

After losing an infant, grieving mothers may still have to cope with postpartum issues, including lactation. This article reviews and addresses care options for lactation concerns after pregnancy, neonatal, or infant loss. Currently, lactation care and advice after loss varies greatly. Lactation consultants are instrumental in providing mothers with anticipatory guidance and evidence-based care. Implementing system-wide training and education regarding this topic will help families receive the information they need to deal with the physiological aftermath of infant loss.

Keywords: Perinatal loss, neonatal loss, pregnancy loss, engorgement, lactation suppression, lactation after loss, breastfeeding grief
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The loss of an infant is a devastating life event. For many mothers, lactation following infant loss only compounds their pain. Care providers often do not know how to support mothers following such a loss and may offer advice that is ineffective and out of date, leaving mothers without proper support. With that in mind, this paper has three goals: (a) to review past and current practices regarding lactation suppression after loss; (b) to explore the emotional, physical, and ethical issues surrounding lactation after loss; and (c) to present care plan strategies for lactation consultants who support mothers after loss. When care providers have a good understanding of the physical postpartum changes, along with the psychological issues following infant loss, they will be able to better serve the bereaved mother.

Types of Loss

The loss of an infant is a personal and unique tragedy for each family. Some types of loss include pregnancy loss (0 to 20 weeks gestation), perinatal death (20 weeks gestation to birth), neonatal death (birth to 28 days postpartum), abortion (elective or medically necessary), loss of an older infant/child, and adoption relinquishment. Pregnancy loss is commonly due to genetic or environmental causes (Lewis, 1997). Perinatal and neonatal losses are often due to umbilical cord or placenta problems causing oxygenation issues, infection, anomalies, or maternal health complications (Glantz, 1997). Losses due to elective or medically necessary abortion, the loss of an older infant, or the loss of an infant through adoption relinquishment also present unique physical and emotional challenges. Whenever

1. melissa@lunalactation.com The author would like to acknowledge the lactation clients she has supported after perinatal/neonatal loss. She feels honored to have learned so much from their collective experiences and shares deeply in their grief.

and however a parent loses an infant, there are many complex physiological and psychological considerations for the family, community, and healthcare providers.

Lactogenesis and Loss

Mothers who suffer a late-pregnancy or neonatal loss may be shocked to discover that their bodies produce milk, even with no infant to feed. Providing anticipatory guidance on the phases of lactogenesis is vital (see [Table 1](#) for a summary of stages). Some mothers want to immediately suppress lactogenesis II because it is a painful reminder of their loss. Other mothers have chosen to prolong lactogenesis for various reasons including: “to feel the pain of my loss,” “to acknowledge the existence of my baby,” “to donate milk to others so some good can come from this loss,” and “to feel close to my baby every time my breasts leak” (anonymous clients, personal communication, 2005 to 2010). Whether a mother chooses to suppress or continue lactation, care providers must be able to provide comprehensive, evidence-based support to help mothers avoid medical complications, such as engorgement and mastitis.

Comprehensive care...plays a significant role in initiating a healthy grieving process for parents after they experience a pregnancy loss. The care... will have a lifelong impact on the family, as they travel down the long, tortuous road to grief integration (Leoni, 1997, p. 376).

Lactation and the Grief Process

Bereavement following the loss of an infant includes emotional and physical manifestations of mourning. Initially following loss, mothers may feel numbness, denial, envy, blame, anger, and failure (Kay et al., 1997). When speaking with grieving mothers, I have found that

many have strong feelings about the lack of lactation support following the loss of their infant. A mother who has lost her infant has also lost her dreams, including dreams of breastfeeding and nurturing her child. One mother summarized her feelings as follows.

Breastfeeding loss is the mourning process that happens when a nursing relationship is lost or never achieves the expectations of the mother (Paige@BabyDustDiaries, 2012).

Kübler-Ross and Kessler (2005), in their book *On Grief and Grieving*, noted that the death of a loved one heightens awareness of all the things the living stand to lose. In this respect, care providers must understand that a mother has not just lost her infant—she is also mourning the loss of how she envisioned feeding, loving, and caring for the infant she will never watch grow up.

Boss's work on ambiguous loss can also help us understand a mother's reaction to infant loss. Boss noted that ambiguous loss occurs when the relationship with the person who died is uncertain or where there is lack of closure. In cases of adoption (the parents realize the infant is still alive but is physically absent from the biological parents' life) (MN Adopt, n.d.), the loss of one twin where the other survives (Ryan, 1997, p.143), or miscarriage or loss where the parents have not had the opportunity to see the infant after birth, "ambiguous loss freezes the grief process and prevents closure, paralyzing couples and family functioning" (Pauline Boss, n.d.).

For a mother who has lost an infant, normal postpartum body changes can be overwhelming. Other challenges include seeing other women with babies, coming home from the hospital empty-handed, and not being acknowledged as mothers (Kay et al., 1997; Leoni, 1997). The milk a mother produces after losing her infant has been referred to as "white tears" (Schwiebert & Kirk, 2010). The suppression or continuation of white tears is a personal choice that is delicately interwoven with a mother's unique experience and expression of grief. Lactation consultants should recognize the value in allowing grief and, by extension, lactation, to take its natural course. Grief is an individualized process and routine protocols may not best suit a mother's unique needs. After the loss of their infant, parents are given many options regarding autopsy, funeral services, photos, and other mementoes of the infant. Yet providers often forget to let mothers choose what they want to do in regard to their lactating breasts: to suppress or to continue lactation. Providing the mother with choices

can empower her at a time when many other aspects of her life feel out of control.

Encourage mothers to seek emotional support after the loss of an infant. Counseling and support following a perinatal loss can significantly shorten the grieving period (Forrest et al., 1982). Support can include professional therapy, community-based support, friends, and religious groups. Mothers should find the best support option for them, and "best" may change as they walk through their grief.

A particularly useful resource for infant-loss support options is www.nationalshare.org.

Lactation Care after Loss: Past and Present Practices

Most past and present practices focus solely on lactation suppression with little regard to the mother's preferences. In the past, common lactation suppression practices included medications and breast binding. There is no universal guideline on how to effectively suppress lactation in postpartum women, so confusion is understandable (Oladapo & Fawole, 2009). Presently, nonpharmacologic approaches are the norm, such as anti-inflammatory support and pumping for breast comfort.

Handouts

(Please access online)

[Care Ideas for Lactation Suppression and Engorgement Following Loss](#)

[Lactation Suppression Care Plan for Mothers](#)

[Lactation after Loss Care Plan Flow Chart for Providers](#)

Pharmacologic Options for Lactation Suppression

In past decades, medications commonly used for lactation suppression included estrogen, testosterone, bromocriptine, and cabergoline. In the United States, these medications were used to suppress lactation up until the 1990s, when increasing awareness about their risks, mainly cardiovascular concerns in predisposed patients, were noted (Rayburn, 1996; Stehlin, 1990). However, some countries, especially those with a high percentage of mothers with HIV, still use these

lactation-suppression medications (Buhendwa et al., 2008). In the United States, pseudoephedrine (Aljazaf et al., 2003) and birth control pills containing estrogen are often suggested to suppress milk (Oladapo & Fawole, 2009). A recent meta-analysis review found weak evidence in favor of suppression medication, primarily bromocriptine, noting that more research comparing pharmacologic versus nonpharmacologic approaches to milk suppression is needed (Oladapo & Fawole, 2009).

Nonpharmacologic Options for Breast Comfort after Loss

Nonpharmacologic approaches to suppression and engorgement management have included binding; icing; cabbage-leaf compresses (Arora et al., 2008; Nikodem et al., 1993); massage; therapeutic ultrasound (McLachlan et al., 1993); lymph drainage (Chikly, 2005); anti-inflammatory supplements (Snowden et al., 2001); application of jasmine flowers (Shrivastav et al., 1988); herbal remedies, such as sage, parsley, and peppermint (Humphrey, 2003; Mills & Bone, 2005); homeopathy (Berrebi et al., 2001; Castro, 1992; Hatherly, 2004; Moskowitz, 1992); and high-dose vitamin B6 (Macdonald et al., 1976; Marcus, 1975).

Engorgement plays a natural role in decreasing milk supply. When the breasts remain full with milk, certain peptides and proteins trigger apoptosis of the milk-making epithelial cells (Cregan & Hartmann, 1999; Wilde et al., 1998). However, unrelieved engorgement and milk stasis can lead to further complications, such as mastitis (Humenick et al., 1994). Even if mothers wish to suppress lactation, some milk removal may be necessary to prevent severe engorgement, especially in multiparous mothers who have lactated before (Humenick et al., 1994). There are mixed reviews on the effectiveness of some nonpharmacologic treatments of engorgement. Spitz, Lee, and Peterson (1998) found that despite using nonpharmacologic options, such as breast binding, ice packs, or analgesics, up to one-third of women still experienced severe postpartum engorgement and breast pain following loss.

In a review of the literature, Snowden et al. (2001) found that prevention of engorgement is key. Engorgement treatments, such as cabbage leaves, gel packs, and ultrasound did help, but this was possibly due to the gentle pressure and massage-like nature of the treatments, rather than the treatments themselves. While oxytocin did not prove to be an effective option for relieving engorgement, *Serratiopeptidase* and a bromelain/trypsin complex significantly improved symptoms, likely due to their potent anti-inflammatory effects.

Homeopathy significantly lowered pain in a double-blind placebo-controlled study (Berrebi et al., 2001). A recent review found that acupuncture was an effective option (Mangesi & Dowswell, 2010). They concluded that although some interventions may be promising, there is not sufficient evidence from trials on any intervention to justify widespread implementation. More research is needed on treatments for this painful and distressing condition (Mangesi & Dowswell, 2010).

Breast binding for lactation suppression has been practiced in various cultures throughout history. Although obstetrics and midwifery texts often list binding as acceptable, little research supports this practice (McGee, 1992). One study found that women in the breast-binding group had more pain, breast leakage, and use of pain-relief measures than women who did not use breast binding (Swift & Janke, 2003). Swift and Janke recommended that breast binding be discontinued as a method of lactation suppression.

Another study by Swedish midwives claimed that breast binding may aid women in their grief as it provided a concrete reminder of their loss (Radestad et al., 1998). Breast binding is a culturally accepted tradition for some, and as such may be emotionally comforting. However, breast binding increases the risk of complications, such as mastitis (Fetherston, 1998; Riordan & Nichols, 1990). Grieving mothers may be more prone to mastitis in general due to increased stress and fatigue, therefore, breast binding is no longer standard of care (Fetherston, 1998; Swift & Janke, 2003). However, if a mother chooses to bind her breasts due to cultural reasons or personal choice, lactation support and anticipatory guidance are vital so that the mother knows how to recognize signs of an impending breast infection.

Lactation Continuation after Loss

Lactation suppression is not the only choice mothers have after losing their babies; milk expression and donation are viable options that can have physical and emotional benefits. Some mothers may express their breasts just long enough to avoid engorgement and comfortably cease lactating. Others may desire to continue expressing their milk for altruistic reasons. The safest and preferred method of milk donation is through a milk bank. Some mothers desire to informally share their milk via informal, community-based, mother-to-mother donation (while being mindful of the risks/benefits and practicing informed consent). One client of mine, Laurinda, describes why she decided to donate.

I used icepacks and cabbage leaves to help make me more comfortable, but the milk just kept increasing. My heart ached as I woke every two hours with breasts engorged with milk and no baby to drink it.... I realized my milk was going to come in whether I wanted it or not. So I made the decision to pump as long as I needed to and find someone who could use it rather than suffer trying to suppress or dry up the milk.... Any time I felt full or uncomfortable, I pumped until empty and froze the milk. But as soon as I spaced out my pumping and pumped a little less each day, I was able to wean very quickly without any engorgement or discomfort. I am sure I could have weaned sooner, but I hesitated to give up that one last physical connection to my sweet baby and wanted to give as much milk as I could (Reddig, 2008, paras. 3–6).

Continuing to lactate may not only be cathartic—it may also lower mothers’ risk of depression. Groër and Davis (2006) have shown that the hormones of lactation can help keep some depressive symptoms at bay by downregulating the stress response. Of course, continuing to lactate alone will not ease a mother’s grief. But it does have the potential to provide some form of protection against postpartum mood disorders (Kendall-Tackett, 2007, 2008).

Individualized Lactation Care after Loss

As members of the healthcare team, lactation consultants have an important role to play when a family has lost an infant. At the very least, a family who has experienced a loss should receive at least one lactation-specific visit before the mother is discharged. Mothers who have not received anticipatory lactation guidance have expressed anger and frustration. Laurinda shared about this painful facet of her experience.

The hospital gave me no lactation education. I specifically asked when it became clear that the nurse was done giving me my “check out” information without mentioning lactation. What little information she gave me was outdated and unhelpful (Reddig, 2008, para. 1).

Lactation consultants can provide a healing presence along with excellent lactation support, which all healthcare providers should strive to offer following a loss.

An important issue in caring for families is continuity of care. Families may receive lactation information from

doctors, nurses, friends, and family. Mixed messages can cause them to feel confused and unsure about the care they are receiving. System-wide protocols and continuing education on the topic of postpartum care after loss should include lactation information so that care providers stay up to date. Having brochures on lactation after loss available in your care setting can be another useful strategy, as can helping mothers find community support.

Assessment is a vital part of forming a lactation care plan. You should assess how the parents view the loss, their cultural preference, and what they currently know in order to develop a plan that will meet each family’s needs. The staff’s agenda must be set aside to allow for fluctuations in the grieving process (Leoni, 1997). Be flexible since grieving families will need time to process and integrate information presented to them, and may abruptly decide to change their minds about some part of the care plan (Leoni, 1997). Decisions on topics, such

Patient Resources

Some hospitals and organizations have patient handouts that are specific to lactation after loss. Below are some examples.

- Children’s Hospitals and Clinics of Minnesota
<http://www.childrensmn.org/manuals/pfs/nutr/027491.pdf>
- Children’s Mercy Hospitals and Clinics in Missouri
http://www.childrensmn.org/content/uploadedFiles/Care_Cards/CMH-11-390p.pdf
- Empty Arms Bereavement Support, Inc.
<http://motherwear.typepad.com/files/final-us-lactation-after-loss-brochure.pdf>

as milk suppression versus donation, and whether she wants a breast pump brought to her room, may be challenging for mothers to make. Remain willing to accommodate the family’s wishes and change plans.

Patients may be discharged within 24 hours after the loss, before the onset of lactogenesis II. Therefore, anticipatory guidance before discharge is vital. [A flow chart](#) may help the healthcare team provide adequate

lactation support after loss. Providing comprehensive lactation care after loss is the mother's healthcare team's ethical duty. Ethical treatment includes respecting the mother's right to choose the lactation care she wants, providing the same level of lactation care to all mothers regardless of their ability to pay, remembering the tenets of the beneficence and nonmaleficence, and treating the mother with dignity.

Call for Research

There is a great need for quality research in regards to lactation after loss. I hope this article provides clinicians and researchers with some ideas on where to begin. Possible topics include patient/staff education, guideline/protocol creation, and lactation suppression/donation options after loss. Because mothers are very vulnerable during this time, researchers will have to employ great sensitivity when designing appropriate studies. As new information and understanding of this topic come to light, I hope clinicians will be able to better implement evidence into practice.

Conclusion

This article is based on my years of experience supporting breastfeeding mothers, including those who have suffered a loss. There is still much more we need to learn about this topic if our clinical care and support for mothers coping with lactation after loss is to be meaningful and evidence-based. Existing research on lactation suppression and breast care after loss is inconclusive and limited. The efficacy of various treatments is still not well established. Hopefully the techniques outlined in this article may provide mothers with some level of comfort during a distressing time. Don't forget that meaningful healing can come from the ritual aspect of providing hands-on care for the mother's aching breasts.

The issues around lactation after loss deserve more recognition than they currently receive. Grieving mothers share stories describing inadequate lactation support following the loss of their infants. This should not be. Lactation support following a loss must become the standard of care. System-wide trainings, protocol reviews, and more research will ensure that bereaved mothers are getting quality lactation care. Mothers who have suffered a loss should be aware that they have options, and providers should strive to support a mother's physical and emotional pain in a way that respects cultural traditions and maternal preference. Acknowledging the unique issues surrounding lactation after loss, and implementing quality care are ways that

professionals can be a source of healing support during a time of great tragedy.

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Melissa Cole, IBCLC, RLC is a board certified lactation consultant in private practice. Melissa has been passionate about providing comprehensive, holistic lactation care and education to parents and healthcare professionals for over a decade. She is an Adjunct Professor at Birthingway College of Midwifery in Portland, OR where she teaches advanced clinical lactation skills. She is active with several lactation and healthcare professional associations including La Leche League and the International Affiliation of Tongue-Tie Professionals.

New Pilot Study Finds Newborn Feeding Behavior Depressed by Intrapartum Oxytocin

Aim: To investigate the effect intrapartum oxytocin administration can have on Primitive Neonatal Reflexes and breastfeeding.

Methods: 20 healthy first-time mothers were included in the study. The babies were videotaped and three independent observers coded the PNRs. The coders did not know which babies had been exposed to oxytocin. At three months, researchers interviewed the mothers about breastfeeding by telephone.

Results: Medium oxytocin dose was 1931.9 ± 1754.4 mUI. A Kappa index >0.75 was obtained for four Primitive Neonatal Reflexes: swallow, jaw jerk, suck and gazing. A negative association was found between oxytocin dose and sucking ($p = 0.03$). At 3 months of life, women exclusively breastfeeding (63.1%) had received a significantly lower average dose of oxytocin than those not exclusively breastfeeding (36.8%) ($p = 0.04$).

Conclusion: In this pilot study, intrapartum exogenous oxytocin seems to disturb sucking and breastfeeding duration. Further studies are required to confirm these results and to ascertain whether there could be other effects of intrapartum oxytocin on newborn behaviour.

Authors: Ibone Olza Fernández, Miguel Marín Gabriel, Ana Malalana Martínez, Aurora Fernández-Cañadas Morillo, Francisco López Sánchez, Valeria Costarelli

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