

# With Woman in Perinatal Loss

## *Accompagner une femme lors d'une mort périnatale*

by Lynlee Spencer, RM

### ABSTRACT

This paper explores how women experience perinatal loss, and how midwives can be supportive under these circumstances. It examines both the features of perinatal loss that unite women into a subculture of bereaved mothers, as well as some sociocultural issues, such as poverty, that can compound their grief. It also addresses the limited professional training that midwives receive in this area, and offers suggestions for how to better prepare them.

### KEYWORDS

*midwifery, perinatal loss, stillbirth, miscarriage, grief, bereavement, cultural competence, education*

### RESUMÉ

Cet article explore le vécu des femmes vivant un deuil périnatal et la manière dont les sages-femmes peuvent leur offrir un soutien. Il examine à la fois les caractéristiques de la perte périnatale qui unit les femmes au sein d'une sous-culture de mères endeuillées ainsi que certains problèmes socioculturels, comme la pauvreté, qui peuvent intensifier leur deuil. Il aborde aussi la formation professionnelle limitée que reçoivent les sages-femmes dans ce domaine et offre des suggestions afin de mieux les préparer.

### MOTS-CLÉS

*pratique sage-femme, mort périnatale, mortinaissance, fausse couche, chagrin, deuil, compétence culturelle, éducation*

#### *Introduction*

When a woman becomes pregnant, everyone believes she will give birth to a healthy baby. Understandably, few entertain the possibility that her pregnancy will not run its expected course. Yet, statistics paint an unfortunate reality for some of these women. The pregnancy outcomes for 2005 in Canada showed the rate of fetal loss – stillbirths, miscarriages, and spontaneous abortions – as 1.0 per thousand pregnancies, excluding 11.8 per thousand therapeutic abortions.<sup>1</sup> Birth statistics for 2007 in Canada showed that stillbirths rates were 7.1 per thousand live births for gestations greater than 20 weeks, and 3.2 per thousand live births for gestations greater than 28 weeks.<sup>2</sup> On the other hand, Canadian death statistics from the same year reported the perinatal death rate of a fetus at 28 weeks or more up to a newborn six

days of age as 6.4 per thousand live births, and the neonatal death rate of a child from birth to 27 days as 3.8 per thousand live births.<sup>3</sup>

Though its definition is controversial, perinatal loss can include miscarriage, therapeutic abortion, stillbirth, and neonatal death.<sup>4</sup> This inclusive description suggests that midwives will, undoubtedly, encounter perinatal loss in some form during their careers. Midwives play an integral role in helping women realize a positive experience, which is especially important when an outcome does not go as planned. They have a professional responsibility to be mindful that perinatal loss can evoke diverse grief reactions, and to make every attempt to respond in a culturally appropriate way.

Yet, midwives are often not trained to provide immediate and ongoing bereavement support in these difficult circumstances. Compassion and good listening skills, while virtuous qualities in any care provider, are not enough preparation for this delicate work. Early in their careers as students, midwives need an opportunity to explore their own values around perinatal death, as well as the social and cultural forces that make grief inherently individual and complex. Reflecting on the experience of perinatal loss within socio-cultural contexts, and learning skills for supporting clients in these unfortunate situations, are important exercises that help prepare midwives for delivering sensitive care when it really counts.

#### *What is Perinatal Loss?*

Defining perinatal loss is challenging and pushes our intellectual boundaries. Midwives are faced with a number of different losses in their practice. Trying to assign meaning or magnitude to these varied experiences is futile, especially when "general assumptions about the impact of a particular loss, based on length of gestation or choice, are likely to be wrong."<sup>5</sup> Perinatal loss is an inherently marginalizing experience. On one level, death occurring before life presents the ultimate paradox.<sup>5,6,7</sup> An already difficult concept to articulate is rendered even more obscure by dominant discourses, which shroud perinatal loss in minimizing language that perpetuates it as an outcome deviating from normal. Language provides clues to values and beliefs in our society, and a number of examples demonstrate how it can silence women's experiences. Some of the more insensitive terminology 'little bits of meat' and 'products of conception' are obviously degrading.<sup>6</sup> Even the seemingly innocuous labels of 'miscarriage' and 'ectopic pregnancy' inadvertently mask the crux of the issue that women who experience perinatal loss are often grieving lost babies regardless of medical, workplace, or legal definitions.<sup>8</sup>

#### *Death, in Modern Times*

With modern civilization came the movement of death out of homes and into hospitals, which led to its medicalization and, ultimately, its interpretation as a failure of medicine as opposed to a natural part of life.<sup>9</sup> Before this time, mortality in pregnancy and

birth was significantly higher, and rituals existed to mourn these losses.<sup>7,10</sup> Even though science has yet to prevent death, Western societies persist in this vein; a pursuit that has replaced intuitive traditions with practical science. Despite advances in medicine, perinatal loss remains a reality for many women, who often perceive the absence of mourning rituals as reflecting a society that does not validate or recognize their experience. Within this context, social expectations are also lacking,<sup>12</sup> perinatal loss is deemed a nonsocial event, and any customary mourning rituals and social support around death are further suppressed.<sup>8</sup>

Modernization has also affected perinatal loss through technologies that can accelerate prenatal attachment. Early pregnancy tests and ultrasound images, for example, confirm pregnancies and make them more salient. To speak of this in absolute terms, early prenatal attachment is an inevitable consequence of technology<sup>13</sup> or a woman's greater bonding with her unborn child leads to more intense grief, are prescriptive and misleading. A poignant editorial by Kirshenbaum<sup>14</sup> highlights the discord arising from societal pressures to form these early attachments within a culture that fails to acknowledge or consider the possibility of perinatal loss. She writes,

*With the clarity of fetal images, we are now tugged beyond the borders that marked the emotional terrain of pregnant women of another time. . . We anoint a barely pregnant woman a mother, yet remain silent about the frequency of miscarriage – a silence that is often received as a message of failure.*

Cultures focused on ideologies of motherhood, she points out, ostracize women with a history of miscarriage who may be reluctant to form these early relationships.

#### *Cultural Contexts*

As Young & Papadatou<sup>15</sup> point out, "grief reactions in other societies must be understood within their cultural context otherwise they can be interpreted as pathological." My limited culture-specific analysis of perinatal loss rituals and conversation with a midwife, who cares for a significant number of South

Asian women, have led me to speculate that cultural practices can often complicate, rather than facilitate, grieving. This midwife explained how midwifery fosters a female-only space within which women from South Asian cultures, where perinatal loss is a female-only event, can talk about their experiences.

Furthermore, one mother recounted her experience of stillbirth within Judaism, a faith that does not sanction traditional ceremonies for babies who do not live at least 30 days. For this mother and her husband, the stifling of traditional mourning rituals and the social support they garner, left them to mourn outside of community, compounding an already difficult experience. It seems as though specific traditions arbitrarily exist until a member of the culture experiences perinatal death and realizes they are unhelpful.

Most literature about perinatal loss unites women's experiences, joining them as sisters in a secret society. Motherhood is often an important turning point and goal in the lives of women, and losing a pregnancy or baby can be experienced as profound failure. Ideologies such as this one must be placed within a cultural context. Taiwanese women, for example, are further bound by an ideology of continuity, where status in a husband's family is dependent on producing a male child.<sup>16</sup> Ideologies of meritocracy essentially, 'you get what you deserve' can also lead to maternal blame.<sup>6,17,18</sup> Societies adhering to these values assign responsibility to women for ensuring their pregnancies go as planned. Midwives, who have helped put reproductive health back into the hands of women, must consider the other side of this increased control and autonomy; it can create a social climate that blames women for perinatal loss. They also need to be mindful of how lobbies to promote midwifery can idealize birth and focus on 'happy endings.'<sup>17</sup> Biomedical and women's health movements share a belief in autonomy over all aspects of reproduction and manufacture positive outcomes, of which guilt and blame are unintended consequences.<sup>17</sup> Even the best prenatal care possible cannot prevent perinatal loss.

The shared experience of disenfranchised grief following perinatal loss makes it easy to ignore any differences. This is especially true when cultural

rituals and traditions are unhelpful. Sadly, research into the experience of perinatal loss by women in poverty, adolescents, lesbians, and immigrants is scarce. One midwife speculated on how poverty might compound perinatal loss by making funeral services financially inaccessible, along with other professional support services. Low-income women might also have less opportunity to take time off work to care for their emotional health. Many societies and cultures also frown upon pregnant women in poverty, viewing them as unsuitable mothers. Low-income women in Mexico who become pregnant and miscarry, for example, face a double marginalization due to gender and poverty.<sup>18</sup> In this social context, a poor woman is guilty both for not preventing a pregnancy and for inducing her own miscarriage. Like low-income women, our society tends to view adolescents as being ill-prepared for parenting responsibilities due to a lack of social and economic independence. As one midwife reflected, a typical response to these adolescents might be 'It's for the best. You're too young.'

For lesbian couples, becoming pregnant in the first place is often quite challenging. Conceiving a pregnancy can require a lot of planning, time, and money. Becoming pregnant again following perinatal loss can seem like a remote possibility.<sup>19</sup> One case study analyzed the multiple perinatal losses of a lesbian woman desperately seeking to be a mother and who interpreted her reproductive difficulties as punishment for 'deviant' sexuality.<sup>16</sup> If a woman is struggling with her identity as a lesbian, and feeling devalued as a woman by society for her sexual choices, she might feel the weight of motherhood ideologies more strongly.

Cultural differences can profoundly affect new immigrants, and Rosenblatt<sup>21</sup> reflects on several features of being an outsider in Western society that contribute to disenfranchised grief. On a practical level, immigrants are sometimes unable to access certain objects and foods necessary for their ceremonies, which one midwife described as a 'cultural cloak' they are unable to wear. Failure to participate in these rituals can lead to serious ramifications. Western society, through ethnocentrism and lack of tolerance for difference,

often limits the behaviours of immigrants and silences their mourning rituals, leaving them to grieve alone in an 'alien world.'<sup>21</sup> It is not just the new homeland, however, that is responsible for complicating the grief of immigrants. Certain taboos from their own culture can create barriers to accessing strategies that are helpful in Western societies, such as psychotherapy and support groups.<sup>16</sup> Another barrier for immigrants is language, which can make it difficult for them to communicate their needs, and translators can unintentionally add interpreter bias.

#### *Cultural Competence*

What does it mean to take a culturally-competent approach to caring for women who experience perinatal loss? Is there value in looking at how different cultures grieve perinatal loss when it seems as though women who have experienced it form their own subculture anyway? Treating people as individuals can limit generalizations, stereotypes, and defining people by difference alone, yet can miss cultural complexities, and gloss over historical, structural and social forces of oppression. Both death and birth are steeped in culture, and the ways in which we experience and express them are not based solely on our own idiosyncrasies.

Recognizing that few, if any, human experiences or rights are universal, cultural competence takes the perspective of cultural relativism, which advocates understanding different cultural practices without imposing our own morals or values. Rosenblatt<sup>21</sup> proposes that health care providers strive to be generalists instead of specialists, and to develop resourcefulness, a great skill for finding information or people to help. One midwife admitted that the internet is an invaluable tool for culture-specific information about grief. Another, who cares for a large number of South Asian women, has developed an informal knowledge base of their cultural practices. Indeed, some cultures have specific rituals around perinatal loss that involve viewing the body

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and its preparation for burial or cremation, and more details are provided elsewhere.<sup>7</sup>

Since we cannot know the rituals of each culture, and run risk of assuming that all members necessarily adhere to them, health care professionals often look to protocols for guidance. At an organizational level, policies can offer individual health care providers with a structure to ensure cross-cultural delivery of inclusive care that represents the needs and concerns of all social constituencies.<sup>22</sup> One bereaved mother,

who has taken a research interest in this area, directed me to a chapter on loss and grief in the *Family-Centered Maternity and Newborn Care National Guidelines*.<sup>4</sup> Not only does this document use inclusive language encouraging health care providers to recognize the many forms of perinatal loss that fall outside their professional discourse but it also offers suggestions on how to help families employ rituals important to them. Under the heading of 'Sociocultural Assessment,' for example, are prompts to ask families about their past experience with death or other crisis situations, and customary ways of approaching them. It also encourages health care professionals to have families consider any cultural or

religious practices that might constrain their grieving process. In speaking with midwives from three different practice groups, I understood that each has its own informal protocol for midwives to follow when a woman under their care experiences perinatal loss. One midwife commented on some limitations of protocols and policies, which can be prescriptive and informed by social norms.

#### *The Role of Midwives*

My research also suggests that midwives might not feel adequately prepared to support women in perinatal loss,<sup>23,24,25</sup> This is discouraging given that they can have important roles in creating positive memories. Most suggestions focus on labour support by facilitating a good birth when the baby is born still or is unlikely to survive once born. Yet, they are involved in other aspects of perinatal loss. When taking the obstetrical history of pregnant women,



for example, midwives often learn of previous perinatal losses, and have an important role in supporting the unique needs of these women. Côté-Arsenault & Marshall<sup>28</sup> offer a stunning account of what pregnancy can be like following perinatal loss, describing the experience as 'one foot in and one foot out.' A woman I interviewed described a similar experience of what it was like to conceive shortly after the stillbirth of her third child, by invoking the symbol of the Janus figure of Greek mythology simultaneously looking backward in grief for her lost child and forward in hope for the one she was carrying.

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Often, the first opportunity to provide supportive care comes with communicating the news of perinatal loss. Unfortunately, health care professionals, including midwives, receive little formal education around communicating potentially distressing news.<sup>27</sup> Thankfully, continuity is built into midwifery's philosophy of care, which facilitates this process. Communicating information is also central to the informed choice standard of midwifery care. Midwives must recognize a woman's need to assume some degree of control in such a helpless situation, while encouraging her to make decisions about place of birth, induction of labour, pain control, and lactation inhibition.<sup>25</sup> A woman I interviewed, who did not have midwifery care at the time of her perinatal loss, could not understand why she was not given the option of taking medication to suppress her milk, which she described as incredibly upsetting. While her primary health care physician justified refusal of this medication based on potentially adverse side effects, she felt powerless. Informed choice is also important to remember in the face of standard hospital and midwifery procedures around taking baby pictures, collecting locks of hair and fingerprints, or any other gesture aimed at creating as many memories as possible. Mander<sup>25</sup> urges midwives to obtain consent for even

these less invasive activities since the main issue is not that women should have these keepsakes, but that they ought to have a choice in the matter. Besides, as she further speculates, '

*We have to wonder... whether we give enough attention to the woman's memories of her actual experience of the loss of her baby.*<sup>29</sup>

Her point highlights that one of the most important roles a midwife can assume in situations of perinatal loss is a quiet and encouraging presence for the woman. As Hey<sup>6</sup> cites,

*I was having a late miscarriage, but I felt at the end as if I had given birth.*

The bereaved mothers I interviewed shared similar experiences. One woman, despite having an unpleasant encounter with the ultrasound technician who first discovered her baby had died, was grateful for the kindness of a midwife who contributed to a beautiful, peaceful birth. Another woman, who described her midwife as wonderful and involved with her three subsequent pregnancies, spoke about how her husband was included in the birth of their stillborn son when her midwife, recognizing his talent for music, suggested he play guitar to support his wife in labour.

Clearly, midwives have an important role in supporting women and their families through perinatal loss. Yet, equally apparent is the absence of education, training, and support in delivering the highest standard of care that is expected of them. Practicing midwives from three different cultures shared common insecurities about lack of experience, knowledge, communication skills, and confidence around perinatal loss.<sup>23</sup> Midwifery students have also vocalized a high level of stress associated with perinatal loss situations, for which they feel inadequately prepared and supported by their programs.<sup>27</sup> I feel strongly that perinatal loss is important content that needs more focus, and that midwifery students need to engage with it outside of clinical settings. Where clinical experience is

insufficient to shape communication skills, formal education can provide general guidelines about simple and direct language, repetition, gauging understanding, leaving space for questions and balancing hope with realism.<sup>27</sup> Furthermore, Health Canada<sup>22</sup> recommends that, "ideally, all health care professionals will have received *academic grounding* and clinical experience in supporting individuals in the grieving process [emphasis added]." Before they begin clinical placements, schools of midwifery have an obligation to provide their students with learning opportunities that give them basic knowledge about different types of perinatal loss, a chance to consider their own feelings about death, and the space to rehearse supportive communication techniques.<sup>29</sup>

Midwives can learn how to bracket their own responses and values around death and grief, in order to better support women. Additionally, studies suggest that health care professionals with life experience in caring for someone in death have well-developed attitudes for subsequent care experiences.<sup>24</sup> Since not everyone has had to confront death or loss in their personal lives, midwifery students might consider volunteering with a hospice, which supports its clients to create a peaceful death. The skills necessary for compassionate care at the end of life are beneficial for ushering in new life, especially when it is brief.

### Conclusion

While there can be no clear guidelines on how to best care for women who have experienced perinatal loss, professional training and education can effectively prepare midwives to be supportive under these circumstances. Their potential to transform adverse outcomes into positive birth experiences puts them in an incredibly delicate and challenging position. Midwives deserve an opportunity to explore how language perpetuates social and cultural values about perinatal loss, and how these forces can marginalize an already disenfranchising experience as well as their own beliefs and attitudes about death and loss. More importantly, pregnant women deserve high quality care from midwives who can be with them in even the most tragic situations.

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