/ content analysis, framework analysis or grounded theory, the findings have more

transferability and potential to contribute to theory building (Williams, 2002). Keeping in mind

the scant qualitative literature addressing the lived experiences of parents whose child had died

from a chronic illness, three studies with mixed methods were included, since there was a

reasonably substantial component of qualitative findings in these studies. Only the qualitative

data in these studies were examined.

Screening Process and Data Extraction

In the initial stage of screening, the title and abstract of all citations obtained through the

search strategy were assessed by the first and second author based on the prescribed inclusion

criteria. Studies that were deemed fit by either author were then carefully evaluated for

appropriateness of inclusion via full-texts by the first and second author. A study was included

only if both authors arrived at the same decision independently. In the event of a conflict

between the first and second author regarding appropriateness for inclusion, the third author

conducted another round of full-text screening, and the third author's decision stood final. Fifty

percent of the excluded materials were also checked by the third author to confirm exclusion.

Details of the screening process are shown in Figure 1.

[Insert Figure 1 about here]

The first author extracted data from each study into a spreadsheet, which was structured

according to the quality assessment criteria established by Thomas and Harden (2008). This

includes evaluation of five criteria related to adequate description of the study's objectives,

context, rationale, methodology, and findings; and four criteria related to adoption of appropriate

strategies to ensure reliability and validity of data collection tools and method of analysis. Only

those studies that were found to fit the research question of the present systematic review and

had clearly stated methods of quality control for data collection and analysis were included in the final analysis.

Data Analysis

Only first order constructs including quotations from respondents in the primary studies were treated as data points, which allowed the elicitation of participants' voices in their purest form while eliminating the risk of the primary author's own interpretation of the data from influencing the overall analysis (Toye et al., 2014). Data analysis followed the three-stage process of thematic synthesis (Thomas & Harden, 2008). In the first stage, line-by-line coding of text was conducted to develop descriptive themes, and create analytical categories, which construct new interpretations and explanations of the data. Following this, inductive codes were developed to capture the meaning and content of a cluster of similar quotes. Finally, the inductive codes were classified into four temporal phases to capture the entire trajectory that parents experience from the time of a child's terminal diagnosis, their treatment, the final day of life, and finally the changes brought about by the death of their child. Regular coding and debriefing meetings were conducted with research team members to maximize credibility, criticality, and authenticity. The coding framework, interpretation of data, and confirmation of themes and theme categories and were agreed upon by all members, finalized by the fourth author and compared to existing literature to ensure investigator triangulation and theory triangulation.

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Results

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Scope and Quality Assessment

Each of the 25 studies included in our review underwent a rigorous appraisal process with the SPIDER tool (Cooke et al., 2012) to determine their appropriateness to answer the research

question of this review, and a thorough quality assessment (Thomas & Harden, 2008) to avoid

drawing unreliable conclusions from primary data. The studied sample, in most cases, involved

individual parents (predominantly mothers), and only a small number of studies examined

father-mother dyads. Three of the reviewed studies focused solely on bereaved fathers. Most

studies recruited participants from local pediatric facilities that work with children dying of

chronic illness. The included studies had varied phenomena of interest such as understanding the

needs of bereaved parents, exploring factors that help them to cope with their child's illness, and

understanding how bereaved parents move beyond the trauma of their child's death towards

meaning making. Most authors adopted a semi-structured face-to-face interview followed by

thematic analysis of the recorded data. Seven of the included studies did not provide information

on research ethics. Most of the included studies indicated how trustworthiness of findings was

achieved (such as procedures of members checking and/ or identification of deviant cases).

Detailed descriptions of the included studies are presented in Table 1.

[Insert Table 1 about here]

Findings from the Thematic Synthesis

The studies included in this review involved more than 500 bereaved parents who were

interviewed either alone or in couple units, from eight countries: United States (n = 11), UK (n =

5), Australia (n = 3), Canada (n = 2), Switzerland (n = 1), Belgium (n = 1), Ireland (n = 1), and

Chile (n = 1). Our thematic synthesis of the data within these studies revealed 13 themes that

illuminate the lived experience of bereaved parents of children who suffered and died from a

chronic life-limiting illness. These themes were further categorized into four analytical

categories that are chronological (i.e., phases 1 and 2) and integrative (i.e., phases 3 and 4).

These four phases and the themes that they encompass reflect the experiences, emotions,

cognitions, and relational behaviors related to EoL caregiving and bereavement. Each of these four phases and the relevant themes within them are discussed below.

Phase 1: Liminal Margin

"Liminal" is a term used in the context of health and illness to describe periods of disruption of life by illness in which structure and routine were abandoned (Little, Jordens, Paul, Montgomery, & Philipson, 1998). In this study, we adopt the term "liminal margin" to describe the first phase in the parental bereavement trajectory, from the diagnosis of the child's chronic life-limiting condition through to the final days of his or her life. The four themes that comprise this phase are elucidated below.

Theme 1: Medical relationships (Number of articles theme has appeared in: *N* = 7). Interactions with healthcare professionals were an important aspect of caring for a child with a chronic illness. In some cases, such interactions were pleasant, assisting parents in effectively maneuvering through the turmoil associated with their child's illness. For example, Berrett-Abebe, Levin-Russman, Gioiella, and Adams (2017) reported:

> And they literally, they will embrace you. If you walked up there tomorrow, they would not forget who you were, they would not forget who your child was, even though you haven't been in there in three years, and they would treat you like you were family." (p.353)

However, our review of studies also raised questions about the extent to which healthcare professionals were appropriately able to support parents through their child's illness trajectory and through bereavement. Several authors described parents' experience with an apathetic healthcare service. This included the use of medical jargon by physicians in discussing their child's illness and prognosis, as highlighted by Davies et al. (2004):

... they were explaining a lot of medical terms [that I] didn't know. I said, "Wait a

minute, time out folks, let's try this again, because I don't understand what you're

trying to say. I don't understand those big $100 words. Let's cut it down to $5

words. (p. 127)

Other authors like Price et al. (2011) noted parents' exasperation with the curative focus

of healthcare culture and the corresponding inadequacy in addressing psycho-socio-spiritual

aspects of care: "... you nearly feel like standing up and saying actually there was a child

involved here you know there's a family involved you know" (p. 1387). Meert et al. (2008)

stated that physicians' practice of concealing the child's diagnosis from parents tended to create

false hope for a better clinical outcome; rather, setting realistic expectations early on would help

parents prepare for the impending death and make informed decisions about their child's EoL

care: "If they say this kid's not gonna make it, or whatever, they need to tell the family that. The

family deserves to know that rather than being led on. It's easier to prepare" (p. 6). It appeared

that medical relationships made a meaningful impact on grieving parents when there was

emphasis on establishing a human-to-human connection but created additional stress when there

was apathy or a lack of effective communication. Parents who felt that they received respect,

sensitivity and compassion from their healthcare team found that it was a supportive resource

during the challenging liminal phase.

Theme 2: Family disarray (*N* = 6). For families of chronically ill children, life tended to

be dictated by changes in the sick child's health condition, as Titus and de Souza (2011)

explained: "We became controlled by James' blood counts and the state of his immune system...

we were so frustrated by thwarted efforts to plan family time!" (p. 455). In a world where

conversations revolved around practical issues such as medical concerns of the sick child,

financial restraints, or nurturance of healthy siblings, spouses found little or no time or energy to invest in their marriage. Davies et al. (2004) reported: "[Wife] and I had very little time and energy for each other. It seemed like all of our conversations were about practical concerns..." (p. 125). Amidst such chaotic family affairs and demands of caregiving, parents admitted that their idea of 'normalcy' had changed completely. This idea was reflected by Jordan et al. (2015):

> The children were just farmed out here and there ... we took it in turns coming home really to try and give some normality to our other children but ... family life with sick children isn't what normal people associate with family life... (p. 845)

Theme 3: Emotional upheaval (*N* = 5). The period of caring for their terminally sick child was described by authors as a disorienting and alienating experience of which parents had reluctantly become a part. Davies et al. (2004) noted the following quote: "You feel that you've been taken out of your life and put into somebody else's movie... the wrong movie" (p. 121). However, the shock and disbelief that parents experienced when they first learned about their child's health condition was gradually integrated into their lives as they carried on with daily living, as Reilly et al. (2008) described: "When we were first told the diagnosis all that you can remember really is the fact that it was terminal... but you learn to live with it..." (p. 550). In sum, the authors described parents' journey of caregiving as an emotional roller coaster whose direction was determined by the unpredictability of their child's prognosis. As Titus and de Souza (2011) put it: "Most of those hopes for a "normal" life disappeared quickly… soon we just hoped that Craig had two good days in a row" (p. 454).

Theme 4: Death contemplation (*N* = 3). The theme of death contemplation reflects the contrast between children's desire and parents' reluctance to talk about dying, as illustrated by DeCinque et al. (2006): "The kids themselves would talk about dying. The parents didn't want to

accept that. We didn't want to talk about it" (p. 76). However, with no intervention from clinical staff in facilitating such a discussion, conversation about death and dying was often left unspoken until the very end. For some families, as highlighted in the work of Foster et al. (2009), even after their child had died, parents could only speculate about what their views might have been regarding the illness or dying: "We never talked about death and dying to him... I don't think he ever knew that this was gonna take his life... I really can't say with confidence that he did" (p. 4). Authors such as DeCinque et al. (2006) emphasized that parents would have benefitted from psychoeducation regarding what to expect at the EoL, typical grief responses, and guidance for healthy coping within the current healthcare system: "I think if they (hospital staff) could get the parents on their own and explain to them the process of dying... I would have liked to have understood the process of the whole thing..." (p. 76).

Phase 2: Holding Space

The second phase of the parental bereavement trajectory was coined Holding Space, which is defined by the moment of the child's death and the varied emotions that surfaced in parents at the time. The single emerging theme from four studies that offered details of this critical and delicate period reveal the need for parents to come to terms with their loss in a holding space that is private, non-judgmental, and compassionate.

Theme 5: Nurturing the child's body (*N* = 4). The literature that was reviewed emphasized parents' need for protected time and space to continue their caregiving role after their child's death, by holding their child or dressing him/ her according to parents' wishes before the last rituals and rites. This was reflected by Price et al. (2011): "And I washed her in pink Next stuff that she wore and she was in her pink ball gown pink tights pink pants I said I'll never bury her in a nappy..." (p. 1388). It appeared that parents also wished to create lasting

tangible or intangible memories with their child after his/her death, as illustrated by Davies (2005):

> I was able to take B into the garden that they have, after she died. It was the
>
> summer and we sat under a parasol. I had tea. This was just me and my mum and
>
> we sat, as we used to in my mum's garden, and we took photos... (p. 296)

Phase 3: Navigating Losses

The third phase in the parental bereavement trajectory is characterized by the navigation between the intense emotionality of child loss, the instability of spousal and social relationships, and the need to reestablish normalcy in everyday living. Five themes of this phase emerging from the analysis are described below.

Theme 6: Anguish and responsibility (*N* = 11). In the immediate aftermath of their child's death, parents found themselves negotiating between setting aside time for their own grief expression and attending to their family and work responsibilities, as described by Barrera (2007): "I have to do my grieving on my own private time and then pull myself together so that I can carry on with my responsibilities" (p. 152). For newly bereaved parents, the anguish of losing their child was further heightened by the realization that they had lost not merely their child but also the entire world that they constructed around care provision for their child. Reilly et al. (2008) reported the following quote: "You feel really, really isolated because the circles that you've been moving in with like the hospices, doctors, the nurses, school... it's like your whole world has collapsed" (p. 551). Other authors such as Denhup (2017) reported on bereaved parents' feeling that their life had changed in so many ways that living in the absence of their child seemed like a new life altogether, as can be seen in this quote:

There's a point in my life where there is line zero ... before Joshua died [is] on top [of the line] and below [the line] Joshua died is now, here on in ... that is my new point ... day one ... There's nothing in my life that I don't think has changed. (p. 352)

Theme 7: Social disconnection (*N* = 9). The emotionally charged experience of losing a child could hardly be described to others, because of the uniqueness of the phenomenon. This in turn resulted in bereaved parents feeling isolated from their social network. For instance, Jordan et al. (2015) reported the following quote: "It's a real strange feeling everybody's going around they've no idea what situation you're in and they're just doing their everyday thing which you used to do" (p. 849). Due to a fear of provoking painful emotions, or a discomfort of talking about a deceased child, friends and relatives often avoided even mentioning the child. However, bereaved parents explained that reminiscing about their child helped them process their feelings, while avoidance made them feel as though their child had been renounced from their family simply because he or she was not physically present anymore. This was highlighted in the work of DeCinque et al. (2006): "I suppose they think that if we mention Kate it will upset us. I find it more upsetting if people don't refer to Kate, as if she is not part of the family" (p. 72). Other authors such as Gear (2014) noted that some bereaved parents felt psychologically safe in creating a physical distance between themselves and their previous social network: "I used to shop two suburbs away... I could just sit and everything would happen around me... I felt safe" (p. 178).

Theme 8: Shared understanding (*N* = 8). Reaching out to other grieving parents, with whom they can share their sense of hurt and seek validation for their emotional state, helped bereaved parents to reconcile with their loss. Reilly et al. (2008) explained: "Because you don't

have to explain what you're feeling. They know... And it helps a lot" (p. 556) Interacting with those who had been in similar circumstances such as themselves helped to reduce bereaved parents' feelings of isolation. This was discussed by Berrett-Abebe et al. (2017): "I think it's good to be able to have connection, see faces, and realize that you're not alone" (p. 353).

Theme 9: Parenting guilt (*N* = 7). Many parents recollected the period of EoL caregiving and reflected upon depriving their healthy children of parental attention and care, as can be seen in this quote from Jordan et al. (2015): *"*And I can remember sort of feeling bad at times thinking you know that they were being neglected" (p. 845). Other parents doubted that they may not be good enough providers for the surviving child amidst their own grieving. Bergstraesser et al. (2015) highlighted that some parents tended to be afraid that their surviving children may continue to struggle with their own emotions even years later: "Both of us [parents] have found a way to cope, but sometimes we have the impression that our two older kids have not worked through their grief" (p. 133). To compensate for their previous neglect, Barrera et al. (2007) reported that many bereaved parents made a conscious effort to rebuild an emotional connection with their surviving children after the death of their sick child: "...my daughter and me, we hang out a lot, we do a lot of neat things together… I think we have become very, very, very close" (p. 153).

Theme 10: Spousal collision (*N* = 5). The stress of EoL caregiving and bereavement had an adverse impact on a couple's marital relationship, as can be seen in this quote from Bergstraesser et al. (2015): "I was in a tremendous crisis, with aggression and fury, which extended over months. I was so angry, had quarrels with [husband] and raged against him even if he did not deserve it" (p. 132). Where stressors in the spousal relationship had existed even

before the diagnosis, the illness and subsequent death exacerbated the prevalent stressors. Titus
and de Souza (2011) reported the following quote:

> James' father and I had marital stress before James' illness... Two months before
> James died I found out his dad was having an affair. I do believe that affair
> happened because it was a place for James' dad to feel in control… by the time
> James' death I found out the affair was still going, so I told my husband to leave.
> (p. 455)

Hooghe et al. (2017) explained that for several couples, the process of grieving their lost
child created discord in what was already a fragile state of affairs due to differences in coping
styles between men and women: "... I'm working, and then she wants to say something... I don't
want that at that time, because... there's no way I can keep on working [if we would talk]..." (p.
5). Thus, although husbands and wives experienced the same stressful situation, they were
unable to support each other in coping with the loss. Instead, it appeared that spouses sometimes
heightened each other's distress rather than alleviating it.

Phase 4: Reconstructing Lives

The profound grief associated with the death of a child spans a lifetime. The journey from
bare survival towards personal growth and reconstruction of life among bereaved parents
involved recognizing the loss as part of the self and redefining their relationship with their
deceased child. Three themes of this phase emerging from the analysis are elucidated below.

Theme 11: Continuing bonds ($N = 11$). Parents' ability to accept their child's death,
integrate it within their redefined life, and sustain a relationship with the personhood of their
child regardless of his/her physical absence was an important aspect of reconstruction of life
after child loss. For some parents, this meant refraining from making changes to their child's

room, occasional physical contact with items associated with their child, engaging in activities that their child enjoyed, or visiting their child's grave as a gesture of reconnection. Dias et al. (2017) stated: "I have a little bear that was made out of one of his blankets like uh, kind of just cuddle with that, remember him wrapped up in it" (p. 321). For other parents, as mentioned in Foster et al. (2009), meaningful auditory and visual representations helped to affirm that their child continued to hold a position of priority within their lives: "... So every time I hear that song I always think about her... music... that was her passion" (p. 5). Further, recounting qualities that they admired in their deceased child, such as their child's love and concern for family members could also help bereaved parents to cope. Additionally, Foster et al. (2011) added that engaging in philanthropic work helped many bereaved parents to maintain a symbolic relationship with their child: "She was a competitive swimmer… and so we're still doing that. We've got a fund for a scholarship in her name" (p. 6).

Theme 13: Meaning making (*N* = 9). Ascribing a sense of meaning and purpose to their child's life and death was an important aspect of bereaved parents' acceptance of their loss, as Hynson et al. (2006) underlined: "It gives us some satisfaction to know that he was here for a purpose and that's the way we sort of look at it and we use it that way" (p. 808). It appeared that in addition to helping them maintain continuing bonds with their deceased child, engaging in philanthropic work also facilitated the process of meaning making, as can be seen in this quote from Rossetto (2014): "We'll take everything that we can, and turn it into a positive experience by taking this foundation and giving other families financial aid, and answering their questions, and trying to be there for them if we can." (p. 533). Other bereaved parents recalled their child's inspirational attributes and the mark that they had left behind despite their limited lifespan. Some also related the death of their child to a path of self-discovery and learning, as discussed by

Reilly et al. (2008): "I've been there, you know, and I've survived it, so it kind of makes you a much stronger person..." (p. 552).

Theme 13: Restorative actions (*N* = 6). A number of articles such as Bergstraesser et al. (2015) underscored that bereaved parents seek respite from their grief by keeping it aside from time to time and doing something unrelated to their child's death, such as watching a film: "Sometimes we need a break; then we might say: "Now we'll watch a movie, just any movie. Yes, we'll take a little break..." (p. 133). Others such as Barrera et al. (2007) focused on parents' tendency to distract themselves from their depressing thoughts and emotions by scheduling a large number of activities both within the home and in the work sphere: "I also do my husband's billing, laundry and stuff, but usually it works in between being in and out of the shopping and various things..." (p. 159). Distraction as a means of coping, albeit temporarily, was especially useful for father who did not receive adequate validation from their social network, as was explained by Bergstraesser et al. (2015): "I entrenched myself - over the weekends… until my wife complained and was concerned about my way of coping. And yes, she was right, I tried to catch up again; I tried hard to find a way back" (p. 132).

Discussion

This is the first known systematic study that comprehensively reviews qualitative literature on the lived experience of parents bereaved due to their child's chronic life-limiting illness. A parental bereavement experience trajectory of child loss with four distinct phases was developed. This trajectory begins from the liminal margins of a child's terminal prognosis, to holding space for the time of dying, to navigating losses associated with death and grief, and finally reconstructing lives through identifying possible pathways to restore normalcy, develop continuing bonds, and create meaning to the bereavement experience [See Figure 2]. The first

two phases are chronological in nature as they follow the illness progression from prognosis to death, while the final two phases are integrative in nature whereby parents move back and forth between phases as they gradually accommodate their loss and grief.

[Insert Figure 2 about here]

Findings from our review align with the Dual Process Model (DPM) of coping with bereavement (Stroebe & Schut, 2010). Bereaved parents oscillate between loss-oriented coping processes such as yearning and crying for their deceased child (Davies et al., 2004; Foster et al., 2011), and restoration-oriented coping processes such as discovering a hobby or going back to work and integrating their child's death into daily life (Barrera et al., 2007; DeCinque et al., 2006). Specifically, the final two phases of our model highlight that coping after child loss can alternate between focusing on the loss and grieving, and adapting to restructured life and altered relationship with the personhood of their child rather than their child's physical presence. Further, in line with the Grief To Personal Growth Model (Hogan & Schmidt, 2002), our findings emphasize the importance of being able to share one's feelings with another person honestly and without fear of judgement to facilitate progression from avoidance towards personal growth (Gear, 2014; Reilly et al., 2008). The findings highlight the significance of re-establishing familial bonds and connecting with individuals who are able to provide an empathic listening ear to bereaved parents. Finally, our findings align with viewpoints such as that of Hogan and Schmidt (2002) that bereavement can permanently transform parents' worldviews and that interventions for bereaved parents need to provide assistance in reconstructing a sense of meaning in life and rediscovering hope for the future.

Clinical and Research Implications

The reviewed literature places considerable emphasis on (1) continuing bonds with a deceased child, (2) constructing a renewed sense of meaning following the loss, (3) social isolation following the death of a child, (4) feelings of regret towards neglected healthy children, and (5) relationships with medical professionals, which can be noted from the content density of the themes. With this understanding, we draw a number of implications from the study that are elucidated below.

Continuing bonds with the deceased child. It is important for bereaved parents to keep the memory of their child alive regardless of his/her physical presence (Hynson et al., 2006; Rossetto, 2014) through engagement in meaningful activities such as helping other parents in a similar situation or engaging in philanthropic work (DeCinque et al., 2006). Practitioners working with bereaved parents can facilitate the process of continuing bonds by introducing novel interventions such as encouraging parents to write their child's biography or engage in other activities to honor their child's memory (Davies, 2004; Talbot, 2002).

Meaning-oriented conversations. Child loss can trigger a crisis of meaning for bereaved parents, and research has shown that those who are able to rediscover a sense of cognitive mastery and renewed purpose during bereavement are able to achieve positive gains from their loss (Wheeler, 2001). To facilitate parents' integration of difficult experiences into their self-narrative, meaning-oriented therapeutic techniques such as reflective journaling or the use of metaphors to capture the spirit of resilience in coping with EoL caregiving and loss can be most useful (Neimeyer, 2006a, 2006b). We encourage healthcare providers to be given adequate training on how to facilitate or support bereaved parents who would benefit from meaning-orientated conversations.

Enhancing social connectedness. The unique nature of child loss can create a wall between bereaved parents and their existing social networks (Gear, 2014; Jordan et al., 2015). An immediate solution to address this problem would be for relevant organizations to facilitate the formation of support groups with parents facing similar crises. Contact with other grieving parents can help to reduce feelings of isolation and create a safe environment for parents to share their emotionally charged experiences (Schormans, 2004; Vega, Rivera, & Gonzalez, 2014). However, a solution to address the fundamental issue would be to create public awareness and psychoeducation on how friends and family can support grieving individuals, thereby developing 'compassionate communities' to provide support to grieving individuals (Aoun, Breen, White, Rumbold, & Kellehear, 2018).

Fostering bonds with surviving children. Unintended neglect towards other healthy children during the period of caring for the terminally ill child and during the early bereavement period when parents are overwhelmed by their own grief can result in feelings of regret (Grinyer, 2012; Olson-Garriott, Gamino, Davies, & Gudmundsdottir, 2015). Other research has found that siblings of terminally ill children may demonstrate emotional and behavioral problems over time, because of their needs being overlooked (Ballard, 2004). Provision of psychoeducation and support for parents at the time of caregiving and during bereavement could play an important role in enhancing siblings' well-being, by drawing attention to their needs and focusing on strategies to help them cope (DeCinque et al., 2006). Programs and support groups catered towards siblings of sick and/or deceased children would also serve to reduce isolation and provide healthy siblings with a network of peers in similar circumstances.

Enhanced parental-professional alliance. Relationships with medical professionals can be an important source of support or a major stressor for parents of terminally ill children

(Davies, Baird, & Gudmundsdottir, 2013; Jordan et al., 2015; Meert et al., 2008). There has been some discussion on the need for greater awareness and training amongst medical professionals to manage appropriately the needs of grieving parents (Price & Jones, 2015). Hospitals can also help connect parents with trained counselors (psychological and emotional support), self-help groups (social support with other bereaved parents), voluntary organizations (educational and pragmatic assistance), and day care services (social activities and support to patients and families), thereby providing a more holistic and seamless healthcare service (Ho & Tan, 2016). Provision of psycho-emotional support services as early as terminal prognosis, and throughout the treatment process, would be helpful for parents to smoothly transition to bereavement (Tan, Docherty, Barfield, & Brandon, 2012). Continued psychosocial care from the hospital can also be an important source of support for the bereaved family even several months after their child has died (Berrett-Abebe, Levin-Russman, Gioiella, & Adams, 2017; Lichtenthal et al., 2015).

Future directions for research. Through our systematic search of the six major databases, we found fewer than 100 studies investigating the experience of parents who have lost their child and youth due to terminal illness, which reflects the dearth of academic investigations within this subject area. Further, within this scarce body of literature, no qualitative or quantitative study was found that examined parental bereavement due to chronic illness and death of one's child among Asian participants. One qualitative study was found which explored the influence of culture on parental bereavement experience in Chinese families (Ho & Brotherson, 2007). Specifically, the authors suggested that some aspects of child death are universal in nature, but culture may also play an important role in shaping the experience of loss and coping. However, this study was excluded from the analysis since it did not meet all aspects of our quality assessment criteria. This then means that the unique needs and experiences of

bereaved parents in Asia remain generally unknown, which is a worrisome finding because of the extent of the death taboo in Asia, especially when the death concerned is that of children and youth (Ho & Chan, 2011). We recommend that future research to address this knowledge gap be prioritized, so that this vulnerable group can be supported in ways that are culturally appropriate and meaningful. Moreover, much of the research obtained through the systematic search represented the voices of bereaved mothers. It would be useful for future studies to focus on the experiences of bereaved fathers. Additionally, keeping in view the stresses of caregiving and bereavement that parents are presented with and gender differences in coping with such stress, it would be useful for future research to examine mother-father dyads and the evolving transactional patterns within a couple's relationship through the parental bereavement experience trajectory, to enhance knowledge about how couples can be supported to during such times. Finally, research could also explore ways in which internet technology can be creatively harnessed to provide continued support to bereaved parents, perhaps through journaling applications or online counseling.

Limitations and Conclusion

Despite its merits, this study is not without its limitations. The systematic review only includes studies that had at least a partial qualitative component; a range of articles with potential supportive data was omitted because of their purely quantitative nature. Although the use of thematic synthesis for data analysis allowed for emphasis on the lived experience of respondents, the construction of meaningful chronological phases and themes is susceptible to the researchers' own subjectivity, despite a high level of inter-researcher consensus. The authors of the primary studies included in our review may have chosen to report merely those themes that they deemed significant; failure to identify a salient thematic category in our review does not necessarily deny

its existence. Further, the application of stringent inclusion/exclusion criteria implied that studies that did not fit within the scope of this review were screened out at the earliest point of detection; but it is possible that some of these excluded studies contained pertinent information relevant to the objective of this study.

Despite these limitations, this study provides support for employing the PRISMA guidelines and method of thematic synthesis to systematically review a body of qualitative research. It comprehensively consolidates existing research to form a refined systematic understanding of the different phases of emotional, psychological and relational experiences of parents bereaved by child loss due to chronic illness. Further, it proposes a novel four-phase trajectory beginning from the time of a child's terminal prognosis, through the phases of death and bereavement, and finally reaching the phase of reconstructing lives via restoring normalcy, establishing continuing bonds and meaning making. Finally, this study offers practical recommendations for enhancing clinical practice and points out research gaps that need to be addressed in future to better support those facing the trauma of their child's death because of life-limiting illness.

References

Aoun, S. M., Breen, L. J., White, I., Rumbold, B., & Kellehear, A. (2018). What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach. *Palliative Medicine*, 1–11. https://doi.org/10.1177/0269216318774995

Attig, T. (2004). Disenfranchised Grief Revisited: Discounting Hope and Love. *OMEGA - Journal of Death and Dying*, *49*(3), 197–215. https://doi.org/10.2190/p4tt-j3bf-kfdr-5jb1

Ballard, K. L. (2004). Meeting the needs of siblings of children with cancer. *Pediatric Nursing*, *30*(5), 394–401. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/15587532

Barrera, M., D'Agostino, N. M., Schneiderman, G., Tallett, S., Spencer, L., & Jovcevska, V. (2007). Patterns of parental bereavement following the loss of a child and related factors. *Omega*, *55*(2), 145–167. https://doi.org/10.2190/OM.55.2.d

Barrera, M., O'Connor, K., D'Agostino, N. M., Spencer, L., Nicholas, D., Jovcevska, V., … Schneiderman, G. (2009). Early Parental Adjustment and Bereavement After Childhood Cancer Death. *Death Studies*, *33*(6), 497–520. https://doi.org/10.1080/07481180902961153

Bergstraesser, E., Inglin, S., Hornung, R., & Landolt, M. A. (2015). Dyadic coping of parents after the death of a child. *Death Studies*, *39*(1-5), 37–41. https://doi.org/10.1080/07481187.2014.920434

Berrett-Abebe, J., Levin-Russman, E., Gioiella, M. E., & Adams, J. M. (2017). Parental experiences with a hospital-based bereavement program following the loss of a child to cancer. *Palliative and Supportive Care*, *15*, 348–358.

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO. *Qualitative Health Research*, *22*(10), 1435–1443. https://doi.org/10.1177/1049732312452938

Davies, B., Baird, J., & Gudmundsdottir, M. (2013). Moving family-centered care forward: Bereaved fathers' perspectives. *Journal of Hospice and Palliative Nursing: JHPN: The Official Journal of the Hospice and Palliative Nurses Association*, *15*(3), 1–12.

https://doi.org/10.1097/NJH.0b013e3182765a2a

Davies, B., Gudmundsdottir, M., Worden, B., Orloff, S., Sumner, L., & Brenner, P. (2004). "'Living in the

dragon's shadow'": Fathers' experiences of a child's life-limiting illness. *Death Studies*, *28*,

111–135. https://doi.org/10.1080/07481180490264501

Davies, R. (2004). New understandings of parental grief: Literature review. *Journal of Advanced Nursing*,

46(5), 506–513.

DeCinque, N., Monterosso, L., Dadd, G., Sidhu, R., Macpherson, R., & Aoun, S. (2006). Bereavement

support for families following the death of a child from cancer: Experience of bereaved parents.

Journal of Psychosocial Oncology, *24*(2), 65–83. https://doi.org/10.1300/J077v24n02

Dias, N., Docherty, S., & Brandon, D. (2017). Parental bereavement: Looking beyond grief. *Death

Studies*, *41*(5), 318–327. https://doi.org/10.1080/07481187.2017.1279239

Doka, K. J. (2005). Ethics, end-of-life decisions and grief. *Mortality*, *10*(1), 83–90.

https://doi.org/10.1080/13576270500031105

Foster, T. L., Gilmer, M. J., Davies, B., Barrera, M., Fairclough, D., Vannatta, K., & Gerhardt, C. A.

(2009). Bereaved parents' and siblings' reports of legacies created by children with cancer. *Journal

of Pediatric Oncology Nursing: Official Journal of the Association of Pediatric Oncology Nurses*,

26(6), 369–376. https://doi.org/10.1177/1043454209340322

Foster, T. L., Gilmer, M. J., Davies, B., Dietrich, M. S., Barrera, M., Fairclough, D. L., … Gerhardt, C. A.

(2011). Comparison of continuing bonds reported by parents and siblings after a child's death from

cancer. *Death Studies*, *35*(5), 420–440. https://doi.org/10.1080/07481187.2011.553308

Gear, R. (2014). Bereaved parents' perspectives on informal social support: "What worked for you?"

Journal of Loss & Trauma, *19*(2), 173–188. https://doi.org/10.1080/15325024.2013.763548

Grinyer, A. (2012). A bereavement group for parents whose son or daughter died from cancer: How

shared experience can lessen isolation. *Mortality*, *17*(4), 338–354.

https://doi.org/10.1080/13576275.2012.730684

Ho, A. H. Y., & Chan, C. L. W. (2011). Liberating dying people and bereaved families from the

oppression of death and loss in Chinese societies: A public health approach. *Governing Death and Loss: Empowerment, Involvement and Participation*, 119–127.

Ho, A. H. Y., & Tan, G. X. L. (2016). Protecting dignity at the end of life. *Handbook of Social Justice in Loss and Grief: Exploring Diversity, Equity, and Inclusion*, 100–108.

Hogan, N. S., & Schmidt, L. A. (2002). Testing the Grief To Personal Growth Model Using Structural Equation Modeling. *Death Studies*, *26*(8), 615–634. https://doi.org/10.1080/07481180290088338

Ho, S., & Brotherson, S. E. (2007). Cultural influences on parental bereavement in Chinese families. *Omega: Journal of Death and Dying*, *55*(1), 1–25. https://doi.org/10.2190/4293-202L-5475-2161

Hynson, J. L., Aroni, R., Bauld, C., & Sawyer, S. M. (2006). Research with bereaved parents: A question of how not why. *Palliative Medicine*, *20*(8), 805–811. https://doi.org/10.1177/0269216306072349

Janoff-Bulman, R. (2010). *Shattered Assumptions: Towards a New Psychology of Trauma*. New York: Simon and Schuster.

Jordan, J., Price, J. E., & Prior, L. (2015). Disorder and disconnection: Parent experiences of liminality when caring for their dying child. *Sociology of Health & Illness*, *37*(6), 839–855. https://doi.org/10.1111/1467-9566.12235

Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., … Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: Explanation and elaboration. *PLoS Medicine*, *6*(7), e1000100.

Lichtenthal, W. G., Sweeney, C. R., Roberts, K. E., Corner, G. W., Donovan, L. A., Prigerson, H. G., & Wiener, L. (2015). Bereavement follow-up after the death of a child as a standard of care in pediatric oncology. *Pediatric Blood & Cancer*, *62*, S834–S869. https://doi.org/10.1002/pbc.25700

Little, M., Jordens, C. F. C., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: A major category of the experience of cancer illness. *Social Science & Medicine*, *47*(10), 1485–1494.

Meert, K. L., Eggly, S., Pollack, M., Anand, K. J. S., Zimmerman, J., Carcillo, J., … National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network. (2008). Parents' Perspectives on Physician-Parent Communication near the Time of a Child's Death

in the Pediatric Intensive Care Unit. *Pediatric Critical Care Medicine*, *9*(1), 2–7.

Neimeyer, R. A. (2006a). Bereavement and the quest for meaning: Rewriting stories of loss and grief.

Hellenic Journal of Psychology, *3*(3), 181–188.

Neimeyer, R. A. (2006b). Narrating the dialogical self: Toward an expanded toolbox for the counselling

psychologist. *Counselling Psychology Quarterly*, *19*(1), 105–120.

https://doi.org/10.1080/09515070600655205

Olson-Garriott, A. N., Gamino, L. A., Davies, E. B., & Gudmundsdottir, M. (2015). Having or adopting

another child: Perspectives from bereaved fathers. *Professional Psychology, Research and Practice*,

46(5), 317–324. https://doi.org/10.1037/pro0000026

Patton, G. C., Coffey, C., Sawyer, S. M., Viner, R. M., Haller, D. M., Bose, K., … Mathers, C. D. (2009).

Global patterns of mortality in young people: A systematic analysis of population health data. *The

Lancet*, *374*(9693), 881–892. https://doi.org/10.1016/S0140-6736(09)60741-8

Price, J. E., & Jones, A. M. (2015). Living through the life-altering loss of a child: A narrative review.

Issues in Comprehensive Pediatric Nursing, *38*(3), 222–240.

https://doi.org/10.3109/01460862.2015.1045102

Reilly, D. E., Huws, J. C., Hastings, R. P., & Vaughan, F. L. (2008). "When your child dies you don't

belong in that world any more" - Experiences of mothers whose child with an intellectual disability

has died. *Journal of Applied Research in Intellectual Disabilities: JARID*, *21*(6), 546–560.

https://doi.org/10.1111/j.1468-3148.2008.00427.x

Rossetto, K. R. (2014). Creating philanthropic foundations to deal with grief: Case studies of bereaved

parents. *Death Studies*, *38*(8), 531–537. https://doi.org/10.1080/07481187.2014.899652

Schormans, A. F. (2004). Experiences following the deaths of disabled foster children: "We don't feel like

'foster' parents." *Omega - Journal of Death and Dying*, *49*(4), 347–369.

Schwab, R. (1992). Effects of a child's death on the marital relationship: A preliminary study. *Death

Studies*, *16*(2), 141–154. https://doi.org/10.1080/07481189208252564

Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavement: A decade on.

OMEGA-Journal of Death and Dying, *61*(4), 273–289.

Swingler, G. H., Volmink, J., & Ioannidis, J. P. A. (2003). Number of published systematic reviews and global burden of disease: Database analysis. *BMJ* , *327*(7423), 1083–1084.

Talbot, K. (2002). *What Forever Means After the Death of a Child: Transcending the Trauma, Living with the Loss*. New York: Brunner-Routledge. Retrieved from https://market.android.com/details?id=book-ItTZf5I9oxwC

Tan, J. S., Docherty, S. L., Barfield, R., & Brandon, D. H. (2012). Addressing parental bereavement support needs at the end-of-life for infants with complex chronic conditions. *Journal of Palliative Medicine*, *15*(5), 579–584. https://doi.org/10.1089/jpm.2011.0357

Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry*, *15*(1), 1–18.

Thomas, J. D., & Harden, A. D. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8:45*, 1–10. https://doi.org/10.1186/1471-2288-8-45

Titus, B., & de Souza, R. (2011). Finding meaning in the loss of a child: Journeys of chaos and quest. *Health Communication*, *26*(5), 450–460. https://doi.org/10.1080/10410236.2011.554167

Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., & Barker, K. (2014). Meta-ethnography 25 years on: Challenges and insights for synthesizing a large number of qualitative studies. *BMC Medical Research Methodology*, *14*, 80. https://doi.org/10.1186/1471-2288-14-80

Vega, P., Rivera, M. S., & Gonzalez, R. (2014). When grief turns into love: Understanding the experience of parents who have revived after losing a child due to cancer. *Journal of Pediatric Oncology Nursing: Official Journal of the Association of Pediatric Oncology Nurses*, *31*(3), 166–176. https://doi.org/10.1177/1043454213515547

Wheeler, I. (2001). Parental bereavement: The crisis of meaning. *Death Studies*, *25*(1), 51–66. https://doi.org/10.1080/07481180126147

Williams, M. (2002). *Making sense of social research*. London: SAGE Publications Inc.

You, D., Wardlaw, T., Salama, P., & Jones, G. (2010). Levels and trends in under-5 mortality, 1990-2008.

The Lancet, *375*(9709), 100–103. https://doi.org/10.1016/S0140-6736(09)61601-9

Table 1

Overview of studies included for data analysis

(Author, year) Country	Aim	Design, data analysis and quality assessment	Sample
(Barrera et al., 2007) Canada	To investigate patterns of parental bereavement.	Mixed methods design with semi-structured interviews and content analysis. Trustworthiness achieved through data triangulation. Ethical approval reported.	N=13 mothers + 7 fathers. Child death due to cancer, congenital heart disease, meningitis, or drowning in the last 19 months.
(Bergstraesser et al., 2015) Switzerland	To explore grief processes of bereaved parents putting particular focus on dyadic coping.	Mixed methods design with in-depth interviews and content analysis. Trustworthiness achieved through inter rater reliability and member checking. Ethical approval reported.	N=23 parent units. Child death due to oncological and non-oncological life-limiting disease 12 months to 5 years prior to interview.
(Berrett-Abebe et al., 2017) USA	To understand how parents experienced participating in a hospital-based bereavement support program.	Focus group discussion with phenomenological analysis. Rigor achieved by investigator and interdisciplinary triangulation. Ethical approval reported.	N=6 mothers + 2 fathers. Child death due to cancer in the last 1 to 6 years.
(Corden, Sloper, & Sainsbury, 2002) UK	To investigate the financial circumstances of bereaved parents.	Semi-structured interviews with framework analysis. Rigor achieved by inter-researcher consensus on finalization of data charts. Ethical approval reported.	N=12 parent units +4 mothers. Child death to oncological and non-oncological life-limiting disease in the last 2 years.
(Davies et al., 2004) USA	To generate descriptions and theoretical explanations of the experiences of fathers whose children were diagnosed with irreversible illness from diagnosis, death and bereavement.	In-depth unstructured interviews with grounded theory analysis. Credibility achieved via members checking and maintaining an audit trail. Ethical approval reported.	N=8 fathers. Child death due to cancer, spinal muscular atrophy, and Tay Sachs in the last 12 to 36 months.
(Davies et al., 2013) USA	To describe fathers' perspectives of professional care provided to the ill child and the family as a whole during the	In-depth interviews, field notes, genograms, and reflexive journaling with grounded theory analysis. Rigor achieved by inter-researcher consensus on	N=60 fathers. Child death due to life-limiting illnesses such as cancer, genetic disorders and heart disease 3 to 36 months prior to interview.

	illness and through the dying process.	interpretations of findings and conceptual models. Ethical approval reported.	
(Davies, 2005)

UK | To explore bereaved mothers' stories of loss and their lived experiences of their child's EoL life care. | Open and non-directive interviews with hermeneutic analysis. Rigor achieved by maintaining an audit trail and documenting the process of data analysis in detail. Ethical approval reported. | N=10 mothers. Child death due to life-limiting condition in the last 3 years. |
| (DeCinque et al., 2006)

Australia | To explore the experiences and needs of parents who received hospital-based bereavement support. | Unstructured interview with thematic analysis. Inadequate information to assess methodological rigor. Ethical approval reported. | N=9 parent units. Child death due to cancer between Jan 1997 and Dec 1998. |
| (Denhup, 2017)

USA | To describe the lived experience of bereaved parents who experienced the death of a child due to cancer. | In-depth interviews with phenomenological analysis. Rigor achieved by prolonged engagement with the data, triangulation, peer debriefing and member checking. Ethical approval reported. | N=5 mothers + 1 father. Child death due to cancer at least 1 year before the interview. |
| (Dias et al., 2017)

USA | To examine parental bereavement challenges during the first six months following the death of their child. | Individual interviews with content analysis. Ethical approval reported. | N= 5 mother + 5 fathers. Child death due to complex chronic conditions 6 months before the interview. |
| (Foster et al., 2009)

USA | To explore bereaved parents' and siblings' reports of legacies created by children. | Open-ended interview with content analysis. Trustworthiness achieved through inter-researcher consensus on coding scheme and member checking. Ethical approval reported. | N=36 mothers +24 fathers. Child death due to advanced cancer. |
| (Foster et al., 2011)

USA | To examine how family members experience continuing bonds within the first year of a child's death. | Mixed methods design, semi-structured interview with content analysis. Trustworthiness achieved through inter-researcher consensus on coding scheme and member checking. Ethical approval reported. | N=36 mothers +24 fathers. Child death due to cancer. |

(Gear, 2014) Australia	To identify and explore the informal social supports that bereaved parents found helpful following the death of their child.	Semi structured interview with content and thematic analysis. Inadequate information to assess methodological rigor. Ethical approval NOT reported.	N=7 mothers +3 fathers. Child death due to brain tumor, leukemia, non-Hodgkin lymphoma, and genetic disorders in the last 4-11 years.
(Grinyer, 2012) UK	To analyze the content of a session of a parental bereavement support group.	Support group recordings with qualitative fortuitous method of analysis. Accuracy of translation and data interpretation achieved through inter-researcher consensus. Ethical approval reported.	N=3 parent units +2 mothers. Child death due to cancer.
(Hooghe, Rosenblatt, & Rober, 2017) Belgium	To examine the different meanings and processes related to talking and not talking with the partner about personal grief experiences after the loss of a child.	In-depth interview with thematic analysis. Inadequate information to assess methodological rigor. Ethical approval NOT reported.	N=12 couples + 2 lone mothers. Child death due to cancer.
(Hynson et al., 2006) Australia	To explore the impact of the research process on bereaved parents, and to identify what elements enhance the experience of research participation.	In-depth interview with thematic analysis. Inadequate information to assess methodological rigor. Ethical approval reported.	N=45 mothers +24 fathers. Child death due to chronic progressive condition.
(Jordan et al., 2015) Ireland	To explore the experiences of parents caring for their dying children throughout the illness trajectory and subsequent death.	Face-to-face interviews with interpretative analysis. Rigor achieved through comprehensive treatment of all data, identification of deviant cases and memo writing. Ethical approval NOT reported.	N=16 mothers + 9 fathers. Child death due to both malignant and non-malignant conditions in the last 24 months.
(Meert et al., 2008) USA	To describe parents' perceptions of their conversations with ICU physicians regarding their child's terminal illness and death.	Semi-structured telephone interviews with qualitative analysis. Inadequate information to assess methodological rigor. Ethical approval reported.	N=39 mothers +7 fathers. Child death due to terminal illness 3-12 months prior to interview.

(Olson-Garriott et al., 2015) USA	To understand the experience of fathers who went on to have a subsequent child after losing a child in pediatric palliative care.	In-depth semi structured interviews with phenomenological analysis. Inadequate information to assess methodological rigor. Ethical approval NOT reported.	N=11 fathers. Child death in a hospital or hospice 3-6 months prior to interview.
(Price, Jordan, Prior, & Parkes, 2011) UK	To explore parents' experiences of caring for dying children with throughout the illness and subsequent death.	Semi-structured in-depth interviews with interpretive qualitative approach to identify common themes and processes. Relevant procedures (Silverman, 2006) to address the validity and reliability of the analysis. Ethical approval reported.	N=6 mothers +9 fathers. Child death due to life limiting condition 6-24 prior to interview.
(Reilly et al., 2008) UK	To explore bereavement experiences of mothers who lose a child with an intellectual disability.	Semi-structured interviews with interpretative phenomenological analysis. Inadequate information to assess methodological rigor. Ethical approval reported.	N=9 mothers. Death of child with intellectual disability at least 12 months prior to interview. The authors argue that parents of children with intellectual deficit are likely to outlive their children, encounter a range of stressors associated with their child's current and future medical and personal needs and suffer from greater mental health problems than parents of typically developing children.
(Rossetto, 2014) USA	To explore meaning making and philanthropic behaviors of bereaved parents' following the deaths of their children.	In-depth interviews with narrative analysis. Inadequate information to assess methodological rigor. Ethical approval NOT reported.	N=7 mothers +4 fathers. Child death due to different causes (only data from death due to cancer has been included).
(Schormans, 2004) Canada	To understand foster parents' experience of the death of a foster child with disabilities.	Semi-structured interviews with grounded theory analysis. Trustworthiness achieved by lengthy, rich and descriptive interviews, peer debriefing and member checking. Ethical approval NOT reported.	N=6 mothers +2 fathers. Child death due multiple disabling conditions, many of which are known to be terminal 2-14 years prior to interview.
(Titus & de Souza, 2011)	To explore parents' experiences of grief	Written/ typed responses to questions with qualitative analysis. Inadequate	N=9 mothers +1 father.

	before and after the death of their child.	information to assess methodological rigor. Ethical approval NOT reported.	Child death due to unstated type of terminal prognosis. 1–5 years prior to interview.
USA			
(Vega et al., 2014) Chile	To understand the lived experiences that help parents to revive after the death of their child due to cancer.	In-depth interview with phenomenological analysis. Inadequate information to assess methodological rigor. Ethical approval reported.	N=3 mothers +5 fathers. Child death due to cancer at least 1 year prior to interview.