Lactation After Loss: The Role of the Lactation Team
Part II: Management and Support Options
GAIL DACAYANAN RD, IBCLC
gaildac@gmail.com
California Breastfeeding Coalition
Creating a Constellation: Charting the Course for Breastfeeding Success

Topics covered today:
- Timely management of lactation after loss in different situations
- Breastmilk donation options
- Breastmilk suppression guidelines
- Resources for bereaved mothers, families and healthcare providers

Pregnancy loss, stillbirth and infant loss
These are some of life's most difficult situations.
A bereaved mother's lactation and options to manage her lactation can be overlooked and mismanaged.
The care that a mother and her family receives after a devastating loss can have a life long impact. In the short term, helping a mother with appropriate counseling, referrals and lactation management can be vital.

The Needs of Bereaved Parents:
- To have their questions answered
- To be understood
- To receive medical explanations
- To know if this will happen again

Disclosure and Fair Use Statement:
I, Gail Dacayanan, have no disclosures of relevant financial relationships with any commercial companies to report in regards to the presentation, “Lactation After Loss: Supporting the Bereaved Mother”. The information on these slides is not a substitute for medical advice, diagnosis or treatment. Always seek the advice of your physician or other qualified medical professional with any questions regarding a medical condition.
The information provided in this presentation is for educational purposes only. This presentation and the corresponding slides may contain copyrighted material, the use of which has not always been specifically authorized by the copyright owner. Wherever possible I include the name of the author of the article or the owner of the image I am posting and give them full recognition.
I believe this constitutes a “fair use” of any such copyrighted material. If you wish to use copyrighted material from this presentation for purposes of your own that go beyond “fair use”, you must obtain permission from the copyright owner.
February, 2016.
Lactation Management—Background

An end of life palliative care protocol for newborns was published in 2002. This was well accepted as a guideline, and it included emotional support for the bereaved mother.


At a training in 2003, Debra Busta Moore, IBCLC, MSN, discussed that no mention was made of breast milk cessation or donation in this end of life palliative protocol.

Debra Busta Moore; Anita Catlin. Lactation Suppression: Forgotten Aspect of Care for the Mother of a Dying Child. Pediatric Nursing. 2003;29(5)

Lactation Management, (continued)

Moore provided important additional guidelines for the management of lactation in women who are producing breastmilk after the tragic loss of a baby.

Lactation care after loss: (Refer to Chart, “Stages of Lactogenesis”)

- Mothers who suffer a pregnancy or neonatal loss will produce milk, and will go through stages of lactogenesis (milk production) even without an infant to feed.
- A pregnancy loss at 16 weeks gestation can proceed into lactogenesis I with the mother producing colostrum. Depending on many factors, this may advance to lactogenesis II which causes a subsequent increase in milk volume produced.
- It is important to provide anticipatory guidance regarding lactation management for each mother’s unique situation.

Please reference Table 3 in your handouts.
Options for the grieving mother:

- To give a grieving mother support regarding the physiological changes of lactation that she will go through is vital. **Validating her personal decisions regarding her breastmilk production or suppression is extremely important.**
- Mothers may want to immediately suppress lactation while other mothers may choose to continue to lactate and express their milk for a variety of reasons, including prolonging the connection they had with their baby.
- Some mothers may want to discard their milk.
- However, many mothers may find that donating their milk to help other babies offers some healing and good to come out of their loss.

Detailed guidelines for lactation care options to give the mother for home care.

- Milk expression and donation
- Milk suppression

Guidelines for breastmilk expression and donation:

1. Some mothers find that donating their milk to babies in need can be very healing.
   a. Mothers may find that expressing and donating their milk helps them through the grief process.
   b. Validates them as mothers
   c. Gives comforting significance to their baby’s life.
2. Frozen, stored milk can be donated (i.e. NICU freezers or home freezers), and any amount is accepted by the Mothers’ Milk Bank (MMB) if she is a bereaved mother. Frozen milk can be stored up to 6 months prior to donation.
Guidelines for breastmilk expression and donation: (continued)

3. There is no set time for a grieving mother to stop lactating, and she can slowly stop lactating as she wishes.
4. The MMB is always in need of breastmilk donations and the milk goes to infants most at-risk.
5. The mother will need to arrange the screening process through the MMB.
6. Important: Make sure that the mother tells the MMB that she has experienced a loss.

Mothers’ Milk Bank of San Jose
contact information:
www.mothersmilk.org
Toll-Free Phone: (877)375-6645
Phone: (408)998-4550
Fax: (408)297-9208
Email: info@mothersmilk.org

Have mothers call the Mother’s Milk Bank (MMB) to begin the screening process if they wish to donate their milk.

For more information on donation they may want to access the web site for the MMB and/or the HMBANA web site. (See previous slide)
1. A telephone screening and history will be done with the mother. Make sure she lets the MMB staff know that she is a bereaved mother.
2. A packet of information will be sent to her to read and review.
3. A medical release form will need to be signed by her doctor (found in the packet). (Bereaved mothers do not need a pediatrician form).
4. The mother needs to consent to and obtain a blood test (paid for by the MMB) to screen for HIV; HTLV; Hepatitis B; Hepatitis C and syphilis.
5. She may opt to donate her milk for research, in which case she fills out a 2 page form and does not need doctors consent or blood work. She can also donate to research if it is found through her history that she cannot donate to recipients.

Information for the Mother...

It is important to inform bereaved mothers that if they have preterm milk to donate to the Mothers’ Milk Bank, their preterm breastmilk differs in many ways from term milk. Their preterm milk contains specific factors which make it a much more valuable source of nutrition for premature infants, protecting them from infections and assisting them with growth.

Katherine E. Gregory and W. Allan Walker
Immunologic Factors in Human Milk and Disease Prevention in the Preterm Infant

Donating Through Grief: The Anderson’s Story

Link to video:
https://m.youtube.com/watch?v=PmId_ekok9s
Breastmilk sharing, additional thoughts:

- The responsibility as to whether to use a bereaved donor’s shared breastmilk lies with the recipient (the mother of the baby receiving the milk) and her level of trust and confidence in the safety of the breastmilk.
- Is the donor reliable in the eyes of the recipient? Is the donor her sister, aunt or close friend? Does the donor have any relevant lab work available? Is she truthful about her medical history and medications?
- This is a gray area and needs more research in regards to safety issues. However, breastmilk sharing is another personal option that a bereaved mother might choose, and it might be the right choice for her.

Risks are associated with breastmilk purchased via the internet.

This differs from breastmilk sharing. The breastmilk is sold, usually on the internet. The bereaved mother needs to know:

- This is not done by the MMB or the HMBANA.
- The donor does not usually personally know the buyer and vice versa.
- If a bereaved mother sells her breastmilk, she may never know if her breastmilk was used to feed a baby in need.
- There are no regulations as far as safety.
- Recent studies have found a variety of potentially harmful contaminants in breastmilk purchased via the internet. (1,2)

The main concerns of breastmilk sharing or the selling of breastmilk:

- Competes with nonprofit collection depots and the donor model.
- Justice—questions about unequal access for ill and healthy infants
- Safety—screening and testing not done
- May be contaminated
- No regulatory body to watch safety
**Specific guidelines for Milk Suppression:**

Tell the mother:

1. Be prepared to take 1 to 3 weeks to reduce the milk supply to the point where you don’t need to remove milk to be comfortable—(depends on many factors).
2. Remove only as much milk (through pumping or hand expression) as needed to keep from feeling too full and uncomfortable. Electric pump recommended.
3. Suggested schedule:
   a. Pump for 5 minutes every 3-4 hours, day one
   b. Pump for 3-5 minutes every 5-6 hours, day two
   c. Pump to relieve discomfort, days three to seven (or more).....

**Specific guidelines for Milk Suppression, (continued):**

Tell the mother:

4. Use cold compresses and chilled cabbage leaf compresses.
5. Do not bind breasts. Wear a supportive bra day and night. No underwire bras. Change damp breast pads frequently.
6. Ibuprofen or Tylenol for pain relief
7. Do not cut down on drinking water and fluids.

**In Summary:**

- Healing from grief after the loss of a pregnancy or a baby is a unique process for every mother and family.
- It is important to give bereaved mothers resources and information to help them make decisions and to support their decisions.
- Help with management and support of lactation after loss is a vital. IBCLC’s play a key role in the healthcare team.
In Summary:

- Social workers and bereavement counselors should provide emotional support and resources regarding lactation management.
- Milk Bank and donation information should be given, allowing mothers the option to donate their milk.
- Mothers should be encouraged to talk about their experience and receive acceptance and validation.

Lactation Support for the Bereaved Mother
A Toolkit
Information for Healthcare Providers
by Jessica Welborn (HMBANA 2012)

Appendix C: A documentation record for the healthcare provider. (A lactation record for a bereaved mother -- parenthesis mine)

Appendix D: A sample hospital policy for addressing lactation with bereaved mothers.

These documents may be useful in your current locations of practice. It is permissable to copy and use both of the documents listed above.

Main references to get you started:
Cole, Melissa; IBCLC, RLC
Lactation after Perinatal, Neonatal or Infant Loss


Busta Moore, D., and Catlin, A

Please see the handouts listing many other references used for this presentation. Thank you!

Recommended website resources for bereaved parents:

- www.emptyarmsbereavement.org
- www.compassionatefriends.org
- www.opentohope.com
- www.nationalshare.org
- www.glowinthewoods.com
- www.sands.org.au

Thank you for attending our presentation!
Questions?
Please contact Rose deVigne-Jackiewicz RN, MPH, IBCLC at 12rosebuds@gmail.com and Gail Dacayanan, RD, IBCLC at gaildac@gmail.com