

Sibling loss - disenfranchised grief and forgotten mourners

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My first encounter with the experience of sibling loss was with a nurse administrator in a neonatal unit that I was interviewing for my dissertation on grief and bereavement. While examining the emergence of hospital protocols for perinatal loss, wondering why a particular set of individuals broke with standard practice to encourage interaction with dying and dead infants, I noted that these individuals had ‘sentinel experiences’, or specific experiences that allowed them to be more sensitive to the needs of grieving parents (Davidson, 2007). Asking her about why she fought so hard to establish compassionate protocols, this participant responded by saying:

‘When I was about three I had a brother die of SIDS [Sudden Infant Death Syndrome] and there was a police investigation and my older brother and I were told to go upstairs and close the door and we sat upstairs, and it was not much talked about after that. You just got on with your life. *I didn’t realize there was another way to have a brother die.*’

(Davidson, 2007, p. 102, emphasis is original¹)

A few years after completing my dissertation, my research examined tattoos as a form of memorialisation. One of the focus groups I conducted was with young adults who had experienced sibling loss. One of their laments was that none of them ever had the opportunity to read about sibling loss, or share their stories and their siblings with others who had also experienced this type of loss. The focus

of grief, they told me, was on their parents. Furthermore, they noted that they held the double weight of their own and that of their parents’ grief.

Their grief at the death of their siblings was disenfranchised. In 1989, Kenneth Doka defined disenfranchised grief 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). The relatively scant literature on sibling loss in the last ten years confirms that, within scholarship, sibling loss is still disenfranchised. Doka’s decidedly influential contribution to our understanding of grief and bereavement corresponded to a decade of interest in sibling loss. David E. Balk (2014) notes that prominent research on sibling loss took place in the 1980s and 1990s, but ‘since the late 1990s sibling bereavement has been studied less than parental bereavement’ (p. 153). Similarly, Julia Samuel (2018) argues that ‘[a]lthough 80 percent of the population have a sibling, we as a society give it less acknowledgement than it deserves as a key relationship in our lives’ (p. 126). And in their longitudinal study of sibling bereavement, from James M. Bolton et al. (2016) ‘Sibling bereavement is an experience with very sparse literature and thus the consequences of losing a sibling are unclear’ (p. 2 of 16). The need for more research on sibling loss was confirmed by my search for scholarly literature published between 2008 and 2018.

The articles I choose for this review take us from research about sibling loss in general to that which focuses on sibling loss from perinatal death through adolescent responses to sibling loss, and include impact on siblings’ voices of experiences with a dying sibling, as well as sibling loss through suicide and murder. The literature for review

¹ Davidson, D. (2007). *The emergence of hospital protocols for perinatal loss, 1950-2000*. Toronto: York University.

is authored by scholars in a range of areas including psychology, thanatology, philosophy, communication studies, humanities, behavioural science, nursing, public health, social work, and family and community medicine, and is conducted through a variety of methods.

I begin with the general topic of sibling grief.

Paris, M. M., Carter, B. L., Day, S. X., & Armsworth, M. W. (2009). Grief and trauma in children after the death of a sibling. *Journal of Child & Adolescent Trauma* 2, 71–80.

[The] death of a sibling marks an end to what is expected to be one of the longest and sometimes most intimate relationships of a lifetime (Paris et al., 2009, p. 72, citing Robinson & Mahone, 1997, p. 477). [And yet,] the number of published studies remains relatively small (p. 78).

Recognising that far more was known about parental grief, and that ‘childhood grief reactions differ in manifestation and duration’ (p. 72) from that of adults, the purpose of this small quantitative study of children’s self reports, was ‘to help inform effective support interventions’ (p. 71). The authors of this 27-participant study noted from previous studies’ findings that although experiences varied widely, even in the same family, the overall risk of behaviour problems, especially in young children, was higher than in the general population. Previous studies also took gender, both of the deceased and living child, as a variable in how children experience grief. They noted that girls tended to score lower in standardised tests and both boys and girls with ‘deceased brothers demonstrated more behaviour problems than other bereaved siblings’ (p. 73).

These researchers were looking at the potential relationships between anticipated and sudden death to trauma and grief reactions of siblings. They hypothesised that ‘siblings who experienced a sudden death would report higher levels of trauma compared to siblings who experienced an anticipated death... [and that] siblings who experienced an anticipated death would report higher levels of grief’ (p. 74). What they found, however, was that grief and trauma reactions were difficult to distinguish. This is more consistent with earlier research showing an integration of grief and trauma wherein ‘[t]rauma and grief may overlap to create a more complex response to bereavement... [and] may, in fact, exist simultaneously as an interrelated set of processes that are difficult to distinguish’ (p. 77). The researchers also found partial support for their hypothesis regarding gender differences noting that ‘boys and girls appeared generally equal in terms of trauma, but female siblings reported greater grief after loss than males’ (p. 77). These researchers acknowledged that while sibling loss research is gaining

attention ‘the number of published studies remains relatively small’ (p. 78).

Funk, A. M., Jenkins, S., Astroth, K. S., Braswell, G., & Kerber, C. (2018). A narrative analysis of sibling grief. *Journal of Loss and Trauma*, 23(1), 1–14.

Siblings are often neglected in their grief. This study brings sibling grief out of the shadows and illustrates the pervasive effects of sibling loss on surviving brothers and sisters (p. 13).

Moving ahead to a study published in 2018, these researchers note also that sibling bereavement is ‘the least researched of all familial loss’ (p. 1), and call for more research in this area, arguing that the impact of sibling loss on the surviving sibling is overlooked’. Similar to the article above, these researchers agree that younger children are at a greater disadvantage as a child’s developmental stage impacts their understanding of death. Narrative interview method was used to allow ‘participants to freely tell their story’ (p. 2), and was followed by a thematic analysis. Key themes included: shared life and identity within the sibling arrangement; sibling death and pivotal moments in time; life after sibling loss and emotional suffering; life after loss and missing roles and changing relationships; and the sibling lives on.

Substantiating and further exploring other research on forgotten and overlooked sibling grievers, these researchers also found parental detachment to be a source of distress. These and other researchers note similar findings indicating ‘that sibling grief impacts daily functioning and can have a profound influence on mental health, including for long-lasting grief reactions’ (p. 12).

Bolton, J. M., Au, W., Chateau, D., Walld, R., Leslie, W. D., Enns, J., Martens, P. J., Katz, L. Y., Logsetty, S., & Sareen, J. (2016). Bereavement after sibling death: a population-based longitudinal case-control study. *World Psychiatry* 15(1), 59–66.

Sibling bereavement is an experience with a very sparse literature and thus the consequences of losing a sibling are unclear (p. 59).

Controlling for the general population, 7243 siblings of children deceased in the Canadian province of Manitoba who died between 1984 and 2009 were matched 1:3 to children who did not have a sibling die during this period. Physician-generated data for this population with universal access to free medical care was examined for both sibling loss and control groups for a period of two years before, to two years after the death of a sibling. This study focused on mental health, the authors hypothesising ‘that bereaved

individuals would have elevated rates of depression and anxiety within two years following the death of their sibling when compared to controls and to pre-death rates' (p. 60).

The study included two age groups, one under 13 and one over 13 years of age, at the time of their sibling's death. The results indicated that the age of the surviving sibling has consequences for their bereavement experience. The younger children (<13 yrs. of age) experienced more social isolation and had fewer friends. As well, the younger age group had a seven-fold increase in depression in pre-adolescence, as well as higher rates of anxiety, and drug use compared to their control group. However, 'siblings aged 13 and older had higher rates of almost every mental disorder examined' (p. 65), and were most likely to receive treatment. These researchers also have noted the effects of social adversity on the bereavement experiences of their sample population, with 'a marked over-representation of income inequality' (p. 65) of affected families. The authors concluded that pre-existing health conditions and social disadvantage do not account fully for the increase in mental health disorders in this sibling population, and call to mental health practitioners to be aware of the vulnerabilities faced by children and youth who have experienced sibling loss.

Now I move to sibling loss through perinatal death.

Kempson, D., Conley, V. M., & Murdock, V. (2008). Unearthing the construct of transgenerational grief: The "ghost" of the sibling. *Illness, Crisis & Loss*, 16(4), 271–284. doi: 10.2190/IL.16.4.aa

A child's death profoundly affects family dynamics, stories, and even other siblings' perceived reasons for being. This influence is often sustained over time to affect not only the lost child's parents and siblings, but also future generations. Health care and mental health workers frequently encounter such stories, but little is known about the actual phenomenon, which may be a form of disenfranchised grief (p. 271).

Recognising long term consequences of sibling loss, these researchers analyse narratives of the sibling loss through the concept of transgenerational grief, similar to the quote by the sister whose sibling died by SIDS which began this research review. The lenses of analysis include history, grief, and family theory. Transgenerational grief, coined by S. Lieberman in 1979, these authors note, refers 'to the lasting influence on the family of deaths that were not adequately acknowledged or mourned' (p. 273). When a sibling dies as an infant, whether before or after birth, the death of a 'ghost' child, or a child that surviving siblings never got to know, may result in unresolved grief due to unresolved mourning from death that has not been adequately acknowledged. This reference to 'ghosts... is used suggest the 'shadows' of memories, stories,

and emotional impacts of a sibling who was never known to the living or surviving sibling(s)' (p. 273).

From their literature review, the authors note, as we have seen elsewhere in this review, that the death of a child may also affect how parents respond to their living children. This may manifest in ways which may be damaging to the survivor, such as a fear of losing their living children, an over or under-involvement with their living children, or idealising of the deceased child in comparison to the living children. Furthermore, there may be feelings of ambivalence toward the next-born child. Some parents may see their living children as a comfort or consolation.

Surviving children may experience feelings of rivalry. Children born after perinatal loss may be intended to 'fill a void' left by the deceased child. The authors note that the:

replacement child assumes the burden of attempting to fill the role of two children within the family: their own person and that of the deceased child. Understandably, this dual effort often results in a loss of one's own individuality and a profound sense of failure with multiple accompanying symptoms (p. 277).

The authors suggest the following considerations for families: family counselling without neglecting the needs of surviving siblings OR family counselling that includes surviving siblings; communicating stories of the unknown sibling and allowing for open discussion; and assisting grieving through creative outlets. The authors conclude by noting the importance of clinicians' understanding of and responding to the needs of those who had a sibling whom they never knew directly.

O'Leary, J. M. & Gaziano, C. (2011). Sibling grief after perinatal loss. *Journal of Prenatal and Perinatal Psychology and Health*, 25(3), 173–193.

Research which studies family grief in response to perinatal loss... generally has focused on parental grief and rarely included sibling grief (p. 173).

Using descriptive phenomenology to allow participants to express their experiences in their own terms, the authors conducted eight case studies to look at different ways siblings were affected by perinatal loss in relation to how their parents handled the loss. Looking at the literature, they noted that in bereaved families, siblings suffer two losses - that of their expected siblings 'and their parents as they knew them before the loss' (p. 174), that these siblings experience disappointment and sadness over a long period of time and that, like the previous study, the impacts extend to later generations.

In addition to the authors' acknowledgement of sibling grief as disenfranchised, their analysis notes the

lack of and the importance of recognition of siblings' needs after perinatal loss. For perinatal loss, as a form of disenfranchised grief, parents themselves receive unsupportive messages that then may be passed on to their surviving children. Difficulty in processing the loss may inhibit parents from reaching out, or knowing how to reach out, to their surviving children. The authors note that clinical practice may still hold erroneous ideas that children may be too young to understand death and perinatal loss, and may be too young to grieve and, as such, their grief goes without appropriate clinical response.

The authors also address the importance of providing developmentally appropriate information, not only about facts and events but also sharing information about feelings and expectations. They argue further that, in order to support siblings, it is most important to recognise their grief, to include the lost sibling in family rituals, and to talk about death and the deceased sibling, thereby facilitating continuing bonds. When parents are effectively supported they will then have the resources to better support their surviving children.

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.

[T]he situation of siblings after stillbirth has been identified as an area into which there has been little research (p. 152).

As with the previous study for this review, these authors stress the importance of the parental role in supporting their surviving children. Their data were gathered from 16 parents who experienced stillbirth, and their study aimed 'to capture parental descriptions of how siblings take leave of and mourn a stillborn brother or sister and how their parents support them' (p. 151) while grieving themselves.

The authors found that parents supported the well-being of the siblings by taking action by: inviting their children to be a part of their own mourning, which seemed to comfort both the parents and the siblings; taking their time to listen to the children and trying to be physically present to answer their questions; helping to make the stillborn baby more of a 'real person' to them; and by the parents showing their own feelings to help normalise their children's grief.

As noted in the title, the authors also investigated the opportunity for siblings to say farewell to their stillborn sibling. About the importance of farewells, they noted that the 'natural atmosphere' in which parents made their decision to have contact with their stillborn baby during

the first 30 minutes after birth was important to whether or not the siblings of the child would be able to say farewell at that time. This 'natural atmosphere' was dependent on the care the parents received in hospital. The authors also noted the opportunity to say farewell at a funeral as important for siblings. Further, the first year period following the stillbirth was also noted as important. Similar to other of the reviews, helping children to create memories of their stillborn sibling also helped to build and continue bonds and proved to be a coping strategy. The authors conclude by arguing, similar to what is noted in other reviews, that further research is needed.

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. doi: 10.1016/j.jpeds.2008.11.053

Little is known about the long-term developmental consequences for surviving siblings of infants who die in the neonatal intensive care unit (NICU), and long-term follow-up studies of these siblings is needed (p. 849).

These authors reported on their interviews with fourteen siblings of infants who died in a NICU between 1980 and 1990, their goal being to 'assess the psychological impact of surviving a sibling who died in the NICU' (p. 849). They argue that even though time in the NICU may be short, the consequences of the experience can remain with the surviving siblings for a lifetime. Their results included discussion of sibling relationships, sibling guilt and gratitude, anxieties, family communications, parental mourning, and rituals. Their findings included participants' desire for involvement with their sibling, that is, being able to being able to view, hold, and care for their ill sibling. Developmental-appropriate support was needed for understanding death and illness. Photographs used to honour their dying and dead siblings served the following functions:

- (1) providing a way of learning about the sibling who died;
- (2) providing a continuing connection with the deceased sibling, helping maintain memories; and
- (3) serving as a vehicle to facilitate communication between parents and surviving children at different developmental stages, triggering conversation (p. 852).

Further, traditions and rituals allow families to honour, mourn, and remember together.

The authors conclude by a call to neonatal teams to consider needs of the surviving siblings, and that '[m]edical providers and family members alike should consider

psychological counselling to gain insight into the emotional responses to death in the NICU (p. 853)'.

Next, I move to siblings' experiences with a dying child beyond infancy.

Russell, C. E. Widger, K., Beaune, L., Neville, A., Cadell, S., Steele, R., Rapoport, A., Rugg, M., & Barrera, M. (2013). Siblings' voices: A prospective investigation of experiences with a dying child. *Death Studies*, 42(3), 184–194. doi: <https://doi.org/10.1080/07481187.2017.1334009>

The limited research documenting siblings' experience has been primarily retrospective and focused on bereavement (p. 184).

These authors investigate siblings' perspectives when a brother or sister was dying at home or in hospital. To do so, using interpretative descriptive methodology, their qualitative study was prospective rather than retroactive, and longitudinal over two years. These siblings experienced both strain and support. One of their resulting themes included siblings' experience with the ill child as playmates, companions, helpers, finding that while 'most siblings spent some time in all three roles, the weight of their involvement shifted over time, their roles taking on more strain as the illness progressed' (p. 187). Another theme was the sibling's experience with their families noting that family time included both separation and strain, but involving a growing sense of strength, communication with and closeness to their family. Siblings had little time for outside activities due to their child care and family responsibilities. Siblings' experiences with peers, although a welcome distraction, required the difficulty of managing social and family time. Maintaining privacy and avoiding questions by peers also proved difficult.

About their personal experiences, siblings noted grief for their impending loss and uncertainty about the future. The siblings found coping strategies that included faith, music, and time spent with their ill sibling, or setting aside their own feelings. Their experiences differed depending on their developmental stages and included what information was presented to them, and how much they participated in physical care of their dying sibling.

What is very interesting, given the many adverse aspects of being a sibling of a dying child, is that these authors found that the 'siblings valued their roles as helpers and consistently wanted to do more to assist with care of the ill child' (p. 190). Similar to other research reviewed here these authors also conclude with a call for support, noting that '[s]iblings can benefit from understanding that they are not selfish, weak, or wrong when they struggle and that they can be supported by their family, friends, community, and professionals' (p. 192).

Next, I move to David E. Balk's discussion of literature of sibling death during adolescence.

Balk, D. E. (2014). *Dealing with dying, death, and grief during adolescence* (pp. 153–160). New York: Routledge.

Complications of disenfranchised grief become intertwined here when adolescents' needs are ignored or dismissed (p. 153).

Balk argues that since the late 1990s the literature has not sufficiently attended to sibling bereavement and that adolescents may become forgotten mourners. Looking at the literature that has been done, Balk notes that the areas of focus on adolescent sibling grief have been on 'self-concept, emotional responses, grades and school work, religion, and family dynamics' (p. 153).

Balk notes that bereaved siblings scored significantly higher on conscience, and some research showed that within 12 months after their sibling died they showed greater maturity than their non-bereaved peers. While adolescents learned to cope with their bereavement, soon after the death of their sibling, they noted their 'shock, guilt, confusion, depression, fear, loneliness, and anger' (p. 155). And while their study habits returned to normal over time, they reported having trouble concentrating on their school work following the death. Adolescents' turn to religion for many occurred only after they questioned and vented anger at God. Interestingly, Balk also noted that 'in the first few months after a sibling's death, religious teenagers report more confusion, whereas non-religious teenagers report more feelings of depression and fear'.

Family dynamics and relationships have been studied in relation to bereaved adolescents as well. While parents express gratitude that their adolescents were coping well and required no special attention, surviving children camouflage their own grief in order to rescue their family and try to secure its survival. The degrees of family coherency prior to the death has consequences for how adolescents respond to their loss. This is explained by differing values placed on family relationships and differing family dynamics. Adolescents may experience not only the loss of their sibling but may fear loss of familial security as well.

Finally, I move to the loss of a sibling through murder and suicide.

Pretorius, G., Halstead-Cleak, J., & Morgan, B. (2010). The lived experience of losing a sibling through murder. *The Indo-Pacific Journal of Phenomenology*, 10(1), 1–13. doi: 10.2989/IPJP.2010.10.1.7.1079

Homicide survivor bereavement, as a grief experience relative to other types of loss following the death of a loved one, is a relatively recent area of interest in the research community (p. 1 of 13).

In their qualitative study, phenomenology was used to explore subjective meanings of sibling loss through murder.

The authors note the vulnerability of young adults in South Africa, with its high rate of murder in this population, leaving an even greater number of bereaved siblings. They note as well the paucity of research, especially that related specifically to youth whether in South Africa or more widely. Similar to what others have noted, these authors note young adult sibling bereavement to be a distinct form, as siblings 'experience a profound feeling of identity confusion... leaving them feeling depressed and isolated... [and] also forces the surviving sibling(s) to take on new roles in the family system' (p. 2 of 13).

Citing evidence that loss through homicide intensifies grief reactions, the authors outline research that 'describes four losses that occur in the aftermath of murder' (p. 2 of 13). First is the primary loss of their personal relationship with the deceased. Second is an intrapersonal loss which shatters the survivors' world views. Third is interpersonal loss due to the fragmentation of family relationships. And the fourth loss is extra-personal by the way of related financial strain. Distress occurs also from knowledge of their deceased loved one's suffering as a result of violence, and their own related feelings of guilt and self-blame.

The following seven themes were taken from their data. First, the participants were shocked at the suddenness and nature of the death by murder. Second, participants spoke of recollection of shared childhood experiences, internalised guilt and shame for not having done enough for their siblings. Third, participants described periods of disintegration and fragmentation within their families. Fourth, they found themselves isolated and in need of support. A desire for justice and revenge against the perpetrators proved the fifth and central theme. Sixth, experiencing religious and existential crises, the participants began to reformulate the meanings they had attached to their world. And finally, despite their grief, participants eventually gained a sense of control and purpose demonstrating their resilience, healing and personal growth, becoming more compassionate and sensitive individuals.

Powell, K. A., & Matthys, A. (2013). Effects of suicide on siblings: Uncertainty and the grief process. *Journal of Family Communication*, 13, 321–339. doi: 10.1080/15267431.2013.823431

Much has been written about suicide loss and grieving, yet not about the sibling survivors of suicide, called the 'forgotten mourners' (p. 321).

The authors begin by acknowledging existing literature on bereavement due to suicide and note that the few existing studies on sibling survivors of suicide focus on depression, PTSD, and anxiety finding these conditions to be higher in sibling survivors than in control groups. Studies on suicide loss also focus on parents' responses, overlooking the

unique loss and grief of surviving siblings who are doubly burdened with their own grief and that of their parents. The authors note that '[t]o manage their grief, siblings must accept that their sibling died by suicide and deal with accompanying challenges and lingering questions of cause.... Making sense out of a suicide, however, may be particularly difficult because the grieved do not have all the answers and the grief itself is unresolved' (p. 323).

The authors were guided by uncertainty reduction theory and uncertainty management theory. Noting '[s]uicide as a particular instance of uncertainty set against a backdrop of negative societal judgment of suicide' (p. 324), these authors conducted in-depth interviews with 45 sibling survivors of suicide, to examine the ways in which sibling survivors manage their grief and uncertainty. They found that loss was experienced variously depending on the participant's level of uncertainty, wherein siblings with the most uncertainty moved to a state of acceptance more slowly than those who felt less uncertainty. Their strategies for reducing uncertainty included questioning others about potential motives and examining their deceased sibling's documents. Those who felt they understood their sibling's reasoning for suicide experienced less uncertainty than those who did not. Some participants reported fluctuating uncertainty due to lingering questions about their sibling's death. Strategies to reduce uncertainty for this group included searching for answers and attending support groups, and attending counselling. Participants who experienced high levels of uncertainty included those who did not recognise any warning signs from their siblings and who thought they knew their siblings well enough to have predicted their suicide. Most of these participants had the profound desire to ask their siblings 'why'.

Participants in each of the three groups managed their uncertainty in three ways: avoiding information and accepting their level of uncertainty; gathering and sharing information about suicide; and seeking social support by connecting with other suicide survivors and communicating positive memories. Irrespective of their level of uncertainty about their sibling's suicide death 'many participants sought to reassure themselves, parents, and others who knew the deceased that they are not to blame for the suicide' (p. 334). Open communication, positive family dynamics, and social support proved to be important in how sibling survivors of suicide managed their grief, in part through the role of each in reducing silence and stigma surrounding suicide.

To summarise, the sibling relationship is understood to be one of the longest lasting and closest of familial relationships. The literature on sibling loss within the last ten years affirms that bereaved siblings are forgotten mourners - insufficiently recognised, not only in clinical practice, in families, and society more broadly, their experiences of grief and bereavement have also been

largely neglected in scholarly research. And yet, they grieve, carrying the double burden of their own and their parents' grief, and they suffer social, emotional, and physical consequences from their loss and their disenfranchised grief. And it is not as if sibling survivors are not reaching

out for support as is noted in the literature reviewed and as seen in the dozens of support groups on Facebook alone that are dedicated to sibling loss, grief, and bereavement. Is it not our scholarly, clinical, and social responsibility to reach back? ■