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“It’s Somebody Else’s Milk”: Unraveling the Tension in Mothers of Preterm Infants Who Provide Consent for Pasteurized Donor Human Milk

Anita Esquerra-Zwiers, MSN, RN¹, Beverly Rossman, PhD, RN¹, Paula Meier, PhD, RN^{1,2}, Janet Engstrom, PhD, RN, CNM, WHNP-BC¹, Judy Janes, BSN, RN², and Aloka Patel, MD^{1,2}

¹Department of Women, Children, and Family Nursing, Rush University, Chicago, IL, USA

²Pediatrics, Section of Neonatology, Rush University Medical Center, Chicago, IL, USA

Abstract

Background—Pasteurized donor human milk (DHM), rather than preterm infant formula, is recommended for premature infants when mother’s milk is not available.

Objective—This study explored the maternal decision-making process in providing consent for DHM feedings.

Methods—In-depth semistructured interviews were conducted with 20 mothers of premature (mean gestational age = 27 weeks, birth weight = 942 grams) infants hospitalized in the neonatal intensive care unit (NICU) in this qualitative, descriptive study. Conventional content analysis was used to analyze the data.

Results—Although only 1 mother had any previous knowledge of DHM, all mothers provided consent for DHM because they “wanted what is best for my baby.” Mothers trusted that DHM was better than formula when their infant’s feeding requirements exceeded their own milk supply. However, most mothers described a tension between wanting their infants to receive only “their” milk and DHM being “somebody else’s milk.” This desire to be the only provider of human milk was more common than concerns about the quality and safety of DHM. The mothers’ tension was mediated by trusting the NICU clinicians’ recommendations, having adequate time to make an informed decision, observing the positive outcomes of DHM, and feeling empowered that they made the best decision for their infant.

Conclusion—The experiences of these mothers reflect the importance of approaching mothers for consent only when DHM is needed, respecting mothers’ beliefs and values about DHM, and providing help in mediating any tension with regard to their infants receiving “somebody else’s milk.”

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Corresponding Author: Anita Esquerra-Zwiers, MSN, RN, Department of Women, Children, and Family Nursing, Rush University Medical Center, 67 N. Division, Holland, MI 49424, USA. Anita_L_Esquerra-Zwiers@rush.edu.

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Keywords

breastfeeding; decision making; donor milk; NICU; premature infants

Background

Own mother's human milk (HM) feedings reduce the risk of serious, costly, and potentially handicapping morbidities during and after the neonatal intensive care unit (NICU) hospitalization in very low birth weight (VLBW; < 1500 grams) and/or extremely preterm (EP; < 32 weeks gestation) and moderately preterm (MP; 32–33 weeks of gestation) infants.^{1–4} Although most NICU clinicians encourage mothers of these infants to provide exclusive HM feedings,^{5,6} not all mothers are capable of producing a sufficient volume of HM,^{7,8} willing to provide HM, or able to provide HM due to maternal contradictions (eg, HIV+, cocaine use, or chemotherapy). Multiple national and international organizations recommend pasteurized donor human milk (DHM) in this population when HM is not available, especially during the critical early postbirth period when the infants transition from intrauterine to extrauterine nutrition.^{9–12} These recommendations have resulted in a significant increase in DHM feedings for premature (including VLBW, EP, and MP) infants over the past decade.^{13,14}

In most NICUs, mothers must provide consent for DHM feedings.^{15–17} However, there are no evidence-based guidelines that inform this process with respect to timing, scripting, or acceptability to mothers. In many instances, consent for DHM is obtained shortly after birth along with other standardized NICU treatment consents. This timeframe often precedes the mother making a final decision about providing HM and/or beginning milk expression. Similarly, the same consent form and process are typically used both for mothers who plan to provide their own HM and for those who do not. Although prior research reveals that mothers have mixed feelings about DHM for their premature infants,^{15,16,18} we could not locate previously published studies focusing on the decision-making processes used by these mothers when asked to provide consent for DHM feedings. Thus, the purpose of this study was to explore the decision-making processes for mothers of premature infants who provide consent for DHM feedings.

Methods

Design

A qualitative descriptive design was used for this study. Study approval was obtained from the institutional review board of Rush University Medical Center in Chicago, Illinois, and all mothers provided written informed consent for participation.

Sample

The inclusion criteria were that the mother was at least 18 years old, spoke and understood English, gave birth to a premature (< 1500 grams and/or < 32 weeks gestation) infant, and had already provided consent for DHM feedings. An initial convenience sample of 8 mothers was studied to collect and categorize data into emerging themes. Two primary

themes were identified in this initial sample of 8 mothers: “wanting what is best for my baby” and “it’s somebody else’s milk.” Purposive sampling was then used to recruit 12 more mothers to further develop these themes and provide an understanding of other issues that reflected the perceptions and experiences of the participants.

Setting

This study was conducted in a 57-bed level III NICU in a Midwestern metropolitan medical center from August 2013 through March 2014 and coincided with a NICU practice change (April 2013) from formula to DHM feedings for all infants > 32 weeks gestation and/or 1500 grams when HM was not available. When data collection for this study began, mothers were routinely asked to provide consent for DHM feedings immediately postbirth when the infant was admitted to the NICU as part of a “consent package” covering all basic NICU treatments. However, after data collection had been completed for 8 mothers, the NICU clinicians became concerned that approaching mothers before DHM was needed influenced the mothers’ initiation of pumping and transmitted mixed messages about DHM being the “same” as own mother’s HM. A neonatologist, neonatal nurse practitioner, or pediatric resident obtained all consents.

Data Collection

One-time semistructured interviews were scheduled with mothers after they provided consent for DHM and when they were available to be interviewed, a median of 4 (range, 1–10) weeks. Digitally recorded interviews were conducted in a private room near the NICU and lasted an average of 32 (12–50) minutes. An interview guide was used to focus on the mothers’ experiences and perceptions of information they had received about DHM. Questions were designed to encourage maternal detailing of interactions with the NICU clinicians and to obtain the mothers’ descriptions of the decision-making process about providing consent for DHM feedings. Exemplars of interview questions are found in Table 1. Maternal and infant demographic data were collected at the end of the interview with a short questionnaire.

Data Management and Analysis

Interviews were transcribed verbatim and assessed for accuracy. Data collection and analysis occurred simultaneously until categories were saturated and no new insights or shared patterns were identified. Conventional content analysis was used to derive categories from the data and capture commonalities and differences across mothers’ perceptions and experiences.¹⁹ Common categories and shared patterns from the data were then identified through within- and across-case analysis to group the data into larger themes.²⁰

Rigor

Rigor was addressed through several strategies. Two authors completed the initial coding of all transcripts to maintain consistency. Once primary categories were derived from the initial analysis, a final sample of 6 interviews was independently coded to assess reliability of coding methods. Any differences in coding were discussed and consensus was reached about the optimal coding to achieve logical and thematic consistency. Regular meetings with the

research team were held to discuss the process. An audit trail of memos during analysis and investigator meetings was maintained.

Results

Sample

Twenty mothers who had provided consent for DHM feedings (for their 22 infants) participated in this study. Table 2 summarizes maternal and infant characteristics. This sample is representative of the NICU population in which this study was conducted, with the majority of the mothers being black (65%), multiparous (60%), younger than 30 years old (60%), eligible for the Special Supplemental Nutrition Program for Women, Infants, and Children (55%), educated beyond high school (80%), and unemployed (60%). Only 1 mother had any knowledge of DHM prior to being asked to provide consent.

Wanting What Is Best for My Baby

An overarching theme of “wanting what is best for my baby” encompassed all reasons for mothers deciding to provide consent for DHM feedings. Mothers placed their trust in the message they received from NICU clinicians that if their own HM was not available, DHM was better than formula in protecting infants from complications of prematurity. Although a majority of mothers ($n = 17$) preferred that only their HM be used, they provided consent for DHM because it was “what is best for my baby.” Mothers offered 1 or more reasons for providing consent (eg, an insufficient HM volume, trust in the NICU clinicians) and 11 mothers approached the consent process with hesitation or caution. With further probes, this hesitation actually represented a tension related primarily to the mothers’ desire to be the only provider of HM for the infant coupled with a negative reaction to their infant receiving “somebody else’s milk.” However, mothers who experienced this tension ultimately reported feeling empowered that by providing consent for DHM, they had made the right decision for their infants. They also denied feeling coerced by the NICU clinicians because they were provided sufficient time and information to make a truly informed decision.

Reasons for Providing Consent for DHM Feedings

Insufficient HM volume—Most ($n = 18$) mothers provided consent for DHM because they expressed a preference for HM only feedings and/or had an insufficient HM volume: “I’d rather have him have that [donor] milk versus the—if he’d get just IV or get nothin’ at this point, or even formula.” Mothers were either unable to provide exclusive HM, were not producing any HM, were concerned that they would not be able to continue providing a sufficient volume of HM as their infants’ requirements increased, and/or were unable to transport their milk to the NICU. Nine mothers identified the inability to meet their infants’ increasing feeding requirements: “I was pumping away really good for like the first few weeks, and then I got out, home, and I don’t—I’m trying to get my milk supply back up to where it’s supposed to be, but it’s going. I’m trying to get as, get a good supply in for him.” Five mothers had a sufficient HM volume at the time of consent but were concerned that their HM volume would not meet the increasing demands of their infants. These mothers chose to provide DHM consent “just in case”: “I consented for it, so I knew that if I didn’t have or if he ran out of milk, or if I either wasn’t producing enough right away, that he

would get the donor milk.” Four mothers provided consent for DHM feedings because they were not producing any HM. Three of the 18 mothers provided consent because they remained at a referral hospital and were unable to transport their own HM to the study NICU.

Trust in the NICU clinicians—For 8 mothers (40%), trust in the NICU clinicians was crucial to their willingness to provide consent: “I’m gonna be honest. When they came to me and said, ‘There’s donor milk and it’s available,’ I remember just thinking—and I didn’t really ask questions. I just knew that it was what she needed. I trust the doctors and the nurses enough that, again, they’re not gonna hurt her; they’re gonna give her what she needs.”

Nominal or no desire to provide HM—Six mothers (30%) provided consent for DHM because they had minimal desire or were unwilling to provide their own HM. In particular, 3 mothers with no intention to breastfeed prenatally either briefly “tried” pumping or chose not to initiate pumping because DHM feedings were available. One mother very honestly shared her feelings about breastfeeding: “But let me tell you the truth. I didn’t care, because I was not planning on breastfeeding. And if he needed milk, he needed to get it from someone else.” Four of the mothers with nominal desire to provide HM expressed concerns over the quality and safety of their own HM: “I’m still on 8 different medicines and I didn’t want to take the risk and they said, ‘Well we have donor milk. Is that something you’d be interested in?’ And I was ‘I’d trust that [DHM] more than my own milk.’”

Approaching DHM Feedings with Caution

It’s somebody else’s milk—Fourteen mothers (70%) characterized DHM as, “It’s somebody else’s milk.” This response was related to an aversion to DHM, jealousy toward the donor mother, or motivation to provide HM. Aversion was often associated with the idea of DHM being a biological substance: “At first I didn’t like it. It’s something that comes out of your body that’s for your baby and it’s not from you. Nowadays people are so sick and all kinds of things and he’s so little; it worries me.” However, mothers also described being envious of donor mothers who could provide HM: “As a mom, partially jealous here, like if I can’t do it [provide milk], I’m kind of jealous that she [the donor mother] can.” Another mother’s reaction to her infant receiving another mother’s milk was stronger: “My initial response was, almost like you think of being in a cat fight. ‘How dare you ask me to give her donor milk?’ You know it’s just a mother’s instinct.” All of these mothers stated that they were willing to provide consent once they understood their infants’ need for DHM. Another mother identified that being approached to provide consent for DHM reinforced the value of HM for her, served as a motivator to begin pumping, and contributed to her desire to donate her extra milk:

I pump every 2 to 3 hours. ... She never had to be on donor milk. And I agreed to that but in my heart I’m like, I don’t want her to get someone else’s. I want to be the one to make her better. But I was thankful it was available if she needed it. ... I’ve often considered seeing if I could donate some of what I have since apparently I’m an overproducer.

DHM quality—The quality of DHM was also a dominant concern among mothers who expressed caution about DHM (n = 6). The mothers' initial hesitancy toward their infants receiving DHM was based on their lack of knowledge about how donor mothers were screened and DHM was processed. Specifically, mothers were concerned about how the donor mothers' genetics, lifestyle choices, dietary habits, and physical well-being might alter DHM quality: "Obviously my initial reaction was 'no way.' I don't want someone else's breast milk in my baby. I have to say that, 'cause like, where's it comin' from? I have no idea. ... It's not just some—forgive me—like crack whore off the street. You don't know where it's comin' from—that's my initial thing. Is it gonna be okay for my baby?" Mothers who expressed concerns about the quality of DHM provided consent for DHM feedings after their concerns were thoroughly addressed by the NICU clinicians.

Paternal hesitation to DHM feedings—Of the 8 mothers (40%) who involved the father in the decision to provide consent, 4 were hesitant because of paternal resistance to DHM: "He [the father] did not like it at all. ... 'No, I want my baby to have regular milk, you know, his momma's milk, and not donor milk.'" Some of these mothers shared the fathers' concerns, but in all cases, the NICU clinicians alleviated these concerns by providing detailed information about the safety of DHM.

Sufficient HM volume—Two mothers were hesitant to provide consent because they believed that they had a sufficient volume of HM to meet their infant's feeding demands, but in reality they did not. After consultation with the NICU clinicians, both mothers realized that their current volumes of HM would not support the planned feeding increases in their infants. These mothers wanted only HM for their infants and provided consent in the event that their own HM volume became insufficient.

Unraveling the Tension

Fourteen mothers spoke of a tension that existed when approached to provide consent. This tension was attributed to their infants having "somebody else's milk" and 1 or more of the following: longing to be the only HM provider, needing more information about DHM, and/or wanting support from their family and friends for their decision. For 9 of these mothers, an insufficient volume of HM also accompanied this tension. For a Jewish mother, the need for religious clarity from her rabbi added to the tension. Although these mothers struggled with the decision to provide consent, they felt that the NICU clinicians gave them sufficient information and time to make the decision. Ultimately, these mothers' tension lessened once they actively engaged in the decision to provide consent for DHM by examining their own limitations and understanding their infant's health needs. A primipara mother conveyed an exemplar of this tension:

And I was like, okay I've never heard of this. And before I said okay, I actually had to talk to a few of my friends who pretty much all had premature babies. And they've never done it. And I was like, oh no. I don't want him getting anybody else's milk. And I think about it, well, if I can't produce enough to feed him and he's too small to be on formula right now, what other, you know, alternatives do I have? I would rather they make sure he has something that's gonna help and sustain him, even if I can't, rather than let him go hungry. So after I was explained about

how the test process and screening goes into testing the milk, I thought about it; I was like, that's something I can, I can go ahead and give a try. 'Cause what can it hurt? But I think based on what I've been through and experienced, I think it's one of the best decisions I could have made.

This tension was further alleviated when mothers were able to observe the positive effect of DHM on their infants' health: "They used donor milk, and he tolerated it just fine. I'm such a fan of donor milk, and I really appreciate moms doing that."

Discussion

In this study, mothers of premature infants provided consent for DHM feedings primarily because they "wanted what was best for their babies." Mothers viewed this decision as an evolving process in which they were engaged and sought information and support from NICU clinicians, family, and friends. The decision was influenced primarily by mothers' trust in NICU clinicians, as evidenced by the fact that only 1 mother had any prior knowledge of DHM. Through conversations with NICU clinicians, the mothers began to associate DHM feedings with "what was best" for their babies when HM was not available. This process was consistent among mothers, regardless of whether they consented immediately or whether the decision was approached with caution. Similarly, the process was the same regardless of whether the mothers' individual reasons for DHM use were related to insufficient HM volume, were related to minimal/no desire to provide their own HM, or reflected a "just in case" strategy.

To our knowledge, this is the first study to report that the primary reason for mothers initially reacting negatively to providing consent to DHM was the idea that their infants would be receiving "somebody else's milk" rather than concerns about the safety and quality of DHM. Although a few mothers voiced an aversion to DHM being a biological substance, most mothers reported a tension simply because they wanted their infants to receive their milk. Although the terminology "somebody else's milk" has been previously reported,^{15,18,21,22} it has not been linked to the DHM consent process with respect to mothers wanting to be the only HM provider. It has long been recognized that providing HM for a NICU infant is the "one thing that only the mother can do" when professionals assume most other caretaking activities.²³⁻²⁶ Insidiously, the availability of DHM has changed this dynamic with remarkably little study of its effect on NICU mothers' perceptions of maternal role identity and self-esteem. Our findings indicate that although mothers perceived the angst of wanting to be the only provider of HM, they did not verbalize this directly to NICU clinicians at the time of consent but instead made a timely decision to ensure that their infant received "what was best" for their babies. These findings have important implications for DHM talking points (Table 3) in the NICU. In most NICUs, the informed consent documents for DHM feedings focus primarily on concerns related to the safety, quality, risks, and benefits of DHM. Although these elements are important, our findings also support the inclusion of language that addresses the superiority of HM over DHM, as well as a specific section within the consent that focuses on the normalcy of negative maternal reactions to the feeding of "somebody else's milk."

The mothers in this study who expressed caution about providing consent for DHM feedings stated that the NICU clinicians helped them mediate the tension between “wanting what is best for my baby” and “it’s somebody else’s milk.” The mothers indicated that by encouraging them to ask questions and discuss DHM with their friends and family before making a decision, the NICU clinicians communicated respect for their beliefs and values. These findings are consistent with previous studies that reported the effect of NICU clinician messaging on mothers changing the decision from formula to HM for their premature infants.^{6,23,27} Like those mothers, the mothers in this study expressed pride in knowing that they had listened to all the information and made an informed decision that was in the best interests of their infants.

In addition, although minimizing the number of separate consents during the early NICU hospitalization may seem logical to NICU clinicians, our findings suggest that mothers do not desire routine bundling of DHM information into a “treatment consent package” but would prefer a separate, sensitively written consent document. From the perspective of timing, the early consent process often preceded the mothers’ own HM decision or HM expression attempts and did not permit discussion of DHM with family, friends, or religious leaders. Additional research might focus on whether there is an ideal time for acquisition of consent for DHM use.

This study was limited to a sample of English-speaking mothers from a single setting that has an established NICU culture of providing families with comprehensive, individualized, and specialized clinical and educational support on lactation and the science of HM feedings.²⁸ Thus, our findings may not be generalizable to other NICUs without this level of support for the use of mother’s own HM. In addition, studies conducted with different populations (eg, non-English speaking, higher socioeconomic status) would add to our findings on maternal perceptions because it is possible that these maternal perceptions vary on the basis of cultural and demographic characteristics.

Conclusion

These findings suggest that obtaining consent for DHM should not be conceptualized as a single event but, rather, as a process for which mothers need time to evaluate and integrate their beliefs and values with the information presented to them by NICU clinicians. This process is facilitated by approaching mothers for DHM consent only when DHM is needed for infant feeding, not including DHM discussions and consent processes in an overall NICU consent package, providing accurate and consistent information that focuses on the superiority of mother’s own HM over DHM, acknowledging maternal negative reactions to “somebody else’s milk,” and reinforcing the temporary nature of DHM feedings. Mothers also valued the role of NICU clinicians in mediating any tension with regard to their infants receiving “somebody else’s milk.”

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Well Established

Pasteurized donor human milk (DHM) is recommended for premature infants when mother's milk is not available. Mothers typically provide consent for DHM feedings. Prior research reveals that mothers have mixed feelings about DHM for their premature infants.

Newly Expressed

Obtaining consent for DHM should not be conceptualized as a single event but, rather, as a process for which mothers need time to evaluate and integrate their beliefs and values with the information presented to them by neonatal intensive care unit clinicians.

Table 1

Sample Interview Questions.

Maternal Experience	Donor Milk Interview Question
Infant's current condition	First of all, I'd like to know how your baby is doing. (Probe: How much did your baby weigh at birth? How much does he/she weigh now?) Tell me a little bit about your birth experience. Why did you deliver so early?
Pregnancy	While you were pregnant, how did you think you were going to feed your baby? If breastfeeding, how long did you think you'd breastfeed?
Providing milk	Have you been providing milk for your baby since he/she was born? How is pumping going for you? (Probe: What does it mean for you to provide milk for your baby?)
Reaction to donor milk	Do you remember when someone first talked to you about donor milk? Can you tell me what your first reaction was when you heard that your baby might need it? Why do you think your baby needed donor milk? As you learned more about donor milk, did your feelings about it change? If so, in what way? What did you know about donor milk before you had your baby? What concerns did (or do) you have about your baby(ies) receiving donor milk? How were these concerns addressed? If your baby has received donor milk, how do you feel about him/her receiving it now?

Table 2

Maternal and Infant Characteristics.

Maternal Characteristic	N = 20	
	No.	%
Race		
Black	13	65
Latina	3	15
Non-Latina, white	4	20
WIC eligible	11	55
Education		
High school	4	20
Some college	9	45
College graduate	7	35
Marital status		
Unmarried	7	35
Married	10	50
Unmarried living with FOB	3	15
Employment status		
Unemployed	12	60
Employed part-time	2	10
Employed full-time	6	30
Single birth	17	85
Multiparous	12	60
Prenatal feeding intentions		
Formula	6	30
Breast milk	13	65
Both	1	5
Previous breastfeeding experience ^a	10/12	83
Previous knowledge of DHM	1	5
Maternal age, mean (range), y	28.8	21–40
N = 22 ^b		
Infant Characteristic	Mean	Range
Infant birth weight, g	942	454–2126
Gestational age at birth, wk	27	23–32
	No.	%
DHM use		
DHM + HM	12	54.5
Initially DHM + HM, only HM at time of interview	4	18

Initially DHM + HM, only formula at time of interview	2	9
None, exclusive HM	3	14
DHM only, no HM ever	1	4.5

Abbreviations: DHM, pasteurized donor human milk; FOB, father of baby; HM, mother's human milk; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

^aMultipara only.

^bOne twin deceased.

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Table 3

Talking Points for NICU Clinicians about DHM Feeding Consent.

Subtheme	Goal	Talking Points
“It’s somebody else’s milk”	Help the mother understand that her reactions are normal.	Lots of mothers who first hear about donor milk use these same words and feel the same way. It is only natural to want to be the only person providing milk for your baby. We have known for over 100 years that many mothers tell us that providing their milk is the only thing they feel they can do, so it is really hard to think you have to share this special task—even if it is just for a short time.
	Clarify the NICU’s preference for mother’s HM.	Donor milk is not the same as your own milk. It is safe and preferable to formula early in life, but your milk has special nutrition and protection that cannot be provided by donor milk. Donor milk helps us avoid the use of formula until your own milk is established, and then we won’t need the donor milk anymore.
DHM quality	Reinforce information that the mother may have missed during initial discussions about DHM.	All of the donor milk that we use in our NICU is from an accredited donor human milk bank. This means that all of the milk donors have passed health and blood tests and their milk has been tested, too. Even after testing, the milk is pasteurized—just like milk you buy in the store—to make sure that it does not have germs. It comes to us frozen and we defrost it as we need it for our babies. We handle it very carefully and make sure that it is safe for your baby. Most important, donor mothers are or were breastfeeding their own healthy babies and just want to help other mothers who might have trouble getting their own milk established.
Paternal hesitation	Reinforce the fact that fathers often question why DHM is necessary.	Lots of fathers have concerns about donor milk. Do you know why he has doubts? Would it make it easier if we can talk to both of you at the same time?
Sufficient HM volume	Help the mother plan ahead for the contingency of not having enough of her own milk if it is likely that the infant will need more than she has available.	Right now, you have enough milk for your baby and that is just great! As your baby grows, we will continue to increase the feeding volume. Have you thought about what you would like to do if your baby’s feedings increase and we would need to give some extra milk until you can catch up with him or her?

Abbreviations: DHM, pasteurized donor human milk; HM, mother’s human milk; NICU, neonatal intensive care unit.