REVIEW ARTICLE

Tasked for Compassion: Initiating Reproductive Grief Care in the Neonatal Intensive Care Unit

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Abstract

The experience of parenting a premature or ill infant in the neonatal intensive care unit (NICU) can be overwhelming and traumatic. Parents who have previously endured a reproductive loss may find that an accumulation of escalating distress related to nurturing a neonate while receiving care in intensive care compounded with lingering grief from a prior perinatal loss can overwhelm their capability to cope. The ambiguous nature of perinatal loss and societal disenfranchisement of the grief often results in a prolonged or complicated bereavement trajectory which can inhibit bonding, mental health, and physical wellness. The frequent contact and perinatal conversations between parents and clinicians provide opportunities for essential discussions about emotional vigor, grief, and bereavement. A review of the literature and current research found that initiating conversations and care modalities that facilitate Worden's "tasks of grieving" can foster a necessary healing pattern for bereaved parents. These efforts will theoretically nurture parent–child bonding and promote desirable neonatal outcomes.

Keywords: Bereavement, Fetal demise, Miscarriage, Neonatal intensive care unit, Perinatal loss, Reproductive grief, Stillbirth.

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Fundamentals of Reproductive Loss and Trauma

Reproductive loss is common, occurring in up to a quarter of all pregnancies, and recurrent pregnancy loss is also related to subsequent neonatal morbidity and mortality.[1,2] Parents experiencing difficulty grappling with an infant enduring significant morbidity in the intensive care are more likely to have experienced reproductive loss or issues with infertility.[3] Additionally, advanced maternal age, multiple gestation pregnancies, and reproductive technology have been linked to increased neonatal morbidity and mortality.[4–8]

In the past two decades, with the emergence of perinatal palliative care, more efforts have been made to implement efficacious perinatal bereavement into maternity services.[9,10] However, recent studies have shown that the progression to provide sufficient perinatal grief support in NICU is still slow in meeting the need.[11–17] Currently, in the United States, there is no standard of care for reproductive grief after miscarriage (<20 weeks gestation), which often occurs in the home or emergency setting and where healthcare support for grieving, though necessary, is typically absent.[18,19] Because gestational age is not necessarily linked to the intensity of the emotional reaction to the loss, the impact of grief subsequent to miscarriage should not be underestimated.[20–23] Complicated reproductive grief reactions also pose a compelling risk for maternal–fetal attachment problems for subsequent pregnancies.[24,25] It is highly probable that NICU parents with a history of successive reproductive loss will be more at risk for prolonged, complicated grief reactions and attachment challenges in bonding with a fragile and/or ailing neonate.

Reproductive Story and Ontological Death

Developmental psychologists have described how the unconscious narrative and attachment to future children begins long before conception.[26–30] In childhood, desires and expectations for future offspring are envisioned and integrated into an individual's reproductive story, but this longstanding aspiration can be shattered with experiences of miscarriage, stillbirth, or infertility.[28] Often those impacted by reproductive loss experience waning trust in their bodies, health, healthcare, and ability to procreate their longed for progeny.[28,31] This wounding experience can have long-standing implications for the individuals' mental health, wellbeing, relationships, and future bonding with subsequent children.[32] There are very few longitudinal studies on reproductive grief reactions, but one study reported that the risk for complicated grief after perinatal loss is 59% or greater when evaluated two years after the loss.[33]

The loss of a pregnancy or infant can disrupt or crush an individual's view of the world and fundamental beliefs about their place and purpose of existence. Reproductive loss is often associated with ontological death, resulting in the disruption of long-standing beliefs about the meaning of life which can have far-reaching implications on future relationships, intimacy, spirituality, and self-actualization.[34,35] Frequently, self-blame and shame surround the experience of loss. These reactions which are reported by parents experiencing any form of reproductive loss can further hinder the parents' ability to reconstruct their reality without the desired child.[36–40] Reproductive grief reactions can be lengthy, spanning more than ten years in some studies.[18,41] Furthermore, in the

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absence of healing bereavement support, subsequent adversities experienced in the perinatal periods can trigger self-preservation and detachment which can in turn impact bonding and optimal neonatal trajectory.[41–45] When multiple factors indicating parental wellness and adjustment after the loss of a child were looked at simultaneously, one study demonstrated that indicators of actual resilience could be attributed to only about 5% of the parents.[46]

Barriers to Grieving Reproductive Loss

Ambiguity – Experiences of loss during the perinatal period lack the physical evidence and shared memories that are usually associated with death and mourning. Reproductive morbidity is an ambiguous loss that hinders the grieving trajectory for the bereaved.[23,47] Lang and her colleagues[48] found several factors that contributed to the ambiguity and suffering of perinatal loss, including aspects of viability, disposition of fetal remains, the painful or traumatic physical process of losing the pregnancy, and the disclosure of the loss to others.

Disenfranchisement – Healthy coping in response to loss is heavily reliant upon societal support and acknowledgement of the grief experience.[49] In Western society, the loss of a pregnancy or infant is often associated with secrecy and cultural silence.[36] For instance, first trimester losses are not openly discussed in social spheres, and parents are often told by other family members or close friends not to share news of a pregnancy until the second trimester (when the risk of miscarriage has significantly lowered). In a 2008[50] article in *The New York Times*, a father wrote after experiencing the stillbirth of his son, "When a parent dies or a partner–when we lose someone who has lived in the world–there are customs, worn paths to follow, ways to talk about it. But I didn't see any path with this. Was I supposed to keep quiet and pretend nothing had happened? I couldn't accept that."

Paradox of Reproductive Loss – Contrary to common societal beliefs, the attachment to an expected child usually endures after a perinatal loss. Researcher Berry and her colleagues[51] (p. 25) found that "perinatal loss is a paradoxical experience in which parents often feel misunderstood and alone". There is a disconnection and often a disparity between the grief that parents may experience years or decades after a loss and the support they receive from care providers, family members, and encountered social spheres.[34] Disenfranchised reproductive grief is typically met with social assimilations that cling to expressions that minimize or ignore the experience rather than compassionately meeting the patients' needs.[51] Those providing care need to be aware of their own assumptions, and in turn strive to provide a more holistic approach to care. This requires planning to meet the parents' needs and affirm the intrinsic values they associate to their loss.

Trauma Informed Reproductive Bereavement Care – The value of efficacious bereavement care, provided at any point after a reproductive loss, cannot be underscored enough. Decades of research have demonstrated the potential for chronic maladaptive dysfunction of the sympathetic nervous system in reaction to trauma and lasting biopsychosocial impact which can reduce an individual's capacity to cope, adapt, and learn.[52–55] Many situations of reproductive loss are traumatic and require support from healthcare professionals to foster wellbeing and resilience. Bereavement modalities that authentically focus on emotional healing and affirm the dignity of the human experience of loss are needed rather than shifting to an atomistic physiological focus.[54–57] Active and engaged professional and family enfranchisement of grief are associated with better long-term parental outcomes.[58–61]

Simplicity yet Difficulty of a Compassionate Approach

Misconceptions about how the grief experience can impact physical or mental well-being are evidenced in inadvertent yet hurtful language patterns that frequently accompany reproductive loss and include comments like "it's common" or "you can just have another one".[62–65] Since the perinatal bereavement experience is outside of western cultural and societal norms, healthcare providers often report feeling awkward or uncomfortable acknowledging and addressing grief.[36,44,66,67] However, helpful interventions, which may initially seem too simplistic to be efficacious, can prove to be a challenge for care providers to utilize and assimilate into practice.[11,68–70] Understanding grief theory and the rationale behind what may seem sentimental or domiciliary can undergird a structured and ameliorating approach to the care of families anguished by reproductive loss.[22] Since knowledge alone is typically not an effective method of changing provider practices,[71] active communication practice, role play, and case study simulations are preferable exercises for correcting or enhancing these aspects of professional performance.[72]

Validating the Loss and Grief Experience

An initial and important facilitator of processing grief is acknowledgement of the loss and validation of the subsequent grief.[73] For instance, some studies revealed that when this task is neglected or ignored, parents reported anger and resentment towards healthcare providers which contributed to a complicated grief trajectory.[48,74,75] Empathetic responses to loss and grief can mitigate the risk for prolonged or maladaptive grief responses (Table 1).[74,76] Additionally, satisfaction in health care services improved when the loss and grief were validated by the care providers.[77]

Table 1: Interventions that foster acceptance of reproductive loss

Communication strategies	• Empathetically acknowledge the loss[78–80] • Use language free of jargon and medical terminology[63] • Provide handouts[81] • Encourage journaling[25,73]
Efficacious resources	• Provide grief education[47,60] • Involve supportive persons[58,59,61,82] • Offer chaplain assistance[83]
Fostering remembrance	• Discuss intentional memory making[11,68,84] • Provide keepsake items[68,85] • Inquire about aspects of pregnancy and thoughts about their child that they would cherish and/or like to honor[69,86] • Assess cultural or spiritual preferences[25,87,88]
Enduring assistance	• Provide a grief care packet with discharge instructions[47] • Send a sympathy card or letter signed by the staff/provider(s) at the time of the loss[89]

Allowing Painful Emotions Associated with the Loss

Another important way to support those grieving a reproductive loss is to allow for open expression of painful emotions and concerns about the loss and grief process (Table 2). Encouragement and provision of an environment conducive to share private feelings should be offered during private discussions about the care of their child or family member.[90] In a 2021 study on early pregnancy loss, one participant with multiple miscarriages wrote, "I feel broken. Like there's something wrong with me or I'm doing something wrong. I feel like a horrible wife because I know my husband shares my dreams of a big family. It hurts me so bad that I can't give him that or give my daughter a sibling. I don't know how to deal with it, because outside of parenting my child, I am no one" (p. 10).[18]

Fostering the Adjustment for Life After the Loss

After any death, individuals must come to terms with the life adjustments necessary for living without the one lost. There are often multiple life circumstances, activities, roles, dreams, practices, and social contacts that change as a result of each loss and a shift from one's "normal" associations and patterns of living. There are also changes that will occur with one's fundamental beliefs about life and what brings them meaning as described earlier with the concept of ontological death.[34] Often, bereaved individuals will try to maintain balance by clinging to what they have always done only to discover that the way forward has changed and requires multifaceted adjustment[73] (Table 3). Because of the disenfranchised nature and ambiguity associated with reproductive loss, many find the associated grief trajectory to be uniquely challenging. "A miscarriage is hard because there is no funeral. There is no service of remembrance. There is no formal marking of a life passing. To me, that felt like there was no moving forward. I felt torn into pieces. My husband hurt, but no one else missed our baby."[18]

Table 2: Interventions that facilitate emotional healing

Communication modalities	• Encourage sharing of emotions[90,91] • Affirm uniqueness of reaction[79,80] • Normalize reaction[92] • Allow ample time to process information[63,93] • Encourage journaling[25,73] • Assess desired cultural mourning practices/expression of grief[66,82,94,95]
Efficacious resources	• Acknowledge partner's grief reaction[96] • Provide grief education and supportive modalities[92] • Involve interdisciplinary team[97–99]
Enduring remembrance	• Discuss symbolism in healing (positive associations)[68,73,100] • Consider resources or referrals for creative or art therapies[73]
Follow-up assistance	• Schedule and make follow-up phone calls[101–103] • Reassess grief intensity (PGIS/PGS)[22,39,69]

Table 3: Interventions that help bereaved adjust to the loss

Communication modalities	• Offer follow-up visit to discuss diagnosis in-depth (interdisciplinary)[34,69]
Efficacious resources	• Suggest joining support group/ blog[69,100,104] • Connect parents with perinatal loss organizations[100,103] • Suggest strategies for communicating the loss to others[105]
Enduring remembrance	• Encourage journaling of journey through loss and moving forward without the child[25,106]
Follow-up assistance	• Send out sympathy card(s)[89] • Assess and mitigate unhealthy behaviors[107]

Table 4: Interventions that support an enduring connection to the lost child

Communication modalities	• Continue using the name/gender of lost child[68,69,76,93,100] • Inquire about strengths and challenges coping[108]
Efficacious resources	• Make bereavement counseling options available throughout care interactions[99]
Enduring remembrance	• Birthstone/jewelry/dedications[68,89] • Suggest keepsakes (birth announcement, newspaper dedication, hospital blanket, etc.)[20,68,89]
Follow-up assistance	• Milestone cards/calls (birthday, key holidays, etc.)[89] • Offer bereavement ceremonies in the community or hospital[86,109,110]

Memorializing to Develop an Enduring Connection to the Lost Child

Cultivating meaning and enduring connections to the deceased is an important aspect of adjusting to loss.[73] Those grieving reproductive losses typically find that this task is more challenging because shared memories or items of remembrance may be few or absent.[48] By providing tangible aspects of perinatal experiences, such as sonography photographs, and encouraging discussion about memorable aspects of the pregnancy or infancy, the care provider can facilitate emotional healing (Table 4). Berry and colleagues[34] (p. 6) found that memory making was important and "a majority (92%) of the parents stated they continue to celebrate their [deceased] child's birthday."

Conclusions

Perinatal loss is a painful reality for those working in the NICU and the parents they interact with daily. Heartrending and emotional conversations when communicating various aspects of loss are vital for supporting the bereaved. The impact of what is said and done has lasting implications for parental well-being. Bereavement education and coaching can improve relational efficacy and

occupational satisfaction. Additionally, it is crucial that care providers seek debriefing and support for a resilient professional trajectory.[12] Utilizing the tasks of grieving[73] for theory-driven interventions that include evidence-based reproductive grief care, communicative modalities, and practical applications, no matter how simplistic they might seem will foster healing and improve parent provider alliances and neonatal bonding experiences.

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