DISTINGUISHING BETWEEN FEEDING HUMAN MILK AT THE BREAST AND FROM A BOTTLE

A Dissertation

Presented to the Faculty of the Graduate School

of Cornell University

in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

by

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February 2016

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Cornell University 2016

National breastfeeding surveillance questions in the U.S. ask solely about infant human milk (HM)-consumption, and not about mode of HM-feeding—at the breast or from a bottle. This is problematic because most HM-feeding mothers express their milk, as well as or instead of feeding at the breast, and expressed HM is fed to their infants from bottles. Thus, current breastfeeding surveillance questions do not fully describe the range of HM-feeding behaviors employed by families in the U.S. Our aims were to (1) explore practices for feeding HM at the breast and from a bottle qualitatively, and (2) develop and administer surveillance questions that elicit information about mode of HM-feeding, and use these questions to explore prevalence of HM expression and expressed HM-feeding among a national sample.

Qualitative data came from semi-structured interviews with 41 mothers in upstate New York who had experience with HM expression. Interviews covered topics related to at-the-breast and expressed-HM feeding. We identified themes in the transcripts using inductive analysis. We used this formative qualitative data to develop a survey to explore at-the-breast feeding, HM expression, and expressed-HM feeding among a national sample of mothers. We administered the survey to a convenience sample of 451 mothers, recruited through ResearchMatch.org.

Participants in our qualitative study described strategies for HM-feeding that ranged from predominant at-the-breast feeding to exclusive expressed HM-feeding. However, results from both studies indicated that the predominant strategy employed by HM-feeding mothers is a combination of both at-the-breast feeding and expressed-HM feeding. Among participants in our survey, the proportion of HM-fed infants consuming HM from a bottle was ~70% or greater at 3, 6, and 12 months. Our qualitative work highlighted that HM sharing is a complex behavior influenced by many contextual factors. Awareness of informal HM sharing was high in both our studies, and 7% of mothers in our quantitative sample had fed their infant another mother's HM.

The complex range of practices for feeding HM described here highlight problems for studying, monitoring, and promoting optimal infant feeding behaviors. It is time for public health officials to recognize at-the-breast feeding and expressed-HM feeding as distinct behaviors, and count them separately. Both maternal HM expression and expressed-HM feeding require in-depth study so that the health outcomes associated with these behaviors can be understood and so mothers and families can be provided with evidence-based recommendations about optimal infant feeding practices.

BIOGRAPHICAL SKETCH

Elizabeth J O'Sullivan completed her Bachelor of Arts (Mod) degree in Physiology at Trinity College, Dublin in 2006. This degree sparked her interest in nutrition and metabolism and she went on to complete her Bachelor of Science degree in Human Nutrition and Dietetics at Trinity College, Dublin and her Postgraduate Diploma in Human Nutrition and Dietetics at Dublin Institute of Technology in 2010. Her training as a dietitian introduced her to maternal nutrition and infant feeding, and the importance of breastfeeding for the maternal-infant dyad.

Elizabeth came to Cornell University with the goal of learning about the promotion and support of breastfeeding, the barriers to successful breastfeeding, and ways to address these barriers. She plans to take the knowledge she has gained at Cornell and establish a career promoting and supporting breastfeeding in Ireland.

DEDICATION

This dissertation is dedicated to my favorite person, Luke.

ACKNOWLEDGEMENTS

I am grateful to many people for their support, guidance, and assistance throughout this process. First, I want to thank my advisor, Dr. Kathleen Rasmussen, who has molded me into the scientist I am today. Kathy has patiently answered my many questions, offered useful and thoughtful advice about work- and life-related issues, and warned me of the dangers of the lonely gerund. I have the deepest respect and admiration for Kathy, and I hope I make her proud in the future.

Next, I would like to acknowledge the members of my dissertation committee. I consider myself extremely lucky to have selected a committee I respect *and* like so very much. Drs. Patricia Cassano and Lindy Williams were so generous with their time, and provided feedback and support whenever I needed it. Dr. Jeff Sobal provided advice on everything from sample extensiveness in qualitative research to wedding dress shopping, thank you. Finally, Dr. Sheela Geraghty was my personal cheerleader throughout this process and was always ready to provide feedback and encouragement from a distance; I am immeasurably grateful.

I would also like to acknowledge my funding sources, the International Fulbright Science and Technology Award, the Jean Hankin Nutritional Epidemiology Award from the Academy of Nutrition and Dietetics Foundation, and support from both the Division of Nutritional Sciences and the Human Ecology Alumni Association at Cornell University. This work would also not have been possible without the mothers who gave their time to discuss their experiences with me, I truly appreciate it.

I am grateful for the encouragement I received at different points in my life to pursue education. I am thankful that my parents, Mary and Larry, value learning and have always been willing to financially and emotionally support my educational endeavors. I am also grateful to the teachers who have made a lasting impression on me over the years, particularly Mr. Kevin Hussey and Dr. Paul Mathias. Without their encouragement, whether they know it or not, I may never have even begun a Ph.D.

Starting this Ph.D. program took me far away from my beloved partner, family, and friends, something I never wanted to do. However, the friends I made at Cornell have made Ithaca feel like home, which is an outstanding feat. I have had so much fun with you all and appreciate the wonderful send-off you have given me as I prepare to leave Ithaca. Had I been part of a more unclubbable group, I would not have enjoyed myself so much. I have a knack for making great friends and I am also grateful to those I have known ~30 years (Ciara, Trish, Karl), and ~20 years (Jenny, Jean, Juliana), because they, along with my family and partner, have made me the person I am today.

I also thank my immediate family—Mary, Larry, Claire, Alan, and Thomas—and those that joined the family along the way—Ollie, Amy, Katelyn, and Niamh—for their support and love. I'm especially thankful to my sister for never letting my wonderful nieces forget about their aunty Lizzy while she was living in "Ba-merica." Last, but most certainly not least, I thank my partner, Luke for his unwavering patience, support, faith, and love.

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CHAPTER 1

INTRODUCTION

Breastfeeding is globally recognized as the ideal mode of infant feeding; national and international health organizations recommend exclusive breastfeeding for 6 months, followed by the introduction of appropriate complementary foods and continuation of breastfeeding for 1 year or more (1, 2). These recommendations are based on a large body of evidence that links sub-optimal breastfeeding behavior with poorer infant and maternal outcomes (3-5). It is well established that, compared to feeding at the breast, consuming infant formula is associated with an increased risk of otitis media, gastroenteritis, respiratory tract infections, atopic dermatitis, asthma, obesity, type 1 and 2 diabetes, childhood leukemia, sudden infant death syndrome, and necrotizing enterocolitis (3). Additionally, recent evidence suggests that breastfeeding results in small, but statistically significant and clinically important increases in child IQ (4, 6). Among mothers, breastfeeding for longer than 12 months is associated with a decreased risk of reproductive cancers (7, 8), cardiovascular disease (9), and type 2 diabetes (2).

Although prevalence of breastfeeding initiation and duration has been increasing in the U.S. since a nadir in the 1970s (10, 11), this increase has been slow. National breastfeeding targets (12) are produced every decade, and the targets increase over time, aiming for continuous improvement in breastfeeding practices. Although the increase in the proportion of women who initiate breastfeeding has kept up with the increasing targets, the prevalence of breastfeeding at 6 and 12 months postpartum has not. Thus, improving breastfeeding outcomes remains a prominent public health goal (13). However, infant feeding practices in the U.S. have changed drastically in recent times (14, 15), and much of the human milk (HM) now fed to infants is offered from a bottle as well as, or instead of, at the breast (16). This shift in infant feeding practices has implications for how we study, recommend, and measure breastfeeding.

The changing landscape of human milk-feeding

Women in the U.S. are attempting to meet national or personal HM-feeding goals in an environment that is largely unsupportive of at-the-breast feeding. Roughly 14% of infants are delivered in Baby-Friendly facilities (17), and many infants receive infant formula in the first few days of life while in the hospital (18). Additionally, breastfeeding care and support from health professionals is inadequate (19, 20) or disorganized across the continuum of care from pregnancy to postpartum (20, 21). Finally, inadequate maternity leave policies mean that mothers return to work quickly postpartum and are separated from their infants. Postpartum return to work is associated with shorter breastfeeding duration (22, 23), reduced breastfeeding intensity (24), and a reduced ability to meet personal HM-feeding goals (25).

In response to this unsupportive environment, HM-feeding women may use breast pumps to solve physical problems with at-the-breast feeding (26-28), to express HM while at work (16, 27-29) or they may quit work if they cannot—or are not offered the opportunity to—feed at the breast or express HM at work (30, 31). Using breast pumps to solve problems with at-the-breast feeding is not a new concept as breast pumps in some form or another have been available for centuries (32). However, rapid technological advancement in the early 21st century has resulted in the production of electric breast pumps (33) that are efficient, portable, and more affordable.

Investigators who conducted the earliest studies exploring HM expression in the U.S. in the early 2000s typically focused on how mothers combined HM feeding and postpartum return to employment (34, 35) or how HM expression and expressed-HM feeding is used as a strategy for feeding preterm infants (36, 37). Prevalence of HM expression among mothers of preterm infants has also been explored (38). Geraghty and colleagues studied prevalence of HM expression among ~350 Ohio mothers, with the hypothesis that mothers of preterm or multiple gestation infants would express HM more often than mothers of term singletons (38). Contrary to their expectations, there was no difference in the prevalence of HM expression by length or plurality of pregnancy (38). Interestingly, 5% of HM-feeding mothers in this study exclusively fed expressed HM and did not feed at the breast for the duration of HM feeding and only 16% of HM-feeding mothers fed solely at the breast for the duration of their lactation (38). Although this 2005 study was the first to describe prevalence of HM expression in the U.S., it was limited in size and all respondents gave birth in the same facility, limiting generalizability.

Since then, publications from the Infant Feeding Practices Study II (IFPS II) (39), a longitudinal study of infant feeding practices through the first year of life provide us with the most detailed national data about HM expression and expressed-HM feeding in the U.S. The IFPS II was conducted by the Centers for Disease Control and Prevention (CDC) and the Food and Drug Administration between 2005 and 2007 and consisted of 1 prenatal questionnaire and 10 postpartum questionnaires. Participants in this cohort were drawn from a nationally distributed consumer opinion panel in the U.S. but the final survey sample was not nationally representative. Compared to a nationally representative sample, a higher proportion of women participating in the IFPS II were older, middle-income, white, employed, and well-educated (39).

Of all the HM-feeding women surveyed in the IFPS II, 6% fed their infants only expressed HM and never fed directly at the breast (40). Among HM-feeding mothers of infants 1.5 – 4.5 months old, 85% expressed their milk successfully at some point during their child's infancy (16). Regular HM expression was more common among women of higher income; however, nearly one-sixth of women below 185% of the Poverty Income Ratio also expressed their milk regularly. Occasional pumping was common; ~40% of all respondents expressed occasionally, regardless of maternal income or participation in the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) (16). These data highlight that HM expression is ubiquitous and is not solely a behavior associated with maternal characteristics (e.g. socio-economic status, postpartum employment) or infant characteristics (e.g. preterm birth). Although these are the most detailed national data about HM expression and expressed-HM feeding practices of U.S. mothers, describing HM expression was not the primary goal of the ISPS II. As a result, its questions did not always separate at-the-breast feeding and expressed-HM feeding. Additionally, minimal national data leave us unable to describe national trends in prevalence of HM expression and expressed-HM feeding.

Data from the Perth Infant Feeding Study I (PIFS I) in 1992/'93 and the PIFS II in 2002/'03 provide information on the proportion of mothers in Perth, Australia who express their milk and the change in prevalence of HM expression over time (26). Both studies were conducted in public hospitals in Perth and, in contrast to the IFPS II in the U.S., the sample was biased towards lower socio-economic groups. The proportion of women who expressed HM nearly doubled in the decade between the 2 studies; the peak prevalence of HM expression occurred in the first 6 weeks postpartum (26). Similar trends were described by researchers in Singapore

(41), who conducted a survey among mothers who gave birth between 2000 and 2008. In this sample, prevalence of HM expression was highest among mothers of infants born in 2008 (41).

Although we lack data about the trends in HM expression over time in the U.S., reimbursement for breast pumps is now mandated by the Affordable Care Act in the U.S. (42), and this increased accessibility of breast pumps suggests that more women will have access to breast pumps, thus, prevalence of HM expression is unlikely to decrease with time.

Maternal motivations for expressing human milk and expressed human milk-feeding

Based on the focus of early research on HM expression and expressed-HM feeding, one would assume that mothers express HM if they are trying to maintain HM feeding upon postpartum return to work or to provide HM for a preterm infant. However, based on data from the IFPS II (16), HM expression is common among mothers of term infants and mothers who are not in full-time employment. The most common reasons for HM expression selected by IFPS II participants were "[for] someone else to feed infant," "[f]or an emergency supply," and "[t]o relieve engorgement" (16). Clearly, these are not specific to mothers of preterm infants and those returning to work.

Quantitative studies published since the IFPS II was conducted provide us with additional insight into motivations for HM expression. In 2010 Clemons and Amir (28) administered an online questionnaire to members of the Australian Breastfeeding Association to obtain (i) data on the prevalence of HM expression, (ii) information on the decisions women made about HM expression, (iii) information on the reasons for expressing HM, (iv) information on women's experiences of using breast pumps, and (v) comments on women's experiences of expressing HM and attitudes of family and friends. Mothers were instructed to choose reasons for HM expression from a pre-constructed list of 23 options; to "store extra breast milk" was the most common option selected (57%) and "not enough milk/to make more milk" was considered the most important reason by mothers (28). However, nearly 7% of mothers chose the "other" option, indicating that the reasons pre-defined by the investigators were insufficient to describe maternal motivations for HM expression fully.

Qualitative research can be complementary to quantitative research and provide a deeper understanding of maternal motivations for HM expression as participants are not limited by investigator-defined response options. A seminal qualitative study published in 1988 described motivations for HM expression as maternally motivated (relief of engorgement, prevent leaking, and reassurance about supply) or infant motivated (to remove contaminated HM, to provide HM during absences, to stimulate HM production, to teach the infant how to use a bottle, and to avoid feeding infant formula) (43). Although the authors report motivations for HM expression from the maternal perspective (43), this study may lack relevance to contemporary women, who are returning to work earlier and in greater numbers, and who have access to better and more portable and affordable breast pumps.

Most recently, qualitative work has differentiated between mothers' motivations for HM expression and their reasons for expressed-HM feeding (44). Motivations for HM expression that had not been part of the pre-defined list offered in the IFPS II included expressing to gauge HM supply or infant intake, to establish HM supply early postpartum, and, as previously reported by qualitative researchers (43), to “bottle-train” infants. Interestingly, motivations for HM expression changed over time depending on the success, availability, and desirability of at-the-breast feeding (44). Although providing HM while the mother was away at work was described as one motivation for expressing HM, unemployed mothers also expressed HM and mothers in this qualitative study viewed HM expression as essential to meeting HM-feeding goals, even if they only expressed HM occasionally (44).

Thus, HM expression and expressed-HM feeding are common behaviors employed by nearly all mothers, regardless of their demographic characteristics, employment status or the circumstances around the birth of their infant. These behaviors are problematic for two major reasons. First, recommendations for and national surveillance of HM feeding typically focus on what is consumed by infants—human milk or infant formula—and do not comment on the mode of delivery of the milk. This emphasis on the product, HM, instead of the process, breastfeeding, suggests that mode of delivery is not important. Second, research about the maternal and infant outcomes associated with HM expression and expressed-HM feeding is minimal (14). Thus, we have only a limited understanding of the impact of these behaviors on maternal and infant outcomes.

Breastfeeding surveillance in the United States

National breastfeeding surveillance is necessary for the planning, implementation, and evaluation of interventions and programs designed to improve breastfeeding outcomes. Surveillance is also essential to track progress toward national breastfeeding goals; the CDC publishes annual statistics (11, 45) to track progress toward meeting Healthy People 2020 targets (12) for the initiation and duration of any and exclusive breastfeeding. These statistics are based on responses to four infant feeding questions on the National Immunization Survey (NIS), a survey primarily designed to provide estimates of vaccination coverage for U.S. children aged 19 – 35 months old. In 2000, the CDC held a meeting about breastfeeding surveillance systems and decided that questions about breastfeeding should be added to the NIS because funding for a dedicated breastfeeding survey would be difficult to procure, and because the sampling strategy of the NIS meant that prevalence estimates for each state and some metropolitan areas could be obtained (46). Since 2001, these questions have been the primary source of data for national monitoring of breastfeeding prevalence.

The NIS contains 4 questions that ask caregivers about the infant's intake of HM, infant formula, juice, cow's milk, sugar water, baby food, and water. Collectively, these questions are used annually by the CDC to report breastfeeding initiation, duration and exclusivity. At the time these questions were added to the NIS (2001), the possibility of adding questions about HM expression, expressed HM-feeding, reasons for not breastfeeding, and reasons for discontinuing breastfeeding was discussed (46). However, the participants in the meeting could not come to a consensus about the utility of these questions in a surveillance system so they were not included (46). Given the high prevalence of HM expression and expressed HM-feeding found among HM-feeding mothers in the IFPS II (16), and the potential health outcomes associated with these behaviors, it may be necessary to revisit this decision and reconsider if indicators for HM expression and expressed HM-feeding should be included on national breastfeeding surveillance systems.

The importance of measuring expressed human milk-feeding

Distinguishing between modes of HM feeding is essential because the limited research available suggests that expressing and feeding expressed HM is a different psychosocial and biological experience for both the mother and the baby than at-the-breast feeding, and that expressed-HM feeding may have negative consequences for infant health. Based on IFPS II data, it has been reported that infants fed from a bottle in early infancy, regardless of the type of milk being fed, are more likely to empty their bottle or cup in later infancy (47) and bottle-feeding HM is associated with greater infant weight gain over the first year of life (48). Using data from the IFPS II and its 6-year follow-up study (49), Li *et al*. found that mothers who encouraged their infant to finish all of their bottle, again regardless of the type of milk in the bottle, were more likely to encourage their children to eat all of the food on their plate (50). Conversely, at-the-breast feeding has been associated with a more responsive maternal feeding style (51), and greater satiety responsiveness in children (52). Together, these data imply that bottle-feeding, even when the bottle contains HM, may have a deleterious effect on infants' self-regulation of milk intake and may be associated with undesirable parental feeding styles, both of which could negatively affect the protective relationship that is postulated to exist between breastfeeding and childhood obesity (53).

From an immunological perspective, the added equipment used in the process of HM expression (e.g. nipple shields, valves, a bag or bottle for storage in the refrigerator or freezer or a bottle, cup or spoon for feeding) increases the risk of bacterial contamination of HM (54, 55). In one study, HM expressed using breast pumps had significantly higher bacterial contamination than milk expressed by hand (56), and the majority of women who express in the U.S. use breast pumps (16). Storage of expressed HM at temperatures typical of home freezers can cause lysis of immunological cells, and microwave thawing of frozen HM, a practice not recommended but still performed by 12% of mothers (57), decreases other anti-infective factors in the milk (58). The antioxidant activity of HM also decreases when stored at both refrigerator and freezer temperatures, with a greater decrease seen at lower temperatures and in samples stored the longest (up to 7 days) (59). Interestingly, although the antioxidant activity was reduced in the stored HM it remained significantly superior to that of infant formula (59). Additionally, mothers who feed at the breast can launch an almost immediate immune response specific to a child's exposure to pathogens through the enteromammary pathway (60). Feeding HM that has been frozen exposes the child to immunoglobulins specific to the pathogens in their environment at the time of HM expression, not the time of consumption. Whether or not frozen HM would be beneficial for a sick child weeks or months after it was expressed is unknown.

From a nutritional perspective, HM fed from a bottle or other feeding vessel is no longer a dynamic fluid (61); the concentrations of fat, carbohydrates and other components remain the same throughout the entire feed. It has been proposed that the change in carbohydrate, fat, ghrelin, and leptin composition of HM over the course of a feed is an indicator of satiety to the infant (62). Thus, absence of this indicator may impact infants' ability to self-regulate their dietary intake. Use of different containers for HM collection, storage, and feeding may reduce the fat content of the milk as fat adheres to the sides of HM-feeding tubes in the neonatal intensive care unit (63). Additionally, the nutritional composition of HM changes over time (61) and stored HM does not have the same nutritional composition as HM fed from the breast without the use of cups or bottles. Short-term storage of HM reduces the concentration of ascorbic acid (64), with increased duration of storage causing a more marked decrease. Storing HM in temperatures found in household freezers can result in the hydrolysis of triglycerides and the appearance of free fatty acids in the milk (65).

It has also been suggested that the beneficial effects of breastfeeding on a child's IQ may result from a combination of the nutritional composition of HM and also the psychosocial dialogue between the mother-infant dyad during feeding (66). This interaction may be disrupted or entirely eliminated if expressed HM is fed from a bottle, particularly when this bottle feeding is not done by the infant's mother or other interested family member.

Another outcome important to public health that may be affected by at-the-breast feeding, HM expression, and expressed-HM feeding is the duration of any HM feeding. Although published qualitative research suggests that mothers feel that expressing HM allowed them to feed HM for longer (28), quantitative studies in which the association between expressed-HM feeding and duration of HM feeding has been assessed have had conflicting results. Positive associations have been found between maternal use of a breast pump and increased duration of any HM feeding (67, 68), but inverse associations have also been found linking higher frequency of maternal HM expression (44, 69) and expressed-HM feeding (38) and decreased duration of any HM feeding. Emphasizing the complexity of this relationship, Dabritz and colleagues (70) found a negative association between maternal breast pump use in the hospital and any HM feeding at 6 months but a positive association between any maternal breast pump use in the first 6 months postpartum and almost exclusive HM feeding at 6 months. Most recently, Forster and colleagues (71) reported a positive association between direct at-the-breast feeding in the first 24 - 48 hours of life and any HM feeding at 6 months. These data suggest that there is a nuanced and complex relationship between HM expression, expressed-HM feeding, and at-the-breast feeding, and that this relationship likely depends on other factors. These studies highlight the importance of using clear and consistent terminology to describe these distinct behaviors.

Discordance between duration of maternal HM production and duration of infant HM consumption has implications for maternal health. Breastfeeding has repeatedly been associated with reduced maternal postpartum weight retention (PPWR) in the literature (72-75). Breastfeeding was negatively associated with PPWR at 6 months postpartum in a sample of American women (74), at 6 and 18 months postpartum in a sample of Danish women (73), with this association maintained for as long as 3 years postpartum in a Norwegian study (75). Greater intensity of breastfeeding was also important, as full breastfeeding had a greater effect on PPWR than partial breastfeeding (74, 75). An association between increased duration of lactation and a reduction in risk factors for maternal cardiovascular disease has also been described recently (76-84). Breastfeeding has both short-term beneficial effects, lasting up to 6 years after cessation of breastfeeding (76, 78), and long-term beneficial effects, lasting to late adulthood and post-menopause (80). Accurate measurement of duration of maternal HM production is essential to future research into associations between breastfeeding and maternal health outcomes. With most HM-feeding mothers storing HM in the freezer (57), it is now possible for the duration of maternal HM production and the duration of infant HM consumption to be different. Using infant HM consumption duration as a proxy for maternal HM production duration may be inappropriate and could confound associations between lactation duration and PPWR, and maternal outcomes related to cardiovascular disease.

The differences in infant outcomes by feeding mode suggest that the established benefits of breastfeeding may not result solely from the composition of HM and that at-the-breast feeding may provide additional benefits beyond those related to the nutritional and immunological components of HM. This, along with our current inability to measure maternal behaviors accurately, highlight the importance of considering not just what an infant is consuming, but also how that substance is being fed. As such, we should be asking women about HM feeding mode in research and on national surveillance surveys. Indeed, to further establish the impact of HM expression and expressed-HM feeding on maternal and infant health outcomes, we must ask about them.

The need to clarify indicators of HM feeding has been highlighted in the literature (85-87), with specific emphasis on including indicators for feeding HM from a bottle. One group of authors pointed out that: "[HM feeding] duration may be assessed by asking how long the child was breastfed, how long the woman breastfed or pumped, or the age when the child stopped receiving breast milk. Women whose infant received expressed or donor milk would likely respond to these questions with different answers" (85).

Following their commentary in which they questioned the definitions used in breastfeeding research (87), Noel-Weiss *et al*. recently published a description of a new tool that they developed to measure patterns of infant feeding for breastfeeding research (88). The tool they developed is administered by a research assistant in person or over the phone, and is used to elicit information about what an infant consumed (e.g. HM, formula, solid food) and how the infant was fed (e.g. at the breast, from a bottle) in the past 24 hours or the past 7 days (88). This tool can be used to measure patterns of infant feeding prospectively over time. However, the authors emphasize that the number of data collection time points should be determined based on the research question of interest to those using the tool (88). The authors suggested new terminology and used the terms “breastfed” and “breast milk-fed” to describe infant feeding from the baby’s perspective (88).

What remains unknown about human milk expression and expressed-human milk feeding?

HM expression and expressed-HM feeding are understudied behaviors and little is known about the strategies employed by women to express their milk and feed it to their infants, and how these strategies change over time. Of the studies published to date reporting longitudinal trajectories of HM feeding, most report only at-the-breast feeding (89-92). In a retrospective survey, in which information on both maternal HM production and infant HM consumption were elicited, Geraghty *et al*. (93) reported that these behaviors were not always synchronous within a dyad, and that patterns of HM production and consumption were highly variable. Understanding the range of ways women use HM expression as a sole or ancillary strategy for feeding HM is the first step towards developing questions that distinguish between at-the-breast feeding and expressed-HM feeding and, thus, investigating maternal and infant outcomes associated with these behaviors. Although Noel-Weiss and colleagues developed a tool for measuring infant-feeding categories, this tool was predominantly designed for prospective research studies (88) and was not designed to measure how infants were fed from birth. Thus, survey questions that allow us to establish mode of infant feeding from birth to cessation of HM feeding are necessary.

Although investigators have reported differences in infant outcomes between at-the-breast feeding and expressed-HM feeding using data from the IFPS II, we still don't know the association between expressed-HM feeding and outcomes relating to infant infection. Increased incidence of infectious disease among formula-fed infants (94, 95) is one of the strongest motives for promoting breastfeeding. It remains unclear whether the association between breastfeeding and decreased incidence of infant infections is attenuated when HM is fed from a bottle.

This information is necessary because HM expression and expressed-HM feeding are supported by the existence of laws to promote and protect HM expression in the workplace in the U.S. The very existence of such laws suggests that expressed-HM feeding is an acceptable alternative to at-the-breast feeding. However, the scientific community are beginning to learn that this may not be the case, and mothers themselves are questioning the equivalence of these feeding modes. Mothers have reported frustration and uncertainty about the use of the word breastfeeding in the context of expressed-HM feeding (44), and have voiced a desire for more information on the health outcomes associated with expressed-HM feeding (96).

Thus, the ambiguity in the use of the term breastfeeding is problematic for research, surveillance, and clinical care. Inconsistent use of the term breastfeeding in research leaves us unable to (i) interpret evidence linking breastfeeding as an independent variable to maternal and infant health outcomes, (ii) make inter-study comparisons, and (iii) establish maternal and infant health outcomes associated with HM expression and expressed-HM feeding. On a national level, using infant HM-consumption as a proxy for maternal-infant dyadic at-the-breast feeding behaviors is simplistic and does not capture the complexity of HM feeding. Additionally, the current questions may be inappropriate as a measure of maternal lactation duration. Finally, if we aren't clear about the health outcomes associated with different feeding behaviors, how can clinicians advise families about best practices for infant feeding?

Distinguishing between feeding human milk at the breast and from a bottle

Based on this review of the literature, the aims of this dissertation were twofold. First, we aimed to understand how mothers used expressed-HM feeding as a sole or ancillary strategy for infant feeding, and whether there were any common strategies that mothers used. Second, we aimed to develop, test, and administer a comprehensive infant feeding questionnaire that accurately distinguished between at-the-breast feeding and expressed-HM feeding and includes indicators for HM expression.

The research described in the following chapters addresses these aims using a mixed-methods, sequential exploratory design. The first study was a qualitative interview study conducted among 41 mothers from 4 counties in upstate New York. Mothers described their experiences with at-the-breast feeding, HM expression, expressed-HM feeding, and HM sharing in semi-structured interviews. The second study was informed by the first; using data from qualitative interviews we developed a retrospective, self-administered, online survey about infant feeding. This survey was administered online to a convenience sample mothers of infants aged between 19 and 35 months old.

The structure of the chapters in this dissertation reflects the sequential design of this mixed-methods research (97). Chapters 2 and 3 report the results of the qualitative study; Chapter 2 focuses on how mothers incorporate HM expression and expressed-HM feeding into their infant feeding trajectories and Chapter 3 describes maternal experiences with and attitudes toward HM sharing. Chapter 4 is the bridge between the qualitative and quantitative work and describes the development, construct validity, and reliability testing of our survey. Finally, epidemiologic findings about the prevalence of at-the-breast feeding, HM expression, and expressed-HM feeding using survey data are presented in Chapter 5.

CHAPTER 2

HUMAN MILK EXPRESSION AS A SOLE OR ANCILLARY STRATEGY FOR INFANT FEEDING: A QUALITATIVE EXPLORATORY STUDY

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Abstract

Breastfeeding is recommended by public health officials because of the positive health outcomes observed among infants fed at the breast compared with those bottle-fed infant formula. However, in the U.S., a significant proportion of human milk (HM) is now fed from bottles. This mode of infant feeding is rarely measured or described in research studies or monitored by national surveillance systems. Consequently, little is known about expressed-HM feeding as an infant feeding strategy or the associated health outcomes. Our objective was to understand how mothers use HM expression and expressed-HM feeding as a sole strategy or in combination with at-the-breast feeding to feed HM to their infants. We conducted semi-structured interviews with 41 mothers with experience of HM expression and expressed-HM feeding. Data were analyzed for subthemes related to the pre-selected major themes of maternal HM production and infant HM consumption. Many mothers produced more HM than their infant was consuming at any given time and stored it in the freezer. This enabled some infants to consume HM weeks or months after it was expressed; some mothers voiced concern about the appropriateness of this. Four basic HM-feeding strategies emerged, ranging from predominant at-the-breast feeding to excusive expressed-HM feeding. However, the predominant strategy was a combination of at-the-breast feeding and expressed-HM feeding. These results highlight that the term breastfeeding may no longer be sufficient to describe the range of modes of providing HM to infants. To understand the health outcomes associated with expressed-HM feeding, new terminology may be needed.

Introduction

Human milk (HM) feeding rates have been rising consistently over the last decade (11) as women endeavor to meet recommendations to exclusively breastfeed for 6 months, followed by the introduction of appropriate complementary foods and continuation of breastfeeding for 1 year or more (1, 2). These recommendations are based on a large body of evidence associating sub-optimal breastfeeding behavior with poorer infant outcomes (3). However, formative studies providing evidence for these recommendations typically compared children who were fed HM directly at the breast with those who were fed a HM substitute from a bottle (3, 4). In the contemporary U.S., these may no longer be the most appropriate infant feeding comparison categories.

Based on data from the Infant Feeding Practices Study II (IFPS II), a longitudinal U.S. survey cohort, most HM-fed infants are no longer fed solely at the breast. The majority (85%) of HM-feeding mothers in the IFPS II expressed HM when their infant was between 1.5 and 4.5 months old (16); this expressed HM was then offered to their child from a bottle. Six percent of HM-feeding mothers in the IFPS II only fed HM from a bottle and never from the breast (40). Although we have insufficient data to tell whether prevalence of HM expression and feeding has been increasing in the U.S. over time, in Australia (26) and Singapore (41), countries where data from infants born in different years are available, prevalence of HM expression has increased. Given that reimbursement for breast pumps is now mandated by the Affordable Care Act (42) in the U.S., prevalence of HM expression is, at least, unlikely to decrease.

Despite this shift in HM-feeding modes, the National Immunization Survey (NIS) questions (**Table 2.1**) that are used by the Centers for Disease Control and Prevention (CDC) to report prevalence of HM-feeding are only about infant HM consumption, regardless of feeding mode. This means that we do not collect information specifically about dyadic at-the-breast feeding. In spite of that, responses to these questions are routinely used to report prevalence of maternal-infant breastfeeding behaviors (13).

HM expression and expressed-HM feeding are of public health importance because, depending on the location and duration of storage, expressed HM loses important nutritional (98, 99) and functional (59, 100) components. Short-term storage of HM reduces the concentration of vitamin C (64), with increased duration of storage in the freezer causing a more marked decrease. Storing HM in household freezers can result in the hydrolysis of triglycerides and the appearance of free fatty acids in the milk (65), and the lysis of the cellular components of the milk (100, 101). In addition, expressed-HM feeding as a behavior may affect the duration of any HM feeding. This association has been only minimally studied and results to date have been inconsistent; some authors (67) reported a positive association between use of a breast pump and duration of any HM feeding, while others (69) reported the opposite.

In-depth studies focusing on HM expression have not reported data about longitudinal HM-feeding trajectories (28, 43, 102). Of the studies published to date reporting longitudinal trajectories of HM feeding, most report only at-the-breast feeding (89-92). In one study, a retrospective survey, in which information on both maternal HM production and infant HM consumption were elicited, the authors (93) reported that these behaviors were not always

Table 2.1: National Immunization Survey HM-feeding related questions

Number	Question text	Indicator reported by CDC
1	Was [child] ever breastfed or fed breast milk?	Breastfeeding initiation
2	How old was [child's name] when [child's name] completely stopped breastfeeding or being fed breast milk?	Breastfeeding duration
3	How old was [child's name] when (he/she) was first fed formula?	Breastfeeding exclusivity
4	This next question is about the first thing that [child] was given other than breast milk or formula. Please include juice, cow's milk, sugar water, baby food, or anything else that [child] may have been given, even water. How old was [child's name] when (he/she) was first fed anything other than breast milk or formula?	Breastfeeding exclusivity

synchronous within a dyad, that patterns of HM production and consumption were highly variable, and that infant HM consumption was an inappropriate proxy for maternal HM consumption.

We conducted this research with the *a priori* objective of exploring our belief that the word breastfeeding alone may be insufficient to fully describe HM-feeding in the U.S. for the purposes of research or surveillance. We explored behaviors related to maternal HM production and infant HM consumption separately, as they are no longer a synchronous dyadic behavior. This research goes beyond what has previously been published by exploring patterns of HM expression and HM feeding qualitatively. The objective of this paper is to identify routine behaviors related to maternal HM-production and infant HM-consumption, about which minimal data are collected in research studies or by national surveillance systems.

Subjects and methods

Sample Selection and Recruitment

We recruited 41 mothers from 4 counties in upstate New York who had experience with HM feeding and breast pump use or hand expression and whose child was between 1 and 3 years old. This age-range was chosen to sample mothers similar in demographic characteristics to those sampled by the NIS, namely mothers of children aged 19 – 35 months. Mothers were recruited between August 2012 and June 2014 through notices in pediatric offices, cafés, stores that sold infant products, emails to parenting listservs, and by snowball sampling (Appendix A). Mothers were selected purposively for heterogeneity on characteristics associated with HM-feeding: age, socioeconomic status, marital status, employment status, and parity (103), as this was likely to provide a sample that were heterogeneous for practices related to HM expression.

Data Collection

Using an interview guide (Appendix B), the first author conducted one qualitative, semi-structured, in-depth interview with each mother after she provided signed informed consent. Interviews occurred at a location of the mother's choice, usually her home or a local café. Interviews lasted an average of 58 minutes (range 26 – 121 minutes) and we provided a $10 gift card as compensation. The interview explored at-the-breast feeding, HM expression, and expressed-HM feeding behaviors. Mothers were probed for additional information but interviews were largely participant-led. Demographic information was collected by questionnaire at the end of the interview. Interviews were audio-recorded, transcribed verbatim, and verified for accuracy. Data collection continued until data saturation was reached—the point at which no new information was obtained. This research was approved by Cornell University's Institutional Review Board.

Data Analysis

Using a predominantly grounded theory approach (104), we iteratively analyzed the transcripts using a combination of predetermined and emergent codes. The 2 predetermined codes reflected our *a priori re*search objectives and are shown in this analysis as the major themes (maternal HM production and infant HM consumption) and emergent codes are shown as sub-themes. The predetermined codes reflect our objective of exploring HM production and HM consumption as distinct behaviors. We used ATLAS.ti software (version 7) to manage data analysis and data analysis was discussed in weekly debriefing meetings. All names in the text are pseudonyms.

Results

A total of 41 mothers, aged 21 - 42 years, participated in this research. Most (85%) were married, 78% had at least a college degree, and 56% were multiparous. A small number of mothers (n = 3) described their experiences of providing HM to premature infants but most infants were born at term. As required by the study inclusion criteria, all mothers had experience with HM expression, either by hand or with a breast pump. Our two major *a priori* themes were (i) maternal HM production, and (ii) infant HM consumption. Within each of these major themes, three subthemes related to HM expression and expressed-HM feeding behaviors that deviate from the conventional use of the term breastfeeding emerged from the data. An additional major theme emerged from these data: (iii) how mothers describe breastfeeding and expressed HM-feeding.

Theme 1: Maternal HM-production

Many mothers expressed more HM than their child was consuming at a given time and built up a stockpile of HM in the freezer that was stored for long periods of time. Mothers put a lot of thought into how best to use this stored HM; some voiced concerns about feeding “old” HM that had been stored for a while to their infants. Finally, maternal over-production of HM also allowed some mothers to continue HM feeding after they stopped lactating. These three sub-themes are described in detail below.

Maternal over-production of HM

HM expression, specifically the use of breast pumps, enabled many mothers to extract more milk from their breasts than their infant was consuming at a given time. Several mothers began expressing HM early in their child's life purposefully to build up a stockpile of HM to be fed to their infant when they returned to work or for some other period of maternal-infant separation. A few mothers expressed HM even though their infant refused to drink from a bottle, which created a stockpile of HM. The volumes of HM stored by mothers varied considerably, from a few ounces to thousands of ounces.

> "…there was slowly a stockpile building up and the stockpile really happened at 12 months, we went on vacation for a month. And um, she didn't have a bottle the whole time, and then when we came back, she refused to take a bottle ever again. But I still physically had to pump." (Olive)

> "I just pumped like hell to store it and I have [at work] a giant walk-in freezer. And so I went like crazy. And it was just like box after box after box. I would fill a diaper box and then my husband would bring it in…" (Colette)

Maternal practices and concerns around using stored HM

Most mothers who built up a stockpile of HM in their freezer typically placed very high value on the milk, often calling it "liquid gold," and they voiced strong desires not to waste any. Some mothers placed such high value on their stored HM as a product that they saved it in the freezer for a time when they perceived it to be especially important, for example, when their child was sick:

> “I did save eh the milk for more than 6 months, ‘cause … we would go to play dates and he’d get in contact with kids that was in daycare so he was getting a lot of colds and it’s like ‘oh I wanna give him my breast milk to help’ ‘cause I thought like, you know, having more immune assistance will help him.” (Wendy)

In two extreme examples, mothers fed infant formula or introduced solid foods into the infant’s diet earlier than desired because they felt like they were using up their stockpile of frozen HM too quickly and they wanted the HM to last longer:

> “That was also why we started him on solids a little earlier than we wanted. We started him on solids at about 4 months because we were trying to curb how much [breast] milk he was drinking” (Fiona)

> “I didn’t want to use up all my stored breast milk so maybe I would give her one bottle of formula so we could keep [the HM] for later…” (Tanya)

As a result of maternal stockpiling, several infants were fed HM many weeks or months after it was expressed. Some mothers voiced concerns about whether or not stored HM was appropriate for their infant given that the composition of HM changes over time:

> “Um, I don’t know if it’s a real great concern but I was, you know, developmentally just wondering if what I pumped for him when he was 2 months old, developmentally would that be the best option for him when he was 10 months old.” (Krista)

> “…the later ones have more fat or have more something. Something … more related to what age he is, is what he needs … So there was a time when I was worried about that so, then I, I started taking the more current [bag of HM].” (Diana)

Difference between duration of maternal HM production and infant HM consumption

For a small number of mothers, their stockpiling behavior allowed them to feed HM from the freezer for weeks or months after they had stopped lactating. Other mothers discussed friends doing this; it was generally considered a good idea:

> "I kept her on breast milk until about 8 months, I stopped pumping at 6 but I had almost 2 months uh worth. And that was great, was to walk into the freezer and go 'that's awesome, that was me!'" (Colette)

> "…I have a friend who pumped lots of extra milk and still fed for a couple of months after she stopped breastfeeding, she still gave her bottles of her milk. But I only know of one person like that did that, it's a good idea." (Orla)

<u>Theme 2: Infant HM consumption</u>

The second theme comprises subthemes related to HM-feeding strategies employed by mothers to feed HM to their infants, infants "breastfeeding" without their mothers present, and infants consuming another mother's HM.

HM-feeding strategies

Each mother in this sample described a unique infant feeding trajectory over the first year of her infant's life. However, at any given time point along their trajectory, all mother-infant dyads in this sample could be categorized into 1 of 4 types of basic HM-feeding strategies involving a combination of at-the-breast feeding, and refrigerated or frozen expressed-HM feeding to provide their infants with HM (**Figure 2.1**). Infant feeding trajectories were complex as mothers moved into and out of the different HM-feeding strategies over time depending on their

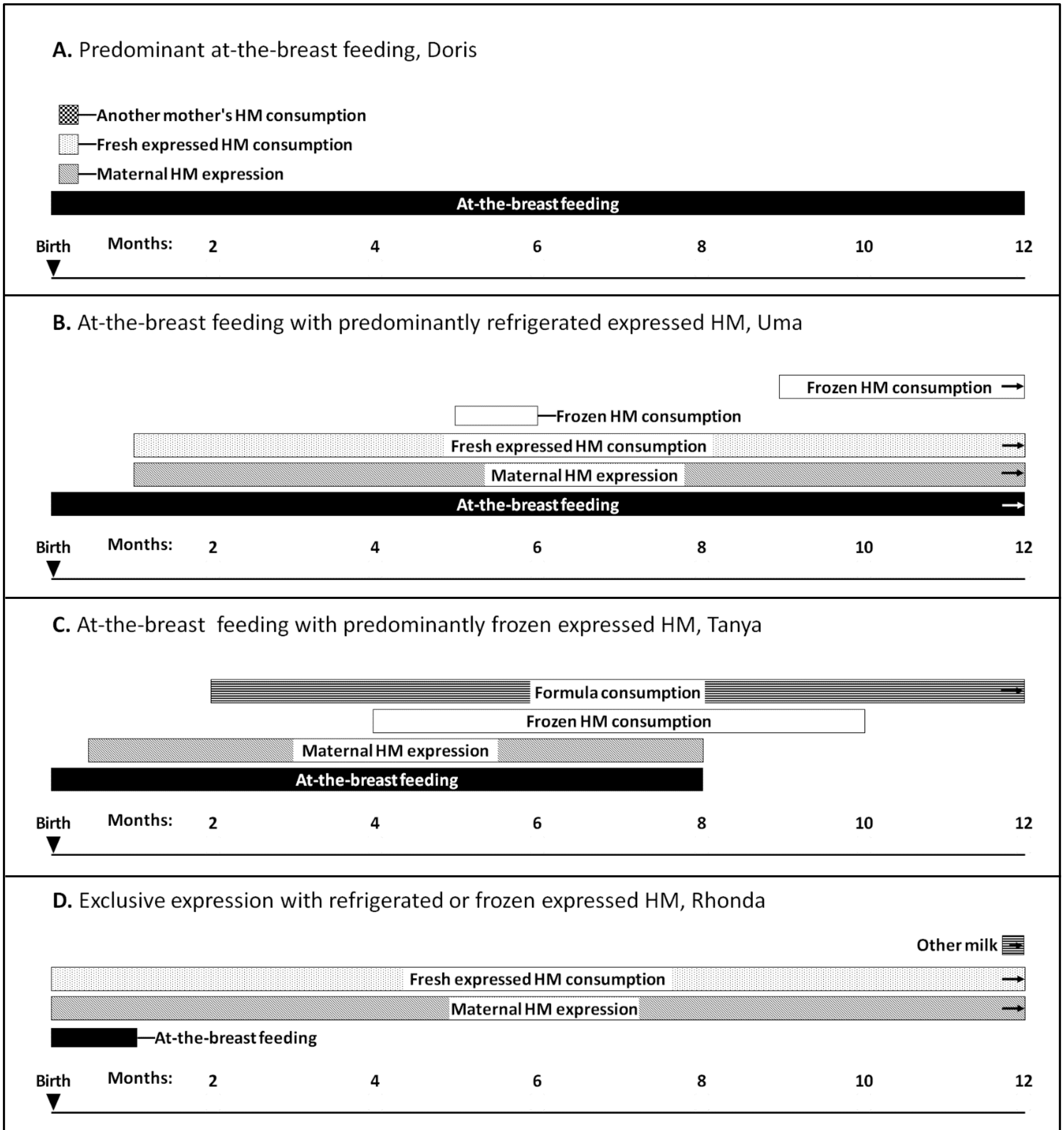

Figure 2.1: HM-feeding trajectories over the first 12 months of life of 4 mother-infant dyads. Each dyad is a representative example of the 4 basic HM-feeding strategies. For clarity, only milk-based feeds are included in these diagrams; infant consumption of solid foods is not pictured. Arrows indicate that some behaviors continued beyond 12 months.

circumstances. The four basic HM-feeding strategies employed are described here in order of increasing reliance on HM expression and expressed-HM feeding and, thus, deviation from at-the-breast feeding. A brief description of a representative mother is offered for each strategy. These mothers were specifically chosen because together they participated in all behaviors described across all sub-themes presented in this paper.

Strategy 1, Predominant at-the-breast feeding: A few mothers only expressed HM occasionally and were able to predominantly feed directly at the breast. This infant feeding strategy was typical of mothers who did not return to full-time employment outside the home. Mothers in this category used breast pumps to help their milk "come in" early postpartum, to provide milk for their infant during a short-short term separation or to relieve engorgement.

> "I pumped a little bit here and there but it was um, it was basically on demand." (Xena)

A few mothers who predominantly fed at the breast intended to provide expressed HM for their infants either so the baby's father could feed or so the mother could return to work. However, their infants refused to take a bottle so they continued with at-the-breast feeding.

> "She never liked [bottles] so um, I think a couple of times my mom took her and my mom said she cried before she even took it because she just didn't want it. And um, then I realized I could never leave her." (Irene)

For example: Doris (Figure 2.1; Trajectory A) expressed HM because she experienced a delay in her milk coming in. Her infant was fed a small amount of Doris's expressed HM and another mother's HM for a week. Once her milk came in, Doris resumed at-the-breast feeding.

Strategy 2, At-the-breast feeding with predominantly refrigerated expressed HM: Some mothers expressed HM regularly and stored it in the refrigerator so that it could be fed the next day by a non-maternal caregiver, typically a paid daycare provider or the infant's father. This strategy was common among working mothers who had access to a breast pump and had somewhere to pump in the workplace.

> "I just would put the milk in my fridge [at work] and bring it home at night, dump it into the bottles that [my husband] was gonna use the next day and wash out the pump bottles and pack everything up again and bring it back [to work]." (Adele)

Refrigerated milk was typically only stored for a day or two and most mothers labeled the bottles so that the oldest milk would be fed to the child first:

> "…most of the daily milk would come from the milk that I had pumped the previous day at work and we had a system of labeling and kind of order within the um, the refrigerator so that [husband] would know to use the oldest milk first." (Uma)

For example: Uma (Figure 2.1; Trajectory B) expressed HM to build up a stockpile of frozen HM and to feed refrigerated HM while she was at work. Her infant was fed some freshly expressed HM before Uma went back to work to get used to bottle-feeding. Her infant was fed a lot of frozen HM when Uma first returned to work and then the infant settled into a routine of consuming HM that had been expressed the previous day. Later in infancy, refrigerated HM was topped-up with HM from the freezer.

Strategy 3, At-the-breast feeding with predominantly frozen expressed HM: Similar to strategy 2, this strategy was often employed by working mothers. However, mothers who used frozen HM either worked to build up a large stockpile of frozen HM before returning to work or they regularly produced too much HM to store in the refrigerator for a short amount of time, resulting in a stockpile building up in the freezer. Mothers employing this strategy also typically labeled their milk with the date it was expressed and often had complicated strategies for storing milk in their freezers and rotating it so that they used the oldest milk first. In some cases, mothers were expressing milk freshly each day, putting the fresh milk in the freezer, and feeding their infant milk from the freezer that had been stored for months:

> "I freeze it in 5-ounce quantities and I typically use the oldest milk that I've pumped … so everyday I'm freezing and then pulling out the older milk so that it can thaw and use so that it doesn't get too old. So it's like a constant full time job washing all the parts and setting up the pump" (Pilar)

For example: Tanya (Figure 2.1; Trajectory C) expressed HM to build up a stockpile of frozen HM and to feed HM while she was at work. Tanya was not confident in her ability to exclusively provide HM so she introduced infant formula at 2 months. She had HM stored in the freezer and her infant went to daycare with half HM and half infant formula. After stopping at-the-breast feeding, Tanya still had HM in the freezer and her child was fed half HM and half infant formula for another 2 months until she transitioned to consuming only infant formula.

Strategy 4, Exclusive expressed-HM feeding with refrigerated or frozen expressed HM: The reliance on HM expression associated with this strategy was typically incompatible with full-time employment. Mothers in this study who used this strategy primarily employed it because their infant was not well and could not suckle at the breast or their infant refused the breast after several months of successful at-the-breast feeding:

> "…at 8 months he started biting me. …So, I actually had to switch and I couldn't breastfeed anymore and I had to really express all of his milk … I was pumping four or five times a day to meet his needs and it was exhausting. So at 10 months, I think I stopped pumping at least one of those four times a day and started giving formula 'cause I just couldn't [continue pumping so much]." (Bridget)

However, there were a small number of mothers who said that they preferred being in control of their own schedule and felt that exclusive expression and expressed-HM feeding allowed them to manage their time better:

> "What I liked was that I was in control of the schedule. …I liked that I had direct control of when I can do it." (Violet)

For example: Rhonda (Figure 2.1; Trajectory D) expressed HM because of a medical problem with at-the-breast feeding. Her infant consumed HM that had been expressed the previous day. Rhonda was expressing extra HM and storing it in her freezer hoping she could stop lactating at 6 months postpartum and continue feeding HM until her infant was 1. However, Rhonda tasted her frozen HM at 6 months postpartum and felt it had expired; she discarded it all.

These infant feeding strategies describe how infants were fed at a given time and were not static across infancy. Most mother-infant dyads switched between strategies throughout infancy depending on life events, resulting in distinct trajectories for each dyad. Some mothers began with predominant at-the-breast feeding and switched to incorporate expressed-HM feeding when they returned to work. A couple of mothers switched from predominant at-the-breast feeding to exclusive expressed-HM feeding when their child refused the breast. Several mothers stopped expressing HM when their child was over 1 year of age and reverted back to providing all HM at the breast because they felt they were able to provide sufficient food and other milk to supplement at-the-breast feeding when they were separated from their infant.

Infants "breastfeeding" without the mother present

For many mothers, regardless of which HM-feeding strategies they used, predominant at-the-breast feeding was preferred. Many mothers only fed at the breast when they were with their baby and when infants consumed expressed HM, it was most often fed by someone other than their mother. An exception to this general rule were mothers who exclusively expressed and fed expressed HM (strategy 4); these mothers often fed expressed HM. Non-maternal caregivers who fed HM included the infant's father, grandparent, some other relative or a paid daycare provider. In one instance, an infant was able to consume HM and not require any formula or other milk-based supplements for an entire week in the absence of her mother:

> "And then beginning of May, so she was 11 months, my husband took a trip for a week, and took the kids, and took my milk." (Sadie)

Infants consuming shared HM

For some mothers, HM feeding was valued above all other forms of infant feeding. This led a small number of mothers to procure another mother's HM to feed to their infant when they could not provide their own. For the most part, infants who received shared HM consumed it from a bottle and were not fed at another mother's breast. Mothers were typically motivated to use shared HM because they were experiencing a short-term problem with at-the-breast feeding. In these instances, shared HM bridged a gap until the infant's mother could provide her own HM (e.g. Figure 2.1; Trajectory A).

Theme 3: How mothers describe breastfeeding and expressed HM-feeding

Throughout interviews, mothers described their experiences with at-the-breast feeding and expressed HM-feeding. Although we did not ask what mothers considered breastfeeding to mean to them, some used language that suggested equivalence between the two behaviors:

> "I breastfed all my children for the first year. They only received breast milk, as far as I know … so I pumped when I went back to work and everything and my [daycare] providers fed them milk I guess." (Eve)

> "It wasn't different for [baby] … there's separation but he's still getting the same food." (Fiona)

Conversely, other mothers used language that clearly described at-the-breast feeding and expressed HM-feeding as different behaviors, for them and their infant:

> ""'…it's not an intimate experience when you're sitting there with a pump and you know, looking through magazines or waiting to be drained…" (Xena)

> "…when [my husband] tried to hold her like you would hold a baby when you're breastfeeding, like [baby] was not at all interested in anything that was sort of like breastfeeding but not breastfeeding." (Olive)

Discussion

By analyzing infant feeding qualitatively from the maternal perspective, we found that the majority of mothers in this sample used many different HM-feeding strategies, incorporating HM expression and expressed HM-feeding. This is of interest because the studies describing the benefits of breastfeeding compared infants fed infant formula from a bottle with those fed at the breast, which may no longer be the predominant HM-feeding strategy.

Of the infant feeding trajectories presented, mother-infant dyads in 3 of the trajectories would be classified as breastfeeding for 12 months by the NIS questions even though the mode of HM feeding ranged from predominantly feeding directly at the breast to predominantly feeding expressed HM from a bottle. One mother-infant dyad would be classified as breastfeeding for 10 months even though the mother stopped producing HM at 8 months postpartum. Our novel findings, and their unique pictorial representation, highlight that contemporary HM-feeding strategies in the U.S. differ from how most health professionals and researchers talk about, recommend, and measure breastfeeding.

As these data show, transfer of HM to an infant, as measured by the NIS questions, is not always the same as breastfeeding, as reported by the CDC. Considering the infant feeding strategies and trajectories described by mothers in this study, the current breastfeeding surveillance questions are insufficient to report prevalence and intensity of either at-the-breast feeding or expressed-HM feeding. Thus, reports based on these questions oversimplify contemporary infant feeding practices.

The strategies for transferring HM to infants described in this paper raise several important questions: If an infant is being fed HM that has been stored, is that considered breastfeeding? If an infant is consuming HM after his/her mother has stopped lactating, is that considered breastfeeding? If an infant is being fed HM by a non-maternal caregiver, is that considered breastfeeding? If an infant is consuming another mother's milk, is that considered breastfeeding? These questions are important because the current national breastfeeding surveillance questions in the U.S. are infant-centric and consider any transfer of HM to the infant to be breastfeeding.

This may be an appropriate use of the word for some mothers, who used the term breastfeeding to have broad and multifaceted meanings that included expressed HM-feeding. However, use of the word breastfeeding may be problematic for mothers who spoke about at-the-breast feeding and expressed HM-feeding as different behaviors. Use of the word breastfeeding by researchers and public health officials is also problematic as it doesn't fully describe the complex HM-feeding behaviors described in this paper. This is important because the behaviors described in this paper have four public health implications for both mothers and their infants.

First, health professionals and those involved in promoting optimum infant feeding should be aware that mothers may not be interpreting infant feeding recommendations as they expect. For example, saving stored HM and meting it out slowly to avoid using up stored HM too quickly implies that some mothers in this study traded breastfeeding exclusivity for prolonged breastfeeding duration. This prioritization of breastfeeding duration over exclusivity may reflect how mothers internalize breastfeeding promotion messages. This is supported by research conducted in Australia (105) in which fewer parents were aware of the recommendation to exclusively breastfeed for 6 months than were aware of the recommendation to continue any breastfeeding to 12 months.

Second, labeling the duration of infant HM intake as breastfeeding duration is problematic because the duration of infant HM consumption is not an appropriate proxy for intensity and duration of maternal HM production. There is a growing body of research in which associations between duration of maternal lactation and maternal health outcomes are reported. Thus, maternal lactation is an exposure of epidemiological importance. The focus on infant HM consumption in the U.S. national breastfeeding surveillance questions is of concern because it limits our ability to measure intensity and duration of maternal lactation. Greater intensity of breastfeeding is associated with less postpartum weight retention, and full breastfeeding has a greater effect than breastfeeding in combination with formula-feeding (74, 75). The greater effect seen with full breastfeeding suggests that the volume of milk removed from the breasts is important in the association between lactation and postpartum weight retention. Recent research also described an association between increased duration of lactation and a reduction in risk factors for maternal cardiovascular disease (9). The associations between lactation duration and postpartum weight retention and maternal outcomes related to cardiovascular disease warrant continued study. Accurate measurement of lactation intensity and duration is essential to such research.

Third, insufficient research has been published about the health outcomes associated with HM expression and expressed-HM feeding. Both the altered composition of stored HM and bottle-feeding HM have implications for infant health. Through the enteromammary pathway, mothers who feed at the breast can launch an immune response specific to a child's exposure to pathogens at a given time (60). Feeding HM that has been stored in the freezer exposes the child to immunoglobulins specific to the pathogens in their environment at the time of HM expression, not the time of consumption. This is important because some mothers in this study saved frozen HM for a time when their infant was sick. Whether or not frozen HM would be beneficial for a sick child months after it was expressed is unknown. Studying health outcomes associated with expressed-HM feeding is difficult because few researchers measure HM-feeding mode. However, publications based on IFPS II data have described associations between expressed-HM feeding and greater growth velocity (48) and increased risk of coughing and wheezing episodes in the first year of life (106). Measurement of HM-feeding mode is essential to expand our understanding of the health outcomes associated with feeding expressed HM.

Fourth, until we know more about why, how, and how many women are participating in HM sharing, we will be unable to provide families with evidence-based, best-practice advice about their infant feeding choices. The consequences of feeding an infant another mother's HM are unknown. The extent to which this behavior is of public health concern depends on the prevalence of HM sharing, something that is not currently measured nationally. Research about HM sharing to date has mainly focused on women who have participated in the behavior (107, 108). However, recent research suggests that awareness of this behavior is high among a broad sample of mothers (109).

The main strength of this study is its qualitative methods. Qualitative research allows the researcher to explore ideas in more detail than a survey (110) and may reduce investigator-introduced bias by allowing data collection to be participant-led (110). This study was limited by the geographic location from which the mothers were recruited; it is unclear whether findings from this sample are transferable to other populations. The majority of our participants were white, older, and more educated than the general population of mothers. However, this demographic breakdown is not surprising as it reflects the population of HM-feeding women in the U.S. (111).

Conclusion

The HM-feeding strategies and trajectories described by mothers in this study are far more complex than the behaviors described by the data that is collected by the current national breastfeeding survey questions. Although many mothers in this study voiced a preference for direct at-the-breast feeding, their personal circumstances (e.g. returning to paid employment) led them to employ alternative HM-feeding strategies. Consequently, in an attempt to meet national or personal breastfeeding goals, many mothers practice their own variation of breastfeeding by incorporating HM expression and expressed-HM feeding. If researchers, public health professionals, and clinicians are interested in obtaining information solely about infant HM consumption, then questions that do not distinguish between at-the-breast feeding and expressed HM-feeding may be sufficient. However, the HM-feeding strategies described in this paper have public health implications and warrant further study. Thus, future research and national surveillance should use survey questions that appropriately delineate modes of infant feeding and allow reporting of maternal duration of lactation, infant duration of HM consumption at the breast, and infant duration of HM consumption from a bottle as the distinct behaviors that this study has shown they are. Such data would enable us to compare maternal and infant health outcomes across HM-feeding strategies and advise families about optimal infant feeding practices.

CHAPTER 3

INFORMAL HUMAN MILK SHARING: A QUALITATIVE EXPLORATION OF THE ATTITUDES AND EXPERIENCES OF MOTHERS

Elizabeth J O'Sullivan, Sheela R Geraghty, Kathleen M Rasmussen

Abstract

Background: Little is known about women's participation or likely participation in informal human milk (HM) sharing. The Food and Drug Administration recommends against feeding infants shared HM acquired directly from individuals or through the Internet.

Objectives: This study explored the experiences of and attitudes toward HM sharing among mothers with experience of HM feeding and breast pump use, regardless of whether or not they had participated in HM sharing.

Methods: We conducted qualitative, semi-structured, in-depth interviews with 41 mothers from 4 counties in upstate New York, asking about their attitudes toward HM sharing. Interviews were transcribed and analyzed inductively.

Results: Most mothers were aware of informal HM sharing and some had personal experience with sharing. Many mothers reported a willingness to provide their own HM if they had extra HM, and their own child had enough. Mothers were less trusting about receiving HM, voicing concerns about the dietary intake or disease status of potential providers. Mothers felt that whether or not they participated in HM sharing would depend upon the situation; e.g. the age of their child or the child in need, and who the other mother in the sharing partnership was. Mothers were most amenable to sharing with a family member or close friend. A novel finding was the involvement of lactation consultants and midwives, who coordinated HM exchanges for mothers in this sample.

Conclusions: Awareness of HM sharing was high in this sample. Depending on the situation, mothers may consider participating in informal HM sharing and they may be facilitated by health professionals. Future research is required to establish the benefits and risks associated with informal HM sharing.

Introduction

Breastfeeding is the optimal way to feed infants from birth to 6 months with the introduction of complementary foods at 6 months and continued breastfeeding to 1 year and beyond (1, 2). Increasing rates of initiation of human milk (HM)-feeding in the United States over the last few decades (10, 112, 113) suggest that mothers recognize the superiority of HM. For those who cannot, or choose not to produce HM, infant formula is usually the alternative infant feeding choice. However, before infant formula became widely available, mothers who could not feed their infant at the breast often employed the services of a wet-nurse (114). More recently, the development of infant formula and convenient feeding bottles has made artificial feeding a feasible alternative to wet-nursing (115).

However, for mothers who cannot produce sufficient HM, do not want to use a HM substitute, and whose infants do not qualify for milk from the Human Milk Banking Association of North America (116), feeding their infant another mother's HM may be considered a viable option. The increasing use (16) and ubiquitous availability of breast pumps has enabled some women to build a store of HM that they may choose to share with another mother (117).

Currently, the Food and Drug Administration (FDA) recommends against feeding an infant HM "acquired directly from individuals or through the Internet" (118). Here we refer to this type of milk sharing as informal HM sharing—freely sharing HM that has not been tested or pasteurized—to distinguish it from using HM from a milk bank, which does test and pasteurize milk. The professional organization for doulas, childbirth and lactation educators discourages their members from "acting as barters for [informal] milk sharing" (119). Similarly, La Leche

League policy states that leaders should not use their position “set up any type of milk-sharing network” (120).

However, reports of women informally providing HM for infants who are not their own have been published in the media and scientific literature since the 1980s (107, 117, 121-130). In a recent survey of Ohio mothers, awareness of HM sharing was high (109), with 77% of the 499 respondents stating that they had heard about a child being fed HM from another mother or a mother providing HM for a child that was not her own. Although awareness of HM sharing was high, only 25% had considered sharing and fewer than 4% of respondents reported that they provided or received HM (109).

In the last decade, the launch of websites specifically for HM sharing (131-133) has facilitated online HM sharing (134), but little is known about informal HM sharing on a smaller scale—between families, friends, and within communities. Previous researchers have used qualitative methods to explore reasons for and attitudes toward HM sharing among mothers who had previously done so (121-125), but less is known about the attitudes of women who have never shared HM and their likelihood of future participation in informal HM sharing.

The aim of this study was to gain a deeper understanding of women’s awareness of and attitudes toward informal HM sharing, and motivations for participating in this behavior, regardless of whether or not they had previously done so.

Methods

<u>Sample Selection and Recruitment</u>

We recruited 41 mothers from 4 counties in upstate New York who had experience with feeding HM and using a breast pump and whose child was between 1 and 3 years old. Mothers were recruited between August 2012 and June 2014 through notices in pediatric offices, cafés, stores that sold infant products, emails to parenting listservs, and by snowball sampling (Appendix A). Mothers were selected purposively for heterogeneity on characteristics associated with HM feeding: age, socioeconomic status, marital status, employment status, and parity (103, 135). Mothers were not selected for heterogeneity on practices for HM sharing, and HM sharing was not mentioned in any recruitment materials.

<u>Data Collection</u>

The first author conducted one qualitative, semi-structured, in-depth interview using an interview guide (Appendix B) with each mother after she provided signed informed consent. Interviews occurred at a location of the mother's choice, usually her home or a local café. Interviews lasted an average of 58 minutes (range 26 – 121 minutes) and we provided a $10 gift card as compensation. The interview covered topics related to at-the-breast feeding and expressed-HM feeding and mothers were probed for additional information. HM sharing was the last item discussed to build up rapport before introducing a potentially sensitive topic, and to see whether HM sharing came up spontaneously before being introduced by the researcher. Mothers who brought up HM sharing first were asked the same general questions about the topic as other mothers. Demographic information was collected by questionnaire at the end of the interview. Interviews were audio-recorded, and transcribed verbatim. This research was approved by Cornell University's Institutional Review Board.

Data Analysis

Through detailed and repeated reading of transcripts, we identified themes in the data using an inductive approach (136). We created and iteratively adapted codes throughout the analysis. Each interview was coded by both the lead author and a research assistant; data analysis was discussed in weekly debriefing meetings. We conducted member checks by discussing our findings with 2 mothers who participated in HM sharing and requesting feedback. These mothers felt that our understanding of HM sharing reflected their individual situations. We used ATLAS.ti version 7 software to manage data analysis. All names in the text are pseudonyms.

Results

The 41 mothers, aged 21 – 42 years, came from diverse socio-economic backgrounds and 9 mothers had participated in HM sharing (**Table 3.1**). There were no obvious differences in attitudes toward HM sharing by age or education status. Opinions about HM sharing did differ depending on whether mothers were discussing providing or receiving HM.

Major themes that emerged were (1) the awareness of, (2) consideration of, (3) concerns about, (4) motivations for, and (5) routes of HM sharing.

Awareness of HM sharing

Most mothers were aware of informal HM sharing, and many were positive about it saying that it's "great" and a way to "put all of that work [of pumping] to some kind of positive use." However, a few mothers described HM sharing as "weird" or "a gross concept." Often, mothers introduced the topic before the researcher inquired about it, indicating a high level of awareness.

Table 3.1: Participant characteristics, n = 38 [1]

Characteristic	**Number**
Age	
≤ 30	10
31 – 35	16
36 – 40	10
> 40	2
Returned to work less than 6 months postpartum	
Yes	21
No	20
Education	
High school or some college	6
College	11
Post-college	21
WIC participation [2, 3]	9
Married/partner	35
Index child is the mother's first child [4]	18
Provided shared HM	5
Received shared HM	4

[1] Some data are missing on 3 participants who did not complete demographic questionnaires
[2] WIC, the Special Supplemental Nutrition Program for Women, Infants, and Children
[3] Based on interview content, actual n may be higher
[4] One first-time mother described her experiences of breastfeeding and expressing human milk for twins

Mothers had read about HM sharing online, in magazines, had heard about it from friends or on the radio or knew someone who had either informally provided or received HM.

> "… there's a mom's group here in [town] that I belong to and I've seen a woman who has both offered and coordinated a donation of breast milk." (Zoe, Non-sharer)

One mother was made aware of informal HM sharing by a lactation consultant:

> "… the private lactation consultant … mentioned that she very informally … helps set up relationships with people giving each other breast milk. … she said 'I try really hard not to get involved,' but she said, 'I do pass names on and then like interactions happen in like parking lots and stuff like that.'" (Colette, Non-sharer)

Other mothers also mentioned discussing HM sharing with lactation consultants, midwives, La Leche League leaders, doulas and pediatricians.

<u>Considering HM sharing</u>

Many mothers said that they would consider participating in HM sharing; these mothers were generally more open to the idea of providing HM than to receiving it.

> "…the only way that I considered myself being a part of it was if I had more, then I would like to give it away." (Gaby, Non-sharer)

Many non-sharers said that if they heard of an infant in need of HM through family, friends or the community "grapevine," they might offer to provide HM. Some said that if they needed HM they might ask another mother that they knew who was HM feeding or "put the word out there" in the community. Some mothers had researched HM sharing quite thoroughly and had been in contact with someone about possibly sharing HM.

> "I … found several online forums and put out there that I had milk to donate but I never got any request back," (Uma, Non-sharer)

For those who considered providing HM but did not, either they did not have enough to give away, they found the process of finding a recipient mother too difficult, the person to whom they had intended giving HM to no longer required it or they felt that other mothers would not want their milk. For those who considered receiving HM but did not, either they did not like the person who was offering, they felt it would be too difficult to source a consistent supply of HM or their husband was against it.

Some mothers described very specific circumstances under which they might be willing to provide or receive HM and several mothers who originally said that they would not receive HM from another felt differently when asked if they would accept HM from a close friend or relative.

> "…my friend [name] upstairs. She said 'oh I found a bunch at the bottom of the freezer and I threw it out,' and I was like 'what the hell? Like, I would have given that to my kids.' … Um, so someone close to me, I absolutely would have done it." (Violet, Non-sharer)

Some found it difficult to say, even hypothetically, whether they would participate in HM sharing.

> “So borrowing somebody else’s milk is kind of like borrowing somebody else’s dentures … it’ll do but it’s not made for them. So I don’t know. I don’t know if we were in that situation what we would do.” (Xena, Non-sharer)

<u>Concerns about HM sharing</u>

The most salient concern of mothers when discussing providing HM was that their own infant had enough; many mothers who had excess, or thought they were producing sufficient, HM were open to providing HM to another mother.

> “… [Baby] was at my mom’s house … so he already had some milk that he was eating, he was fine. So I’m like ‘well it’s extra, do you want it?’ So... She took it.” (Nora, Provider)

Some felt that others might not want their HM because of their coffee or alcohol consumption. A few mothers said that they would be unwilling to provide HM to another because it was personal and they would feel “weird about it.”

> “I expect [my own child] to like it and want it because she’s part of me but it’s just weird to give it to someone a part of someone else.” (Orla, Non-sharer)

Mothers discussed more concerns about receiving HM; the most salient concerns related to the potential provider being unknown to the recipient mother, her dietary intake, drug and medication intake, and disease status.

> “I didn’t know if like if I borrowed breast milk from somebody and they were HIV positive, if the baby could get that. So that would be my number one concern…” (Megan, Non-sharer)

Concerns about hygienic expression and handling of HM, not wanting an infant to form a bond with another mother, not liking the potential provider, and the opinion of the infant's father were also reported, but less commonly.

Motivations for HM sharing

Mothers described altruistic motivations for providing HM including helping a mother whose milk supply was low, who was having problems with at-the-breast feeding or who was sick and taking medications that prevented at-the-breast feeding.

> "… my sister is currently pregnant and if I knew that she was having problems with nursing or couldn't nurse for some reason, like I would definitely hand it right over to her…" (Sadie, Non-sharer)

Altruistic motivations for providing HM also included helping infants perceived to be in need because they were thin, were not developing appropriately or their mother had died. Younger, sick, and visibly "malnourished" infants were described as being particularly in need of HM.

> "…a couple of weeks or month ago… [Husband] heard a story about a mother who had died during giving birth. And … that there might come up a call for donating milk." (Freya, Non-sharer)

Additionally, mothers with excess HM were motivated to provide their milk so that it wouldn't go to waste.

> "It was like 30 bags I just donated to some moms [through the Internet] because I just realized I had way too much in the freezer that I was probably not going to be able to use." (Pilar, Provider)

Motivations described for receiving HM included experiencing a delayed onset of lactogenesis II, delivering a premature infant, taking medications that are contraindicated while at-the-breast feeding, inability to pump sufficient HM during maternal-infant separation, low milk supply, to assess a problem with at-the-breast feeding or to provide HM for a fostered or adopted infant.

> "I do have another friend who tried to breastfeed her baby and because of some reason she couldn't produce milk and so she did have friends who donated their milk to her, at least like in the first couple of months of her baby's life." (Yasmin, Non-sharer)

Mothers described maintaining HM feeding in the face of a short-term problem or obstacle with at-the-breast feeding as a motivation for receiving HM. In these circumstances, shared HM bridged a gap until the recipient mother could provide her own, thus avoiding using HM substitutes.

> "…we needed my son's weight gain to get up there so he could you know, have the energy to learn how to nurse properly and I needed to heal because my nipples were destroyed at that point." (Adele, Recipient)

Mothers in this study who participated in HM sharing were very positive about their experiences and were either very happy to have been able to help someone in need or very grateful to have received HM from another mother.

<u>Routes for HM sharing</u>

In this study, sharing occurred through different routes. Some HM sharing occurred between family and friends:

> "…my sister-in-law …I was giving her some frozen milk for a little while. I forgot about that…" (Nora, Provider)

> "…[my friend] called me and asked if she could have this, all the milk that I had stockpiled and so I gave her like hundreds of ounces of milk…" (Olive, Provider)

Exchanges were also mediated through third parties that connected providers and recipients who were not previously known to one another. Third party mediators included websites specifically for coordinating HM exchanges, lactation consultants, midwives, and La Leche League leaders.

> "… so the lactation consultant was at our house and so she called the midwife that knew the donor and, and then the midwife just immediately called the donor and within … 10 minutes they called back and said 'yeah, she's got tons of milk, just come over…'" (Doris, Recipient)

> "…through, um, some lactation consultants, um, I found out that she needed breast milk like immediately. And so I gave her my entire supply." (Hazel, Provider)

Healthcare professionals mentioned most often as mediators of exchange in this sample were lactation consultants and midwives. Though some exchanges in this sample occurred between family or friends, third parties were used by some mothers and seen by others as another potential route for organizing an exchange. For example, when describing how she might get shared HM if she needed it, one mother said:

> "…the lactation consultant ended up calling me at some point asking me, she was trying to find milk for a mom who needed it. So probably [midwife], [lactation consultant], they're like my go-to gals for anything…" (Holly, Provider)

To summarize these results, Figure 3.1 and Figure 3.2 provide an overview of the factors important to mothers in this study when discussing providing HM and receiving HM, respectively. Before participating in HM sharing, mothers must become aware of the practice and must then make a decision about whether or not to participate; this decision is influenced by many contextual factors. These figures highlight the contextual variables important in a mother's decision to participate in HM sharing, and also the most salient motivations for participating in HM sharing.

Discussion

This research extends our knowledge about attitudes toward informal HM sharing by including women who have not previously shared, thus adding their voices to the literature. Although the attitudes of some mothers echoed the 'yuk factor' previously described (137), the majority of attitudes toward HM sharing were positive, with many mothers especially open to the idea of providing HM to others. Mothers were most open to the possibility of sharing HM with people they knew or other people in their community. This type of informal HM sharing is currently understudied as most research on the topic in the U.S. has focused on online HM sharing (107, 108).

Our finding that women who highly value HM but cannot feed their own and have a strong desire to avoid HM substitutes may consider using shared HM is congruent with the findings of others (125, 138). Our finding that family and friends with excess HM may be likely to provide it has also been reported previously (117, 125). Our inclusion of women who had never previously shared HM and the finding that, under certain circumstances, many of them would consider HM sharing is a novel addition to the literature. Given that 25% of women reported considering

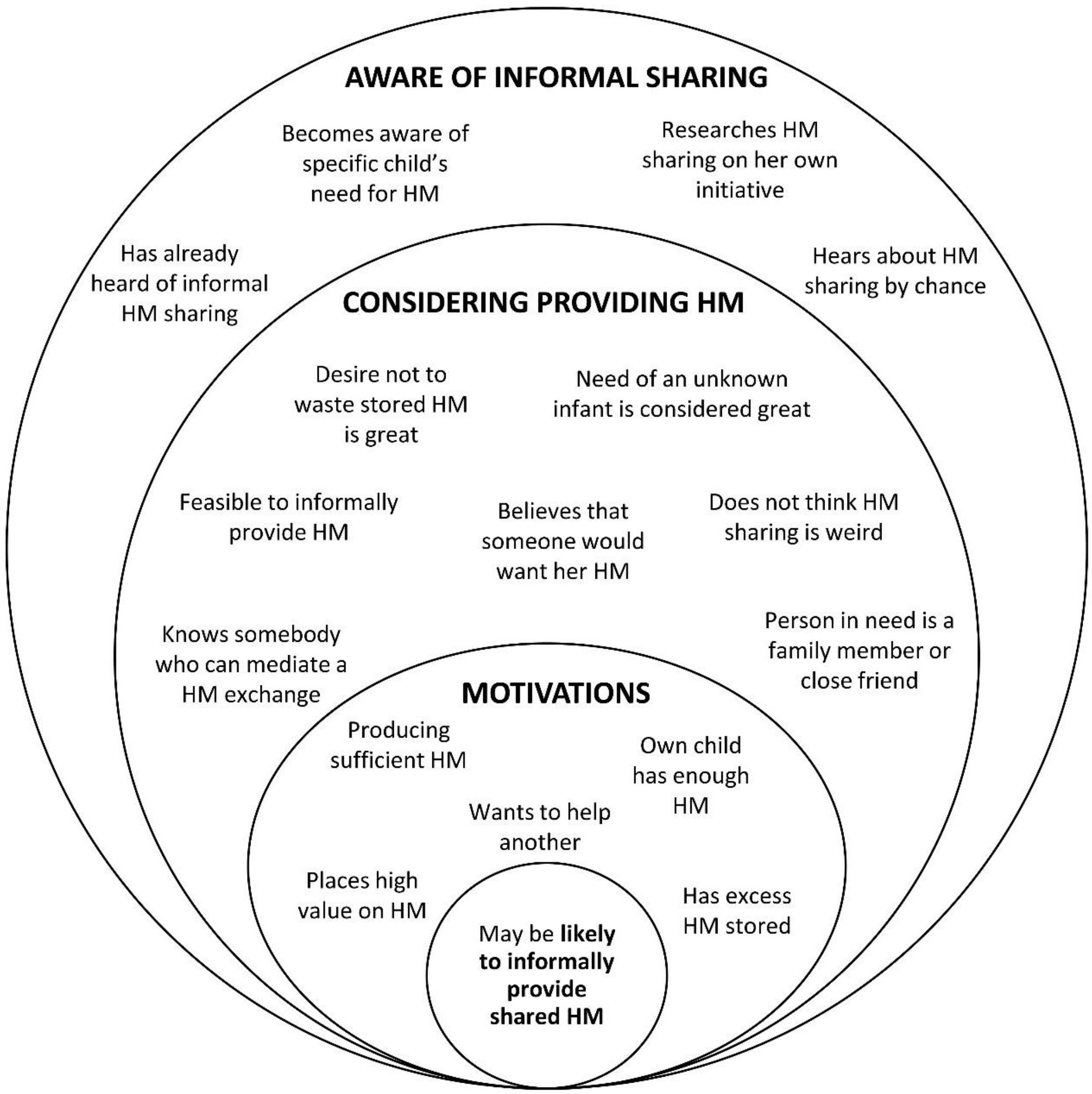

Figure 3.1: Important factors related to informally providing shared human milk, based on data from women who have and have not participated in human milk sharing.

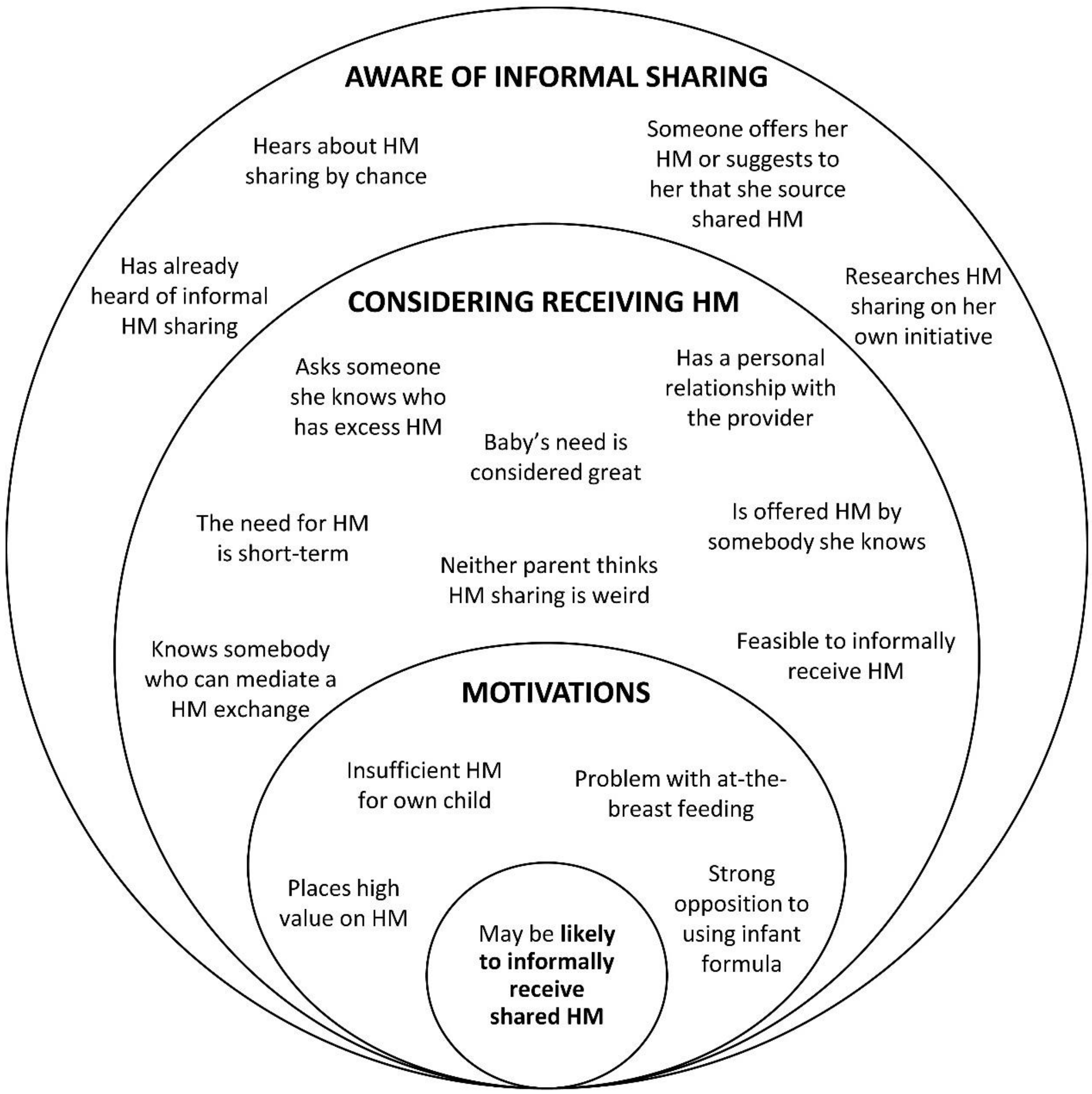

Figure 3.2: Important factors related to informally receiving shared human milk, based on data from women who have and have not participated in human milk sharing.

HM sharing in previous research (109), and that the safety of HM sharing is unknown, it is now even more important that health professionals understand why and how women might informally share HM.

Mothers' concerns about receiving HM primarily focused on the dietary intake and disease status of the potential provider mother, with minimal concern reported about the HM expression and handling practices of potential provider mothers. This is of particular interest because microbial contamination of expressed HM bought online is reported to be high (139), which suggests unhygienic handling of HM. Although these results may represent the "worst-case scenario" (140) for HM sharing, they highlight the need for future research on HM expression and storage, the impact of HM contamination on infant health, and the safety of HM sharing. The unknown safety of shared HM, particularly the potential for disease transmission and HM contamination, is why the FDA recommends against HM sharing (118). The apparent low priority of hygienic HM handling and potential contamination among our respondents is of public health importance and warrants further study.

Our finding of healthcare professionals acting as intermediaries in the informal exchange of HM is of great interest from a public health perspective. One previous researcher reported that "…attitudes of medical doctors [toward HM sharing], as reported by the respondents, were generally positive" (124). Another stated that "for five respondents [HM sharing] was viewed as a logical solution or had been suggested by a health worker" (138). On the other hand, another (122) reported that healthcare professionals had a "risk-focused approach to the concept of sharing body fluids," and were not unanimously supportive of the practice. However, our finding is reminiscent of the historical practice of physicians in the late 1800s and early 1900s sourcing wet-nurses for infants who were not fed by their biological mother (114, 141). These physicians were motivated by a combination of a strong preference for HM and the knowledge that artificial feeding, most often with cow's milk, led to "disastrous results" (141). Although contemporary infant formula is a safer alternative to HM than cow's milk, a strong preference for HM may still motivate some healthcare professionals to mediate informal HM exchanges.

The involvement of healthcare professionals in the contemporary context is interesting because mediating informal HM exchanges is discouraged by some professional organizations (119, 120). It has been suggested that healthcare professionals have a responsibility to inform mothers of all of their options when it comes to infant feeding, including HM sharing, and the benefits and risks of each option (142). However, the experiences of some mothers in this study, where healthcare professionals facilitated HM exchanges, goes beyond information provision. It is important for health professional organizations to be aware of the practices of their members.

Strengths and Limitations

The strengths of this study include its qualitative approach allowing more detail than a survey and letting participants respond with what they deem to be most important, instead of limiting them to the investigators preconceived response options. This study is limited in transferability, like most qualitative investigations, because of the small geographic area from which participants were recruited.

Conclusion

The need for research on the "safety of peer-to-peer milk exchange *as practiced by parents*" (emphasis added) (140) has been recently highlighted. This study adds to the body of knowledge about why and how informal HM sharing is occurring at the community level. We found that mothers were aware of HM sharing in their community, mothers generally had positive attitudes toward the practice, and we identified factors important to mothers when considering HM sharing. Health professionals and those interested in public health should be aware that informal HM sharing is occurring at the community level, so they can be prepared to respond to questions about HM sharing. Health professional organizations also should be aware of the practices of their members in mediating HM exchanges. Additional research is needed to expand on the factors associated with participation in HM sharing and the associated benefits and risks to mothers and infants.

CHAPTER 4

DEVELOPMENT, CONSTRUCT VALIDITY, AND RELIABILITY OF THE CHILD FEEDING SURVEY: A CONTEMPORARY INFANT FEEDING SURVEILLANCE TOOL

Elizabeth J O'Sullivan, Kathleen M Rasmussen

Abstract

Background: The current national breastfeeding surveillance tool in the U.S., the National Immunization Survey, considers the maternal-infant dyad to be breastfeeding for as long as the infant is consuming human milk (HM). However, in the contemporary U.S. many infants are fed HM from a bottle as well as, or instead of, at the breast. Expressed-HM feeding may lead to different health outcomes than at-the-breast feeding. Given this, improved data collection about mode of HM feeding is important.

Objective: To develop a construct-valid and reliable cross-sectional, self-administered, online survey about infant feeding that enables categorization of infants by (i) source of nutrition: own mother's HM, another mother's HM, infant formula or other, and (ii) mode of feeding: at-the-breast or from a bottle.

Design: We developed the Child Feeding Survey (CFS) through a review of the literature and modified it based on formative qualitative research. We assessed construct validity of our survey questions using cognitive interviewing (n = 10) and modified it again based on feedback from participants. We then conducted a test-retest reliability study on the final survey with 39 mothers who completed the survey twice, 1 month apart.

Statistical analyses: Question reliability was assessed using paired equivalence tests with equivalence margins of half a month and one month for continuous variables and weighted Cohen's kappa for ordinal variables.

Results: Reliability of the CFS was high among mothers of infants aged 19 – 35 months, with the majority of continuous variables equivalent to within half a month. Weighted Cohen's kappa for ordinal variables was between 0.71 and 0.82, indicating substantial to almost perfect agreement.

Conclusion: The CFS is a construct-valid tool to measure duration, intensity, and mode of infant HM consumption and duration of maternal HM production that is reliable within 19 – 35 months postpartum. Use of this tool will be essential to establish the impact of HM expression and expressed-HM feeding on maternal and infant health outcomes in future research.

Introduction

Prevalence of any and exclusive breastfeeding in the United States is reported based on responses to four questions on the National Immunization Survey (NIS) that ask solely about infant human milk (HM) consumption (143). These questions do not ask about dyadic at-the-breast feeding behavior. This is important because the majority of breastfeeding mothers in the United States now express HM (16), which is subsequently offered to their child from a bottle. Consequently, national surveillance questions are insufficient for reporting the prevalence of at-the-breast feeding.

Distinguishing between modes of HM feeding in research studies and on national surveillance surveys is important because it is biologically plausible that expressed-HM feeding may result in different infant health outcomes than at-the-breast feeding. Although few studies have been published in which the association between mode of HM feeding and infant outcomes has been explored, bottle-feeding HM has been associated with greater infant weight gain over the first year of life (48), greater bottle-emptying behaviors later in infancy (47), greater incidence of coughing and wheezing (106), and with mothers encouraging their children to eat all the food on their plate later in childhood (50). Given that these data suggest that bottle-feeding HM may have a negative effect on infant health outcomes, data should be collected about specific HM-feeding mode, not just infant HM consumption. Prior published studies suggest that this is an important research question.

The need to distinguish between infants fed directly at the breast and those fed expressed HM has been emphasized in the literature (86, 87, 144, 145) and several recent publications have called for the development of new definitions for HM feeding and the consistent use of these definitions in national surveillance and research (85-87, 144, 146-148). Following their commentary questioning the breastfeeding definitions currently used by researchers (87), in 2014 Noel-Weiss *et al*. published a description of a survey that they developed to measure patterns of infant feeding for breastfeeding research (88). Their survey is administered by a research assistant—in person or over the phone—and asks about both what an infant consumed (e.g. HM, formula, solid food) and how the infant was fed (e.g. at the breast, from a bottle) in the previous 24 hours or the previous 7 days (88). The authors recommend that this tool be used to measure patterns of infant feeding prospectively over time (88), with the number of data collection time points determined by the researchers depending on their research question.

Prior to the publication of the survey developed by Noel-Weiss and colleagues (88), in 2010 Geraghty and Rasmussen (14), proposed, but never tested, alternative questions for collecting data about HM feeding for surveillance purposes. These questions were created to measure the initiation and cessation of at-the-breast feeding and expressed-HM feeding separately, and asked about maternal and infant behaviors since birth.

We have taken the work of Geraghty and Rasmussen (14) further by modifying, adding to, and testing the questions previously proposed. Here we report the development, construct validity assessment, and reliability testing of the Child Feeding Survey (CFS). The CFS is a cross-sectional, self-administered, online infant feeding survey developed for surveillance purposes that enables categorization of infants by (i) source of nutrition: own mother's HM, another mother's HM, infant formula or other, and (ii) mode of feeding: at-the-breast or from a bottle.

Methods

This study consisted of three phases: survey development, construct validity testing, and reliability testing. All phases of this research were approved by Cornell University's Institutional Review Board.

Survey development and face validity

To expand on the set of questions proposed by Geraghty and Rasmussen (14) (**Table 4.1**), we conducted exploratory, semi-structured qualitative interviews with mothers of infants aged 19 – 35 months. Our aim was to understand how mothers with infants of a similar age to those who are sampled by the NIS spoke about HM feeding, and the range of HM-feeding behaviors they practiced. The methods for this qualitative study are described elsewhere in more detail (Chapters 2 and 3; Appendices A and B). Briefly, interviews took place between August 2012 and June 2014 and covered a range of topics related to at-the-breast feeding and expressed-HM feeding and mothers were probed for additional information. We reviewed interview transcripts and modified the survey questions developed by Geraghty and Rasmussen (14) based on language used by mothers in this qualitative study. We also added questions about behaviors that were not covered by the Geraghty and Rasmussen (14) survey. Before assessing the construct validity of this survey, we elicited feedback on our questions from HM-feeding researchers, a clinician, and a Certified Lactation Counselor.

Construct validity

In survey research, construct validity refers to how well "whatever is purported to be measured actually has been measured" (149). Cognitive interviewing can assess construct validity as it

Table 4.1: Questions proposed by Geraghty & Rasmussen (14) to more accurately define human milk feeding initiation and cessation

<table>
<tr><th></th><th colspan="6">Day of life / day postpartum of</th></tr>
<tr><th></th><th colspan="3">Initiation of feeding options</th><th colspan="3">Cessation of feeding options</th></tr>
<tr><th>Action</th><th>At breast</th><th colspan="2">Hand-expressed/pumped</th><th>At breast</th><th colspan="2">Hand-expressed/pumped</th></tr>
<tr><td>Breastmilk extraction by mother</td><td rowspan="2">How many days old was [child’s name] when [mother’s name] first fed him/her directly at the breast?</td><td colspan="2">On what postpartum day did [mother’s name] first begin to hand-express or pump her milk?</td><td rowspan="2">How many days old was [child’s name] when [mother’s name] stopped feeding him/her directly at the breast?</td><td colspan="2">On what postpartum day did [mother’s name] stop expressing or pumping milk from her breasts?</td></tr>
<tr><td>Breastmilk consumption by child</td><td colspan="2">How many days old was [child’s name] when he/she was first fed any of (his/her) mother’s hand-expressed or pumped breastmilk?</td><td colspan="2">How many days old was [child’s name] when he/she was no longer fed any of (his/her) mother’s expressed or pumped breastmilk?</td></tr>
<tr><th></th><th>Another mother’s milk</th><th>Formula</th><th>Juice/water</th><th>Another mother’s milk</th><th>Formula</th><th>Juice/water</th></tr>
<tr><td>Breastmilk substitute consumption by child</td><td>How many days old was [child’s name] when (he/she) was first fed another mother’s breastmilk?</td><td>How many days old was [child’s name] when (he/she) was first fed formula?</td><td>How many days old was [child’s name] when (he/she) was first fed anything other than breastmilk or formula (i.e., juice water)?</td><td>How many days old was [child’s name] when (he/she) was no longer fed another mother’s breastmilk?</td><td>N/A</td><td>N/A</td></tr>
</table>

involves administering a draft version of the survey questions, eliciting responses to questions, and collecting additional information from respondents about the questions and how they selected their response (150). This helps the investigator ensure that the questions are eliciting the intended data (150). Between September and December 2014, we conducted cognitive interviews among a sample of 10 mothers of children aged 19 – 35 months to assess the construct validity of our modified survey. The goal of our cognitive interviews was to identify (i) questions that were unclear or contained inappropriate wording, and (ii) problematic survey layout or question order. We recruited mothers through a local social service agency, by word-of-mouth, snowball sampling, and through a mother and baby listserv (Appendix C).

The first author met women at a location of their choice, typically their home or a local café. She explained that we were trying to improve survey questions and were interested in hearing about any problems mothers encountered when taking the survey or any feedback they may have about making the questions easier to answer. Participants then provided informed consent and proceeded to take the online survey on a laptop. The survey typically took 10 minutes to complete (range 9 – 13 minutes). After participants completed the survey, we used retrospective verbal probing (151) to learn more about question comprehension, information retrieval, decision making, and confidence in responses. Following an interview guide (Appendix D), we probed participants about each question to assess whether it was understood as intended. All interviews were audio-recorded with informed consent and we compensated participants with $20 cash. The cognitive interviewing process was iterative and modifications were made to the survey after 2 interviews, and again after 3 additional interviews. After these 5 interviews, none of the participants had reported experience with HM sharing and had, thus, automatically skipped questions on the survey about sources of shared HM. As such, these questions were cognitively tested with the next 5 participants at the end of the process described above, even though only one had experience of providing or receiving shared HM. The final round of 5 interviews resulted in only very minor modifications to the survey, and cognitive interviewing ceased.

Survey reliability

The final, construct-valid CFS was administered online to a sample of ~500 women as part of a larger study; a subsample completed the survey twice between March and May 2015 to assess reliability. Participants were recruited through ResearchMatch, a non-profit organization that matches researchers with volunteers interested in research (152). We asked participants in the larger study at the end of the survey if they would be willing to complete it again in one month's time. Those that opted to complete the survey a second time were sent it again by email one month after their first completion date. We provided participants with a $5 electronic gift card each time they completed the survey.

Statistical analysis

Paired equivalence tests were used to establish equivalence of continuous responses to questions administered one month apart to examine reliability. Continuous variables were considered equivalent if they did not differ by half a month in either direction. Variables that were not equivalent at the half a month equivalence margin were tested with an equivalence margin of 1 month. We chose to study equivalence margins of half a month and 1 month as recommendations for HM feeding are given in months and prevalence of HM feeding is most often reported in months. Thus, we assume that these equivalence margins will be meaningful to those involved in collection of national HM-feeding statistics. Previous investigators have also used these margins for assessing reliability of infant feeding practices (153, 154). For the reliability analysis, we considered 1 month to be equal to 30.44 days (365.25 days in 1 year divided by 12), and all variables were converted into days, though mothers had the option to report in days, weeks or months. A weighted Cohen's kappa coefficient was used to assess reliability of ordinal responses. A kappa value of 0 – 0.2 indicates slight agreement, 0.21 – 0.4 indicates fair agreement, 0.41 – 0.6 indicates moderate agreement, 0.61 – 0.8 indicates substantial agreement, and 0.81 – 1 indicates almost perfect agreement (155). Analyses were conducted with SAS software (version 9.3; SAS Institute).

Results

Based on qualitative and cognitive interviews, we modified the Geraghty and Rasmussen survey (14) by modifying existing questions and adding new ones.

<u>Qualitative interviews</u>

Question modification: Based on qualitative interviews, we modified questions to use the child's age as a reference for maternal behaviors (Appendix E). Previous questions (14) used the phrase "[o]n what postpartum day…" to ask about the initiation and cessation of maternal behaviors. However, during qualitative interviews mothers used phrases like "I probably started pumping around, when my son was around 4 weeks old…" or "Um, the first time I pumped, I, I remember that the first time I left him, he was 4 months old. And I, I think it was probably around that time…" or "I stopped expressing at um, after Christmas of the second year so when he was 21 months…" For this reason, we used a consistent format for our questions, always asking "[h]ow old was [child] when [behavior of interest started or stopped]" regardless of whether questions were about infant or maternal behaviors.

Question addition: Based on data from qualitative interviews, we added questions about the frequency of maternal HM expression and infant HM feeding (Appendix E). The aim of these questions was to distinguish mothers who expressed and fed expressed HM rarely from those who did so more frequently. Mothers in our qualitative interviews often described HM expression and expressed-HM feeding as episodic behaviors; thus, simply asking about the initiation and cessation of expressed-HM feeding is insufficient to describe the intensity of expressing and bottle-feeding HM.

Additionally, for mothers who provided their infant with another mother's HM, we included questions about the source of shared HM. These questions attempt to distinguish between receiving HM from a milk bank and the informal HM sharing that may occur between family, friends, community members or online.

<u>Cognitive interviews</u>

An online version of the survey developed based on qualitative interviews was created using Qualtrics software. We used this version of the survey to assess construct validity and usability via cognitive interviews. This resulted in another round of question modification and addition.

Question modification: This survey was originally conceptualized to be administered to the primary caregiver of infants aged 19 – 35 months, mimicking the sampling strategy of the NIS.

However, after conducting 2 cognitive interviews we decided to only administer our survey to mothers. The version of the survey created based on qualitative interviews was in a format that could be completed by a father or other non-maternal caregiver and questions asked about when a child was first fed “his/her mother’s breast milk.” The phrase “his/her mother” was replaced throughout with “your” when we made the decision to administer the survey to mothers only.

All questions related to the starting and stopping of maternal and infant behaviors were modified to begin with the question stem: “If day 0 is the day [child] was born, how old was [child] when [behavior of interest started or stopped].” This is because respondents replied with 0 or 1 day to mean the infant’s first day of life, depending on their personal preference. This would be problematic if someone first fed their child at the breast on the child’s second day of life and replied “1 day” to this question as they considered day 0 to be the first day of life.

Questions about timing of starting and stopping maternal HM expression went through several iterations. As these behaviors are often episodic, some participants had difficulty when asked about the “first” time they expressed HM. Mothers described trying it in the hospital or early in infancy but not actually expressing regularly until a later date. When the words “started” and “stopped” were used, mothers typically interpreted this to mean when they started and stopped expressing regularly, as opposed to the very first instance. We wanted to elicit information on regular behaviors so we retained the words “started” and “stopped” in questions about initiation and cessation of maternal HM expression. In responding to the question about frequency of maternal HM expression, mothers described their answer as an average of their behavior over the whole time they were expressing.

The question about introduction of foods and liquids other than breast milk or formula also went through several iterations. We simplified the more detailed NIS question to "How old was [child] when he was first fed anything other than HM or formula." However, when answering this question some mothers only responded about other liquids that the child was fed, and did not think about foods. As such, the question was modified to the final version: "If day 0 is the day [child] was born, how old was he when he was first fed any foods or liquids other than breast milk or formula?"

Finally, questions asking about feeding another mother's HM originally asked about "another woman's breast milk." Participants in cognitive interviews found the use of the word "woman" strange and impersonal in this context, so it was modified to "another mother's breast milk."

Question addition: Two out of ten cognitive interview participants requested a question about the cessation of infant formula feeding. They were frustrated that they were unable to indicate that their child only received infant formula for a short period of time (< 3 days). We decided that it was important to include a question about cessation of formula feeding for participant satisfaction, and we also considered it an important variable to measure as it may help get a better estimation of an infant's total dose of HM feeding.

Finally, during cognitive interviews some mothers were eager to explain some of their responses to the infant feeding questions. Although we didn't plan on collecting free-text, explanatory, comments in our larger study a priori, we included a text box at the end of the survey asking mothers if they had any additional comments or feedback.

Reliability study

Fifty-two participants completed the final version of the CFS (Appendix E) twice, and a total of 39 were included in the final analysis for the reliability study (**Figure 4.1**). We excluded participants who reported a different gender or date of birth for their infant on the second iteration of the survey (n = 7), under the assumption that they were completing the survey solely to receive the incentive. The suspicion that some participants were perhaps fabricating responses prompted us to conduct internal consistency checks to assess whether other participants' responses were suspicious or implausible. These checks highlighted several participants with large discrepancies in the timing of initiation and cessation of maternal or infant behaviors between the two iterations of the survey. We excluded participants if the timing of initiation or cessation of 3 behaviors differed by ≥ 60 days between the two iterations of the survey (n = 3). We also excluded participants if they reported participating in a behavior (e.g. maternal HM expression) and provided details about the initiation and cessation of that behavior on one survey, but said that they never participated in the behavior on the other survey (n = 6). Finally, we excluded one participant who reported stopping a behavior before starting it. In total, 13 participants were excluded.

The final sample was predominantly white, married, and well-educated (**Table 4.2**). Reliability of the survey was high, with the majority of continuous variables equivalent to within half a month (**Table 4.3**). Those that were not equivalent to within half a month were equivalent to within 1 month, except for timing of last consuming another mother's HM (Table 4.3). Weighted Cohen's kappa for ordinal variables related to what the infant was consuming at 3, 6, and 12 months were between 0.71 and 0.77, indicating substantial agreement (**Table 4.4**). Weighted

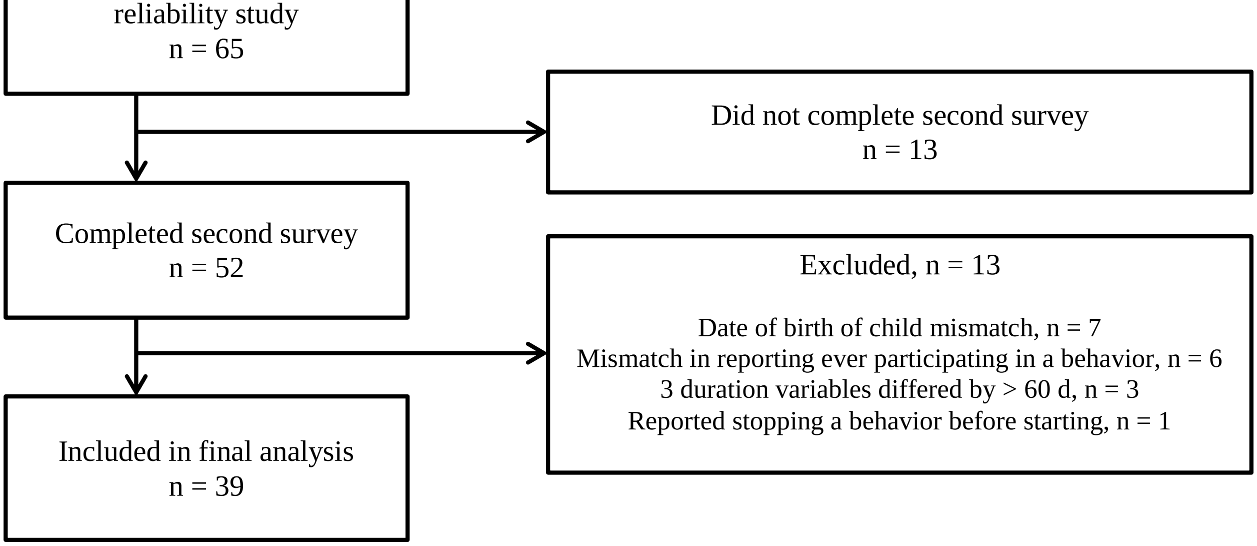

Figure 4.1: Flow chart of participants in the reliability testing of the Child Feeding Survey

Table 4.2: Demographic characteristics of reliability study participants, n = 39

Characteristic [a]	**n (%)**
Maternal age	
Less than 25	1 (2.6)
25 – 29	10 (25.6)
30 – 34	11 (28.2)
35 – 39	13 (33.3)
40 or older	4 (10.3)
Infant age, mo [b]	
< 24 months	7 (18)
24 – 30 months	19 (48.7)
> 30 months	13 (33.3)
Maternal education	
High school or less	2 (5.1)
Some college	4 (10.3)
Associate degree	4 (10.3)
Bachelor’s degree	12 (30.8)
Master’s degree	9 (23.1)
Doctorate	8 (20.5)
Maternal BMI	
Underweight	3 (7.7)
Normal-weight	16 (41)
Overweight	12 (30.8)
Obese	8 (20.5)
Ethnicity	
Hispanic/Latino	4 (10.3)
Non-Hispanic	35 (89.7)
Race	
White	36 (92.3)
Black or African American	1 (2.6)
Asian	2 (5.1)
U.S. residence region	
Northeast	3 (7.7)
Midwest	16 (41)
South	13 (33.3)
West	7 (18)
Timing of postpartum return to full-time work	
Did not return to work	5 (12.8)
Returned to work part-time only	9 (23.1)
Less than 6 weeks	3 (7.7)
More than 6 weeks less than 3 months	5 (12.8)
More than 3 months less than 6 months	14 (35.9)
Greater than 1 year	3 (7.7)

Marital status	
Married	37 (94.8)
Not married	2 (5.2)
WIC participation	
Yes	6 (15.4)
No	33 (84.6)

Table 4.3: Paired equivalence tests for survey questions with continuous responses

Construct measured:	*Mean (90% CI) difference in days reported*	*Assessment at equivalence margin of ½ month*	*Assessment at equivalence margin of 1 month*
Dyad first fed at the breast	-0.12 (-0.26, 0.02)	Equivalent	Equivalent
Dyad last fed at the breast	-3.6 (-9.8, 2.5)	Equivalent	Equivalent
Mother started expressing	1.9 (-1.5, 5.4)	Equivalent	Equivalent
Mother stopped expressing	11.6 (0.14, 23.1)	Not equivalent	Equivalent
Infant first fed expressed HM	3.12 (-2.7, 9)	Equivalent	Equivalent
Infant last fed expressed HM	0.06 (-11.3, 11.4)	Equivalent	Equivalent
Infant first fed formula	2.5 (-1.7, 6.7)	Equivalent	Equivalent
Infant last fed formula	0.92 (-14, 15.8)	Not equivalent	Equivalent
Infant first fed shared HM (n=3)	5.8 (-8.3, 20)	Not equivalent	Equivalent
Infant last fed shared HM (n=3)	14.9 (-9.3, 39.2)	Not equivalent	Not equivalent
Infant first fed food/liquids other than breast milk or formula	-11.1 (-28, 5.8)	Not equivalent	Equivalent

Table 4.4: Reliability of survey questions with ordinal responses

Construct measured	*Weighted Cohen's kappa*
Frequency of maternal HM expression	0.8
What infant was consuming, 3 months	0.73
What infant was consuming, 6 months	0.71
What infant was consuming, 12 months	0.77
Proportion of HM consumed at the breast, 3 months	0.8
Proportion of HM consumed at the breast, 6 months	0.81
Proportion of HM consumed at the breast, 12 months	0.82

Cohen's kappa for ordinal variables related to frequency of maternal HM expression and the proportion of HM that was fed to the infant at the breast were between 0.80 and 0.82, indicating almost perfect agreement (Table 4.4).

Discussion

We have developed a construct-valid and reliable survey to measure duration, intensity, and mode of infant HM consumption, duration of infant formula consumption, incidence of infant consumption of another mother's HM, and duration of maternal HM production. Test-retest reliability of our survey was high when questions were repeated 1 month after the first administration within a follow-up period of 19 – 35 months and most responses to continuous questions about timing of initiation and cessation of maternal and infant behaviors were equivalent to within half a month. Only 1 question was not equivalent to within 1 month. It asked about when the infant stopped consuming another mother's HM. Our sample size for this question was low (n = 3), which likely reduced our power to detect significance. However, incidence of ever feeding another mother's HM was consistently and reliably captured by the survey.

The only question with a continuous response that was not equivalent at the half-a-month margin was a question about the timing of maternal cessation of HM expression. As described separately, HM expression can be an episodic behavior (Chapter 2) and even though we tested this question using cognitive interviews, it remains possible that not all mothers interpret this question in the same way. Mothers may have responded with the time they stopped expressing regularly, the last time they expressed and provided the HM to their infant or the last time they expressed HM to relieve engorgement. It's possible that these times are all different, which would impact the reliability of this question. Future investigators should be aware of the difficulties of measuring episodic behaviors and should test their survey questions to ensure they measure the intended constructs.

Timing of introduction of complementary foods was also equivalent to within 1 month, but not half a month. Timing of introduction of complementary foods has been shown by other investigators (153, 154) to be less accurately recalled than timing of cessation of breastfeeding. The final variable that was equivalent to within 1 month, but not half a month, was timing of cessation of infant formula feeding. To our knowledge, reliability of recall of this question has not been tested by other investigators. We speculate that this indicator was less reliably recalled because it is a less memorable event for the mother as infant formula feeding may be gradually substituted with cow's milk or other complementary foods. When we looked at reliability of these questions among mothers with younger infants and thus, a shorter recall period, responses were still not equivalent to half a month, but were equivalent to within 1 month.

We are not the first investigators to develop a contemporary infant feeding measurement tool. In response to the deficiencies they previously highlighted in the literature (87), Noel-Weiss and colleagues also developed a tool to measure infant feeding patterns more accurately (88). This work was published in 2014 (88), after the majority of our research had been completed. However, although their overall goal was similar to ours, in that they aimed to develop questions that could produce feeding categories that would include type, amount, and mode of feeding, their focus was on a tool that could be used in research settings (88). There is a high burden involved on the part of a researcher to collect data using their tool—including repeated phone calls to currently breastfeeding mothers to ask about infant intake in the previous 24 hours or 7 days—likely making it inappropriate for infant feeding surveillance.

This research is novel in that it reports development of a survey to measure prevalence of HM-feeding behaviors for the purpose of infant feeding surveillance. Many published reports about the development, validity, and reliability of HM-feeding surveys have focused on attitudes toward (156, 157), maternal self-efficacy surrounding (158, 159) or maternal experiences with (102) HM feeding. Our research goal to develop construct-valid and reliable questions that measure contemporary maternal and infant behaviors more accurately is timely given the shift in infant feeding practices away from the dichotomy of breastfed *v*. bottle-fed with the inclusion of the hybrid behavior—bottle-feeding expressed HM (16, 44).

The main strength of this study is the extensive development and testing of the final survey. This survey went through several iterations before the final version. We obtained input from leaders in the field of HM-feeding research, a clinician, Certified Lactation Counselors, and experienced HM-feeding mothers to develop the survey.

A limitation of this research was the number of participants excluded from the reliability analyses (25%, n = 13). This reduced sample size may have limited our power to declare some of our variables equivalent at the half-a-month margin. Another limitation of this research is that only one participant who had participated in HM sharing that had a chance to review these questions at the cognitive interview stage. It was difficult to recruit specifically for this activity so most cognitive interview participants had no experience of HM sharing. To overcome this limitation, 5 cognitive interview participants were asked to review all questions about HM sharing and offer their feedback and advice even though they had never shared HM with another mother. Few participants in the reliability study had also fed their infant another mother's HM (n = 3). This reduced our power to test the equivalence of responses to questions about initiation and cessation of feeding another mother's HM.

Conclusion

The tool we have developed may be useful to researchers retrospectively exploring the associations between HM expression and expressed-HM feeding and maternal and infant health outcomes. Depending on their specific research questions, investigators may consider drawing upon this bank of construct-valid and reliable questions in their research. More detailed measurement of HM-feeding behaviors is also clinically important because it is unclear whether the many known benefits of HM feeding result from the composition of HM, the mode of delivery of this milk or a combination of these two. Currently, physicians, dietitians, nurses, and lactation consultants have no evidence-based response to the common query: "Can't I just pump my milk and feed it to my baby from a bottle? What difference does it make?" Before clinicians can answer this question, careful study of the possible benefits and/or risks associated with HM expression and expressed HM feeding—behaviors that are understudied given their high prevalence in the population—is warranted. Appropriate measurement of HM-feeding mode is essential to such research.

CHAPTER 5

DISTINGUISHING BETWEEN FEEDING HUMAN MILK AT THE BREAST AND FROM A BOTTLE: COMPARISON OF NEW HUMAN MILK-FEEDING SURVEILLANCE QUESTIONS TO CURRENT NATIONAL SURVEILLANCE QUESTIONS

Elizabeth J O'Sullivan, Sheela R Geraghty, Patricia A Cassano, Kathleen M Rasmussen

Abstract

Background: Maternal human milk (HM) production and infant HM consumption are no longer necessarily synchronous behaviors because most mothers express HM and it is bottle-fed to their infants. However, infant HM consumption is the sole emphasis of questions on the U.S. annual National Immunization Survey (NIS) used for national breastfeeding surveillance. We hypothesized that more than 50% of infants who are classified as breastfed at 3, 6, and 12 months by the NIS questions would also be receiving HM from a bottle.

Methods: A convenience sample of 451 adult mothers of infants aged 19 – 35 months recruited through ResearchMatch.org completed a cross-sectional, online survey about infant feeding. The survey consisted of the NIS questions and new, more detailed questions about infant feeding mode.

Results: Based on responses of women in our sample to the NIS questions, breastfeeding prevalence at 3, 6, and 12 months was 73%, 63%, and 39%. Based on responses to our new questions, most (93.9%) HM-feeding women expressed their milk at some point. At 3, 6, and 12 months of age at least 70% of infants who consumed HM were consuming at least some HM from a bottle.

Conclusions: Not including mode of feeding on national breastfeeding surveillance surveys does not capture the complexity of contemporary infant feeding practices. Future research and national surveillance should include consider including measures of expressed-HM feeding, and maternal HM expression to enable researchers to explore infant outcomes associated with expressed HM-feeding.

Introduction

It is well established that bottle-feeding infant formula is associated with worse infant outcomes (3, 5) than at-the-breast feeding. This knowledge informs the continued national promotion of breastfeeding (2). However, with the availability of efficient breast pumps, the simple classification of infants as "breastfed" or "bottle-fed," with bottles containing infant formula, is no longer appropriate (44). With ~62% of mothers of children under 3 in the United States (U.S.) working outside the home (160), it is not surprising that a significant proportion of mother's human milk (HM) is now expressed and fed from a bottle (16, 38, 40). This expressed HM may have been refrigerated or frozen and it is typically fed to the infant by someone other than the mother (96). Reports from a recent survey also indicate that a small proportion of infants are fed another mother's HM from a bottle (109), further highlighting the complex landscape of HM-feeding in the U.S.

Despite this complexity, the tool used by the Centers for Disease Control and Prevention (CDC) to report national breastfeeding prevalence only asks about infant consumption of HM. This national breastfeeding surveillance tool is the National Immunization Survey (NIS), which has contained questions specifically designed for monitoring breastfeeding prevalence since 2001 (46). On this survey, breastfeeding duration is determined by responses to the question "[h]ow old was [child] when [child] was last breastfed or fed breast milk?" The questions do not ask about the mode of HM-feeding or who is feeding the baby. The CDC use the NIS questions to report national breastfeeding prevalence for both mothers and infant. Thus, a mother-infant dyad is considered to be breastfeeding for as long as the infant is consuming HM. This may have been a reasonable assumption before efficient breast pumps were affordable and accessible to many women; however, given the widespread use of breast pumps (16), maternal HM production and infant HM consumption are no longer necessarily synchronous behaviors. Moreover, the word "breastfeeding" is too simple to describe contemporary infant HM feeding practices. The importance of standardized definitions of breastfeeding behaviors for the purpose of research and surveillance has been repeatedly emphasized over the past two decades (46, 85, 87, 146), with several researchers specifically calling for indicators that distinguish between at-the-breast feeding and expressed-HM feeding (85, 87, 161). While this dissertation research was ongoing, another group of researchers (88) published a description of a tool that distinguishes between at-the-breast feeding and expressed-HM feeding that they developed to collect infant feeding data prospectively from mothers. However, their tool (88) was not designed to collect retrospective data about infant feeding from birth, as is desirable for the purpose of surveillance.

Inconsistent use of breastfeeding definitions across studies reduces researchers' ability to infer causality for a link between an exposure (e.g. exclusive breastfeeding) and an outcome of interest, and it also impedes researchers' ability to perform meaningful comparisons between studies that have defined the exposure to HM differently. This is especially important in the case of expressing and bottle-feeding HM because recently published data associated expressed-HM feeding with higher infant growth velocity during the first year of life (48, 162), higher risk of wheezing and coughing (106), lower satiety responsiveness in children (52), and less desirable maternal feeding styles and children's eating behavior at 6 years postpartum (50). Given that data suggest that HM feeding mode is related to infant health outcomes, understanding the limitations of the ways infant HM exposure is currently defined is an important epidemiological concern.

The aims of this research were twofold. The primary aim was to compare new HM-feeding questions, which include indicators for HM expression and expressed-HM feeding, with national surveillance questions (NIS) that do not distinguish between feeding HM at the breast and feeding HM from a bottle. Based on data from the IFPS II (16), 58% of HM-feeding mothers expressed HM in the 2 weeks prior to the postpartum month 5 survey. Thus, we hypothesized that more than 50% of infants who are classified as breastfeeding at 3, 6, and 12 months by the current (NIS) national breastfeeding prevalence questions will also be receiving HM both directly at the breast and from a bottle.

Second, we aimed to explore additional behaviors of public health significance about which data are not currently collected by national surveillance systems, namely the discordance between the duration of maternal HM production and infant HM consumption, timing of cessation of infant formula consumption (only initiation is measured), infants receiving HM from another mother, and mothers providing HM to another infant.

Methods

Data collection

Between March and July 2015, we conducted a cross-sectional, self-administered survey that included both the NIS breastfeeding prevalence questions, new HM-feeding questions (the Child Feeding Survey; CFS, Appendix E) that were developed to elicit information about HM fed at the breast and HM fed from a bottle since birth, and demographic questions. Development, construct validity, and reliability of the CFS is described elsewhere (Chapter 4).

Our new questions (Appendix E) asked about the initiation and cessation of at-the-breast feeding, maternal HM cessation, expressed-HM feeding, infant formula feeding, feeding of another mother's HM, and the timing of introduction of foods or liquids other than HM or infant formula. For questions that asked about timing of initiation and cessation of maternal expressing and infant feeding behaviors, mothers were offered the opportunity to answer in days, weeks, months or some combination of these. The timing of initiation and cessation of expressing and feeding behaviors were then recorded in days for analyses. We also asked mothers a categorical question about the proportion of HM that their infant consumed from a bottle at 3, 6, and 12 months postpartum. Response options to this question about mode of HM-feeding at different times were "only at the breast," "mostly at the breast, some from a bottle," "half at the breast, half from a bottle," "some at the breast, mostly from a bottle," and "only from a bottle." This set of new questions included a prompt encouraging mothers to think carefully about their responses and to try to report as accurately as possible.

Participants were recruited through ResearchMatch, a national health volunteer registry that was created by several academic institutions and supported by the National Institutes of Health as part of the Clinical Translational Science Award program (152). We contacted all women in the registry aged between 18 and 50 years with a recruitment message indicating that we were recruiting mothers of children aged 19 – 35 months to participate in a survey about infant and child feeding. Those who were interested in participating clicked a link in the email indicating their interest; this allowed ResearchMatch to release their contact details to the investigators. Mothers were then sent a personalized link to the survey. The first page of the survey explained the purpose of the study in detail and respondents were informed that participation was voluntary and confidential. Respondents read the consent information and clicked a button labeled "I AGREE" to begin the survey. Proceeding to complete the survey was considered participant's consent to participate in this research. Participants were compensated with a $5 electronic gift card for their time, which was emailed to them within 24 hours of survey completion. This protocol was approved by Cornell University's Institutional Review Board.

Sample

The survey was completed by a convenience sample of 496 women over 18 years old with children aged 19 – 35 months. The child's age range was chosen to mimic the sampling strategy of the NIS. All mothers were eligible to participate, whether they ever fed HM or not. The survey was only offered in English. We chose our sample size to estimate the population prevalence of a rare behavior, feeding an infant another mother's HM. Based on a survey conducted among Ohio mothers (109), we expected that the population prevalence of HM sharing would be ~4%. Using this as the assumed true prevalence, we calculated that we would need 464 subjects to estimate the true prevalence of feeding infants another mother's HM with a confidence of 95% and precision of 5%.

Data cleaning and variable creation

Implausible and logically impossible responses to questions about infant feeding and demographic questions were modified or removed during data cleaning. In some cases (n = 9 for feeding questions, n = 1 for demographic questions), implausible responses appeared to be typographical errors based on responses to other questions in the survey; these values were manually altered to the likely correct response. In cases where there was no obvious correct response (n = 1 for feeding questions, n = 12 for demographic questions), these values were set to missing.

Internally inconsistent participants were identified in 3 ways. First, participants who indicated that they stopped a behavior (e.g. expressing HM) before they started it (n = 20). Second, participants who reported continuing a feeding behavior for longer than their child had been alive (n = 4). Third, participants whose responses were inconsistent across the two versions of survey (the NIS questions and the CFS questions) they completed (n = 4). These participants were excluded from analyses.

The continuous responses to questions about initiation and cessation of maternal expressing and infant feeding were used to create dichotomous variables to indicate whether the mother-infant dyad was at-the-breast feeding, whether the mother was expressing HM, and whether the infant was consuming expressed HM at 3, 6, and 12 months.

Data analysis

To test our hypothesis, we calculated the proportion of infants who were consuming HM at 3, 6, and 12 months, regardless of mode of consumption, using responses to the NIS questions. We also calculated the proportion of infants who were exclusively consuming HM at 3 and 6 months using responses to the NIS questions. These proportions were compared with responses to the CFS questions that clearly distinguish between at-the-breast feeding and expressed-HM feeding. This allowed us to (i) explore the detailed information about HM feeding that is not routinely collected by the national breastfeeding surveillance questions, and (ii) explore the prevalence and intensity of expressed-HM feeding among a national sample.

The discordance between the duration of maternal HM production and infant HM consumption, the timing of cessation of infant formula consumption, and the prevalence and routes of HM sharing were all explored using descriptive statistics. All analyses were conducted using SAS version 9.3 software (SAS Institute, Inc., Cary, NC).

Results

The survey was completed online by 496 mothers (**Figure 5.1**). Participants who had questionable responses based on the reliability study (Chapter 4) were excluded from analyses (n = 13). Participants who had questionable responses discovered during data cleaning (n = 28) were also excluded from the final analyses. Finally, participants who provided demographic information but did not complete any questions about infant feeding (n = 4) were excluded. Thus, final analyses include 451 participants with complete information on at-the-breast feeding, maternal HM expression, and infant HM consumption.

The majority of mothers in this sample were white, non-Hispanic, 30 years of age or older, married, normal-weight, had at least a bachelor's degree, and had infants who did not participate in WIC (**Table 5.1**). Although we aimed to recruit mothers of infants aged between 19 and 35 months old, the final sample included some infants younger than 19 months (~4%) and some older than 35 months (~13%).

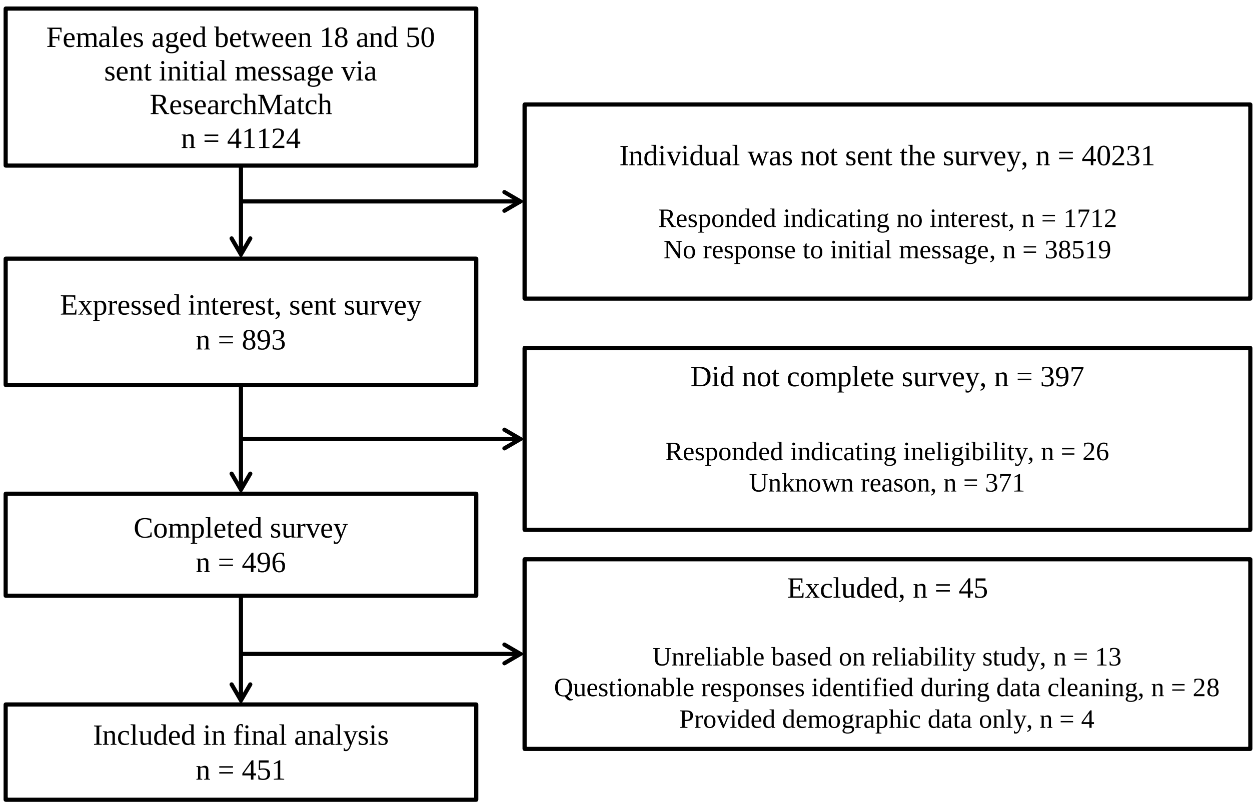

Figure 5.1: Flow chart of participants in the Child Feeding Survey, 2015

Table 5.1: Demographic characteristics of participants in the Child Feeding Survey 2015, total n = 451

Characteristic	Number (%)
Maternal age, y	
< 30	127 (28.2)
≥ 30	324 (71.8)
Infant age, mo [b]	
< 19	19 (4.2)
19 – 24	107 (23.7)
24 – 30	152 (33.7)
31 – 35	116 (25.7)
> 35	57 (12.6)
Maternal education [b]	
Less than bachelor's degree	138 (30.6)
Bachelor's degree or higher	313 (69.4)
Maternal BMI [b, c], kg/m^2	
< 18.5 (underweight)	15 (3.3)
18.5 – 24.9 (normal-weight)	192 (42.6)
25 – 29.9 (overweight)	129 (28.6)
≥ 30 (obese)	115 (25.5)
Ethnicity	
Hispanic/Latino	27 (6)
Non-Hispanic	424 (94)
Race	
White	382 (84.7)
Black or African American	47 (10.4)
Other	22 (4.9)
U.S. residence region [b]	
Northeast	54 (12.1)
Midwest	160 (35.7)
South	165 (36.8)
West	69 (15.4)
Returned to work postpartum	
No	77 (17.3)
Yes, part-time only	91 (20.5)
Yes, full-time	277 (62.2)
Marital status [b]	
Married	354 (78.5)
Not married	97 (21.5)
Index child was adopted [a]	
Yes	6 (1.3)
No	445 (98.7)
Number of children mother has given birth to [b]	
1	196 (45)
> 1	240 (55)
Infant ever participated in WIC [c]	
Yes	117 (25.9)
No	334 (74.1)

[a] Based on participant-initiated self-report
[b] At survey completion
[c] BMI, body mass index; WIC, the Special Supplemental Nutrition Program for Women, Infants and Children

Prevalence of HM-feeding compared with national data

Based on the responses of participants in this CFS sample to the NIS questions, 88% of infants were ever fed HM. At 6 and 12 months postpartum, 63.2% and 39.2% of infants, respectively, were consuming HM. Based on the latest national data available from the CDC based on NIS questions, national prevalence of ever consuming HM, and HM consumption at 6 and 12 months is 80%, 51.4%, and 29.2%, respectively (163). Thus, mothers in our CFS sample were more likely to provide any HM across the first year of infancy than a national sample. Based on the responses of participants in the CFS sample to NIS questions, the prevalence of exclusive HM-feeding in our sample was 22.6% at 3 months and 8.2% at 6 months. This is lower than the reported national prevalence of 43.3% at 3 months and 21.9% at 6 months. Note, the CDC data reflect the behaviors of children born in 2012 but our sample includes children born in 2011, 2012, and 2013.

Prevalence and frequency of maternal HM expression

Of the HM-feeding mothers in this CFS sample, 93.9% expressed their HM at some stage. Timing of initiation and cessation of HM expression were not normally distributed: mothers started expressing HM at a median of 6 (range 0 – 538) days postpartum, and they stopped at a median of 243 (range 0 – 775) days postpartum. The median duration of maternal HM expression was 227 (range 0 – 768) days. The majority (54.2%) of HM-feeding mothers reported that they expressed HM several times every day.

Differences in classification of HM-feeding mode by survey type

When the responses of individual mothers are compared by question type (i.e. to both the NIS questions and the continuous CFS questions about initiation and cessation of feeding behaviors), the proportion of infants not consuming any HM is roughly the same at all times. However, there were minor differences in participants' responses about ever feeding HM, such that a small number of mothers (~ 0.5%) indicated that they never breastfed or fed breast milk in response to the NIS questions, but subsequently reported a short duration (< 2 days) of HM-feeding (either at-the-breast or from a bottle) on the CFS survey.

Overall, the CFS questions provide us with more detailed information about mode of HM-feeding; although ~88% of mothers ever fed HM, fewer than 10% of all mothers only ever fed HM at the breast (**Column 2, Figure 5.2**). A small proportion of women only ever fed expressed HM (~3%) and the vast majority of all mothers (~75%) used a mixed-mode HM-feeding style including at-the-breast feeding and at least some expressed-HM feeding (Figure 5.2).

Mixed-mode HM-feeding was the predominant feeding style across the first year of the infant's life, which confirmed our first hypothesis. Of the infants who consumed HM at 3, 6, and 12 months, >55% were fed with a mixed-mode HM-feeding style (**Figure 5.3**). Prevalence of exclusive HM-feeding was similar regardless of question type (CFS *v.* NIS; **Figure 5.4**).

Based on maternal responses to the categorical question about the proportion of HM the infant was consuming at the breast and from a bottle at different times, the majority of infants were consuming HM from a bottle at 3, 6, and 12 months (**Table 5.2**). This also supported our first

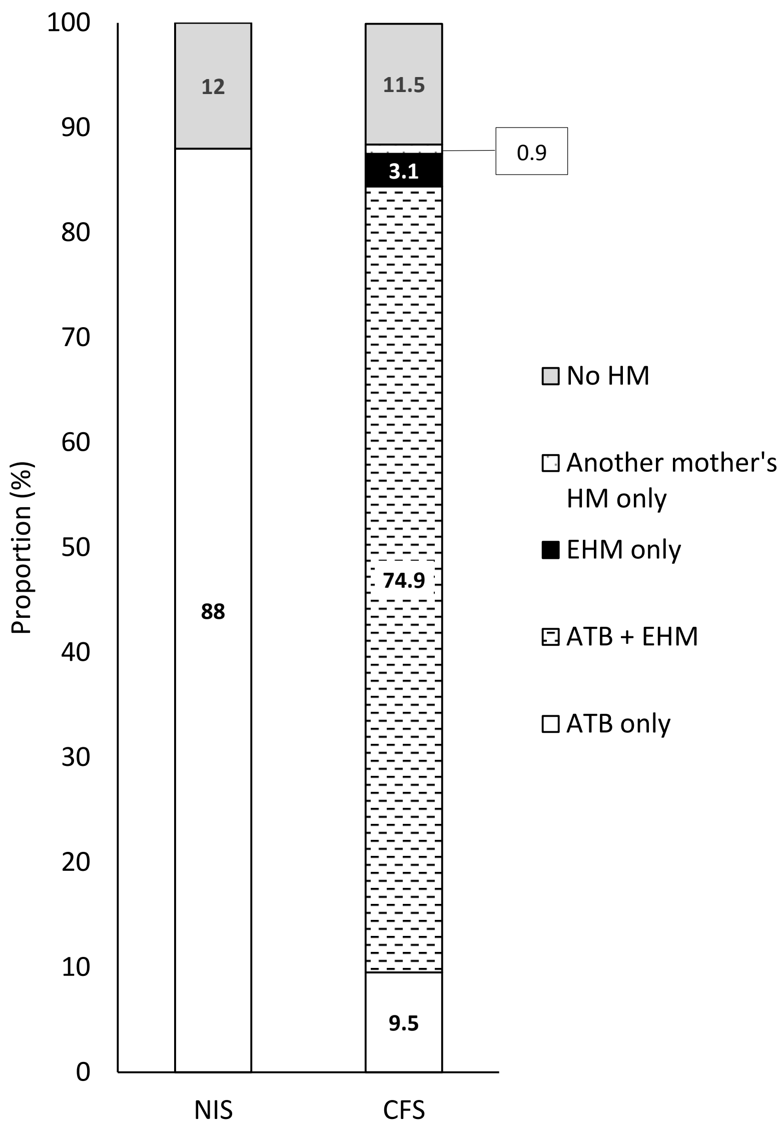

Figure 5.2: Proportion of infants in the Child Feeding Survey (2015) ever fed human milk by question type (NIS v. CFS), calculated using responses to questions about timing of initiation and cessation of feeding behaviors.

Abbreviations used: ATB, at-the-breast; CFS, Child Feeding Survey; HM, human milk; EHM, expressed human milk; NIS, National Immunization Survey.

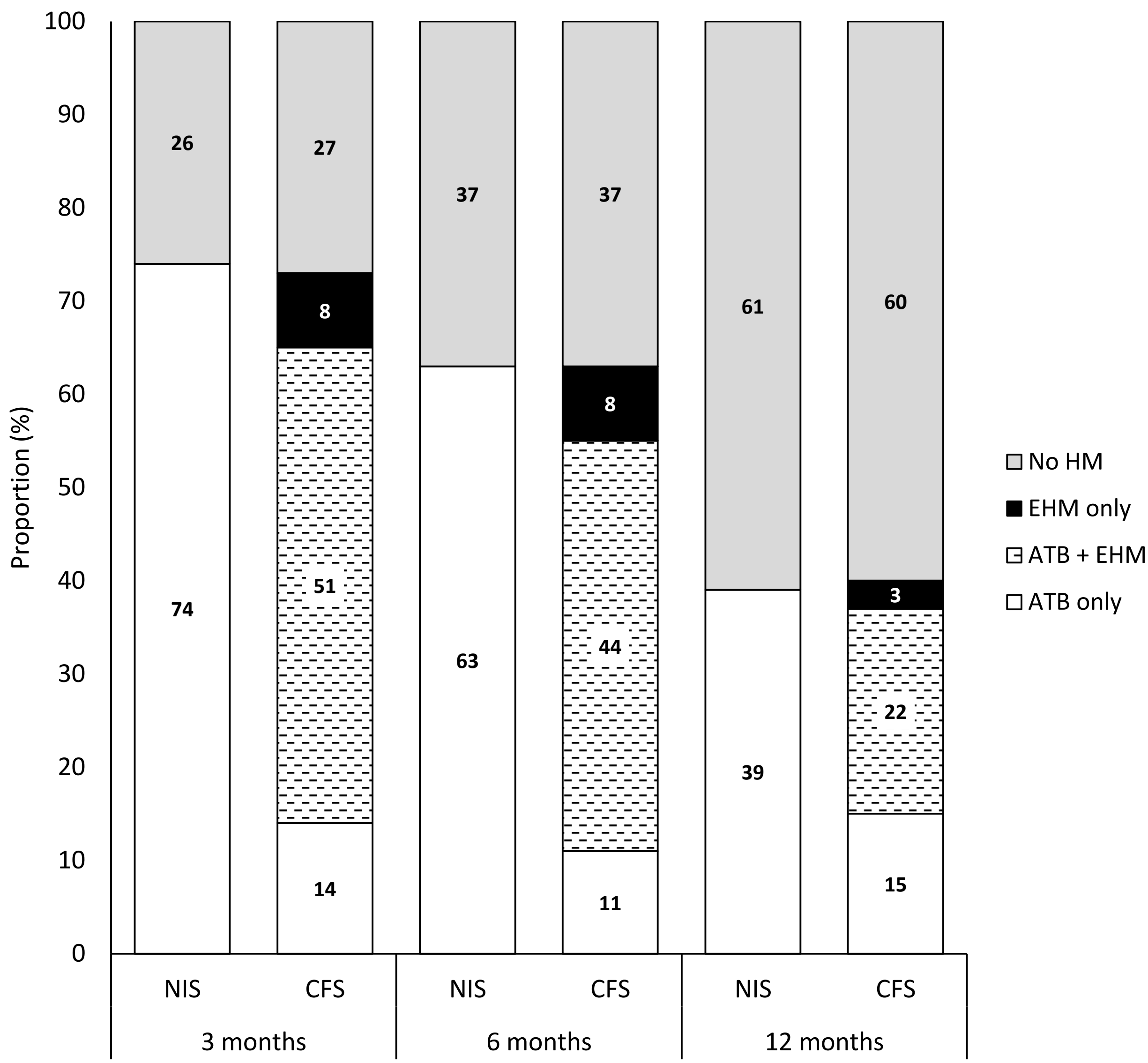

Figure 5.3: Prevalence of human milk-feeding at 3, 6, and 12 months in the Child Feeding Survey (2015) by question type (NIS v. CFS), calculated using responses to questions about timing of initiation and cessation of feeding behaviors.

Abbreviations used: ATB, at-the-breast; CFS, Child Feeding Survey; HM, human milk; EHM, expressed human milk; NIS, National Immunization Survey.

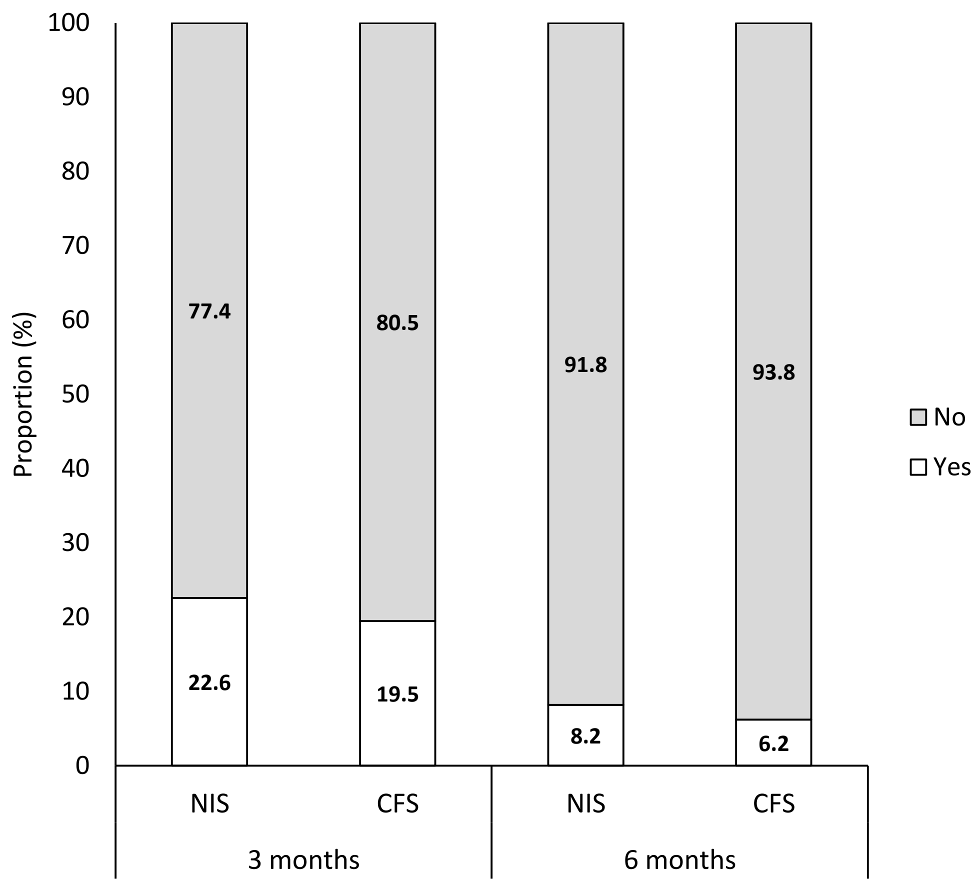

Figure 5.4: Prevalence of exclusive human milk-feeding at 3 and 6 months in the Child Feeding Survey (2015) by question type (NIS v. CFS), calculated using responses to questions about timing of initiation and cessation of feeding behaviors. Abbreviations used: CFS, Child Feeding Survey; NIS, National Immunization Survey

Table 5.2: Prevalence and mode of human milk-feeding in the first year postpartum by question type [NIS continuous response questions v. CFS continuous response questions v. CFS categorical response questions] among 451 participants in the Child Feeding Survey, 2015 [1, 2]

Question(s) used[3]	Response type[4]	HM-feeding category	Ever	3 mo	6 mo	12 mo
NIS Q1, 2	Continuous	Yes	88	73.6	63.2	39.2
		No HM	12	26.4	36.8	60.8
CFS Q1, 2, 5, 6	Continuous	ATB only	9.5	14.4	11.5	14.4
		EHM only	3.1	7.5	7.8	3.1
		ATB and EHM	74.9	50.8	44.1	22.2
		No HM	12.4	27.3	36.6	60.3
CFS Q12	Categorical	ATB only	-	22.8	9.8	9.3
		EHM only	-	8.1	9.6	5.9
		Most ATB, some EHM	-	29.4	17.5	7.5
		Half ATB, half EHM	-	11.1	22.3	10.9
		Some ATB, most EHM	-	4.3	6.6	10
		No HM	-	24.4	34.3	56.4

[1] Values are percent of the total n
[2] Abbreviations used: ATB, at-the-breast; CFS, Child Feeding Survey; HM, human milk; EHM, expressed human milk; NIS, National Immunization Survey
[3] See Appendix E for full text of survey questions from which these data are obtained
[4] Continuous questions asked about timing of initiation or cessation of a behavior relative to the child's birth and responses were used to create dichotomous variables at 3, 6, and 12 months. Categorical questions asked mothers about mode of feeding at 3, 6, and 12 months, specifically.

hypothesis. At 3 months postpartum, nearly 70% of HM-feeding mothers reported that their infants were consuming at least some HM from a bottle. However, at-the-breast feeding was the predominant HM-feeding mode at this time (Table 5.2). At 6 and 12 months postpartum, the proportion of infants who consumed HM from a bottle increased, as did the proportion of HM they received from a bottle relative to at-the-breast (Table 5.2).

<u>Additional behaviors of public health significance measured in the CFS that are not measured by the NIS</u>

Discordance between the duration of maternal HM production and duration of infant HM consumption: Of the mothers in this sample who ever fed HM, 9.1% (n = 36) continued to feed expressed HM for at least 4 weeks after they stopped lactating. This time was chosen to reflect discordance based on the distribution of the difference, in days, between duration of infant HM consumption and duration of maternal HM production. The 75th percentile was 0, i.e. the duration of maternal HM production and infant HM consumption were the same, and the 90th percentile was 28 days, which we chose as our cut-off for discordance. The median duration of infant HM-feeding after cessation of maternal lactation—among those who continued to feed expressed HM for at least 4 weeks after cessation of maternal lactation—was 57 days (range 28 – 162). Of those who fed expressed HM for at least 4 weeks after cessation of maternal lactation, 61% (n = 22) provided an answer to the NIS questions that reflected duration of maternal HM production, not infant HM consumption. Fewer mothers (39%, n = 14) provided an answer to the NIS questions that reflected duration of infant HM consumption, which was, thus, not reflective of their own duration of HM production.

Cessation of feeding infant formula: The majority (75%) of mothers reported that their infant had ever consumed infant formula in response to the new feeding questions. Of these, 5.2% of infants (n = 17) received infant formula for less than 3 days. Six of these mothers reported that their infant never consumed infant formula in response to the NIS questions but subsequently reported short durations of feeding infant formula in response to the CFS questions.

Feeding another mother's milk and providing HM for other infants: Most (94%) mothers in this sample had heard of infants consuming another mother's HM. However, a smaller number (21.5%) had actually thought about feeding their own infant another mother's HM, and an even smaller proportion of the total sample had actually fed their child another mother's HM (7.1%). Of those who fed their infant another mother's HM, most of the milk was received from a friend or other person the mother knew (**Table 5.3**). More mothers thought about providing their milk to another (52.5%) than considered receiving it. Similarly, a higher proportion of mothers actually provided their milk to another (11.8%) than received it. Of those who provided their HM to another, most (51%) provided it to a friend or other person they knew, and a large proportion (37.7%) donated their HM to a milk bank (**Table 5.4**).

Discussion

The CFS survey questions that distinguish between at-the-breast feeding and expressed-HM feeding describe them as distinct behaviors that may not start and stop at the same time. The vast majority of HM-feeding mothers in this sample expressed HM, and most reported that they did so several times per day. At all times across infancy that we explored, the predominant HM-feeding strategy of mothers in our sample included at-the-breast feeding in combination with

Table 5.3: Source of other mother's human milk that was fed to infants in the Child Feeding Survey, among those who ever fed their child another mother's human milk, n = 32 [a]

Source	Number (%)
Given donor breast milk while in the NICU [b]	4 (12.5)
Given by a health professional or breastfeeding support specialist (e.g. midwife, lactation consultant, nurse, breastfeeding peer counselor) when mother and baby were home after giving birth	3 (9.4)
Given by a relative	4 (12.5)
Given by infant's other mother who was also lactating [c]	1 (3.1)
Given by a friend or other person mother knew	19 (59.4)
Given by somebody mother met online that she never met in person	3 (9.4)
Given by somebody mother met online that she met in person to exchange the milk [c]	1 (3.1)
Purchased from milk bank [c]	1 (3.1)
Purchased from somebody that mother didn't know personally	1 (3.1)
Purchased breast milk from somebody mother met online that she never met in person	1 (3.1)

[a] Mothers could choose more than one option
[b] NICU, Neonatal Intensive Care Unit
[c] Response volunteered by participant, not an investigator-initiated option

Table 5.4: Routes of human milk sharing and donation among participants in the Child Feeding Survey, among mothers who ever gave their human milk to another mother, n = 53 [a]

Recipient	**Number (%)**
Donated to a milk bank	20 (37.7)
Given to a relative	13 (24.5)
Given to a friend or other person mother knew	27 (50.9)
Given to somebody mother didn’t know personally	19 (35.9)
Sold milk and met with person to exchange	1 (1.9)
Sold milk to somebody she never met	4 (7.6)

[a] Mothers could choose more than one option

expressed-HM feeding. National data based on the NIS survey questions classify all mother-infant dyads simply as breastfed for the duration the infant is consuming HM. Given that the NIS questions ask how long an infant was “breastfed or fed breast milk,” the breastfeeding classification by the NIS could be taken to mean a combination of at-the-breast feeding and expressed-HM feeding. However, this does not reflect the behavior of the mothers who were only feeding at the breast or those who were only feeding expressed HM.

This less extensive classification of maternal and infant behaviors is important because public health authorities (2) recommend that women breastfeed because of the associations between breastfeeding and positive infant outcomes (3)—associations that are based on studies comparing infants fed at the breast with those fed infant formula from a bottle. However, mothers respond to breastfeeding recommendations by combining at-the-breast feeding and expressed-HM feeding, a feeding style that may modify the benefits of breastfeeding, and is itself associated with negative outcomes.

Our results indicate that the mixed-mode HM-feeding style is now the predominant HM-feeding style in the U.S. These results are similar to those of Hornbeak *et al*. (41), who reported an increasing prevalence of expressed-HM feeding and mixed mode HM-feeding among infants born between 2000 and 2008 in Singapore. Given that a mixed-mode HM-feeding style is the predominant strategy in the U.S., and that expressed-HM feeding may not convey the same benefits as at-the-breast feeding, the outcomes associated with this feeding mode warrant further, and more in-depth, study.

Our results not only describe the complexity of HM-feeding, but also the complexity of measuring these behaviors. Using dichotomous variables created from responses to questions with continuous responses, ~14% of dyads are classified as solely at-the-breast feeding at 3 months postpartum (Figure 5.3). In contrast, using responses to a question that asks specifically about the proportion of HM fed at the breast, ~23% of dyads are classified as solely at-the-breast feeding at 3 months postpartum (Table 5.2). This difference is because expressed-HM feeding may be an episodic behavior and simply asking about the initiation and cessation of this behavior insufficiently describes the behavior of infants who started consuming expressed HM sometime before 3 months, stopped consuming it sometime after 3 months, but were fed only at the breast at 3 months.

The difficulty in measuring HM-feeding behaviors highlighted here is essential for other investigators to consider as they develop studies to compare infant outcomes by mode of HM-feeding. The exposure of interest depends on the research question being explored. Take, for example, the association between breastfeeding and the development of the infant gut microbiome. Compared with formula feeding, breastfeeding is associated with the development of a more favorable gut microbiome (164, 165), and a favorable gut microbiome is associated with reduced risk of metabolic and immune diseases (165). However, expressed-HM feeding could possibly result in an infant gut microbiome that is less favorable than that of the infant fed at the breast. This is because practices commonly employed by mothers for storing and reheating expressed HM (57) can decrease the pH and change the bacterial profile of the milk (101). Thus, the proportion of expressed HM consumed could be an important exposure when exploring the complex relationships among infant feeding, the gut microbiome, and health outcomes.

The other behaviors of public health interest that we reported, about which no national data are currently collected, suggest a need for revision of the survey questions that are currently used for national breastfeeding surveillance. Based on formative qualitative data (Chapter 2), we predicted that some mothers would continue feeding HM after they had stopped producing HM. We also predicted, *a priori*, that these mothers would respond to the NIS question "[h]ow old was [child] when [child] was last breastfed or fed breast milk?" with the age of the infant when he/she last consumed HM. Using this age to calculate and report breastfeeding duration would overestimate the mother's duration of lactation. What mothers actually reported was surprising. The majority (61%) of mothers who continued to feed expressed HM after they stopped lactating provided an answer to the NIS question that reflected their own duration of lactation. Thus, using that age underestimates duration of infant HM consumption, contributing to misclassification of infant feeding exposures. This finding adds to the evidence for the need to improve questions for measuring infant feeding.

In this study, when presented with questions that asked about both the initiation *and* cessation of infant formula feeding, 6 mothers who had previously indicated that their child never consumed infant formula provided information about formula feeding. We suspect, based on our formative research, that these mothers were willing to report infant formula feeding if they could also report that this only continued for a short duration. This is important for two reasons. First, if investigators are interested in studying cow's milk protein allergy, an outcome for which a small intake of infant formula might be important to measure, they may misclassify infants as never formula-fed if they only ask about initiation of infant formula-feeding. Second, when mothers in our cognitive interviews were not offered the opportunity to provide a timing of infant formula cessation, they were frustrated. This is information that mothers felt was important to report, which may be sufficient justification for collecting the data, even if they are not of interest to the investigators.

Finally, the proportion of infants in this sample ever fed another mother's HM was higher than previously reported among mothers of infants born in 2011 from Ohio (109). A small proportion of infants in this study consumed pasteurized donor HM, which is unlikely to be a concern to public health officials. However, when we exclude infants who received donor HM, 6.2% of infants in our sample consumed another mother's HM, which remains higher than the ~4% reported in the study from Ohio (109).

<u>Strengths and limitations</u>

The main strength of this study is the development of survey questions based on formative qualitative research conducted among mothers with experience of the feeding behaviors we investigated here (Chapter 2 and 3). The survey was also rigorously tested to ensure the questions were contextually appropriate and reliable (Chapter 4). Additionally, by administering the survey online to a larger sample from a wide geographic area, we were able to verify the inferences we drew from our smaller qualitative study, conducted in a single geographic location (Chapters 2 and 3). The similar conclusions drawn from these studies, particularly the finding that a mixed-mode HM-feeding style is the predominant HM-feeding style, supports their generalizability.

However, the mode of survey administration is also one of the primary limitations of this study. Because we administered this survey online to a convenience sample of mothers recruited through ResearchMatch.org (152), we have no way to ensure our respondents were actually mothers of infants aged between 19 and 35 months old. Although we conducted internal consistency checks to identify and discard implausible responses, we cannot be certain that we identified all of the respondents with questionable data.

Conclusion

Our results highlight that the term breastfeeding does not describe the full range of infant feeding behaviors employed by mothers and families. The current means by which breastfeeding is measured nationally has limited ability to describe at-the-breast feeding and expressed-HM feeding; it also does not capture the complexity of the ways infants are fed HM today. The majority of HM-feeding mothers are expressing HM several times every day and the majority of infants are being fed HM both at the breast and from a bottle. This is important because we know that mode of HM-feeding is associated with infant health outcomes, and that mode of HM-feeding is often not addressed on infant feeding surveys. Thus, our results provide justification for the revision of current national breastfeeding surveillance surveys to better reflect infant feeding practices.

CHAPTER 6

CONCLUSIONS

The findings from the mixed-methods research described in this dissertation contribute to our understanding of how mothers in the U.S. use human milk (HM) expression and expressed-HM feeding, in combination with or instead of at-the-breast feeding, to provide HM to their infants. An in-depth understanding of how mothers use breast pumps to provide HM to their infants is particularly timely given that reimbursement for breast pumps was recently mandated as part of the Affordable Care Act (42). This will make breast pumps more available and affordable to more mothers, likely increasing the extent to which they are used. Our work is additionally important because it provides qualitative and quantitative exploratory information about two understudied and related behaviors: feeding infants another mother's HM and providing HM to an infant other than the mother's own.

Summary of research findings

Findings from both our qualitative and quantitative studies highlight the complexity of HM-feeding practices in the U.S. Our description of HM feeding as some combination of at-the-breast feeding, expressed-HM feeding, and feeding another mother's HM raises questions and concerns about the use of the word breastfeeding to describe contemporary HM feeding.

In Chapter 2, we reported mothers' descriptions of their HM-feeding strategies including at-the-breast feeding, expressed-HM feeding, feeding another mother's HM or any combination of the three. The strategy that mothers employed at any given time was subject to change over the course of infancy, and was related to other lifestyle and contextual factors, such as infant illness or maternal employment. The most common strategy was a combination of at-the-breast feeding and expressed-HM feeding, which was particularly common among mothers who returned to work postpartum. Expressed-HM feeding was typically made possible through the use of breast pumps, although some mothers hand-expressed their milk. Breast pump use, in particular, allowed some mothers to express large quantities of HM, build up a stockpile of HM in their freezer, and feed it to the infant at a later date. In our detailed qualitative description of the strategies employed to feed HM, we highlighted patterns of maternal HM production and infant HM consumption that were often not occurring simultaneously. Our results also highlight that how mothers conceptualize and operationalize HM-feeding is not always in accord with the understanding of the word breastfeeding as a mother feeding her own infant directly from her breast.

The availability of breast pumps also facilitated mothers to feed their infants another mother’s expressed HM or to provide their own HM to another mother for the purpose of feeding this milk to her child, described in detail in Chapter 3. This novel exploration of HM sharing among a sample of women who have and have not participated in HM sharing provided us with insights into the awareness and consideration of HM sharing, as well as concerns about, motivations for, and routes of HM sharing. These results are important because, although infants have been consuming other mother’s milk through direct at-the-breast feeding since time immemorial (32), breast pump use now enables mothers to provide their infant with another mother’s expressed HM from a bottle. This has the potential to increase the number of mothers and possible geographic locations from which shared HM is sourced, which is further enabled by online HM sharing websites (131-133). Awareness of HM sharing was high in both our qualitative and quantitative (Chapter 5) studies, indicating that this is not a geographically isolated issue, unique to the location in which we conducted our qualitative research.

Our qualitative results about HM-feeding strategies were also supported by our survey that used quantitative methods to explore the diverse range of HM-feeding practices (Chapter 5). We found that combining at-the-breast feeding and expressed-HM feeding was the predominant strategy employed by HM-feeding mothers across the first year of their infant's life. Only a small proportion of mothers who completed our survey fed their infants only at the breast for the duration of their lactation, and a small proportion fed their infants only expressed HM. These results mirror the findings in our qualitative study. Not only did our survey help us understand the prevalence of a diverse range of behaviors for feeding HM, but we were also able to compare how two different sets of surveillance questions classified these maternal-infant behaviors.

By collecting data about only an infant's consumption of HM and using these data to report breastfeeding prevalence, public health authorities are simplifying a complex behavior that deserves more detailed assessment. Given the known adverse outcomes of expressed-HM feeding related to infant growth (48), infant health (106), and maternal and infant behaviors later in childhood (50), collapsing the range of HM-feeding behaviors into one category and calling it breastfeeding is simplistic. The complex range of practices for HM-feeding described in this dissertation highlight problems for studying, monitoring, and promoting infant feeding behaviors. This work is directly relevant to researchers, public health officials, clinicians, and mothers and their families.

Implications for researchers

These findings, and those of others (44), highlight a number of interesting avenues of research that must be explored, predominantly centering on the outcomes associated with expressed-HM feeding and optimal strategies families can employ to feed HM to their infants. Given the recent dramatic shift in infant feeding practices, it is imperative that this work is done sooner rather than later. The last time such a shift was seen—from predominant at-the-breast feeding to predominant infant-formula feeding in the 1900s—it was decades before the adverse outcomes associated with this shift were elucidated (32). Although there has been a gradual reversion from formula-feeding to at-the-breast feeding since the nadir of this practice in the 1970s (10, 11), we are now deviating from this recommended behavior once more. The most recent shift has been toward a mixed-mode HM-feeding style that includes both at-the-breast feeding and expressed-HM feeding, which has occurred with minimal understanding of the impact of these behaviors (44).

Our qualitative and quantitative results not only suggest avenues for future research, but they also provide insights into three important methodological issues that researchers should consider before conducting a study related to infant feeding.

First, specific *a priori* definitions of both the exposure and the outcome of interest are essential to any research designed to understand outcomes associated with HM-feeding behaviors. For example, if one is interested in exploring the established association between maternal lactation and postpartum weight reduction (73), the amount of HM extracted from the mother's breasts is likely the primary exposure of interest. Given women's current behavior patterns, using the duration of infant HM consumption to describe this exposure is likely inappropriate. A subset of the Child Feeding Survey questions we developed could be used by researchers depending on their question of interest. In the above example, researchers may want to ask the questions about duration of at-the-breast feeding, duration of maternal HM expression, and frequency of maternal HM expression.

Second, as highlighted by Noel-Weiss and colleagues (88), careful and deliberate choice of terminology is essential in any presentations, publications, or other research descriptions of HM feeding. It would also be helpful if researchers provided the text of the questions they used for collecting data about infant feeding. This research highlights that the terms “breastfeeding” and “bottle-feeding” are problematic. However, some researchers still use the term “bottle-feeding” (91) without distinguishing what is in the bottle; given the behaviors described in this dissertation, this term is no longer sufficiently clear.

Third, when investigating a behavior that can be as emotionally charged as HM feeding, it may be wise to build in the opportunity to receive additional feedback from respondents about their experiences. In our cognitive interviews, mothers were eager to explain the reasons why they participated in various behaviors. This desire to explain behaviors led us to include two questions on our survey. First, we included a question about the timing of cessation of infant-formula feeding (described in detail in Chapter 4). Second, we included an open-ended, free-text box at the end of the survey and asked mothers for “…any comments or feedback.” Roughly 19% of mothers provided information in this box, and most expanded on an answer they had provided elsewhere in the survey. Based on our cognitive interviews, we believe that including this type of question will provide useful information and increase respondent satisfaction with this type of survey.

Implications for national public health policy and infant feeding surveillance

The goal of public health is to protect, promote, and advance the health and safety of the nation (166). The CDC's Division of Nutrition, Physical Activity, and Obesity's webpage states that they are "committed to increasing breastfeeding rates throughout the United States and to promoting and supporting optimal breastfeeding practices toward the ultimate goal of improving the public's health" (167). The weight of the published research clearly demonstrates that breastfeeding is the optimal way to feed infants (3). Accordingly, the national public health recommendation is to breastfeed exclusively for 6 months with the introduction of appropriate complementary foods and continued breastfeeding to 1 year and beyond (2). However, given the hybrid mode of "breastfeeding," feeding HM from a bottle, it is not clear how to operationalize these recommendations. Our findings suggest four key ways that public health policy and infant feeding surveillance could be improved.

First, public health policies should place more focus on the process—breastfeeding—rather than the product—human milk. Based on the accommodations provided to HM-feeding women in the U.S. (e.g. an appropriate place to pump at work, and access to "breastfeeding equipment") (42), public health policies currently focus on ensuring that mothers can express HM to feed to their infant. This emphasis on the product over the process has been described previously in the literature, particularly in the field of anthropology (168). It is also reflected in the qualitative work presented in this dissertation where some mothers chose to feed expressed HM in place of at-the-breast feeding. The emphasis on the product over the process is problematic because of the recently published research describing poorer outcomes among infants fed HM from a bottle compared with those fed at the breast (48, 50, 106). These reports imply that the benefits of breastfeeding result from a combination of both the product *and* the process; thus, the mode of delivery of HM matters. Based on data from mothers in our qualitative study who did not return to work, a high frequency of maternal HM expression was suggestive of a problem with at-the-breast feeding. Perhaps, with more social support or support from lactation consultants, these mothers may have been assisted to increase the extent to which they fed at the breast. Thus, public health policies should promote, support, and protect at-the-breast feeding specifically.

Second, and perhaps counterintuitively based on the argument above, public health authorities should also provide more information and support about HM expression and expressed-HM feeding. Although we believe that at-the-breast feeding deserves greater support, mothers are currently using HM expression and expressed-HM feeding as infant feeding strategies with minimal guidance from public health authorities. This is unsatisfactory given that this is the predominant HM-feeding strategy employed by mothers in the U.S. Although there are guidelines available about the storage and handling of expressed HM (169-172), these guidelines are inconsistent about the appropriate duration of HM storage on a countertop, in the refrigerator or in the freezer. Among mothers in our qualitative sample (173), the inconsistency of guidelines about the appropriate storage duration of expressed HM led to maternal confusion, frustration, and desire for more information. Thus, consistent guidance about appropriate expressed-HM feeding is warranted. Development of such guidelines will depend upon researchers studying optimal strategies for HM-feeding, which will likely require governmental funding.

Third, our qualitative data support a move toward providing paid maternity leave to all mothers in the U.S. Mothers in our qualitative study expressed a preference for at-the-breast feeding over expressed-HM feeding (Chapter 2), and many primarily used breast pumps to provide HM for their infant while they were at work. If these mothers were provided with paid time off postpartum and supported to feed their infant at the breast, they may feed HM for longer, as suggested by data from other developed countries (174).

Fourth, although there may currently be insufficient data to suggest that national infant feeding recommendations should be reevaluated, it is time for public health officials to reevaluate their use of the term breastfeeding and use terminology that distinguishes at-the-breast feeding and expressed-HM feeding as distinct behaviors. The U.S. national breastfeeding surveillance questions do not describe either the duration of at-the-breast feeding or duration of expressed-HM feeding. At best, the NIS questions have the potential to describe the total duration of any HM feeding, regardless of mode. However, for some mothers in our sample, i.e. those who continued feeding expressed HM after they stopped lactating, the NIS questions were insufficient to describe duration of any HM consumption by infants. Furthermore, the NIS surveillance system questions do not measure infants fed another mother's HM, which was reported by a sizeable proportion (~7%) of participants in our survey. Finally, the NIS questions also do not capture the number of infants ever fed infant formula in the U.S. A small proportion of mothers in our sample did not report infant formula-feeding in response to the NIS questions, but they subsequently reported a short duration of infant formula-feeding when offered the opportunity to provide both the timing of initiation and cessation of infant formula-feeding.

We do not propose that developing new indicators for HM feeding will be easy. The range of strategies employed by mothers is diverse, and these strategies change over the course of infancy, making it difficult to categorize infants as simply "at-the-breast fed" or "expressed-HM fed." However, we may be able to classify infants by the proportion of HM that is consumed at-the-breast *v.* from a bottle. Our categorical question asking mothers about the proportion of HM their infant consumed at-the-breast *v.* from a bottle is a construct-valid and reliable question that could be used for this purpose.

Implications for clinical practice

Our findings suggest two key ways in which clinicians may optimize their interactions with families on the topic of HM-feeding. First, clinicians require contextually appropriate education and training in the provision of advice about and support for both at-the-breast feeding and expressed-HM feeding. This is particularly important because research available to date suggests that health professionals' understanding of and attitudes toward breastfeeding already require improvement (21, 175-177). Now, with a new mode of HM feeding available to mothers and their desire to know more about the associated benefits and risks (173), clinicians must be prepared to manage both at-the-breast feeding and expressed-HM feeding mothers.

Second, accurate description of HM-feeding behaviors is also necessary for clinical practice because accurate use of terminology when speaking to mothers is essential. One mother in our qualitative study spoke about how frustrated and upset she became when her health care providers consistently asked her if she was "breastfeeding or bottle-feeding" implying that "bottle-feeding" meant "formula-feeding." As this mother was providing HM from a bottle, she felt unable to answer this question, and felt like her feeding style was not recognized by her health care providers.

Implications for mothers

It is assumed that all mothers want what is best for their infants. Mothers who have internalized the message that "breast is best," may do everything they can to ensure they provide HM for their child. For women who must return to work postpartum in the contemporary U.S., this necessarily involves bottle-feeding expressed HM. This necessity poses two major problems related to health equity.

First, if expressing HM at work isn't possible or sustainable for a mother and she is not provided with sufficient support to feed at the breast, she is at a disadvantage relative to others because she cannot fulfil her desire to feed at the breast. Her infant is also at a disadvantage because he/she does not reap the benefits of at-the-breast feeding. Based on our qualitative data, the mothers who will be best able to combine HM feeding and postpartum return to work are those with the most flexible work schedules, the most supportive coworkers and employers, a private and comfortable place to pump, and an appropriate place to store expressed HM during the work day. Given that mothers of lower socioeconomic status are more likely to be working in jobs with less flexible hours and working conditions than mothers of higher socioeconomic status, their reduced likelihood of expressing sufficient HM while at work perpetuates an already existing health inequity, as low income is consistently associated with poor breastfeeding outcomes (103, 135). The consequences of not being able to pump sufficient HM at work for the infant include earlier-than-desired introduction of infant formula or solid foods to curb expressed-HM consumption so that stored HM would last longer (Chapter 2). The most effective way to improve health equity across income groups is to provide paid maternity leave and lactation support to all mothers.

Second, both expression of HM and feeding expressed-HM feeding are time- and labor-intensive behaviors that require both physical and psychological work of mothers. These factors related to maternal quality of life are important to consider when exploring the implications of HM expression and expressed-HM feeding. Mothers in our qualitative study described the physical work of the act of expressing and of carrying equipment to and from their place of work. Psychological work involved the management and rotation of expressed HM between work, daycare, and the home, and between the refrigerator and the freezer. Several mothers in our qualitative study had complex systems to ensure that expressed HM would be used and not wasted (173). The additional work for mothers associated with HM expression and expressed-HM feeding has also been described in other recent qualitative work on this topic (44). In a society where breastfeeding is often closely linked with "good motherhood" (178), women may feel that they are expected to engage in these time-consuming and demanding behaviors, thus placing extra strain on them (179). The physical and psychological work associated with HM expression and expressed-HM feeding, in addition to or instead of at-the-breast feeding, adds to the unpaid, family work that women are often more burdened by than men (180), and thus perpetuates gender inequalities.

There is an implicit order to the implications of HM expression and expressed-HM feeding described in this dissertation. Infant feeding recommendations cannot be changed until research is conducted about the optimal strategies for infant feeding, and clinicians cannot, or will not, change their practice until infant feeding recommendations are changed. Finally, mothers won't benefit from the knowledge about optimal feeding strategies until research is conducted and infant feeding recommendations are changed. Thus, there are many unanswered questions that require in-depth study so that we can provide mothers and families with evidence-based recommendations about optimal infant feeding practices.

Unanswered questions

What is now urgently needed is information about the maternal and infant health outcomes associated with HM expression and expressed-HM feeding. To begin to understand these health outcomes, we need to know more about the consequences of maternal HM expression and HM storage and handling practices for the content of expressed HM. The availability of a questionnaire that distinguishes between at-the-breast feeding and expressed HM-feeding, as developed in this dissertation, will support this much-needed research.

Researchers in the field of lactation are continuously learning more about the components of HM, a dynamic fluid that is known to contain a wide range of non-nutritive bioactive factors (61). Of these non-nutritive factors, recent research has focused on HM oligosaccharides (181) and the cells found in HM (182, 183). Human milk oligosaccharides are involved in shaping the infant gut microbiome, and also have immune functions that may help prevent infant infectious diseases (184). Many of the cells in HM are immune cells, and the percentage of the immune cells in HM increases in response to maternal or infant infection (183), emphasizing the dynamic nature and functionality of HM. Leukocytes, the immune cells in HM, were once thought to be the predominant cell type in HM (185), however, recent ground-breaking research has shown that the majority of the non-immune cells in HM are of epithelial origin, including stem cells (185). The functions of the cells in HM have not yet been fully elucidated, but their presence in the milk implies a function. It is likely that these cells shape infant development in ways we can only begin to guess.

We currently know very little about the impact of HM expression, expressed-HM storage in the refrigerator or freezer, and subsequent re-heating HM on these functional components of HM. As we learn more about the complex nature of this bioactive fluid, we must remember that the majority of HM-fed infants in the U.S. consume a substantial amount of HM from a bottle, thus, we must consider the impact of expression, storage, reheating, and feeding from a bottle on the composition of HM.

In addition to this emphasis on the product, HM, we also need to understand more about contextual factors that interrupt the process of at-the-breast feeding. Most HM-feeding mothers express their HM and the association between HM expression and the duration of any-HM feeding and at-the-breast feeding is complex. Based on the research of others (44, 70), this relationship is likely dependent upon other contextual and lifestyle factors that are associated with both HM expression and duration of any-HM feeding and at-the-breast feeding. Because our survey included questions about frequency of maternal HM expression and the duration of any-HM feeding and duration of at-the-breast feeding, it would have been possible to explore relationships between frequency of maternal HM expression and duration of HM-feeding. However, we recognize that these variables alone are insufficient to explore this relationship.

Based on the qualitative and quantitate work of Felice (44), and our own qualitative work (Chapter 2), the motivations for HM expression must be understood for any associations between frequency of HM expression and duration of HM-feeding to be interpreted. A more holistic approach to studying the association between HM expression and duration of any-HM feeding and at-the-breast feeding, which includes developing an in-depth understanding of contextual factors including motivations for HM expression, is essential.

Strengths and limitations of this mixed-methods dissertation

The mixed-methods sequential approach employed in this dissertation has four major strengths. First, data from our qualitative study informed the design of the survey used for our quantitative research. This helped us to understand the range of behaviors that would be important to measure in our quantitative survey. Cognitive interviews with mothers ensured construct validity of our survey and helped ensure that it would be easy for participants to complete.

Second, conducting two studies—a qualitative study consisting of semi-structured interviews and a quantitative study consisting of self-administered survey—about HM-feeding practices increases our confidence in our findings, as they are in accord with one another. Data from both of this studies place a mixed-mode HM-feeding style as the predominant HM-feeding strategy employed in the U.S. Data from both studies also indicate that awareness and consideration of HM sharing are high, and that mothers would be more likely to share HM with someone they know.

Third, findings from our qualitative research provided important insights into our quantitative results. An in-depth understanding of practices for HM feeding from the maternal perspective helped us interpret our survey findings, particularly the interaction between frequency of maternal HM expression and our variable for postpartum return to work. Among mothers who did not return to work, a high frequency of HM expression was associated with poorer outcomes. This is not surprising when we consider that, among the participants in our qualitative research, those who did not return to work *and* expressed HM with a high frequency were those who had infants with some problem with at-the-breast feeding (e.g. low mouth muscle tone from Down syndrome or premature birth).

Finally, by conducting our survey after our qualitative study, we were able to explore HM sharing among a geographically diverse sample. Our qualitative study was geographically limited as the respondents were all recruited in the same state. Given the high prevalence of receiving HM from another mother and providing HM to another mother described in Chapter 3, we were unsure whether this was a location-specific phenomenon. Although the prevalence of HM sharing was lower in our survey study (Chapter 5), we were able to establish that this behavior is not location-specific, and may be more common than previously reported (109).

Individually, our qualitative and quantitative studies had additional strengths. Conducting our qualitative interviews retrospectively among mothers of infants < 3 years allowed us to develop a better understanding of maternal and infant behaviors because, although some women were still proving HM when interviewed, most mothers described the entirety of their HM-feeding experience. This allowed us to describe their HM-feeding trajectories across infancy and, thus, to identify the range of different classifications of infant feeding possible. We also employed strategies to establish trustworthiness of our data. We conducted member checks with 2 participants in our qualitative study to check the conclusions we were drawing about HM sharing were appropriate.

We mimicked the methods of the NIS as far as practicably possible to assure that the comparison between our new survey questions and the NIS survey questions would be valid and reflect how actual respondents to the NIS survey may respond to different HM-feeding survey questions. Additionally, the way we recruited participants for our survey was novel and efficient. It allowed us to access a diverse population of women who had access to the internet and had already expressed interest in participating in in research.

Unfortunately, this recruitment method also came with limitations. Online recruitment of subjects, without any identifying or background information, introduces the possibility that participants may fabricate responses so that they can participate in the study and receive the incentive offered. When ~200 surveys had been completed, we identified a small number of survey responses that seemed implausible by doing routine spot-checks of individual survey responses. Upon the discovery of implausible responses, we suspected that perhaps some people had responded to the survey solely to receive the incentive. We subsequently halted recruitment and obtained IRB approval to remove any mention of the incentive (a $5 electronic gift card) from our recruitment materials before restarting recruitment. However, those we excluded from our final analyses due to implausible responses came equally from those who completed the survey before and after recruitment materials were modified. Thus, although we have made every attempt to reduce the errors associated with fabricated responses to our survey, we cannot guarantee that the noise in our data created by inclusion of potentially implausible responses has been completely eliminated.

It is also likely that some degree of selection bias limits our qualitative study. We only recruited mothers with experience with HM expression for this study. Thus, we cannot comment on the opinions about or attitudes toward the infant feeding strategies we describe in Chapter 2 or toward HM sharing among mothers who never expressed HM. Thus, the opinions and attitudes of formula-feeding mothers, and those who never expressed HM, are missing from these findings.

This research is innovative in concept because we recognized that the comparison categories “breastfed” and “bottle-fed” used ubiquitously to date in infant feeding research are inadequate and inappropriate in the current context. It is also innovative in approach as we created a contemporary and appropriate infant feeding questionnaire informed by in-depth formative qualitative research of infant feeding behaviors form the maternal perspective. Our presentation of our results, particularly the pictorial representation of infant feeding trajectories, is novel and helps to visually explain the complexity of contemporary infant HM feeding.

This research is significant because we took the first step toward establishing whether mode of HM delivery is associated with maternal and infant health outcomes by developing a measurement tool that distinguishes between feeding HM at the breast from feeding HM with a bottle. This tool categorizes infants by *how* they are being fed as well as by *what* they are being fed and accurately calculates duration of maternal milk production. In future research, these questions will be useful to establish the effect of HM expression and expressed-HM feeding on maternal and infant health outcomes. However, a strong note of caution is warranted here. Researchers should be specific when they describe their exposure of interest, and they should be sure that the questions they use to measure that exposure are valid. As highlighted by the comparison between continuous questions that ask about timing of initiation and cessation of behaviors and a question that asks about proportion of HM fed from a bottle at different time points, how information is elicited affects how feeding behavior in mother-infant dyads is categorized.

In conclusion, this work highlights the complexity of HM feeding and the difficulty in measuring HM feeding as an exposure for research purposes. This work indicates that referring to infants as “breastfed” or “bottle-fed” is too simple and, thus, is insufficient to describe contemporary infant feeding practices.

APPENDIX A

QUALITATIVE STUDY RECRUITMENT MATERIALS

CALLING ALL MOMS!

Do you have a child aged 1 – 3?

Did you ever feed your child expressed / pumped milk?

Have you finished breastfeeding and pumping?

We are looking for volunteers to take part in a study of breast milk expression and pumping

As a participant in this study you will be asked to take part in an hour-long interview at a location of your choice

To thank you for your time you will receive a $10 gift card for a local store

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For more information about this study, please contact:
Liz O'Sullivan: (607) 379-5624
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APPENDIX B

QUALITATIVE INTERVIEW GUIDE

Numbered (1 – 10 and a – h) questions represent semi-structured questions that were asked. Sub-sections (i – vii) of these numbered questions were things that were probed for if this information was not disclosed in the participant's original response. Not all probes were asked of each mother as interviews were participant-led.

1. When you were pregnant, how did you envision feeding your baby once he/she was born?
    a. When did you make this decision?
    b. What/who influenced this decision?
    c. How motivated/determined were you to follow your planned feeding mode?
    d. Can you tell me a bit more about this motivation?

2. Tell me about the first time you fed your baby
    a. Did you get any help or advice from anybody in the hospital?
        i. Doctor, nurse, lactation consultant
    b. Did anybody speak with you about pumping your breast milk?

3. Can you describe when you first thought about pumping your milk?
        i. Had you heard about pumping from friends/doctors/television/media?
        ii. What pump did you buy and how did you choose it?
    a. Tell me about your first attempts at pumping your milk
        i. How old was your baby?
        ii. What were some things that influenced your decision to first pump your milk?
    b. When were you first exposed to a breast pump? [Sometimes asked as "do you remember when you first saw or heard of a breast pump?"]
        i. In the hospital (prior to birth or in the maternity ward)
        ii. Friends/family had one themselves
        iii. Received a gift prior to the birth of your baby
        iv. Purchased personally before you had your baby
    c. Walk me through the process of pumping your milk
        i. How often did you pump your milk?
        ii. What influences your decision to pump your milk at any given time?
            E.g. Relief of engorgement, encouragement of milk production, build up a store for future feeding, separation from baby, to allow someone else to feed the baby,
        iii. Can you describe in detail how you go about pumping your breast milk?
            1. How do you choose which breast to pump?
            2. What time of day do you pump?
        iv. What do you do with expressed breast milk when you're finished pumping?

d. Where do you store excess expressed breast milk?
    i. What type of containers? Glass bottle, plastic bottle, plastic bag
    ii. In the fridge/freezer/elsewhere
    iii. Do you label/mark breast milk with the date/time it was expressed
    iv. Typically how much breast milk do you have stored at any given time?
e. Walk me through the process of feeding your baby expressed breast milk
    i. How do you decide which container of milk to feed?
    ii. Is the milk thawed/heated?
    iii. How is the thawing/heating done?
    iv. Who prepares the bottle?
    v. How much HM is put into the bottle?
    vi. Who gives the bottle to the baby?
    vii. How do you decide who feeds the baby?
f. How long did your baby consume expressed breast milk for?
    i. Until what age in months?
    ii. Was the baby still being fed at the breast?
    iii. Was the baby introduced to infant formula or solid foods?
    iv. Were you continually pumping during this time?
    v. If not, how long after you had stopped pumping did you continue to provide breast milk to you baby? (i.e. how much HM was stored)
g. What were some of the factors that influenced your choice to pump your milk?
h. If you were feeding breast milk both directly at the breast and from a bottle during a given time period, how did you decide to feed at the breast or provide breast milk in a bottle?

4. Did you receive any information on how to pump and how to feed your baby pumped milk?

5. Tell me about the last time your baby breastfed, the last time he/she consumed breast milk, and the last time you pumped milk.

6. Do you have any friends who have had different pumping experiences?

7. How do you think that pumping your breast milk has impacted your breastfeeding experience?
    a. What are the perceived advantages?
        i. Do you feel it has enabled you to provide breast milk for longer?
    b. Have you encountered any barriers to breast milk expression?

8. Describe your ideal breastfeeding experience.

9. Have you ever heard of anyone sharing or donating breast milk
    a. How do you feel about that?

10. Have you ever considered sharing or donating your milk?
    a. Tell me more about why that is so.
        i. When did you first consider sharing/donating breast milk?
        ii. Have you discussed this with friends or medical professionals?

    b. Have you ever shared or donated your breast milk?
        i. What factors influenced your decision to share / donate your breast milk?
        ii. Walk me through the process of sharing/donation
        iii. How did you contact the person you were sharing your milk with?
        iv. How did you package and send the milk?

11. What support do you feel you have in your choice to breastfeed your baby?
    a. Partner, family, friends, medical
    b. Where did you get information related to breastfeeding from?

APPENDIX C

COGNITIVE INTERVIEWS RECRUITMENT MATERIALS

CALLING ALL MOMS!

Do you have a child aged between 19 and 35 months?

Did you ever breastfeed?

We are looking to talk to mothers about breastfeeding for roughly 1 hour

In appreciation for your time you will receive $20

For more information, please contact:

Liz O'Sullivan: (607) 379-5624

eo238@cornell.edu

CALLING ALL MOMS!

Do you have a child aged between 19 and 35 months?

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APPENDIX D

COGNITIVE INTERVIEW GUIDE

Thank you very much for taking the survey, I really appreciate your help.

1. Before we go into the questions in detail do you have any comments about the survey?

2. Were the instructions in the red boxes clear?

3. How did you find the length of the survey?

4. How did you find the order of the response options (days, weeks, months)?

5. Now that you completed the whole survey, would you answer the first 4 questions differently?

I would now like to go through some of the questions one by one to see what you thought. Please tell me if you found any question confusing. If some things are not easy to understand, I would really like your help fixing them. Don't be afraid to tell me that there is something wrong, that's what this is all about!

1. If day 0 is the day [child] was born, how old was he when he was first fed **directly** from your breast? __**Probe**__: Can you tell me what this means in your own words? __**Probe**__: What were you thinking about when you answered this question? 2. Thinking only about feeding from your breast, if day 0 is the day [child] was born, how old was he when he completely stopped feeding **directly from your breast**? __**Probe**__: Can you explain how you came up with this answer? 3. If day 0 is the day [child] was born, how old was he when **you started** pumping or hand-expressing breast milk? __**Probe**__: In your own words, could you tell me what this question means? __**Probe**__: What did you include as "pumping or hand-expressing"? __**Probe**__: Is it confusing to use the child as a reference for mom's behavior? 4. If day 0 is the day [child] was born, how old was he when **you stopped** pumping or hand-expressing breast milk? __**Probe**__: Can you explain how you came up with this answer? __**Probe**__: How sure are you of this answer? __**Probe**__: Can you tell me about when you stopped pumping or hand-expressing? __**Probe**__: Was this the very last time?	**NOTES**

5. For this next question, please pick the option that best describes your experience with **pumping or hand-expressing your breast milk**. I never did it I rarely did it I did it once or twice a week I did it on most days of the week I did it once or twice every day I did it several times every day Other **<u>Probe</u>**: Can you describe how you came up with your answer? **<u>Probe</u>**: Did you find an option that worked for you? 6. If day 0 is the day [child] was born, how old was he when he was first fed **your pumped** breast milk? **<u>Probe</u>**: Was the location of this question ok? Or would it be better if I put this after "when did you start pumping?" **<u>Probe</u>**: Can you tell me how you came up with that answer? 7. If day 0 is the day [child] was born, how old was he when he completely stopped being fed **your pumped** breast milk? **<u>Probe</u>**: Can you tell me what you were thinking when you answered this question? (Use birthday as a reference?) 8. If day 0 is the day [child] was born, how old was he when he was **first** fed infant formula? **<u>Probe</u>**: Can you tell me what you were thinking when you answered this question?	

9. If day 0 is the day [child] was born, how old was he when he completely stopped being fed **infant formula**? **<u>Probe</u>**: How sure are you of this answer? 10. If day 0 is the day [child] was born, how old was he when he was first fed **any foods or liquids** other than breast milk or formula? **<u>Probe</u>**: Can you tell me in your own words what this question means? **<u>Probe</u>**: What were you thinking about when you answered this question? 11. Please complete the following sentences about **what** [child] was drinking when he was 3, 6, and 12 months of age. When [child] was 3 months old, he was drinking… Breast milk only, no other liquids Mostly breast milk, but some other liquids About half breast milk, half other liquids Some breast milk, but mostly other liquids No breast milk **<u>Probe</u>**: Can you tell me in your own words what this question is asking? **<u>Probe</u>**: How hard was this question to answer? **<u>Probe</u>**: How sure are you of your answer for each time point? **<u>Probe</u>**: What does "mostly breast milk" mean to you? **<u>Probe</u>**: What does "some breast milk" mean to you?	

12. Some babies might drink breast milk from a bottle, cup, or spoon as well as at the breast. Please complete the following sentences about **how [child] was drinking breast milk** when he was 3, 6, and 12 months of age. Only at the breast Mostly at the breast but some breast milk from a bottle, cup, or spoon About half at the breast and half from a bottle, cup, or spoon Some at the breast but mostly from a bottle, cup, or spoon Only from a bottle, cup, or spoon S/he was not drinking any breast milk **Probe**: Can you tell me in your own words what this question is asking? **Probe**: Can you tell me how you came up with your answer? **Probe**: How hard was this question to answer? **Probe**: Did you feel like there was an option that fit your situation? 13. Please check all that apply. Where have you heard about a child being fed breast milk from another mother? I have never heard of a child being fed breast milk from another mother Friend or relative News, TV, radio, magazine Website for parents Website specifically about breast milk sharing Social media (Twitter, Facebook etc.) Doctor or health care provider Other **Probe**: Is there anywhere else that was missed? **Probe**: Tell me more about this.	

<u>Probe</u>: Did these questions about breast milk sharing seem out of the blue? Should they have a separate introduction? 14. Have you ever **thought about** feeding [child] another mother's breast milk? **<u>Probe</u>**: What do you think it means to “think about feeding your child another mother’s breast milk”? 15. Was [child] ever fed **another woman's** breast milk, even one time? **<u>Probe</u>**: Can you tell me what you were thinking when you answered this question? 16. If day 0 is the day [child] was born, how old was he when he was first fed **another mother’s** breast milk? **<u>Probe</u>**: Can you tell me how you came up with this answer? **<u>Probe</u>**: Who were you thinking of when you answered this question? **<u>Probe</u>**: Did you include family members and all possible people who may have given [child] milk, even one time? 17. If day 0 is the day [child] was born, how old was he when he completely stopped being fed **another mother’s** breast milk? **<u>Probe</u>**: How hard was this question to answer?	

18. For the time that [child] was fed **another mother's** breast milk, was this milk fed: Rarely Once or twice a week On most days of the week Once or twice every day Several times every day Other **<u>Probe</u>**: Can you describe how you came up with your answer? **<u>Probe</u>**: Did these choices work for you or would you have preferred a different option? 19. **Please read the following questions and select yes, no or unsure as appropriate** Did your child ever get donor breast milk while in the Neonatal Intensive Care Unit (NICU)? **<u>Probe</u>**: In your own words, could you tell me what this means? When you were at home after giving birth, was breast milk ever given to you by a health professional or breastfeeding support specialist (e.g. midwife, lactation consultant, nurse, breastfeeding peer counselor)? **<u>Probe</u>**: In your own words, could you tell me what this means? **<u>Probe</u>**: Can you tell me how you think this question is different from the one above?	

Was breast milk ever given to you by a relative? **<u>Probe</u>**: Who were you thinking of when you answered this question? Was breast milk ever given to you by a friend or other person you knew? **<u>Probe</u>**: Who were you thinking of when you answered this? **<u>Probe</u>**: If you were given breast milk but didn't give it to your child, would you count this? Was breast milk ever given to you by somebody you met online that you never met in person? **<u>Probe</u>**: In your own words, could you tell me what this means? Have you ever purchased breast milk from somebody that you know? **<u>Probe</u>**: In your own words, could you tell me what this means? Have you ever purchased breast milk from somebody that you don't know personally? **<u>Probe</u>**: In your own words, could you tell me what this means? **<u>Probe</u>**: Do you consider exchanging money for shipment of milk to be "purchasing"?	

Have you ever purchased breast milk from somebody you met online that you never met in person? **Probe**: In your own words, could you tell me what this means? 20. Have you ever **thought about** providing your breast milk to a child who is not your own? **Probe**: Can you tell me what this question means in your own words? **Probe**: In what situations might you think about providing breast milk to another child? 21. Have you ever donated, shared, or sold your own breast milk? **Probe**: What people were you thinking of when you answered this? **Probe**: What do you think "donated" and "shared" mean in this context? 18. Please read the following questions and select yes or no as appropriate. Have you ever donated your breast milk to a milk bank? **Probe**: What is a "milk bank," to you? Have you ever given your breast milk to a relative? **Probe**: Can you tell me what you were thinking when you answered this?	

Have you ever given your breast milk to a friend or other person you know? **Probe**: What people were you thinking of when you answered this? Have you ever given your breast milk to somebody you don't know personally? **Probe**: What people were you thinking of when you answered this? Have you ever sold your breast milk to somebody and met with them to exchange the milk? **Probe**: What people were you thinking of when you answered this? Have you ever sold your breast milk to somebody who you never met? **Probe**: In your own words, could you tell me what this means?	

Finally, do you have any suggestions to make this survey easier for mothers to take?

THANK YOU!

APPENDIX E

CHILD FEEDING SURVEY

Questions about maternal and infant behaviors	Response option
1. If day 0 is the day [child] was born, how old was he/she when he/she was first fed directly from your breast?	Days / Weeks / Months / Never
2. Thinking only about feeding directly from your breast, if day 0 is the day [child] was born, how old was he/she when he/she completely stopped feeding directly from your breast?	Days / Weeks / Months / Never
3. If day 0 is the day [child] was born, how old was he/she when you started pumping or hand-expressing breast milk?	Days / Weeks / Months / Never
4. If day 0 is the day [child] was born, how old was he/she when you stopped pumping or hand-expressing breast milk?	Days / Weeks / Months / Never
5. If day 0 is the day [child] was born, how old was he/she when he/she was first fed your pumped or expressed breast milk?	Days / Weeks / Months / Never
6. If day 0 is the day [child] was born, how old was he/she when he/she completely stopped being fed your pumped or expressed breast milk?	Days / Weeks / Months / Never
7. If day 0 is the day [child] was born, how old was he/she when he/she was first fed infant formula, even one time?	Days / Weeks / Months / Never
8. If day 0 is the day [child] was born, how old was he/she when he/she completely stopped being fed infant formula?	Days / Weeks / Months / Never
9. If day 0 is the day [child] was born, how old was he/she when he/she was first fed any foods or liquids other than breast milk or formula?	Days / Weeks / Months
10. For this next question, please pick the option that best describes your experience with pumping or hand-expressing your breast milk.	I never did it I rarely did it I did it once or twice a week I did it on most days of the week I did it once or twice every day I did it several times every day Other
11. Please complete the following sentences about what [child] was drinking when he/she was 3, 6, and 12 months of age: When [child] was 3 (6, 12) months old, he/she was drinking…	Breast milk only, no other liquids Mostly breast milk, but some other liquids About half breast milk, half other liquids Some breast milk, but mostly other liquids No breast milk
12. Some babies might drink breast milk from a bottle, cup, or spoon as well as at the breast. Please complete the following sentences about how [child] was drinking breast milk when he/she was 3, 6, and 12 months of age: When [child] was 3 months old, he/she was drinking breast milk…	Only at the breast Mostly at the breast but some breast milk from a bottle, cup, or spoon About half at the breast and half from a bottle, cup, or spoon Some at the breast but most from a bottle, cup, or spoon Only from a bottle, cup, or spoon He/she was not drinking any breast milk

Questions about human milk sharing and donating [a]	Response option
1. Was [child] ever fed another mother's breast milk, even one time?	Yes/No
a) If day 0 is the day [child] was born, how old was he/she when he/she was first fed another mother's breast milk? [b]	Days / Weeks / Months
b) If day 0 is the day [child] was born, how old was he/she when he/she completely stopped being fed another mother's breast milk? [b]	Days / Weeks / Months
c) Did your child ever get donor breast milk while in the Neonatal Intensive Care Unit (NICU)? [b]	Yes/No
d) When you were at home after giving birth, was breast milk ever given to you by a health professional or breastfeeding support specialist (e.g. midwife, lactation consultant, nurse, breastfeeding peer counselor)? [b]	Yes/No
e) Was breast milk ever given to you by a relative? [b]	Yes/No
f) Was breast milk ever given to you by a friend or other person you knew? [b]	Yes/No
g) Was breast milk ever given to you by somebody you met online that you never met in person? [b]	Yes/No
h) Have you ever purchased breast milk from somebody that you know? [b]	Yes/No
i) Have you ever purchased breast milk from somebody that you don't know personally? [b]	Yes/No
j) Have you ever purchased breast milk from somebody you met online that you never met in person? [b]	Yes/No
k) Have you ever thought about providing your breast milk to a child who is not your own?	Yes/No
2. Have you ever donated, shared, or sold your own breast milk?	Yes/No
a) Have you ever donated your breast milk to a milk bank? [c]	Yes/No
b) Have you ever given your breast milk to a relative? [c]	Yes/No
c) Have you ever given your breast milk to a friend or other person you know? [c]	Yes/No
d) Have you ever given your breast milk to somebody you don't know personally? [c]	Yes/No
e) Have you ever sold your breast milk to somebody and met with them to exchange the milk? [c]	Yes/No
f) Have you ever sold your breast milk to somebody who you never met? [c]	Yes/No

[a] Questions 1 and 2 were displayed to all mothers
[b] These questions were only displayed to mothers who indicated that their infant was fed another mother's human milk
[c] These questions were only displayed to mothers who indicated that they had shared, donated or sold their own milk

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