

The need for bereavement support following perinatal loss

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‘Perinatal loss is physically, emotionally, spiritually, and mentally taxing on parents and families. The grief that parents experience following the loss of a child is difficult to overcome and may never be fully resolved’ (LeDuff, Bradshaw, & Blake, 2017, p. 352).

The theme I have chosen to review for this research round-up is the need for bereavement support for women and families following perinatal loss specifically, here, support from healthcare professionals. By the mid-1980s hospitals began to recognise and respond to perinatal loss in ways that acknowledged women’s grief through practices to help assuage that grief and make meaning of their experiences (Davidson, 2011, 2008). Key to these practices are the interactions and supports provided by healthcare professionals, especially those with the closest contact to women during and just after their loss (Davidson 2011, 2008; Säflund, Sjögren, & Wredling, 2004). However, as will be seen later in this review, monitoring women’s well-being and extending support to subsequent pregnancies is also important.

Across the relevant literature, terms used to describe loss during or shortly after pregnancy vary by, for example, jurisdiction, weight, or gestational term. In my own work, and for our purposes as related to the articles for this review, I use the term ‘perinatal loss’ to include: loss of a baby/fetus at any stage of gestation where the loss occurs in hospital or can be supported by healthcare professionals; this includes babies miscarried or born prematurely, born still, or a baby who dies within 28 days after a live birth (a commonly understood as the ‘neonatal period’).

I used Google Scholar to begin my search for relevant articles published in 2017. My choice of four articles from four different journals, written by researchers from different scholarly perspectives (psychology, sociology and social

work, nursing, occupational therapy) was intentional. I begin this review with ‘The presence and predictors of complicated grief symptoms in perinatally bereaved mothers from a bereavement support organization’ (McSpedden, et al., 2017, pp. 112-117) written by psychologists and published in *Death Studies*. These authors note that while most mothers do not experience ‘complicated grief’, monitoring and providing supports to bereaved mothers is important to their health. Note here that the next three articles I have chosen for this review follow the theme of perinatal loss requiring more professional and social recognition and support, including opportunities for memory-making.

McSpedden, M., Mullan, B., Sharpe, L., Breen, L. J., & Lobb, E. A. (2017). The presence and predictors of complicated grief symptoms in perinatally bereaved mothers from a bereavement support organization. *Death Studies*, 4(2), 112–117.

The authors of this study found that while most mothers bereaved by perinatal loss did not develop complicated grief, a significant number scored higher for complicated grief up to five years postbereavement than for many other bereaved populations. Additionally, they found that the presence of living children may be a factor protecting women bereaved by perinatal loss from developing symptoms of complicated grief. Their study suggests that perinatally bereaved mothers should be routinely monitored as treatment may become indicated. Monitoring is especially important because complicated grief is recognised as a risk factor for psychological comorbidity, including for suicide.

Complicated grief is understood here as one of two main diagnostic criteria for disordered grief, one of which is prolonged grief disorder, and the other complicated grief. Both

disordered grief and complicated grief ‘describe intense distress; a range of cognitive, emotional, and behavioral symptoms; and functional impairment, all persisting for at least 6 months’ (McSpedden et al., 2017, p. 112). The authors differentiate perinatal bereavement from other types of bereavement as that which is often sudden and unexpected, and where experiences and memories of the child are limited and may be culturally unrecognised as loss, with few opportunities to engage in socially recognised rituals.

The authors’ findings are based on the participation of 121 perinatally bereaved mothers drawn from a bereavement support organisation in Australia. Their findings are also consistent with other studies that show a higher instance of complicated grief for parents bereaved by the loss of a child from illness. Also consistent with the authors’ findings of the presence of complicated grief are several studies showing mothers bereaved by perinatal loss have elevated levels of psychopathology. This study contributes to our understanding of the presence and predictors of complicated grief for perinatally bereaved mothers and suggests the need for greater support.

Murphy, S., & Cacciatore, J. (2017). The psychological social, and economic impact of stillbirth on families. *Seminars in Fetal & Neonatal Medicine*, 22 129–134.

Following the theme of support for mothers and families experiencing perinatal loss, the authors of this article explore research published over the last ten years that examines the psychological, social, and economic impact of perinatal loss on families. Analysis of the literature in terms of psychological impacts included identifying dimensions of the grief experienced, and noted that parents suffer from a range of emotions including guilt, shame, blame, regret, fear, stigma, and a sense of wanting to die. Some research has found that mothers express stronger emotions and more intrusive thoughts than fathers. The impact of perinatal loss on couples ranges from becoming closer to greater potential for troubled relationships. It seems that where grieving between partners is incongruent, marital discord following perinatal loss is more likely to occur.

Recent research has seen some focus on the needs of families following perinatal loss, including those of siblings. Parents have noted being more anxious, fearful, and overprotective of living siblings. However, the literature also notes debates about a pathological overprotection of subsequent children. Siblings have noted that their parents may be temporarily less available to them, especially at times they may need their parents the most. Research shows that it is important for siblings to be informed about grief and involved in mourning rituals so that they are allowed to express their own grief. The authors note that ‘Siblings, then, mourn both the baby and the loss of their previous relationship with their parents’ (Murphy & Cacciatore,

2017, p. 130). The examination of research on subsequent pregnancies and parenting after loss finds increased levels of anxiety for both parents, but higher levels for mothers; fathers felt overlooked in the research on pregnancies subsequent to loss; fathers also felt they had to present a strong front despite feelings of vulnerability. The theme of support for subsequent pregnancies is also seen in the fourth article reviewed here.

The authors also examined research that discusses consequences of post-mortem contact with the baby which, prior to the 1980s, was usually not even allowed in hospitals. Whereas it is now standard practice to at least offer the parents the option of seeing their baby, some researchers have posited the notion of the ‘assumptive offer’ – that is, to offer rather than to ask, so that ‘the experience is normalized, and, ... [noting that] asking any mother if she wants to see her baby is an ‘unnatural question’ (Murphy & Cacciatore, 2017, p. 130, drawing from the work of Erlandsson, Warland, Cacciatore, Radestad, 2013). What Murphy and Cacciatore note from the literature is that the psychological consequences of seeing one’s baby post-mortem is influenced by the *way* in which the baby is offered, and the degree of compassionate care by staff, as well as availability and access to post-hospital support. The authors also suggest that policies around medical care, such as, for example, the duration between a diagnosis of an intrauterine death and stillbirth may increase psychological trauma. However, while debate over post-mortem access continues, the authors ‘note that a systematic review of studies in this area found that 21 out of 23 studies reported positive outcomes for parents who had seen or held their baby, and that the role of the healthcare practitioners was key’ (Murphy & Cacciatore, 2017, p. 131).

Following their examination of psychological impacts of perinatal loss, the authors report on the mixed results of the social impact and support as perceived by parents. They note that both individual resilience and strong social support, including strong intimate relationships, serve as protection against negative long-term outcomes. While research done on perinatal loss in low-income countries is increasing, the grief experienced by women and families in these countries is still largely unacknowledged. Bereavement groups and support found via the Internet are seen to reduce symptoms of post-traumatic stress as well as establishing new relationships and resources to help make meaning out of loss. We will see more focus on the benefits of meaning-making in the third article for review.

While the literature on the psychological and social impacts of perinatal loss, specifically here within the last ten years, is considerable, the authors note a ‘dearth of research on the economic impacts’ (Murphy & Cacciatore, 2017, p. 132). What the literature does describe, however, are costs associated with child death more generally. Beyond funeral costs, lost wages due to bereavement, and parents’

return to work out of financial need rather than ‘readiness’ to return, research has found that not only do these factors pose a social burden, but the parents may incur lower wages over their life course. Specific to perinatal loss, researchers have begun to consider related healthcare costs, including during subsequent pregnancies where women may be considered high risk.

To date, however, most of the literature has been on the experiences of white, middle class, heterosexual couples. Research into the experiences of those who are ‘doubly-disenfranchised’ is called for. In addition to noting the need for more research and more nuanced research, Murphy and Cacciatore, having described the importance of the role of healthcare practitioners in mediating negative impacts after perinatal loss, offer four key practice points for professionals: the way in practitioners offer parents the chance to see their baby; validating parent’s loss (a point taken up in the following article); recognising that the loss is a loss to the entire family; and providing additional support in subsequent pregnancies (a point taken up here in the final article).

LeDuff, L. D., Bradshaw, W. T., & Blake, S. M. (2017). Transitional objects to facilitate grieving following perinatal loss. *Advances in Neonatal Care* 17(5) 347–353.

Following on the practice points suggested for professionals by Murphy and Cacciatore (2017), Lawrence D LeDuff, Wanda T Bradshaw, and Stephanie M Blake’s (2017) review of the literature demonstrates the role and importance of healthcare providers in helping parents make meaning of their experiences of perinatal loss. To facilitate healthy grieving, the authors argue for the use of ‘transitional objects’, as ‘mementos that validate the meaning of parenthood – even if the physical act of parenting was brief’ (LeDuff, Bradshaw, & Blake, 2017, p. 347). These objects can both help fill the void felt by ‘empty arms’ and validate the legitimacy of parenthood. Related to the inclusion of transitional objects such as lockets of hair, foot and hand prints, blankets, and stuffed animals, the authors also note the importance of bereavement rituals such as bathing, clothing, and photographing.

While older theories of loss have argued that it is best to move away from the deceased, more recent theories argue that maintaining connections can be a healthy way to grieve, and to move toward emotional healing. Despite the few studies questioning the use of rituals and transitional objects to facilitate healing, the authors note that ‘[t]he leading organizations of neonatal and perinatal medicine agree that the creation of memory-making opportunities is an important step in the healing of parents and families following a perinatal loss’ (LeDuff, Bradshaw, & Blake, 2017, p. 352).

Similar to the recommendations for care as related specifically to healthcare providers in the other articles for this

review, these authors recommend training specific to palliative and bereavement care, both in undergraduate nursing programs and for new nursing graduates. Along with a continuity of care, whenever possible, medical management should include planning along *with* parents allowing them as much control as possible.

Meredith, P., Wilson, T., Branjerdporn, G., Strong, & Desha, L. (2017). ‘Not just a normal mum’: a qualitative investigation of a support service for women who are pregnant subsequent to perinatal loss. *BMC Pregnancy and Childbirth* 17(6), 12 p. doi: 10.1186/s12884-016-1200-9

While the authors of the first article for this review called for continued monitoring and support, and the authors of articles two and three drew our further attention to bereavement needs, authors of the final article move forward to consider women’s pregnancy needs after loss. Here, Meredith et al., (2017) present their findings based on qualitative interviews with women during their subsequent pregnancies. While support for women immediately following perinatal loss has been relatively well-noted in the literature, these authors argue that ‘less is known about services during a subsequent pregnancy for women with a history of perinatal loss’ (Meredith et al., 2017, p. 2 of 12).

Using a thematic analysis of interviews with 10 mothers who were pregnant following a perinatal loss and attending a hospital-based Pregnancy After Loss Clinic (PALC), they identified seven themes and suggested recommendations for support services for subsequent pregnancies. First, the mothers felt they and their families benefitted greatly from support they received from the PALC. Second, the mothers were especially appreciative that at the PALC their pregnancy experiences were understood as unique, and their emotions as mixed. Third, participants noted that the PALC included ‘continuity of care, accessibility, availability, flexibility, and regularity’ (Meredith et al., 2017, p. 6 of 12), in addition to being able to develop rapport with as set of consistent care providers. Fourth, participants spoke about their experiences with other services in the hospital noting a contrast between interactions and support between other services and those more specialized services of the PALC. Fifth, their research documents recommendations for extending the PALC’s existing services to include ‘pre-conception, antenatal, intrapartum, and post-natal care’ (Meredith et al., 2017, p. 8 of 12). Sixth, participants called for appropriate alternative services, including similar services outside of the PALC’s catchment area, and services designed to meet more of the needs of family members. Seventh, using their experiential knowledge, the mothers provided advice to other women in pregnancies subsequent to loss; their advice included the use of a range of coping strategies that they themselves found to have been helpful.

The authors note that while this small study depicts experiences of women in one particular service, the results are reflective of the literature on pregnancy following loss more broadly. Consistent with the other articles chosen for this theme are Meredith et al.'s findings for a need for greater and continued support for women's anxieties and for more understanding by healthcare professionals.

Reviewer's comments

Elsewhere (Davidson, 2017, 2011, 2008 for example), I have noted the need for caring others to share in the 'grief-work' of bereaved persons. Griefwork is understood as the labour shared and negotiated by caring others, including healthcare professionals and grieving persons in an attempt to assuage grief and make meaning of loss. The articles chosen for this review all speak to the need for this type of support, particularly here support for those bereaved by perinatal loss. It may be difficult for those who have no personal experience of perinatal loss to understand that pregnancy, especially to those whose babies have died, is more than 'expecting' a child – rather, it is a holistic and embodied experience. In pregnancy we may already experience our babies, and ourselves as mothers – through our behaviours and our intentions. And yet, when our babies die, we are left with 'empty arms', and advice by others that should just 'move on'.

What struck me most, both personally and as research that is new to me, from Murphy and Cacciatore, is the research on post-mortem contact with one's baby. When my babies died shortly after birth in 1975 and 1977 I was not given the choice of having contact with them. I would argue that this contributed to the complicated grief I experienced as discussed in McSpedden et al.

When LeDuff, Bradshaw, and Blake write about transitional objects that can both fill the void felt by 'empty arms' and validate the legitimacy of parenthood, I remember leaving the hospital on two occasions with empty arms. I remember being in hospital after the births and deaths of my babies, being told that 'I was not a mother'. I remember this over forty years later, and I remember the short but meaningful lives of my babies. And I value those who have since participated in my griefwork by supporting me and helping me make meaning out of my losses.

I also noted above from LeDuff, Bradshaw, and Blake that while older theories of loss have argued that it is best to move away from the deceased, more recent theories argue that maintaining connections can be a healthy way to grieve, and to move toward emotional healing. While I was encouraged to move away, my grief became complicated as we saw in McSpedden et al. McSpedden et al. also write about continuing, rather than severing bonds. After seeking support from and participating in bereavement groups and taking up related scholarly work, not only was I able to make and give meaning to my losses, but I became empowered to continue the bonds that began in my pregnancies, and that will not be severed. My experiences, and what is noted in the articles for this review, support the model of understanding grief and bereavement through continuing bonds. Further to helping make sense out of and dealing better with experiences of loss, the continuing bonds model suggests and supports new directions for improved bereavement practice. For further reading on the subject of continuing bonds, I recommend *Continuing bonds in bereavement: New directions for research and practice* (Klass & Steffen, eds, 2018). ■

Davidson, D. (2008). A technology of care: Caregiver response to perinatal loss. *Women's Studies International Forum, Special Edition, Women and Technologies of Reproduction* 31(4), 278–284.

Davidson, D. (2011). Reflections on doing research grounded in my experience of perinatal loss: From auto/biography to autoethnography. *Sociological Research Online* <http://www.socresonline.org.uk/16/1/6.html>.

Davidson, D. (2017). Art embodied: Tattoos as memorials. *Bereavement Care* 36(1), 33–40.

Erlandsson, K., Warland, J., Cacciatore, J., Radestad, I. (2013). Seeing and holding a still-born baby: mothers' feelings in relation to how their babies were presented to them after birth - findings from an online questionnaire. *Midwifery* 29(3), 246–250.

Klass, D., Steffen, E. M. (eds) (2018). *Continuing bonds in bereavement: New directions for research and practice*. New York: Routledge.

Säflund, K., Sjögren, B. & Wredling, R. (2004). The role of caregivers after a stillbirth: Views and experiences of parents. *Birth* 31(2) DOI: 10.1111/j.0730-7659.2004.00291.x