

RESEARCH ARTICLE



Hiding in Plain Sight: A Narrative Review of Non-Parental Relatives' Perinatal Grief

Rennie Bimman^a and Nancy Graham^b

^aDivision of Palliative Care and Geriatric Medicine, Massachusetts General Hospital, Boston, Massachusetts, USA; ^bPalliative Care, Ottawa, Ontario, Canada

ABSTRACT

Perinatal loss is often immensely painful for families, yet remains unrecognized despite its ubiquity. Perinatal loss frequently leads to disenfranchised grief, and members of family systems less proximate to the loss are at risk for additional disenfranchisement. Grandparents and siblings are especially vulnerable to complications in perinatal grief due to intersecting and disenfranchising factors of identity, including age, role within family, and type of loss. The purpose of this narrative review was to examine their experiences in order to provide informed support. Medline via OVID was searched using specific terms to identify articles for inclusion. Content from each article was screened, synthesized, and codified according to salient themes. Evidence found attested to the uniquely complex grief experiences these populations face as a result of their confluent disenfranchisement, and their overwhelming lack of support and recognition. New insights uncovered may inform clinicians as they assess needs and provide support to these oft-ignored grievers. Significant research gaps remain in this subtopic, such as firsthand perspectives of nonparental grievers, data on other extended family members, and the effect of additional psychosocial stressors on nonparental perinatal grief. As recent legal restrictions curtail reproductive healthcare access, the need for support and research is especially salient.

KEYWORDS

Abortion; grandparents; grief; perinatal loss; siblings

Introduction

The devastating impact of perinatal loss on individuals and families is concerningly underestimated. Perinatal loss is an “umbrella” term for experiences of pregnancy loss and infant death occurring before or shortly following birth and can include miscarriage, stillbirth, elective abortion, and neonatal death (Al-Maharma et al., 2016). Miscarriage occurs before the 20th week of pregnancy, and stillbirth is defined as the death of a fetus after 20 weeks (Searing, 2022; Stanford Medicine Children's Health, 2024).

CONTACT Rennie Bimman, BSW, MSW, LICSW  rbimman@mgh.harvard.edu  Division of Palliative Care and Geriatric Medicine, Massachusetts General Hospital, Boston, MA, USA

© 2025 Taylor & Francis Group, LLC

At least 1 in 4 pregnancies end in miscarriage; however, this number may be as high as 2 in 4, due to underreporting as well as unawareness of pregnancy in early stages (Searing, 2022). UNICEF (2023) reports that approximately 1.9 million babies, or one every 16 seconds, were stillborn in 2021. Rates of stillbirth skew higher across low- and middle-income countries and in rural areas (Burden et al. 2016; Cleveland Clinic, 2023). Four million neonatal deaths occur annually (Sisay et al, 2014), and stillbirth and neonatal mortality combined constitute almost half of annual global child deaths under five years of age (Sisay et al., 2014; World Health Organization [WHO], 2024a). Despite modern medical innovations, perinatal loss remains shockingly common (Burden et al., 2016). It is crucial to include elective abortion in discussion of perinatal loss. This type of loss engenders grief as readily as any other, and yet those grieving it are too often invalidated and even actively harmed in their experiences (Nichols, 1989). Three in 10 pregnancies, globally, end in induced abortion (WHO, 2024b). Lack of legal access to abortion care and support further complicates these experiences (WHO, 2024b). Perinatal loss of all types is underreported, and unrecognized despite its staggering frequency (Al-Maharma et al., 2016; Burden et al., 2016; Desai et al., 2021; Sisay et al., 2014). It remains under-prioritized as a global health concern (Burden et al., 2016; Simelala, 2024; Sisay et al., 2014; UNICEF, 2023).

Perinatal loss can be a debilitating experience. A range of emotional, psychological, behavioral and social consequences of grief have been observed in parents, including social disconnectedness, difficulty functioning, generalized anxiety disorder, depression, intimate partner violence, self-esteem challenges, and substance use, in the immediate aftermath and years following a perinatal loss (Al-Maharma et al., 2016; Burden et al., 2016). Parents may be at risk for prolonged grief disorder, which impairs basic functioning for over six months, or conversely, may consciously or subconsciously suppress grief, which can result in compounded reactions later (Al-Maharma et al., 2016). These intensified and complex emotional reactions unfortunately exemplify the consequences of disenfranchised grief, defined by Doka (1989) as “the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported” (p. 4). Perinatal loss is a seminal example of disenfranchised grief. Its inherent lack of societal recognition and validation dangerously complicates and compounds the experiences of grieving families (Burden et al., 2016; Nichols, 1989).

Calls for support of bereaved parents experiencing this profoundly invisible loss are gaining currency. Awareness is especially growing of the particularly damaging consequences for mothers, as complicated by hormonal and physiological factors present during the initial bereavement period (Tran et al., 2023). Fathers are at times acknowledged for their doubly disenfranchised

positionality and lack of recognition as grieving parents (Burden et al., 2016), as mothers tend to receive any available attention. For family members other than parents, the under-recognition of perinatal grief is exponentially higher. When nonparental griever are discussed in the context of perinatal loss, they are often identified in terms of providing support to the parental griever, without reference to their own grief experiences (Clarke, 2015; Fenstermacher & Hupcey, 2019). Without recognition of their own valid grief within family systems, these individuals may remain invisible, unsupported, and fundamentally disenfranchised.

Not only is the relative familial positionality of nonparents, especially grandparents and siblings, a risk factor in their disenfranchisement, their typical chronological age is also predictive of this. Grandparents and siblings are often respectively very old and very young, and Doka (2002) highlighted that “despite evidence to the contrary, both the very old and the very young are typically perceived by others as having little comprehension of or reaction to the deaths of significant others” (p. 13). As a result, they are “excluded from discussions and rituals concerning the loss” (Doka, 2002, p. 13). Given that disenfranchisement can lead to more complicated and challenging grief experiences, and that their identity as griever of perinatal loss is under-recognized both because of their family roles and their ages, it can be presumed that nonparental relatives may also be at great risk in perinatal bereavement.

Nonparental griever may be at significant risk of suffering in silence, and in dire need of support. Grief inevitably uniquely affects not only individuals within a family but the functioning of the family system as a unit (Delalibera et al., 2015; Glatt, 2018). This review is informed by the theoretical constructs of disenfranchised grief (Doka, 2002), and of intersectionality, pioneered by Crenshaw (1991), which examines how multiple axes of marginalization can combine and compound experiences of oppression. The importance of the perspective of intersectionality has been emphasized with regard to how systemic inequities impact, challenge, and disenfranchise grief experiences: suffering and invisibility in grief is increased for those with marginalized identities, and compounded by social norms devaluing certain losses (Sawyer, 2023). This review sought to establish new insight on the multifactorial nexus on which the disenfranchisement of perinatal loss, the disenfranchisement of older and younger individuals, and the disenfranchisement of nonparents within family systems, may intersect to complicate grief experiences. Given that informed, individualized support is crucial in healthy experiences of grief (Glatt, 2018; Turner & Stauffer, 2023), it is imperative to understand the experiences of non-parental griever in order to best support them. Therefore, this research aimed to investigate the present state of knowledge on this under-addressed phenomenon.

Purpose statement

Given the limited knowledge on and the significance of the experiences and needs of nonparental family members grieving perinatal loss, the purpose of this review is:

1. To summarize and categorize the available literature on the grief experiences of nonparental relatives (NPRs) experiencing perinatal loss (PL)
2. To describe themes, similarities, and information about the nature of these experiences
3. To examine the implications of these themes for clinicians (including healthcare practitioners in medical settings, grief professionals, and others, across disciplines) supporting individuals and families in their grieving process following perinatal loss

Methods

The present narrative review utilized the SANRA standards developed by Baethge et al. (2019) to consolidate and interpret a range of relevant literature on the perinatal loss experiences of nonparental griever and to determine gaps in existing knowledge.

A computer-assisted search of the literature was conducted in MEDLINE via Ovid (1946 to present) in February 2024. The following search strategy was used in Medline. All publication types, including case reports and conference abstracts, were included in the search. A manual search through reference lists in the reviewed articles was also conducted.

Search strategy

A comprehensive list of search terms was developed encompassing the following three concepts: perinatal loss, nonparental relatives, and grief. Please see [Appendix A](#) for all keywords and subject headings used in these searches.

Inclusion and exclusion criteria

Peer-reviewed literature was considered appropriate for inclusion in this review if the article included specific content focused on the perinatal loss experiences of nonparental familial griever. “Perinatal loss” was operationalized as pregnancy and infant loss occurring at any point before birth, and up to one year following birth. Articles referencing any losses in the NICU were included. Articles discussing the deaths of children

older than one year were excluded. “Nonparental” was limited to family members, and did not include professionals experiencing their clients’ perinatal losses. Studies were included that collected original quantitative or qualitative data, as were personal or professional commentaries, perspectives, and opinion pieces. There were no geographic limitations regarding publication location. Only articles available in English or French were included. Data parameters were set from January 2000 to February 2024 to focus on the most current research published in this area.

Data extraction

As presented in Figure 1, the database search resulted in 386 unique titles and abstracts. 3 additional sources were obtained through citation searching, resulting in a total of 389 unique titles and abstracts. Both authors then screened each title and abstract independently. Cases of discrepancy were discussed together by both evaluators to determine consensus on eligibility. This initial title and abstract screening yielded 54 articles considered suitable for full-text review. 335 articles were excluded during this screening process because the content of their title and abstract did not

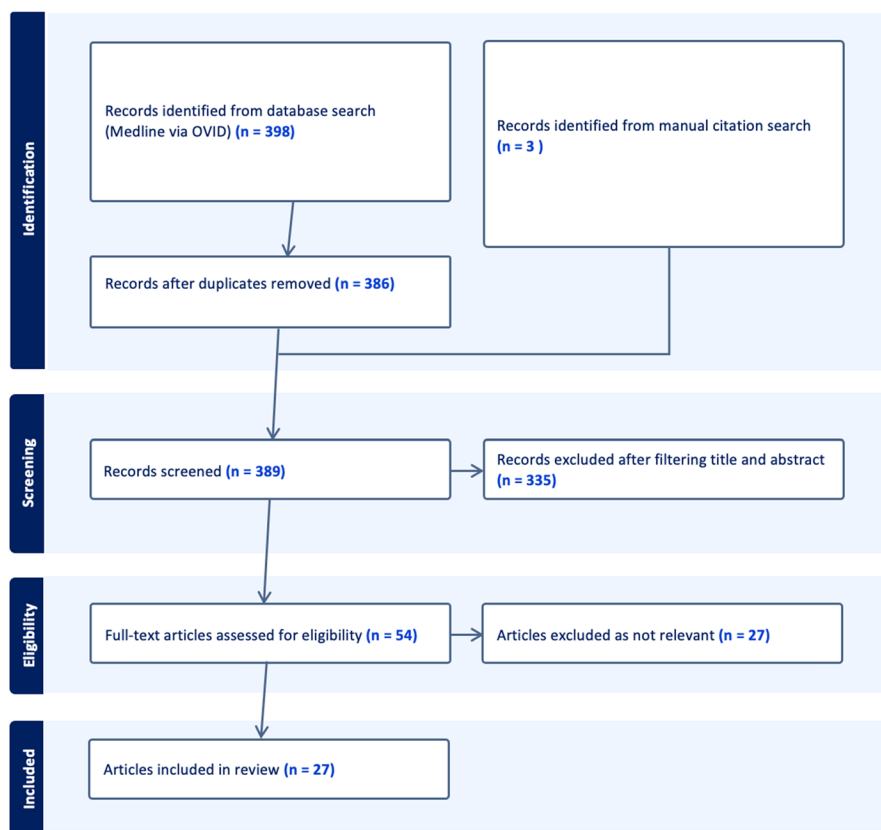


Figure 1. Flow diagram for the identification of articles, inclusion and exclusion screening.

indicate a specific focus on the perinatal loss experiences of nonparental relatives, and was therefore not within the scope of the present review. The full text of these 54 articles was then independently screened by both authors, via the above process. A total of 27 articles ultimately met inclusion criteria and were designated for data extraction. 27 other articles were excluded following this full-text review as their content did not appropriately meet criteria for the current review.

Information from each of the 27 full-text articles identified for review was tabulated in a word processor, indicating: the type of reference (i.e., research article, editorial, etc.), methodological approach (i.e., qualitative/quantitative/mixed methods, etc.), the sample population (i.e., siblings, grandparents, or both), followed by unstructured field notes by author [RB] focusing on key findings, insights, major themes, and unique aspects of each article. An inductive process followed to develop and define overall themes: ideas which recurred throughout multiple articles ($n = >4$) were tabulated as data was extracted. Nine substantive themes were identified that appeared consistently throughout the articles (see results below): attention to parents' grief; continuing bonds and attachment in grief; grief experiences and emotions; unique dimensions of grief; changes to identity, roles, and family systems; influence of developmental and life stages; gender; culture, religion, spirituality, and ritual; need for support. Some themes were established through combining ideas from the author's field notes—for example, "unique dimensions of grief" was created by fusing former sub-themes of "disenfranchised grief," "ambiguous loss," and "population-specific grief reflections." The nine themes were then formally defined and operationalized. The themes, with their working definitions as operationalized during this phase of the extraction process are depicted in [Table 1](#). Each article was then reviewed again, and specific details on each theme as mentioned in each article were documented in a spreadsheet. Included articles are named and mapped to themes in [Table 2](#).

Results

The specific content that supports each of the nine themes identified: attention to parents' grief; continuing bonds and attachment in grief; grief experiences and emotions; unique dimensions of grief; changes to identity, roles, and family systems; influence of developmental and life stages; gender; culture, religion, spirituality, and ritual; need for support; is described in each corresponding section below. This review sought to explore the perinatal grief experiences of nonparental family members. The literature predominantly revealed a focus on grandparents and siblings with little attention to other family members. The themes discussed herein therefore specifically relate to grandparent and sibling experiences of grief.

Table 1. Coding legend of themes identified in this review, as defined for data extraction process.

Theme alphabetization	Definition and description
Theme A	Attention to parents' grief: <i>articles which described nonparental griever focusing on or referencing parental grief, including altering their behavior due to this focus or describing feeling concerned for parental grievers in their own narratives of grief, as well as articles referencing social norms expecting nonparental grievers to attend to parents' grief.</i>
Theme B	Continuing bonds and attachment in grief: <i>articles referencing behavior and reflection on the part of nonparents focused on maintaining connections with the deceased infant, as well as memory-making efforts engaged in by nonparental grievers.</i>
Theme C	Grief experiences and emotions: <i>articles describing the grief experiences, behaviors, emotions, and other sequelae of nonparental grievers.</i>
Theme D	Unique dimensions of grief: <i>articles discussing additional specific phenomena in nonparental grief experiences, especially disenfranchised grief, ambiguous loss, experiences specific to either grandparents or siblings, and reference to narratives of "double loss."</i>
Theme E	Changes to identity, roles, and family systems: <i>articles exploring the systemic impact of perinatal loss on families including discussion of changes to relationships and positionality of grievers within families, and changes vis-à-vis their own specific personal identities.</i>
Theme F	Influence of developmental and life stages: <i>articles discussing the influence of other life course factors on grief experiences, including the differential impact of grief at different stages in life and/or the impact of co-occurring life stressors and transitions on grief.</i>
Theme G	Gender: <i>articles exploring the unique impact of gender in grief, including for siblings and grandparents, and for parents as their grief subsequently impacted nonparental grief.</i>
Theme H	Culture, religion, spirituality, and ritual: <i>articles discussing the role of group-specific rites and customs in grief, including lack of access to this in perinatal loss, as well as cultural norms, beliefs, and values specifying responses to perinatal loss.</i>
Theme I	Need for support: <i>articles emphasizing the lack of resources and/or research in the area of nonparental perinatal grief, either as expressed by nonparental grievers themselves or observed by article author(s).</i>

Attention to parents' grief

A prevalent theme identified in the literature was that NPRs' perinatal grief experiences are impacted by their connection to the grief experiences of parents. NPRs' grief may involve or focus on attuning to and observing the parental grievers' experiences, and they may develop narratives regarding how their own grief differs (Avelin et al., 2014; Erlandsson et al., 2010; Gunn, 2011; O'Leary & Warland, 2013). Both siblings and grandparents commonly reported feeling fear, concern, or worry with regard to the parents' grief (Avelin et al., 2014; Clossick, 2016; Erlandsson et al., 2010; Fanos et al., 2009; Forhan, 2010; Gunn, 2009, 2011; Lockton et al., 2020, 2021a, 2021b, 2023; O'Leary & Warland, 2013; Roose & Blanford, 2011; Warland et al., 2011; White et al., 2008). Some siblings worried specifically for their parents' health in the wake of PL (Avelin et al., 2014; Erlandsson et al., 2010). Certain grandparents felt that their concern for their children's grief actually superseded their concern for themselves and their own grief experiences (White et al., 2008). Lockton et al. (2020) cite a grandmother expressing concern that "I don't want it to sound like it's as bad as um my daughter's loss, it's different" (p. 404).

Table 2. Content of included articles ($N=27$), mapped to themes.

Author(s)	Type of reference	Nonparental population discussed	Themes
Alexandre et al. (2016)	Journal Article—Qualitative	Siblings	D
Avelin et al. (2014)	Journal Article—Qualitative	Siblings	A, B, C, D, E, F, H, I
Bartellas and Van Aerde (2003)	Journal Article—Review	Siblings	C, E, I
Bennett and Chichester (2015)	Journal Article—Meeting Abstract	Grandparents	A, B, C, D, H
Callister (2006)	Journal Article—Continuing Education (Review)	Grandparents and Siblings	B, C, D, E, F, H
Clossick (2016)	Journal Article—Review	Grandparents and Siblings	A, C, E, I
Davidson and Letherby (2014)	Journal Article—Ethnographic Study	Grandparents and Siblings	D, I
Erlandsson et al. (2010)	Journal Article—Qualitative	Siblings	A, B, C, F, H
Fanos et al. (2009)	Journal Article—Qualitative	Siblings	A, B, C, D, E, H
Fernández-Sola et al. (2020)	Journal Article—Qualitative	Grandparents and Siblings	B, C, D
Forhan (2010)	Journal Article—Autoethnography	Grandparents and Siblings	A, B, C, D, E, F, H, I
Gunn (2009)	Journal Article—Personal Reflection	Grandparents	A, C, E, H
Gunn (2011)	Journal Article—Personal Reflection	Grandparents	A, B, C, D, H, I
Kiguli et al. (2015)	Journal Article—Qualitative	Grandparents	A, H
Lockton et al. (2020)	Journal Article—Qualitative	Grandparents (grandmothers)	A, B, C, D, E, G, H, I
Lockton et al. (2021a)	Journal Article—Qualitative	Grandparents (grandfathers)	A, B, C, D, E, G, H, I
Lockton et al. (2021b)	Journal Article—Qualitative	Grandparents (grandmothers)	A, B, C, D, H, I
Lockton et al. (2023)	Journal Article—Participatory Action Research	Grandparents	A, B, D, G, I
Murphy and Jones (2014)	Journal Article—Review	Grandparents	B, C, D, E, F, I
O'Leary and Warland (2013)	Journal Article—Qualitative	Grandparents and Siblings	A, B, C, D, F, H
Pantke and Slade (2006)	Journal Article—Quantitative	Siblings	D, G, I
Pinto et al. (2006)	Journal Article—Quantitative	Siblings	D
Roose and Blanford (2011)	Journal Article—Mixed Methods	Grandparents and Siblings	A, B, F, G, H, I
Sandler et al. (2013)	Journal Article—Qualitative	Siblings	B, C
Sisay et al. (2014)	Journal Article—Qualitative	Grandparents	A, F, H
Warland et al. (2011)	Journal Article—Qualitative	Siblings	A, B, C, D, E, G, I
White et al. (2008)	Journal Article—Qualitative	Grandparents	A, B, D, E, G, H, I

Siblings and grandparents were observed to desire and/or try to support parental grievors (Avelin et al., 2014; Fanos et al., 2009; Forhan, 2010; Gunn, 2009; Lockton et al., 2021a, 2021b, 2023). Some articles referenced the challenge of this—noting grandparents who desired to take away their child's pain but could not (Gunn, 2009; Lockton et al., 2021a), or who appreciated guidance regarding *how* to help grieving parents (Roose & Blanford, 2011), or siblings who felt they could not be sufficiently present for their grieving parents and therefore felt inadequate and guilty (Avelin et al., 2014). Grandparents appeared to be more impacted than siblings by their concern for parents' grief experiences—some grandparents identified the etiology of this as a parental instinct within themselves to protect their child (Lockton et al., 2021a, 2021b). Kiguli et al. (2015) observed grandmothers in rural eastern Uganda who encouraged their sons to marry new women following stillbirth. In the Amhara region of Ethiopia, women

of older generations similarly endorsed the common practice of the dissolution of marriages in circumstances of repeated PL, however this was not observed in the Oromiya region (Sisay et al., 2014). O’Leary and Warland (2013) observe American grandparents urging parents to suppress their grief reactions and “[b]uck up, stiff upper lip, and move on,” including a bereaved mother being instructed by her mother-in-law not to talk about grief with her son (the bereaved father). These efforts may have originated in a motivation to help and protect their families, however this led to difficult outcomes for parents (O’Leary & Warland, 2013).

In certain circumstances, concern for parents’ grief led NPRs to alter their actions or behaviors, including suppressing their own grief responses (Avelin et al., 2014; Erlandsson et al., 2010; Lockton et al., 2020, 2021a, 2021b). Notably, Lockton et al. (2021a) identify that some grandparents endeavored to support the bereaved parents *by* visibly expressing emotion to emphasize the importance of the baby. Bennett and Chichester (2015) identify that the social expectation, perpetuated often by clinicians, that grandparents should provide support to bereaved parents, is a mechanism by which grandparents are disenfranchised. Efforts to suppress grief are evidence of nonparental griever’s engagement with self-disenfranchisement, the phenomenon by which a griever “may disenfranchise himself or collaborate in his own disenfranchisement” (Kauffman, 1989, p. 25), often as influenced by external narratives invalidating and deprioritizing their grief. The suppression of grief typically has the opposite impact—compounding and exacerbating emotion (Doka, 1989). Clinicians—including medical providers during loss events, bereavement counselors, and others—can combat and prevent self-disenfranchisement by promoting recognition of NPRs’ identity and emotion as griever’s while *also* validating their need and effort to support parental griever’s.

Continuing bonds and attachment in grief

The literature frequently commented on the maintenance of continued relationships with the deceased infant as this impacted and benefited NPRs—both siblings and grandparents were seen to develop attachments to infants, including during pregnancy, and to maintain those connections following loss (Avelin et al., 2014; Bennett & Chichester, 2015; Callister, 2006; Erlandsson et al., 2010; Fanos et al., 2009; Fernández-Sola et al., 2020; Forhan, 2010; Gunn, 2011; Lockton et al., 2020; Lockton et al., 2021a; Lockton et al., 2023; Murphy & Jones, 2014; O’Leary & Warland, 2013; Roose & Blanford, 2011; Sandler et al., 2013; Warland et al., 2011; White et al., 2008). The nurturing of continuing bonds (Klass et al., 1996) has more recently become recognized as a healthy practice in grief. The literature affirms that these bonds are just as necessary and influential for

nonparental grievers, while also identifying unique nuances of maintaining these bonds when grief is disenfranchised.

Various articles commented on the importance of, and ways to maintain, a continued relationship with the deceased. Warland et al. (2011) comment on siblings' opportunity to feel close to their infant siblings by maintaining a close relationship with a parent. Other grandparent and sibling behavior also served to maintain the felt presence of the deceased, including talking about the baby as a family together (Fernández-Sola et al., 2020; Forhan, 2010; Sandler et al., 2013; White et al., 2008), siblings talking to the baby directly (Forhan, 2010), or including the baby in imaginative play (Erlandsson et al., 2010). Forhan (2010) observes a sibling seeking reassurance from a parent that they will always have a baby sibling. Other siblings created drawings of the baby, including as represented by angels (Erlandsson et al., 2010; Fernández-Sola et al., 2020). One sister wrote a song with her father honoring the baby's memory (Sandler et al., 2013). Fanos et al. (2009) emphasize the strong motivation of siblings to maintain these relationships. Grandparents viewed their deceased grandchildren as being as present as their surviving grandchildren, including counting them when asked how many grandchildren they have (Bennett & Chichester, 2015; Lockton et al., 2020, 2021b). Some grandparents expressed interest in charity work or awareness-raising as a form of seeking meaning and continuing bonds (Lockton et al., 2021b).

Both siblings and grandparents appreciated the opportunity to meet, see, and/or hold the baby, and visit at hospital, before or after death (Avelin et al., 2014; Lockton et al., 2021a; Murphy & Jones, 2014; Roose & Blanford, 2011). This adds insight to existing evidence of the benefits of parents meeting their deceased infants (Kingdon et al., 2015; Rådestad et al., 2009), a previously discouraged practice. One article identified in this review (Sandler et al., 2013) explicitly recommends the expansion of this practice to include siblings. With this insight, clinicians, especially in healthcare settings, can now advocate for siblings and grandparents to access opportunities to spend time with a perished infant, if it is within parents' preferences—for instance, encouraging bereaved parents to invite these relatives to delivery rooms, and offering support and normalization for young children who may be in attendance.

Bennett and Chichester (2015) describe grandparents getting memorial tattoos for their grandchildren. Memorial tattoos have become recognized as a means of building and displaying one's continued relationship with the deceased (Cadell et al., 2022), and this review affirms the particular relevance of this practice for these disenfranchised perinatal grievers. Tangible transitional objects and keepsakes were important in the grief experiences and continuing bonds of both siblings and grandparents. Photographs and/or albums were frequently cited, as well as locks of hair,

handprints and footprints, teddy bears or other animals, Christmas ornaments, memorial jewelry, quilts, and even memorial gardens or trees (Avelin et al., 2014; Fanos et al., 2009; Lockton et al., 2020, 2021a; Roose & Blanford, 2011; White et al., 2008). Many of the transitional objects identified as helpful to NPRs are resources that healthcare systems can invest in to provide to families upon a loss, such as modeling clay to make hand and footprints of a deceased infant. Care settings can build community partnerships with volunteer photographers who can take memorial photos at bedside. Practices such as these are growing more common—clinicians can advocate to ensure that grandparents and siblings are also offered such resources.

Grief experiences and emotions

Grief experienced in the context of PL by NPRs can encompass a range of unique emotions and reactions which may evolve over time. Lockton et al. (2020) observe grandmothers experiencing more intense initial grief emotion followed by a perceived obligation to resume normal activity. Callister (2006) comments on siblings experiencing acute initial emotions, including disappointment, sadness, and anger, with longer-term emotions centering around sadness and helplessness. Sadness is overwhelmingly observed in both grandparents and siblings (Avelin et al., 2014; Callister, 2006; Clossick, 2016; Forhan, 2010; Lockton et al., 2021a, 2021b; Sandler et al., 2013; Warland et al., 2011), and tears and crying are also explicitly noted for both populations (Callister, 2006; Fernández-Sola et al., 2020; Lockton et al., 2020, 2021a). Lockton et al. (2021b) specifically observe a grandmother choosing to acknowledge and engage with her sadness for the purpose of coping well enough to then care for the parental grievers.

Anxiety was observed in both siblings and grandparents (Avelin et al., 2014; Bartellas & Van Aerde, 2003; Clossick, 2016; Fernández-Sola et al., 2020; Gunn, 2011; Murphy & Jones, 2014; Sandler et al., 2013), and fear (Bartellas & Van Aerde, 2003; Erlandsson et al., 2010; Fernández-Sola et al., 2020; Forhan, 2010; Lockton et al., 2020), however siblings experienced unique foci in their fear and anxiety, including fear of death (Forhan, 2010), anxiety about their parents dying (Sandler et al., 2013), and fear of darkness (Erlandsson et al., 2010). Anxiety and fear regarding future pregnancies was observed in both grandparents and siblings (Fanos et al., 2009; Lockton et al., 2020). Fernández-Sola et al. (2020) note that some siblings may respond in their grief by avoiding bonding with other siblings for fear of loss. Both siblings and grandparents experienced shock (Lockton et al., 2020; Sandler et al., 2013)—Lockton et al. (2021b) explore the specific dimension of grandmothers' surprise upon learning the prevalence of perinatal loss.

Both grandparents and siblings experienced aspects of isolation, including feelings of loneliness and otherness (Avelin et al., 2014; Bennett & Chichester, 2015; Lockton et al., 2020, 2021b). Avelin et al. (2014) note feelings of isolation among bereaved half-siblings, feeling themselves to be outsiders in the context of their family systems' losses. Lockton et al. (2020) observe that internalizing grief is not helpful to grandparents, however may be inevitable in the absence of external support. Both siblings and grandparents identified a sense of yearning, be that longing for their baby sibling (Erlandsson et al., 2010) or "an expressed desire to do anything to take away the pain of this loss for their child" (Lockton et al., 2020, p. 404). Anger (Callister, 2006; Forhan, 2010; Sandler et al., 2013) was observed more explicitly in sibling populations. Lockton et al. (2021b) observed grandparents experiencing frustration, with specific regard to the lack of information and support available to them in their grief.

The literature notes the impact of grief on nonparents' health and functioning (Avelin et al., 2014; Erlandsson et al., 2010; Fanos et al., 2009; Gunn, 2009), including sleep, with some grandparents experiencing a lack of or inability to sleep (Gunn, 2009) and some siblings experiencing nightmares (Fanos et al., 2009). Avelin et al. observe bereaved adolescents experiencing some "inattention" (2014, p. 559), at least in the short term.

Certain emotional reactions were observed uniquely in siblings, including vulnerability, despair, feeling a sense of injustice, aggressiveness, and feeling left out or helpless (Avelin et al., 2014; Callister, 2006). Siblings were observed to experience specific cognitive dimensions of their grief, including cognitive distortions (Clossick, 2016), having difficulty understanding the loss and/or their own reactions to it, and having newfound existential considerations (Avelin et al., 2014).

Other emotional reactions were observed uniquely in grandparents, including feelings of stress, lacking control (Gunn, 2009), and denial (Lockton et al., 2020). One grandparent identified their unique reaction to the loss of one twin grandchild, observing dual processes of anxiety and hope (Gunn, 2011). Certain grandparents actually articulated an awareness of the lack of acknowledgement of their emotions in their external environment (Gunn, 2011), whereas this was not observed in siblings.

Unique dimensions of grief

A number of co-occurring factors serve to differentiate PL as a uniquely challenging experience for nonparental grievers. The literature affirmed the hypothesis that the identity and relative positionality of NPRs leads their grief to become disenfranchised, especially influencing the unique nature of their experiences (Bennett & Chichester, 2015; Callister, 2006; Davidson & Letherby, 2014; Lockton et al., 2023). The literature also

frequently noted the phenomenon that PL experiences do not involve just one loss, but often engender multilayered concurrent losses. Frequently observed was the distinct experience of grandparents experiencing a dual loss narrative: grieving for their own lost grandchild and grieving for the loss their child is experiencing (Callister, 2006; Davidson & Letherby, 2014; Lockton et al., 2020, 2021a; White et al., 2008). One grandparent described this experience as being “kicked in the guts twice” (Lockton et al., 2020, p. 404). Another grandmother reflected “I sit with her and I cry with her. She cries for her daughter and I cry for mine” (Callister, 2006, p. 229).

Siblings also experienced a dual narrative of loss—the loss of their infant sibling, and the intangible loss of their parents’ full functional ability to care for them. Siblings perceived changes in parenting styles following loss, due to the impact of parents’ grief (Avelin et al., 2014; Fernández-Sola et al., 2020; Warland et al., 2011). Maternal grief may impact the behavior of children born subsequent to loss (Pinto et al., 2006; Alexandre et al., 2016). Pinto et al. (2006) uncovered a possible link between the unresolved mourning of a bereaved mother and ADHD in children born after stillbirth. Various parenting styles can emerge in the wake of PL, ranging from overprotective to neglectful, impacting bereaved siblings’ self-esteem and mental health, and leading to possible feelings of either overprotection or abandonment (Fernández-Sola et al., 2020; Pantke & Slade, 2006). Pantke and Slade (2006) particularly observe higher degrees of protective parenting subsequent to PL. Interestingly, some siblings reported feeling gratitude in response to the consequences of loss, e.g. families’ having more financial resources spread among fewer children (Fanos et al., 2009). None of the siblings in Warland and colleagues’ 2011 investigation felt overprotected, with one reflecting he had “been spoilt and stuff and looked after a bit better” (p. 631) as a result of the loss.

In addition to these dual loss narratives, other concurrent losses may be perceived and grieved by NPRs. For siblings, these included the loss of dreams of having a bigger family (Avelin et al., 2014), of an imagined future sibling relationship (Fernández-Sola et al., 2020; Forhan, 2010), and of the opportunity to get to know a sibling they would have been curious to learn about (Warland et al., 2011). Lockton et al. (2020) also note experiences of grandparents losing hope of becoming grandparents to living grandchildren, especially in instances of difficulty conceiving. These losses are indicative of ambiguous loss, a concept pioneered by Dr. Pauline Boss (1999) describing grief phenomena lacking finality or clarity. PL is naturally ambiguous, as impacted by lack of clarity regarding fetus viability, or the challenge of mourning a baby the griever did not meet (Boss & Yeats, 2014; Lang et al., 2011). This review identified evidence that NPRs are specifically impacted by the ambiguous nature of this loss (Lockton et al., 2020; Murphy & Jones, 2014), and that this may cause NPRs to question their own grief responses (Lockton et al., 2020). Some siblings

articulated the ambiguous nature of the loss of a sibling they did not fully know as paralleling their relational experience with estranged relatives, or grandparents that died before their birth (Warland et al, 2011).

NPRs observe PL to be uniquely painful, including compared to other losses throughout the life course. Grandparents specifically indicated that PL is unique and unlike any other grief they have known (Lockton et al., 2020, 2021a). Grandparents also emphasize the unique nature of each instance of PL if they have experienced multiple, including the bittersweet loss of one twin, and the difference in perceived acuity of losses in the first trimester versus full term stillbirth (Gunn, 2011). Grandparents may be uniquely impacted by the PL of a grandchild if they themselves experienced a previous PL as parents firsthand (Davidson & Letherby, 2014; Fernández-Sola et al., 2020; Lockton et al., 2021b; Murphy & Jones, 2014). Some such grandparents articulate that their present-day loss of a grandchild may make them newly conscious of their own previous PL, however that experiencing the loss of their grandchild is different and uniquely difficult (Lockton et al., 2021b) especially because of the dual loss phenomenon (Davidson & Letherby, 2014). Fernández-Sola et al. (2020) observe one grandmother who, having experienced a PL years earlier in a socio-temporal context that invalidated her grief, found beneficial opportunity to newly grieve upon her daughter's PL, remembering and grieving for both her deceased daughter and her granddaughter.

PL is fundamentally unique as it falls outside the realm of natural, expected death in the life course. Even for children who already have experienced the loss of older relatives, the PL of a sibling can engender new and more complicated grief reactions, such as fear and anger, as it is unexpected and unnatural (Forhan, 2010). Avelin et al. (2014) note that siblings of PL, unlike any other family members, may live the longest with their grief. Families experience ripples of grief throughout the life course, including when future deaths may renew grief emotions. O'Leary and Warland (2013) discuss the experiences of an adult, born subsequent to a PL, who supported her mother's newly-intense grief for her deceased sibling following her father's death. This evidence affirms the need for life-course, family-systems-focused attention to the phenomenon that *grief begets grief*—new loss can be influenced by, and re-impact, past loss experiences. Clinicians should always assess for how an individual's loss history narrative impacts their present grief. This review affirms the need for consistent and unique attention to this for nonparental grievers.

Changes to identity, roles, and family systems

PL has a profound systemic impact on families, including NPRs' conceptions of their own identities and roles. For example, siblings may

experience a transition from identifying as siblings, to identifying as bereaved young adults (Avelin et al., 2014). Similarly, especially if the loss was of a first child, grandparents may newly relate to their children as they join them in their identity as parents (Gunn, 2009). Siblings' previously-held childhood beliefs and perceptions of their parents' fallibility may shift, learning for the first time that their parents may not be able to protect them from or prevent all harm and tragedy (Fanos et al., 2009; Forhan, 2010).

Grief inevitably impacts interactional dynamics within families (Glatt, 2018); this review affirms that perinatal grief is no exception. Various role change sequelae were identified that can occur in nonparental grievers' PL experiences (Avelin et al., 2014; Clossick, 2016; Lockton et al., 2020; Murphy & Jones, 2014; White et al., 2008) that clinicians can assess for and support in grieving family systems. PL transpires in the context of preexisting family dynamics, including already-strained relationships, and can bring families closer or drive distance among members, creating new dynamics or deepening existing patterns (Lockton et al., 2020, 2021a; Murphy & Jones, 2014; White et al., 2008). PL can either lead to communication breakdown and lack of understanding, or increased supportive communication, between and among parents and siblings (Avelin et al., 2014; Fanos et al., 2009). Clinicians treating any members of families, including parents, can offer support in nurturing familial communication and psychoeducation regarding the impact of PL on internal family systems.

Birth order of siblings impacted their experience of grief, including whether they were alive prior to the perinatal loss or born after, as well as whether they already had siblings prior to the loss or if it signified their sole opportunity to have a sibling. Siblings born *after* perinatal loss were often conscious that their life may not have otherwise existed, impacting their emotions and conceptions of the loss, as well as their sense of identity, including feelings of gratitude or guilt about their life (Fanos et al., 2009; Warland et al., 2011). Avelin et al. (2014) note a sense of enrichment felt by teens following loss. Fanos et al. (2009) observe that some children experienced feelings of guilt due to cognitive distortions that they had caused the death, or guilty perceptions that their parents had not grieved in order to spare them distress. Similarly, Clossick (2016) identified the experience of self-blame in siblings regarding their parents' grief. Both grandparents and siblings felt responsibility and guilt, which included dimensions of magical thinking regarding having caused the PL, especially for siblings (Avelin et al., 2014; Bartellas & Van Aerde, 2003; Callister, 2006; Fanos et al., 2009; Murphy & Jones, 2014).

Influence of developmental and life stages

The literature affirms that siblings and grandparents are also uniquely positioned and challenged in their experiences of PL due to their ages and life stages. Ascending to the role of grandparent is already a significant life transition, involving concepts of identity, and many grandparents often struggle with anticipating potential loss (Murphy & Jones, 2014). As youth, siblings may be navigating developmental transitions and loss at once, which may make grief more challenging (Avelin et al., 2014). Sisay et al. (2014) highlight the impact of generational and age-based positionality on grief experiences, observing generational differences in beliefs about etiology of loss: older women in their study associated PL as being caused by evil spirits, whereas younger girls identified other possible causes such as problems with birthing attendants, social causes such as poverty, or maternal health issues. Similarly, children's beliefs and understanding about death and loss may be impacted by their temporal age: siblings of PL are uniquely positioned in that they may be tasked with learning about death and grief for the first time as they experience it firsthand (Callister, 2006; Roose & Blanford, 2011). Erlandsson et al. (2010) observe siblings aged five and older reading age-appropriate books about death and the afterlife with their families. Roose and Blanford observe one young sibling who remarked "Oh, so that's how babies look when they go to Heaven" (2011, p. 83) in response to their deceased sibling's facial abnormalities. Children may experience different grief reactions based on their age both in the short- and long-term: the age at which they experience a loss can impact their specific grief emotions, and their grief responses will evolve as they integrate the loss throughout life (Erlandsson et al., 2010; Forhan, 2010; O'Leary & Warland, 2013). Younger bereaved children may have more of a need to speak about their lost infant sibling a lot, whereas older children may spend more time thinking rather than talking about their grief (Erlandsson et al., 2010). Older children may speak less about their grief for fear of disturbing their parents, instead appearing more worried, tense, or silent (Erlandsson et al., 2010).

Gender

Gender, broadly, influences NPRs' experiences of PL, especially secondary impacts of gender differences in parental grieving. Mothers are observed to be more overprotective than fathers in response to PL, which, as observed above, can influence bereaved siblings' wellbeing, mental health, and grief responses (Pantke & Slade, 2006). Some siblings observed differing reactions in mothers compared to fathers, noting more outward emotional expression and external mourning in mothers, and though they

felt supported by both parents, emphasized their emotional closeness and sensitivity to their mothers (Warland et al., 2011). Gender differences in parental grief responses to perinatal loss will also impact grandparent experiences. White et al. (2008) identified that both mothers and fathers felt talking about their baby was important, but mothers were more likely to speak with family members, especially with their own mothers (bereaved grandmothers), whereas fathers, when they did speak about grief, tended to do so more with their wives than with their mothers (bereaved grandmothers). One grandfather himself noted that his son (bereaved father) spoke more about emotions with his own wife (bereaved grandmother) than with him (Lockton et al., 2021a).

Gender also directly impacted the grief behaviors of NPRs. Lockton et al. observe that significantly more grandmothers responded to their 2023 survey than grandfathers, and comment that this may be a reflection of male hesitancy to seek support in loss. In their 2020 study, their team attempted to recruit grandparents of any gender, however only grandmothers signed up. Roose and Blanford (2011) also observe that grandfathers participated less in support initiatives.

Culture, religion, spirituality, and ritual

Factors related to culture, religion, and spirituality, including associated values and beliefs, appeared to have a salient impact on NPRs' grief experiences, and their beliefs and schemas about loss (Avelin et al., 2014; Forhan, 2010; Gunn, 2009, 2011; Kiguli et al., 2015; Roose & Blanford, 2011; Sisay et al., 2014). Sisay et al. (2014) observe that in rural Amhara and Oromiya regions of Ethiopia, outwardly mourning PL is not typical or encouraged. Perinatal losses, especially babies under a certain age, are regarded as unknown and not human, and typically hidden, as influenced by cultural conceptions and definitions of personhood (Sisay et al., 2014). Jennie Gunn (2011) comments on American cultural expectations and traditions dictating that grandparents are to be "silent and strong" (p. 273), and her own adherence to this as a grandmother. This mirrors expectations and desires to be strong observed in Australian grandparents (Lockton et al., 2020, 2021a, 2021b). Gunn (2011) also comments on cultural norms forbidding parents' interference with adult children's lives. She questions how other cultures might dictate grandparent behavior in grief, lamenting the need for research on this (Gunn, 2011). Clinicians should heed this warning from a bereaved grandparent herself, in their awareness, investigation, advocacy, and support for NPR experiences of PL. Further, clinicians employing an approach of cultural humility (Yeager & Bauer-Wu, 2013) should attune to the unique influences of culture on each individual NPR they encounter, and seek to reduce micro- and

macro-level barriers challenging their ability to experience their grief in accordance with cultural expectations and traditions.

Articles commented on both siblings and grandparents seeking out spirituality and religious rituals, such as personal prayer (Gunn, 2011; O'Leary & Warland, 2013). Gunn (2009) comments on the centrality of prayer as a resource for grandparents, especially as they are unable to do or control anything else about the experience. Forhan (2010) comments on the spiritual aspects of siblings' grief, observing children engaging in prayer as a supportive resource. Roose and Blanford (2011) similarly observe religiosity in bereaved siblings' integration of loss in their expressed belief that their deceased sibling is in heaven. Despite wishing for access to last rites for her grandchild, Gunn (2011) critiques that no chaplaincy services were offered to her family in the hospital, a salient absence given the significance of religion in the American south. Her observation affirms prior evidence that religious rituals, including funeral services, are often inaccessible and non-normative in PL (Nichols, 1989), illuminating the specific disenfranchising harms of this for grandparents. Similarly, other grandparents appreciated being able to be present throughout the loss process and in bereavement ritual, including being able to visit hospitals and attend funerals (Roose & Blanford, 2011). Doka (2002) highlights that the societal disenfranchisement of older and younger individuals often leads to the exclusion of both of these populations from rituals commemorating any loss. A dual, intersecting instance of disenfranchisement is here observed: funeral ritual is broadly uncommon in PL, and, the very old and young are frequently excluded from funeral and other ritual in various loss experiences. Clinicians can address these intersecting harms by advocating for access to traditional ritual in PL—including normalizing requests for hospital spiritual care services at bedside—and encourage and educate on the importance of including nonparents of all ages.

Several articles commented on the participation of NPRs in the preparation and/or execution of funeral or memorial ceremonies when they were possible. Erlandsson et al. (2010) observed bereaved siblings decorating their infant siblings' coffins. Grandparents were also observed to help with instrumental tasks of funeral planning, especially as a means of supporting the parents (Lockton et al., 2021a; Roose & Blanford, 2011; White et al., 2008). Whether or not funeral ritual was available, nonparents engaged in other, innovative rituals of their own including one-time events, as well as repeated, built traditions. Candle-lighting was frequently referenced, as were traditions marking the deceased infant's birthday (Bennett & Chichester, 2015; Fanos et al., 2009; White et al., 2008). White et al. (2008) note grandparents sending an annual birthday card to the parents. Callister (2006) notes one grandparent's ongoing tradition of visiting an infant's grave. Roose and Blanford (2011) observe grandparents' repeated

participation in memorial programs or symbolic memorial walks. Doka identifies the importance of disenfranchised grievers building personalized “alternative rituals” (Doka, 2002, p. 139) especially where traditional ritual is unavailable, as these families have evidenced. Well-informed, grief-literate clinicians can support families in developing these, and encourage the ongoing inclusion of nonparental grievers.

Need for support

The literature emphasizes the need for support and research in the area of PL, and the monumental gaps regarding NPRs (Avelin et al., 2014; Bartellas & Van Aerde, 2003; Clossick, 2016; Davidson & Letherby, 2014; Forhan, 2010; Gunn, 2011; Lockton et al., 2020, 2021a, 2021b, 2023; Murphy & Jones, 2014; Pantke & Slade, 2006; Roose & Blanford, 2011; Warland et al., 2011; White et al., 2008). Parental grievers’ lack of understanding or awareness of grandparents’ and siblings’ grief (Bartellas & Van Aerde, 2003; Murphy & Jones, 2014; White et al., 2008), may lead to their not offering support. Lack of support creates risk and complications for nonparental grievers. Bartellas and Van Aerde (2003) comment that bereaved siblings experiencing anxiety in their grief may have difficulty resolving this themselves, without support. Multiple sources commented on bereaved grandparents’ unmet need for information: about perinatal loss and grief in general, expectations moving forward especially during future pregnancies, and/or guidance about helping their grieving child and other family members, including other grandchildren (i.e., bereaved sibling NPRs) (Lockton et al., 2021a, 2021b, 2023; White et al., 2008).

Various articles remarked on grandparents’ appreciation for support when it was available to them, underlining its absence otherwise (Davidson & Letherby, 2014; Lockton et al., 2021b; Lockton et al., 2023; Roose & Blanford, 2011; White et al., 2008). Davidson and Letherby (2014) highlight grandparents’ gratitude for having found support in an online peer forum. Some grandparents reflected explicitly that it is helpful and important to have someone to talk to Lockton et al., (2021a, 2021b). Some grandparents highlighted needs for specific, tangible support, including with memory-making (Lockton et al., 2023). Other articles underscore the potential availability of nontraditional or non-kin supports in the absence of familial support, including connections to other bereaved grandparents through support group programs, support from peers or employers, or other broader, informal connections (Lockton et al., 2021a, 2021b, 2023; Roose & Blanford, 2011). Avelin et al. (2014) observe similar patterns in siblings, who tend to find support in peers and friends, as well as with other siblings, rather than their parents. Grandparents often themselves identify the dearth of support available to them, and their need for it (Gunn, 2011;

Lockton et al., 2020, 2021a, 2021b, 2023; Roose & Blanford, 2011; White et al., 2008), with some noting that the support they did receive was subpar or minimized their emotions (Lockton et al., 2021b). Certain grandparents became isolated due to the combination of their own attempts to protect their children from observing their grief, and their wider communities' failure to welcome or support their grief experiences (Lockton et al., 2020). Isolation is often a challenging result of disenfranchised grief, as individuals shoulder the double burden of complex grief challenges suffered in the absence of typical supports (Doka, 2002). Clinicians must consider the palpable needs identified in this review as a call to action for urgent support for these unique populations.

Discussion

It is known that support, community, and connectiveness is crucial in grief (Kauffman, 1989; Turner & Stauffer, 2023). Evidence specifically supports this in parental experiences of perinatal loss (Al-Maharma et al. 2016). This review evidences that this is as true for grandparents and siblings of PL, two particularly and intersectionally disenfranchised populations. Losses which involve political or moral complexity can be particularly stigmatized. Given new legal restrictions on reproductive healthcare, including but not limited to abortion care, PL will continue to be a major example of this, with nonparental griever at extra risk of further disenfranchisement. Lack of accessible abortion care will lead to terminations carried out under duress and involving trauma that can only complicate grief processes. Legislative restrictions on reproductive healthcare more broadly, beyond abortion care, will complicate all perinatal health *and* loss experiences. Further, disenfranchised griever may actually be more likely to seek professional support where informal support is inaccessible within their personal networks (Doka, 1989). For these reasons, it is imperative that clinicians are aware of and equipped to support the particularly unique experiences of nonparental griever of PL.

This review highlights the unique position of nonparental griever within the context of PL, and how this affects various dimensions of their grief. Clinicians, including healthcare practitioners in medical settings, grief professionals, and others, across disciplines, can use these findings to adapt grief interventions to the needs of this population. The literature illuminates common grief-related sequelae, such as continuing bonds, guilt, and role changes, adding new insight regarding how they are experienced specifically by NPRs. With these new insights, clinicians may mobilize to apply their existing knowledge of concepts like ambiguous loss and disenfranchised grief to support and promote recognition of NPRs' unique experiences and needs. Clinicians supporting nonparental griever as

individuals, treating family systems, or even solely working with parental grievors, may be able to enrich their practice efficacy by adapting to the needs of these disenfranchised, at-risk populations.

The disenfranchisement of grief often effectuates escalation of emotion (Aloi, 2011; Corr, 1999; Doka, 2002), posing additional risk. Many of the emotions identified by NPRs in this review are typical and possible in grief, but this evidence highlights their unique dimensions for this population and bolsters evidence of the need for attention to their experiences. Certain emotions observed for NPRs, including “anger, guilt, and powerlessness” (Corr, 1999, p. 4), are specifically recognized for their prevalence in disenfranchised grief. Knowing and better understanding these unique emotional potentialities can aid clinicians in attuning support and advocating for recognition of this population’s disenfranchisement.

Further, guilt is already a recognized grief sequela, especially noted in disenfranchised grief (Corr, 1999), and specifically in perinatal loss—grieving mothers often struggle with guilt and fear regarding having caused their baby’s loss. This review highlights that guilt can impact grievors who are less proximate to the pregnancy and the loss, and uncovers unique dimensions of guilt experienced by grandparents and siblings—including how it is impacted by age related factors in processing. Clinicians can attune existing guilt-focused interventions to be developmentally and age-appropriate for these populations, and normalize discussion of guilt, often a taboo topic.

These disenfranchised intergenerational nonparental grievors, children losing a sibling or grandparents losing a grandchild, are already undergoing sensitive life periods given their chronological ages and developmental stages. It is crucial that clinicians are aware of how perinatal loss may additionally complicate known transitional periods. Bereaved siblings, be they children or adolescents, may be encountering other major life transitions including, as theorized by Erik Erikson, developing a sense of trust in their relationships and environment, gaining skills and a sense of mastery, and nurturing their personal identities (Orenstein & Lewis, 2022). Bereaved grandparents may be encountering health challenges associated with older age, the concurrent losses of peers, as well as navigating developmental transitions incorporating reflections upon their life accomplishments and their influence on future generations (Orenstein & Lewis, 2022). Relationships throughout the life course are foundational to the development and maintenance of a person’s identity. For siblings and grandparents, their life tasks and transitions may be intrinsically linked to their family systems and fundamentally impacted by the loss of a family member, especially when that loss may prevent them from *attaining* the identity of grandparent or sibling, respectively. Additionally, disenfranchised grief is already often associated with “concurrent crises” (Doka, 2002, p. 17)

including practical, financial, and other life stressors caused in the fallout of a loss. Clinicians can use this review's insights to support these populations in navigating life transitions, as uniquely complicated by PL.

The de-prioritization of nonparental grievers, whether effectuated internally by self-disenfranchisement and/or externally via lack of acknowledgement, unfortunately serves a vital societal function, at the expense of these individuals' compounded suffering. Robson and Walter (2013) pointed out the natural and necessary hierarchization of grief, in that grievers with different levels of proximity to a loss cannot be afforded the same privileges and attention, as this carries social and economic risk. Parental grievers must remain at the natural apex of the PL hierarchy, and cannot be recognized on equal footing with nonparental grievers. This would jeopardize parents' own opportunity to experience the full range of their own grief, especially as PL is already societally disenfranchised. This may mean that parents' needs at times take precedence over nonparental grievers' needs. For instance, if parents choose not to host a funeral for a deceased infant, grandparents who would have preferred this may be negatively affected. Where equality in grief may be idyllic, it is not realistic; promotion of equitable access to support for nonparental grievers in these experiences needs to take place. This is echoed in the stipulates of *ring theory* (Silk & Goldman, 2013) which envisions those impacted by grief in concentric circles based on their proximity to the loss or crisis event. Ring theory posits that grievers should rely on those in outer circles for their own support, while providing support to those in circles more proximate to the loss (Brindle, 2020; Silk & Goldman, 2013). Though hierarchies in grief are inevitable, the disenfranchisement of nonparental grievers is not: parents can be prioritized, while other grievers *also* receive sufficient attention and support. Clinicians may be well-placed on the outermost rings of a loss event, as are other laypeople encountering perinatal loss experiences in everyday life, who can invite and support discussions of loss with nonparents. Clinicians especially can assist nonparental grievers by acknowledging and tactically supporting their loss experiences within, and without needing to disrupt, the hierarchical structures of grief.

Limitations and future directions

This review explored the experiences of nonparental grievers of PL, using inclusion criteria that enabled a variety of perspectives to illuminate information. Articles included in the review featured parents' insights regarding their own children or parents in grief, professionals' observations of their clients, as well as some firsthand perspectives from NPRs. Though all of these perspectives proffered important insight, it is most crucial to seek primary perspectives from populations who are marginalized. Future

research should seek to more readily incorporate firsthand accounts of NPRs' grief in order to enrich understanding of their experiences.

Although the experiences of non-parental family members experiencing PL were explored, the review only garnered sufficient salient information on grandparents and siblings. Some articles refer to wider family networks, for instance, Fernández-Sola et al. (2020) make brief mention of the sibling of one parent struggling with the loss of a baby. O'Leary and Warland (2013) highlight a bereaved parent's reflection that her own grandfather, the deceased infant's great-grandfather, expressed emotion alongside her. Some articles reference broader familial networks only with regard to how those systems could support parental griever. Other members of families may also be struggling immensely with PL and become even further disenfranchised in the absence of any acknowledgement. Further research should explore the wider systemic impact of PL on extended family members, including aunts and uncles, cousins, great-grandparents, etc.

Siblings and grandparents are disenfranchised on the basis of intersecting aspects of their identities: their ages, their role positions within families, and their experience of a loss which itself is unacknowledged (disenfranchised) within society. This review found that these factors conspire to additionally complicate and challenge these individuals' grief experiences. It is possible, therefore, that additional layers of marginalization would further complicate NPRs' grief experiences. In the screening process, certain articles were identified which explored the unique dimensions of PL for families with diverse racial, gender, and sexual identities, including the unique grief challenges engendered by systemic inequity (Black & Fields, 2014; Nurse-Clarke et al., 2024). However, these articles were ultimately excluded as they did not address the experiences of nonparental grievers. Social determinants of *grief* (Scott, 2020) can threaten or privilege certain grievers' experiences. 2017 data indicates that Black, Hispanic, American Indian and Alaska Native infants have higher mortality rates than white infants (Scott, 2020). Perinatal mortality for non-Hispanic Black women more than doubles that for non-Hispanic white populations and especially impacts younger women (Fenstermacher & Hupcey, 2019). Institutional and systemic racism and inequity result in health and care disparities which can make PL more common, and more complicated, for those with marginalized identities (Cleveland Clinic, 2023; Scott, 2020). Recent and ongoing efforts to restrict elective abortion in the U.S. will inevitably complicate perinatal grief experiences and will continue to especially and disproportionately affect people of color, who already constitute more than half of those seeking abortions (Abrams, 2023). Additional socioeconomic concerns such as financial pressures are known to impact and complicate parental grief of PL (Al-Maharma et al. 2016). Not enough is known about the specific dimensions of compounded marginalization

and comorbid psychosocial stressors on the existing disenfranchisement of NPRs in PL. Future research should seek to address this gap, and advocacy and support efforts should target these hidden needs.

Conclusion

Grandparents and siblings bereaved by perinatal loss are resoundingly identified as *forgotten* grievers (Fernández-Sola et al., 2020; Murphy & Jones, 2014), enduring painful perinatal grief in silence. This review identified insight on the uniquely positioned experiences of nonparental grievers of perinatal loss and also highlighted what is yet to be explored, including the need for more firsthand input from NPRs, perspectives of other extended family members, and insight regarding the impact of additional social determinants on NPRs' grief. In the face of such continued invisible grief, social workers have a responsibility to be informed, to support, and to advocate—to remember the forgotten.

Acknowledgements

Rennie Bimman would like to express her appreciation to Dr. Esme Fuller-Thomson, a tireless advocate for social work clinician scientists, whose excellent teaching and encouragement enabled and inspired this work. Rennie Bimman would also like to extend the most heartfelt gratitude to co-author Nancy Graham, whose crucial clinical wisdom and thoughtful analysis fortified this project, and whose ongoing mentorship is a remarkable gift.

Funding

The author(s) reported there is no funding associated with the work featured in this article.

References

- Abrams, Z. (2023). Abortion bans cause outsized harm for people of color. *Monitor on Psychology*, 54(4), 24. <https://www.apa.org/monitor/2023/06/abortion-bans-harm-people-of-color>
- Alexandre, M., Votino, C., De Noose, L., Cos Sanchez, T., Gague, J., & Jani, J. (2016). The impact of prior medical termination of pregnancy on the mother's early relationship with a subsequent infant. *The Journal of Maternal-Fetal & Neonatal Medicine*, 29(8), 1238–1243. <https://doi.org/10.3109/14767058.2015.1043260>
- Al-Maharma, D. Y., Abujaradeh, H., Mahmoud, K. F., & Jarrad, R. A. (2016). Maternal grieving and the perception of and attachment to children born subsequent to a perinatal loss. *Infant Mental Health Journal*, 37(4), 411–423. <https://doi.org/10.1002/imhj.21570>
- Aloi, J. A. (2011). A theoretical study of the hidden wounds of war: Disenfranchised grief and the impact on nursing practice. *ISRN Nursing*, 2011, 954081–954085. <https://doi.org/10.5402/2011/954081>

- Avelin, P., Gyllenswärd, G., Erlandsson, K., & Rådestad, I. (2014). Adolescents' experiences of having a stillborn half-sibling. *Death Studies*, 38(6–10), 557–562. <https://doi.org/10.1080/07481187.2013.809034>
- Baethge, C., Goldbeck-Wood, S., & Mertens, S. (2019). SANRA—A scale for the quality assessment of narrative review articles. *Research Integrity and Peer Review*, 4(1), 5. <https://doi.org/10.1186/s41073-019-0064-8>
- Bartellas, E., & Van Aerde, J. (2003). Bereavement support for women and their families after stillbirth. *Journal of Obstetrics and Gynaecology Canada: JOGC=Journal D'obstetrique et Gynecologie du Canada: JOGC*, 25(2), 131–138. [https://doi.org/10.1016/s1701-2163\(16\)30209-2](https://doi.org/10.1016/s1701-2163(16)30209-2)
- Bennett, N., & Chichester, M. (2015). Ripples in the pond: Caring for extended family members after a perinatal loss. *BMC Pregnancy and Childbirth*, 15(S1), A17. <https://doi.org/10.1186/1471-2393-15-S1-A17>
- Black, B. P., & Fields, W. S. (2014). Contexts of reproductive loss in lesbian couples. *MCN. The American Journal of Maternal Child Nursing*, 39(3), 157–162. <https://doi.org/10.1097/NMC.0000000000000032>
- Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Harvard University Press.
- Boss, P., & Yeats, J. (2014). Ambiguous loss: A complicated type of grief when loved ones disappear. *Bereavement Care*, 33(2), 63–69. <https://doi.org/10.1080/02682621.2014.933573>
- Brindle, A. (2020). Understanding ring theory: A guide to compassionate support in traumatic child loss. *Sudden Unexplained Death in Childhood Foundation*. <https://sudc.org/mental-health-awareness-month-a-compassionate-approach-to-supporting-fathers-in-grief-2/>
- Burden, C., Bradley, S., Storey, C., Ellis, A., Heazell, A. E. P., Downe, S., Cacciatore, J., & Siassakos, D. (2016). From grief, guilt pain and stigma to hope and pride - A systematic review and meta-analysis of mixed-method research of the psychosocial impact of stillbirth. *BMC Pregnancy and Childbirth*, 16(1), 9. <https://doi.org/10.1186/s12884-016-0800-8>
- Cadell, S., Reid Lambert, M., Davidson, D., Greco, C., & Macdonald, M. E. (2022). Memorial tattoos: Advancing continuing bonds theory. *Death Studies*, 46(1), 132–139. <https://doi.org/10.1080/07481187.2020.1716888>
- Callister, L. C. (2006). Perinatal loss: A family perspective. *The Journal of Perinatal & Neonatal Nursing*, 20(3), 227–234. <https://doi.org/10.1097/00005237-200607000-00009>
- Clarke, J. (2015). Perinatal grief as a deeply social experience: Perspectives of bereaved parents. *BMJ Supportive & Palliative Care*, 5(1), A18. <https://doi.org/10.1136/bmjsp-care-2015-000906.56>
- Cleveland Clinic. (2023, September 6). Stillbirth. *Cleveland Clinic*. <https://my.clevelandclinic.org/health/diseases/9685-stillbirth>
- Clossick, E. (2016). The impact of perinatal loss on parents and the family. *Journal of Family Health*, 26(3), 11–15.
- Corr, C. (1999). Enhancing the concept of disenfranchised grief. *OMEGA - Journal of Death and Dying*, 38(1), 1–20. <https://doi.org/10.2190/LD26-42A6-1EAV-3MDN>
- Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity, and violence against women of color. *Stanford Law Review*, 43(6), 1241–1300. <https://doi.org/10.2307/1229039>
- Davidson, D., & Letherby, G. (2014). Griefwork online: Perinatal loss, lifecourse disruption and online support. *Human Fertility*, 17(3), 214–217. <https://doi.org/10.3109/14647273.2014.945498>
- Delalibera, M., Presa, J., Coelho, A., Barbosa, A., & Franco, M. H. P. (2015). Family dynamics during the grieving process: A systematic literature review. *Ciencia & Saude Coletiva*, 20(4), 1119–1134. <https://doi.org/10.1590/1413-81232015204.09562014>

- Desai, S., Lindberg, L. D., Maddow-Zimet, I., & Kost, K. (2021). The impact of abortion underreporting on pregnancy data and related research. *Maternal and Child Health Journal*, 25(8), 1187–1192. <https://doi.org/10.1007/s10995-021-03157-9>
- Doka, K. (1989). Disenfranchised grief. In K. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow* (pp. 3–11). Lexington Books.
- Doka, K. (2002). Introduction. In K. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp. 5–22). Research Press.
- Erlandsson, K., Avelin, P., Säflund, K., Wredling, R., & Rådestad, I. (2010). Siblings' farewell to a stillborn sister or brother and parents' support to their older children: A questionnaire study from the parents' perspective. *Journal of Child Health Care*, 14(2), 151–160. <https://doi.org/10.1177/1367493509355621>
- Fanos, J. H., Little, G. A., & Edwards, W. H. (2009). Candles in the snow: Ritual and memory for siblings of infants who died in the intensive care nursery. *The Journal of Pediatrics*, 154(6), 849–853. <https://doi.org/10.1016/j.jpeds.2008.11.053>
- Fenstermacher, K. H., & Hupcey, J. E. (2019). Support for young black urban women after perinatal loss. *MCN. The American Journal of Maternal Child Nursing*, 44(1), 13–19. <https://doi.org/10.1097/NMC.0000000000000485>
- Fernández-Sola, C., Camacho-Ávila, M., Hernández-Padilla, J. M., Fernández-Medina, I. M., Jiménez-López, F. R., Hernández-Sánchez, E., Conesa-Ferrer, M. B., & Granero-Molina, J. (2020). Impact of perinatal death on the social and family context of the parents. *International Journal of Environmental Research and Public Health*, 17(10), 3421. <https://doi.org/10.3390/ijerph17103421>
- Forhan, M. (2010). Doing, being, and becoming: A family's journey through perinatal loss. *The American Journal of Occupational Therapy*, 64(1), 142–151. <https://doi.org/10.5014/ajot.64.1.142>
- Glatt, A. (2018). A death in the family: The differential impacts of losing a loved one. *Canadian Journal of Family and Youth / Le Journal Canadien de Famille et de la Jeunesse*, 10(1), 99–118. <https://doi.org/10.29173/cjfy29344>
- Gunn, J. (2009). Little boy blue. *Neonatal Network*, 28(6), 405–406. <https://doi.org/10.1891/0730-0832.28.6.405>
- Gunn, J. (2011). The grandparent's journey. *Neonatal Network*, 30(4), 273–274. <https://doi.org/10.1891/0730-0832.30.4.273>
- Kauffman, J. (1989). Intrapsychic dimensions of disenfranchised grief. In K. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow* (pp. 25–29). Lexington Books.
- Kingdon, C., Givens, J. L., O'Donnell, E., & Turner, M. (2015). Seeing and holding baby: Systematic review of clinical management and parental outcomes after stillbirth. *Birth*, 42(3), 206–218. <https://doi.org/10.1111/birt.12176>
- Kiguli, J., Namusoko, S., Kerber, K., Peterson, S., & Waiswa, P. (2015). Weeping in silence: Community experiences of stillbirths in rural eastern Uganda. *Global Health Action*, 8(1), 24011. <https://doi.org/10.3402/gha.v8.24011>
- Klass, D., Silverman, P. R., & Nickman, S. L. (Eds.). (1996). *Continuing bonds: New understandings of grief*. Taylor & Francis.
- Lang, A., Fleiszer, A. R., Duhamel, F., Sword, W., Gilbert, K. R., & Corsini-Munt, S. (2011). Perinatal loss and parental grief: The challenge of ambiguity and disenfranchised grief. *Omega*, 63(2), 183–196. <https://doi.org/10.2190/OM.63.2.e>
- Lockton, J., Due, C., & Oxlad, M. (2020). Love, listen and learn: Grandmothers' experiences of grief following their child's pregnancy loss. *Women and Birth*, 33(4), 401–407. <https://doi.org/10.1016/j.wombi.2019.07.007>
- Lockton, J., Oxlad, M., & Due, C. (2021a). Grandfathers' experiences of grief and support following pregnancy loss or neonatal death of a grandchild. *Qualitative Health Research*, 31(14), 2715–2729. <https://doi.org/10.1177/10497323211041331>

- Lockton, J., Oxlad, M., & Due, C. (2021b). Knowing how to help: Grandmothers' experiences of providing and receiving support following their child's pregnancy loss. *Women and Birth*, 34(6), 585–592. <https://doi.org/10.1016/j.wombi.2020.10.006>
- Lockton, J., Oxlad, M., & Due, C. (2023). Grandparents' pregnancy and neonatal loss network: Designing a website for grandparents bereaved by the perinatal loss of a grandchild. *Pec Innovation*, 3, 100228. <https://doi.org/10.1016/j.pecinn.2023.100228>
- Murphy, S., & Jones, K. S. (2014). By the way knowledge: Grandparents, stillbirth and neonatal death. *Human Fertility*, 17(3), 210–213. <https://doi.org/10.3109/14647273.2014.930190>
- Nichols, J. A. (1989). Perinatal death. In K. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow* (pp. 117–126). Lexington Books.
- Nurse-Clarke, N., Freedle, A., Bindeman, J., Jarvis, J., & Sember, J. (2024). Perinatal bereavement in racially, culturally, and gender diverse families. *MCN. The American Journal of Maternal Child Nursing*, 49(2), 81–87. | <https://doi.org/10.1097/NMC.0000000000000983>
- O'Leary, J., & Warland, J. (2013). Untold stories of infant loss: The importance of contact with the baby for bereaved parents. *Journal of Family Nursing*, 19(3), 324–347. <https://doi.org/10.1177/1074840713495972>
- Orenstein, G. A., & Lewis, L. (2022). *Erikson's stages of psychosocial development*. StatPearls. <https://www.ncbi.nlm.nih.gov/books/NBK556096/>
- Pantke, R., & Slade, P. (2006). Remembered parenting style and psychological well-being in young adults whose parents had experienced early child loss. *Psychology and Psychotherapy*, 79(Pt 1), 69–81. <https://doi.org/10.1348/147608305X52667>
- Pinto, C., Turton, P., Hughes, P., White, S., & Gillberg, C. (2006). ADHD and infant disorganized attachment: A prospective study of children next-born after stillbirth. *Journal of Attention Disorders*, 10(1), 83–91. <https://doi.org/10.1177/1087054705286058>
- Rådestad, I., Surkan, P. J., Steineck, G., Cnattingius, S., Onelöv, E., & Dickman, P. W. (2009). Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery*, 25(4), 422–429. <https://doi.org/10.1016/j.midw.2007.03.005>
- Robson, P., & Walter, T. (2013). Hierarchies of loss: A critique of disenfranchised grief. *Omega*, 66(2), 97–119. <https://doi.org/10.2190/om.66.2.a>
- Roose, R. E., & Blanford, C. R. (2011). Perinatal grief and support spans the generations: Parents' and grandparents' evaluations of an intergenerational perinatal bereavement program. *The Journal of Perinatal & Neonatal Nursing*, 25(1), 77–85. <https://doi.org/10.1097/JPN.0b013e318208cb74>
- Sandler, C. L., Robinson, E., & Carter, B. S. (2013). Loss in the NICU: Sibling matters. *The American Journal of Hospice & Palliative Care*, 30(6), 566–568. <https://doi.org/10.1177/1049909112460331>
- Sawyer, T. C. (2023). African American sibling loss: A sister's perspective. In R. B. Turner & S. D. Stauffer (Eds.), *Disenfranchised grief: Examining social, cultural, and relational impacts* (pp. 17–31). Routledge.
- Scott, S. D. (2020). *Social determinants of grief: The impact of black infant loss* [Webinar]. National Institute for Children's Health Quality. <https://www.youtube.com/watch?v=mEgUi5LGN7k>
- Searing, L. (2022, August 2). Up to 1 in 4 pregnancies may end in miscarriage. *The Washington Post*. <https://www.washingtonpost.com/health/2022/08/02/miscarriage-risk-pregnancy/>
- Silk, S., & Goldman, B. (2013, April 7). How not to say the wrong thing. *Los Angeles Times*. <https://www.latimes.com/nation/la-oe-0407-silk-ring-theory-20130407-story.html>
- Simelala, N. (2024). The unacceptable stigma and shame women face after baby loss must end. World Health Organization. <https://www.who.int/news-room/spotlight/why-we-need-to-talk-about-losing-a-baby/unacceptable-stigma-and-shame>
- Sisay, M. M., Yirgu, R., Gobeze, A. G., & Sibley, L. M. (2014). A qualitative study of attitudes and values surrounding stillbirth and neonatal mortality among grand-

mothers, mothers, and unmarried girls in rural Amhara and Oromiya regions, Ethiopia: Unheard souls in the backyard. *Journal of Midwifery and Women's Health*, 59(1), S110–S7. <https://doi.org/10.1111/jmwh.12156>

Stanford Medicine Children's Health. (2024). Stillbirth. <https://www.stanfordchildrens.org/en/topic/default?id=stillbirth-90-P02501>

Tran, H. T., Nguyen, T. T., Nguyen, O. T. X., Mathisen, R., & Cassidy, T. M. (2023). Case report: I feel like a mother to other babies: Experiences and perspectives on bereavement and breastmilk donation from Vietnam. *Global Women's Health*, 4, 1198738. <https://doi.org/10.3389/fgwh.2023.1198738>

Turner, R. B., & Stauffer, S. D. (2023). Disenfranchised grief: The complicated interweave of death and non-death losses. In R. B. Turner & S. D. Stauffer (Eds.), *Disenfranchised grief: Examining social, cultural, and relational impacts* (pp. 3–23). Routledge.

UNICEF. (2023, January 9). Never forgotten: The situation of stillbirth around the globe. *UNICEF Publications*. <https://data.unicef.org/resources/never-forgotten-stillbirth-estimates-report/#:~:text=Progress%20since%202000,a%2035%20per%20cent%20reduction>

Warland, J., O'Leary, J., & McCutcheon, H. (2011). Born after infant loss: The experiences of subsequent children. *Midwifery*, 27(5), 628–633. <https://doi.org/10.1016/j.midw.2010.06.019>

World Health Organization. (2024a). *Newborn mortality*. World Health Organization. <https://www.who.int/news-room/fact-sheets/detail/newborn-mortality>

World Health Organization. (2024b). *Abortion*. World Health Organization. <https://www.who.int/news-room/fact-sheets/detail/abortion>

White, D. L., Walker, A. J., & Richards, L. N. (2008). Intergenerational family support following infant death. *International Journal of Aging & Human Development*, 67(3), 187–208. <https://doi.org/10.2190/AG.67.3.a>

Yeager, K. A., & Bauer-Wu, S. (2013). Cultural humility: Essential foundation for clinical researchers. *Applied Nursing Research: ANR*, 26(4), 251–256. <https://doi.org/10.1016/j.apnr.2013.06.008>

Appendix A

Keywords and Subject Headings

Concepts

1	Perinatal loss
2	Nonparental relatives
3	Grief

Keywords

1	(perinatal loss OR prenatal loss OR postnatal loss OR pregnancy loss OR perinatal death OR infant death OR miscarriage OR abortion OR TFMR OR termination for medical reasons OR fetal demise OR fetal mummification OR stillbirth).ti,ab,kf OR Fetal Death/ OR exp Stillbirth/
2	(nonparental relatives OR nonparent* OR famil* OR relative OR relatives OR sibling* OR brother? OR sister? OR aunt? OR uncle? OR grandmother? OR grandfather? OR grandparent? OR cousin?).ti,ab,kf OR Families/ OR Family Members/ OR Family Member/ OR Relatives/ OR Filiation/ OR Kinship Networks/ OR Kinship Network/ OR Family Life Cycle/ OR Family Research/ OR Family/ OR exp Family Relations/ OR Grandparents/ OR Siblings/
3	(griev* OR mourn* OR bereav*).ti,ab,kf OR Bereavement/ OR Grief/ OR exp Disenfranchised Grief/
4	1 AND 2 AND 3