

The emergence and effect of hospital protocols for perinatal loss in Canada



Deborah Davidson

Associate Professor of Sociology, York University, Toronto
debd@yorku.ca

Abstract: The 1980s and 1990s saw the remaking of the meaning of perinatal death in¹ Canadian hospitals from that of the silencing to the recognition and attention to women's grief (Davidson, 2007). By the mid-twentieth century both birth and death were increasingly removed from the home and placed in healthcare and funeral facilities (Aries, 1981; Walter, 1994). Beginning in the 1950s when hospital birth had become the general social norm, death around the time of birth became a new institutional concern. Using a symbolic interactionist approach, I document how this new standard of care emerged as perinatal bereavement protocols in the Canadian context. Situating the emergence in its historical context, it is examined here through the time-relevant literature – that is, the literature that influenced the changes from the 1960s through the early 2000s. Then, examined through more recent literature, I illustrate how the protocols continue to work for one extended family after their experience of stillbirth in 2012.

Keywords: perinatal loss, bereavement, griefwork, hospital protocols

After the institutionalisation of hospital birth, perinatal death was managed without the hospital recognition of 'a mother's highly variable emotional, psychological, physical, and social response to the involuntary loss of her fetus or infant' (Peppers, 1989, p. 135, citing Peppers & Knapp, 1980a, p. 155). Without this recognition, women were quickly separated from their dying or dead babies and the grief they may have experienced was silenced. But during the mid 1980s through the 1990s, a group of compassionate caregivers began to recognise that this standard did not provide what women and families needed. I show how it became the institutional expectation that for women who suffered perinatal death it was the duty of hospitals to recognise and respond to their grief. My assertion is that while changing attitudes around death, and changes in technology and medical specialisation conditioned the shift in hospital practices, it was a subset

of healthcare providers who developed and actuated the change. They did so first through individual agency and then through collective action. Finally, I conclude with an example of the protocols at work in 2017.

My approach

Inspired by my own experiences of pre-term birth leading to perinatal loss occurring before the institutional shift, my methodology employs a symbolic interactionist approach to show how key actors, as innovators of the protocols, came to understand women's experience of perinatal death. This approach is based on three core principles: people act based on meaning; these meanings are derived through social interaction; and to help make sense of their social worlds, the meanings are managed and transformed through interpretation (Blumer, 1962). To examine the institutional shift I drew first from two interdisciplinary bodies of scholarship covering the period of the emergence between the 1950s and the early 2000s: the social science

¹ Loss occurring around the time of birth, including therapeutic abortion, miscarriage, stillbirth, and neonatal death.

of perinatal loss, and the history and sociology of death and dying. As well, I reviewed Health Canada and hospital documents related to birth practices during this period, and conducted 35 open-ended, semi-structured interviews with key actors (nurses, chaplains, doctors, social workers and bereaved mothers who advocated for change) who were responsible for the development of the protocols.² Next, illustrating how the protocols work in present day, I drew from literature on perinatal loss that followed the institutionalisation of the protocols from the early 2000s onward.

Social science literature on perinatal loss, the 1960s through the beginning of the 21st century

The literature on perinatal loss was preceded by the psychoanalytical literature of the 1950s, which employed and amended Freudian concepts from earlier in that century. Freud proposed that 'grief work' was work done by the grieving individual to sever ties with the deceased (Stroebe & Shut, 1999). However, Bowlby's (1961, 1979) work on attachment theory, from the 1950s to the early 1980s, became important to a new understanding of maternal grief. His theory of continuing bonds provided justification for women maintaining, rather than severing, ties with their dead babies. Bowlby's work was taken up by pediatricians Klaus and Kennell (1976) who brought awareness and discussion of the widely practiced separation of infant and mother to medical and general audiences.

Some professionals began to be influenced by their interactions with the women themselves as well as by the developing literature on bereavement and death. By the 1960s, a small number of clinical reports written by psychiatrists (Toetder, Lasker, & Janssen, 2001) emerged as part of a broader interest in bereavement and, from that, in the 1980s a social science literature on perinatal loss began to appear. First was the awareness of perinatal death as a little-understood tragedy (see Borg & Lasker, 1982; Klaus & Kennell, 1976; Leon, 1992, 1990; Peppers & Knapp, 1980b; Raphael-Leff, 1991; Reinhartz, 1988, 1987; Savage, 1989; Zeanah, 1989). Next was a quantitative literature on grief, mourning, gender differences, and patient satisfaction (see Covington & Theut, 1993; Gilbert & Smart, 1992; Goldbach, Dunn, Toetder, & Lasker, 1991; Harper & Wisian, 1994; Moohan, Ashe, & Cecil, 1994; Theut, Zaslow, Rabinovich, Bartko, & Morihisa, 1990; Slade, 1994; Smith & Borgers, 1988; Stinson, Lasker, Lohmann, & Toetder, 1992).

The early and mid 1990s saw feminist literature concerned specifically with women's experiences (see Braun & Berg, 1994; Cecil, 1996a, 1996b; Hebert, 1998;

Layne, 2003, 1997, 1996, 1992, 1990; Letherby, 1993; Malacrida, 1999, 1998; Raphael-Leff, 1991; Simonds & Rothman, 1992). Particularly influential are the works of Simonds and Rothman (1992) regarding maternal grief as timeless with its silencing historically conditioned, and Layne (2003, 1997, 1996, 1992, 1990), arguing that a 'veil of silence' around pregnancy loss did not serve women's wellbeing. By the late 1990s, the institutionalisation of the perinatal bereavement protocols gave voice to maternal grief experienced under these historically-specific conditions.

A socio-historical understanding of death, the 1980s through the beginning of the 21st century

By the beginning of the 21st century, numerous socio-historical analyses of death had been published (see, for example, Ariès, 1981; Armstrong, 1987; Auger, 2000; Clark, 1993; Homans, 2000; Littlewood, 1993; Mellor, 1993; Prior, 2000; Seale, 1998; Small, 2001; Small & Hockey, 2001; Walter, 2000, 1994, 1993). This literature was in general agreement that death was then understood to be hidden in institutions, sanitised, professionalised, subject to rationalisation and control. The second half of the 20th century as the historical context in which the protocols emerged can be seen in the work of Walter (1994), who argued that there occurred a 'revival of death' where modern medicine and more traditional elements of death are combined for a 'more personal way of death, disposal and/or grief' (Walter, 1994, p. 204). While birth still occurred primarily in hospital with the use of technology, the historical context was now such that hospital protocols for perinatal bereavement emerged.

The emergence of perinatal support groups as a 'more personal way of death, disposal and/or grief'

It was in the 1960s and 1970s that the death awareness and self-help movements also emerged. And it was an increasingly generalist use of psychology along with the women's movement that helped pave the way for pregnancy loss support groups. In Canada, Bereaved Families of Ontario (BFO) was founded by bereaved parents, with support from specialists in grief and bereavement serving as 'a resource both in the development of on-going programs and in the support and training of volunteer group facilitators' (Bereaved Families of Ontario, 2002).³ This exemplifies what Walter (1994) refers to as a more personal way to grieve, but where medical professionals still play a

² Ethics approval for this research was received from York University, Toronto, Canada.

³ This is similar to the circumstances that began SANDS/UK (www.sands.org.uk/about-sands/who-we-are/our-history) and SHARE/US (<http://nationalshare.org/about-share/our-history/>).

role. Thus far, I have provided a brief social and historical context for the emergence of the protocols. Next, I describe how maternal grief was denied and women were silenced prior to the protocols.

Denying perinatal death as loss: hospital practices, 1950–1985

By the 1950s, 76% of births in Canada were in hospitals (Mitchinson, 2002, p. 175). Accordingly, life and death decisions about dead and sick or dying babies was now no longer made in the privacy of the home between parents and physicians or midwives. The institutional response to such losses was one of dismissal though separation and silence – that the event was best forgotten. In his description of the circumstance of the stillborn or premature death in the 1960s, Sudnow (1967, p. 100, p.112–113, emphasis added) observed:

'[M]other' [is] to sleep when a biologically troublesome infant is delivered . . .

Should the mother detect trouble . . . she is vaguely and evasively told not to worry, and gas is quickly given . . . to manage at least temporarily the task of separating the relative from the scene of the death.

Sudnow's observations illustrate birth and death practices in this period where women were alienated from their babies as these practices became increasingly medicalised and institutionalised.

Further evidence of the dismissal of women's experiences of birth and loss was recognised by Klaus and Kennell (1976, p. 212) noting that: 'When a newborn dies in the hospital, all evidence of his [sic] existence is usually removed with amazing rapidity, and nothing is left to confirm the reality of his death'. Klaus and Kennell interviewed women to make several recommendations that were contrary to the existing standard. These early recommendations included: not separating parents from their babies, recognising and acknowledging grief, avoiding the use of tranquilisers in favour of listening to the women, understanding grief as normal rather than pathological, and training staff to be able to support parents.

Women were routinely separated from their dead or dying babies, their grief unrecognised or dismissed. And yet hospital staff, as the first people present at the birth and death, were often untrained. As Borg and Lasker (1982) noted: 'In far too many hospitals, staff members are untrained in ways of helping parents . . . These hospitals have either not established policies for responding to tragic birth events or they fall back on restrictive policies that make the experience even more traumatic' (p. 124). Similarly, Kirkley-Best, Kellner, and Ladue (1985) reported obstetricians' attitudes to stillbirth and concluded that physicians require more information 'in order that their

relationships with grieving patients be most effective' (p. 326).

Situating action through compassionate care and renegotiating hospital order

'What varieties of men and women now prevail in this society and in this period? . . . In what ways are they selected and formed, liberated and repressed, made sensitive and blunted?' (Mills, 1959, p. 7, emphasis added)

'It was only some very brave individuals in the past that started this ball rolling'. [nurse, #32]

After describing the socio-historical conditions that prepared the ground for the shift, I move to proximate conditions; that is, the individual actors who were sensitised to women's needs, exercised their individual agency, and formed a critical mass to shift the institutional pattern of dismissing grief in perinatal death. Looking for people who were responsible for the shift, first I recruited through purposive sampling. Then, building from an initial small network of healthcare professionals who responded, I secured more interviews through snowball sampling. Reaching what I felt was a saturation sample, working from my interview data from 35 participants, I argue that while the participants for this research were passionate in their roles as innovative and compassionate caregivers, it was a specific experience for each that first sensitised them to the social-emotional needs of women. As they exercised their agency – first as individuals, then as affinity groups – they began to translate their compassion for women into interventions to manage the grief experienced in perinatal death.

I discovered three ways in which these actors became sensitised to maternal grief: experiences of death during their childhood, experiences related to their work as healthcare professionals, and their own or others' experiences of reproductive or child loss. These 'emotional pasts are important tools used in the interpretation and construction of present emotions, to situate selves and others' (Mattley, 2002, p. 363) and thus, foundational to action. Examples include the following.

Experiences of death during their childhood:

'When I was about three, I had a brother die of SIDS and there was a police investigation and my older brother and I were told to go upstairs and close the door . . . and it was not much talked about after that . . . I didn't realize there was another way to have a brother die . . . Because [as a nurse] I was there and gave people options, they are in a different place.' [nurse administrator, #15]

Experiences of perinatal loss through work as health care professionals:

'There were two women who had just come into labour and delivery. I took one woman and my co-worker took another. The woman I took said to me "you should have taken the other patient". I asked her why and she said, "because my baby is dead" I said "your baby died, how awful. I am delighted to be looking after you". *That lady changed my practice I thought who more needs support than this woman?*' [nurse, #6]

Experiences of reproductive loss or the loss of a child:

'I experienced years of infertility, and witnessed perinatal losses in friends I was an educator who taught pediatrics I did my Master's Degree on perinatal loss.' [nurse, #19]

As one chaplain described: 'we either give up or try to do something' [chaplain, #20]. Rather than choosing to 'give up', they began 'to try to do something' for the women in their care.

These caregivers felt they needed to modify their roles to reposition themselves closer to the women to understand their needs. Once they questioned their role expectations, such as dismissal of grief, caregivers formed alliances in affinity groups where team development made broader change possible. Moving towards collective action, one nurse noted what was reiterated by many participants. 'I had an amazing and passionate nurse manager in labour and delivery whose values and mine were very much akin I thought that between the two of us we could really move mountains and implement a bereavement program, which we did' [nurse, #32].

It became apparent that these key actors recognised and cared about women's suffering. They remade their roles to allow for interventions to help mitigate against the trauma of perinatal death.

Participants related the importance of listening as a way of learning about grief and developing protocols, as illustrated here:

'The changes were nurse-driven because nurses are with the patient in the middle of the night when they need comforting.' [nurse, #5]

'Because of feedback from families ... we have always maintained a file of photos and items of memory so the families could come back to reconnect.' [chaplain, #26]

Participants also renegotiated the existing hospital order through practices such as: discussing babies' deaths with their patients, changing the practice of separating mother

from baby, and modifying baptismal practices. As noted by this physician:

'It was in about 1975 that I started to do something for the parents of the little ones who died who I'd been looking after. This involved ... taking babies out of incubators and off ventilators and letting parents hold them.'

One chaplain described the baptismal procedure as follows:

'Generally ... we only do an emergency baptism when families request it and the baby is usually alive. A family might want a baptism even though the baby was dead If I talk to the family and I realize that a blessing or a dedication just won't do, I will do a baptism from my theological understanding that I think the baby was alive in the mother's womb and it has died and has been resurrected and is now safe in God's arms so it is living.' [chaplain, #11]

Through compassionate care and their exercise of agency, key actors began to give voice to women's grief and began to develop responsive interventions. With a momentum for change, collective action would now see the emerging protocols come to fruition as a new standard of care.

Collective action, 'griefwork' and a new standard of care

Medical, academic and popular literature of the second half of the 20th century, and key actors, working together with women in their care, set the stage for a new standard of care. This was accomplished through collective action: '[a]ction that people engage in as a group and formulate as a response to problematic conditions, often in opposition to existing societal norms' (Sandstrom, Martin, & Fine, 2003, p. 201). Key actors' common goal was to develop and implement a caring response *with* and for grieving women, so that women did not have to rely solely on individual emotion work. Given my interactionist approach, coining a more appropriate term for this particular collective action, I refer to 'griefwork', a social science concept, as the labour shared and negotiated between grieving persons and caring others (Davidson, 2007). This is a response to the earlier understanding of perinatal loss as well as to the conventional literature on bereavement's uses of 'grief work', noted above as a Freudian psychological concept as work done by an individual. The bereavement protocols represent *collectively negotiated* interventions based in a new understanding of perinatal death, maternal grief, and caregiver responsibility (Davidson, 2007).

Participants explained that collective action provided the confidence needed to ‘solidify their views’ [nurse, #31], noting ‘I couldn’t have done these things myself. My team did them’ [nurse, #19]. Collectively, members vetted ideas, supported each other, initiated, innovated, negotiated and shared responsibility. These strategies were important, because: ‘coalition was key to change’ [physician, #8], and it required multidisciplinary participation by nurses, social workers, physicians, genetics counsellors, bereavement counsellors, and parents.

Collective action also occurred through extra-local action on two fronts: one moving outward from hospitals, and one moving into hospitals from other institutions. Different hospitals, for example, worked together, often relying on hospitals with neonatal intensive care units for guidance. Collective action also came from the Canadian Pediatrics Society, particularly through its Fetus and Newborn Committee, which helped secure support on a national level. Earlier Health Canada documents (1968, 1975), also reviewed, do not include reference to grief after perinatal loss. In the 1987 edition we see a shift to family-centred maternity with a only brief mention of perinatal loss and grief. It was not until Canada’s *National Guidelines* (Health Canada, 2000, p. 4th edition) that national-level bereavement protocols were anchored as expectations for care. This represented a new conceptualisation of perinatal loss and its emotional impact on patients, family, and healthcare providers, describing grief as a ‘normal, healthy, healing, and loving response’ (Health Canada, 2000, p. 8.5) to loss. ‘Good grief’ it notes, entails ‘remembering and reliving – a notion that challenges the unthinking advice often given to parents who have lost a child...’ (Health Canada, 2000, p. 8.5).

Perinatal bereavement protocols: supportive, facilitative, and informational interventions

The protocols embody work practices that co-ordinate a series of social relations through supportive, facilitative and informational interventions which can co-occur in practice. *Supportive interventions* ‘focus on reassuring parents that their expressions of grief are encouraged and accepted – no matter the form. Healthcare providers also need to take time just to “be” with grieving parents’ (Health Canada, 2000, Table 8.5). Some examples include: ‘[h]and-holding or a touch on the brow or soothing sounds of empathy and encouragement, of being with women in the middle of the night when they need comforting’ [nurse, #5], as well as the provision of options ‘including not seeing their baby, and the option to change their mind’ [nurse, #6]. Quiet bereavement rooms give families private space in which to spend time with the babies. Yearly memorial services for all babies who have died are held for families and the caregivers who have supported them.

Facilitative interventions intercede on behalf of grieving women and describe relations of caregivers to institutions and people other than the grieving women, and are directed at making the loss real, co-ordinating care, helping families navigate the legal requirements, and helping them prepare for the future (Health Canada, 2000, Table 8.5).

Cleaning and food services staff, pathologists, phlebotomists, transport, morgue staff and funereal services are among those involved as the practice crosses professions.

Social workers and chaplains help to arrange welfare services to cover basic funeral costs. Caregivers also partner with the morgue and with funereal services outside of the hospital as noted by one participant:

‘We created a sacred space in our morgue saying “Baby Resting Here” so parents know great care is taken with their baby. The transition from womb to grave didn’t have to happen in one day. They could have time before the baby was buried.’ [nurse, #6]

Facilitative interventions also include photography and the provision of mementos as well as official and unofficial certificates of birth and death, helping women make memories and having something to take home with them.

Informational interventions connect women with texts and organisations outside the hospital to help them make decisions and regain a sense of control during their experience of grief, and:

‘... include providing information about grief and what parents can expect in terms of their own responses... Other interventions entail verbal and printed information about burial and cremation procedures, memorial services, legal requirements, hospital regulations, and community services including bereaved parent support groups.’ (Health Canada, 2000, Table 8.5)

One chaplain, for example, researched and developed a catalogue of multi-faith and multicultural traditions regarding death practices [chaplain, #11]. The need for information is not always immediate and caregivers may be ‘on call’ to provide information years after the event of death, as described here: ‘I have a mom whose child died three-and-a-half years ago who emailed me and said...I need your help... She had unresolved questions that needed to be answered...I got her some answers [nurse, #2]’. Other informational interventions include the provision of printed material, resources about the burial of miscarried babies, bereavement kits including information about bereavement services, genetic counselling, and autopsy results.

While the *National Guidelines* secured perinatal bereavement protocols as a new way of managing perinatal

death in hospital culture, these guidelines represented a systematic form of what compassionate caregivers were already doing in practice. The development of the perinatal bereavement protocols was interaction-driven, based on human need and human response.

Understanding perinatal loss through the 21st century literature

Since the emergence of the protocols in Canada and elsewhere by the early 2000s, a new literature has emerged. From this literature on the protocols and their efficacy, four key points have been well documented. First, is that perinatal death can have long-lasting effects, including anxiety, depression, and PTSD (see, for example, Cassidy, 2018; Murphy & Cacciatore, 2017; Basile & Thorsteinnsson, 2015; Koopmans, Wilson, Cacciatore, & Flendy, 2013; Gravensteen, Helgadóttir, Jacobsen, Rådestad, Sandset, & Ekeberg, 2013; Pullen, Golden, & Cacciatore, 2012; Cacciatore, 2012; Cacciatore, 2010; Turton, Evans, & Hughes, 2009; Fielding, Haddow, Wilson, & Fernandes, 2009). Second, it is reported that this loss is still ‘one of the most disenfranchised and misunderstood types of loss’ (Cacciatore, 2012, p. 1). Third, the creation of memories of their babies and their experience supports positive outcomes (see, for example, Basile & Thorsteinnsson, 2015; Capitulo, 2005). Fourth and finally, as was supported by all of the above, ‘Primary healthcare interventions and a strong family and social support network are invaluable to parents and families around the time a baby dies’ (Koopmans et al., 2013, p. 2). It is this fourth point that I refer to as ‘griefwork’ – the labour shared and negotiated between grieving persons and caring others (Davidson, 2011, 2007, 2008; Davidson & Letherby, 2014).

The protocols and griefwork: from ‘dead baby’ to ‘granddaughter’

The following story demonstrates the protocols at work and the importance of griefwork as labour shared and negotiated by grieving persons and caring others (as opposed to the primarily psychological concept of grief work as individual emotional labour). In 2017, an opportunity arose to examine how the protocols worked for one extended family with whom I have a relationship through marriage. My husband’s cousin, Angus, who my husband had not seen in 50 years, came to visit from Nova Scotia in 2017. His story brought me to this research and into this extended family. He told us about how, because of his postmortem interaction with his daughter’s ‘dead baby’, she became his ‘granddaughter’. In 2012, Angus and his wife Betty got a call saying that their daughter Tracey’s baby was born still. On the five-hour drive to Halifax, Nova Scotia, Angus felt sorrow for his daughter, but didn’t experience loss of his own. When they got to the hospital, Tracey was holding Jonah Wynn and asked Angus if he

wanted to hold and rock Jonah. Angus was shocked at the thought of holding a dead baby but, not wanting to distress Tracey further, he rocked the baby for a long time. Because Tracey had almost died after Jonah’s birth, she remained in hospital for an unusual period of three weeks. *Every day of those three weeks, every time Tracey asked, Jonah was brought to her, while she was alone or with family and friends.* Furthermore, upon release from hospital, Tracey and husband Brad brought Jonah home for her funeral.

Knowing how Angus reacted to holding a ‘dead baby’, I wondered how others who spent time in hospital with Tracey and who attended her home funeral felt. So I examined it sociologically, using a symbolic interactionist framework where meaning is made through interaction – specifically here interaction with Tracey and postmortem Jonah, and then with other family members. To do so, I interviewed four of Jonah’s grandparents and five others who were at the hospital and who, for the following six years, to honour and remember Jonah, participated in the Halifax Walk to Remember, remembering deceased babies.

Discussion with Tracey and the hospital chaplain confirmed that the protocols set out in the 2000 Health Canada Document had been at play during Tracey’s hospital stay. My interviews revealed three themes: shock and surprise; a desire to comfort Tracey; Tracey’s encouragement to others to interact with Jonah positioning Jonah as a family member, rather than as a ‘dead baby’.

Comments showing shock and surprise included:

‘One thing I was surprised and shocked at was that Tracey was able to see Jonah at any time. [Some family members] didn’t agree that the hospital should put Tracey through that but only she and Brad would really know what it was like to lose Jonah so ... it was totally up to her and what she needed to do to survive this.’

But wanting to comfort Tracey, they tried not to appear shocked or surprised to her.

‘Tracey wanted us to know her before we had to let her go. At first, I couldn’t hold Jonah because I was still in shock, but later I held her and I loved her.’

‘I could not say no even though I wanted to. I did not feel attachment toward the baby at that time. But encouragement from Tracey was all we needed.’

And it was the encouragement they needed to understand Jonah as a member of their family.

‘But as I sat there and rocked and ... after looking at this beautiful baby girl I was holding in my arms I could feel her growing in my heart ... she went from an unknown stillborn baby to being my granddaughter in a very short time.’ [Angus]

And from other participants:

'The one thing Tracey didn't want to happen was for people to forget or not want to talk about Jonah. There have been so many things we have done *as a family* over the past five years... Walk to Remember, Jonah's Way, Act of Kindness Day [both charities set up to remember Jonah], donating blood because of all of the blood Tracey needed during her recovery, go to the gravesite and decorate it for birthdays and holidays, and donate to the Pre-eclampsia Foundation that Tracey helped establish.'

'Holding Jonah was described as "beautiful, comforting"; I will never forget. Having that bond with Jonah for Tracey has made her get through some very tough days.'

These experiences of holding Jonah are consistent with the literature. While most of the literature on seeing and holding babies born still understands it as a positive intervention (Basile & Thorsteinsson, 2015; Koopmans et al., 2013; Erlandsson, Warland, Cacciatore, & Rådestad, 2013; Cacciatore, 2010; Cacciatore, 2012; Cacciatore & Bushfield, 2007; Rådestad et al., 2007; Capitulo, 2005, a few studies, which have been criticised for methodological weakness, question efficacy of the protocols (Koopmans et al., 2013). Larger longitudinal studies disagree with the studies questioning its efficacy (see Erlandsson, Warland, Cacciatore, & Rådestad, 2013). In their systematic review of the impact on stillbirth from 2007–2017 (Murphy & Cacciatore, 2017), the authors found 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 – *how* the baby was offered, as invitational and normal – was key to the outcomes. This includes 'assumptive bonding' (Erlandsson et al., 2013), where caregivers approach the mother assuming she wishes to see her baby, as a natural option, rather than as a stigmatised one. With an assumptive offer 'the experience is normalized, and... asking any mother if she wants to see her baby is an "unnatural question" (Murphy & Cacciatore, 2017, p. 130). This is also seen to be important to creating the memories that parents find helpful.

To make meaning and memories, it was important for Tracey to have Jonah included in her family, not only at the time of her death but for the future. In her need and wisdom, Tracey's offering of Jonah to family members was also invitational and normal – and a bonding experience with both Tracey and Jonah. Despite some initial reluctance by some, they held Jonah and they bonded with her, as part of their family. Tracey also insisted that, even after three weeks in the morgue, Jonah be brought *home* for her funeral, which was a shock to some of her family members. For Tracey, Jonah was not to be associated only with the hospital. As noted by Cacciatore (2010, p. 693), 'seeing the baby's body helps a mother to begin the process of relinquishment while revising attachment'. A further study (Cacciatore, 2010) notes:

'In a longitudinal study of Dutch parents whose children died at various ages ranging from stillbirth to 29 years of age, parents who had an opportunity to say farewell had lower grief scores than those who did not across the age groups. In addition, those who chose home funerals, that is, they cared for their child's body during the postmortem period in their home, also reported lower grief scores two years following the loss. The researchers suggest that this process assists parents in confronting and realizing their loss (p. 693).

Tracey made sure that her grief and her daughter would not be disenfranchised, but would be seen and validated in death *and* in life (Cacciatore, 2012). And rather than being alone in her mourning, with no one else missing Jonah, Tracey was intentional in that her family recognise her motherhood, her loss, and her daughter Jonah Wynn's place in their family through memories of Jonah and celebrations of her life. How caregivers 'offered' Jonah and sensitively complied with Tracey's three weeks of requests to be with her, and Tracey's family's support, are examples of griefwork. As manifestations of griefwork, the protocols assisted Tracey in dealing with loss and integrating Jonah into her life in meaningful ways.

As a participant observer, I also attended the 2017 Halifax Walk to Remember along with Tracey and other family members, where we walked together in memory and honour of Jonah, my two babies, and all deceased babies. Seventeen years after the institutionalisation of bereavement protocols for perinatal loss, griefwork – the labour shared and negotiated among a grieving person and caring others to integrate the loss into their lives in a meaningful way – was being enacted. Tracey and Brad were not alone and, for the first time in more than 40 years, neither was I.



2017 Halifax Walk to Remember: We are family.

This article is in loving memory of Jonah Wynn MacCharles.

See: In memory of my daughter, Jonah Wynn MacCharles – May 4, 2012

www.youtube.com/watch?v=fG6XJtF8uDE [accessed 22 January 2020] ■

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