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## Winging it: Maternal Perspectives and Experiences of Breastfeeding Newborns with Complex Congenital Surgical Anomalies

Jill Demirci, PhD, RN, IBCLC<sup>1,\*</sup>, Erin Caplan, MA<sup>1</sup>, Beverly Brozanski, MD<sup>2</sup>, and Debra Bogen, MD<sup>3</sup>

<sup>1</sup>University of Pittsburgh School of Nursing, Department of Health Promotion & Development, 440 Victoria Building, Pittsburgh, PA 15261

<sup>2</sup>Children's Hospital of Pittsburgh of UPMC, University of Pittsburgh School of Medicine, Department of Pediatrics, Department of Obstetrics, Gynecology and Reproductive Sciences, Pittsburgh, PA

<sup>3</sup>University of Pittsburgh School of Medicine, Department of Pediatrics, Division of General Academic Pediatrics, Pittsburgh, PA

### Abstract

**Objective**—To describe the experience of breastfeeding (inclusive of breast milk expression/pumping, provision of breast milk via devices, and at-breast feeding) among mothers of newborns with complex congenital surgical anomalies and the contexts under which pro-breastfeeding behaviors and attitudes are facilitated or compromised.

**Study Design**—We used qualitative description to analyze 23 interviews conducted with 15 mothers of newborns undergoing surgery for gastrointestinal, cardiac, or neural tube defects.

**Results**—Breastfeeding experiences were characterized by naivety regarding the importance and rationale for exclusive breast milk feedings and best practices to facilitate milk supply maintenance and transition to at-breast feeds. Maternal breastfeeding views and behaviors were impacted by indeterminate prenatal plans to breastfeed/provide breast milk, limited prior breastfeeding exposure and knowledge, and gaps in postnatal lactation support.

**Conclusion**—Future research should investigate methods to improve exclusive breast milk feeding and facilitate transitions to at-breast feeds among mothers of newborns with surgical congenital anomalies, with consideration of identified barriers.

### Keywords

breast feeding; human milk; congenital abnormalities; intensive care; neonatal; heart defects; congenital; neural tube defects; digestive system abnormalities

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\*Corresponding author: jvr5@pitt.edu, Telephone: +1 724-622-6371.

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## INTRODUCTION

As a nutritionally- and immunologically-dense “superfood,” human milk is of vital importance among preterm, critically-ill, and other vulnerable infants (1). One category of vulnerable infants includes newborns hospitalized in the neonatal intensive care unit (NICU) and undergoing surgery for serious congenital anomalies (i.e., “surgical infants”). For these infants, provision of human milk reduces the risk of nosocomial infections, necrotizing enterocolitis, gastrointestinal and lower respiratory tract infections, and pain; it is also associated with reduced time to full enteral feeds and shorter NICU length of stay (2–5). These clinical outcomes appear to be influenced in part by the protective effect of human milk on gut microbiome diversity (6) and oxidative stress at the molecular level (7). Yet newborns with surgical anomalies and their mothers face multiple barriers to establishment of breast milk feeds. The medical acuity of the infant, preparation for and recovery from surgery, and prematurity and accompanying developmental delays in feeding readiness often contribute to postponement or interruptions in oral feeds and maternal reliance on a breast pump to establish a milk supply. Pump-dependent mothers in the NICU experience environmental stressors, inadequate education on milk supply maintenance with a pump, and limited assistance in transitioning to at-breast feeds, all of which can result in down-regulation of milk volume (8, 9).

Prospective research has identified demographic and medical factors associated with successful establishment and continuation of breast milk feeds among surgical mother-infant dyads (10, 11). However, there is limited research on the breastfeeding experiences of these mothers, including decision-making around breast milk provision, management of milk expression and storage of milk, transition to at-breast feeds, and receipt and interpretation of lactation counseling. This is reflective of a larger dearth of knowledge around feeding and lactation support for vulnerable infants. Compiling such data has implications for the design of breastfeeding education and policy and, in turn, rates of human milk feedings among critically-ill infants, including the surgical NICU population. In this qualitative study, we describe maternal perspectives on breast milk expression and provision, as well as at-breast feeds during the first two months postpartum for newborns with complex congenital surgical anomalies.

## METHODS

### Design

We conducted up to three individual postpartum interviews with mothers whose newborns were undergoing surgery for a serious congenital anomaly. Interviews explored women’s postpartum experiences with breast milk expression and breast milk feedings.

### Sample and Setting

Between November 2016 and May 2017 we approached, screened, and enrolled a convenience sample of postpartum women whose infants were currently receiving care at a Level IV (regional) NICU in northeastern United States. The NICU is a 55-bed regional referral center for congenital anomalies. Eligible women were at least 18 years, were

currently providing/expressing breast milk for the index infant or intended to at the time of approach, and had given birth in the past two weeks to a medically-stable infant who had (or would) undergo surgery for a congenital cardiac, gastrointestinal (GI), or neural tube defect (NTD). All potential participants were referred by NICU clinical staff. This study was approved by the University of Pittsburgh Institutional Review Board. All participants provided written informed consent.

## Data Collection

At the time of enrollment at 1–2 weeks postpartum, mothers completed a survey which included demographics, medical and surgical history of the infant, route and type of any enteral feeds, and plans for provision of breast milk. Data were entered and managed in REDCap electronic data capture tools hosted at the University of Pittsburgh (12). Women were interviewed during the enrollment visit at the infant’s bedside in the NICU, with attempts to re-contact by phone for follow-up interviews two and four weeks later (2–3 and 5–6 weeks postpartum, respectively). Interviews were conducted by the PI or research staff, who were all trained in qualitative interview techniques and had research experience in interacting with mothers of critically-ill infants. Interviews followed a semi-structured script, modified with progressive interviews to reflect emergent themes. The script included questions about the following as they related to milk expression and at-breast feeds: decision-making, prenatal preparation, goals, problems and successes, management, and education and support received. We also queried mothers about their views on donor human milk (DHM) from HMBANA (Human Milk Banking Association of North America)-certified milk banks and awareness of the practice of oral care with breast milk. The former was added as a specific point of inquiry, because even though no infants in the study went on to receive DHM, infants undergoing surgery (particularly GI surgery) are frequent recipients of DHM due to their medical acuity, susceptibility to necrotizing enterocolitis, and often, their prematurity and low birthweight. We asked mothers about milk from HMBANA milk banks specifically, as this is the route for DHM acquisition in U.S. NICUs. As needed, we clarified HMBANA’s rigorous policies surrounding donor screening, milk processing, milk storage, and ethics (13) to differentiate them from for-profit milk banks and informal milk sharing channels. Data collection ceased after we observed minimal variation in previously identified themes and no new themes (i.e., ‘saturation’). Interviews were conducted in English, audio-recorded, and transcribed verbatim.

## Analysis

We used SPSS v. 24 (IBM Corporation, 2016) to compile summary statistics on baseline survey data. For analysis of interview data, we employed qualitative description, a pragmatic approach that stays “close to the data” and prioritizes participants’ own words in their interpretation of events (14). Transcripts were independently and iteratively coded by both JRD and EC for content using Atlas TI v. 7.5.19 (Atlas TI, GmbH Berlin, 2017). Codes were examined for variations, departures, and similarities and condensed into major themes. Coders met regularly throughout data collection and analysis to discuss revisions to the interview guide and coding decisions and consolidations.

## RESULTS

### Sample

Fifteen women completed a baseline interview, five completed at least one follow-up interview, and three completed both follow-up interviews. Those who did not complete follow-up interviews could not be subsequently reached by telephone. Women and their infants are described in Tables 1 and 2. Most women were unmarried, White, first-time mothers, who did not have definitive plans during pregnancy for duration or exclusivity of breast milk feeds. Because few dyads transitioned to at-breast feeds during the study period, the majority of interviews concerned mothers' experiences with milk expression via electric pump.

### Overarching Theme and Summary of Qualitative Findings

A prominent theme that emerged in the interviews concerned women's naivety regarding the importance of breast milk provision specifically for infants undergoing surgery, as well as the implications of current milk expression patterns on future milk availability. The lack of agency and urgency to correct potentially detrimental milk expression practices, plan for future breastfeeding needs (adequate milk supply and transition to at-breast feeds), and seek out lactation support was abetted by several factors. These included women's own ambivalence toward or trivialization of exclusive breast milk feeds against the backdrop of the infant's medical problems, prolonged periods where the infant was not receiving any enteral nutrition, and inconsistent or absent lactation advice from medical personnel. Subthemes included *doing the best thing*, *doing what they tell me to do*, *hooking it up and letting it suck*, and *seeing how it goes*.

#### Subtheme 1: Doing the best thing

Mothers' motivation to express and provide breast milk and/or feed at-breast centered on the general perception of breast milk being the "healthiest," particularly for an infant with medical concerns. Secondary reasons included the expense of formula, bonding anticipated with at-breast feeds, and milk expression as a way to "mother" or care for the infant in a high acuity medical setting. Women cited medical professionals, including nurses at the birth and surgical hospitals and neonatologists, as the main source of information about the health benefits of breast milk and their decision to initiate and continue milk expression efforts; this was especially true for those who were not aware of the surgical diagnosis until after birth and those who had not planned to breastfeed during pregnancy.

...It was the day after I gave birth to her the doctors from [the surgical hospital] were calling saying, "I'd really like for you to breastfeed, to pump at least, and this would be the best thing for her." So of course I'd do it, yeah...I mean I've always known that breastfeeding has probably been better for babies, but they [surgical team] really put in my head that it was...really important at this time right now. (40-year-old multipara, 6 days postpartum, infant cardiac anomaly)

I wasn't planning on breastfeeding. But they said whenever he was born that it would be best if I did with everything going on with him, and that otherwise, they

would use donor milk. So I said whatever I can do to help. (32-year-old multipara, 6 days postpartum, infant GI anomaly)

Although mothers possessed a basic understanding of the importance of breast milk in the context of their infant's diagnosis, they were generally unaware of specific short and long-term advantages of exclusive breast milk feeding for vulnerable infants.

I don't see any problem with [formula supplementation]. I don't know. I mean I think that he'd still be getting all the nutrients from the breast milk even if you are supplementing a little bit, so I can't see it making a big difference. (26-year-old primipara, 7 days postpartum, infant GI anomaly)

[Breast milk] will chunken him up...it gives him more nutrients...not that it's healthier, because I'm sure formula is just as good for him to eat... (25-year-old primipara, 20 days postpartum, infant GI anomaly)

### **Subtheme 1a: Views on Donor Human Milk (DHM)**

While mothers generally had strong preferences for any breast milk over formula, they preferred their own milk over DHM (hypothetically). Women who expressed more negativity toward DHM were those who were more ambivalent toward exclusive breast milk feeds and/or had made a post-birth decision to express and provide breast milk.

There's no way my baby is drinking [donor milk] from somebody else...I know they screen it and everything, but...no, I couldn't... there's no way... I still think it's too gross...I don't know, I guess I'm kind of a germaphobe. (30-year-old multipara, 6 days postpartum, infant GI anomaly)

I guess I'd probably be more comfortable with either my milk or formula as opposed to someone that I don't know or have no knowledge of. (26-year-old primipara, 7 days postpartum, infant GI anomaly)

### **Subtheme 2: Doing what they tell me to do**

Mothers tended to defer to medical staff in both the decision to initiate milk expression and establish feeding and milk expression patterns. This trend was seemingly fostered by a lack of both definitive plans to breastfeed/provide breast milk prior to birth and substantive knowledge about benefits of breast milk and breast milk production. Mothers held neonatologists' breastfeeding recommendations in high regard, even when specifics of why and how milk expression and at-breast feeds might proceed were not discussed (*"I'm just kind of doing what nurses and doctors tell me to do"*). Notably, no women had attempted human milk oral care or were aware of the potential benefits of this practice prior to initiation of oral feeds (15, 16).

While the majority of women were provided an electric breast pump for temporary use by nurses at the delivery hospital, counseling in pump use and milk supply management at both the birth and surgical hospital was generally brief or non-existent. Some education recounted by women was conflicting, inaccurate, or non-evidence-based. This included the perception that one could defer milk expression completely overnight, that infants should demonstrate competence with bottle-feeding expressed breast milk before proceeding to direct at-breast

feeding, and strict adherence to a time-based rather than feeding cue-based feeding schedule—even as the transition to at-breast feeds occurred and the dyad prepared for hospital discharge.

One nurse told me that I could nurse first. Another one told me that I have to give him a bottle first. Kind of up in the air. (18-year-old primipara, 25 days postpartum, infant GI anomaly)

They said when I take her home it's basically when she cries, flips out, starts eating her fist, I know she's hungry. But here [in the NICU], I have to stick to the every three hour [feedings] because they want her to gain weight and show that she's eating or I'll never be able to be discharged with her pretty much...But if she doesn't [breastfeed] whenever they want her to eat, they make me give her [50mL of breast milk by bottle]...and I understand, she does need to eat, she does need to gain weight...but I think it's just confusing for her. (32-year-old multipara, 10 days postpartum, infant GI anomaly)

As a result, some women implemented milk expression patterns that were inadequate to sustain supply and stated that they had observed gradual declines in milk production, even at the time of the initial interview. In general, women were not overly concerned about this, as the volume of milk expressed and stored remained “ahead” of their infants' current enteral feed volumes.

...Sometimes I pump half of a bottle, and sometimes I pump a whole bottle, and it just kind of depends on whenever I do it. I'm not going to worry too much yet...I kind of slacked the past two days ...I'm not worried about it because it's still coming in. I have like seven bottles in my freezer in the room over at the Ronald [McDonald] House... (18-year-old primipara, 6 days postpartum, infant GI anomaly)

[I pump] every three hours. I don't wake up in the middle of the night to pump... I mean I really don't know much about it...It doesn't feel like I'm getting very much but I think that that's normal at the beginning. (32-year-old multipara, 6 days postpartum, infant GI anomaly)

### **Subtheme 3: Hooking it up and letting it suck**

Women perceived milk expression as a time-consuming, but relatively straight-forward process. There was limited insight into the complexity involved in establishing and maintaining a milk supply devoid of direct and frequent infant stimulation at the breast. Women were unaware of different milk-expression techniques (e.g., hand-expression, hands-on pumping) or electric pump mechanics (e.g., stimulation and expression phases). Perceptions mirrored basic instructions provided by NICU staff at both hospitals, which stopped short of rationale for milk expression recommendations and anticipatory guidance regarding milk supply maintenance.

I mean [the NICU nurses] said, of course if I have any questions [about pumping], but it's pretty self-explanatory once you get hooked up to it. They showed me how

to use [the pump] and then after that—it makes sense. So I hook it up and let it suck. (28-year-old primipara, 2 days postpartum, infant GI anomaly)

I haven't needed any help [pumping], actually. I mean [the nurses] did ask, "Do you need any help? Are you doing okay?" And I say, "Yeah I'm fine." So. (25-year-old primipara, 6 days postpartum, infant GI anomaly)

Some mothers did perceive the time, energy, or privacy desired or required for exclusive pumping to be burdensome; at times, they felt the commitment encroached on other important responsibilities and bonding with the infant. This was particularly true for mothers who traveled long distances back and forth from the NICU and those with other children at home. Pumping challenges were also compounded when there were delays in receiving an electric breast pump in either the birth hospital or home setting.

Well, pumping is a huge job. I'm doing it every two to three hours. There's absolutely no way to keep my five-year-old son separated from me, so he's usually sitting right beside me. It's hard to get anything done. I have to pump like right before I leave my house and by the time I make it here, I don't even get to spend much time with [my baby]. I'm like, "Hello," and I'm pumping. (30-year-old multipara, 6 days postpartum, infant GI anomaly)

It's hard with doctors coming in and out all the time, and then you want to make it to rounds, and you want to talk to the doctors and just trying to pump every two to three hours. It's a little bit rough because there's so much going on...but it's just trying to fit it in. (31-year-old primipara, 7 days postpartum, infant GI anomaly)

Some mothers enjoyed pumping and viewed it as a diversion from the gravity of their current situation or as a way to care or provide for the infant.

Yeah I'm actually enjoying [pumping]...It's calming to me. It makes me feel like I'm really giving back to her what she deserves. (40-year-old multipara, 6 days postpartum, infant cardiac anomaly)

#### **Subtheme 4: Seeing how it goes**

Women's orientation to breastfeeding existed mainly in the present. In general, participants did not anticipate issues in sustaining milk supply, maintaining a rigorous milk expression schedule, or transitioning to at-breast feeds, despite the relative complexity and effort involved in these processes. Instead, a "wait and see" approach toward breastfeeding goals and plans was adopted (e.g., "*We're just winging it*"; "*I'm just taking it day by day*"). Consequently, few had considered the future availability of lactation support services. In later interviews, no women had utilized lactation resources outside of the NICU setting, and no infants discharged from the hospital were feeding at-breast.

I want to just see how time goes and how my breasts decide they want to, you know, how much they want to give out...I'm sure there's plenty of numbers and support I can call, visit, or find [for breastfeeding help] so... (40-year-old multipara, 6 days postpartum, infant cardiac anomaly)



Some mothers were more pessimistic or ambivalent toward long-term milk expression or transitioning to at-breast feeds. Their doubts were driven by several factors: competing responsibilities (e.g., employment, other children), unsuccessful prior breastfeeding experiences, trepidation about anticipated physical and emotional toll of breastfeeding, and distrust in oneself to ensure adequate infant intake.

I mean I'd rather just go with the pumping and giving him the bottle because I feel like it's easier. And it already hurts when I pump, so I can only imagine what it would feel like if the baby was doing it. (19-year-old multipara, 13 days postpartum, infant GI anomaly)

I was thinking that [I would try at-breast feeds] before, but seeing that I've just been somewhat used to pumping and he's used to the bottle and stuff, I don't think [I will]. I want to also make sure that he's consuming...all [the NICU physicians] said for me to just keep pumping now so that we can keep an eye on how much he gets. (25-year-old primipara, 20 days postpartum, infant GI anomaly)

## DISCUSSION

The breastfeeding experience of mothers of newborns undergoing major surgery in our study was characterized by a perfunctory focus on the pumping routine. There was minimal reflection on rationale for milk expression or providers' pumping recommendations, implications for deviations in pumping patterns, and plans for milk supply maintenance and transition to at-breast feeds. Although there were some exceptions, mothers' attitudes toward and conceptualizations of breastfeeding appeared to be cultivated through indeterminate prenatal plans to breastfeed/provide breast milk, limited prior breastfeeding exposures and knowledge, and inadequate postnatal opportunities to acquire evidence-based lactation education in the context of a complicated postnatal course and gaps in lactation support services.

Existing research corroborates our findings that surgical mother-infant dyads encounter significant and unique barriers to establishing and sustaining a milk supply and transitioning to at-breast feeds. Barriers include early and repeated mother-infant separation and NPO (nil per os) periods necessitating dependence on a breast pump, lack of timely access to hospital-grade electric breast pumps, and NICU environments without adequate and qualified personnel to assist breastfeeding mothers (8, 17–21). Others have documented surgical anomaly-specific breastfeeding challenges. For example, mothers may be discouraged from touching, handling, or engaging in kangaroo care with infants diagnosed with congenital diaphragmatic hernia due to risks associated with infant stimulation (18); these restrictions can contribute to maternal and infant stress, impaired maternal oxytocin release, and subsequent declines in milk production (22–24). Among infants with congenital heart disease, NICU length of stays are often less than two weeks, precluding establishment of at-breast feeds prior to discharge (20). Infants with spina bifida have a high co-occurrence of Chiari II malformation, which can impact at-breast feeds through impaired ability to latch and coordinate sucking, swallowing, and breathing during feeding (5).



Considering the multitude of barriers, few studies address NICU and post-discharge breastfeeding/breast milk provision rates among newborns with complex congenital surgical anomalies. A 2002 cohort study of 120 infants undergoing surgery at a single hospital system in Mexico demonstrated that rates of breast milk provision during the infant's first hospitalization at less than twenty days of life were comparable to U.S. averages at the time; however, rates of any and exclusive breast milk provision at three months postpartum were 43% and 17%, respectively—well below U.S. population estimates. Rates were lowest among infants with gastrointestinal congenital malformations. Inadequate milk supply was the primary factor associated with cessation or reduction of breast milk feeds (10). Another prospective cohort study of 535 U.S.-based NICU infants revealed that those with any birth defect or who had undergone any surgery were significantly more likely to be formula feeding at hospital discharge versus receiving any breast milk (52% vs. 32% for birth defects; 44% vs. 27% for surgery). Infants born to a teen mother, weighing < 1500 grams at birth, requiring heart surgery, and/or treated with inhaled nitric oxide were significantly less likely to be receiving any breast milk at NICU discharge (11). Conversely, Spatz and colleagues have demonstrated that with excellent support in the NICU setting (e.g., nursing staff highly trained to provide assistance with pumping, early skin-to-skin care, non-nutritive sucking), infants with complex surgical anomalies can transition to 100% at-breast feeds prior to hospital discharge and meet or exceed national breastfeeding rates and Healthy People 2020 breastfeeding goals for duration and exclusivity (3, 25, 26).

Based on existing research and expert opinion, Spatz (27), Nyqvist et al. (28), and Meier and colleagues (8) have proposed guidelines for supporting breastfeeding/breast milk feeds among vulnerable infants in the NICU. These guidelines include the following common components: 1) facilitate an informed decision on breastfeeding/provision of breast milk, through prenatal counseling when possible, regarding specific short- and long-term risks of *not* breastfeeding a vulnerable infant; healthcare providers should be trained in consistent, simple language and skills needed to create a supportive breastfeeding culture; 2) focus on establishing and maintaining an adequate maternal milk supply through provision of a hospital-grade electric breast pump, teaching and observing milk expression skills, and use of assessment tools such as milk expression diaries; 3) teach mothers how to store and feed expressed breast milk; 4) teach and encourage frequent skin-to-skin contact; 5) as soon as possible after extubation, facilitate transition to at-breast feeds through non-nutritive sucking at the breast, use of assistive devices if needed (e.g., nipple shields), and quantifying at-breast milk transfer through test weights; and 6) prepare mothers for breastfeeding after NICU discharge, and facilitate arrangement for follow-up lactation support. Our data also indicate a need to educate mothers of infants in the NICU with congenital surgical anomalies on: 1) the impact of early milk expression patterns on later milk production, taking into account typical daily milk volumes that will eventually be required to meet the infant's growth needs; and 2) the rationale for and value in transitioning to at-breast feeds when the infant is medically stable. A recent prospective cohort study of over three hundred mothers and their very low birth weight infants in the U.S. also suggests that because some women become more amenable to formula use as infant health improves in the NICU setting, there may be a need for scripted talking points about the longer-term health advantages of continued human milk feedings for vulnerable infants (29).

More recently, human milk oral care has garnered attention as a feasible, safe, and effective intervention for vulnerable infants when at-breast feeds are delayed or interrupted (16). This practice involves application of a sterile cotton swab dipped in human milk to infants' lips and buccal surfaces, facilitating systemic absorption of cytokines, secretory IgA, lactoferrin, and other components of human milk (15, 30, 31). Oral care with human milk has been documented to decrease incidence of infant clinical sepsis (15) and appears to impact continuation of milk expression and provision among preterm and surgical mother-infant dyads (16, 18).

Notably, few mothers in our study reported being engaged in any of these recommended breastfeeding support strategies, including non-nutritive sucking, early transition to at-breast feeds, regular skin-to-skin care, or human milk oral care. Mothers also reported inconsistent and conflicting breastfeeding counseling and did not recognize specific advantages of breast milk for infants with surgical anomalies. Importantly, few study mothers had initiated or considered a strategy to initiate at-breast feeds, though research clearly demonstrates the importance of this transition on breastfeeding continuation. One recent medical record review of preterm NICU infants found that mothers who had fed at-breast at least once per day during NICU hospitalization were significantly more likely to still be providing breast milk at one and four months post-discharge (32); the positive association between direct at-breast feeds and duration of breast milk provision has been corroborated by others within samples of preterm and very low birthweight infants as well (33, 34). The fact that study mothers did not endorse utilization/receipt of these support strategies and education is somewhat unexpected, considering the success of a recent interdisciplinary quality improvement initiative in the recruitment NICU, which effectively increased provision of mother's own milk (any) from an average of 45% to over 80% of all infants at NICU discharge. This program incorporated some of the evidence-based and expert-recommended elements discussed above with regard to supporting breastfeeding in vulnerable infants. It also included some unique services and incentives, beginning at prenatal diagnosis and continuing through the NICU hospitalization, designed to increase breast milk provision. It is possible that mothers in our study missed receiving some components of the program by happenstance or that some components were added after mothers' study participation. It is also possible that there are unmet breastfeeding educational and support needs that still exist in the program.

When presented with the hypothetical prospect of using DHM from HBANA-certified milk banks, we found that participants had variable reactions, with women less committed to breastfeeding exhibiting more reservations. Few studies, particularly in the U.S., have examined childbearing women's perspectives on DHM. In a notable exception, a qualitative study conducted in the Midwestern U.S. with twenty mothers of preterm infants documented similar reactions to women in our study. Specifically, mothers had concerns about DHM screening and processing, as well as a general aversion to providing their infant a biological substance from another mother (35). These sentiments are corroborated in research from Turkey and Indonesia, highlighting maternal DHM concerns including infection transmission, nutrient content, and religious conflicts (36, 37). Qualitative work from Australia suggests that mothers would be receptive to DHM for vulnerable infants if they could be assured that DHM was "screened" and "safe," if their partner supported its use, if

providers were knowledgeable and presented DHM as a medical intervention and temporary replacement for their own milk, and if mothers were educated on DHM during pregnancy rather than after birth (38, 39).

A major limitation of our study is generalizability of findings. We recruited a small sample consisting of mainly non-Hispanic white mothers and infants with GI infant surgical anomalies from within a large quaternary NICU; our findings may not be representative of the breastfeeding experience within this or other NICUs or among mothers of infants with non-GI surgical anomalies. Our small numbers, particularly in follow-up interviews, also made it difficult to draw meaningful distinctions in experiences among participants with certain characteristics (e.g., various surgical anomalies, younger/older gestation, demographic groups). In addition, we did not recruit women who did not intend to provide breast milk, though decision-making around feeding choice is an equally worthy point of inquiry to inform prenatal and postpartum counseling and education. Finally, we did not have access to medical record data on infant hospital course or other pertinent data such as birthweight, all of which has the potential to exert influence on the experience of breast milk provision.

## CONCLUSIONS

Mothers of newborns with complex congenital surgical anomalies experience significant barriers to establishment of a milk supply and transitioning to at-breast feeds, which ultimately has the potential to reduce the proportion and duration of human milk feedings in this population. Mothers are not necessarily cognizant of these barriers or their repercussions, including the impact on infant health. Evidence indicates that with comprehensive and coordinated lactation support, ideally beginning prenatally and continuing with skilled NICU staff and community-based resources, mothers of infants with surgical anomalies can provide breast milk and eventually feed at-breast at rates comparable to the general population. Future research is indicated to determine best practices for implementation of support in these settings, including special considerations for different sectors of the surgical population.

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**Table 1**

Sample characteristics as assessed at time of initial interview (N=15).

<b>Characteristics</b>	<b>n (%)</b>
<b>MATERNAL DEMOGRAPHICS AND OBSTETRICAL HISTORY</b>	
<b>Age</b>	
<i>18–24</i>	<i>6 (40)</i>
<i>25–31</i>	<i>5 (33)</i>
<i>32–40</i>	<i>4 (27)</i>
<b>Marital status</b>	
<i>Married</i>	<i>5 (33)</i>
<i>Living together</i>	<i>8 (53)</i>
<i>Single</i>	<i>2 (13)</i>
<b>Education</b>	
<i>Less than high school</i>	<i>2 (13)</i>
<i>High school diploma / GED</i>	<i>5 (33)</i>
<i>Some college or vocational program</i>	<i>5 (33)</i>
<i>Bachelors' degree or higher</i>	<i>3 (20)</i>
<b>Race</b>	
<i>White/caucasian</i>	<i>15 (100)</i>
<b>WIC recipient</b>	
	<i>9 (60)</i>
<b>Employment status prior to delivery</b>	
<i>Working, full-time</i>	<i>8 (53)</i>
<i>Working, part-time</i>	<i>2 (13)</i>
<i>Not working</i>	<i>5 (33)</i>
<b>Planned return to work<sup>*</sup></b>	
<i>No return or uncertain</i>	<i>7 (47)</i>
<i>2–4 weeks</i>	<i>1 (7)</i>
<i>5–8 weeks</i>	<i>2 (13)</i>
<i>9–12 weeks</i>	<i>3 (20)</i>
<i>13 weeks–1 year</i>	<i>2 (13)</i>
<b>Number of prior births</b>	
<i>0</i>	<i>10 (67)</i>
<i>1</i>	<i>3 (20)</i>
<i>2</i>	<i>2 (13)</i>
<b>INFANT</b>	
<b>Gestational weeks at birth</b>	
<i>31–33</i>	<i>4 (27)</i>
<i>34–36</i>	<i>5 (33)</i>
<i>37–40</i>	<i>6 (40)</i>

<b>Characteristics</b>	<b>n (%)</b>
<b>Surgical Diagnosis**</b>	
<i>Neural tube defect</i>	1 (7)
<i>Cardiac defect</i>	1 (7)
<i>Gastrointestinal defect</i>	13 (87)
<b>Timing of surgical diagnosis</b>	
<i>Prenatal</i>	10 (67)
<i>Postpartum</i>	5 (33)
<b>BREASTFEEDING</b>	
<b>Number of prior children for whom breastfeeding was attempted</b>	
<i>0</i>	11 (73)
<i>1</i>	3 (20)
<i>2</i>	1 (7)
<b>Planned duration of <u>exclusive</u> breastfeeding during index pregnancy</b>	
<i>Never planned to exclusively breastfeed</i>	3 (20)
<i>Was unsure or did not think about</i>	7 (47)
<i>&lt; 6 months</i>	1 (7)
<i>6 months</i>	4 (27)
<b>Planned duration of <u>any</u> breastfeeding during index pregnancy</b>	
<i>Never planned to breastfeed at all</i>	3 (20)
<i>Was unsure or did not think about</i>	7 (47)
<i>1 year</i>	4 (27)
<i>&gt;1 but &lt;2 years</i>	1 (7)
<b>Received lactation consult after delivery</b>	7 (47)
<b>Electric breast pump available for use at delivery hospital</b>	13 (87)

\* One mother had returned to work part-time at the time of the second interview.

\*\* Specific diagnoses: gastroschisis, congenital diaphragmatic hernia, omphalocele, tracheoesophageal fistula, esophageal atresia, jejunal atresia, omphalomesenteric duct, Hirschsprung's Disease, spina bifida, and pulmonary artery stenosis



**Table 2**

Infant enteral feeding status and disposition at time of interviews.

<b>Initial Interview (1–2 weeks postpartum; n=15)</b>	
<b>ENTERAL FEEDS</b>	6 (40)
<b>Feeding type</b>	
<i>MOM only</i>	4 (27)
<i>Formula only</i>	0 (0)
<i>MOM + formula</i>	2 (13)
<b>Feeding route(s)</b>	
<i>At-breast</i>	2 (13)
<i>Bottle</i>	3 (20)
<i>Tube feeds</i>	3 (20)
<b>LOCATION</b>	
<i>Surgical hospital</i>	15 (100)
<i>Discharged</i>	0 (0)
<b>Second interview (2–3 weeks postpartum; n=5)</b>	
<b>ENTERAL FEEDS</b>	4 (80)
<b>Feeding type</b>	
<i>MOM only</i>	4 (80)
<i>Formula only</i>	0 (0)
<i>MOM + formula</i>	0 (0)
<b>Feeding route(s)</b>	
<i>At-breast</i>	0 (0)
<i>Bottle</i>	2 (40)
<i>Tube feeds</i>	3 (60)
<b>LOCATION</b>	
<i>Surgical hospital</i>	4 (80)
<i>Discharged</i>	1 (20)
<b>Third interview (5–6 weeks postpartum; n=4) *</b>	
<b>ENTERAL FEEDS</b>	3 (75)
<b>Feeding type</b>	
<i>MOM only</i>	1 (25)
<i>Formula only</i>	1 (25)
<i>MOM + formula</i>	1 (25)
<b>Feeding route(s)</b>	
<i>At-breast</i>	1 (33)
<i>Bottle</i>	3 (75)
<i>Tube feeds</i>	0 (0)
<b>LOCATION</b>	

<i>Surgical hospital</i>	2 (50)
<i>Discharged</i>	2 (50)

MOM=mother's own milk

Note: No infants received donor human milk. In many cases, infants received enteral feeds via multiple routes (e.g., bottle and tube feeds); thus, feeding route data does not sum to 100% of the infants receiving enteral feeds at each time point. Feeding type/route does not sum to total number of mothers of infants completing interviews at each time point, accounting for infants not receiving any enteral nutrition.

\* Three women completed all interviews. The four participants completing the 5–6 week interview includes one participant who was unavailable for the 2–3 week interview.

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