



# The Voice of Mothers Who Continue to Express Milk for Donation After Infant Death

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## Abstract

**Background:** The second stage of lactation with copious milk production occurs after birth regardless of the infant's survival. Previous research indicates that milk donation following a perinatal loss may help some bereaved mothers come to terms with their loss. The purpose of this study was to explore the experience of women choosing to continue to express milk after a perinatal loss specifically for donation to a nonprofit milk bank governed by the Human Milk Banking Association of North America (HMBANA).

**Materials and Methods:** Participants were recruited through HMBANA's milk bank directors' listserv, their bereavement committee, and through their website. Participants were eligible if they donated to an HMBANA milk bank and specifically continued to pump milk for the purpose of milk donation following a perinatal loss. Qualitative interviews were conducted with each participant using a secured web-based platform. Data collection and analysis occurred concurrently using qualitative content analysis until there was acknowledged informational redundancy. Participants' demographic and lactation data were collected and analyzed using descriptive statistics.

**Results:** Over 10 months, 21 participants were interviewed. Donating after perinatal loss has been described as a positive, valuable, and nurturing experience. Diminished grieving, enhanced connection to the infant, establishment of legacy, and creation of a positive from a negative are highlighted in several themes that illuminate the phenomena of bereaved donation.

**Discussion:** The findings of this research are consistent with published literature, but in this study, two subgroups were formed. This enabled the researchers to compare the experience of those with previous breastfeeding experience and those without, which adds to the knowledge about the phenomenon. It provides information for health care professionals (HCPs) to understand the experience of bereaved milk donors and serves as a call to action for HCPs to develop best practices and incorporate lactation management in enhanced, individualized bereavement care for these women.

**Keywords:** perinatal loss, bereavement, milk donation, lactation, grieving

## Introduction

LACTATION IS THE PHYSIOLOGICAL PROCESS that women will experience following delivery of an infant even if death occurs in utero, at birth, or shortly thereafter. Prior research indicates that milk donation after perinatal loss helps

some mothers grieve and bring meaning to their experience. In reviewing the literature on this topic, we identified that most of what has been published focuses on the psychological aspects of milk donation for mothers.

Less is known about some of the challenges these women face in the donation process and whether there are differences

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in the experiences between subgroups of women who donate to a nonprofit milk bank; this focus bears further investigation.

Welborn<sup>1</sup> interviewed 21 bereaved mothers who donated their milk between January 2003 and December 2006 to the San Jose and Ohio Human Milk Banking Association of North America (HMBANA) milk banks. Reported themes include that breast pumping helped participants identify as a mother, recreate meaning, and integrate this experience of perinatal loss and the importance of addressing lactation with bereaved mothers.<sup>1</sup>

Two limitations of this research are that interviews were conducted 15 or more years ago and participants were recruited from only two HMBANA milk banks.

Additionally, Oreg<sup>2</sup> in two studies collected and analyzed two types of data from donors to an HMBANA milk bank. Personal testimonials of 80 bereaved mothers were extracted from HMBANA milk bank websites, mothers' Facebook pages, and personal blogs, and in-depth interviews were conducted with 8 bereaved mothers who donated their milk to an HMBANA milk bank.

In the first study, the importance of milk donation for these women to reestablish their identity as mothers and cope with the loss of their infants was revealed.<sup>3</sup> Oreg also reported that the process of extracting and donating their milk constitutes a grief ritual, which allows mothers to maintain and reconstruct the continuing bond with their child.<sup>2</sup> The methodology used precluded collection of demographic data from the online participants, and data obtained from interviews were from eight mothers whose loss in some cases was years earlier.<sup>2</sup>

The paucity of lactation information available to women who experience perinatal loss has also been described in the literature. One study indicated that whether the infant survived or was stillborn, few parents were completely informed about the option and process to express and donate their milk.<sup>4</sup>

Another study revealed inconsistencies in the information about lactation after perinatal loss given to mothers in Australia.<sup>5</sup> Additionally, an analysis of Australian health care agencies' web-based information found that there was little to no information about lactation after infant death provided online where women of childbearing age may seek it.<sup>6</sup>

There are publications that report findings about milk donation from mothers of living children. A 2017 qualitative study conducted with mothers whose infants were in the neonatal intensive care unit (NICU) found that participants reported they donated milk to have a meaningful and beneficial effect for others, to feel emotionally proud and like a better person, because they received support from hospital staff, and needed to tell their stories.<sup>7</sup>

Research conducted by Osbaldiston and Mingle at an HMBANA milk bank in Texas found that most of the mothers who donated their milk there were married, financially secure, well educated, and healthy and reported the following reasons for milk donation: to help others, they had too much milk, the milk bank needs donations, and they would hope that someone would do the same for them if they needed it.<sup>8</sup>

However, for women who have a perinatal loss, evidence indicates that the experience is different. They grieve multiple losses, including their dreams of becoming a mother, hopes and dreams for their infants, and the desire to breastfeed and/or express milk for their child.<sup>3,9</sup>

While published research gives us some understanding of milk donation and supports the concept that milk donation can assist bereaved mothers in their recovery, some aspects of the experience are not well described. The purpose of this study was to further explore the experience of mothers who express their milk following perinatal loss to donate to an HMBANA milk bank, including experiences that may have affected the process.

## Materials and Methods

A qualitative design was used in this study as this methodology is appropriate to analyze in-depth narrative data collected during interviews with bereaved mothers to interpret the meaning and better understand this phenomenon of expressing and donating milk as they experienced it. Approval to conduct this study was obtained from the Molloy College Institutional Review Board and HMBANA research committee.

Recruitment flyers were distributed through the HMBANA's milk bank directors' listserv, their bereavement committee, and through their website. The senior author is part of HMBANA and their bereavement committee and has worked with the HMBANA Executive Director, who was first contacted about the study. Participants were eligible if they were English speaking and donated to an HMBANA member milk bank during the previous 2 years and specifically continued to express their milk for the purpose of milk donation following a perinatal loss.

To focus only on nonprofit milk banking, women who shared their milk privately or sold their milk were excluded. Research on gender differences in human body donation indicates that altruism is more often a motivation for women rather than a monetary incentive.<sup>10</sup>

Participants contacted the principal investigator directly by email to arrange the interviews. Once informed consent was recorded, information about the participants, such as the state of residence, age, race, religion, marital status, education, employment, pregnancy and lactation history, and the name of the milk bank to which they donated, was collected. This was followed by in-depth interviews lasting 45 to 75 minutes, which were conducted with each participant using a Zoom business account with encryption.

Semistructured questions were used to help guide the interview and enabled participants to focus on their experience in their explanation (see Supplementary Appendix SA1 for the interview schedule). Confirming probes were used during the interviews to validate that the participants' meanings were understood by the researcher.

The interviews were done over a 10-month period from July 2020 to April 2021. All interviews were recorded and then transcribed by a professional transcription service. Data were analyzed concurrently with data collection; interviewing ended when researchers concurred that data saturation was reached.

A qualitative content analysis was utilized wherein the content of the narrative data was coded, categorized, and analyzed for prominent themes. This method enabled the researchers to frame interpretation by examining the similarities and differences within codes and categories and the relationship aspect of the text represented by the themes.<sup>11</sup> Qualitative data analysis software, NVivo 12 Pro, was used for data management.

The initial coding of transcripts was accomplished independently by three researchers who met regularly to discuss emerging themes and compare interpretations. This method of investigator triangulation was used as this has been demonstrated to reduce the risk of bias.<sup>12</sup> Other methods used to maintain the rigor of this research included frequent meetings and ongoing collaboration among the research team throughout the analysis stage.

In addition, member checks were conducted with the study participants using a set of questions based on the themes identified; they concurred that the themes identified reflected their experience. Participants' demographic and lactation data were analyzed descriptively. Pseudonyms were assigned to participants and their infants to ensure confidentiality.

## Results

There was some diversity in the racial/ethnic background and other personal data of the 21 participants. Nineteen percent of the participants were women of color and one was foreign-born. Most of the participants were married, two were single, one was divorcing, and one of the participants was married to a same-sex partner. Despite these differences, the narrative about their experiences was similar.

Both primiparous and multiparous women were represented; 52.4% had older children and previous breastfeeding experience. The most common cause of infant death was either lethal fetal anomalies or preterm birth, but the cause of death was not specified in all cases. See Table 1 for participant data.

The qualitative data analysis yielded seven major themes: (1) an outlet to grieve, (2) a meaningful life, (3) still a mother, (4) a positive from a negative, (5) support and recognition, (6) letting go and moving on, and (7) finding my way. Each theme with representative quotes is detailed as follows.

### *An outlet to grieve*

This theme represents how participants connected milk donation with helping them get through their grief. They reported that continuing to express and donate milk helped them to feel better and offered moments of peace and clarity during a most difficult time.

For example, Marie reported "If I could tell another woman who's lost, who was going to breastfeed...it changed my life. I don't know how I would have gotten through this without being able to pump."

Antonieta described how pumping helped her process her grief, "I don't think we often give ourselves time and space to grieve. You want to move to the next thing...So really that act of meditation that you take when you pump, I think is really, really critical in helping you process your grief."

Carol shared "I would have a picture of my baby in front of me and I'd be pumping...it was a source of therapy."

### *A meaningful life*

Participants described how milk donation helped bring meaning to their child's life. Carol described how donation was a way to honor her child "To me, no matter how short a life is here, it changes your world forever. And to be able to donate milk in honor and in memory of her, it's her legacy."

TABLE 1. PARTICIPANT DEMOGRAPHIC, PREGNANCY, AND LACTATION DATA

Characteristics	N (%)
Birth country	
United States	20 (95.2)
Colombia	1 (4.8)
Race/ethnicity	
White	17 (81)
African American	2 (9.5)
Hispanic	1 (4.75)
Asian	1 (4.75)
Age, years	
25–29	7 (33.3)
30–39	10 (47.6)
40–47	4 (19.1)
Marital status	
Single (partnered)	2 (9.5)
Married	18 (85.7)
Divorced	1 (4.8)
Education	
Some college	3 (14.3)
Bachelor's degree	13 (61.9)
Master's degree	5 (23.8)
Children	
First pregnancy or no living children	10 (47.6)
One or more children	11 (52.4)
Infant status at birth	
Born live	10 (47.6)
Intrauterine fetal demise	11 (52.4)
Cause of death	
Lethal fetal malformations	10 (47.6)
Preterm birth	7 (33.3)
Other/cause unknown	4 (19.1)
Previous breastfeeding experience	
Breastfed one or more children	10 (47.6)
Only pumped milk for feeding	1 (4.8)
None	10 (47.6)
Home state:	
California 3, Connecticut 2, Illinois 2, Indiana 1, Maryland 1, New Jersey 1, New York 2, Oregon 3, Texas 1, Virginia 3, and Wisconsin 2	

Shawna described donation as a way to memorialize her child, "I felt like I wanted to commemorate that moment because it meant a lot to me...one of my child's last gifts to the world."

Rose described how her child's life will make a difference, "It was a legacy... doing something in her name...Some people donate a building in their loved one's name; I donated a gallon of milk. She's going to make a difference now."

### *Still a mother*

This theme describes how donation helped participants feel they were still a mother even after their loss and helped them feel more connected to their child.

For example, Hanna explained "I think in a way it also helped me connect...at least mentally, I imagined that I was still a mother too."

Marie stated that expressing milk "allowed me to live how I would have lived if she was here. I was gonna breastfeed her anyway. It felt good...like I'm still a mom."

Sally described her thoughts “As I was pumping, I thought this is what I’d be doing if I had a baby here. It just kind of nurtured my imagination a little bit and kept me connected to my baby like a real mom.”

Carol said “I was sad and angry...When I pumped, I felt almost normal again, like this is what I would be doing for her and I was her mommy again.”

#### *A positive from a negative*

Participants reflected on the positive effect their donation will have on the lives of others.

For example, Marie stated “...obviously the pregnancy didn’t end the way anybody would have wanted it to, but it made me feel on a small part that like my pain could at least help another family because it’s going to women who needed it... I felt good or more at peace with everything that had happened because I knew I could help someone.”

Naomi thought about the recipient of her milk, “I think it helped with my processing of the loss of him, and I’m really glad that I was able to help, even if it’s in a small way, my loss can somehow be a contributor to a much better ending for somebody else’s child.”

Hanna said “I feel really proud of it. It’s one thing; one way my loss can help other babies...one thing that I feel like I can do that’s positive...”

Camille explained her desire to help infants in the NICU, “The fact that the twins were given donated milk I knew that I wanted to donate. We were really pretty tight for money at that point...we discussed selling the milk, but that just didn’t feel right. So I started doing the process to get the milk donated to an NICU... I wanted someone to get something out of this beyond just our own grief, for there to be some sort of positive.”

#### *Support and recognition*

Participants placed high value on milk bank efforts to recognize their donation and provide a token of thanks and remembrance.

Donna valued the milk bank recognition and tokens of appreciation offered. She said “Yes, I want a T-shirt because I’m proud. They were wonderful, so they really tried to make it as easy as possible. They intentionally kept a little bit of the milk I donated... and sent me back a pendant.... that was a really amazing gift...it made me so happy.”

Hanna stated, “I have to say the support even from just the milk bank itself was so wonderful. They checked in on me from time to time and then...they have a tree in their facility, just like a mural with leaves with the children’s names on it as a place for you to remember and actually memorialize your child...having that extra support was also really, nice. And they also sent me a leaf, so I have one here as well.”

Marie shared “I am so grateful for the woman who walked me through how to pump. I mean I didn’t get that anywhere else...they seem grateful and I’m grateful for them, too, they were all just very genuinely kind and I think that also made a difference.”

Reeva shared “I loved being able to go to their office, see my son’s star up on the sky in the mural...it just felt very honoring, honoring of my son.”

Andrea reported “The nurses showed me how to use the pump and gave me all the information I needed. I was so grateful to them.”

Josie said “I couldn’t have done it without the wonderful staff at the bank, they made it so easy and gave me all of the information and helped me get a pump. They were there for me every step of the way.”

#### *Letting go and moving on*

This theme describes the emotional experience surrounding participants’ decision to stop expressing milk for donation. Participants describe this time as bittersweet, where they wanted to move on, yet were sad to let go of their milk and their last connection to their child.

Carol described her difficulty in letting go “...this is like something that only I can do. So, it gives me like a source of self-worth, I guess. And like a connection with my baby, right? I’m scared that as I stop it will be like another goodbye. You know? The last thing I have from her.”

Rose said “It felt like it was losing her all over again because the milk ..... it my last physical connection.”

Shawna reported feeling sad when she stopped expressing her milk “...because I kind of felt like that was the end of something that my son and I could do together that my body, you know, could provide for someone else.”

Teresa expressed how stopping milk expression stirred up many emotions, “I just didn’t wanna let go. It brought me back to that place when they asked me to take her off the machines, going back to that place is awful. And being able to have that milk, it’s like, you know, people lose a spouse, or a family member and they have a piece of their clothing or something special from them...this is what I have left of my baby. So, it was devastating having to stop. I struggled with it, but I knew in my heart it was time.”

The final donation was also difficult for Andrea “It was hard, dropping off the last of my milk. I remember being very emotional...even though I knew logically this is a good thing, it just was hard letting go of that because I just felt like it’s another loss.”

#### *Finding my way*

Some participants felt that they had little guidance or support to figure out the process surrounding milk expression and in navigating the milk donation process.

Reeva stated, “I didn’t know there were different sizes of flanges. I didn’t know woman’s nipples were that different in sizes. I had no idea. I didn’t know what I was doing. I think some of the barriers honestly were me not having a child that was living.”

Furthermore, participants believed that people have a hard time knowing what to do with a pregnancy loss of any kind, which made it harder to obtain information. Turning to the internet for information, many participants found that more of the guidance found online focused on stopping milk production and not continuing lactation to donate.

Participants also discussed the difficulty of navigating access to a high-quality electric pump because they did not have a living child.

Teresa stated: “I thought like, well, should I get a hand pump and make do.”

Some participants explicitly stated that hospital staff did not provide information about expressing and accessing a breast pump because they were a bereaved mother.

Shawna specifically stated, “But again, if that process had been somehow made easier, then it could have gone on for longer.”

From the participant responses in this sample, we noted a difference in the milk expression experience between those who had breastfeeding experience with older children and those who had not breastfed before.

Sheryl called out the need for specific resources for first-time parents, “Having those resources leaving the hospital and understanding that, especially for first-time moms, just because I’m not leaving with a baby, I’m still leaving with a full pregnancy body and a lot of questions... but I had more questions than answers available to me on that handout.”

These seven themes clearly demonstrate the importance of milk donation for bereaved mothers and the benefit they derived from this after experiencing a perinatal loss. This highlights areas of opportunity for health care providers to assist bereaved parents and potential future research.

## Discussion

There are two important aspects to note in this study. This research was conducted during the COVID-19 pandemic, but data collection was not negatively impacted since the approved study plan specified remote interviews. A response rate could not be calculated since information was distributed through HMBANA member banks, so the number of women who received the recruitment flyer is unknown.

Similar to findings reported by others, participants in our study reported that expressing and donating milk helped them through their grief and reaffirmed their status as a mother, but described that feelings of loss resurfaced when they stopped milk expression and donated for the last time.

Our sample included participants from 11 different states throughout the United States who donated to seven different HMBANA milk banks and were more diverse in background than prior research samples. This study adds to what is known on this topic, in that two subgroups were formed enabling us to compare the experience of those with previous breastfeeding experience and those without.

The subgroup with no breastfeeding experience and whose infants did not survive after birth were very direct about voicing challenges they experienced in getting information and breast pump equipment. These experiences identify areas that need to be addressed to provide appropriate help and support to bereaved mothers in their decision to donate their milk.

These findings provide a call to action to all health care professionals working with childbearing families. Our study participants stated how important continuing to express milk after their loss for the specific intent of nonprofit donation was to their grieving journey and about the inadequacy of the information provided, particularly to those who had not breastfed before. It is imperative that birth centers and hospitals set up perinatal loss programs that include lactation and milk donation information following the death of an infant. All centers could easily partner with an HMBANA milk bank in their region.

Similar to coordination with organ donation, birth centers can facilitate the donation process, screen donors after perinatal loss according to the HMBANA standardized protocol,<sup>13</sup> and develop strategies so that eligible and willing donors can get their blood drawn for required serological testing.

Health care providers should also ensure that the bereaved donor has access to a high-quality, double electric breast pump and continued support.

## Conclusions

This research demonstrated that these women who chose to continue milk expression for the sole purpose of donation after they experienced perinatal loss found this to be a critical part of their grieving process. Many research questions still need attention.

A better understanding of the nuances between mothers whose infants are live-born, but then die, and mothers who experience an intrauterine fetal death or plan for a palliative care birth is needed. Best practices for women who require additional help with milk donation decision-making and the milk expression process need to be identified.

By incorporating lactation management, we can individualize and optimize bereavement care for women who experience a perinatal loss.

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## Ethical Approval Statement

Approval to conduct this study was obtained from the Molloy College Institutional Review Board and the HMBANA Research committee.

## Disclosure Statement

No competing financial interests exist.

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## Supplementary Material

Supplementary Appendix SA1

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