



Pregnancy Loss and Infant Death Alliance

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Position Statement

Lactation After Perinatal Loss Requires Education and Specialized Care



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Position

Lactation After Perinatal Loss Requires Education and Specialized Care

Following any perinatal loss, appropriate care should be provided to the bereaved mother in making choices to respond to lactation when it occurs.

Executive Summary

The death of a baby does not preclude a mother's lactation. In fact, the potential for mothers who have experienced a perinatal or infant loss to produce milk is high, as full Lactogenesis II— the onset of a copious milk supply— is possible from 12 to 14 weeks of gestation. Whether or not lactation is expected, the grief experienced by a mother who is not able to breastfeed or offer breast milk to her baby is profound. Therefore, following any loss, appropriate care should be provided to the bereaved mother in making choices to respond to lactation when it occurs.

There are various categories of perinatal, postpartum, and infant loss. Currently, these are classified as

- Miscarriage or ectopic pregnancy: conception to < *20 weeks gestation
- Stillbirth: 20 weeks to birth
- Neonatal death: birth to 28 days
- Infant/child loss: 28 days and older
- Termination of pregnancy: when fetus has a life-limiting condition
- Adoption: for both the birthing mother and the adoptive mother

**Weeks vary depending on state regulations*

Background and Significance

Key points:

1. Feeding has the ability to define relationship (Chichester & Wool, 2015; Pridham et al., 2010).
2. Feeding is an exemplar of parenting (Pridham et al., 2010).
3. Food or feeding may be symbolic or serve as metaphor, in addition to being physiologic (Limbo & Lathrop, 2014).
4. Feeding is a task with cross-cultural meanings (Chichester & Wool, 2015).



In most of the world's cultures, food and feeding have both physiological and symbolic meanings (Chichester & Wool, 2015). Breast milk or breastfeeding projects strong symbolism as a way of demonstrating and/or defining parental caregiving.

Karen Pridham has cared for and done research on parents and babies for most of her 60-year career. She considers feeding to be “the exemplar of parenting” (Pridham et al., 2010), meaning that feeding, in most parents' minds, is the most significant aspect of caring for a child.

In care offered to bereaved parents, one rarely, if ever, finds an option to place drops of breast milk or colostrum on baby's lips, yet recent research solicited from perinatal hospice mothers showed that most of the 15 mothers in the study felt drawn to offering the breast to a baby who would die soon but was still alive (Limbo & Lathrop, 2014).

The grief experienced by a mother who is not able to breastfeed or offer breast milk to her baby is profound. The following are some examples in the mothers' own words:

The things that made me sad were really just the realities of losing a baby, like, I couldn't hold her, I couldn't, I couldn't nurse her... (Lathrop, 2010b)

But when your baby dies... there's not much you're going to do for your baby. You're not going to feed your baby... (Lathrop, 2010a, p. 141)

... I had lost the baby and I remember when my milk came in, that being a really bittersweet moment, like it was, on the one hand it was sad, because, you know I had all this milk and I couldn't feed this baby... (Limbo & Lathrop, 2014, p. 53).

I think a big part of a mother's experience is being able to feed your child, you know, not being able to do that was odd. (Lathrop, 2010b)

... I had nursed my first child. And so I—I kind of feel like that's just what you do, you know, that's kind of a mother, maternal thing that happens: when you have a baby, you are nursing. And I was—I kind of grieved about that, before I even had the baby. (Lathrop, 2010b)

The interviewer reminded one mother that she had expressed a few drops of breast milk and placed them on her dead baby's lips, a symbolic act of caregiving (Kobler, Limbo, & Kavanaugh, 2007; Limbo & Lathrop, 2014, p. 53).

In a study of parenting motivations, one mother pointed out the relational aspects of breastfeeding a baby with a congenital heart problem (Pridham et al., 2010, p. E11):

Getting a bond with baby through breastfeeding. . .So for me, the bonding experience was really cool and I like the fact that it's me and her.

One presumes the absence of this relational experience would or could add to a mother's grief when her baby dies or is dying.



Implications for Practice

“The pain was just painful and the fullness was just uncomfortable, but I found the fact that it started to leak was emotionally very difficult.” Cait

Caregivers— be they nurses, lactation consultants, physicians, midwives, doulas, chaplains, lab technicians, funeral directors, or others involved in the loss experience— need to be aware of how they influence the grieving process following a loss. The creation and use of a coordinated Perinatal Loss Team that can provide standard support, meaning-making opportunities, and follow-up for family and staff is vital. It is also important to provide staff with self-care education and coping skills. If a staff member is uncomfortable with a particular loss, be sure to involve someone else on the care team who can provide support to the family.

When a baby dies following late miscarriage (>20 weeks), stillbirth, or newborn death, the bereaved mother will require advice and support regarding her breast care needs. The bereaved mother should be informed that she will experience Lactogenesis II between 30-40 hours following the birth/loss of her baby. Should she desire to do so, many mothers will be able to safely and comfortably suppress lactation with support and information from their lactation consultant or other health care provider. A breast care leaflet, brochure, or teaching sheet should be provided to the bereaved mother.

Safe Suppression of Lactation

Non-Pharmacological Measures

- Ice packs applied for 15 minutes every hour will help reduce the swelling of engorgement and provide comfort. Warm compresses should **not** routinely be applied, as this may increase swelling and make the breasts even more uncomfortable.
- Thoroughly rinsed, chilled, raw green cabbage leaves may be wrapped around the breasts inside the bra and worn several times a day until they wilt. Some mothers find that this reduces the swelling of engorgement. The cabbage leaves should not cover the nipple area, and use should be discontinued if the mother experiences a rash or sensitivity reaction.
- A supportive bra should be worn. It is **not** recommended to “bind” the breasts with wraps or an overly-tight bra; consistent pressure on the breasts only delays Lactogenesis II and can cause mastitis or abscess and increase maternal pain. Nursing pads can be worn inside the bra if the breasts leak milk.
- Over-the-counter pain medications, such as acetaminophen or ibuprofen may be taken to reduce breast pain, as instructed by the health care provider.
- If pumping has already established a milk supply, the mother will need to slowly wean away from pumping. This can be accomplished by eliminating one



pumping session every 3 to 4 days until no fullness or discomfort is experienced. She might consider working with a lactation consultant to do so safely.

- Mothers who want to wean more quickly, however, may decide to just “pump to comfort”—pumping a little bit whenever fullness creates discomfort. She should **not** continue to empty the breasts fully, as this triggers full milk production. Other interventions already stated (i.e., ice, cabbage leaves, supportive bra, and pain medication) can be used to reduce discomfort while weaning from the pump.
- Offer the bereaved family the option of donating pumped breast milk. This can be an effective way to cope with the loss of baby and continued lactation. Donated milk is used to feed sick and premature infants. Moms can express milk for a short time or longer, if desired. Early stimulation of pumping or hand expressing will signal the breasts to continue milk production. See the Meaning Making and Resources sections for more details.

Note that even after these initial days, mothers may still produce a few drops of milk for the next several weeks to months, with spontaneous release at triggered moments, such as an infant crying, in the shower, or during sex.

Complementary Medicine

The feedback inhibitor of lactation will decrease milk production where there is an accumulation of milk (stasis) in the breasts (Pollard, 2011). Note: when using any of the following methods, be sure to have the mother work with a trained practitioner:

- Herbs (sage, parsley, peppermint, spearmint, thyme)
- Techniques (therapeutic ultrasound, lymphatic drainage, massage)
- Anti-inflammatories (NSAIDs with increased caution, vitamins B6, B9, B12, C, E, D, specific foods, Bromelain and Trypsin)
- Homeopathy (apis mellifica, belladonna, bryonia, lac caninum, phytolacca decandra, pulsatilla)
- Acupuncture and traditional Chinese medicine

Pharmacological Measures

Pharmacological measures to suppress lactation may be indicated in situations where a bereaved mother finds natural methods of suppression very challenging and distressing. However, there are few medications that do not bring significant side effects—such as thromboembolism, cerebral accident, myocardial infarction, and mortality—with their use. For example, bromocriptin (Parlodel) was used for many years and is now associated with heart attacks and strokes. Diethylstilbestrol (DES) was also used but is now a known carcinogen. High doses of estrogen bring risk of potentially dangerous blood clots. Cabergoline (Dostinex) is



used in some countries but has not been approved for suppression of lactation by the U.S. Food and Drug Administration (FDA). At this time, there are no FDA-approved medications for lactation suppression.

Any client wishing to use medication for rapid suppression of milk in the post-loss phase should be working closely with their healthcare provider who can provide individualized care and close monitoring for side effects, drug interactions, and effectiveness.

Meaning Making: Parenting Opportunities and Rituals

Rituals and parenting opportunities related to breastfeeding—whether they be cultural, religious, or familial— can provide some form of reconciliation to the loss being experienced by the mother and her family. When counseling the bereaved mother following a loss, the most important aspect is to listen to her wishes, desires, and hopes, and to advocate for these to the extent possible in your care setting. Options may include

- Provide the parents the opportunity to provide skin-to-skin care to the baby following delivery, to the extent possible.
- Provide the mother and other parent the opportunity to offer the breast to a dying baby (Kobler, Limbo & Oakdale, 2012) or to place a few drops of milk or colostrum on the lips of a baby who has already died.
- It is important to discuss with the bereaved mother what she would like to do with her milk:
 - Offer a keepsake of breast milk for the mother to take home. She can decide at a later date how she might want to use that milk.
 - The mother may want to pump breast milk and/or put baby “to the breast,” whether living or recently deceased.
 - Inquire if she would like to take her breast milk home, discard it, or donate it to a human milk bank. Provide contact details for the nearest milk bank, if desired; families can contact the milk bank directly. Mothers will be asked to take (free) blood tests in order to donate.
 - In a small number of cases, mothers may wish to continue to pump in order to provide milk for other ill and premature babies and/or to feel connected to their baby. Donation of milk may help a grieving mother to find some meaning in the experience of her baby’s death (Welborn, 2012).
 - A mother may have her breast milk stored on the neonatal unit if her baby has been a patient there for any length of time.



- The use of camouflage-patterned fabric can be helpful as the mother copes with milk production. She can be counseled to wear a patterned top or blouse to hide any leaking milk during this period.
- To protect sore breasts when being hugged closely, the mother might place one arm across her chest. She can offer the other arm to give and receive comfort.

See the Resources for Parents and Professionals section below for further development of memory-making related to breastfeeding.

Resources for Parents and Professionals

Lactation Support

Human Milk Banking Association of North America (to locate an appropriate milk bank for donations): <https://www.hmbana.org>

International Lactation Consultant Association (professional organization of International Board Certified Lactation Consultants who can provide assistance to mothers): <http://www.ilca.org>

La Leche League International (mother-to-mother support, encouragement, information, and education about breastfeeding): <http://www.llli.org>

Breast Milk Keepsakes

Baby Bee Hummingbirds (Australian provider of breast milk jewelry):
<http://babybeehummingbirds.com.au>

Breast Milk Keepsakes (UK provider of breast milk jewelry):
<http://www.breastmilkkeepsakes.co.uk>

Life's Journey Jewelry Creations (US provider of breast milk and baby hair jewelry):
<http://www.lifesjourneyjewelrycreations.com>

Mommy Milk Creations (options for mothers to create keepsakes of their breast milk after a loss): <http://mommymilkcreations.com>

Mom's Own Milk Ltd. (UK provider of breast milk jewelry): <http://www.momsownmilk.com>

Sacred Legacy Arts (US provider of breast milk, hair, and other DNA jewelry):
<http://www.sacredlegacyarts.com>



General Bereavement Support

Compassionate Friends (support for families and friends in the grieving process):

<http://www.compassionatefriends.org>

Empty Arms (miscarriage, stillbirth, and infant loss support in Western Massachusetts):

<http://www.emptyarmsbereavement.org>

Faith's Lodge (retreat site, support for families facing a loss or medically complex condition for their infant/child): <http://www.faithslodge.org>

First Candle (resource for helping families through the difficult time following an infant/child loss): <http://www.firstcandle.org>

Glow in the Woods (blog, discussion forums, library, and support for infant loss):

<http://www.glowinthewoods.com>

Grief Watch (bereavement resources, products, and links): www.griefwatch.com

Loving Your Baby (resources in multiple languages for grieving families, as well as lactation options): <http://www.lovingyourbaby.ca>

Mothers in Support and Sympathy (MISS) Foundation (a non-profit organization providing immediate and ongoing support for grieving families and caregivers):

<http://www.missfoundation.org>

Open to Hope (online forum to support people who have experienced loss, to help them cope with their pain, heal their grief, and invest in their future): <http://www.opentohope.com>

Perinatal Hospice & Palliative Care (resource when an infant/child has been given a life-limiting diagnosis): <http://www.perinatalhospice.org>

Postpartum Support International (information about perinatal mood and anxiety disorders, including risk factors, symptoms & treatments): <http://www.postpartum.net/>

Resolve Through Sharing (support materials for those who are grieving, and training and support materials for those who provide care for patients and families experiencing loss through dying and death) <http://www.ResolveThroughSharing.org>

Sands Stillbirth and Neonatal Death Charity (support for those affected by the death of a baby, working to improve the care bereaved parents receive, and promoting research to reduce the loss of babies' lives): <http://www.sands.org.au> and <http://www.uk-sands.org>

Share Pregnancy Loss and Infant Loss Support (serving those whose lives are touched by the tragic death of a baby through pregnancy loss, stillbirth, or in the first few months of life):

<http://www.nationalshare.org>



Still Birthday (support prior to, during, and after perinatal loss, providing lactation suppression support, milk donation, and other breast milk options after loss): <http://www.stillbirthday.com>

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