

“SHE WAS GIVING MY CHILD THE ESSENCE OF LIFE”:
A MIXED-METHODS INVESTIGATION OF HUMAN MILK SHARING EXPERIENCES,
PRACTICES, AND RISK PERSPECTIVES

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by

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Cornell University 2021

Human milk sharing (HMS) is a poorly understood, emergent infant-feeding practice involving the commerce-free exchange of expressed human milk (HM). In this dissertation, we took an exploratory mixed-methods approach to investigate HMS experiences, practices, and risk perspectives among milk-sharing parents.

Ethnographic interviews were conducted with 30 HMS recipients in Washington, DC. Interviews were recorded, transcribed, and iteratively analyzed using an inductive approach to identify and analyze emergent themes. These data were used to inform the development of a quantitative online survey of milk-sharing practices that was distributed to 168 HMS participants (98 recipients, 70 donors) in Washington, DC. Descriptive analyses were used to summarize the data by donor/recipient status. Latent profile analysis (LPA) was used to identify discrete risk perspectives among donors and recipients.

Our survey results demonstrated that HMS participants achieved a high duration of lactation and HM-feeding and recipients engaged in a wide variety of risk-mitigation practices. While

sociodemographically similar, donors and recipients differed substantially in their maternal experiences and infant-feeding practices. The LPA detected heterogeneity in risk perspectives among HMS participants, which underscored the complexity of infant feeding risk constructions. The LPA results confirmed that HMS risk is interpreted relative to infant-formula risk. Beliefs about infant formula and the importance of donor familiarity emerged as important constructs in parents' risk perspectives.

Our qualitative study demonstrated that the experience of HMS recipients is often a product of infant-feeding challenges that evoke feelings of guilt and shame. Emergent themes about recipient decision-making revealed careful and thoughtful analysis of infant-feeding options. Trust of breastfeeding mothers, a high value placed on human milk, and mistrust of infant formula played key roles in the decision to milk share.

These findings highlight important features of the milk-sharing experience and emphasize the need for evidence-based, non-judgmental support for families who experience breastfeeding challenges or seek alternative infant-feeding options. Better understanding of the risk perspectives held by HMS participants is critical for elucidating parental decision-making processes and developing more targeted approaches to patient care and messaging about infant feeding.

BIOGRAPHICAL SKETCH

Jennifer Peregoy earned her B.S. in Zoology from the University of Maryland College Park in 2005 and her M.P.H. in Epidemiology and Global Health Practice from the University of South Florida in 2010. For her Master's thesis, she studied the syndemic of HIV infection, food insecurity, and child malnutrition in rural Swaziland. This experience exposed her firsthand to the severe impact of undernutrition on the health of women and children, particularly in low-resource settings.

After earning her MPH, Jennifer spent 4.5 years working at the CDC – first at the National Center for Health Statistics as a survey statistician, and then at the Center for Global Health as a Rosenfield Global Health Epidemiology Fellow. As a Rosenfield Fellow, she worked on HIV surveillance in Rwanda and Mozambique under the PEPFAR program. Her time spent working in Rwanda and Mozambique further exposed her to the global health community and various types of global health actors and programs, which solidified her decision to focus her career in maternal and child nutrition. Jennifer was accepted into the doctoral program at Cornell University in 2015, where she was fortunate to have the opportunity to work with Dr. Kathleen Rasmussen. Jennifer's doctoral research focuses on human milk sharing practices and risk perspectives.

Jennifer's long-term goals are to build a career in public health nutrition that focuses on making meaningful improvements in the lives of marginalized women and children through effective public health nutrition solutions.

This dissertation is dedicated to my father, Jerry Grant Peregoy.

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number one supporter throughout my life and made so many sacrifices so that I could have opportunities that he was never afforded in life. My father was a self-trained naturalist and raised me to be curious about the world around me, which led me to study biology. I owe so much of who I am to my father; my heart is heavy that he is not here to witness the culmination of my doctoral journey. I am also grateful to my mother, Rosalie Huddleston Cesal, a feminist in her own non-radical way, who taught me the strength of womanhood and the importance of self-reliance. So much of the strong and determined woman I have become is due to the values and principles she instilled in me from a young age. Thank you for everything, Mom and Dad.

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LIST OF ABBREVIATIONS

B-HM – Banked human milk

E-HM – Expressed human milk

FF – Formula feeding

HM – Human milk

HMBANA – Human Milk Banking Association of North America

HMS – Human milk sharing

IBCLC – International Board-Certified Lactation Consultant

IFP – Infant feeding practice

LPA – Latent profile analysis

PMT – Protection motivation theory

RDS – Respondent-driven sampling

SDM – Shared decision-making

SEM – Socioecological model

S-HM – Shared human milk

CHAPTER 1

INTRODUCTION

It is widely accepted that the best start in life is provided by exclusive breastfeeding for 6 months, with continued breastfeeding for one year or longer. The benefits of breastfeeding are numerous and far-reaching, with more still being discovered. Following optimal breastfeeding practices decreases the risk of infant mortality, otitis media, upper respiratory infections, allergies, SIDS, asthma, child obesity, and necrotizing enterocolitis, among others (1-3). However, parents who aren't willing or able to provide enough human milk (HM) to meet all their children's nutritional needs must supplement with either HM substitute or donor HM. In a contemporary variation on an ancient practice, many families are turning to peer-to-peer HM sharing (HMS) to feed their infants. However, there is scant research on this emergent infant-feeding practice and the implications of HMS are not well understood. Rigorous scientific investigations on this topic are needed to better understand the decision to engage in milk sharing, the practices involved, how HMS is experienced by participants, and the benefits and risks associated with the practice.

This dissertation focuses on understanding the milk sharing experience from two complementary perspectives: a broad ethnographic view (taking an emic approach) and a focused quantitative assessment of practices (etic approach). Emic ethnographic approaches aim to reveal categorizations that emerge from the data, while etic research approaches reflect the *a priori* categorizations and prioritizations of the researcher (4). The goal is to triangulate these two complementary types of data with the existing literature to develop a more holistic and nuanced understanding of this complex and poorly understood infant feeding practice. This research begins to fill some of the knowledge gaps by generating evidence on milk sharing that is needed for the development of more effective clinical practice and public

health recommendations that are informed by and relevant to the contemporary, lived realities of parents.

Emergence of HMS

Public health officials and clinicians consistently promote exclusive breastfeeding for 6 months and continued breastfeeding for 2 years or longer. It is well established that following these breastfeeding recommendations optimizes growth and cognitive development, and decreases illness incidence, severity and duration compared to suboptimal breastfeeding (1-3). This messaging has created widespread public awareness that “breast is best” and formula is nutritionally and immunologically inferior, associated with numerous health risks. However, despite this awareness, American women are falling far short of achieving the targets set for breastfeeding duration and exclusivity (5). Many women are unable to meet their breastfeeding goals because of barriers that are biological (e.g., lactational insufficiency, poor breast health, or taking medications incompatible with breastfeeding), social (lack of social support for breastfeeding, cultural norms of formula feeding), and structural (e.g., institutionalized racism, inadequate access to health services, lack of paid parental leave, workplace policies incompatible with breastfeeding) (6-8).

When a woman is unwilling or unable to produce enough HM to fully cover her infant’s dietary needs, she needs to find an alternative source of food. Historically, before there was widespread access to safe infant formula, donor HM would have been sought from someone geographically close to her who could feed her infant at their breast: a relative, a wet nurse, or someone from her local community (9, 10). In modern times (since the invention of safe HM substitutes), the woman would have typically turned to commercial infant formula to feed her baby (and a small minority might attempt to make homemade infant formula). However, relatively recently, HMS has emerged as an unconventional alternative infant feeding strategy

(11, 12). HMS is defined as the commerce-free exchange of HM occurring outside of the formal milk banking system. It is important to note that this phenomenon is distinct from milk selling, which is also done peer-to-peer but includes a financial transaction. HMS is a contemporary transformation of historical milk sharing – one that still relies on a donor with surplus milk and a recipient with a milk deficiency but is no longer limited by temporality and geographic proximity due to the modern inventions of refrigeration, internet, and the double-electric breast pump.

Supply and Demand

Modern HMS is a practice comprising three key players: donors (parents), recipients (parents), and the consumers (children). Donors are parents who have surplus HM they do not need for their own child and recipients are parents who have a HM deficit and have decided they'd like to supplement their child's diet with donor HM. The consumers are the infants and children who ultimately drink the shared HM (S-HM) once their parents have procured it and prepared it for feeding. It is instructive to examine both the supply and demand sides of HMS to appreciate the antecedents of the practice.

Donors (supply). Numerous factors contribute to the increase in the number of parents with surplus HM to donate. First and foremost is the relatively recent availability of more affordable, double-electric breast pumps, which has resulted in a rapid expansion of the proportion of breastfeeding women who rely on breast pumps to extract their milk (13, 14). Once the milk has been expressed, having access to freezers has enabled women to store their expressed human milk (E-HM) for later use (15, 16). This removes the imperative to feed the milk soon after expression as it can now be safely stored for 6-12 months (17). But perhaps the bigger question is: what is compelling women to stockpile so much expressed milk? This is a complex and under-researched topic, so there isn't yet a clear answer to this question.

However, material from the lay press and “mommy” internet sites suggest that there is a pervasive general anxiety about having sufficient E-HM supply in the case of illness, separation from infant, or returning to work. Additionally, *perceived* milk insufficiency is one of the of the most common concerns cited by breastfeeding women in the US and is associated with suboptimal breastfeeding outcomes (18, 19). Perceived milk insufficiency may also contribute to the development of a pumping dependency, which can increase milk production above that needed by their infant and create a surplus.

Recipients (demand). The numerous factors that lead to the development of a demand for HM can be grouped into four overarching categories: infant, maternal, cultural, and policy-related factors. Infant factors refer primarily to the infant’s health status, which includes factors such as growth faltering, being born prematurely, lip and/or tongue tie, dietary sensitivities or allergies, and the many other health conditions that may contribute to an infant either not responding well to infant formula or not establishing a successful breastfeeding relationship. Maternal factors are more diverse and cover a wide range of influences, such as attitudes and beliefs regarding infant feeding practices, social support specific to breastfeeding, experiences during labor, childbirth, and postpartum, and socioeconomic status—just to name a few.

Importantly, maternal health contributes to the demand for HM as many women who intend to breastfeed experience health issues that prevent them from doing so. Such issues include use of medications contraindicated while breastfeeding, breast abnormalities, health conditions that affecting lactation, breast cancer, etc. Cultural factors also play a significant role in creating strong demand for HM. These include a widespread cultural mindset shift to view breastfeeding as a key behavior of a “good mother,” and growing level of concern around the potential negative effects of formula feeding. And finally, several key public policy factors have increased the demand for HM. The most significant among these is the lack of paid,

federally mandated parental leave, which forces many postpartum women to return to work far too soon before their breastfeeding relationship with their infant is well established. Finally, the shortage of HM within the milk banking system means that many families seeking HM do not qualify for banked HM (B-HM), and instead turn to a peer-to-peer model of milk donation (20-22).

Prevalence of Milk Sharing

It has been reported that up to 77% of women are aware of HMS and 25% have *considered* sharing their milk, but relatively few (4-10%) have done so (23-25). The modern HMS landscape is thought to be predominantly organized around the internet, where global websites such as *Eats on Feets* and *Human Milk 4 Human Babies* have been developed to facilitate the direct sharing of HM between families (26). Anecdotal evidence suggests that web-mediated HMS has risen rapidly since the introduction of these HM sharing websites around 2006. In 2012, it was reported that there were more than 170 Facebook groups facilitating HMS in over 50 countries, reflecting a strong interest in HMS by women and families globally (27). The proliferation and popularity of these HMS websites has likely only increased since then. This web-mediated HMS typically links two mothers or families who live near one another but were previously strangers and facilitates the development of a commerce-free milk-sharing relationship based on the principles of mutual trust and exchange.

HMS Participants

Parents who seek S-HM typically experience some kind of difficulty with lactation itself or with the context in which they must pump and feed their own milk (among mothers), are highly motivated to feed their infants HM (or conversely highly averse to feeding their infants

formula), do not qualify for B-HM from accredited non-profit milk banks¹, and/or cannot afford to purchase B-HM from for-profit milk banks² (27, 28). Therefore, the increasing demand for HM has exceeded the supply available through accredited milk banks, and it appears that this unmet need has galvanized the recent development and expansion of modern HMS (11).

Given the potential risks associated with the informal exchange of HM, it is important to understand who engages in HMS and why these parents choose to seek an informal milk donation arrangement. Most studies of HMS have recruited participants online through Facebook groups or websites for milk sharing and/or breastfeeding, and the vast majority of these participants have been White, highly educated, employed, and of high socioeconomic status – a demographic group that reflects the broader pattern of women with the highest prevalence of breastfeeding in the US (8, 26). From a large online survey of 867 HMS participants, both donors and recipients reported higher-than-average values for maternal education, exclusive breastfeeding, and breastfeeding duration (28). However, compared to donors, recipients reported significantly lower income, education, and social support for breastfeeding, reflecting the broader political economy of breastfeeding in the United States. These findings have led researchers to speculate that HMS may be a phenomenon predominantly practiced among non-Hispanic White women of higher educational attainment and SES.

¹According to HMBANA guidelines, the triage for priority in receiving donor milk is granted in order of priority, as follows: sick premature infants, well premature infants, infants less than twelve months of age with varying medical conditions, research contracts for clinical use in well-designed studies, individuals more than twelve months old with varying medical conditions, well infants for short-term use, and finally, laboratory research.

²When allocating donor milk, recipient families are often left to fully cover the costs of obtaining donor milk. Several HMBANA milk banks, however, provide financial assistance to outpatient families in need through charitable care programs and methods including donations, subsidies, and grants. Many third-party payers cover the cost of donor milk with proper physician prescriptions and documentation.

To date, there has not been a single study conducted on HMS in the Black community – contributing to a complete silence in the narrative about how Black Americans fit into the emergent world of HMS. However, it would be presumptuous to infer from this limited body of research that Black parents are not participating in milk sharing. It is more likely that the study designs used (e.g., online sampling of exclusive milk-sharing websites) have been ineffective at accessing Black parents who engage in HMS. This suggests that we need to rethink our approach to studying milk sharing if we want to broaden the discourse and our understanding to include Black Americans – a particularly important subgroup of women who are at high risk of the predictors of suboptimal breastfeeding practices, developing suboptimal breastfeeding practices, and poor infant health outcomes.

Risk and Risk Perceptions

Risk can be defined in many ways, but a general definition is “a measure of the probability and severity of adverse effects,” while risk perception is “the ability of an individual to discern a certain amount of risk” (29). From a public health perspective, it is important to assess risk to understand the potential adverse effects of a given exposure, but understanding risk perceptions is just as important because perceptions are strong determinants of behaviors. That is, if the actual risk of an exposure is very high (e.g., smoking is strongly causally associated with incident lung cancer), but individuals’ perception of that risk is low (e.g., they believe that smoking only slightly elevates their risk of lung cancer), then they will be more likely to engage in the risky behavior. An important related concept is risk tolerance, which is “a person’s capacity to accept a certain amount of risk” (29). To use the smoking-lung cancer example, individuals may accurately perceive the risk of smoking as high for developing lung cancer, but if they have a higher level of risk tolerance then they will still be more likely to smoke than others with a lower risk tolerance. These three concepts (risk, risk perception, and

risk tolerance) are interrelated and influence one another (e.g., inaccurate risk perceptions may lead to higher risk tolerance levels, which can contribute to engaging in riskier behavior).

The practice of HMS poses a variety of potential risks. The magnitude of risk remains unknown, but it is likely variable and dependent on the health and health behaviors of the person expressing the milk, the extent of screening conducted before exchanging milk, and the type of risk-mitigation strategies employed. Public-health concerns about the unregulated exchange of raw, unpasteurized HM include the potential for transmission of pathogens (e.g., HIV, CMV, and syphilis), sharing of undesirable substances (e.g., tobacco, prescription medications, and illicit drugs), and microbial contamination from suboptimal expression, storage, and transport practices (11, 12, 30). Keim et al. have shown that HM sold online (i.e., commodified HM) is of demonstrably inferior quality – containing tobacco and caffeine metabolites, with high microbial contamination, and even adulterated with cow's milk – and poses higher risk to infants when compared to B-HM (31-35).

However, it is noteworthy that the population of women who sell their milk is likely distinct from women who share their milk without financial remuneration. Mothers who choose to donate in HMS are typically altruistically motivated and have surplus milk stored in their freezer, milk that was originally expressed with the intention to feed it to their own infants (36). In a 2018 study, Perrin et al. analyzed and compared the characteristics of various commerce-free expressed milk samples: S-HM, B-HM, mother's own milk expressed for her own infant, and milk that was donated via a commerce-free health professional-facilitated milk sharing program (37). They found no differences in the rates of total aerobic bacterial or coliform growth, antimicrobial protein content, macronutrient content, or water content across the groups of milk samples. As the first evidence generated on S-HM quality, this study suggests that S-HM is comparable in composition and quality to expressed mother's own milk

and E-HM being donated to milk banks for the content analyzed. However, they did not ascertain if these samples differed in their content of many of the contaminants considered by Keim et al. (31-35). Together, these findings suggest that commerce-free models of HM exchange may be similar in quality to mother's own milk, whereas the addition of financial incentives likely substantially increases the risk of HM contamination and dilution.

It has been demonstrated that mothers who receive S-HM actively engage in risk assessment and mitigation strategies. In a cross-sectional survey about risk perceptions and risk management among HMS donors and recipients, Gribble found that all recipients reported practicing some type of risk-mitigation strategy, including asking personal questions of the donor, obtaining medical clearance from the donor, ensuring the donor is breastfeeding her own infant, and heat treating the S-HM (38). However, recipients had incomplete knowledge of the risks of HMS. For example, only 46% of recipient participants indicated that HM could be contaminated with drugs, and 34% of participants indicated that unhygienic HM expression or storage practices could result in milk contamination. Although HMS indeed carries health risks, many HMS participants have also reported concerns about the risks associated with formula feeding, including illness, contamination, problematic ingredients, and feeding problems (25, 27). Ultimately, there is no risk-free infant feeding option, and the risks are greatest before the introduction of solid foods when HM (or HM-substitute) is the sole source of infant nutrition.

Overall, HMS recipients seem to derive their comfort with using S-HM from their knowledge of and relationship with their donors, with particular emphasis on mutual trust (39). Research findings suggest that most HMS recipients engage in a careful risk assessment and conclude that the risks of formula feeding are greater than those of feeding S-HM and, furthermore, that the benefits of feeding S-HM outweigh the risks. However, to develop more effective risk-

communication strategies, a better understanding is required of how milk-sharing participants perceive these risks, and importantly, how their perceptions influence their infant feeding decisions and practices.

Public Health and Nutrition Implications

HMS has implications for public health and child nutrition. Research is just now beginning to describe the ways in which E-HM differs from HM fed at the breast. There are compositional changes in the milk as a result of expression and storage practices. These changes may be nutritional, microbial, or immunological (40). The numerous parts and supplies involved in HM expression with electric pumps provide opportunities for bacterial contamination. Storage of E-HM in the refrigerator or freezer causes lysis of immunological cells and reduce the antioxidant activity in E-HM (40-42). Feeding bottled HM substantially alters the physiological process of milk consumption compared to feeding at the breast (FAB). Feeding E-HM has been associated with increased risk of otitis media, diarrhea, and upper respiratory infections in infants compared to those fed at the breast (43, 44). The retrograde saliva flow that occurs during FAB (45-47) is absent in the case of milk expression, thus potentially altering the immunological composition of E-HM and rendering it less targeted for environmental pathogens. Furthermore, feeding E-HM that has been frozen for a period of time means that the antibodies in the milk at the time of expression may no longer be relevant to the infant at the time of consumption. This may reduce the anti-infective properties of breastmilk by adding a time lag.

Given that milk sharing is predominantly based upon the exchange of frozen E-HM, the practice has all the above-mentioned concerns associated with feeding E-HM, but with the additional complexity of decoupling the mother-infant dyad. The HM originally expressed for a mother's own infant is now being consumed by another infant in a different environment,

often at a different age, who may have different immunological and nutritional needs. This presents additional infant feeding challenges and questions. Is milk that was expressed for one child still appropriate for another child to consume? What role does the chronobiology of HM play in HMS? Are there immunological benefits to a child consuming E-HM from multiple women? We know that age-matching the milk between donor child and recipient child is important, but how large an age gap is acceptable? Unfortunately, scientists don't yet have the answers to these questions. There are also broader public-health implications of this practice that have not yet been carefully examined. What implications do HMS have for "breastfeeding" trends? It is conceivable that HMS could improve "breastfeeding" trends by increasing the proportion of infants who are consuming HM (who would have otherwise been consuming formula) – a goal universally agreed upon by clinical and public-health experts. Viewed in this way, milk sharing could be framed as a mechanism to address infant food insecurity by redistributing surplus HM to infants with insufficient access to HM.

Gaps in Practice and Research

Widespread stigma associated with milk sharing (48-52) means that parents (particularly recipients) may feel ashamed or uncomfortable discussing it with their medical providers, even to ask questions. It has been reported that HMS participants often do not discuss milk sharing with their healthcare providers and most do not view healthcare providers as important sources of information for their infant feeding choices (51, 53). This results in a missed opportunity for an open and informative discussion between patient and provider; parents interested in HMS as an infant feeding strategy often resort to searching the internet for information to guide their decision-making process. Information on the internet varies dramatically in quality and accuracy and is often not the best source of high-quality scientific information. It is preferable for clinicians to have informed discussions with their patients

about the evidence-based risks and benefits of HMS (51). Of course, additional scientific evidence is needed to support such conversations.

There is scant research on HMS. It is an emergent phenomenon and, thus, the research literature on it is also now emerging. It is also an innately difficult subject to study because milk sharing families constitute a “hidden population,” meaning that they engage in a behavior that is stigmatized, are unlikely to disclose their status as a member of that population (and thus, their friends and family members may not even be aware of their status), and no sampling frame exists to reach them (51, 54). Inasmuch as this population is difficult to reach, it impedes the conduct of rigorous scientific studies on the practice. Additionally, most of the research conducted on HMS to date has focused on the population of milk sharing families who connect online. However, this only constitutes a part of the broader HMS community, as there are many families who milk share but never use an online website to do so (55). Within the small body of research on HMS, there is little focus on the subjective experience of milk sharing or on risk and risk perceptions relative to HMS decision-making. This dissertation aims to fill some of these important research gaps.

Research Approach

Socioecological Framework. Socioecological models are useful in examining complex health problems characterized by multiple spheres of influence, dependencies across levels of influence, unpredictable or nonlinear human behavior, and multiple adaptive interrelated systems. Bronfenbrenner’s socioecological model (SEM), often applied to public health problems, focuses on contributing factors at the microsystem, mesosystem, exosystem, macrosystem, and chronosystem levels to arrive at an overall ecological systems perspective presented in an integrated and overlapping macro-level view (56). As a result of its

comprehensiveness and ease of use, SEM has been modified and adapted extensively to examine various complex health behaviors such as smoking cessation, risky sexual practices, or diabetes management, and it provides a robust framework for designing targeted interventions (57). As a theoretical lens for this research, SEM will guide a critical analysis of the interactive determinants of infant feeding decisions and practices, as applicable to contemporary HMS.

Applying an SEM lens to this research accounts for the nonlinear and complex nature of HMS, emphasizing factors within the larger ecological landscape that influence infant feeding decisions and practices (Figure 1). This conceptual framework was inspired by Frieden’s

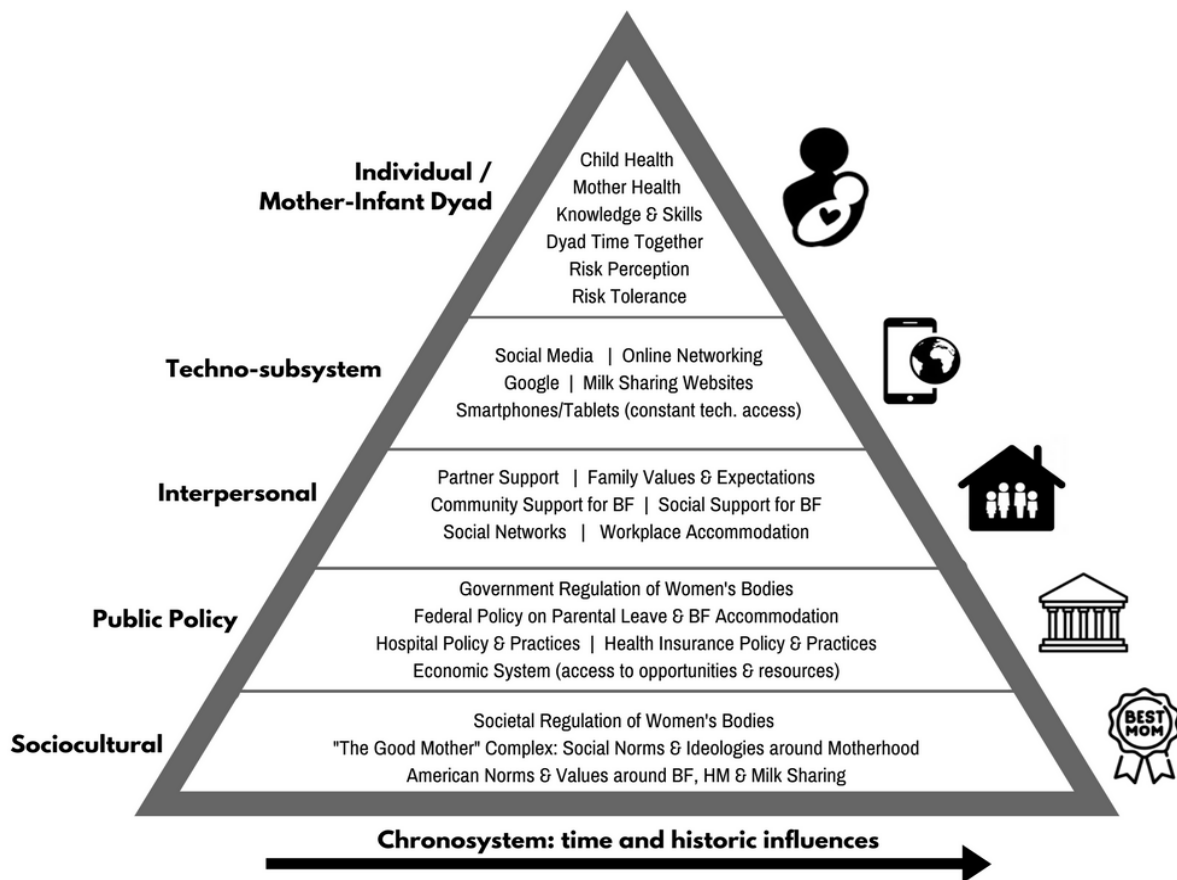


Figure 1. Conceptual framework illustrating a socioecological model of factors influencing contemporary HMS.

pyramid of public health impact (58) and developed as a way to visualize the multiple overlapping layers of influence on the HMS practices. This SEM framework incorporates two features that are not commonly seen in SEM frameworks: the techno-subsystem and the chronosystem. The techno-subsystem is influential in the development and practice of HMS because contemporary HMS is heavily reliant on the use of the internet, computers, and mobile phones to connect donor and recipient families. In the context of HMS, the chronosystem refers to the temporal evolution of cultural beliefs and norms regarding infant feeding practices, as well as the developments in technology that have given rise to modern HMS (e.g., refrigeration and the widespread availability of double-electric breast pumps). The intricacy of the model and its heavy emphasis on contextual determinants of infant feeding practices will result in an SEM framework that differs substantially across families of different backgrounds and socioeconomic status. By grounding this research in socioecological theory, we expect to generate a more holistic view of the breastfeeding ecology as it relates to HMS from the myriad sociocultural and structural determinants of infant feeding practices. We do not aspire to create a comprehensive SEM framework for HMS. Instead, we expect that the data generated from this research will reveal the SEM constructs that HMS recipients identify as most salient to their experiences. In turn, these constructs guide the analysis and interpretation of the data.

Protection Motivation Theory. In the literature on risk perception and risk tolerance, Protection Motivation Theory (PMT) is frequently used to predict and interpret risk-taking and protective behaviors (29). PMT expands expectancy value theory to incorporate reward and self-efficacy as constructs (59). According to PMT, risk-taking behavior is determined by

a careful consideration of threat severity, likelihood of negative consequences for the individual, and protective measure or coping strategy effectiveness (Figure 2). According to PMT, the initiation of protective (or risky) behaviors is guided by two cognitive processes: threat evaluation (threat-appraisal process) and selection of coping strategies (coping-appraisal process). Inputs to the model include environmental information sources (observational and verbal) and intrapersonal sources (personality characteristics, prior experiences, etc.). An individual facing a given threat would engage in both cognitive processes to determine their coping mode, which may be either adaptive or maladaptive (i.e., risky or protective).

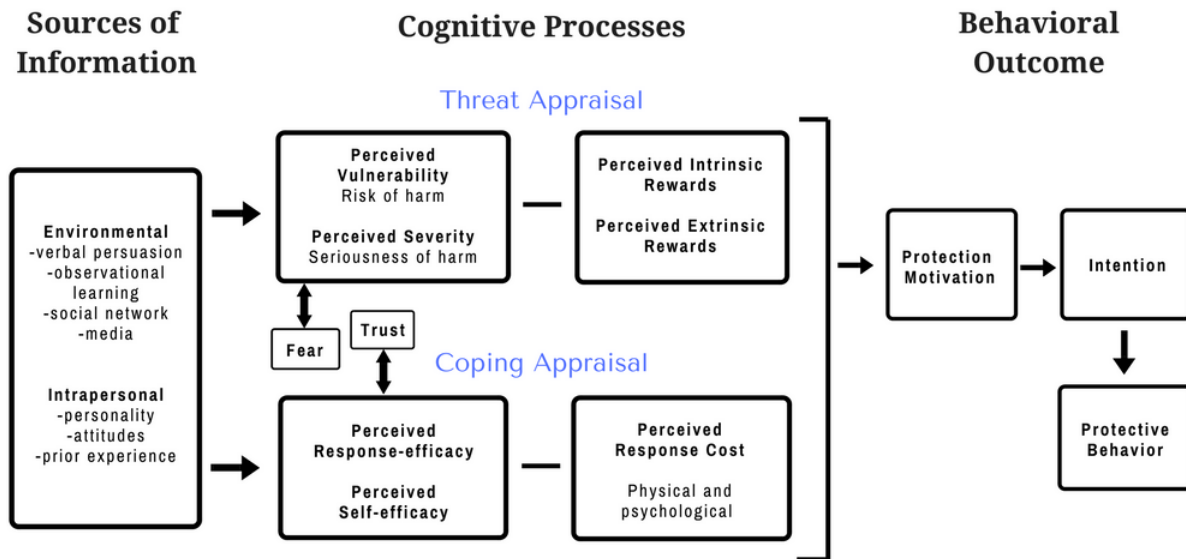


Figure 2. Conceptual Framework of Protection Motivation Theory, adapted from Floyd et al. (2000).

The coping-appraisal process involves two distinct types of efficacy: *response-efficacy*, the degree to which a protective behavior is expected to provide protection against the threat, and *self-efficacy*, an individual's perception of their own ability to successfully carry out the coping behavior. The threat-appraisal process includes assessing intrinsic and extrinsic

rewards, and estimating threat severity, along with perceived vulnerability. The threat-appraisal and coping-appraisal processes combine to yield a final behavioral determination (adaptive or maladaptive). *Optimism bias* is an important concept relevant to PMT, accounting for people taking risks and feeling adequately shielded from harmful consequences because they overestimate the effectiveness of protective measures or underestimate their personal vulnerability to a given threat. PMT will be applied to interpret the findings on HMS risk perceptions and risk-mitigation behaviors of parents who have engaged in the practice.

Conceptual Framework

Conceptualizing parental cognitive frameworks helps to improve our understanding of the infant feeding decision-making process, and the case of HMS is no exception. These cognitive frameworks account for the various sources of information parents receive about their infant feeding options, as well as their judgments and perceptions about the various costs, benefits, and risks involved with each option. All these factors feed into parental decisions and behaviors, and more specifically, will determine how the chosen infant feeding strategy is implemented (e.g., risk-mitigation strategies employed as part of an HMS arrangement).

The conceptual framework that guided this research (Figure 3) is adapted from PMT and posits that individuals' infant feeding decisions and behaviors are determined after they have engaged in the dual cognitive processes of threat appraisal and coping appraisal, much of which may be happening at a subconscious level. This process incorporates individual perceptions about a threat's severity and their vulnerability to it, rewards associated with the

risk behavior, as well as the response-efficacy of any protective behaviors, self-efficacy in performing these behaviors, and any costs associated with the protective behaviors.

Ultimately, this is a cost-benefit analysis of the perceived risks and benefits associated with each infant feeding option, combined with perceptions about the effectiveness of available risk-mitigation strategies and confidence in one’s ability to perform these strategies.

In the case of parents who choose to practice HMS, we posit that these parents typically engage in this cognitive assessment by comparing infant formula to S-HM because of insufficient mother’s HM (either expressed or fed at the breast) to fully nourish their child. Thus, parents engaging in HMS have compared the risks and benefits of formula to HMS and decided that the HMS risks are lower or the benefits are greater, relative to infant formula. It

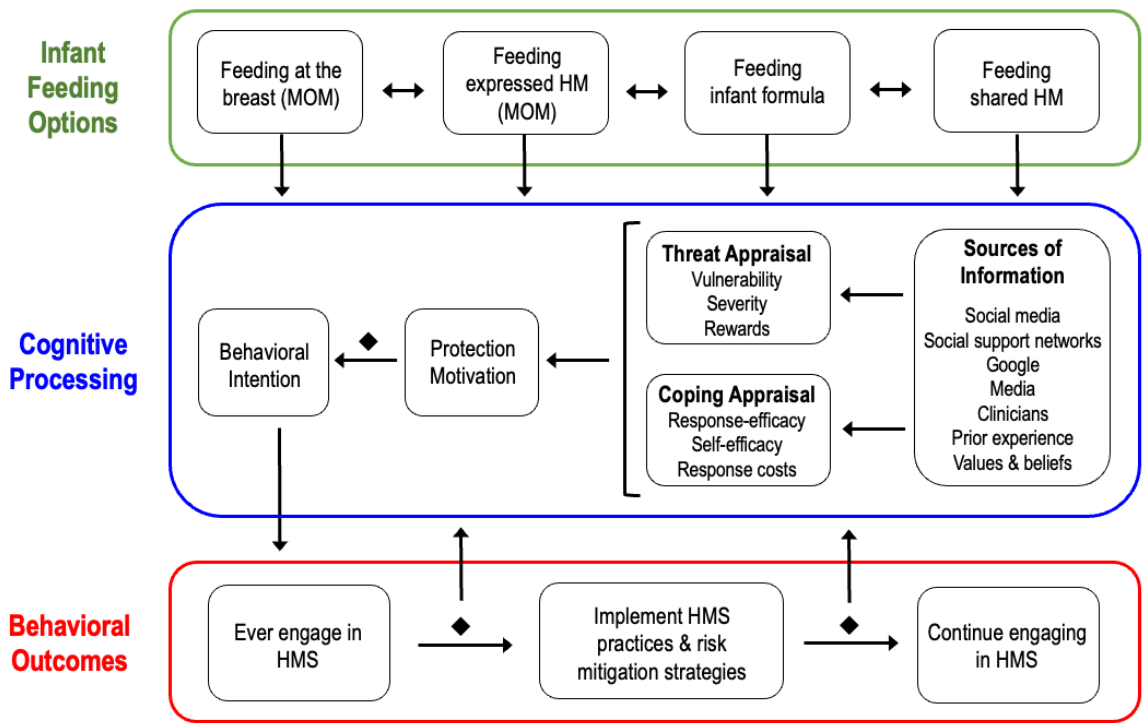


Figure 3. Conceptual framework guiding this dissertation research on infant feeding decision-making, adapted from Protection Motivation Theory. Diamonds indicate decision points.

is important to emphasize that these cognitive processes are influenced by parents' previous infant feeding experiences and are modified by the multitude of contextual factors previously discussed in the SEM of HMS (captured in Figures 2 and 3 under *Sources of Information*).

Another important feature of the proposed conceptual framework is the iterative nature of the risk assessments conducted at various time points (indicated by black diamonds and arrows pointing towards the blue box), each with a slightly different purpose and potentially different inputs. For example, the threat and coping appraisals conducted for the initial decision to milk share vs. formula feed may be brief (especially when parents view it as a temporary need), followed by a more rigorous assessment once HMS parents are deciding what risk-mitigation strategies, if any, to employ. The proposed research will examine the key constructs in these cognitive processes to better understand how parents arrived at their decision to milk share and why they chose specific HMS behaviors, and furthermore, which determinants are most salient to these decisions.

A Mixed-Methods Investigation of Human Milk Sharing

This dissertation research employs an exploratory mixed-methods approach³ by using the ethnographic data gathered in Phase I to inform the development of the quantitative assessment in Phase II (Figure 4). The first research phase consisted of an ethnographic investigation of milk sharing practices and experiences among a sample of HMS recipients in the Washington, DC metropolitan region. The second research phase included the

³By an exploratory mixed methods approach, we mean that the qualitative data will be collected first and used to inform the collection of the quantitative data (as contrasted to an explanatory design, where the order is reversed).

development and implementation of a quantitative web-based survey of HMS practices, attitudes, beliefs, and perceptions.

This dissertation aims to fill gaps in knowledge about how HMS is experienced and practiced, how milk-sharing parents perceive infant feeding risks, and how they make infant feeding decisions. In this dissertation, we are guided by the following specific aims:

AIM 1. Identify and critically analyze narratives of infant feeding experiences among milk-sharing recipients.

AIM 2. Quantify HMS practices among a geographic network of milk-sharing parents and identify differences between donors and recipients.

AIM 3. Identify risk perspectives held by milk-sharing parents and identify correlations between risk perspectives, infant feeding practices, and HMS practices.

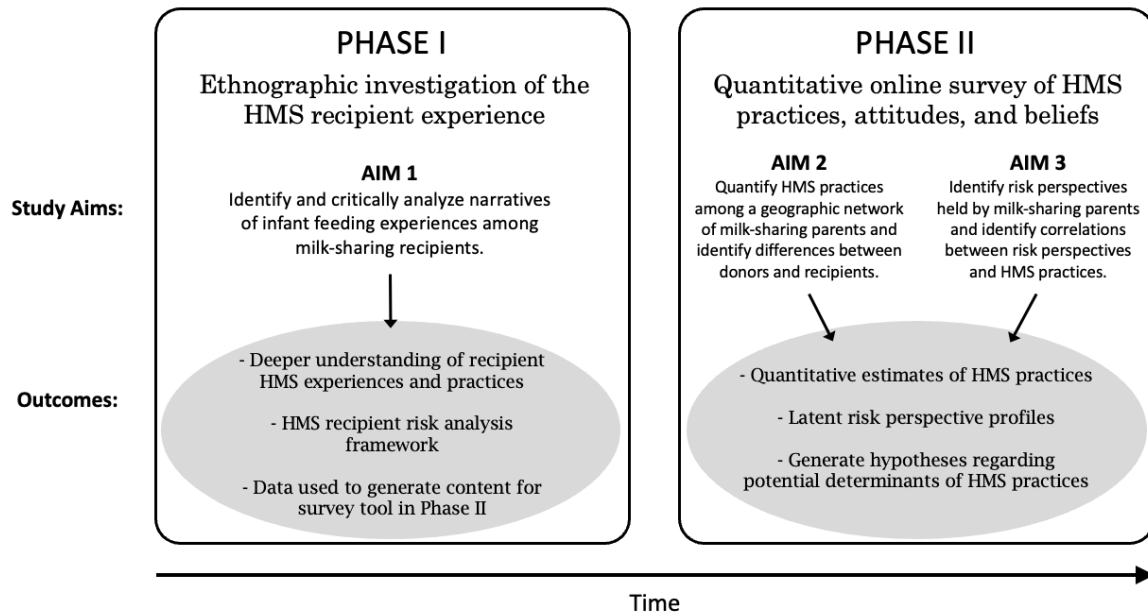


Figure 4. Dissertation research approach.

The first study phase consisted of an ethnographic investigation of parents who have participated in HMS *as recipients* in the past 12 months. Ethnography is a systematic approach to collecting information about social and cultural life, including the contextually specific beliefs, perceptions, values, and behaviors of individuals and communities (60). As a research approach, ethnography differs from the biomedical sciences in that it uses the researcher as the primary tool of data collection. We employed a common ethnographic technique, the in-depth interview, which explores topical domains relevant to the research question through in-depth conversations with key informants from the community of interest. In-depth interviews are particularly useful for exploring cultural knowledge and beliefs, and for gaining rich description of behaviors and practices (60).

When exploring cultural perspectives, it is important to consider intra-cultural variation within groups. A historical problem in health and anthropological research has been the assumption of cultural, cognitive, and behavioral homogeneity, neglecting the different perspectives and experiences of individuals within a given culture (61). No culture is entirely homogenous, though for the sake of parsimony and categorization it may be tempting to assume so. In reality, cultural perspectives are highly nuanced and diverse, and it is the researcher's role to notice, seek, and report those areas of diversity. The concept of intra-cultural variation is particularly salient in the context of HMS because HMS networks are composed of individuals who are apparently similar in terms of sociodemographic profile, but who have different experiences and beliefs, and are united by their shared value of HM. The degree to which HMS participants share common cultural perspectives about infant feeding practices and risk perceptions remains unexplored.

The second study phase consisted of the design and implementation of a web-based quantitative survey among milk-sharing parents (donors and recipients) residing in the greater

Washington, DC metropolitan region. This phase of the research involved the development, cognitive testing, and usability testing of the detailed survey tool. The data collected from this tool were then used to address Specific Aims 2 and 3.

Throughout this dissertation, careful attention was paid to the use of language in describing specific populations. When describing the research samples and their specific responses, the terms respondents, study participants, recipients, donors, and mothers are used because the samples consisted of people who self-identified as women. When describing decisions made jointly by both parents or when extrapolating the results to the broader population of milk-sharing parents, the terms parents and families (e.g., donor parents or recipient families) are used.

The analytic chapters in this dissertation are presented from the broadest population to the most focused and thus, are not in the order in which the research was conducted. In Chapter 2, we present the results of the quantitative survey of HMS practices among HMS donors and recipients. In Chapter 3, we report findings from the latent profile analysis of risk perspectives related to infant feeding practices among HMS donors and recipients. In Chapter 4, we describe emergent themes from the ethnographic investigation of recipient milk sharing experiences. Finally, in Chapter 5, we summarize our research findings, discuss the strengths and limitations, consider the research and public health practice implications of our work, and suggest future research directions.

CHAPTER 2

RESULTS FROM THE MILK SHARING PRACTICES SURVEY

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Abstract

Background: Human milk sharing (HMS) is growing in popularity as an infant feeding strategy in the United States. HMS parents represent a hidden population because it is a non-normative and frequently stigmatized behavior. Thus, gaining access to HMS participants is challenging, and research on this topic remains limited.

Objective: To describe and compare the infant-feeding practices, HMS practices, and factors influencing infant feeding decisions among a geographically-defined network of milk-sharing donors and recipients in Washington, DC.

Methods: A detailed online survey was distributed to milk-sharing parents in the DC region. Bivariate analyses were used to summarize and describe the data by donor/recipient status when possible. Group differences were tested using ANOVA for continuous variables and chi-square tests for categorical variables.

Results: Donors and recipients were demographically similar. Recipients were significantly more likely than donors to have experienced any one of: complications of labor and delivery, traumatic birth, postpartum depression, and a negative breastfeeding experience. Donors had a higher mean lactation duration (15.3 months) than recipients (11.0 months), while recipients were more likely to have fed infant formula or banked human milk to their child. Most recipient children were healthy, term infants, but 33% had been diagnosed with a tongue and/or lip tie. Recipients' decisions to participate in HMS were influenced by their social networks and online resources, and motivated by lactation challenges, beliefs about breastfeeding being the biological norm, infant hunger, and infant formula intolerance. Donors' decisions to participate in HMS were motivated by altruism and practicality.

Conclusions: Compared to donors, recipients faced numerous health challenges and achieved shorter durations of lactation and human-milk feeding. HMS recipients represent a vulnerable group of women who may require additional psychosocial and lactation support to improve their health and breastfeeding outcomes. Additional research is needed to investigate the associations between HMS participation, lactation outcomes, and infant-feeding practices.

Introduction

Human milk (HM) is the ideal form of infant nutrition, providing numerous health benefits for both infant and mother (2, 3, 62). Public health and medical authorities recommend that infants be exclusively breastfed for 6 months, with continued breastfeeding for one year or longer, as desired by mother and infant (63-66). However, American women are falling short of those goals. According to the most recent national-level data, 84.1% of infants born in 2017 started breastfeeding, 58.3% of infants were still breastfeeding at 6 months, and only 25.6% were exclusively breastfed for 6 months (5). The high proportion of women who initiate breastfeeding shows that they desire to breastfeed, while the steep subsequent decline in this proportion indicate that they are having difficulty doing so. Foremost among the reasons for early cessation of breastfeeding is that American women live in a policy environment that is not supportive of breastfeeding. The United States is one of the only high-income countries without federally mandated, paid parental leave. This forces many women to return to work soon after giving birth, which is associated with reduced breastfeeding duration and intensity (67-73). Many workplace environments are not conducive to expressing HM, and access to high-quality lactation support is limited and inconsistent (68, 69, 74, 75). This unsupportive environment has made it challenging for women to breastfeed successfully.

Parents who are unable to breastfeed exclusively and need to supplement their infant have several options. The default option used by most parents is commercial infant formula. However, infant formula has numerous drawbacks. It is expensive, has a history of quality-control issues in other countries, such as contamination with heavy metals or *Cronobacter*

species (76, 77), and can cause constipation, reflux, or other feeding difficulties. Compared to at-the-breast feeding, formula feeding is also associated with an increased risk of numerous undesirable health outcomes, including otitis media, respiratory infections, SIDS, diabetes, obesity, and allergies (2, 3, 62, 64, 78-81). Another potential option for supplementing infants is to use banked HM (B-HM) from a HM bank. However, there are currently only 31 HM banks run by the Human Milk Banking Association of North American (HMBANA) and demand far exceeds the supply (82, 83). The limited supply of B-HM is typically reserved for the most sick and vulnerable infants in NICU settings. Therefore, B-HM is inaccessible to most families who need to supplement their infant. Another supplemental feeding strategy has recently emerged, namely human milk sharing (HMS), a contemporary form of an ancient practice. For this research, HMS is defined as the commerce-free exchange of HM between individuals and excludes HM exchange with remuneration or with organizations.

Contemporary HMS is a relatively new infant-feeding practice enabled by the ready availability of surplus frozen expressed human milk (E-HM). In the industrialized, high-income populations where milk sharing has been studied, mothers rely substantially on HM expression to feed their own infants (84, 85). This has created an environment ripe for HM exchange, where some women are unable to produce enough milk to feed their infants and others produce in excess, accumulating sizable quantities of E-HM in their freezers. In the United States, HMS donors have been shown to be demographically similar to the women who donate to HMBANA milk banks (86). HMS recipients are often mothers with a strong desire to breastfeed but who experience breastfeeding challenges and lactation insufficiency (28, 48, 52, 53, 87). Parents whose infants are experiencing inadequate growth or are

intolerant of infant formula are another important subgroup of HMS recipients (23, 28, 51, 53).

The self-regulated and peer-to-peer nature of HMS renders it a highly individualized and heterogeneous set of practices. Prior research has shown that much of HMS is facilitated through the internet, where donors and recipients connect using Facebook groups and milk-sharing websites (11, 23, 25, 28, 87). Less is known about milk sharing operating at a local level among friends, family, and community members. It has been shown that decisions to engage in milk sharing are influenced by perceptions of and attitudes toward infant formula (27, 53, 88, 89). Recipients' risk-mitigation practices are highly contextual and vary according to their familiarity with the donor (26, 27, 38, 48, 55, 88).

Gaps in the literature on milk sharing literature are numerous because HMS research is still in its infancy. Limited research has been done on risk-mitigation practices and risk perceptions associated with milk sharing. Behavioral determinants of HMS, such as infant feeding attitudes, beliefs, and knowledge, have been under-investigated. Inasmuch as HMS is a hidden behavior, which renders it difficult to sample milk-sharing participants, the prevalence of milk sharing remains unknown, although recent studies indicate that awareness of HMS and participation in it are growing (23, 25). The HMS literature is dominated by the experiences of White women of high socioeconomic status, leaving the experiences of minorities and lower socioeconomic groups underrepresented. To date, no studies have been conducted on the effect of HMS on breastfeeding trajectories or infant health outcomes, an important area of inquiry.

HMS has generated significant controversy because of the “yuk factor,” whereby the notion of feeding one woman’s milk to another child has been shown to generate feelings of disgust or aversion (90, 91), as well as the potential risks involved. Microbial and viral pathogens can be transmitted in HM (92-96). HM can also be contaminated with prescription or recreational drugs, or altered by suboptimal practices during expression or storage that could lead to microbial contamination or loss of nutrients (17, 41, 42, 97-99). Given these potential risks, numerous organizations, including the FDA and HMBANA, have released statements cautioning against sharing human milk and positioning it as a high-risk behavior (100, 101). Yet the practice has continued to increase in popularity, underscoring the strong demand for HM (11, 23, 25) and highlighting the importance of expanding research on this increasingly prevalent practice.

The primary objective of this study is to describe the infant-feeding practices, HMS practices, and infant feeding decision-making factors among a geographically defined network of milk-sharing parents in the greater Washington, DC metropolitan region. Furthermore, we aim to describe important differences between donors and recipients in their infant feeding practices.

Methods

Design. This study employed a cross-sectional web-based survey. The web-based design allowed busy parents with small children at home to participate in the study whenever they could find the time to do so. This study was evaluated by Cornell University’s Institutional Review Board prior to its initiation and was granted exempt status.

Study Population. The study population of interest was the network of milk-sharing parents in the greater Washington, DC metropolitan region. Inclusion criteria for the study were: aged 18 years or older, English-speaking, had shared milk in the past 18 months, had shared milk *with a peer*, and lived or worked in the Washington DC region at the time of milk sharing.

Survey Tool Development. The development of the survey questionnaire was heavily informed by the findings of a previously conducted ethnographic study with HMS recipients (Chapter 4). From those semi-structured interviews with milk-sharing recipients, a detailed understanding was gained about how milk sharing is organized and practiced, and what the experience is like from the recipient perspective. This knowledge was first used to develop broad content themes, and then to guide the design of the questions and response choices, which formed the basis for the first draft of the survey tool. The survey tool was then shared with research colleagues and several personal friends who had milk shared themselves, resulting in many helpful survey modifications.

Next, a validation study was conducted, which employed cognitive interviewing to assess construct validity and to refine the survey questions to improve their clarity and validity. Cognitive interviewing is a qualitative method that examines the question-response process, specifically the processes and considerations used by respondents as they interpret the questions and form responses. For this validation study, mothers were recruited through local Facebook groups, the birth worker community, and locally posted flyers in Ithaca, NY. Eleven cognitive interviews were conducted during March-April 2019. The survey was distributed in a paper format to allow participants to take notes as they completed the survey.

Participants were asked to mark any question they were unclear about, confused by, or simply thought had an odd wording. Participants were timed as they took the survey, and immediately after completion the cognitive interviews commenced. A cognitive interview guide was used, and participants also contributed substantially to the direction of the interview, as they often offered interpretations of the questions that were unanticipated or pointed out a valid response option that had been omitted, to give a few examples. As the cognitive interviews were being conducted, the study team made real-time modifications to the survey so that it was an iterative process of fine-tuning and improvement.

The second round of survey validation (n=8 interviews) was conducted in an online format during June 2019, combining cognitive testing with online usability testing. Participants in this round completed the Qualtrics survey online, and then a phone call was scheduled shortly after to discuss the survey. During this phase of survey development, the goal was to continue to improve question wording and options for responses, and to discover and correct issues with the web-based version of the survey. After completion of these cognitive interviews, the survey was modified according to the feedback received. The final version of the Qualtrics survey is included in Appendix A.

Data Collection. The online survey was distributed during July 2019 – May 2020 through 4 primary channels. First, an email was sent to all participants of the previously conducted ethnographic study (Chapter 4), asking them to share the recruitment flyer among their networks. Second, an email was sent to DC-area birth workers (primarily doulas and lactation consultants) requesting that they share the study recruitment flyer with their clients. Third,

study recruitment ads were posted on DC-area milk sharing Facebook groups and numerous DC-area parent email listservs (e.g., Mothers on the Hill [MOTH], Silver Spring Parents, Mothers of North Arlington [MONA], etc.). And fourth, eligible participants were encouraged to share the survey link with their peers, a technique sometimes referred to as snowball sampling. Survey recruitment materials are included in Appendix B. Within 48 hours of survey completion, all eligible respondents received a participation incentive in the form of an Amazon gift card.

Data Analysis. All data cleaning, recoding, and analyses were performed using SAS Studio version 9.04. Bivariate analysis was conducted of sociodemographic factors, infant-feeding practices, attitudes, and beliefs by donor/recipient status (D/R status) wherever possible. Differences by D/R status in continuous variables were tested using ANOVA and in categorical measures using chi-square tests or Fisher's exact tests for small cell sizes.

Results

Sample Characteristics. Overall, 168 respondents completed the survey; 58% of the sample were donors and 42% recipients (Table 1). Nearly all respondents identified as female. Therefore, when describing this sample, female gender pronouns will be used. Most respondents were 35-44 years old, but the recipients were significantly older than donors ($p < 0.05$). The majority of the sample were non-Hispanic White, married, and highly educated; nearly two-thirds of the sample had a masters or doctoral degree. Approximately two-thirds of the sample were employed full-time.

Table 1. Sociodemographic characteristics of study participants

Demographic characteristic	Recipients (n=70)		Donors (n=98)		Total (n=168)	
	N	%	N	%	N	%
Current age ^a						
18-24 years	1	1.5	0	0.0	1	0.6
25-34 years	32	47.1	62	67.4	94	58.8
35-44 years	34	50.0	30	32.6	64	40.0
45-54 years	1	1.5	0	0.0	1	0.6
Gender identity						
Female	70	100.0	91	98.9	161	99.4
Racial/ethnic background						
White	61	88.4	77	83.7	138	85.2
Black	0	0.0	3	3.3	3	1.9
Asian	4	5.8	7	7.6	11	6.8
Latino / Hispanic	2	2.9	3	3.3	5	3.1
Multi-ethnic or other	2	2.9	2	2.2	4	2.5
Marital status						
Single/never married	2	2.9	2	2.2	4	2.5
Married/domestic partnership	68	97.1	90	97.8	158	97.5
Partner's gender identity						
Male	62	88.6	87	94.6	149	92.0
Female	5	7.1	2	2.2	7	4.3
Non-binary	1	1.4	1	1.1	2	1.2
Highest level of education completed						
Associates degree/some college	5	7.1	4	4.3	9	5.6
Bachelor's degree	22	31.4	27	29.3	49	30.2
Master's degree	34	48.6	48	52.2	82	50.6
Doctoral level degree	9	12.9	13	14.1	22	13.6
Current employment status						
Unemployed - full-time parent	11	15.7	15	16.3	29	17.9
On parental leave	4	5.7	2	2.2	6	3.7
Employed part-time	12	17.1	9	9.8	21	13.0
Employed full-time	43	61.4	65	70.7	108	66.7
Estimated annual household income						
< \$49,999	4	5.7	2	2.2	6	3.7
\$50,000 - \$99,999	12	17.1	11	12.0	23	14.2
\$100,000 - \$149,999	17	24.3	21	22.8	38	23.5
\$150,000 - \$199,999	11	15.7	21	22.8	32	19.8
\$200,000 - \$299,999	15	21.4	28	30.4	43	26.5
\$300,000 or more	11	15.7	9	9.8	20	12.3

^ap < 0.05

The sample was nearly evenly divided between primiparous and multiparous women, with a mean of 1.6 liveborn children (Table 2). The majority of participants carried their pregnancy

to term (90%) and had vaginal births (74%). A three-fold higher percentage of recipients experienced labor and delivery complications compared to donors (37% vs. 11%, respectively). Recipients were approximately twice as likely as donors to report that the birth was a traumatic experience for them (35% vs. 19%, respectively). A high proportion of all respondents had experienced postpartum anxiety (41%), while recipients were approximately 3 times as likely as donors to have experienced postpartum depression (38% vs. 13%; $p < 0.0001$). Approximately 86% of the sample were employed at the time of their child's birth. The majority took partially or fully paid parental leave for a duration of 12-23 weeks. Employment status and the characteristics of parental leave did not vary by D/R status.

Breastfeeding Experiences and Infant-Feeding Practices. Breastfeeding experiences differed significantly between donors and recipients (Table 3). The mean duration of most recent lactation (among respondents no longer feeding HM) was longer among donors than recipients (15.3 v. 11.0 months; $p < 0.05$). In their lifetime of lactation experience, recipients were significantly less likely than donors to have ever produced more milk than needed by their child ($p < 0.0001$), and significantly more likely to have ever: had difficulty producing enough milk for their child ($p < 0.0001$), been diagnosed with a health problem affecting lactation ($p < 0.005$), and fed infant formula to their child ($p < 0.005$). Overall, 29% of all respondents reported that they had ever exclusively pumped to feed their child. Interestingly, 30% of recipients ever produced more milk than they needed, and 21% of donors ever had difficulty producing enough milk. Recipients were significantly more likely to rate their breastfeeding experience negatively (29%) compared to donors (7%). In contrast, nearly half of donors rated their breastfeeding experience as very positive.

Table 2. Pregnancy and birth characteristics of the study participants

Pregnancy or birth characteristic	Recipients (n=70)		Donors (n=98)		Total (n=168)	
	N	%	N	%	N	%
Singleton child ^a	66	94.3	98	100	164	97.6
Primiparous	37	53.6	51	52.0	88	52.7
Maternal age at youngest child's birth ^a						
Less than 18 years old	4	5.7	3	3.1	7	4.2
18-29 years	7	10.0	12	12.2	19	11.3
30-34 years	29	41.4	62	63.3	91	54.2
35-39 years	25	35.7	21	21.4	46	27.4
40 years or older	5	7.1	0	0.0	5	3.0
	Mean	SD	Mean	SD	Mean	SD
Number of liveborn children	1.6	0.8	1.6	0.7	1.6	0.7
Maternal health complications						
Had complications during pregnancy	17	24.3	15	15.3	32	19.0
Had complications during labor/delivery ^b	26	37.1	11	11.2	37	22.0
Considered the birth traumatic ^a	24	35.3	18	18.6	42	25.5
Ever experienced PP depression ^b	26	38.2	13	13.4	39	23.6
Ever experienced PP anxiety	28	41.2	39	40.2	67	40.6
Gestational age at birth						
28-31 weeks	2	2.9	3	3.1	5	3.0
32-36 weeks	5	7.1	7	7.1	12	7.1
37+ weeks	63	90.0	88	89.8	151	89.9
Vaginal birth	47	67.1	77	78.6	124	73.8
Employed at the time of child's birth	60	85.7	84	85.7	144	85.7
Parental leave situation						
I reduced my hours or took unpaid leave	6	10.0	15	17.9	21	14.6
I took partially or fully paid leave	49	81.7	61	72.6	110	76.4
I stopped working	4	6.7	5	6.0	9	6.3
Parental leave duration						
1-7 weeks	5	8.6	5	6.2	10	7.2
8-11 weeks	8	13.8	13	16.0	21	15.1
12-15 weeks	27	46.6	34	42.0	61	43.9
16-23 weeks	15	25.9	20	24.7	35	25.2
24+ weeks	3	5.2	9	11.1	12	8.6

Abbreviations: PP=postpartum.

^ap < 0.05^bp < 0.0001

Table 3. Breastfeeding experience and infant-feeding practices among study participants

Breastfeeding or infant feeding characteristic	Recipients (n=70)		Donors (n=98)		Total (n=168)	
	Mean	SD	Mean	SD	Mean	SD
Duration of most recent lactation (months) ^{a,b}	11.0	6.8	15.3	6.7	13.2	7.1
Total lifetime lactation duration (months) ^a	16.0	12.1	19.3	11.8	17.7	12.0
For ANY of their children, had ever:	N	%	N	%	N	%
Produced HM	66	94.3	97	99.0	163	97.0
Nursed directly at the breast	64	97.0	96	99.0	160	98.2
Pumped milk to feed their child	66	100.0	94	96.9	160	98.2
Exclusively pumped to feed their child	24	36.4	22	23.4	46	28.8
Had difficulty producing enough HM ^c	54	81.8	20	20.6	74	45.4
Produced more HM than needed ^c	20	30.3	90	92.8	110	67.5
Been diagnosed with a health problem that affected lactation ^b	13	18.6	3	3.1	16	9.5
Fed infant formula to their child ^b	50	71.4	43	43.9	93	55.4
Infant-feeding practices used with the child of most recent lactation						
Child has ever received infant formula ^c	45	64.3	32	32.7	77	45.8
Child is currently receiving infant formula	4	5.7	4	4.1	8	4.8
Child is currently receiving HM	40	57.1	68	69.4	108	64.3
	Mean	SD	Mean	SD	Mean	SD
Duration of HM consumption (months) ^a	11.8	6.1	14.1	6.5	12.9	6.3
Infant-feeding practices used during first 3 months for the child of most recent lactation	N	%	N	%	N	%
Feeding at the breast of nursing parent	62	88.6	93	94.9	155	92.3
Nursing parent's own E-HM	52	74.3	72	73.5	124	73.8
S-HM ^c	40	57.1	1	1.0	41	24.4
Commercial infant formula ^b	29	41.4	23	23.5	52	31.0
B-HM ^b	11	15.7	1	1.0	12	7.1
Overall, how do you feel about your breastfeeding experience with your youngest child? ^b						
Big frown	4	6.15	0	0	4	2.48
Small frown	15	23.08	7	7.29	22	13.66
Neutral	11	16.92	5	5.21	16	9.94
Small smiley	24	36.92	36	37.5	60	37.27
Big smiley	9	13.85	46	47.92	55	34.16

Abbreviations: HM = human milk; E-HM = expressed human milk; S-HM = shared human milk; B-HM = banked human milk.

^aAmong respondents no longer human milk feeding

^bp < 0.05

^cp < 0.0001

Milk-Sharing Donors. Respondents who donated milk were asked a shorter series of questions about their children and milk sharing practices than those who received milk. Donors reported initially getting the idea of milk sharing from themselves (44%), someone in an online

Table 4. Factors related to donors' decision to milk share

Factor related to the decision to milk share	Donors (n=97)	
	N	%
Where did you initially get the idea of milk sharing?		
Myself	43	44.3
Someone in an online community	27	27.8
Friend or family member	26	26.8
Someone in my breastfeeding support group	25	25.8
Lactation consultant	13	13.4
Partner / significant other	6	6.2
Online search	5	5.2
My doctor or my child's doctor	5	5.2
Midwife	5	5.2
Ever considered donating to a milk bank	50	51.0
Ever initiated the milk bank screening process (n=50)		
No	37	74.0
I started the screening process but never finished	9	18.0
I went through screening but wasn't approved as a donor	2	4.0
I went through screening and was approved as a donor	2	4.0
Reasons provide for not considering donating to a milk bank (n=48)		
I felt like it would be too time consuming and/or expensive	41	85.4
My milk had already been expressed	30	62.5
I preferred to donate my milk locally	28	58.3
I was donating specifically to someone I knew	28	58.3
Other reason not listed	17	35.4
Object to the costs charged by milk banks	11	22.9
I wanted to know the family who was receiving my milk	7	14.6
There wasn't a milk bank collection place close to me	6	12.5
I had concerns about milk kinship	4	8.3
Most important reasons for donating milk directly to another family		
Generally wanted to help someone who needed milk	72	73.5
Had excess expressed milk that my child didn't need	66	67.3
Didn't want my expressed milk to go to waste	66	67.3
Knew a specific family who needed milk and wanted to help them	55	56.1
Think breast milk is important	54	55.1
Knowing that not everyone can make enough milk	37	37.8
Would want someone to give me milk if I couldn't produce enough	29	29.6
Had milk my child couldn't drink because of dietary allergy or sensitivity	13	13.3
Too difficult/time consuming to donate to milk bank	7	7.1
My milk was expressed prior to being screened as a milk bank donor	6	6.1
Previous experience with milk sharing	5	5.1

community (28%), a friend or family member (27%), or someone in their breastfeeding support group (26%) (Table 4). Approximately half of the donor respondents had ever

considered donating their milk to a milk bank, but the majority of those did not go through the screening process (74%). The major reasons reported for not considering donating their milk to a milk bank were that they felt like it would be too time consuming and/or expensive (85%), their milk had already been expressed (63%), they preferred to donate their milk locally (58%), or because they were donating specifically to someone they knew (58%). The most important reasons cited for deciding to donate their milk in an HMS arrangement were that they generally wanted to help someone who needed milk (74%), they had excess EHM that they didn't need (67%), they didn't want their EHM to go to waste (67%), and they knew a specific family who needed milk (56%).

Donors reported a mean of 2.3 recipients, with 0.9 of those being someone to whom they donated milk on more than one occasion (Table 5). Nearly three-quarters of donors (72%) reported donating only surplus E-HM that they had intended to feed to their own children (72%). Most donors reported initially connecting with recipients through an online group (63%) or their recipient was someone who they already knew (47%). Nearly all donors (98%) had ever used online resources to find a recipient. Donors most often reported that they donated their milk to a friend (39%), an online acquaintance they *did not* meet in person (39%), or an online acquaintance they *did* meet in person (24%). Approximately one-quarter of donors only donated their milk to friends or family (26%). Finally, milk was primarily exchanged directly in person (84%), with 21% of donors reporting that they had exchanged milk indirectly (21%). When initially connecting with recipients, the most frequently discussed issues were the age of the milk, prescription drugs, alcohol consumption, age-matching the milk, diet quality, and caffeine and tobacco use.

Table 5. Donors' milk-sharing practices

Milk-sharing practice	Donors (n=97)	
	Mean	SD
Total number of recipients	2.3	1.8
Number of repeat or ongoing recipients	0.9	0.8
Type of milk donated	N	%
Surplus E-HM originally intended to feed my own child	70	72.2
HM that I expressed specifically for donating	5	5.2
Both surplus HM and HM expressed for donating	23	23.7
Initial method for connecting with recipient parents		
Online group (e.g., EOF, BF listserv, etc.)	62	63.3
I already knew them	46	46.9
Facilitated through a mutual friend / acquaintance	16	16.3
Facilitated through a lactation consultant	5	5.1
Facilitated through a midwife or doula	4	4.1
Ever used online resources to find a recipient	96	98.0
Ever donated milk to the following individuals		
Friend	38	38.8
Online acquaintance that you have not met in person	38	38.8
Online acquaintance that you have met in person	23	23.5
Someone you connected with through an intermediary	14	14.3
Family member	8	8.2
Someone you met in your local community (offline)	5	5.1
Only donated milk to friends or family	25	25.5
Exchanged milk		
Directly (met donor to pick up milk)	82	83.7
Indirectly (gave milk to someone else to give to recipient)	21	21.4
Received via mail / shipped	1	1.0
Via cross-nursing	2	2.0
Issues discussed when connecting with a new recipient		
Age of the milk	62	63.3
Prescription drugs	54	55.1
Alcohol consumption	51	52.0
Age-matching the milk to the age of the recipient baby	47	48.0
Diet quality	47	48.0
Caffeine consumption	47	48.0
Tobacco use	32	32.7
Your general health status	27	27.6
Milk pumping and storage practices	20	20.4
Health status of your child(ren)	16	16.3
Other lifestyle factors	16	16.3
Overall cleanliness & hygiene	15	15.3
Not applicable - was donating to a close friend or family member	14	14.3
Infectious disease test results (e.g., HIV, hepatitis, or other)	14	14.3
Recreational drug use	13	13.3
Other issue	13	13.3
Health status of the recipient's child	8	8.2
None of the above	4	4.1

Abbreviations: E-HM = expressed human milk; HM = human milk; EOF = Eats on Feets; BF = breastfeeding.

Milk-Sharing Recipients. Recipients were asked a series of questions about the child for whom they were milk sharing (Table 6). Among the 69 respondents, 87% were the biological parent to the child who received shared milk, while 10% were non-relatives in custody. The mean age of the recipients' children at the time of the survey was 14 months and the mean age at which they began consuming S-HM was 4.6 months. Approximately 83% of the recipient children had no major health issues, while 17% had either temporary or ongoing dietary allergies or sensitivities. One-third of the recipients' infants had been diagnosed with a tongue and/or lip tie (TLT) and 78% of those children had the TLT surgically released at a mean age of 4.8 weeks.

We assessed factors influential to the recipients' decisions to milk share (Table 7). HMS recipients initially got the idea of milk sharing as an infant feeding option from someone in their breastfeeding support group (45%), followed by their doula (32%), friend or family member (29%), or partner (22%). Very few respondents cited their doctor, midwife, or lactation consultant as the source of the initial idea to milk share. Before deciding to milk share, many parents weighed other options for how to feed their child. Approximately 80% of the recipients in this sample considered reducing their hours at work or school and 22% considered obtaining milk from a milk bank. Approximately one-third of the recipients stated that, at the time they began milk sharing, their need for breast milk was urgent or extremely urgent.

Table 6. Characteristics of recipients' children

Child characteristic	Recipients (n=69)	
	Mean	SD
Child age (months)		
Age when began milk sharing	4.6	4.0
Current age	14.0	12.2
Does the child have any health issues?	N	%
No	57	82.6
Yes, and currently still does	5	7.3
Did in the past, but no longer	6	8.7
Does the child have any dietary allergies, sensitivities, or intolerances?		
No	47	68.1
Yes, and currently still does	8	11.6
Did in the past, but no longer	4	5.8
Uncertain	10	14.5
Was the child ever diagnosed with a tongue or lip tie?		
No	40	58.0
Tongue or lip tie	8	11.6
Both tongue and lip tie	15	21.7
Uncertain / other	6	8.6
Who was involved in diagnosing the tongue or lip tie?		
Lactation consultant	19	82.6
Pediatrician	14	60.9
MD / DO	7	30.4
Pediatric dentist	7	30.4
Chiropractor	4	17.4
Other	2	8.7
Did you have the tongue/lip tie released?		
Yes	18	78.3
No	5	21.7

Abbreviations: MD = medical doctor; DO = doctor of osteopathy.

Respondents were asked about which resources were most influential in their decision to participate in milk sharing. The most influential ones were other breastfeeding mothers, other caregiver, their own professional training, their partner, and online breastfeeding resources (e.g., KellyMom). Some participants cited healthcare providers (12%) or official statements on milk sharing (9%) as influential to their decision. The respondents' two most important reasons for milk sharing were that the breastfeeding parent had insufficient milk supply or a lactation problem (57%) and that breast milk is the biologically normal way of feeding babies (44%). The two most frequently cited child-related reasons were that their baby was intolerant

Table 7. Factors related to recipients' decision to milk share

Factor related to the decision to milk share	Recipients (n=69)	
	N	%
Where did you initially get the idea of milk sharing?		
Someone in my BF support group	31	44.9
Doula	22	31.9
Friend or family member	20	29.0
Partner / significant other	15	21.7
Someone in an online community	13	18.8
Online web search	4	5.8
Before deciding to milk share, what other options did you consider?		
Reducing hours at work or school	55	79.7
Milk bank	15	21.7
Homemade infant formula	6	8.7
Considered no other options	6	8.7
Commercial infant formula	3	4.4
Animal milk	3	4.4
When you began milk sharing, how urgent was your need for breast milk?		
Not at all urgent	15	21.7
A little urgent	30	43.5
Urgent	14	20.3
Extremely urgent	10	14.5
Who or what resources most strongly influenced your decision to milk share?		
Other breastfeeding mothers	31	44.9
Other caregiver	18	26.1
My own professional training	18	26.1
Partner / significant other	17	24.6
Other online breastfeeding resources (e.g., Kelly Mom)	16	23.2
Eats on Feets or HM4HB websites	14	20.3
Your doctor or your child's doctor	8	11.6
Official statements about milk sharing	6	8.7
What were your most important reasons for deciding to milk share?		
BF parent had insufficient milk supply or lactation problem	39	56.5
Breast milk is the biologically normal way of feeding babies	30	43.5
Beliefs about the rights of babies to have breast milk	25	36.2
Baby was intolerant of formula	20	29.0
Baby seemed hungry after being fed at the breast	19	27.5
Convenience or an opportunity that presented itself at the right time	17	24.6
It was free	17	24.6
Baby had insufficient weight gain or significant weight loss	15	21.7
Work or school made it impossible to meet the baby's breast milk needs	15	21.7
Baby was sick or had a serious health problem	11	15.9
Other	9	13.0
Psychological or emotional distress	7	10.1
Baby was having difficulty nursing at the breast	6	8.7
Religious or philosophical beliefs about using infant formula	5	7.2
BF parent needed to take medication incompatible with lactation	4	5.8

Abbreviations: BF = breastfeeding; HM4HB = Human Milk for Human Babies.

of infant formula (29%) and the baby seemed hungry after feeding at the breast (28%).

Approximately one in five recipient respondents reported that an important reason for milk sharing was that “work or school made it impossible to meet the baby's breast milk needs.”

Numerous HMS practices were assessed (Table 8). HMS recipients in this sample milk shared for an average duration of 3.3 months with a mean of 3.4 donors. While milk sharing, 86% of recipient infants were still consuming their mother’s own milk and 71% were still feeding at their mother’s breast during part or all of the HMS arrangement. Nearly all recipients exchanged milk with donors by meeting directly, with very few reporting that they had milk shipped to them. The majority of recipients reported initially connecting with donors in online groups (55%) and through a midwife or doula (52%). S-HM was most commonly received from a friend (67%), followed by an online acquaintance that they *did* (39%) or *did not* (29%) meet in person. Forty-two percent of recipients reported only receiving S-HM from friends or family.

The estimated total volume of milk reported to have been shared between donors and recipients is shown in Figure 5. The majority of respondents (55%) exchanged a total of less than 250 ounces. The reported volume of S-HM exchanged did not differ significantly by D/R status.

Recipients varied substantially in the risk-mitigation practices employed (Table 9). Only 6% of recipients had ever heat-treated S-HM and the most commonly cited reasons for not heat treating it were that they trusted the milk was clean and safe (68%), they didn’t know it was

Table 8. Recipients' milk-sharing practices

Milk sharing practice	Recipients (n=69)	
	Mean	SD
Total estimated duration of HMS (months)	3.3	3.4
Number of one-time donors	3.4	4.2
Number of repeat or ongoing donors	1.3	1.8
Approximate proportion of child's milk intake that was comprised of S-HM (during milk sharing arrangement)	N	%
A little or some	25	36.2
About half	17	24.6
Most or all	22	31.9
It varied	5	7.2
Child was receiving mother's own milk while milk sharing	59	85.5
Child was still feeding at the mother's breast while milk sharing		
Yes - throughout the milk sharing arrangement	40	58.0
Yes - only during part of the milk sharing arrangement	9	13.0
No	10	14.5
Exchanged milk		
Directly (met donor to pick up milk)	66	95.7
Indirectly (donor gave milk to someone else to give to you)	17	24.6
Received via mail	3	4.3
Initial method for connecting with donors		
Online group (e.g., EOF or HM4HB, parent listserv, etc.)	38	55.1
Facilitated through a midwife or doula	36	52.2
Facilitated through a lactation consultant	12	17.4
Other	9	13.0
Facilitated through a mutual friend / acquaintance	2	2.9
I already knew them	1	1.4
Ever received milk from the following individuals		
Friend	46	66.7
Online acquaintance that you have met in person	27	39.1
Online acquaintance that you have not met in person	20	29.0
Other	12	17.4
Family member	9	13.0
Someone you connected with through an intermediary	6	8.7
Only shared milk with friends and family	29	42.0

Abbreviations: HMS = human milk sharing; S-HM = shared human milk; EOF = Eats on Feets; HM4HB = Human Milk 4 Human Babies.

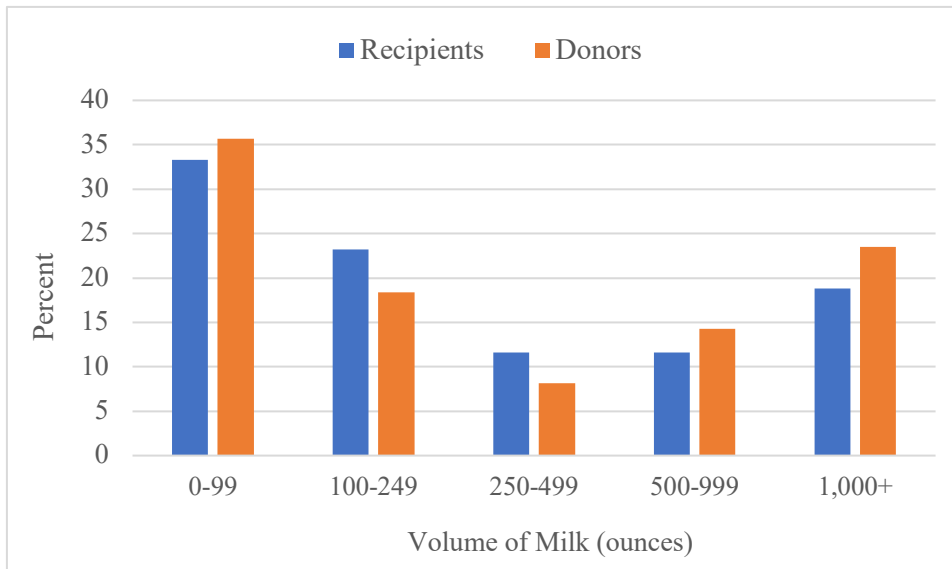


Figure 5. Total estimated volume of shared milk exchanged among survey respondents, stratified by D/R status.

an option (55%), and they wanted to preserve the “good things” in the milk (34%). The majority of recipients did not screen any donors by asking personal questions of them (64%), while 25% screened everyone. When meeting a new donor, the issues most commonly discussed were prescription drugs (55%), alcohol (51%), caffeine (42%), and tobacco use (39%), donor’s diet quality (38%), and age-matching the milk to the age of the recipient’s child (36%). Recipients employed numerous other risk-mitigation strategies, including meeting in public or bringing a companion when picking up milk (51%), asking the donor about their medical history (39%), searching the donor online (38%), examining the appearance of the donor, their house, or their children (35%), discussing milk sharing with a healthcare provider (32%), and blending different donor's milks together when feeding it to their child (30%). Fifteen percent of recipients had ever rejected milk from a potential donor.

Table 9. Recipients' risk-mitigation practices

Risk mitigation practice	Recipients (n=69)	
	N	%
Ever heat treated S-HM before feeding it to recipient child	4	5.8
Reasons provided for not heat treating the S-HM (n=65)		
I trusted the milk was clean and safe	44	67.7
I didn't know that was an option or it didn't occur to me	36	55.4
I wanted to preserve the "good things" in the milk	22	33.8
My child was healthy and not preterm or sick	15	23.1
Screened donors by asking personal questions of them		
No	44	63.8
Yes – screened everyone	17	24.6
Yes – only screened people not familiar to me	4	5.8
Yes – screened some people but not all, regardless of familiarity	4	5.8
Issues discussed when connecting with a new donor		
Prescription drug use	38	55.1
Alcohol consumption	35	50.7
Caffeine consumption	29	42.0
Tobacco use	27	39.1
Donor's diet quality	26	37.7
Age-matching the milk to the age of my baby	25	36.2
Other item	24	34.8
Overall cleanliness and hygiene	23	33.3
Heat treatment of the breast milk	22	31.9
Donor's overall health status	17	24.6
Religious or philosophical beliefs	12	17.4
None of these	12	17.4
Other medical records	7	10.1
Age of the milk	6	8.7
Other risk-mitigation practices employed		
Managed pickup by meeting in public or bringing a companion	35	50.7
Asked donor about their medical history	27	39.1
Looked up the donor online	26	37.7
Examined appearance of the donor, their house, or their children	24	34.8
Discussed milk sharing with a healthcare provider	22	31.9
Blended different donor's milks together when feeding	21	30.4
Ensured the milk was kept at appropriate temperature during transport	14	20.3
Carefully examined milk containers for cleanliness	14	20.3
Ensured the donor was breastfeeding their own child	12	17.4
Prayed or meditated	11	15.9
Asked others about the donor to get a sense of their reputation	6	8.7
Introduced the shared milk slowly to watch for adverse reactions	5	7.2
Ever rejected milk from a potential donor	10	14.5
Reasons provided for rejecting the milk (n=6)		
Donor was taking a drug/medication I wasn't comfortable with	2	33.3
The milk was too old	2	33.3
I was not comfortable with the donor's medical history or health status	2	33.3

I had a bad feeling about the donor or the situation	1	16.7
Donor's medical records weren't available	1	16.7
The donor wanted payment	1	16.7

Abbreviations: S-HM = shared human milk.

Discussion

This research makes a significant contribution to the literature by describing in considerable detail the practices, motivations, and experiences among a network of milk-sharing parents in an American metropolitan region. We found that HMS participants are achieving a high duration of lactation and HM feeding and are engaged in a wide variety of risk-mitigation practices. We also found that, while sociodemographically similar, donors and recipients differ from each other in their maternal experiences and infant-feeding practices.

Although efforts were made to recruit a diverse sample in ethnicity, socioeconomic status, and milk sharing type (online vs. community-based), ultimately this was a homogenous sample of non-Hispanic White, highly educated, married, employed women of high socioeconomic status. Thus, our sample composition mirrors that of other HMS studies (22, 26, 28, 53, 102), as well as reflects the characteristics of mothers with the highest rates of breastfeeding in the US (8). It remains unknown if these are an unbiased sample of the population of milk-sharing parents, or if we and others have done an inadequate job of finding and including the full range of milk-sharing participants. Prior results from a large (n=867) online survey of online milk-sharing participants demonstrated that donors reported significantly higher income and educational attainment compared to recipients (28). However, in our smaller geographically-defined sample, donors and recipients were similar in these characteristics.

The significant differences between recipients and donors in their birth and postpartum experiences are an important finding of this work. HMS recipients were more likely than donors to have experienced complications of labor and delivery, a traumatic birth, postpartum depression, and an overall negative experience with breastfeeding. This builds upon previous research that found that a higher proportion of recipients had cesarean deliveries and preterm births compared to donors (28). Interestingly, a high proportion of both donors and recipients (41%) in our sample reported experiencing postpartum anxiety, underscoring the pressures on busy working mothers juggling competing responsibilities. Together, these findings suggest that HMS recipients are a vulnerable group of women who encountered compounded maternal medical and mental health challenges, and require additional psychosocial and lactation support to improve both their mental health and their breastfeeding outcomes.

This research revealed interesting patterns in infant-feeding practices among HMS participants. Both recipients and donors reported a high mean duration of their most recent lactation, which reflects a strong commitment to breastfeeding in this population and is supported by previous research (28). Of particular interest is that 20% of donors ever had difficulty producing enough milk and 30% of recipients ever produced more milk than needed. These findings demonstrate that both recipients and donors experience challenges during their breastfeeding journeys. Women may serve as both donors and recipients during a given lactation period, implying the potential for crossover between donor and recipient status, as found in previous research (26). Overall, 45% of all respondents indicated that they had ever had difficulty producing enough milk, which raises questions about actual versus perceived lactation insufficiency. Perceived lactation insufficiency is common among

breastfeeding women and is associated with breastfeeding discontinuation and non-exclusivity (103-108). Additional research is warranted to investigate the role perceived lactation insufficiency plays in milk sharing.

A higher proportion of our respondents had exclusively pumped than was reported in another U.S. population (6.9%) (13). It is logical that exclusive pumping is a common infant-feeding practice among this population given that contemporary HMS requires a steady supply of surplus E-HM, which is enabled by the use of breast pumps. Although it is relatively easy to appreciate why a mother who is experiencing breastfeeding challenges (latch issues, in particular) might turn to exclusive pumping to feed her infant and then to receiving S-HM, it is less intuitive to understand the motivations for donor mothers to pump exclusively and, thus, not feed at the breast. It may be that some HMS donors use exclusive pumping as a strategy to manage excessive supply. Further research is warranted to better understand the reasons for exclusive pumping, another breastfeeding topic with a disappointing paucity of data.

It has been suggested that the emergence of HMS has negatively impacted milk banks by competing for the same pool of eligible donors, thus reducing the B-HM supply available for milk banks and neonatal intensive care units (109-112). However, our results highlighted the characteristics of recipient infant and donors that suggest HMS participants would not have been eligible to receive HM from or donate it to HMBANA milk banks. The recipient infants in this study were primarily healthy, full-term babies who began to receive shared milk at a mean age of 4.6 months. The modest HMBANA milk supply is typically reserved for preterm,

sick, and vulnerable infants. Therefore, it is highly unlikely that the recipients in this study would have been eligible to receive B-HM. Many HMS donors also would not have been eligible for milk bank donation, given that HMBANA milk banks require donors to complete a detailed screening process *prior to* expressing the milk to be donated. Many donors in this sample did not consider donating to a milk bank because they believed the process would be too time consuming and/or expensive, had already expressed their milk, preferred to donate their milk locally, or were donating specifically to someone they knew. Taken together, these findings suggest that the practice of HMS may not be in direct competition with human milk banks because the two types of donated milk serve different needs among distinct groups.

The decision to seek S-HM is of interest to public-health researchers and clinicians because it is helpful to know what factors are most salient to parents when making this decision, and what alternative options they consider to be potentially viable. The alternative most frequently considered by recipients before deciding to milk share was reducing hours at work or school. This finding suggest that full-time employment is a key barrier to breastfeeding success among women experiencing breastfeeding challenges. At first glance, it seems surprising that only 4% of recipients reported considering infant formula (and an additional 9% considered homemade infant formula) as an alternative strategy before deciding to milk share. However, this is possibly partially explained by the 41% of recipients who fed infant formula to their baby in their first 3 months of life and the 29% who cited formula intolerance as a major reason for milk sharing. Unfortunately, it wasn't possible to test these associations statistically due to small cell sizes. Investigating the proportion of HMS recipients who view infant formula as a nonviable supplementation strategy remains a research question of interest.

Respondents were asked to reflect on their most important reasons for deciding to milk share. Given that this as a complex and multifactorial decision, they were allowed to select up to 5 reasons from a list of 23 options. The most important reasons cited by donors for deciding to milk share were altruistic (wanting to help another family) and practical (they had surplus HM and they didn't want it to be wasted). The five most important reasons cited by recipients were that the breastfeeding parent had insufficient milk supply or a lactation problem, HM was the biologically normal way of feeding babies, their belief in the rights of babies to have access to HM, their baby was intolerant of formula, and their baby seemed hungry after being fed at the breast. These reasons are congruent with prior research on motivations for HMS (27). Another interesting feature of these data is that the reasons for milk sharing that were critical of infant formula were not commonly selected. For example, only 7% of recipients cited "philosophical or religious beliefs about using infant formula" and only 1 recipient cited "concerns about infant formula" as being *important* to their decision to milk share. This finding suggests that this sample of HMS recipients were likely more motivated by pro-human-milk beliefs than by anti-formula beliefs.

Study participants engaged in certain HMS practices with important implications for the quality of S-HM. First, we found that the S-HM was predominantly exchanged directly between donors and recipients, eliminating the risks posed by shipping HM (*e.g.*, temperature dysregulation, microbial growth, and leakage). Second, the majority of donors in this study donated E-HM originally intended to feed to their own children, suggesting that the S-HM *quality* is likely to be similar to that of E-HM mothers are feeding to their own children.

Indeed, a recent study analyzed samples of S-HM, B-HM, and E-HM expressed for a mother's own infant, and found no difference in the rates of total aerobic bacterial or coliform growth, lysozyme activity, sIgA activity, lactose, fat, protein, or water content between the samples (37). Taken together, these findings suggest that, while mothers may not consistently follow human milk handling and storage guidelines (113, 114), there is some evidence that the quality of S-HM is similar to that of E-HM mothers are feeding their own infants.

The respondents' engagement in risk-mitigation practices varied substantially. Nearly two-thirds of recipients did not screen any of their HMS donors, a significantly higher proportion than reported in previous HMS studies (55). To investigate if this low prevalence of donor screening was related to the high proportion of recipients in our study who received S-HM only from friends or family, we conducted a bivariate analysis and found that recipients who only shared milk with friends and family (n=29) were significantly less likely to have screened their donors (odds ratio=3.5, 95% confidence interval=1.2–10.3). Thus, it appears that relationship with donor was a key driver of screening behavior among this sample.

Few recipients had ever heat treated the S-HM because they trusted it was clean and safe, did not realize that home-pasteurization was an option, or wanted to preserve the beneficial HM components. The majority of the infants of HMS recipients were described as healthy, which may have contributed to recipients' views of pasteurization as unnecessary. Both donors and recipients reported discussing drug, alcohol, tobacco, and caffeine use as well as quality of the donors' diets with their prospective donors/recipients, a pattern that is congruent with previous research (38). Recipients employed a wide variety of additional risk-mitigation

practices, similar to those described in other studies (26, 38). These findings demonstrate that recipients are aware of risks associated with HMS and take steps to ensure the suitability of their donors. However, poor hygiene and inadequate milk handling and storage practices were not cited as primary concerns among this sample, which may indicate low awareness of the potential for bacterial contamination of HM.

Strengths and Limitations. This study has several notable strengths. The survey tool development was heavily informed by the findings of an ethnographic study with HMS recipients, resulting in a survey tool closely aligned with the lived experiences of milk-sharing parents. The survey tool then went through two rounds of cognitive testing and refinement to ensure its construct validity. Another strength of this study is the highly detailed nature of the survey tool, covering a wide range of experiences, attitudes, beliefs, and behaviors. These features render the survey tool the core strength of this research.

There are several limitations to this study. The use of non-random sampling techniques introduced potential bias into the sample. Our reliance on online recruitment strategies likely underrepresented HMS parents who don't use the internet to connect with other parents (e.g., are active on local parenting listservs or breastfeeding support groups). Therefore, the data from this survey cannot be extrapolated to the general population of milk-sharing parents. Furthermore, because the survey was limited to HMS participants in the Washington, DC area, these findings are limited in their generalizability to other settings. The study inclusion criterion of having milk shared within the past 18 months introduces the potential for recall bias among parents who have milk shared many months ago, potentially during a stressful and

sleep-deprived period in their lives. However, this was minimized in our study because 74% of respondents had milk shared in the 9 months prior to taking the survey. Finally, by focusing the survey on the recipients' experiences, this research provided less information about donors. Additional research is needed to expand our knowledge about the motivations and behaviors of HMS donors.

Conclusions

This research adds to the body of knowledge on milk sharing by describing in considerable detail the practices, motivations, and experiences among a geographic network of milk-sharing parents, and identifying important differences between donors and recipients. We found that overall, HMS participants are achieving a high duration of lactation and HM-feeding, recipients are engaged in a wide variety of risk-mitigation practices, and while sociodemographically similar, donors and recipients differed substantially in their maternal experiences and infant-feeding practices. The recipients' decisions to milk-share were influenced by social networks and pro-HM attitudes, while donors were motivated by altruism and practicality. Additional research is needed to address the many remaining questions about this understudied infant feeding practice.

CHAPTER 3

LATENT PROFILE ANALYSIS OF RISK PERSPECTIVES AMONG MILK-SHARING PARTICIPANTS

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Abstract

Background: Human milk sharing (HMS) is an emergent infant-feeding practice (IFP) used by many parents to augment the quantity of human milk (HM) fed to their infant. When deciding if and how to share milk, participants must weigh competing risks and benefits. HMS risk perspectives are complex, nuanced, and understudied.

Objective: The primary objective of this study was to identify risk perspectives among a sample of milk-sharing parents and to characterize how these risk perspectives are associated with individual characteristics, IFP, and HMS practices.

Methods: Data were obtained from a cross-sectional survey of HMS participants (n=168).

Responses to questions about IFP risk perceptions were used to conduct a latent profile analysis, stratified by donor/recipient status. The latent risk-perspective profiles were characterized using a descriptive analysis of individual characteristics and IFPs by profile and donor/recipient status.

Results: Two discrete risk-perspective profiles were identified among donors and three among recipients. Donor Profile 1 members (89% of the sample) did not prefer HMS over FF, slightly agreed that breastfeeding is an important part of being a good mother, disagreed that the risks of FF are severe, and agreed that they weren't too concerned about the risks of FF because their child was healthy. Donor Profile 2 members (11% of the sample) held strong beliefs that the potential negative consequences of formula feeding (FF) are severe and that FF is to be avoided if possible. Among recipients, Profile 1 members (59% of the sample) strongly valued familiarity with their donors, felt more comfortable with HMS than FF, believed breastfeeding is an important part of being a "good mother," and felt that avoiding FF was important to them. Recipient Profile 2 members (24%) were the least concerned about risks of infant formula, least likely to agree that breastfeeding is important to being a good mother, and felt equally

comfortable with HMS and FF. Recipient Profile 3 members (17%) did not feel that familiarity with donors was important, felt more comfortable with HMS over FF, and were motivated by avoiding FF. For the IFP of recipients, Profile 2 members were the least likely to have ever produced milk for their child ($p<0.02$), most likely to have fed infant formula to their child of their most recent lactation ($p<0.01$), and had the lowest breastfeeding knowledge score compared to the other risk-perspective profiles ($p<0.01$). Profile 3 members were the most likely to have initially connected with donors via an online group ($p=0.01$), to have received shared HM from an online acquaintance they did not meet in person ($p<0.01$), and to have exchanged milk with donors indirectly ($p<0.01$). Profile 3 members also had the highest mean number of donors (6.2; $p<0.05$).

Conclusions: HMS risk perspectives are complex and formed relative to perceptions of infant formula. The identification of discrete risk perspectives among HMS participants revealed an important source of intra-cultural diversity related to IFP. These risk perspectives are associated with IFP and HMS practices in important ways. Better understanding of the risk perspectives held by HMS participants is critical for elucidating parental decision-making processes and developing more targeted approaches to care and messaging about infant feeding.

Introduction

All parents must regularly engage in highly complex decision-making that involves making risk calculations. This parental journey as a “risk manager” begins with conception and continues throughout the child’s life and is largely viewed as a maternal responsibility (115-117). Some examples of such decisions include genetic testing during pregnancy, infant sleeping arrangements, vaccine schedules, water safety practices, use of screen time, and how much freedom to give children as they begin engaging in riskier activities (*e.g.*, riding a bicycle). The numerous decisions parents make about how to feed a child involve many risk calculations. These are often viewed as primarily maternal decisions and are contentious, laden with emotion, and carry social and moral judgement (116-119).

The first decision parents must make about infant feeding is whether they intend to feed human milk (HM). The public-health recommendation in the U.S. is to exclusively breastfeed for 6 months, with continued breastfeeding for at least 1 year (64, 120). While breastfeeding may not be the modern cultural norm, it is still the biological norm for humans. HM is the preferred form of nutrition for infants and feeding-at-the-breast (FAB) is the preferred mode of delivery of that milk (121). This means that parents who choose to feed their infant HM in a bottle or choose to feed something other than HM are deviating from the biological norm and the recommended infant-feeding practice (IFP). In the United States, approximately 84% of women ever breastfed their child, 35% were still breastfeeding at 12 months, and only 26% exclusively breastfed through 6 months (5). Estimates for feeding expressed HM (E-HM) vary, ranging from 69% to 85% of breastfeeding mothers (122). These data demonstrate that IFP of American parents vary widely and, as a nation, we are falling short of the public-health

goals for infant feeding.

Any parent who chooses to deviate from IFP recommendations must engage in a series of decisions that involve the consideration of risks and benefits of this choice. To illustrate the complexity of IFP decisions, one can examine the common example of a breastfeeding mother who must return to work full-time at 6 weeks postpartum. Assuming she cannot bring her infant to work and has a job that is conducive to pumping, she must first decide if she wants to pump while at work or transition her infant to formula. If she chooses to pump, she must decide on the type of breast pump to purchase, develop a pumping schedule, find an adequate location to pump, decide on which types of bottles and nipples to use, develop a bottle-feeding schedule for her infant while she's at work, etc. If she chooses to feed formula, she must decide on which types of bottles and nipples to use and which type of formula to purchase (a complex decision, given the many different formulas on the market, all touting different formulations and benefits). She might choose to mixed feed, as many working mothers do. In this case, she must make all the decisions just described about pumping *and* formula feeding, and determine how to make it all work together. Adding to the complexity, none of these are one-time decisions but must be revisited and revised under continually evolving circumstances for both mother and infant. This example reveals the hidden complexity behind the seemingly simple question "how do you want to feed your baby?"

Parental cognitive frameworks are fundamental to the decision-making process for IFP (123-125). Each IFP offers potential risks and benefits that must be weighed to arrive at a decision. Often, risks and benefits are either not known or incompletely understood, so parents must

make decisions with incomplete information. Furthermore, individual-level knowledge, values, beliefs, and attitudes all influence the *perceptions* of the risks and benefits of each option. What may be perceived as a benefit by one mother could legitimately be perceived as a risk by another mother. For example, a breastfeeding mother who desires independence might perceive time away from the baby as a significant benefit of expressing her milk. Another breastfeeding mother who doesn't have that same desire for physical independence and highly values her breastfeeding relationship might view milk expression as a risk because she fears that her infant may grow too accustomed to the bottle and then reject the breast. This common example offers one illustration of how risk perceptions differ based on parental knowledge, attitudes, beliefs, and values that change how they use and interpret information.

Understanding the ways that individuals process these competing IFP risks and benefits cognitively is important because these processes influence their intentions and behaviors. Analysis of cultural patterns is instructive for exploring intra-cultural variation within a given culture (126). Prior research has found that HMS participants are a predominantly homogenous group of White, educated women of socioeconomic privilege (22, 26, 28, 53, 87, 88, 102). Given the apparent homogeneity of HMS participants, it is tempting to assume that these parents share a common cultural perspective on IFP. However, for a full understanding of this subject, it is important to examine these assumptions and explore the areas of intra-cultural diversity and heterogeneity that exists among them (61). This is important because it may inform the development of more targeted care and support approaches based on variations in cognitive frameworks related to IFP.

Research on risk perceptions is challenging because of the complexity of the underlying determinants of risk perception combined with the subconscious nature of much of human decision-making. In the case of HMS, understanding decision-making processes is complicated by the number of competing options involved. Parents are never making the decision to milk-share in isolation, but rather relative to the other options available to them (e.g., commercial or homemade infant formula, or banked HM). Thus, the risks and benefits of each option are considered *relative* to one another to arrive at a decision. In the case of HMS recipients, these important decisions are often being made during times of stress and emotional distress, rendering them even more difficult (52).

The theoretical orientation that guided our views of risk perception and decision-making involving the analysis of risk is the Protection Motivation Theory (PMT). PMT expands upon expectancy value theory to incorporate reward and self-efficacy as constructs (59). According to PMT, risk-taking behavior is determined by a careful consideration of threat severity, likelihood of negative consequences for the individual, and protective measure or coping strategy effectiveness (Figure 3). According to PMT, the initiation of protective (or risky) behaviors is guided by two cognitive processes: threat evaluation (threat-appraisal process) and selection of coping strategies (coping-appraisal process). Inputs to the model include environmental information sources and intrapersonal sources. An individual facing a given threat would engage in both cognitive processes to determine which coping mode to use; these may be either adaptive or maladaptive (i.e., risky or protective). The coping-appraisal process involves two distinct types of efficacy: *response-efficacy*, the degree to which a protective behavior is expected to provide protection against the threat, and *self-efficacy*, an

individual's perception of their own ability to carry out the coping behavior successfully. The threat-appraisal process includes assessing intrinsic and extrinsic rewards, and estimating threat severity, along with perceived vulnerability. The threat-appraisal and coping-appraisal processes combine to yield a final behavioral determination. In this research, PMT was used to assess and interpret IFP risk perceptions and risk-mitigation behaviors among HMS participants.

Risk perceptions held by milk-sharing participants have been understudied and are thus poorly understood by the scientific community. Risk-mitigation strategies and risk perceptions among HMS participants have only been carefully examined by Gribble (38). She found that mothers who received shared HM (S-HM) actively engaged in risk assessment and mitigation strategies, including screening donors, asking for donor medical records, and heat-treating the S-HM. Her study revealed that HMS recipients had incomplete knowledge of the potential risks associated with the practice. However, she also found that HMS participants identified numerous risks associated with infant formula, and likely deemed the risks of HMS to be more acceptable to them. This represents an important first step in understanding how risk is perceived and mitigated among HMS participants, and emphasized the comparative nature of risk in relation to making infant feeding decisions.

The aim of the present study was to contribute to this small body of literature on risk perceptions among HMS participants. Our research objective was to identify distinct risk perspectives among a sample of milk-sharing parents and to identify associations between risk perspectives and individual characteristics, IFP, and HMS practices.

Methods

Research Design. The data for this analysis were collected with a detailed, cross-sectional online survey, the Milk Sharing Practices Survey (MSPS), which is described in detail in Chapter 2. Briefly, the MSPS tool was developed as the product of an in-depth ethnographic study of milk-sharing recipients in the Washington, DC region, which was then carefully tested and iteratively improved using cognitive interviews with both recipients and donors. This study was evaluated by Cornell University's Institutional Review Board prior to its initiation and was granted exempt status.

Measures. The MSPS included an IFP risk module composed of 54 questions for recipients and 50 questions for donors (Appendix A). The majority of these questions consisted of a series of statements that the respondents were asked to rate according to how strongly they agreed or disagreed with them. They responded on a scale of 1 to 11 (1 = strongly disagree, 11 = strongly agree, and 6 = neutral). These statements covered a range of underlying risk-perception constructs featured in PMT, such as severity, controllability, uncertainty, vulnerability, self-efficacy, and fear of specific risks. Some statements also positioned HMS relative to formula feeding (FF) to directly assess comparative risks of the two most commonly used IFP among HMS families.

Statistical Analysis. The data used for the latent profile analysis (LPA) were the responses to the MSPS, which are described in detail in Chapter 2. The analytic sample was 168 individuals, with 70 recipients and 98 donors. SAS Studio version 9.04 was used for all data cleaning, recoding, manipulation and the tidyLPA package in R Studio version 1.4.1106 (R

version 4.0.4) was used to conduct the LPA. LPA was used to classify participants into risk-perspective groups. LPA is a person-centered technique that analyzes response patterns to identify unobserved heterogeneity in multiple continuous response variables, resulting in the creation of discrete profiles (127). Once the LPA profiles have been determined, participant likelihoods of profile membership are calculated probabilistically. LPA was conducted separately for donors and recipients because the samples were determined to be substantially different in their risk considerations so that combining them was inappropriate.

The number of variables needed to be substantially reduced before conducting the LPA. Our target number of variables to include in the LPA models was 10, based on advice received from a team of statisticians at Cornell's Statistical Consulting Unit. The variable-reduction process was conducted separately for donors and recipients. First, variables with low variability ($SD \leq 2.0$) were removed because they had limited capacity to distinguish among respondents. Next, correlation matrices were examined for the remaining variables to identify those that were correlated. Moderately-to-highly correlated variables (defined as $r \geq 0.45$) were either used to eliminate variables (for conceptually dissimilar constructs) or to create composite variables (for conceptually similar constructs), which were constructed as the mean responses for the 2-3 highly correlated variables. The variable-reduction process described above resulted in a subset of 16 variables for the recipients and 13 variables for the donors. Missing values were imputed for the remaining risk variables using the SAS STDIZE procedure and group-mean method. The missingness ranged from 1.4% to 11.4% for the recipients' risk variables, and was 6.1% across all donor risk variables. Next, exploratory LPA models were run using permutations of these variables to identify the variables that offered

the lowest discriminatory power, which were then eliminated. This exploratory modeling process resulted in a final set of 10 variables each for recipients and donors (described in Table 10).

Table 10. Variables input into the latent profile analysis of risk perspectives

Risk variable ¹	Statement	Construct
HMS fear	Feeding someone else's breast milk to my child made me feel nervous or afraid (Recipient). Having someone else's child drink my breast milk made me feel nervous or afraid (Donor).	Fear (HMS)
HMS familiarity	My level of comfort with milk sharing is highly dependent on my level of familiarity with the donor/recipient.	Trust (HMS)
HMS over FF	I feel more comfortable feeding breast milk to my child than formula, even if it is someone else's milk.	Comparative risk
HMS self-efficacy (SE)	I feel confident in my ability to milk share in a safe way.	Self-efficacy (HMS)
HMS severity ²	The potential negative consequences of milk sharing are serious, immediate, and long-lasting.	Severity (HMS)
Good mom	Breastfeeding is an important part of being a good mother.	Reward
Fear of not BF ³	My child not being exclusively breastfed would (or did) make me feel sadness, shame, or failure. – AND – My child not being breastfed made (or would make) me feel nervous or afraid.	Fear (BF)
FF avoidance	It is important to me to avoid feeding formula to my baby.	IFP value
FF severity ²	The potential negative consequences of formula feeding are serious, immediate, and long-lasting.	Severity (FF)
FF vulnerability	I'm not too concerned about the risks of formula feeding because my baby is healthy and strong	Vulnerability (FF)
Parental risk tolerance ⁴	Specific to your role as a parent: how would you describe your level of comfort in taking risks related to the personal safety and health of your child(ren)?	Risk tolerance

Abbreviations: HMS = human milk sharing; FF = formula feeding; BF = breastfeeding.

¹Unless otherwise noted, variable response scale was 1 to 11, with 1 = strongly disagree, 11 = strongly agree, and 6 = neutral.

²Composite variable calculated as the mean of the 3 components of severity (serious, immediate, and long-lasting).

³Composite variable calculated as the mean of the two variables listed.

⁴Response scale was 1 to 4, with 1 = very comfortable taking risks, 2 = somewhat comfortable taking risks, 3 = somewhat uncomfortable taking risks, and 4 = very uncomfortable taking risks.

The best-fitting, latent-profile models were determined using the model-fit statistics log-likelihood (LL), Akaike information criterion (AIC), Bayesian information criterion (BIC), and entropy. Once the optimal number of latent risk-perspective profiles was identified for

donors and recipients, respondent characteristics, IFP, and HMS practices were compared across risk-perspective profiles. Differences in continuous variables were compared across risk-perspective profiles using ANOVA and differences in categorical measures across risk-perspective profiles were tested using Fisher’s exact tests because of small cell sizes.

Results

LPA Model Selection

LPA models were for run separately for donors and recipients, estimating between one and four latent profiles (Table 11). For both donors and recipients, the four-profile model did not reach convergence. Among donors, the model fit statistics for the three-profile model had the lowest values for LL, AIC, and entropy, while BIC was the lowest for the two-profile model. Based on the high entropy value and low BIC value, combined with the goal of parsimony, the two-profile model was selected as the best fit for the donor data. Among recipients, all model fit statistics were the best for the three-profile model.

Table 11. LPA donor and recipient model fit statistics by number of estimated profiles.

Latent Profile	Donor Models				Recipient Models			
	LL	AIC	BIC	Entropy	LL	AIC	BIC	Entropy
1	-2295	4630	4681	1	-1544	3128	3173	1
2	-2212	4506	4612	0.992	-1502	3086	3178	0.765
3	-2177	4479	4639	0.933	-1444	3011	3151	0.929

Abbreviations: LL, log-likelihood; AIC, Akaike information criterion; BIC, Bayesian information criterion.

Description of the LPA Model for Donors

The final LPA model for donors revealed two latent risk-perspective profiles (described in Table 12 and Figure 6). Profile 1 members (89% of the sample) did not prefer HMS over FF, slightly agreed that breastfeeding is an important part of being a good mother, disagreed that the risks of FF are severe, and agreed that they weren’t too concerned about the risks of FF

because their child was healthy. Profile 2 members (11% of the sample) strongly preferred HMS over FF, felt more confident in their ability to milk share safely, had greater fear associated with not breastfeeding their child, more strongly agreed that avoiding FF is important to them, strongly agreed that the potential negative consequences of FF are severe, and strongly disagreed that they aren't concerned about the risks of FF because their child is healthy. Figure 6 displays the interquartile ranges by profile, demonstrating that although the median values may have differed across the two profiles, there was also significant overlap in the range of values.

Table 12. Donor and recipient LPA model variable estimates by risk-perspective profile

LPA Input Variable	DONORS		RECIPIENTS			P value
	Profile 1 (n=87)	Profile 2 (n=11)	Profile 1 (n=41)	Profile 2 (n=17)	Profile 3 (n=12)	
HMS fear	3.65*	1.45*	5.66	4.52	2.75	0.004 ¹
HMS familiarity	5.26	4.37	9.50	8.42	2.49	<0.0001 ²
HMS over FF	5.98**	9.90**	8.87	6.25	10.70	<0.0001 ³
HMS self-efficacy	9.07*	10.50*	8.95	6.77	9.17	<0.0001 ⁴
HMS severity	5.99	4.80	6.85	5.72	5.67	0.1453
Good mom	7.19	9.18	8.70	4.26	7.77	<0.0001 ⁴
No BF fear	7.45*	9.76*	8.59	6.70	8.34	0.0032 ⁵
FF avoidance	7.21**	10.80**	7.80	4.84	8.68	<0.0001 ⁴
FF severity	4.56**	9.10**	6.83	4.11	7.00	<0.0001 ⁴
FF risks not a concern	7.28**	1.97**	-	-	-	
Parental risk tolerance	-	-	3.12	2.85	2.58	0.15

Abbreviations: HMS = human milk sharing; FF = formula feeding; BF = breastfeeding.

* P <0.05

** P <0.0001

¹Pairwise comparisons: only Profile 1 and Profile 3 are statistically different.

²Pairwise comparisons: only Profile 1 is not statistically different from Profile 2.

³Pairwise comparisons: all classes are statistically different from each other.

⁴Pairwise comparisons: only Profile 1 is not statistically different from Profile 3.

⁵Pairwise comparisons: only Profile 1 and Profile 2 are statistically different.

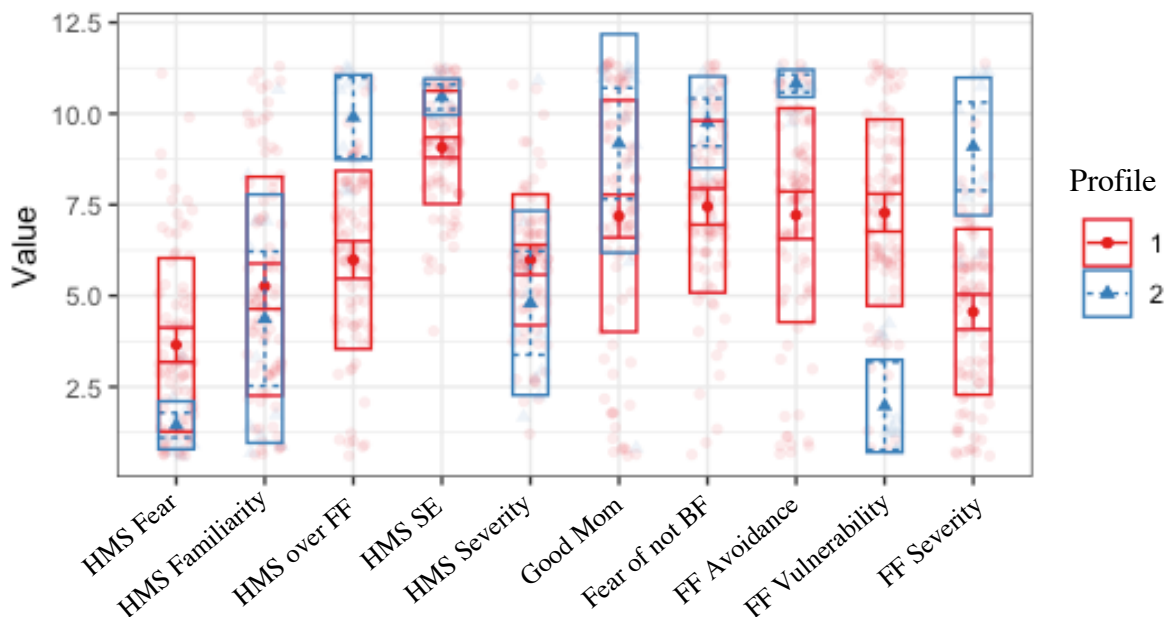


Figure 6. Donor latent profile analysis model variable estimates by risk-perspective profile. This box plot shows the median and range of values for each input variable by risk-perspective profile. The boxes represent the interquartile range (from the 25th percentile to the 75th percentile), while each faded dot represents an observation. The bold red dots and blue triangles represent the median value for Profiles 1 and 2, respectively.

Description of the LPA Model for Recipients

The LPA for recipients revealed three discrete latent risk-perspective classes, with 59% of the sample in Profile 1, 24% of the sample in Profile 2, and 17% of the sample in Profile 3 (Table 12 and Figure 7). Profile 1 respondents were characterized by strong agreement that familiarity with their donor was important, moderate agreement that they were more comfortable with HMS over FF, moderate agreement that breastfeeding is an important part of being a good mother, and moderate agreement that avoiding FF is important to them. Profile 2 respondents were characterized by moderate agreement that familiarity with their donors was important, being equally comfortable with HMS and FF, disagreement that breastfeeding is an important part of being a “good mother,” disagreement that avoiding FF is important to them, and disagreement that potential risks of FF are severe. Finally, Profile 3

respondents were characterized by strong disagreement that feeding someone else's HM to their child made them feel nervous or afraid, strong disagreement that familiarity with their donors was important, strong agreement that they were more comfortable with HMS over FF, moderate agreement that their child not being breastfed would make them feel nervous or afraid, and moderate agreement that avoiding FF is important to them. Parental risk tolerance did not differ significantly across the 3 profiles. Figure 7 displays the interquartile ranges by profile, demonstrating that although the median values may have differed across the three profiles, there was also significant overlap in the range of values.

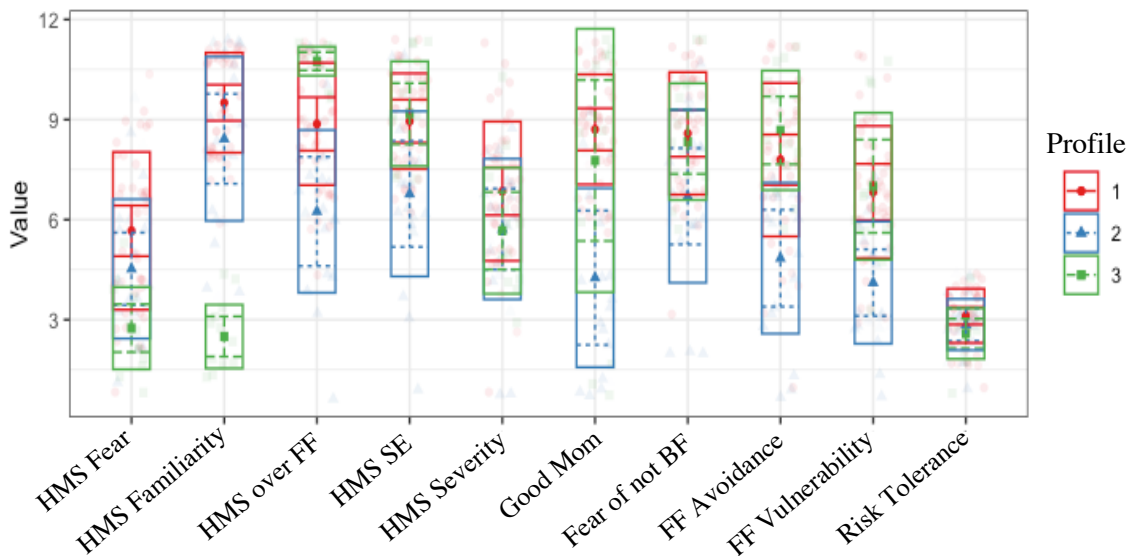


Figure 7. Recipient LPA model variable estimates by risk-perspective profile. This box plot shows the median and range of values for each input variable by risk-perspective profile. The colored boxes represent the interquartile range (from the 25th percentile to the 75th percentile), while each faded dot represents an observation. The bold red dots, blue triangles, and green squares represent the median value for Profiles 1, 2, and 3, respectively.

Maternal Health Characteristics by Risk-Perspective Profile

Maternal characteristics were examined by risk-perspective profile, stratified by donor/recipient status (Table 13). Among donors, no statistically significant differences were

detected in maternal characteristics by risk-perspective profile. Among recipients, Profile 3 members were the most likely (67%) to have considered the birth a traumatic experience ($p<0.05$). There were no other statistical differences in recipient maternal health characteristics by risk-perspective profile.

Table 13. Maternal health characteristic by risk-perspective profile

Maternal characteristic	DONORS		RECIPIENTS		
	Profile 1 (n=87)	Profile 2 (n=11)	Profile 1 (n=41)	Profile 2 (n=17)	Profile 3 (n=12)
	N (%)	N (%)	N (%)	N (%)	N (%)
Primiparous	47 (54.0)	4 (36.4)	18 (43.9)	12 (75.0)	7 (58.3)
Singleton child	87 (100)	11 (100)	38 (92.7)	16 (94.1)	12 (100)
Term birth	77 (88.5)	11 (100)	37 (90.2)	16 (94.1)	10 (83.3)
Cesarean delivery	20 (23.0)	1 (9.1)	13 (31.7)	6 (35.3)	4 (33.3)
Pregnancy complications	15 (17.2)	0 (0)	9 (22.0)	4 (23.5)	4 (33.3)
Labor and delivery complications	11 (12.6)	0 (0)	14 (34.2)	5 (29.4)	7 (58.3)
Considered the birth traumatic	16 (18.4)	2 (18.2)	13 (31.7)*	3 (17.7)*	8 (66.7)*
Ever experienced PP depression ²	11 (12.6)	2 (18.2)	13 (31.7)	6 (35.3)	7 (58.3)
Ever experienced PP anxiety ²	34 (39.1)	5 (45.5)	17 (41.5)	4 (23.5)	7 (58.3)

Abbreviations: PP = postpartum.

* $P < 0.05$

¹Statistical testing conducted by donor/recipient status using contingency tables with Fisher's exact test.

²Either clinically diagnosed or self-diagnosed.

Infant-feeding Practices by Risk-Perspective Profile

Donors. Donor breastfeeding experience and IFP were examined by risk-perspective profile (Table 14). All Profile 2 members were still feeding HM to their child, compared to just 66% of Profile 1 members. No other statistically significant differences were detected.

Recipients. Recipient breastfeeding experience differed significantly by risk-perspective profile (Table 15). Profile 2 members were the least likely to have ever produced milk for their child(ren) ($p<0.02$) and most likely to have fed infant formula to the child of their most recent lactation ($p<0.01$). Duration of HM-feeding did not differ significantly by risk-

perspective profile. There were no statistically significant differences by risk-perspective profile in the IFP used during the first 3 months of life. Profile 2 members had the lowest breastfeeding knowledge score compared to the other risk-perspective profiles ($p < 0.01$).

Table 14. Donor breastfeeding experience and IFP by risk-perspective profile

Infant-feeding Practice	Profile 1 (n=87)		Profile 2 (n=11)		P value ¹
	N	%	N	%	
For ANY of their children, had ever:					
Produced breast milk	86	98.9	11	100.0	1.0000
Nursed directly at the breast ²	85	98.8	11	100.0	1.0000
Had difficulty producing enough milk ²	17	19.8	3	27.3	0.6918
Produced more milk than needed ²	79	91.9	11	100.0	1.0000
Pumped milk to feed their child ²	84	97.7	10	90.9	0.3059
Exclusively pumped to feed their child ²	22	25.6	0	0.0	0.1098
Been diagnosed with a health problem affecting lactation ²	2	2.3	1	9.1	0.3031
Fed infant formula to their child	39	44.8	4	36.4	0.7509
For the child of most recent lactation:					
Has ever received formula	30	34.5	2	18.2	0.4958
Is currently receiving formula	4	4.6	0	0.0	1.0000
Is currently receiving HM	57	65.5	11	100.0	0.0166
IFP used during first 3 months of baby's life:					
Fed at the breast	82	94.3	11	100.0	1.0000
Nursing parent's own E-HM	67	77.0	5	45.5	0.0627
Shared HM	0	0.0	1	9.1	0.1122
Commercial infant formula	22	25.3	1	9.1	0.4497
Banked HM	1	1.1	0	0.0	1.0000
Breastfeeding knowledge score (max 120) ³	91.5	12.2	97.4	15.0	0.1481

Abbreviations: HM = human milk; IFP = infant feeding practice; E-HM = expressed human milk; BF = breastfeeding.

¹Statistical testing conducted for categorical variables with contingency tables and Fisher's exact test, and for continuous variables with ANOVA.

²Among those who had ever produced breast milk.

³Breastfeeding knowledge score is a composite variable calculated from agreement with 12 statements (max score of 10 each) about the health benefits of breastfeeding, HM composition, and HM handling and storage guidelines.

Table 15. Recipients' breastfeeding experience and IFP by risk-perspective profile

Infant Feeding Practice	Profile 1 (n=41)		Profile 2 (n=17)		Profile 3 (n=12)		P value ¹
	N	%	N	%	N	%	
For ANY of their children, had ever:							
Produced breast milk	41	100	14	82.4	11	91.7	0.0161
Nursed directly at the breast ²	40	97.6	14	100	10	90.9	0.2501
Had difficulty producing enough milk ²	34	82.9	11	78.6	9	81.8	0.9029
Produced more milk than needed ²	15	36.6	2	14.3	3	27.3	0.3000
Pumped milk to feed their child ²	41	100	14	100	11	100	-
Exclusively pumped to feed their child ²	13	31.7	8	57.1	3	27.3	0.2010
Been diagnosed with a health problem affecting lactation ²	8	19.5	1	7.1	4	36.4	0.1827
Fed infant formula to their child	26	63.4	16	94.1	8	66.7	0.0522
For the child of most recent lactation:							
Has ever received formula	22	53.7	16	94.1	7	58.3	0.0081
Is currently receiving formula	1	2.4	3	17.6	0	0.0	0.0752
Is currently receiving HM	25	61.0	7	41.2	8	66.7	0.2923
IFP used during first 3 months of baby's life:							
Fed at the breast	39	95.1	13	76.5	10	83.3	0.0813
Nursing parent's own E-HM	33	80.5	11	64.7	8	66.7	0.3593
Shared HM	21	51.2	9	52.9	10	83.3	0.1373
Commercial infant formula	13	31.7	9	52.9	7	58.3	0.1455
Banked HM	8	19.5	1	5.9	2	16.7	0.4289
	Mean	SD	Mean	SD	Mean	SD	P value
Duration of HM-feeding for child of most recent lactation ³	13.7	7.3	9.3	4.1	10.5	1.7	0.1857
Breastfeeding knowledge score (max 120) ⁴	94.1	13.5	82.1	13.2	89.7	11.7	0.0091 ⁵

Abbreviations: HM = human milk; IFP = infant feeding practice; E-HM = expressed human milk.

¹Statistical testing conducted for categorical variables with contingency tables and Fisher's exact test, and for continuous variables with ANOVA.

²Among those who had ever produced breast milk.

³Among those no longer HM-feeding.

⁴Breastfeeding knowledge score is a composite variable calculated from agreement with 12 statements (max score of 10 each) about the health benefits of breastfeeding, HM composition, and HM handling and storage guidelines.

⁵Pairwise comparisons: only Profile 1 score is statistically significantly different from Profile 2 score.

HMS Practices of Recipients by Risk-Perspective Profile

There were no statistically significant differences by risk-perspective profile for the age of recipient child when initiating HMS (range: 3-5.3 months) or total duration of HMS (range: 2.7-5 months) (Table 16). Several HMS practices differed significantly by risk-perspective profile. Profile 3 members were the most likely to have initially connected with donor parents via an online group (p=0.01), to have received S-HM from an online acquaintance they had

Table 16. Recipient HMS practices by risk-perspective profile

HMS Practice	Profile 1 (n=41)		Profile 2 (n=17)		Profile 3 (n=12)		P value ¹
	Mean	SD	Mean	SD	Mean	SD	
Age of child at initial HMS (mos.)	5.3	4.4	4.3	3.3	3.0	3.4	0.2126
Total duration of HMS (mos.)	3.1	3.5	2.7	2.7	5.0	3.8	0.1584
Number of one-time donors	2.8	3.3	2.9	4.5	6.2	5.7	0.0453 ²
Urgency of HM need at HMS initiation:	N	%	N	%	N	%	0.1558
Not at all urgent	10	24.4	4	23.5	1	8.3	
A little urgent	13	31.7	10	58.8	7	58.3	
Urgent	12	29.3	1	5.9	1	8.3	
Extremely urgent	5	12.2	2	11.8	3	25.0	
During HMS, amount of child's HM intake comprised of S-HM:							0.0708
A little or some	18	43.9	6	35.3	1	8.3	
About half	8	19.5	3	17.6	6	50.0	
Most or all	13	31.7	6	35.3	3	25.0	
It varied	1	2.4	2	11.8	2	16.7	
Child was still consuming MOM during HMS	37	90.2	12	70.6	10	83.3	0.1445
During HMS, child was still FAB of nursing parent:							0.4282
Yes - throughout HMS arrangement	27	65.9	6	35.3	7	58.3	
Yes - only during part of HMS arrangement	5	12.2	3	17.6	1	8.3	
No	5	12.2	3	17.6	2	16.7	
Initially connected with donor parents via:							0.0134
Online group ³	19	46.3	8	47.1	11	91.7	
Facilitated through midwife or doula	23	56.1	10	58.8	3	25.0	
Facilitated through lactation consultant	7	17.1	3	17.6	2	16.7	1.0000
Received S-HM from the following individuals:							0.3225
Friend	27	65.9	13	76.5	6	50.0	
Online acquaintance you met in person	15	36.6	5	29.4	7	58.3	
Online acquaintance you have NOT met in person	8	19.5	4	23.5	8	66.7	
Other	7	17.1	1	5.9	4	33.3	
Family member	5	12.2	2	11.8	2	16.7	
Exchanged milk with donors:							0.1163
Directly (met donor to pick up milk)	40	97.6	16	94.1	10	83.3	
Indirectly (received S-HM through intermediary)	6	14.6	4	23.5	7	58.3	
Received via mail / shipped	2	4.9	0	0.0	1	8.3	0.5506
Ever heat-treated S-HM before feeding it to child	3	7.3	1	5.9	0	0.0	1.000
Screened donors by asking personal questions:							0.6934
Did not screen my donors	25	61.0	10	58.8	9	75.0	
Everyone	11	26.8	4	23.5	2	16.7	
Only strangers, not friends or family	2	4.9	1	5.9	1	8.3	
Some people but not all, regardless of familiarity	2	4.9	2	11.8	0	0.0	

Other risk-mitigation strategies used:							
Met in public or brought a companion	19	46.3	9	52.9	7	58.3	0.7999
Asked donor about medical history	14	34.1	8	47.1	5	41.7	0.6628
Looked up the donor online	13	31.7	8	47.1	5	41.7	0.5150
Examined appearance of the donor, their house, or their children	13	31.7	7	41.2	4	33.3	0.7354
Discussed it with a healthcare provider	13	31.7	5	29.4	4	33.3	1.0000
Blended different donor's milks together	13	31.7	3	17.6	5	41.7	0.3393
Ensured HM was kept at an appropriate temp during transport	10	24.4	1	5.9	3	25.0	0.2582
Examined HM containers for cleanliness	8	19.5	3	17.6	3	25.0	0.8410
Ensured donor breastfeeding own child	7	17.1	2	11.8	3	25.0	0.6849
Prayed / meditated	8	19.5	3	17.6	0	0.0	0.3075

Abbreviations: HMS = human milk sharing; HM= human milk; S-HM = shared human milk; FF = formula feeding; BF = breastfeeding; FAB = fed at the breast; MOM = mother's own milk.

¹Statistical testing conducted for categorical variables with contingency tables and Fisher's exact test, and for continuous variables with ANOVA.

²Pairwise comparisons: only Profile 1 and Profile 3 are significantly different.

³Online group such as Eats on Feets, HM4HB, breastfeeding listserv, etc.

not met in person ($p < 0.01$), and to have exchanged milk with donors indirectly ($p < 0.01$).

Profile 3 members also had the highest mean number of donors (6.2; $p < 0.05$). No other statistical differences were detected in HMS practices by risk-perspective profile. The estimated total volume of S-HM received did not differ significantly by risk-perspective profile, although the greatest proportion of Profile 3 members reported receiving 1,000 ounces or more (Figure 8).

Recipients' Attitudes About Their HMS Experience by Risk-Perspective Profile

Profile 3 members were the most likely to rate HMS as being very important in helping them reach their infant-feeding goals ($p < 0.01$), and all Profile 3 members had an overall positive attitude towards their milk-sharing experience (Table 17). Profile 2 members were the most likely to be uncertain about milk sharing again in the future themselves ($p < 0.05$).

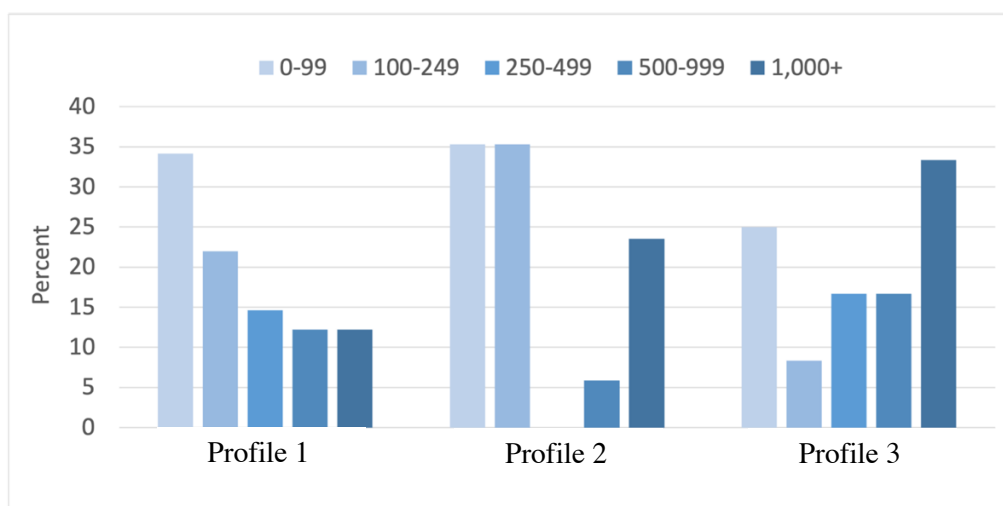


Figure 8. Percent of recipients receiving each category of total volume of S-HM (in ounces), by risk-perspective profile.

Table 17. Recipients' attitudes about their HMS experience by risk-perspective profile.

HMS Attitude	Profile 1 (n=41)		Profile 2 (n=17)		Profile 3 (n=12)		P value ¹
	N	%	N	%	N	%	
How important was HMS as a strategy in helping you reach your infant feeding goals?							
Not important	2	4.9	2	11.8	0	0.0	0.0025
Somewhat important	11	26.8	8	47.1	2	16.7	
Important	11	26.8	6	35.3	1	8.3	
Very important	16	39.0	1	5.9	9	75.0	
Overall, how do you feel about your HMS experience?							
Negative	1	2.4	1	5.9	0	0.0	0.1135
Neutral	1	2.4	1	5.9	0	0.0	
Positive	37	90.2	13	76.5	12	100	
Would you recommend HMS to a friend who was experiencing breastfeeding challenges?							
Yes	36	87.8	11	64.7	11	91.7	0.0593
Maybe / it depends	3	7.3	6	35.3	1	8.3	
No	1	2.4	0	0.0	0	0.0	
Would you milk share again in the future if you needed to supplement your child?							
Yes	37	90.2	11	64.7	11	91.7	0.0414
Maybe / it depends	3	7.3	5	29.4	1	8.3	
No	0	0.0	1	5.9	0	0.0	

Abbreviations: HMS = human milk sharing

¹Statistical testing conducted using contingency tables with Fisher's exact test.

Discussion

This research contributes to our knowledge about HMS by filling knowledge gaps about risk perspectives and decision-making related to IFP. We provided a detailed description of how HMS participants conceptualized risk associated with IFP and examined how these risk perspectives were associated with individual characteristics, IFP, and HMS practices. An important finding is that HMS participants do not conceptualize risks of HMS in isolation, but rather relative to risks of feeding infant formula. Among both donors and recipients, attitudes and beliefs about infant formula were important in distinguishing between risk-perspective profiles. We found that a faction of both donors (Profile 2) and recipients (Profile 3) felt strongly about avoiding infant formula and perceived the risks of FF as severe. These findings align with previous research that demonstrated that HMS recipients had numerous concerns about infant formula, had weighed the risks associated with both formula feeding and milk sharing, and decided that the risks of HMS were more acceptable (38). Our study extended these findings and demonstrated that the group of recipients who were the most strongly opposed to infant formula (Profile 3) also milk shared more intensely than the other two groups, as evidenced by having the highest mean number of donors. These findings suggest that negative attitudes toward and beliefs about infant formula are an important contributor to the decision to engage in HMS as an infant feeding strategy and may predict more intensive HMS practices.

The latent risk-perspective profiles produced by the LPA modeling largely align with what would be predicted by PMT. According to PMT, those who would be more likely to practice HMS more intensely and with fewer risk-mitigation controls would have a greater fear of FF,

greater perceived vulnerability to the risks of FF, greater trust of S-HM, and greater perceived rewards of practicing HMS. Profiles 1 and 3 both preferred HMS over FF, felt that breastfeeding was an important part of being a good mother (which may be viewed as an intrinsic reward of HMS), had some fear associated with not breastfeeding, and agreed that avoiding FF was important to them. Where these two profiles differed was in the degree of fear associated with feeding another woman's milk to their child (Profile 3 members did not have that fear) and whether their level of comfort with HMS was dependent on familiarity with the donor (not important to Profile 3 members). Profile 3 members had the highest number of donors, were the most likely to have accepted S-HM from online acquaintances who they did not meet, and were the most likely to have received S-HM indirectly. In this case, the greatest fear of FF and greatest perceived susceptibility to the risks of FF were associated with an increased drive to avoid FF. Or, conversely, the absence of fear of HMS and the lack of concern about donor familiarity were associated with fewer risk-mitigation practices. This demonstrates that, as predicted by PMT, fear was an important factor in motivating HMS recipients to engage in the protective behavior of being more cautious in choosing their donors.

These findings are important because they suggest that the “protective behavior” is interpreted relative to what is viewed as the threat. To parents who view FF as the greatest threat among their IFP options, their protective behavior would be to avoid FF (and potentially to use S-HM). Conversely, to parents who view receiving S-HM from a stranger to be the greatest threat, they are more likely to FF or to only accept S-HM from someone they know. These findings suggest that fear and the importance of donor familiarity are important sources of

intra-cultural variability in HMS parental cognitive frameworks of infant feeding. Moreover, these findings underscore the importance of *relative* risk in informing these cognitive processes and influencing IFP behaviors.

The LPA for donors revealed just two latent risk-perspective profiles, with the majority of donors classified in Profile 1. This suggests that there may be greater homogeneity in risk perspective among donors than recipients, which is potentially due to the lower risk faced by HMS donors compared to recipients. Donors generally had a high degree of self-efficacy about their ability to practice HMS safely and having other infants drink their milk did not make them feel nervous or afraid. Donors also did not feel that familiarity with their recipients was important in helping them to feel comfortable with milk sharing.

The two latent risk perspectives that emerged from the LPA for donors showed that beliefs and attitudes toward infant formula were the major factors that distinguished the two perspectives. Members of the minority risk perspective (Profile 2) held strong beliefs that the potential negative consequences of infant formula are severe and that infant formula is to be avoided if at all possible. Not surprisingly, this group strongly preferred HMS over formula feeding. In contrast, members of the majority risk perspective (Profile 1) were more neutral in their views of infant formula and slightly disagreed that the potential negative consequences of formula feeding are severe. This group did not prefer HMS over FF. Unfortunately, due to the small size of Profile 2, it was not possible to distinguish characteristics and IFPs of donors that differed by risk-perspective profile. Nevertheless, we can conclude that while HMS donors do have some variability in risk perspective distinguished by their attitudes toward

infant formula, they all generally have high self-efficacy and low fear associated with donating their milk in peer-to-peer HMS arrangements.

This analysis revealed three latent-risk perspectives among HMS recipients. Similar to the donors, these risk perspectives were largely distinguished by the recipients' beliefs and attitudes toward infant formula. However, in contrast to donors, recipients' risk perspectives were also distinguished by the degree of importance they placed on their familiarity with the donor. The finding that those in the majority risk-perspective (Profile 1) strongly preferred to be familiar with their donor is congruent with previous research that showed that milk sharing is heavily reliant on mutual trust between donors and recipients (27, 39, 48, 128). However, our research revealed an important subgroup of HMS participants – those who don't prioritize familiarity with their donor – and suggests that these HMS participants may be less likely to engage in risk-mitigation strategies, such as donor screening. This study was a first step in investigating the association between risk perspectives and HMS behaviors, and therefore has generated interesting hypotheses worthy of investigation. Better understanding the association between risk perspectives and HMS practices is critical to support the development of targeted risk-communication messages and thus, warrants further research.

An interesting finding to emerge from this risk perspective analysis is that all respondents – donors and recipients alike, regardless of their risk-perspective profile – were neutral about the severity of the potential negative consequences of HMS, which may reflect their uncertainty about this subject. This is perhaps unsurprising, given the lack of scientific studies on HMS broadly and, more specifically, on the actual risks of HMS practices. Prominent

government, public health, and clinical organizations have issued statements cautioning against HMS (100, 101, 129). However, these statements are primarily based on the theoretical potential negative consequences of HMS. The data needed to assess the likelihood of a negative health outcome associated with feeding S-HM to an infant are currently unavailable (21). In contrast, the benefits of feeding pasteurized B-HM to premature and sick infants in the neonatal care unit are well documented (130-135) as are the risks of feeding infant formula (2, 3, 62, 78-80).

Much can be learned from the PMT constructs that were eliminated from the LPA of risk perspectives, either because of low variability in response values or because they offered low predictive value in the modeling. Social and practical risks of HMS (e.g., being stigmatized or judged negatively, requiring a lot of time and planning) emerged as unimportant in defining recipients' risk perspectives. Most respondents strongly agreed that "women have been sharing their breast milk for centuries," and thus the low variability in responses resulted in its elimination. Self-efficacy and perceived control of the risks of HMS were also eliminated from the LPA models because both variables had low variability in responses (with most respondents rating them as neutral). Other PMT constructs with low response variability included perceived rewards of HMS and trust in the altruistic motivations of donors (everyone agreed with these statements with SD of 2 or less). Finally, recipients unanimously had low perceived vulnerability to risk of harm from HMS (as measured by the statement, "My baby is likely to experience the potential negative consequences of milk sharing"), and thus this variable was not included in the final model. This suggests that optimism bias may play a role in cognitive frameworks among HMS recipients. These PMT constructs excluded from the

final LPA models yield important insights into the foundational beliefs common to HMS participants, providing theoretical considerations for future research on cognitive frameworks of HMS risk perceptions.

Strengths and Limitations

This research had several limitations. The modest sample size limited our statistical power to detect differences between groups of donors and recipients and among latent classes, and limited our ability to conduct a more rigorous statistical analysis of risk perspectives (e.g., by including more variables related to risk perception in the LPA models). The online survey approach that we used relied on the ability of respondents to provide accurate and honest responses. Inasmuch as self-reported data are known to be affected by recall bias, we excluded parents who had milk-shared more than 18 months ago to minimize this source of bias. Finally, the possibility of confirmation bias and reverse causality cannot be ruled out because participants were answering the survey questions about their practices, attitudes, and beliefs simultaneously and retrospectively. It is quite possible that HMS behaviors influenced risk perspectives. With the cross-sectional survey approach used, directionality of such associations cannot be determined. Thus, the direction of the identified associations between risk perspectives and behaviors remains unknown and is a fertile area for future research.

This study also had several important strengths. The highly detailed nature of the survey tool that we employed permitted a rich and nuanced examination of infant feeding risk perspectives. The extensive data collected about attitudes, beliefs, and practices related to milk sharing, breastfeeding, and infant formula allowed us to characterize *relative* risk

perceptions, another key strength of this analysis. In addition, this study employed LPA, a powerful person-based statistical approach that is used to uncover hidden heterogeneity within an apparently homogenous sample (127). This technique allowed us to assess patterns of responses within an individual, which revealed how beliefs and attitudes about IFP cluster to form broader risk perspectives. By applying this methodology to identify intra-cultural diversity within HMS participants, we have advanced our understanding of cognitive frameworks for parental decision-making in this population.

Conclusions

HMS risk perspectives are complex and not formed in isolation, but rather relative to perceptions of infant formula. Risk perspectives held by HMS recipients align with what would be predicted by PMT. Our findings revealed that recipients' risk perspectives are associated with IFP and HMS practices in important ways. Donors and recipients alike were uncertain about the severity of HMS risks, which reflects the paucity of data on HMS and underscoring the need for rigorous scientific study of the practice. Development of a better understanding of the risk perspectives held by HMS participants is critical for elucidating parental decision-making processes. This information can help to inform public health guidelines and clinical practice that is responsive to the lived realities of modern parents. Additional research is needed to expand our understanding of risk perspectives related to HMS and identify ways in which those perspectives are associated with HMS practices.

CHAPTER 4

“I FELT SHAME, I FELT LONELY, AND I FELT LIKE NOBODY TOLD ME”:

THE RECIPIENT MILK-SHARING EXPERIENCE

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Katherine L. Dickin, Kathleen M. Rasmussen

Abstract

Background: Contemporary human milk sharing (HMS) is of interest to clinicians and public health practitioners because it is an emergent infant-feeding practice with potential health implications. Much of the scientific investigation into HMS has focused on categorizing and enumerating practices, with limited attention paid to the parental experience of HMS.

Objective: To characterize the recipient milk-sharing experience within two specific areas of inquiry: (1) What are the most salient features of the HMS recipient experience? (2) How do recipients navigate HMS decision-making?

Methods: In-depth, semi-structured interviews were conducted with 30 mothers in the Washington, DC area who had milk-shared in the past 18 months. Interviews were audio recorded, transcribed, and iteratively analyzed using an inductive approach to identify, analyze, and interpret emergent themes.

Results: The recipients' milk-sharing experiences featured intense and sometimes conflicting emotions. The most frequently mentioned emotions were trust, gratitude, guilt, and shame. Trust of breastfeeding mothers and human milk, along with mistrust of infant formula and healthcare providers played a key role in the decision to milk share. Faced with numerous breastfeeding challenges, recipient mothers demonstrated high levels of dedication and perseverance in feeding human milk to their infants, underscoring the high value they placed on human milk. Some recipients reported having negative interactions with healthcare providers about infant feeding in which they did not feel heard, believed, or respected. Emergent themes about recipient decision-making revealed careful and thoughtful analysis of infant-feeding options. Many recipients viewed banked donor milk as inaccessible to them

and pasteurization of shared human milk as both unnecessary and undesirable for their healthy, term infants.

Conclusions: These findings highlight important features of the recipient milk-sharing experience and emphasize the need for evidence-based, non-judgmental support for families experiencing breastfeeding challenges or seeking alternative infant-feeding options.

Introduction

Human milk sharing (HMS) is an ancient infant feeding practice with deep historical roots. Ancient Greek and Byzantine physicians discussed the use of wet nurses in written text as early as 50 AD (10). According to the Greek physician, Soranus of Ephesus (98-138 AD):

“The baby should be fed with maternal milk; this is the most familiar to him. For the baby the mother is the most beloved person and it is natural to be fed by the mother. But if there is an obstacle the best feeder (wet nurse) should be chosen... The baby can become strong, if born from another and raised by another, in case his mother is prevented from providing him with food due to some disease.”

Historically, HMS was practiced as an infant fed at the breast of a woman other than its mother. This typically would have occurred if the mother had died, had health complications, or was unable to breastfeed for any reason. Prior to the invention of safe human milk (HM) substitutes, finding someone to breastfeed such an infant was a matter of survival: without HM, the baby would die. In recent years, a contemporary version of HMS has emerged, one that is heavily reliant on the commerce-free sharing of frozen expressed HM (E-HM) between parents.

Contemporary HMS is a relatively recent phenomenon, made possible by “the quiet revolution,” i.e., the recent development and widespread use of efficient double electric breast pumps (14). According to the 2005-2007 Infant Practices Study II, 85% of breastfeeding mothers of young infants had expressed HM at least once since the birth of their child, with more than half commencing in the first week postpartum (84). That proportion is now likely higher because the availability of pumps increased after the passage of the 2010 Patient Protection and Affordable Care Act mandated that health insurance companies cover their

cost. The ubiquity of HM expression is dramatically changing the “breastfeeding” landscape in that mothers are increasingly opting to replace some or all at-the-breast feeding with E-HM fed using bottles (136). It is readily acknowledged by the scientific and public health communities that HM expression has become an integral part of HM feeding in contemporary societies (13, 14, 84, 137-141). Scientists are actively seeking to understand the myriad potential ways in which this new infant feeding practice may modify the benefits of the traditional breastfeeding relationship. One unintended consequence of this increase in HM expression is, for the first time, the availability of a surplus of frozen E-HM, which supplies modern HMS practices.

As an infant-feeding practice, HMS encompasses a variety of different forms and arrangements. The duration and intensity of HMS engagement, along with risk mitigation practices, vary substantially among parents. Many HMS recipients milk share for a short time while overcoming a breastfeeding challenge, while others may milk share for a year or longer, incorporating shared human milk (S-HM) as a core component of their infant feeding routine. Some HMS parents only share milk with people they already know through their social network, while others connect with unfamiliar parents through online platforms. Documented risk mitigation practices include, among others, screening of the donor’s health status and lifestyle, getting to know the donor, home pasteurizing the S-HM, ensuring the S-HM has been stored appropriately, age-matching the S-HM to the age of their own baby, and many others. Because HMS is a self-regulated practice, each donor-recipient dyad creates a system that works for them, rendering HMS a patchwork of widely disparate practices.

Contemporary HMS is of interest to clinicians and public health practitioners alike because it is an infant-feeding practice that we know little about and carries potential implications for the health of both donor and recipient families. For example, recent studies in the human milk literature have sought to identify and quantify the ways in which expressed human milk differs from human milk fed at the breast. There is growing evidence that the process of expression, storage in various containers, and potential exposure to temperature changes can significantly alter the nutritional and non-nutritional composition of the milk in ways that may limit the health benefits conferred to the infant (40, 42, 43, 142, 143). In the case of HMS, parents are not only feeding expressed human milk to their infant, but what they are feeding is from someone other than the infant's mother, disrupting the mother-infant breastfeeding dyad. The implications of this modification of the traditional breastfeeding relationship remain unknown.

Much of the scientific investigation into HMS has focused on categorizing and enumerating practices, similar to the survey results presented in Chapter 2. Only limited attention has been paid to the parental *experience* of milk sharing, positioning the parents engaged in the practice as the experts with experiential knowledge to share. In the present study, we analyze qualitative interviews with HMS recipients about their experience with milk sharing. First, we present emergent themes about the experience of parents receiving shared milk, and then we seek to understand recipients' decision-making perspectives. The goal of this research was to develop an understanding of the recipient experience of HMS, with two specific inquiries: (1) What are the most salient features of the HMS recipient experience? and (2) How do HMS recipients navigate HMS decision-making?

Methods

Formative Research. Initial formative research⁴ was conducted to inform the study design, methodology, and tool development and validation. During June 2017, 11 informal key informant interviews were conducted with birth workers (midwives, doulas, and lactation consultants) in the greater Washington, DC metropolitan region. Key informants were purposively selected for diversity in terms of clinical practice type and location. The purpose of conducting these interviews was to better understand milk sharing knowledge and practices, as well as the range of perceptions and attitudes about milk sharing. It was important to learn about potential differences in milk sharing experiences and perspectives by type of clinical practice.

A number of interesting and helpful findings emerged from this preliminary work. First, discussions with key informants indicated that the milk sharing network in Washington, DC is extensive and highly active. Each informant had numerous experiences with milk-sharing connections and indicated that this behavior is now more common in their networks. They further detailed, however, that widespread stigma against milk sharing remains, leaving some women hesitant to discuss the practice with friends, family, and healthcare providers. Thus, milk sharing may be far more common than generally believed because it is largely a hidden practice. Birth workers regularly facilitate milk sharing between their clients, sometimes as intermediaries, whereby the individuals exchanging milk never meet or even learn each other's names. It is important to note that women who can afford to hire a doula are a specific

⁴This proposal defines formative research as initial interviewing conducted (prior to the formal study). The purpose of these interviews was to provide information of importance to the study design, methodology, and materials.

subpopulation (higher income, higher education, more likely to intend to breastfeed), and therefore recruiting solely through the DC doula network would not have led to adequate sample diversity.

Finally, none of the key informants knew of any lower-income parents participating in HMS. Several lactation consultants with a non-profit organization serving lower-income, Black communities in Southeast DC reported that they were unaware of milk sharing occurring in their communities and had never fielded inquiries about it. They felt that the struggle in these communities was around increasing breastfeeding initiation, and that milk sharing (which requires a local surplus of human milk) was simply not an option in their communities. From this information, we concluded that it would be difficult to find and/or access low-income parents who have participated in HMS.

Participant Recruitment. Participants were recruited via email advertisements circulated among the DC birth-worker network, advertisements on local milk sharing Facebook groups, and parent email listservs. The target population was the geographically-defined network of milk-sharing parents in the Washington, DC region. Study inclusion criteria were as follows: aged 18 years or older, English-speaking, had shared milk within the past 12 months, had shared milk *with a peer* (i.e., not through a milk bank), and lived or worked in the greater Washington DC region. This study was approved by the Human Subjects Committee of the Cornell University Institutional Review Board.

Data Collection. The first round of interviews was conducted during October 20 – December 11, 2017 and the second round during February 15-22, 2018. Written informed consent was obtained from each participant prior to their interview. The first author conducted one in-depth, semi-structured interview with each participant in a location of their choosing, typically in their home or at a café near their home or workplace. The interviews lasted approximately 60-90 minutes. Interviews were flexibly structured using an interview guide (Appendix C) that covered the following themes: breastfeeding experience, risk perceptions of infant feeding options, milk sharing experiences and motivations, and social networks. This last section presented a short series of questions about participant social network sizes and structures, designed as a feasibility study to assess whether a web-based respondent-driven sampling (RDS) survey would be an appropriate methodology for this population. The interviews were conducted informally and conversationally, allowing respondents to feel at ease and help guide the discussion. Demographic information was collected by questionnaire at the end of each interview. All interviews were audio-recorded, and participants received a \$30 Amazon gift card in exchange for their participation. Field notes were completed within 24 hours of interview completion.

Data Analysis. Interview audio recordings were transcribed verbatim by study staff using either Trint transcription software or by a professional transcription service, Rev. Interview transcripts were imported into Atlas.ti version 8.4.5, which was used for all subsequent analysis. We iteratively analyzed the transcripts using emergent codes. The coding process involved an inductive approach to identify, analyze, and interpret emerging patterns of meaning, which we refer to as “themes.” The analysis focused on providing a rich thematic

description of the full data set, an approach that is particularly useful when investigating an under-researched topic (144). Epistemologically, the analysis was conducted using a ‘contextualist’ approach, meaning that we viewed it as important to generate a picture of how respondents understood and constructed meaning from their experiences, and that also provided insights into the ways in which the broader social context informs the construction of those meanings.

Results

Sample Characteristics

A total of 30 women participated in the study. The sample of HMS recipients was primarily non-Hispanic White, married, highly educated, employed, and of high socioeconomic status (Table 18). The mean age of the participants was 35 years, and the mean age of their youngest child (for whom they milk-shared) was 9.7 months at the time of the interview.

Table 18. Ethnographic participant characteristics

Characteristic	Mean	SD
Age (years)	35.0	4.9
Age at first childbirth (years)	32.7	5.1
Number of liveborn children	1.6	0.9
Infant age (months)	9.7	6.3
	N	%
Holds a graduate degree	18	60
Employment status		
Part-time	3	10
Full-time	18	60
Married or domestic partner	27	90
Non-Hispanic White	22	73
Estimated annual household income		
< \$50K	2	6.7
\$50-99K	5	16.7
\$100-149K	9	30.0
\$150-199K	5	16.7
\$200K+	9	30.0

The Recipients' Milk-sharing Experience

The milk sharing experiences described by recipients were laden with intense and sometimes conflicting emotions. Every ethnographic participant discussed some aspect of the emotional landscape of milk sharing. The most frequently mentioned emotions were trust, gratitude, guilt, and shame. Additional emergent themes were maternal dedication and perseverance, and unpleasant interactions with healthcare providers.

Trust. Forming a milk-sharing relationship often relies heavily on trust between the donor and recipient. Trust was discussed in a variety of ways. Many mothers talked about their deep reliance on trust and the mother-to-mother connection to feel comfortable with HMS. Some recipients reported trusting their donor, who was referred to them through a trusted source, such as their doula, lactation consultant, or midwife. The knowledge that a trusted contact knew and vouched for the donor was a significant source of comfort for many recipients. Sometimes women cited trust as a reason for not screening their donors by asking probing questions about their diet, health, and lifestyle. These recipients found it unnecessary to heavily screen their donors because they had already decided that their donors were trustworthy:

We felt confident that the connection through our doula was a safe one. We did ask the mom some questions about her diet and her medical history. But nothing too probing because, again, this was a trusted reference. – Cheryl

Other recipients readily trusted donor mothers because a willingness to donate surplus milk and get nothing in return indicated their inherent goodness as human beings:

I guess, again, because it's part of this community, I just, you know people don't necessarily all have the same values as you, but you assume if

someone's going to reach out and offer you their frozen milk, they probably are probably a good person. – Helen

These are moms helping moms. Like, when you offer these things, it's like, you have to have a level of trust. So I have a higher level of trust than he [partner] does, which is fine. – Amanda

Trust was also inspired in recipients when donors freely offered information about their diet, health, and lifestyle upfront, a common practice in the milk-sharing community. Because these donors were so forthcoming with personal information disclosures, a strong foundation of trust was engendered with their recipients:

I only had one donor and I trusted her because of all the information she was giving me. She was being so upfront about things that I hadn't thought about. Like does it matter that she owns dogs? Does it matter if she owns horses? But you know, she was telling me them, so to me, it's like, I do not think she would intentionally contaminate the milk. Because of how she was... Like she told me what prescription drugs she took...I think because she was so upfront, I didn't even get a chance to think of some of this stuff. – Mary

Finally, a foundational source of trust mentioned by many recipients was the fact that donors fed the same milk to their own healthy infants. Many recipients returned to this fact again and again as justification for their trust that the milk was safe for their own infants to drink. This trust relied in part on their knowledge that breastfeeding women tend to be careful about what they consume and how they care for themselves, and also on their belief that all mothers want the best for their babies.

I mean, these women are making this milk for their own children, in peer-to-peer. They just happen to have extra. So if they're going to feed it to their kid...I would have higher standards for my own children. You know what I'm saying? I wouldn't offer somebody something that I wouldn't give to my own baby. But I guess someone could be totally gross, but...you gotta hope, I mean, every mom I know washes their hands like twenty times a day, so... I could be naive, but it doesn't feel naive. It feels like I trust other women, you know? – Helen

Failure, guilt, and shame. All study participants had a strong intention to breastfeed and many of them were unable to do so as they had envisioned. Many women described feelings of guilt, shame, and sadness that they failed to fully nourish their child as they had intended.

Well, I mean your body is supposed to do a thing. And if it can't do the thing, you have a lot of emotions about it. Particularly while you're postpartum and trying to figure out the rest of your new identity. – Cheryl

*The first two weeks were really rough emotionally... really, really hard... because there was extreme guilt, and I don't think it was linked to the formula, I think it was just linked to the fact that I wasn't able to breastfeed successfully. I mean, I think there was just a lot of... I would say guilt is probably the biggest thing, guilt and then I mean it got to a point of despair, like...really that was the emotion that I was feeling even though it sounds kind of dramatic looking back on it now, but that's really what I was feeling. Especially because what I anticipated for my birth was so different, what I anticipated for my breastfeeding experience was so different, so it was just nothing ever goes according to plan, which I expected, but not in this way.
– Janet*

Recipients sometimes blamed themselves for their inability to exclusively breastfeed, even though many of them had health conditions that were beyond their control, such as insufficient glandular tissue, inability to lactate after undergoing localized radiation treatment for breast cancer, multiple sclerosis, or taking necessary medications incompatible with breastfeeding. Many recipients mourned losing the breastfeeding journey they had envisioned and desired, and this grief often went unrecognized by others.

She's totally fine now, but...it was traumatic. Yeah, it was hard... There's like, you know, there's another new human and a toddler and all the stuff that comes with normal postpartum and then trying to push through all of that and there's some pride in being able to feed your baby. And feeling like I was failing her and I wasn't giving her the best. It, um, really messed with my emotions. – Stacey

In my process of kind of mourning the breastfeeding component, and not being able to exclusively breastfeed him...But it was kind of processing the whole thing, processing the fact that he WAS going to have some formula,

he WAS going to be drinking milk from other people that were not me ... so it was all of that I processed at once so that I didn't have to mourn each component. – Janet

Dedication and perseverance. Many recipients experienced lactation challenges and described the stress and exhaustion of trying different strategies to feed their babies. They endured difficult feeding schedules, sleep deprivation, and physical pain to nourish their infants. These experiences often accompanied complex decision-making about supplementation while processing the complex emotions associated with the inability to fully breastfeed their child.

*It was very stressful. And of course, you're, I was exhausted. You know...she was up multiple times a night. And I just didn't know what to do. So we tried formula because you know, we did it with our first daughter, and even though it, we were both unhappy about it, I was like well, look, I'm not going to starve my baby out of some prideful need to be her only food source. But Isabelle did not like formula. We also figured out that she was lactose intolerant or whatever it is for babies. So I completely cut dairy out of my diet. She had really bad reflux. So I kept dairy out of my diet... So then we, we tried a soy formula, and I mean, it just was disgusting. It smelled ter-, like of course she didn't want it. So we tried formula, and she did take a few bottles of it over the course of several weeks, but she really like, I think the babysitter had to like keep trying to give it. You know, she just did not want it. So, that wasn't working. I was back at work. I was exhausted. Pumping wasn't going well...I also tried some supplements. Um, for better or for worse. And, but in the meantime, I was down like, I think it was something like at least three ounces a day. I had less than she needed. So I was like, where am I going to get this?
– Helen*

So the lactation consultant was great, but they put me on a schedule. And we started domperidone and titrated it up. So they had me pumping every two hours beginning to beginning for 30 minutes. And then, I would first put her to the breast. And I would tandem pump. And then when she got frustrated, which after we started giving her the bottle, even though I put the preemie nipples on the bottles, she would get frustrated pretty fast. So once that happened, I would pass her over to my husband, who would then finish up with, we were syringe feeding her to start. And he would take whatever little milk I had saved in the fridge and do it through a syringe.

And when that was done, he would give her some formula. And then I would finish off the pumping for 30 minutes and then repeat an hour and a half later. It was awful (laughs). No one's getting any sleep. Xavier finally was like, you have to sleep, even if it's for four hours. I mean yeah, it was a zoo. And then the domperidone, they ended up putting me on the max dose, which I don't really remember what that was at this point. But I was taking pills every I think four to six hours. And by the end of it, I was producing maybe six to eight ounces a day. So I only made it to like six weeks. Because I really like, wasn't a mom at that point anymore. I was like hooked up to a freaking machine to get not much. By that point, I mean, she was starving. And you're like exhausted, and yeah... So I mean, I gave it the good old try.
– Betsy

Gratitude. Most participants expressed feeling deeply grateful for and indebted to their donor(s). Several recipient mothers described the immensity of their gratitude such that they felt inadequate trying to express it; the donated milk was a priceless gift.

So much milk. It was unbelievable. And such an incredible gift because she just handed it over to us. I wrote both of them - the friend and the mom - thank you notes, just to say you have brightened a dark day. Because it really was terrible getting the diagnosis, but then same day to know that there was an option really helped. And it really helped me push through my emotions on it because I knew I had a plan. – Cheryl

I told her [the donor] that, you know, that she was giving Raven a gift that had no... it's priceless. You know, she was giving the gift of life. My family's from India, and when I was growing up my mom always said that the biggest, most respectful thing you can do for someone is give them a glass of water because you're giving them life. Because water is essential to life. And I always thought that way about Gia [the donor]. You know, she was giving Raven the essence of life. – Sydney

Multiple recipients found that receiving S-HM decreased their distress around their inability to breastfeed as intended. These mothers were relieved to provide their children with the health benefits associated with human milk feeding.

It gave me a lot of peace of mind that I was able to do something for his immune system. And give him, you know, somebody's gut biome - even if it wasn't mine. I think my husband would tell you, you know, I was a mess

over it. So having an option that allowed him to get some breastmilk was a relief to everybody. – Cheryl

Feeling not heard, believed, or respected by healthcare providers. Some participants discussed unpleasant interactions with their healthcare providers. These participants felt that they were not listened to or believed by their healthcare providers when they voiced concerns and knew that something was not right. They had sought help because they knew that something was wrong and were frustrated when they weren't taken seriously by their providers.

I was like, my baby is hungry. I know it. The pediatrician is saying no. The lactation, a peer counselor at the birth center is saying no. But my baby is not gaining weight and he's not happy. And like, I think something's going on, and I don't think he's getting enough. – Tonya

I never breastfed a baby before, but I knew damn good and well that it was not supposed to feel like that. And I was like, you know, and I felt like 99% of the people were telling me to buck up. You know, like even my pediatrician being like, well it hurts in the beginning. And I'm like, you know, I've been through a lot of psychological and physical trauma. I know what hurt is, and this is not how it's supposed to feel... And I felt like it was all up to me to figure out a doctor that would, like to fight for a prescription. To get her tongue-tie even analyzed. To figure out how to get donor milk. To fight with everybody that I'm not putting her on formula. – Kim

Other participants described having negative interactions with healthcare providers when discussing their HMS participation. Some participants felt as if their ability to make an informed choice on infant feeding was disrespected. Other participants felt stigmatized or patronized by their provider's approach to the discussion. Flavia describes telling hospital staff that she wanted to feed donor milk from a friend to her premature newborn twins who were in the NICU:

So then the doctor came in and was like, you know, it's really dangerous to use anybody else's milk. At this point, I think I lied and I told them that I knew her. I said it was a friend. And he was like, it doesn't matter. It's very dangerous. It's your, you know, your milk is for your baby he said, and her milk is for her baby. He said we can't have the donor milk possibly contaminating other milk in here. You just don't know what's in it. Something to that degree. And he was just mean about it. – Flavia

Healthcare providers were sometimes perceived as being authoritative in their bedside manner. Participants described experiences where they felt bullied or intimidated by healthcare providers to feed formula to their infants.

So they were trying to force me to supplement formula instead of say, for example, saying oh, you could supplement with donated breast milk. So that's why I was so against it. So when they were giving me this or that as options, I had to say no, I'm going to do my best with breastfeeding. – Zara

...The hospital kept pushing formula, saying that I had to use formula to raise her sugars, and I said no. I'll bring another mom in here to nurse her before my milk fully comes in, and all of a sudden, they had donor milk at the hospital. So I used a supplemental nursing system to feed her extra... You know, they literally made it seem that I would like get in trouble if I didn't give it [formula]. – Lila

But then ultimately he had lost so much weight in the hospital that they would not release me. They saw my, um, hesitation with formula, that they wouldn't release me unless I would feed him formula in front of them. Because his weight had dropped so much. – Samantha

A few participants described having respectful and informative conversations with their healthcare providers, where they felt heard by their provider and felt like their parental decision-making autonomy was respected.

You know my pediatrician is great because she was always very open just about breastfeeding in general... I volunteered it [that she was milk sharing] because I had medical questions, you know. I was like oh, you know... you can't like actually catch something from breast milk, right? Like should I worry about that? This is a friend. And also, because we were doing a little... We were pretty neurotic Type A people, so like we'd pack it on ice. But like occasionally we'd exchange it at like a coffee date and then

I'd drive home with it and I was sort of like, well you know I think it defrosted about X amount. And so I had asked my pediatrician those questions. She's good with resources. So when she wasn't knowledgeable, she like, went and checked it out. – Rose

Emergent Themes on Parental Decision-Making

Mistrust of commercial infant formula. In discussions about infant feeding beliefs and values, many respondents directly or indirectly alluded to their mistrust of infant formula and formula manufacturers. Numerous recipients reported a lack of trust in the composition of infant formula because of production issues, such as contamination, previous recalls, or lack of regulation:

Well, it's made in a factory. You have no idea what's actually in there, if there's any contamination. You know, you hear of bad formula from China. Like babies dying, and oh my god, like who knows? There could be rat poison. Some angry person putting it in (laughs). You just don't know, right? – Helen

It just freaks me out that there could be a possibility of contamination. Whether it's insects or lead or metal fragments. Or, you know, every two minutes, it's something. You know, they shut down a factory because I don't know what got into it and then there is a recall. Like that, that, that chemical concept of it just kind of freaked me out. – Sheena

Some participants believed that the infant formula companies could not be trusted because of their motivations to make a profit ahead of a genuine interest in infant health. For example, Rebecca did not take issue with the content or quality of infant formula, rather she was angered by the practices of infant formula manufacturers and refused to buy their products:

Well, I never felt good about giving him formula. The formula companies, I just think they're very underhanded in the way that they promote their products and try to get women to use it who don't need to use it. I think it's completely unnecessary. There's plenty of good reasons to use formula. If they could just focus on those, and sell based on that, but I think they actually try to get women not to breastfeed so that they'll use formula. And so, it makes me very mad, and I don't want to use their product. – Rebecca

I don't trust any of this stuff. And, and the formula is included in it because it's made by corporations that profit off of it. And they're going to cut corners and look at their bottom line. They're not looking at the health of the baby. They're looking at their bottom line. I mean, I wouldn't expect them to do anything else, but I also don't trust them because of that.
– Gabrielle

Another commonly cited source of mistrust was concern about the nutritional content and quality of infant formulas. Many participants didn't trust infant formula as a safe and nutritious alternative to human milk.

It's junk food, you know, it will keep a kid alive that's for sure, but it's not something that I want to feed him every day all the time. – Gabrielle

I am concerned about, just contamination as far as pesticides with soybeans, and there's tons of soy in formulas. So I was concerned about just health, and growing a human on stuff that I myself wouldn't consume.
– Melinda

On the other end of the spectrum of infant formula attitudes, some participants viewed infant formula as a safe substitute for human milk and were not averse to using it or mistrustful of it. These participants did not avoid infant formula because of mistrust, but more typically because they viewed it as unnecessary.

So my opinion is kind of like, I believe that formula, you know, it's a miracle of science. There's a lot of babies that are alive today that wouldn't be if there, if it weren't for formula. But for me, having like a full term, normal, healthy baby, healthy delivery, I find it very unnecessary. And I think it definitely serves its purpose, but for me, it just doesn't seem like something that I would need. – Paula

Mistrust of healthcare providers. An additional source of mistrust mentioned by participants was mistrust of healthcare providers. Some participants believed their healthcare providers lacked information and knowledge on breastfeeding and were thus not viewed as trusted sources of infant feeding advice.

From what my understanding is, that pediatricians in general have little to no training in nursing and breastfeeding. If, maybe not even a full class, you know, a couple hours are covered. So she [their pediatrician] was not in a position to provide much advice [about breastfeeding]. – Samantha

Kim discussed how she valued her own intuition and beliefs on infant care over expert recommendations. She believed that while scientists and physicians are confident in their medical perspectives, history reveals that such experts are frequently wrong, and later change their recommendations.

Like she sleeps on her side, not on her back. She doesn't like to sleep on her back. You know? (laughs) I don't think... she hasn't died yet. I know it's not safe, but they also used to tell you to put kids on their stomach, not on their back. So I feel like everybody's opinion changes every couple seasons. Well, and that was my mom not breastfeeding. Like it was the doctors who were like this [formula] is better for your baby. – Kim

Lila, who was a birth doula and had successfully breastfed four of her own children, discussed her puzzlement and infuriation with western healthcare system opposition to HMS, given that their own fervent recommendations champion the numerous benefits of human milk. Because of this perceived hypocrisy, Lila didn't trust infant feeding advice from healthcare providers and questioned their motivations.

I mean, it's infuriating to me, honestly... I mean mainstream science supports breast milk. I mean, they've broken it down and evaluated every aspect of human milk. So you can't deny that. And even though the science backs it, I really don't find that obstetricians and pediatricians truly feel that breast is best... Because if they did, they would be encouraging moms to find human milk. But they don't. It's 'here is a can' [of infant formula]. And obstetricians selling their information. Because how does that milk [infant formula] show up in my mailbox? I'm sorry, who gave that information? I mean, money talks, and the pediatricians definitely get a kickback. And so do obstetricians. – Lila

However, several respondents described having trusting relationships with their healthcare providers. These participants trusted that their providers were knowledgeable and would direct them toward the best and safest infant feeding option for their baby.

During his stay in the NICU, he was getting some, like a preemie formula, first because my milk didn't come in. Also because I mean, it helps him gain weight faster... he was three pounds, ten ounces. He was really tiny. Um, so, I mean, they don't really ask your permission. I suppose if I had planned or knew it was a possibility that I could have a baby staying in the NICU, I could've done research. But I was wholly unprepared for what options and what would be best. So you know, they said, it's the best thing to do is to give them formula to fatten them up. And I was like okay, like I don't have a medical degree. I trust you. – Rachel

High value placed on human milk. All participants placed a high value on human milk, often describing it as an incredibly precious resource. Women regularly mentioned their discomfort or even horror at the idea of HM being wasted or discarded.

When people say, oh, whenever you feed the baby from the bottle, like whatever that isn't finished should be thrown away. Nope. You've got to be kidding me. Those six ounces are like gold (laughs). Right to the fridge... – Betsy

I was sitting on the plane to Tanzania and there was a woman next to me. Um, we were both pumping on the flight (laughs). I'm having to dump the milk down the drain in the plane. And we were like, oh my god, like... it's just ughhh. There's nothing worse than having to dump milk. Um, really nothing worse [emphatic]. – Abhi

Other participants valued human milk in relation to the hard work of the donors to produce, collect, and store it.

You've got these really busy moms who are like, well shoot. We've got a freezer that's overflowing. We don't know what to do with it. Um, we're not going to toss it because like you have that... talk about emotional attachment to that milk that you've pumped... Blood, sweat, and tears. – Beth

Recipients would not hold donors to a higher standard than themselves. An important theme emerged around standards for donor behavior. Numerous participants felt that it was important to hold realistic expectations for their donors and would not apply standards that they themselves would not meet. For example, women who regularly consumed caffeine did not expect a donor to abstain from caffeine, and women who didn't sterilize their pump after each use did not ask probing questions about their donor's pumping practices. This theme relates to recipient decision-making because it informed their characterization of donor suitability and appropriate donor screening.

I've always been afflicted with bad headaches and had to go off all my prescriptions when I got pregnant. So I was taking over-the-counter medication to try and cope with my headaches. So Sutton was already receiving medicine from me. So far be it from me to say don't have Tylenol in your milk because I was doing that myself. – Samantha

So I didn't really worry about the donor mom's caffeine because I was having caffeine. Um, and I don't think she was. I think she told me she wasn't as well. So I was like, oh, her milk's better than mine. (laughs) Like you know, I take metformin. I take this and that. So, the things that she was taking, I looked up and they were all classified as okay for breastfeeding and everything. – Mary

Well, we're not perfect here. And I don't really expect a mom to be super perfect either. Um, we do the best we can as far as food goes. And I would assume that that's the way it is with the other moms. – Ayana

Attitudes towards human milk pasteurization. A variety of perspectives were shared on the value of human milk pasteurization. Some recipients didn't realize that they could home-pasteurize the S-HM they received. Others knew that they could pasteurize the milk but didn't feel capable of adding another step in their already complicated infant feeding routines.

They gave me instructions [on how to home-pasteurize]. I did not. When you're triple feeding, unless you have an employee, like someone at home helping you, that's just not an option. – Kim

We did not [home pasteurize the milk]. We were aware that that was something we could do. And without meaning to sound like terrible parents, it was just too much work. We understood that risks exist, but, yeah. It was too much work. – Cheryl

Other recipients knew that pasteurizing the milk was an option, but specifically desired raw human milk. These women felt that pasteurizing the S-HM would neutralize protective ingredients in the milk, rendering it less beneficial to their children.

You know, I don't know whether I'd go through a milk bank. I do think that there's some you know, um, I guess, some gain to be had in non-pasteurized breast milk. Because I think there's just so much that probably gets killed in the heating process. – Rachel

Attitudes towards human milk banks. Awareness of human milk banks and knowledge about their practices varied widely among participants. Many participants had never heard of human milk banks and didn't know it was an option available to them. Participants who did know about milk banks commonly believed that banked human milk (B-HM) was inaccessible. Some mothers investigated getting B-HM and could not find how to access it, while others perceived B-HM as only available to sick and premature infants.

So, from like the D.C. milk bank or whatever, I couldn't figure out how I would get milk from them from their website. I'm like, I have a library degree, and I was like, I can't figure out how I would get [donor milk] from you...I was like, I will buy milk. Like I'm not a grad student anymore. I will pay the money. She doesn't want formula...But I couldn't figure out how to buy milk. And maybe I'm just stupid, but I really couldn't, it was like, if you want to donate, like that was very easy to find. And I was like, but what about... who gets the milk then? Do you know? Who actually gets the milk? – Helen

Um, I had looked, and...so the hospital said all of our donor milk is for babies, like you know, very very preemie, you know like, they can't even have formula...Um, and then I did look into a couple of like, I tried to Google some milk banks. Not a lot came up, but what did come up was that they directly like give to hospitals or like directly give to organizations. It

wasn't like I would be able to walk in and be like hey I need twenty ounces of milk for, you know, three days' or whatever. Um, so, that was a little bit discouraging. And then it also made me feel like I was taking away from babies that needed it more.

– Stacey

One participant, Sheena, considered requesting B-HM for her twins, but she was uncomfortable with the practice of pooling milk from multiple women used by milk banks. Given her Muslim faith and beliefs around milk kinship, she strongly preferred to receive milk from mothers who she knew and had met in person.

You know, for my purposes, I wasn't sure because I know there is like milk banks where they take all the milk and put it together and kinda make it like a formula. Right? They combine it. So, for my purposes that wouldn't work. My top preference would be to know individually who these women were and to use it one at a time. Um, because of the factor of them being linked to those people. – Sheena

Sheena elaborated on her cultural beliefs around milk sharing and the importance of knowing her donors. She also mentioned avoiding potentially awkward or uncomfortable discussions with donors about her beliefs.

From my perspective, these babies are bound to these women. But I don't wanna like freak them out and be like, 'Oh, my kids are actually your kids now because that's my cultural belief'... I don't know. Like how do you say that to (laughs) somebody who doesn't know of that? You know? So I was like, I'm just not gonna say anything, and just make sure that I have record. You know, I could tell my kids, 'You can't marry anyone from Virginia.' (laughing) Just in case, you got to know like, I need their histories. Because I don't want you to marry your, you know, like milk brother or something like that. Because we do believe that there is a transfer of DNA. – Sheena

Distinction made between the needs of sick, vulnerable infants and those of healthy, term

infants. Multiple women made their infant feeding decisions based on their child's health status (i.e., healthy, full term infants) and would have made different choices if their child had been ill or born preterm.

I probably would've gone with the non-pasteurized [donor milk], which was like the more peer to peer sharing one. I felt like the pasteurized one was probably more for like um, immune suppressed or more fragile babies I guess you could say. And having like a full term, healthy baby, I didn't feel like that was necessarily needed. – Paula

He wasn't he wasn't a preemie, he wasn't not thriving, like he's in the 90 percentile. Like, he's not having a problem, so I wasn't concerned [about age matching the milk]. – Red

A small set of case studies is included as an appendix to further highlight the complexity of the IFP decision-making process for these milk-sharing recipient families (Appendix D).

Discussion

This research contributes to the knowledge base about milk sharing by providing a detailed account of the milk-sharing experience from the recipient perspective. We outlined the complex, often fraught, emotional contours of the recipient milk-sharing experience. Of particular interest is the relationship between trust and mistrust, and recipient attitudes and values, which ultimately form the basis for decision-making and advice-seeking behaviors. We also presented identified emergent themes related to the recipient decision-making process around infant feeding. We focused on the recipient's perspective because, within the donor-recipient dyad, recipients typically experience the greatest lactation and infant feeding challenges. Additionally, from the biomedical risk perspective, HMS presents greater potential risk to recipient infants than to donor infants. This presents an opportunity to improve care and support to help HMS recipients reach their infant feeding goals and minimize risk. We will frame the discussion of these results using the socioecological model (SEM) conceptual framework (Figure 1).

Our findings suggest that, at the individual level of the SEM (i.e., the mother-infant dyad), infant-feeding challenges cause significant stress and emotional duress for many HMS recipients. The women in this sample highly valued human milk, were strongly committed to breastfeeding, and were unable to breastfeed as intended for various reasons. Their inability to achieve their infant feeding goals caused many women to feel guilty, ashamed, and even desperate. These findings are supported by prior research that found postpartum depression and anxiety (often attributed to breastfeeding challenges), are common among HMS recipients and that S-HM use was associated with improved mental health (52). Indeed, several participants in our study cited stress reduction and relief as important benefits of milk sharing. Together, these findings suggest that milk-sharing recipients may be at a higher risk for experiencing postpartum depression and anxiety. Clinicians and public health professionals should be aware of this heightened risk and proactively provide additional psychosocial support to mothers who experience breastfeeding challenges. Even in the absence of clinically diagnosed postpartum depression and anxiety, the emotionally fraught experience of a mother who is unable to breastfeed as intended calls for heightened sensitivity from care providers.

At the interpersonal level of the SEM, an important aspect of the recipient milk-sharing experience was trust in the donors. Trust was established with donors through the exchange of personal information, by their shared maternal identities, and by having a trusted person attest to their suitability as donors. This finding is aligned with previous research, which positioned trust and gratitude as prominent features of the milk-sharing experience and trust as an important contributor to recipient comfort with milk sharing (27, 39, 128, 145, 146). This

mutual trust in women united by the common identity as breastfeeding mothers is an important feature at the interpersonal level that defines the HMS recipient experience and heavily influences their IFP decision-making.

Interpretation of the emotionally charged experiences of these study participants must occur within their larger sociocultural context. Contemporary motherhood in western societies has been dominated by “intensive mothering” expectations, defining “good mothers,” as those who intensively engage in every aspect of their children’s lives and development (147). Core components of intensive mothering include child protection against all harms, elevation of children’s needs above the mother’s, and adherence to expert childcare recommendations (115). Thus, one key element of being a *good mother* in contemporary western societies is to breastfeed, which accomplishes all three of the above-mentioned criteria. Breastfeeding mothers invest significant time and labor, and prioritize their children’s needs above their own needs, desires, and often comfort, while following modern medical and public health recommendations. Women receive overt and subtle messaging that not breastfeeding is damaging to their children and to their identity as a *good mother*, regardless of whether they choose not to breastfeed or are unable to do so. The mothers in our study felt like failures, in large part because they have internalized these broader sociocultural messages and the pressure to perform motherhood in a narrowly prescribed manner to be viewed by society, and indeed, themselves, as *good mothers*. Within this context, a woman’s choice to source human milk from other women and confer its benefits to her child can indeed be viewed as a creative and radical (by modern-day standards) strategy to preserve *good mother* status. These choices can be viewed on a modern continuum of allomothering, the ancient practice whereby

mothers help nourish and care for each other's children (148).

The emergent themes on parental decision-making revealed the different ways in which women conceptualize and manage risk related to HMS. Recipients' thoughtful analyses of the potential risks involved in feeding both formula and S-HM undermine common media portrayals of HMS recipients as uneducated or ignorant of the risks involved. This is in accordance with previous research on risk among HMS parents, which found that recipients are aware of risks associated with using S-HM and take action to mitigate these risks (38, 48, 87, 89, 145, 149). Our study sample was composed of highly educated mothers who carefully considered comparative risks (both real and perceived) and used their personal circumstances, beliefs, and values as their basis for accepting the risks of HMS over those of infant formula.

Mistrust of infant formula companies and the belief that formula is nutritionally inferior to human milk were particularly influential in these decisions and emphasize the broader impact of shifting sociocultural norms for infant feeding. Concerns about the risks of formula feeding have been important behavioral determinants in previous HMS studies (38, 89). Indeed, there is empirical evidence demonstrating that, compared to breastfeeding, formula feeding is associated with an increased risk of ear infections, gastrointestinal infections, asthma, type 2 diabetes, overweight and obesity, among others (2, 3, 78). In our study, mothers conducted research on and raised valid concerns about these risks, while also citing the numerous benefits of human milk, such as mother-infant bonding and infant immune protection. Combined, these factors created a strong belief in the value of human milk and contribute substantially to breastfeeding intentions. If women receive constant, non-nuanced messaging

that 'breast is best,' then their decision to use S-HM when faced with breastfeeding challenges can be seen as highly rational.

Risk mitigation practices were influenced by parental infant feeding beliefs, attitudes, and perceptions. Most recipients in this study did not heat-treat the S-HM before feeding it to their infants. This decision seemed to be based on their view of pasteurization as *unnecessary* because their infants were healthy and the S-HM was also fed to the donor mother's own healthy infant ("proving" its safety), and *undesirable* because doing so would inactivate the components of HM that distinguish it from infant formula in supporting infant health. This belief is supported by numerous studies demonstrating that pasteurization significantly reduces the function of important nutritional and immunological components of HM, including vitamin C, immunoglobulin A, lysozyme, and lactoferrin by as much as 80% (150-154). This raises the question of the appropriateness of HM pasteurization for healthy, term infants.

A related theme mentioned repeatedly by participants in our study was that the needs of preterm or sick infants were specifically identified as being different from those of healthy, term infants. Our sample of mothers primarily had healthy, term infants, which was reflected in their risk analysis and risk mitigation strategies. Finally, banked donor milk was viewed as inaccessible by our study participants, a perception that has been observed in several other studies (20, 22, 27). Thus, donor banked milk, which has been pooled and pasteurized to protect preterm, sick, and vulnerable infants, may not be an appropriate (or desirable) source of infant nutrition for the majority of infants receiving S-HM in peer-to-peer arrangements.

Our findings reveal the complicated nature of the patient-provider relationship around HMS, another important feature of the interpersonal level. Lack of respectful dialogue and shared decision-making about infant feeding decisions emerged as a key theme. Many HMS recipients mistrusted their healthcare providers' motivations, perceived them as uneducated about lactation, and held lingering negative feelings about discussing milk sharing with their providers. Stigmatization of milk sharing by healthcare providers has been previously documented, resulting in HMS participants withholding information from providers who they perceived as judgmental or non-supportive (48). Other research has shown that HMS recipients reported receiving less lactation support from pediatricians than donors (28) and that low perceived pediatrician support for breastfeeding is associated with poor breastfeeding outcomes (155, 156). Together, these findings suggest a need for improvement in the quality of clinical support for breastfeeding.

The HMS recipients in this study represent a growing group of American mothers who are strongly committed to breastfeeding and value the benefits of human milk for infants, but are unable to breastfeed successfully. We argue that our public policy, medical, and public health systems have failed these mothers. The lack of federally mandated, paid parental leave in the United States denies women adequate protected time with their infants during a critical window for establishing a solid breastfeeding relationship. While breast pump mandates and protected time to pump in the workplace serve the logistical aspects of human-milk feeding, these policy provisions do not support the establishment of successful breastfeeding *relationships*. The inconsistent availability of high-quality lactation support (75) means that many women lack access to the timely, skilled assistance that could make the difference

between a successful, sustained breastfeeding relationship and one that fails. Healthcare providers who directly support lactating mothers could benefit from greater education and training on lactation to deliver better support. Finally, public health messaging about infant feeding should be re-examined and refined to enhance sensitivity and minimize harm. The potential harms of using risk-based language in breastfeeding promotion has recently received considerable attention in the scientific literature (115, 119, 157-159). Additional research is needed to understand the comparative effects of risk-based vs. benefit-based language in breastfeeding promotion. The goal should be to encourage women to breastfeed and to provide the support they need to establish healthy breastfeeding relationships; when breastfeeding as intended remains impossible, women should be equipped with nuanced, evidence-based, non-judgmental messaging and advice about alternative infant feeding options.

Strengths and Limitations. This research has several notable strengths. This research is underpinned by the intentional positioning of recipient mothers as experts whose experiences with infant feeding hold great wisdom and knowledge. The use of semi-structured, open-ended interviews created opportunities for in-depth discussion and flexibility to explore topics and themes of interest based on each participant's unique experience. The majority of published research on HMS comes from an 'etic,' biomedical perspective, and is thus limited in its scope and ability to capture the lived realities of milk-sharing parents. This examination of the HMS recipient experience from an 'emic' perspective gives voice to these stigmatized, non-normative maternal experiences and deepens our understanding of decision-making among HMS recipients.

This study also has some limitations worth noting. Although efforts were made to recruit a diverse sample, ultimately this was a fairly homogenous sample of married, highly educated, high SES White women in an American city, mirroring the sociodemographic composition of samples found in other research on HMS (26, 28, 53, 55, 87, 88, 102). It is unknown if these findings can be extrapolated to other communities and other populations of women. In particular, given the uniqueness of the American maternal and family policy and cultural landscape, these results are likely to be quite different from the experiences of milk-sharing parents outside of the United States. Furthermore, although this study did not use sex as an eligibility requirement, the final sample was composed entirely of women. Therefore, this research does not represent the experience of others (such as fathers and trans men) who sought shared milk for their children.

Another limitation of this study is that the perspectives of healthcare providers were not represented, thus precluding a balanced portrayal of the patient-provider relationships discussed in this research. Given this limitation, these results can only be interpreted as the recipient perspective of their relationships with their healthcare providers and not as the full picture. Nevertheless, these findings are provocative and suggest the need for additional research on the patient-provider relationship in the context of HMS, which includes both the patient and provider perspectives.

As with all ethnographic research, the first author was the research instrument, and thus, there is some inherent subjectivity and bias involved in the collection and interpretation of these data. It is particularly relevant that I was obviously pregnant during the qualitative interviews,

which most certainly impacted my relationship with the participants, though it is difficult to determine exactly how this may have affected their responses. I was also actively breastfeeding during the thematic analysis of the data. I have endeavored to maintain my objectivity, though I acknowledge that complete objectivity is impossible given my personal identity and experience as a mother and breastfeeding woman. Ultimately, I believe that this part of my identity and my own life experience adds value to this research. Thus, I acknowledge my position relative to this research as both a strength and a limitation.

Conclusions

We found that the milk-sharing recipient experience is characterized by a complex emotional landscape of trust, mistrust, guilt, shame, and gratitude. Trust in breastfeeding mothers and human milk, and mistrust of infant formula and healthcare providers played a key role in the decision to milk share. In the face of numerous breastfeeding challenges, recipient mothers demonstrated high levels of dedication and perseverance in their efforts to feed human milk to their infants. Interactions with healthcare providers about infant feeding were sometimes described as negative experiences, where recipients did not feel heard, believed, or respected.

Recipient parents engaged in careful and thoughtful decision-making about infant feeding.

Our analysis revealed the different ways in which they conceptualized and managed HMS-related risk. Many recipients viewed banked donor milk as inaccessible and pasteurization of shared human milk as unnecessary and undesirable for their healthy, term infants. Finally, many recipients emphasized the importance of holding realistic expectations for donors by not applying standards that they themselves would not meet. Taken together, these findings

highlight important features of the recipients' HMS experience and emphasize the need for evidence-based, non-judgmental support for families who experience breastfeeding challenges or seek alternative infant-feeding options.

CHAPTER 5

CONCLUSIONS

This mixed-methods doctoral dissertation contributes to our knowledge of the practices, experiences, and risk perceptions of parents who have milk shared. This work describes and analyzes the decision-making processes around infant feeding of parents who share human milk (HM). These results can contribute to policy and clinical guideline development that help the parents and infants who most need support to reach their infant feeding goals.

Summary of research findings

In Chapter 2, we reported the results of a quantitative survey of human milk sharing (HMS) practices among the geographic network of Washington DC area milk-sharing parents.

Donors and recipients were similar in sociodemographic profile but had significantly different childbirth and postpartum experiences. Compared to donors, recipients were more likely to have delivered twins, experienced labor and delivery complications and postpartum depression, and to now describe their births as traumatic. Breastfeeding experiences of donors and recipients also differed. Donors reported longer mean duration of lactation and had fewer difficulties producing enough milk. Interestingly, at some point in their parenting lives, a substantial proportion of recipients had produced more milk than they needed, and a substantial proportion of donors had difficulty producing enough milk. This indicates the dynamic and temporal nature of lactation challenges, which render moot any strict classification of parents as “donors” or “recipients.” Recipients were more likely to describe

their breastfeeding experiences negatively than donors; donors' responses were nearly unanimously positive. Infant feeding practices also differed by donor or recipient status. Recipients had a lower mean duration of human milk feeding and were twice as likely to have fed infant formula to their child.

The survey data reveal interesting findings about recipients and their infants. One-third of HMS recipient infants had been diagnosed with a tongue or lip tie, 17% had a dietary intolerance or sensitivity, and 16% had a health issue. In assessing factors related to recipient decision-making, we found that HMS recipients turned to their social support networks rather than seek information and support from clinicians or professional organizations. Before deciding to milk share, 80% of recipients considered reducing hours at work or school, which suggests that these environments may be barriers to breastfeeding success. Milk sharing practices varied substantially among recipients, with some noteworthy trends. During the milk-sharing period, nearly all recipient infants still consumed their mother's own milk and more than half still fed at their mother's breast. This finding underscores the supplementary nature of milk sharing as an infant-feeding strategy. Among both donors and recipients, online websites and parent listservs were typical means for connecting with other parents for milk sharing. Nearly all donors reported donating surplus expressed human milk (E-HM) originally intended for their own children. Among donors, the most frequent reasons for milk donation included the desire to help another family, possession of excess E-HM, and the desire to avoid wasting it.

In Chapter 3, we presented a latent profile analysis of donor and recipient risk perspectives, revealing the latent heterogeneity in risk perspectives among an apparently homogenous group. These findings demonstrate that risks associated with formula feeding and milk sharing are viewed comparatively, and that parental attitudes toward infant formula influence milk sharing attitudes and practices. Our analyses showed that, among both donors and recipients, members of the minority risk-perspective group viewed formula as risky and were not concerned about the degree of familiarity with their HMS donor/recipient. Among recipients, members of this minority risk-perspective group engaged in milk sharing more intensively than the other groups, were most likely to connect with donors online, and were the most likely to have received shared human milk from donors they had never met.

Finally, in Chapter 4 we presented ethnographic data that provide a detailed look at recipients' experiences and decision-making processes. Importantly, these qualitative data highlight the complexity of, and the depth of emotion evoked by, the recipients' milk-sharing experience. Participants shared stories of maternal dedication and perseverance in their breastfeeding attempts, with determination undeterred by weeks or even months of difficult feeding schedules, discomfort, and pain. Many recipients viewed these difficulties less as something that was happening to them and more as an indication of their own failure to fulfill the role of mother. Turning to milk sharing as a result of not being able to fully breastfeed as intended elicited contrasting feelings of guilt and shame, but also gratitude and relief.

Several emergent themes from the ethnographic work inform our understanding of how recipients make infant-feeding decisions. Many recipients expressed trust in other

breastfeeding mothers and mistrust of infant formula, formula manufacturers, and healthcare providers. Recipients described negative and unpleasant interactions with healthcare providers because they didn't feel heard or respected by their providers. When considering characteristics of suitable donors, recipients didn't think it was appropriate or fair for them to hold their donors to higher standards than themselves. And finally, banked HM was viewed as inaccessible or undesirable, while pasteurization of HM was viewed as unnecessary and undesirable for healthy infants.

Theoretical implications

Risk perceptions are notoriously difficult to measure with any degree of accuracy because of the largely subconscious nature of assessing risk, and because numerous underlying constructs help form a risk perception. This research took a first step at categorizing and quantifying risk perspectives among milk-sharing parents. Our analysis revealed that milk-sharing risks cannot be viewed in isolation, and must rather be considered relative to other available infant-feeding options. This is an important finding that informs future studies on risk perceptions related to infant feeding.

Another interesting finding reported in Chapter 3 is that numerous PMT constructs were eliminated from the LPA of risk perspectives, either because of low variability in response values or because they offered low predictive value in the modeling. For example, social and practical risks of HMS were unimportant in defining recipients' risk perspectives. Self-efficacy in practicing HMS safely, perceived control of the risks of HMS, and perceived rewards of HMS were eliminated from the LPA models because of low variability in

responses. Finally, recipients unanimously had low perceived vulnerability to risk of harm from HMS, suggesting that HMS recipients may be prone to optimism bias regarding HMS risks. These PMT constructs excluded from the final LPA models imply that these constructs may be homogenous, foundational beliefs shared by HMS participants. These findings provide an initial evidence base for future research on cognitive frameworks of HMS risk perceptions.

In Chapter 4, we learned about the stress, anxiety, and emotional duress that recipients often experience when deciding to milk share. Linking these findings to the latent profile analysis of Chapter 3, it is likely that HMS recipients do not make purely rational (deliberative) decisions, but also rely on experiential (gut-level intuitive reactions to a threat) and affective (emotional reactions to a threat) inputs to arrive at their overall risk perception. During their interviews, mothers repeatedly mentioned their “mom instincts,” or “trusting their gut,” or “it just felt right” to make infant feeding decisions. This is an important distinction, as many theoretical models that predict protective health behavior focus heavily on the deliberative component of risk perception, which is likely insufficient in studying an emotionally charged topic such as infant feeding. Future studies on risk perceptions in HMS should consider incorporating the recently proposed TRI-RISK model of risk perception by assessing the affective, experiential, and deliberative components of risk perception (160). The TRI-RISK model has been demonstrated to provide better predictive validity of health protective behaviors compared to unidimensional and bidimensional risk perception models (160, 161).

Building upon the importance of including the emotional and experiential aspects of risk perception in HMS research, the results from Chapter 4 clearly indicated that our conceptual framework guiding this research (Figure 3) was inadequate, as it excluded emotional inputs into the IFP decision-making processes. Therefore, we have revised our framework to feature emotional state and sense of urgency as important inputs into the decision-making process for infant feeding practices in the context of HMS (Figure 9).

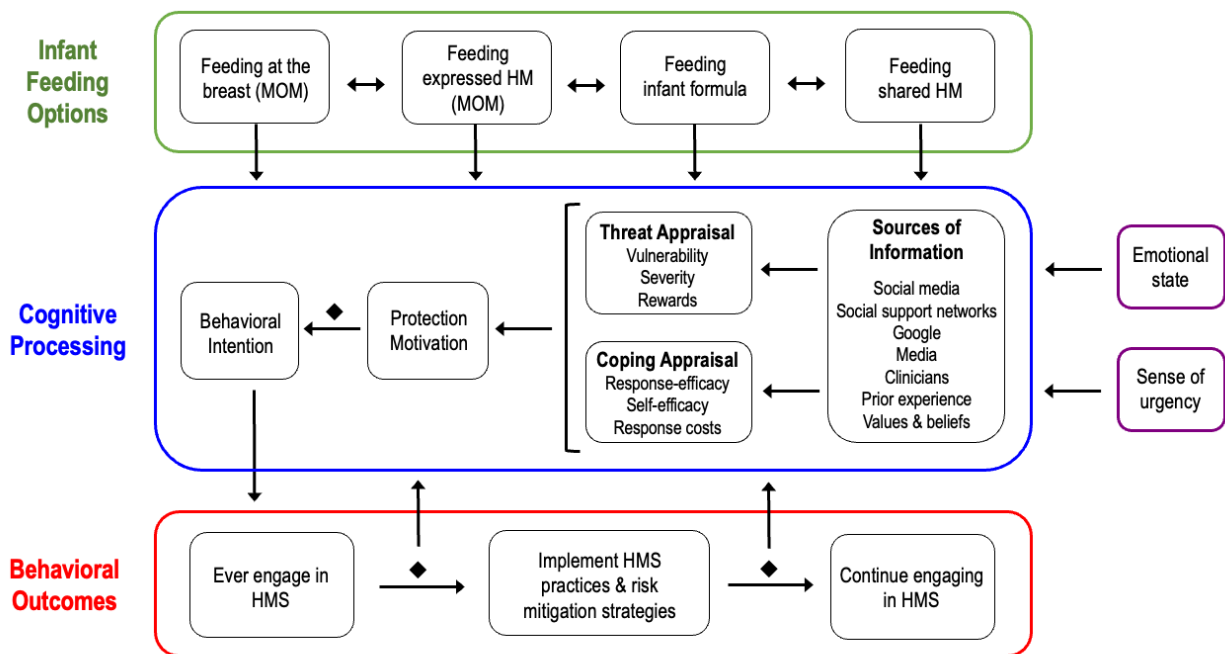


Figure 9. Revised conceptual framework on infant feeding decision-making in the context of HMS, adapted from Protection Motivation Theory. ♦ indicate decision points.

Methodological implications

Peer-to-peer HMS is a difficult phenomenon to study because HMS families constitute a “hidden population,” meaning that they engage in a behavior that is stigmatized, they are unlikely to disclose their status as a member of that population, and there is no sampling frame to reach them (54, 162, 163). We first attempted to reach this population using

respondent-driven sampling (RDS), a peer-referral sampling and analytic technique used for hidden populations. The goal of using RDS was to validate the methodology in the HMS network and produce generalizable, unbiased population estimates of HMS practices. Unfortunately, the method was unsuccessful for sampling HMS parents, and we ultimately stopped the RDS sampling and completed the study with simple convenience sampling. Nonetheless, this study revealed novel findings about the structure of the HMS network (Appendix E). Respondents reported small mean network sizes (3.1 among recipients, 3.6 among donors), which are below the threshold recommended (5) for RDS studies (163-166).⁵ The milk-sharing relationships in the RDS sample were predominantly weak social ties, which has important implications for peer-referral methods. Jointly, these findings suggest that the structure and density of HMS networks may not be adequate to support a peer-referral methodology.

Online survey implementation came with a key challenge. Online surveys that do not require personally identifying information are vulnerable to infiltration by cybercriminals that complete surveys under different email addresses to collect multiple incentives for participation. This occurred during our survey and was discovered because of suspicious patterns of response and strange email addresses. When the issue was identified, we paused the study and implemented preventive practices, namely all participation incentives were mailed to the physical address in the Washington, DC provided by respondents. This action along with additional cybersecurity measures—adding a survey password, using bot-detection

⁵These data are not presented in the dissertation but were presented at the International Society for Research on Human Milk and Lactation's 2020 Virtual Research Conference (Appendix E).

features, and prohibiting more than one response from the same IP address—ultimately preserved the integrity of our study. This experience highlights the importance of planning for potential cyberattacks and building risk-mitigation and security measures into any methodology for online survey research.

Clinical practice implications

Our qualitative findings point to the patient-provider relationship as one that is sometimes complicated and challenging, yet provides the opportunity for continued investigation to consider the sometimes different priorities of HMS families and the clinicians who treat them. Many study participants describe provider interactions as lacking in respectful, reciprocal dialogue. These women felt dismissed and condescended to at a particularly vulnerable and even desperate moment in their parenting journeys and concluded that their providers were not equipped with all the information necessary to help make their urgent infant-feeding decisions. A radical feminist analysis might consider these women's experiences against the backdrop of western medicine as a fundamentally patriarchal institution that has historically disregarded women's agency and pain, and that continues to fail women today (167-170). While structural sexism and misogyny in healthcare may indeed be at play in this study context, a more nuanced and sophisticated analysis would also explore the conflict of values and risk structures that emerge in the patient-provider relationship. This is a key area of potential future study, best served by a research design that includes perspectives of both healthcare providers and their patients who engage in HMS.

Families hold strong beliefs about the value of HM, their intended breastfeeding experience, and the possible problems related to infant formula. They have been told that “breast is best” and, not only do women believe this assertion, but they have also woven it into their identities as mothers (116, 117). Infant formula does indeed lack the constituents that make HM actively beneficial (*e.g.*, immunological factors, stem cells, human milk oligosaccharides, etc.), which is why HM is recommended globally over formula. The choice to engage in HMS is typically not focused on infant nutrition, but constructed in terms of the *health* benefits of HM (and conversely, the lack of health benefits offered by infant formula). Many HMS participants are not particularly troubled by safety concerns, especially because they view their infants as generally healthy and seem to not recognize the potential for microbial contamination of E-HM. Understanding the recipients’ journey to obtain human milk’s advantages for a child could inform the design of clinical approaches to help families transition through this challenging period. Families who experience breastfeeding difficulties represent a vulnerable population that needs additional support and sensitivity from providers, who are uniquely positioned to offer evidence-based guidance on infant-feeding practices. Future investigation into holistic, patient-centered care models applied to this population could inform the design of such support structures and of patient education interventions that help close knowledge gaps.

Many recipients described their healthcare providers as staunch opponents of milk sharing who believe it to be a risky, irresponsible parenting choice. This is supported by previous literature revealing that HMS participants withhold information from their physicians in fear of stigmatization or negative reactions (48, 128, 171). But if physicians are bound by the

Hippocratic oath of “do no harm” and, if they believe that HMS could do harm, then their resistance is understandable and is certainly worth exploring. Our research did not include interviews with physicians or other healthcare providers, so we must turn to the literature and some educated guesses in our interpretation of this data. Many physicians operate under the “fed-is-best” principle, and while most would not claim that infant formula is equal to HM, they would likely affirm its general safety and effectiveness at providing the nutritional factors that infants need to thrive. Although parents may think their infants are healthy, some of them may not be growing well, and some might be actively distressed because of inadequate nutrition, which physicians are trained to observe and treat. Other factors could be influencing patient-provider interactions as well. Perhaps some providers project their own fatigue or disillusionment onto their HMS patients, who they may perceive as “anti-science” and akin to, say, parents who refuse to let their children receive routine childhood immunizations. Or perhaps providers are operating under their own feminist principles, assuredly presenting infant formula as a viable feeding option to women who are struggling to breastfeed precisely to liberate them from intensive mothering’s constraints and demands around breastfeeding. Healthcare providers, just as mothers, are not a monolith and the complexities of provider perspectives (informed by their individual beliefs, values, and training) may hold important insight into these key moments of family interaction with the health system. Ethnographic studies of patient-provider interactions that include both patient and provider perspectives are well-suited to answer these questions.

The common thread of the perspectives of both families and providers is the limited evidence on which they based their attitudes and decisions. Providers seem to be concerned about

transmission of infection from S-HM, but there is inadequate evidence on the risks of recipient infants acquiring a viral or bacterial infection as a result of consuming S-HM. By contrast, there have been documented cases of infection associated with inadequate breast pump sanitation when women express milk to feed their own infants (93), yet clinicians frequently facilitate access to breast pumps and encourage women to pump their milk. The contradictions that emerge from this lack of clear evidence made study participants doubt the counsel of healthcare providers. HMS parents prioritize giving their children the ability to fight a future infection, which is a property of the same milk that providers fear will infect infants. HCP and HMS parents differ in terms of what they value and prioritize, they are both working with limited information, *and* they are both correct because E-HM is not sterile, and because raw HM does have anti-infectious properties (17, 93, 96, 172, 173). Space should be created for these ambiguities within the patient-provider dialogue. Ultimately, except in the case of clear medical necessity, a provider's role is not to usurp parental decision-making power. Rather, providers should present patients with the risks and benefits of all potential infant-feeding options in a non-judgmental manner. Doing so would signal their respect and support for patient autonomy and for parents' ability to make informed choices best suited to their individual circumstances and value structures.

While our sample size is small, we succeeded in giving voice to a group of women who were determined and sometimes desperate to feed their children human milk. We believe that representing their views in the literature matters. It is difficult, however, to draw any firm conclusions given the one-sided nature of the study. The providers' perspectives are needed to continue mapping the different value and risk structures at play at the patient-provider

relationship site, and to identify the moments for potential intervention. From there, messaging and communication strategies around areas of scientific ambiguity can be developed and tested to improve patient-provider interactions. Providers' awareness of the different risk and value structures at play for patients around HMS could help them frame their own risk perceptions in a manner that acknowledges the tensions between the "breast-is-best" and "fed-is-best" camps, while honoring parental agency in navigating the uncertain infant-feeding terrain.

Public health and policy implications

Public health professionals and the mothers who participated in this research share a common goal: they both value the benefits of human milk and want mothers to breastfeed successfully. HMS recipients intended and strongly desired to breastfeed but were unable to do so for varied reasons. From a socioecological view, it is apparent that the U.S. policy environment fails mothers. In the context of this study, the lack of federally mandated, paid maternity leave contributed to the stress and lactation failures experienced by participants. Women in the U.S. have often just recovered from childbirth and established a solid breastfeeding relationship with their infants when they must return to work. A critical policy recommendation to improve breastfeeding outcomes and the maternal experience is to enact federally mandated, paid maternity leave to ensure that women who want to breastfeed have the opportunity to do so. Lengthier paid maternal leave periods are associated with greater breastfeeding duration (67, 69, 70, 74).

Public health professionals and mothers alike celebrated the enactment of the Affordable Care Act, which mandated that health insurance providers cover the cost of breast pumps. Although improved access to high-quality breast pumps indeed helps women to continue feeding HM to their infants, breast pumps are not usually needed to support women to feed *at the breast*, which is an important public health goal. E-HM differs from HM fed at the breast in numerous ways we are just now discovering. These include altering the nutritional, bacterial, and immunological composition of HM. In addition, E-HM is fed from a bottle, which changes the physiology of infant suckling in ways that may be associated with dysregulation of satiety signaling, which creates an increased risk of overweight, obesity, and otitis media (43, 44). At-the-breast feeding appears to be the optimum choice, given that feeding E-HM to infants may subject them to new risks that we do not yet fully understand. Improved breast pump access combined with inadequate maternity leave has essentially created a policy environment that prioritizes *expressed human milk feeding*, often at the expense of the dyadic breastfeeding relationship, and with added labor for women who must manage pumping at inopportune times in inconvenient locations and then spend time cleaning their collection equipment. Policy shifts are imperative if we are to support mothers actively to reach their goals for feeding at the breast, rather than passively encouraging them to express and feed HM from a bottle.

The qualitative and quantitative findings of this study jointly point to the inadequacies of our milk-banking system in meeting the growing demand for HM. First, milk banks are viewed as inaccessible by most HMS participants, a finding concordant with previous research (20-22). Many donors had already expressed their milk and it was being stored, and thus they were not

able to donate this milk to milk banks (which require screening to be completed before the HM is expressed); they also viewed the screening process as too time consuming. HMS recipients often did not qualify to receive banked HM (B-HM) because it was not available near them or because their infant did not meet the strict eligibility requirements (B-HM is prioritized for infants who are preterm, sick, or in the neonatal intensive care unit).

Furthermore, recipients who did have access to a milk bank⁶ after discharge from the hospital, could not afford its high price (up to \$7 per ounce). Our HM banking system meets the needs of a small, select group of infants who are preterm or sick. Second, the milk processing system employed by milk banks, which involves pasteurization, was viewed as inappropriate to meet the preferences of many study participants who expressed their desire for raw, unpasteurized human milk. For these parents, pasteurization of the milk is undesirable because it diminishes the health benefits of HM, and unnecessary because they believe their infants are healthy. Finally, the standard practice of pooling milk from multiple donors to create a homogenized batch of banked donor milk directly conflicts with some parents' cultural and religious preferences, a well-documented phenomenon (174-178).

As a result, the milk banking system in the United States meets the needs of only the most medically fragile and vulnerable infants. Donor milk is functionally unavailable to many parents who desire HM for their children. This conclusion highlights the need for milk banks to expand their donor pool and HM supply pipeline to meet the needs of a larger population of

⁶The Breastfeeding Center for Greater Washington (<https://www.breastfeedingcenter.org>) offers HMBANA banked human milk but they do not ensure availability because medically fragile infants are prioritized. Furthermore, to receive this B-HM, the patient must have a prescription from their healthcare provider for donor milk, and must be currently working with an IBCLC. Most insurance companies do not cover the cost of outpatient use of B-HM and the cost is currently (as of July 2021) set at \$5.33 per ounce.

infants in need of HM. Prior research has found that the failure of healthcare providers to act as an information source on HM banking is a considerable barrier to women who might wish to donate their surplus HM to milk banks (22). Therefore, one viable mechanism for expanding the donor of donors is through disseminating HM banking information via healthcare providers, to spread awareness of HM banks among their patients. Healthcare providers have considerable influence on breastfeeding behaviors (179-181), and providing information about milk banks prenatally is preferred by potential donors (182). Making these proposed changes would substantially improve the HM banking system in the US by expanding its availability and increasing its supply, creating a viable alternative to milk sharing that mitigates a substantial proportion of the risk inherent in HMS. Additional research is needed on developing effective strategies to increase awareness of HM banks and reduce barriers to HM bank donation.

Hospital policy is the final arena for improving access to HM for all infants. The first recommendation is for hospitals to allow the use of S-HM among healthy, term infants while hospitalized after delivery. Several ethnographic participants were prohibited from using S-HM due to hospital policy. Families felt pressured and even bullied into using formula in the hospital, undermining their strong commitment to breastfeeding and the benefits of HM, and disregarding their decision-making autonomy absent any serious health issues. Although using S-HM more broadly in the hospital setting raises liability issues, liability release forms would begin to address these concerns. A small sample of interested hospitals could be engaged in a pilot study on the impact of hospital policies allowing the use of S-HM.

Even absent such changes in hospital policies, numerous other strategies could be employed to improve the quality of support provided to postpartum women who intend to breastfeed. These approaches include enhanced education of hospital staff on the physiology of lactation, increasing availability of International Board-Certified Lactation Consultants (IBCLC), quality improvement initiatives, and emphasizing patient-centered care models, as recommended by the Institute of Medicine (183).

Strengths and limitations of the research approach

One key strength of this research was its sequential, exploratory mixed-methods design. The body of literature on milk sharing is very small because it is just now emerging. Therefore, initiating this research with an ethnographic study that featured the experiential knowledge of HMS recipients allowed us to generate a detailed understanding of how HMS is organized and practiced. With this foundational knowledge, we constructed a detailed survey that measured the full range of milk-sharing practices, behaviors, and experiences by milk-sharing participants. The qualitative and quantitative data provide complementary lenses for examining milk sharing. In addition to survey design, the ethnographic data also informed the analysis of the survey data, which enriched our understanding of the results. These complementary data were indispensable for creating a rich and nuanced understanding of the complexity and range of milk-sharing practices, experiences, and risk perceptions among milk-sharing parents.

Another key strength of this research is the high level of detail included in the Milk Sharing Practices Survey. The highly detailed survey tool examined numerous aspects of infant

feeding, including the practices, attitudes, beliefs, and perceptions related to both milk sharing and formula feeding, allowing for the examination of *comparative* risks. This fills an important gap in the milk sharing literature. Conducting cognitive interviews with mothers who had milk shared allowed us to improve and refine the survey tool, ensuring its construct validity.

The primary strength of our study of risk perspectives was our analytic approach. Latent profile analysis (LPA) is a sophisticated person-based (as opposed to variable-based) statistical method used to identify typologies and profiles of individuals within seemingly homogenous groups (127). This quantitative technique is therefore helpful for detecting intra-cultural variation. Employing LPA enabled us to examine individual response patterns and to identify how attitudes and beliefs clustered together to form broader risk perspectives, and to further analyze how these risk perspectives were correlated with behaviors. This approach was much more informative than examining group-level means of attitudes and beliefs, which would not have revealed how these beliefs and attitudes relate to one another within an individual to form broader infant feeding perspectives.

Our research also has several limitations. The first and most obvious limitation of the quantitative study was its insufficient sample size. The target sample size set for this study was 250 respondents, with an even proportion of donors and recipients. However, sampling challenges persisted throughout the survey implementation, limiting our ability to reach the target. By not achieving the target sample size, we were limited in our ability to detect differences between donors and recipients as well as across LPA risk-perspective profiles.

The modest sample size also limited our ability to investigate uncommon practices, such as home-pasteurization of S-HM, and subpopulations of interest, such as parents of multiples or infants with tongue or lip ties.

Our online survey was likely affected by both recall bias and selection bias. We attempted to reduce recall bias by requiring participants to have shared milk within the last 18 months. Given that milk sharing typically occurs during times of stress and sleep deprivation, however, participants may not have recalled specific details accurately, such as quantities of milk and dates of recalled events. Selection bias is likely at play because we used non-random sampling techniques and primarily recruited participants via online platforms, such as local parent listservs, milk sharing Facebook groups, and through birth-worker referrals. It is therefore possible that specific sub-populations are underrepresented in this study, such as minority parents, HMS parents who don't regularly use online resources, and HMS parents who never received support from a doula or lactation consultant.

The survey research findings are limited by the cross-sectional nature of the study design, which introduced the potential for confirmation bias and reverse causality. Respondents were answering the survey questions about their HMS practices and attitudes and beliefs concurrently and retrospectively. Therefore, it is likely that for some participants, their HMS practices affected their attitudes and beliefs. For example, a recipient who received S-HM from donors unfamiliar to her (perhaps due to an urgent need for HM) and did not suffer any negative consequences from doing so might retrospectively state that donor familiarity is not important to her, even if it was at the time of milk-sharing. Thus, the associations identified

between HMS risk perspectives and practices are merely associations and directionality cannot be inferred. However, they are suggestive of interesting areas of future inquiry, perhaps with prospective research designs that allow for stronger causal inference.

Another limitation of this research is that we did not separately assess the three components of the recently proposed tripartite model of risk perception (160). When the survey was under development, the tripartite model of risk perception was unknown to us. We took a more traditional approach to assessing risk perceptions, by measuring fear, severity, vulnerability, and other constructs known to influence risk perceptions. However, given the emotionally charged nature of infant feeding, it seems likely that separately assessing the deliberative, affective, and experiential components of risk perception for milk sharing and formula feeding would have revealed a more complete understanding of risk perceptions among milk-sharing participants.

Our qualitative and quantitative studies were both limited in sample diversity. These samples included predominantly non-Hispanic White, highly educated, married women of high socioeconomic status, which is similar in profile to the samples of many other research studies on milk sharing (26, 28, 38, 48, 51, 55, 88). This limits our ability to extrapolate results to other populations of interest, such as same-sex male couples, Blacks, Hispanics, and Asians. Additionally, use of homogenous samples further perpetuate the lack of representation of minority groups in the scientific literature. This limitation is problematic. We made concerted efforts to recruit a more diverse population by sharing our recruitment flyers with Black doulas and lactation consultants and a non-profit maternal health organization that serves the

Southeast DC area. Despite these efforts, very few Black women participated in the study. It is difficult to know why we were unsuccessful in these recruitment efforts. Regardless of the reasons, the lack of representation of Black parents remains a major shortcoming in this research, and in the broader body of literature on milk sharing.

Ethnographic reflexivity

As with all ethnographic research, the first author was the research instrument, and thus, there is some inherent subjectivity and bias involved in the collection and interpretation of these data. It is particularly relevant that I was obviously pregnant when I was conducting the interviews, which most certainly impacted my relationship with the participants. It is difficult to say how my pregnancy status would have affected the participants' perceptions of me. For some, they might have been inclined to leave out some particularly scary or upsetting details of their experience for fear of upsetting or scaring me. For others, they may have felt more comfortable openly sharing details of their childbirth and breastfeeding experiences because my pregnant status labeled me as a member of the broader community of mothers. From my personal perspective, I believe that for the majority of the interviews, my pregnant status engendered a feeling of camaraderie and sisterhood, while also allowing the participants to feel safe welcoming me into their home and around their children (which is where most of the interviews took place).

Another personal experience impacted my subjectivity and relation to the data and indeed, the theme more broadly. I gave birth to my first child in March 2018 and proceeded to have an extremely difficult and – in retrospect – traumatic breastfeeding experience that was strangely

similar to those described by many of the participants of this study. I, too, struggled with the emotional weight of not being able to exclusively breastfeed my child, and I mourned the loss of the breastfeeding journey that I had so deeply desired. When I returned to this work after taking parental leave, I found it very difficult to read the interview transcripts and relive these experiences because I had not yet fully processed or healed from my own traumatic experience. It took a long time before I felt clear-headed enough to re-engage with this data in a state of emotional balance and scientific curiosity. I have endeavored to maintain my objectivity to the best of my ability, but even so, I must acknowledge that it is truly impossible to remain completely objective given my personal identity and experience as a mother and breastfeeding woman. However, I also believe this part of my identity is also a strength of this research. Given that I am a member of this community of parents, of women, and of milk-sharers, I am uniquely positioned to understand the experiences of milk-sharing parents on a deeply personal level. There is no urge as primal as a mother's drive to care for, protect, and nourish her child. Only a mother who has been in the position of caring for an infant who isn't thriving can understand how that feels. Thus, I acknowledge my position relative to this research as both a strength and a limitation.

Recommendations for future research

As a research community, our most urgent need is for high-quality studies on maternal and infant health outcomes associated with various infant-feeding practices, including HMS. The health outcomes associated with E-HM feeding (of mother's own milk) are still understudied and thus, poorly understood. Milk sharing adds a layer of complexity with its disruption of the mother-infant dyad. Prospective studies designed to assess important outcomes associated

with HMS, formula feeding, and E-HM feeding would fill a critical gap in the literature by providing quantitative data on the actual risks associated with these competing infant-feeding practices. Findings would inform clinical policy and recommendations, and patient education, messaging, and communication strategies around infant feeding.

The patient-provider relationship and its influence on infant feeding decision-making and practices is another important area ripe for exploration. This is certainly of interest in relation to milk sharing, but also more broadly around infant-feeding practices (e.g., formula feeding, introduction of complementary foods, etc.). Given the apparent discrepancy between the value and risk structures related to infant feeding held by parents and healthcare providers, both quantitative and qualitative research is needed to understand how infant feeding cognitive frameworks differ between these groups. Such research should incorporate patient and provider perspectives, and include sociodemographic diversity to support a comprehensive mapping of value and risk structures on infant feeding, and how such cognitions influence patient-provider interactions and patient satisfaction.

As healthcare delivery increasingly embraces patient-centered care models, opportunities exist for building healthier patient-provider relationships built on trust and mutual respect. Shared decision-making (SDM) care models, for example, emphasize patient-centered care that “is respectful of and responsive to individual patient preferences, needs, and values” and allows those values and preferences to guide clinical decisions (183, 184). SDM models feature the *bidirectional* exchange of information, options, and preferences, ultimately allowing for a mutually agreed upon decision that is aligned with patient preferences, beliefs,

and values. Future studies could test the impact of using SDM models on breastfeeding challenged women.

Research is also needed to understand how milk sharing influences the duration of breastfeeding and human milk feeding. HMS may, in fact, be an unconventional strategy to enhance the quantity and duration of HM feeding among recipient infants. We have recently discovered that even a small amount of formula feeding is associated with significant changes in the infant gut microbiome (185-187). Therefore, we should seek to understand how milk sharing may function as an infant formula avoidance strategy, with potential implications for the recipient infant gut microbiome.

Risk perceptions are important because they drive human behavior. It is thus critical that we gain deeper understanding of risk perceptions associated with HMS so we can understand parental motivations and support these parents more appropriately. Given that the modest sample size in our survey limited our ability to detect group differences and subpopulations of interest, an important area of future research is to design additional studies with larger sample sizes to assess risk perceptions among milk sharing parents. Furthermore, it would be ideal if these studies included the three distinct components of risk perceptions recently proposed by Ferrer et al. (160).

Another recommendation for future research is to study the composition and quality of S-HM. To date, only one published study has examined the quality and composition of HM from HMS, milk banks, and mother's own milk, and found no statistical differences between them

(37). However, additional research is needed to extend this work further to different geographic populations and constituents of HM as well as possible contaminants that could be introduced by the process of pumping, storing, and rewarming E-HM before feeding.

Conclusions

In conclusion, this mixed-methods dissertation has contributed to the body of scientific literature by highlighting the ways in which HMS recipients and donors are different from and similar to each other, detailing the unique challenges faced by recipients, describing the range of milk-sharing practices, and demonstrating how infant-feeding risk is constructed among milk-sharing parents. This work has generated important questions and concerns about the benefits and risks of milk sharing, the quality of patient-provider interactions around infant feeding, and the complexity of comparative risk perceptions in infant feeding. Finally, we have illuminated numerous implications of this work for scientific research, clinical practice, and public health policy.

APPENDIX A
MILK SHARING PRACTICES SURVEY

Q1.1 Thank you for your interest in taking our survey about milk sharing. This research is important because there is very little scientific data on milk sharing practices, even though milk sharing seems to be becoming more commonly practiced.

By taking time out of your busy schedule to answer these questions, you are contributing to the first effort to collect systematic data about how milk sharing is practiced by modern parents. This is critical evidence needed to inform the development of more effective clinical and public health recommendations that are relevant to the lived realities of parents.

What is expected of you as a research participant?

You will be asked to complete a detailed online survey about your infant feeding practices, experiences with peer milk sharing, attitudes and beliefs towards infant feeding, and your social networks. The survey takes between 20-30 minutes to complete. If you can't complete the survey all at once, you can save your progress and come back to finish the survey at another time.

As a thank you for your time and effort, you will receive a \$20 Amazon gift card after you have successfully completed the survey.

Q1.2 Please review the attached informed consent form for additional details about the study, including how the data collected from this study will be protected and your confidentiality ensured.

NOTE: You'll need to enable pop-ups in your browser in order to see the attached file.

Once you have read and/or downloaded this file, please advance to the next screen only if you consent to participate in this research.

Q9.7 How did you hear about this survey?

Select all that apply.

- I saw an ad posted on EOF (1)
- I saw an ad posted on HM4HB (2)
- A friend, coworker, or family member told me about it (3)
- Someone I shared milk with told me about it (4)
- My midwife or lactation consultant told me about it (10)
- Other (8)

Display This Question:

If Q9.7 = 8

Q248 If you selected other, please describe:

Q2.1

Before we get started with the survey, please read over the terminology provided below. Understanding these terms will help you answer the survey questions.

Milk sharing. A method of informally exchanging breast milk directly between parents without the exchange of money. Milk sharing does NOT include formal channels of milk exchange such as milk banking. Within the context of a milk sharing arrangement, there is a donor and a recipient.

Shared milk. Breast milk that is obtained directly from another parent without exchanging money. Shared milk does NOT include milk obtained from a milk bank.

Purchased milk. Breast milk that is obtained directly from another parent in exchange for money (or goods/services). Purchased milk does NOT include milk obtained from a milk bank. An example of this might be milk that was purchased directly from another parent who you connected with online.

Banked milk. Breast milk that is obtained from a nonprofit or for-profit milk bank, which has been screened for infectious agents and has been pasteurized.

Cross-nursing. When a child feeds directly at the breast of someone other than his/her nursing parent.

Exclusive pumping. An infant feeding practice where someone exclusively uses a breast pump to induce and maintain lactation as opposed to feeding directly at the breast.

Q2.2 Great! Now let's begin with a few screening questions to make sure you are eligible to take the survey.

Q252 How old are you?

▼ Under 18 (21) ... 85 or older (29)

Q2.5 At the time of milk sharing, did you live or work in the greater Washington, DC metropolitan region?

Note: For the purposes of this survey, the "DC metro region" does includes the surrounding MD/VA area, including Baltimore.

- Yes - I lived there (1)
 - Yes - I worked there (2)
 - Yes - I both lived and worked there (3)
 - No (4)
-

Q251 Do you currently live or work in the Washington, DC metropolitan region?

Note: For the purposes of this survey, the "DC metro region" does includes the surrounding MD/VA area, including Baltimore.

- Yes (1)
 - No (2)
-

End of Block: AGE & LOCATION SCREENER

Start of Block: RECIPIENT SCREENER



Q3.1 Have you (or another caregiver) **ever** fed another parent's breast milk to your child?

- Yes (1)
 - No (2)
-

Display This Question:

If Q3.1 = 1



Q3.2 If **yes**, please select all methods that apply.

- Shared milk (1)
- Purchased milk (2)
- Banked milk (3)
- Cross-nursing (4)

Display This Question:

If Q3.2 = 1

Q3.3 Please indicate when your child last consumed **shared milk**. Please provide your best estimate.

- Less than 1 month ago (1)
- 1-3 months ago (4)
- 4-6 months ago (5)
- 7-9 months ago (2)
- 10-12 months ago (3)
- 13-18 months ago (6)
- More than 18 months ago (7)

Display This Question:

If Q3.2 = 2

Q3.4 Please indicate when your child last consumed **purchased milk**. Please provide your best estimate.

- Less than 1 month ago (1)
 - 1-3 months ago (4)
 - 4-6 months ago (5)
 - 7-9 months ago (6)
 - 10-12 months ago (7)
 - 13-18 months ago (2)
 - More than 18 months ago (8)
-

Display This Question:

If Q3.2 = 3

Q3.5 Please indicate when your child last consumed **banked milk**. Please provide your best estimate.

- Less than 1 month ago (1)
- 1-3 months ago (4)
- 4-6 months ago (5)
- 7-9 months ago (6)
- 10-12 months ago (7)
- 13-18 months ago (2)
- More than 18 months ago (8)

Display This Question:

If Q3.2 = 4

Q3.6 Please indicate when your child last **cross-nursed** (nursed directly at the breast of someone other than their own parent). Please provide your best estimate.

- Less than 1 month ago (1)
- 1-3 months ago (4)
- 4-6 months ago (5)
- 7-9 months ago (6)
- 10-12 months ago (7)
- 13-18 months ago (9)
- More than 18 months ago (8)

End of Block: RECIPIENT SCREENER

Start of Block: DONOR SCREENER



Q4.1 Have you **ever** made your breast milk available to feed another child who isn't your own?

Yes (1)

No (2)

Display This Question:

If Q4.1 = 1



Q4.2 If **yes**, please select all methods that apply.

Donated to another family (1)

Sold milk to another family (2)

Donated or sold milk to a milk bank (3)

Cross-nursed (4)

Display This Question:

If Q4.2 = 1

Q4.3 Please indicate the last time you made your breast milk available to feed another child **through milk sharing**. Please provide your best estimate.

Less than 1 month ago (1)

1-3 months ago (2)

4-6 months ago (3)

7-9 months ago (4)

10-12 months ago (5)

13-18 months ago (7)

More than 18 months ago (6)

Display This Question:

If Q4.2 = 2

Q4.4 Please indicate the last time you **sold your breast milk to another parent/caregiver**. Please provide your best estimate.

- Less than 1 month ago (1)
- 1-3 months ago (2)
- 4-6 months ago (3)
- 7-9 months ago (4)
- 10-12 months ago (5)
- 13-18 months ago (7)
- More than 18 months ago (6)

Display This Question:

If Q4.2 = 3

Q4.5 Please indicate the last time you **donated or sold your breast milk to a milk bank**. Please provide your best estimate.

- Less than 1 month ago (1)
- 1-3 months ago (4)
- 4-6 months ago (2)
- 7-9 months ago (3)
- 10-12 months ago (5)
- 13-18 months ago (7)
- More than 18 months ago (6)

Display This Question:

If Q4.2 = 4

Q4.6 Please indicate the last time you **cross-nursed a child who is not your own**. Please provide your best estimate.

- Less than 1 month ago (1)
- 1-3 months ago (2)
- 4-6 months ago (3)
- 7-9 months ago (4)
- 10-12 months ago (5)
- 13-18 months ago (7)
- More than 18 months ago (6)

Page Break

Q5.1 Great! We've determined that you are eligible to take the survey.

Now we'd like to ask you some questions about your childbirth experience. We ask these questions because research shows that the childbirth experience can significantly impact the breastfeeding experience.

Q5.2 How many children have you given birth to?

- 0 (1)
 - 1 (2)
 - 2 (3)
 - 3 (4)
 - 4 or more (5)
-

Display This Question:

If Q5.2 != 1

Q5.3 Did you give birth to your youngest child or children?

- Yes (1)
 - No (2)
-

Q5.4 Referring to your youngest child or children: is the child a singleton or are they multiples?

- Singleton (1)
 - Twins (2)
 - Triplets (3)
 - Multiples of more than 3 (4)
-

Display This Question:

If Q5.4 != 1

Q5.5 For the rest of the survey, please answer about your multiples, even though the questions typically ask about your singular "child."

Display This Question:

If Q5.3 = 1

Q5.6 How old were you when your youngest child was born?

Age (in years): _____

Q5.7 Were there any complications during the pregnancy of your youngest child?

Yes (1)

No (2)

Display This Question:

If Q5.7 = 1

Q5.8 If so, what complications were there?

Q5.9 Were there any complications during labor and delivery of your youngest child?

Yes (1)

No (2)

Display This Question:

If Q5.9 = 1

Q5.10 If so, what complications were there?

Display This Question:

If Q5.3 = 1

Q5.11 Do you consider the birth to have been a traumatic experience?

- Yes (1)
 - No (2)
 - Don't known / uncertain (4)
-

Display This Question:

If Q5.3 = 1

Q5.12 Did you ever experience postpartum depression, either clinically diagnosed or self-diagnosed?

- Yes (1)
 - No (2)
 - Don't know / uncertain (4)
-

Display This Question:

If Q5.3 = 1

Q5.13 Did you ever experience postpartum anxiety, either clinically diagnosed or self-diagnosed?

- Yes (1)
 - No (2)
 - Don't know / uncertain (4)
-

Q5.14 Referring to your youngest child(ren): at what gestational age was the child(ren) born?

- Less than 28 weeks (1)
 - 28 – 31 weeks (2)
 - 32 – 36 weeks (3)
 - 37+ weeks (4)
 - Don't know / uncertain (5)
-

Q5.15 How was the child born?

- Vaginal (1)
 - Cesarean (2)
 - Don't know / uncertain (3)
-

Q5.16 What kind of professional(s) attended the child's birth?

Select all that apply.

- Midwife (1)
 - Obstetrician (2)
 - Another kind of medical doctor (3)
 - Doula (4)
 - No healthcare provider was present at the birth (5)
 - Other (6)
 - Don't know / uncertain (7)
-

Q5.17 Were you employed at the time your child was born?

- Yes (1)
- No (2)

Skip To: End of Block If Q5.17 = 2

Q5.18 What was your parental leave situation when your child was born?

- I did not take leave (1)
 - I reduced my hours (2)
 - I took unpaid leave (3)
 - I took partially paid leave (4)
 - I took fully paid leave (5)
 - I stopped working (6)
 - Other (7)
-

Display This Question:

If Q5.18 != 1

Q5.19 How much parental leave did you take?

- < 4 weeks (1)
- 4-7 weeks (2)
- 8-11 weeks (3)
- 12-15 weeks (4)
- 16-19 weeks (5)
- 20-23 weeks (6)
- 24+ weeks (7)
- Not applicable (8)

End of Block: PREGNANCY & BIRTH EXPERIENCE [asked of everyone]

Start of Block: BREASTFEEDING EXPERIENCE [asked of everyone]

Q6.1 **Now let's talk a little bit about your breastfeeding experience.**

When answering this first set of breastfeeding questions, please think about ALL OF YOUR CHILDREN.

Q6.2 Did you ever produce breast milk for **any** of your children?

- Yes (1)
- No (2)

Skip To: Q6.10 If Q6.2 = 2

Q6.3 Did you ever nurse **any** of your children at your breast?

- Yes (1)
- No (2)

Q6.4 After your milk came in, did you ever have difficulty producing enough milk for **any** of your children?

- Yes (1)
- No (2)

Q6.5 Did you ever produce more milk than needed for **any** of your children?

- Yes (1)
- No (2)

Q6.6 Did you ever pump your milk to feed **any** of your children?

- Yes (1)
- No (2)

Skip To: Q6.8 If Q6.6 = 2

Q6.7 Did you ever exclusively pump for **any** of your children (i.e, feeding only pumped milk in place of nursing directly at the breast)?

- Yes (1)
- No (2)

Q6.8 What was your longest period of **milk production** for a single child? This includes both nursing at the breast AND pumping.

Display This Question:

If Q5.2 = 3

Or Q5.2 = 4

Or Q5.2 = 5

Q6.9 How long have you spent **producing milk** in total during your lifetime? This includes time spent nursing at the breast AND pumping.
Please add up your lactation experience with **ALL** of your children combined. Just give your best estimate.

Q6.10 Were you ever diagnosed by a healthcare provider with a health problem that affected your milk production?

- Yes (1)
- No (2)
- Don't know / uncertain (4)
- Not applicable (3)

Display This Question:

If Q6.10 = 1

Q6.11 If yes, what was the condition or health problem you were diagnosed with?

Q6.12 Have you ever fed infant formula to **any** of your children?

- Yes (1)
- No (2)

Q6.13 When answering this second set of breastfeeding questions, please only think about your youngest child (or children, if your youngest are multiples).

Display This Question:

If Q6.2 = 1

Q6.14 Are you the nursing parent to this child?

- Yes (1)
- No (2)



Q6.15 During the first 3 months of your baby's life, how did you feed them?

Select all that apply.

- Fed directly at nursing parent's breast (1)
- Fed directly at someone else's breast (cross-nursed) (12)
- Fed nursing parent's own pumped/expressed breast milk (2)
- Fed someone else's pumped breast milk - shared milk (3)
- Fed someone else's pumped breast milk - purchased milk (4)
- Fed donor breast milk from a milk bank (5)
- Fed commercially available infant formula (6)
- Fed homemade infant formula (7)
- Fed cow's milk or other animal milk (8)
- Fed water or other fluids (9)
- Fed solid foods (10)
- Other (11)

Display This Question:

If Q6.15 != 6

And Q6.15 != 7

And Q6.12 = 1

Q6.16 Has your youngest child **ever** received infant formula?

- Yes (1)
- No (2)

Display This Question:

If Q6.16 = 1

Q6.17 Is your youngest child **currently** receiving infant formula?

- Yes (1)
 - No (2)
-

Q6.18 Is your youngest child **currently** receiving breast milk?

- Yes (1)
- No (2)

Q6.19 How long did he or she receive **any** breast milk?

This includes nursing parent's own milk as well as someone else's milk. Please just give your best estimate.

If the baby is still receiving breast milk, please indicate the total duration as of today.

Display This Question:

If Q6.14 = 1

Q6.20 Many parents who breastfeed rely on social and practical support for breastfeeding. Which sources of support, if any, provided helpful support to you during your breastfeeding journey?

Select all that apply.

- Partner / significant other (1)
- Other family members (6)
- Community of other mothers (7)
- Lactation consultant (2)
- Midwife / doula (3)
- Pediatrician or other medical doctor (4)
- Nurse (12)
- Pediatric dentist (11)
- Chiropractor (13)
- La Leche League or other breastfeeding support group (5)
- Online mom or breastfeeding support groups (8)
- Other (9)
- None of the above (10)

Display This Question:

If Q6.14 = 1

Q6.21 Overall, how do you feel about your breastfeeding experience with your youngest child?



- Big Frown(1)
- Small Frown (2)
- Neutral (3)
- Small Smile (4)
- Big Smile (5)

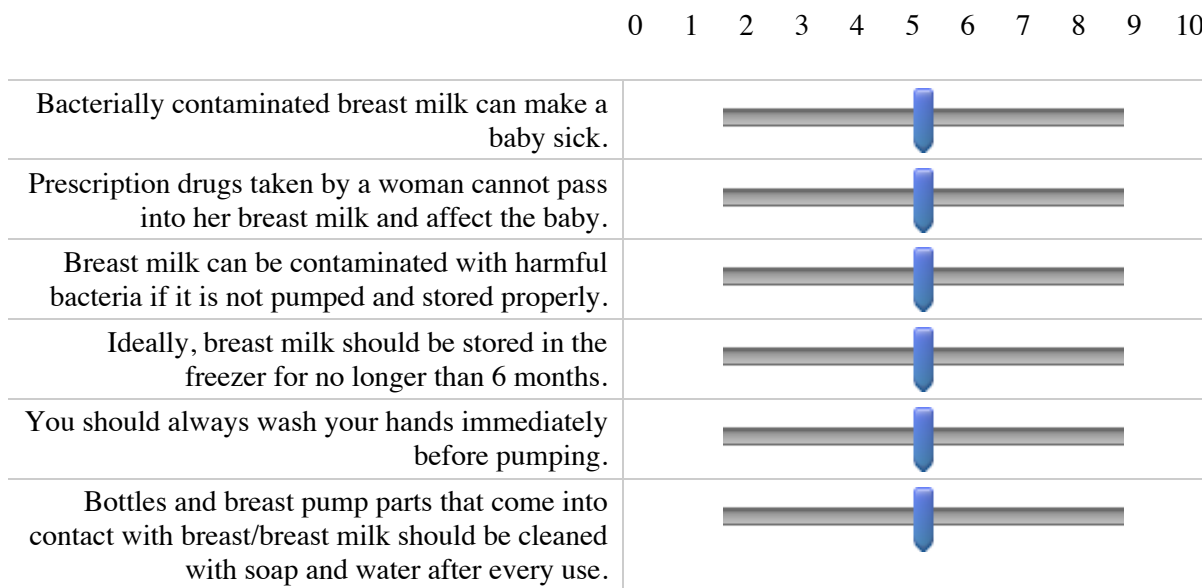
Q6.22 Now we'd like to ask you some questions about your attitudes and beliefs related to breastfeeding. These questions help us to understand your values, preferences, knowledge, and attitudes that pertain to breastfeeding.

Q6.23 Please rate how strongly you agree or disagree with the following statements about BREASTFEEDING.

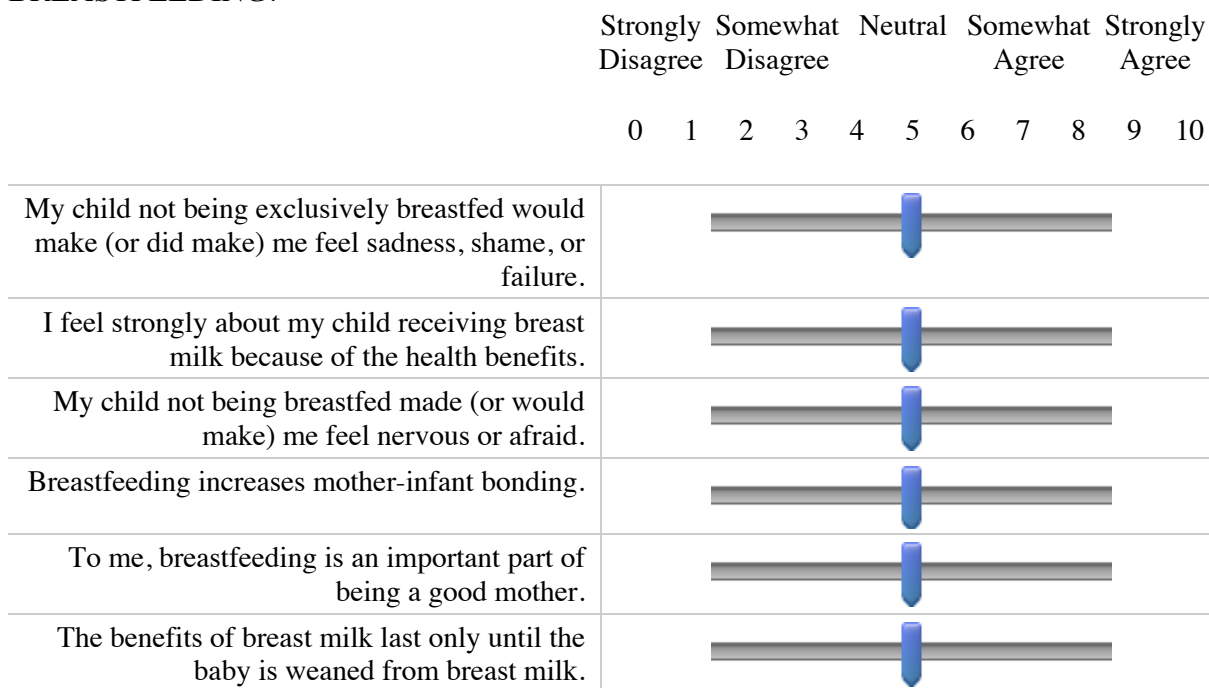
	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree						
	0	1	2	3	4	5	6	7	8	9	10
A breastfed baby is less likely to get ear infections, compared to a formula-fed baby.											
A breastfed baby is less likely to get diarrhea, compared to a formula-fed baby.											
Ideally, all babies would be exclusively breastfed (fed only breast milk) for the first 4-6 months of life.											
Infectious diseases such as HIV and syphilis can be passed through breast milk.											
The composition of breast milk stays the same as the baby ages.											

Q6.24 Please rate how strongly you agree or disagree with the following statements about BREASTFEEDING.

- Strongly Disagree
- Somewhat Disagree
- Neutral
- Somewhat Agree
- Strongly Agree



Q6.25 Please rate how strongly you agree or disagree with the following statements about BREASTFEEDING.



End of Block: BREASTFEEDING EXPERIENCE [asked of everyone]

Start of Block: RECIPIENTS - MILK SHARING PRACTICES [asked of recipients only]

Q7.1 Now we'd like to ask you specifically about your experience with milk sharing. The following questions refer to your experience as a milk sharing RECIPIENT.

If you received shared milk for more than one child, please answer these questions only about the child for whom you most recently milk shared.

If your youngest are multiples and those are the children you milk-shared for, please answer these questions regarding your multiples, even though the questions ask about your youngest child.

Q7.2 What best describes the relationship between you and the child(ren) who received shared milk?

- Birth/biological parent (1)
- Non-biological parent (8)
- Adoptive parent or step-parent (2)
- Foster parent (3)
- Legal guardian (4)
- Other relative in custody (5)
- Non-relative in custody (6)
- Other (7)

Display This Question:

If Q7.2 = 1

Or Q7.2 = 8

Or Q7.2 = 2

Or Q7.2 = 3

Q7.3 Are you the nursing parent to this child?

- Yes (1)
- No (2)

Q7.4 How old was the child when you **began** milk sharing?

If your child was born premature, please use their adjusted age.

Q7.5 How old is the child **now**?

Q7.6 For how long did the child(ren) consume shared milk? If you milk shared at multiple different times, please add up all the times together.

Please just give your best estimate.

Display This Question:

If Q7.2 != 1

Q7.7 During the time of milk sharing, was the mother or birth parent alive?

- Yes (1)
- No (2)

Q7.8 Where did you initially get the idea of milk sharing as a way to feed your child?

Select all that apply.

- Myself (8)
- Someone in my BF support group (9)
- Someone in an online community (10)
- Online web search (13)
- My doctor or my child's doctor (7)
- Lactation consultant (3)
- Midwife (4)
- Doula (5)
- Partner / significant other (1)
- Friend or family member (2)
- Other caregiver (12)
- Other (11)

Q7.9 When you began milk sharing, how urgent was your need for breast milk?

- Not at all urgent (1)
 - A little urgent (2)
 - Urgent (3)
 - Extremely urgent (4)
-

Q7.10 When you began milk sharing, what was your emotional state?

Q7.11 When you began milk sharing, what was your physical state?

Q7.12 While milk sharing, approximately how much of the child's milk intake was comprised of **shared milk**?

- A little bit (1)
 - Some (2)
 - About half (3)
 - A lot (4)
 - All of it (5)
 - It varied/varies (6)
-

Display This Question:

If Q7.12 = 6

Q7.13 If you selected "It varied/varies" - please describe in your own words how much of the child's milk intake was comprised of shared milk:

Q7.14 While milk sharing, was the baby still receiving **any** of the nursing parent's own milk?

- Yes (1)
- No (2)
- Don't know / uncertain (3)

Q7.15 While milk sharing, was the baby still nursing at the breast of the nursing parent?

- Yes – throughout the milk sharing arrangement (1)
- Yes – only during part of the milk sharing arrangement (2)
- No (3)
- Don't know / uncertain (4)

Q7.16 Does the child have any health issues?

- Yes (1)
- No (2)
- Did in the past, but no longer (3)
- Don't know / uncertain (4)

Display This Question:

If Q7.16 = 1

Or Q7.16 = 3

Q7.17 If the child did have or currently has a health issue, please describe the health issue(s):

Q7.18 Does the child have any dietary allergies, sensitivities, or intolerances (e.g., sensitivity to cow's milk protein, intolerance to soy, etc.)?

- Yes (1)
- No (2)
- Did in the past, but no longer (3)
- Don't know / uncertain (4)

Display This Question:

If Q7.18 = 1

Or Q7.18 = 3

Q7.19 If yes, what are they?

Q7.20 Was the child ever diagnosed with a tongue tie or lip tie?

- Yes – tongue tie only (1)
- Yes – lip tie only (2)
- Yes – both tongue and lip tie (3)
- No (4)
- Don't know / uncertain (5)
- Other (6)

Skip To: Q7.25 If Q7.20 = 4

Display This Question:

If Q7.20 = 6

Q7.21 If you selected "other," please specify:

Display This Question:

If Q7.20 = 1

Or Q7.20 = 2

Or Q7.20 = 3

Q7.22 Who was involved in diagnosing the tie(s)?

Please select all that apply.

- Pediatrician (1)
- Other medical doctor (MD / DO) (2)
- Dentist (3)
- Lactation consultant (4)
- Chiropractor (6)
- Other (5)
- Not applicable (7)

Display This Question:

If Q7.20 = 1

Or Q7.20 = 2

Or Q7.20 = 3

Q7.23 Did you have the lip or tongue tie released?

- Yes (1)
- No (2)
- Not applicable (4)

Display This Question:

If Q7.23 = 1

Q7.24 How old was the child when you had their lip or tongue tie released?

Please just give your best estimate.

Q7.25 Before deciding to pursue milk sharing (as a recipient), what other options did you consider?

Select all that apply.

- Milk bank (1)
 - Wet nurse (2)
 - Quitting work or school (3)
 - Reducing hours at work or school (10)
 - Commercial infant formula (4)
 - Homemade infant formula (5)
 - Animal milk (6)
 - Other milk (coconut, almond, soy, etc.) (7)
 - None (9)
 - Other (11)
-



Q7.26 Please select the top people or resources that **most influenced** your decision to milk share.

Please select no more than 5 options.

- Your doctor or your child's doctor (1)
 - Other healthcare provider (3)
 - Lactation consultant (5)
 - Midwife (61)
 - Partner or significant other (8)
 - Other breastfeeding moms (6)
 - Mother or birth parent (7)
 - Other caregiver (9)
 - Extended family or friends (10)
 - My own professional training (16)
 - Eats on Feets or Human Milk 4 Human Babies website (11)
 - Expert baby books (60)
 - Other online breastfeeding resources (e.g., KellyMom, mommy blogs, etc.) (13)
 - Professional organization statements about milk sharing (e.g., from the American Academy of Pediatrics) (14)
 - Government statements about milk sharing (e.g., from the WHO, CDC, or FDA) (62)
 - None (17)
 - Other (15)
-



Q7.27 There are many different reasons that parents might decide to milk share. What were your **most important reasons** for deciding to participate in milk sharing?

Please select no more than 5 reasons.

- Baby was sick or had a serious health problem (2)
- Baby was born preterm or low birth weight (3)
- Baby was having difficulty nursing at the breast (4)
- Baby seemed hungry after being fed at the breast (5)
- Baby had insufficient weight gain or significant weight loss (6)
- Baby was intolerant of formula (7)
- Baby was sensitive or allergic to something in the breastfeeding parent's diet (8)
- Health professional advised that breastfeeding would be best for the baby (18)
- Breastfeeding parent was ill (9)
- Breastfeeding parent needed to take medications not safe for breastfeeding (10)
- Breastfeeding parent had insufficient milk supply or lactation problem (11)
- Breastfeeding parent had a drug or alcohol abuse problem (12)
- Breastfeeding was too painful (13)
- Health professional advised breastfeeding parent not to breastfeed (17)
- Beliefs about the rights of babies to have breast milk (1)
- Religious or philosophical beliefs about using infant formula (14)
- Concerns about infant formula (15)
- Psychological or emotional distress (16)
- Breast milk is the biologically normal way of feeding babies (19)
- Convenience or an opportunity that presented itself at the right time (20)
- Work or school made it impossible to meet baby's breast milk needs (21)
- It was free (22)
- Other reason not listed above (23)

Display This Question:

If Q7.27 = 23

Q7.28 Other reason not listed above - please specify:

Q7.29 With the child for whom you most recently milk shared, when you first considered milk sharing, what concerns did you have?

Please drag and drop the list of potential concerns into categories according to how concerned you were about them. Within each group, the ordering of concerns does not matter. When sorting these concerns, it may help to think about how much you thought about each of these concerns when you were first considering milk sharing, and whether or not you did anything to minimize the risk associated with each of them.

Wasn't aware of or didn't think about	Not at all concerned about	Somewhat concerned about	Very concerned about
_____ Age-matching the donor milk to my baby (1)	_____ Age-matching the donor milk to my baby (1)	_____ Age-matching the donor milk to my baby (1)	_____ Age-matching the donor milk to my baby (1)
_____ Donor's sociodemographic characteristics (2)	_____ Donor's sociodemographic characteristics (2)	_____ Donor's sociodemographic characteristics (2)	_____ Donor's sociodemographic characteristics (2)
_____ Donor's health status (31)	_____ Donor's health status (31)	_____ Donor's health status (31)	_____ Donor's health status (31)
_____ Donor's diet quality (3)	_____ Donor's diet quality (3)	_____ Donor's diet quality (3)	_____ Donor's diet quality (3)
_____ Donor's caffeine consumption (4)	_____ Donor's caffeine consumption (4)	_____ Donor's caffeine consumption (4)	_____ Donor's caffeine consumption (4)
_____ Donor's prescription drug use (7)	_____ Donor's prescription drug use (7)	_____ Donor's prescription drug use (7)	_____ Donor's prescription drug use (7)
_____ Donor's alcohol consumption (5)	_____ Donor's alcohol consumption (5)	_____ Donor's alcohol consumption (5)	_____ Donor's alcohol consumption (5)
_____ Donor's tobacco use (6)	_____ Donor's tobacco use (6)	_____ Donor's tobacco use (6)	_____ Donor's tobacco use (6)
_____ Donor's overall cleanliness and hygiene (32)	_____ Donor's overall cleanliness and hygiene (32)	_____ Donor's overall cleanliness and hygiene (32)	_____ Donor's overall cleanliness and hygiene (32)
_____ Donor's milk pumping and storage practices (15)	_____ Donor's milk pumping and storage practices (15)	_____ Donor's milk pumping and storage practices (15)	_____ Donor's milk pumping and storage practices (15)
_____ Illicit drugs in milk (e.g., marijuana, opioids) (9)	_____ Illicit drugs in milk (e.g., marijuana, opioids) (9)	_____ Illicit drugs in milk (e.g., marijuana, opioids) (9)	_____ Illicit drugs in milk (e.g., marijuana, opioids) (9)

_____ Health status of the donor's baby and/or other children (13)

_____ Infectious disease transmission (14)

_____ Age of donor milk (e.g., how long it had been frozen) (16)

_____ Intentional dilution or contamination of breast milk (17)

_____ Nutritional content of milk (18)

_____ Lipase content of milk (25)

_____ Bacterial contamination of milk (27)

_____ Interacting with a stranger (20)

_____ Not having enough information to make an informed decision (26)

_____ Being too time-consuming to find donors and meet with them to exchange milk (28)

_____ Being judged negatively by family or friends (29)

_____ Lack of regulation (e.g., in the way that milk banks have systems in place for donor screening and processing of donor milk) (30)

_____ Health status of the donor's baby and/or other children (13)

_____ Infectious disease transmission (14)

_____ Age of donor milk (e.g., how long it had been frozen) (16)

_____ Intentional dilution or contamination of breast milk (17)

_____ Nutritional content of milk (18)

_____ Lipase content of milk (25)

_____ Bacterial contamination of milk (27)

_____ Interacting with a stranger (20)

_____ Not having enough information to make an informed decision (26)

_____ Being too time-consuming to find donors and meet with them to exchange milk (28)

_____ Being judged negatively by family or friends (29)

_____ Lack of regulation (e.g., in the way that milk banks have systems in place for donor screening and processing of donor milk) (30)

_____ Health status of the donor's baby and/or other children (13)

_____ Infectious disease transmission (14)

_____ Age of donor milk (e.g., how long it had been frozen) (16)

_____ Intentional dilution or contamination of breast milk (17)

_____ Nutritional content of milk (18)

_____ Lipase content of milk (25)

_____ Bacterial contamination of milk (27)

_____ Interacting with a stranger (20)

_____ Not having enough information to make an informed decision (26)

_____ Being too time-consuming to find donors and meet with them to exchange milk (28)

_____ Being judged negatively by family or friends (29)

_____ Lack of regulation (e.g., in the way that milk banks have systems in place for donor screening and processing of donor milk) (30)

_____ Health status of the donor's baby and/or other children (13)

_____ Infectious disease transmission (14)

_____ Age of donor milk (e.g., how long it had been frozen) (16)

_____ Intentional dilution or contamination of breast milk (17)

_____ Nutritional content of milk (18)

_____ Lipase content of milk (25)

_____ Bacterial contamination of milk (27)

_____ Interacting with a stranger (20)

_____ Not having enough information to make an informed decision (26)

_____ Being too time-consuming to find donors and meet with them to exchange milk (28)

_____ Being judged negatively by family or friends (29)

_____ Lack of regulation (e.g., in the way that milk banks have systems in place for donor screening and processing of donor milk) (30)

Q7.30 When contacting a new donor did you ever discuss any of the following issues?

Select all that apply.

- Age of donor's baby (e.g., age-matching the milk to the age of my baby) (1)
- Donor's sociodemographic characteristics (2)
- Donor's diet quality (3)
- Donor's caffeine consumption (4)
- Donor's alcohol consumption (5)
- Donor's tobacco use (6)
- Donor's prescription drugs (7)
- Recreational drug use (9)
- Donor's overall cleanliness & hygiene (11)
- Infectious disease test results (e.g., HIV, hepatitis, or other) (12)
- Other medical records (16)
- Health status of the donor (17)
- Health status of the donor's baby and/or older children (18)
- Health status of my baby (19)
- Milk pumping and storage practices (20)
- Age of donor milk (e.g., how long it had been frozen) (21)
- Heat treatment / home pasteurization of breast milk (22)
- Religious or philosophical beliefs (23)
- None of the above (25)
- Not applicable – never met the donor(s) (26)
- Other issue not listed above (27)

Display This Question:

If Q7.30 = 27

Q7.31 If you selected "other issue not listed above," please specify:

Q7.32 How did you **initially connect with** parents who were looking to donate their milk?
Select all that apply.

- Online group (e.g., Eats on Feets or HM4HB Facebook group, breastfeeding listserv, etc.) (1)
- I already knew them (e.g., friend or family member) (4)
- Facilitated through a mutual friend/acquaintance (5)
- Facilitated through a midwife or doula (6)
- Facilitated through a lactation consultant (7)
- Other (8)

Display This Question:

If Q7.32 = 8

Q7.33 If you selected "other," please specify:

Q7.34 Did you ever receive milk from the following individuals?
Select all that apply.

- Friend (1)
- Family member (2)
- Online acquaintance that you **HAVE** met in person (3)
- Online acquaintance that you **HAVE NOT** met in person (4)
- Someone you connected with through an intermediary (e.g., a midwife or doula) (7)
- Someone you met in your local community offline (5)
- Other (6)

Q7.35 With the child for whom you most recently milk shared, how many different donors did you get shared milk from? Please give your best estimate and only count repeat donors once.

If you have milk shared for more than one child, please only think about your youngest child when answering this question.

Number of different donors: _____

Q7.36 How many of those donors were repeat or ongoing donors?

Number of repeat donors: _____

Q7.37 Giving your best estimate, for the child for whom you most recently milk shared, how many ounces of shared milk did you obtain in total?

Please include milk from ALL milk sharing donors but exclude any milk received from milk banks.

- 0-24 ounces (4)
- 25-49 ounces (5)
- 50-74 ounces (6)
- 75-99 ounces (7)
- 100-249 ounces (12)
- 250-499 ounces (8)
- 500-999 ounces (9)
- 1,000+ ounces (10)
- Don't know / uncertain (11)

Q7.38 With the child for whom you most recently milk shared, how did you exchange milk with your donors?

Select all that apply.

- Directly (met donor to pick up milk) (1)
 - Indirectly (did not meet donor, but donor gave milk to someone else to give to you) (2)
 - Received via mail/shipped (3)
 - Via cross-nursing (5)
 - Other (4)
-

Q7.39 Did you ever heat treat the shared milk before feeding it to your child? This would include scalding, holder pasteurization, flash pasteurization, etc.

- Yes (1)
- No (2)
- Don't know / uncertain (3)

Skip To: Q7.43 If Q7.39 = 2

Q7.40 What kind of heat treatment technique did you use?

Select all that apply.

- Scalding (1)
 - Flash pasteurization (2)
 - Holder pasteurization (3)
 - Other (4)
 - Don't know / uncertain (5)
-

Q7.41 How often did you heat treat the shared milk?

- Once (1)
 - The first few times (2)
 - Sometimes (3)
 - Usually (4)
 - Every time (5)
-



Q7.42 Why did you choose to heat treat the shared milk?

Select all that apply.

- To kill any unwanted bacteria (1)
 - To kill any viruses (2)
 - Because my child was vulnerable – sick, preterm, or had a compromised immune system (3)
 - To improve the taste of the milk / high lipase content (4)
 - My healthcare provider advised me to heat treat the milk (5)
 - Someone else advised me to heat treat the milk (6)
 - Other (7)
-

Display This Question:

If Q7.39 = 2

Q7.43 If no, why did you choose not to heat treat the shared milk?

Select all that apply.

- I didn't know that was an option or it didn't occur to me (1)
 - I wanted to preserve the "good things" in the milk (2)
 - It was too much work / too time consuming (3)
 - I was too stressed out to learn and incorporate another new step in feeding my baby (4)
 - My child was healthy and not preterm or sick (5)
 - I trusted that the milk was clean/safe (6)
 - Other (7)
-

Q7.44 Some parents screen potential milk sharing donors by asking personal questions of them. With the child for whom you most recently milk shared, did you ever do this with any of your donors?

- Yes (1)
- No (2)
- Don't know / uncertain (3)

Skip To: Q7.46 If Q7.44 = 2

Skip To: Q7.46 If Q7.44 = 3

Q7.45 Who did you screen?

- Everyone (1)
 - Only strangers, not friends or family (2)
 - Some people but not all, regardless of familiarity (3)
 - No one (4)
-

Q7.46 In addition to the methods already mentioned, did you do anything else to minimize your concerns about milk sharing?

Select all that apply.

- Asked other people about the donor to get a sense of their reputation (1)
- Discussed it with a healthcare provider (16)
- Looked up the donor online (Facebook, Google, etc.) (2)
- Examined appearance of the donor, their house, or their children (3)
- Asked donor about their health/medical history (4)
- Ensured donor is breastfeeding her own child (5)
- Carefully examined milk containers for cleanliness (6)
- Managed pick-up by meeting in public or bringing a companion along (7)
- Ensured the milk was kept at an appropriate temperature during transportation (8)
- Mixed the shared milk in with nursing parent's own milk when feeding (9)
- Blended several different donor's milks together when feeding (10)
- Introduced the shared milk slowly to watch for any adverse reactions from baby (11)
- Had professional monitoring from a lactation consultant (17)
- Prayed / meditated (12)
- None of the above (14)
- Other method not listed above (15)

Display This Question:

If Q7.46 = 15

Q7.47 Please specify what else you did to minimize your concerns about milk sharing:

Page Break

Q7.48 Was your partner supportive of you **milk sharing**?

- Yes (1)
- No (2)
- Somewhat (3)
- Unsure (4)
- Not applicable (5)

Display This Question:

If Q7.48 = 3

Or Q7.48 = 2

Q7.49 If you answered 'No' or 'Somewhat', please briefly describe why you felt that your partner wasn't entirely supportive of you milk sharing.

Q7.50 Did you ever discuss milk sharing with friends or family members (other than your spouse or partner)?

- Yes (1)
- No (2)

Skip To: Q7.52 If Q7.50 = 2

Q7.51 If yes, who did you discuss milk sharing with?

Select all that apply.

- Coworkers (1)
 - Friends (5)
 - Family members (2)
 - Other moms in my community (3)
 - Other (4)
-

Display This Question:

If Q7.50 = 2

Q7.52 If no, why didn't you discuss milk sharing with friends or family members?

Select all that apply.

- It never came up in conversation (1)
- I was afraid of feeling judged (2)
- I knew they would have negative opinions about it (3)
- I didn't think it was anyone else's business (4)
- I felt emotional about my journey with breastfeeding & milk sharing (5)
- Other (6)

Q7.53 Did you ever feel like friends or family members negatively judged you for milk sharing?

- Yes (1)
- No – never mentioned it to friends or family (2)
- No – they knew, but were neutral or didn't say anything to make me feel judged (3)
- No – they knew and were supportive of milk sharing (4)

Q7.54 How important were the following factors in making you feel more comfortable with milk sharing?

Drag and drop the list of factors into categories according to their level of importance to you. Within each group, the ordering of concerns does not matter.

Not applicable	Not at all important	Somewhat important	Very important
_____ Donor was nursing their own child (1)	_____ Donor was nursing their own child (1)	_____ Donor was nursing their own child (1)	_____ Donor was nursing their own child (1)
_____ Donor had been screened as an official donor for a milk bank (2)	_____ Donor had been screened as an official donor for a milk bank (2)	_____ Donor had been screened as an official donor for a milk bank (2)	_____ Donor had been screened as an official donor for a milk bank (2)
_____ Donor was very forthcoming with details about their	_____ Donor was very forthcoming with details about their	_____ Donor was very forthcoming with details about their	_____ Donor was very forthcoming with details about their

lifestyle & health status (3)	lifestyle & health status (3)	lifestyle & health status (3)	lifestyle & health status (3)
_____ I knew the donor – they were my friend/relative (4)	_____ I knew the donor – they were my friend/relative (4)	_____ I knew the donor – they were my friend/relative (4)	_____ I knew the donor – they were my friend/relative (4)
_____ I developed a relationship with the donor (5)	_____ I developed a relationship with the donor (5)	_____ I developed a relationship with the donor (5)	_____ I developed a relationship with the donor (5)
_____ My donor and I shared a mutual trust (6)	_____ My donor and I shared a mutual trust (6)	_____ My donor and I shared a mutual trust (6)	_____ My donor and I shared a mutual trust (6)
_____ Knowing that I always had the option to reject the milk if I wasn't comfortable with it (7)	_____ Knowing that I always had the option to reject the milk if I wasn't comfortable with it (7)	_____ Knowing that I always had the option to reject the milk if I wasn't comfortable with it (7)	_____ Knowing that I always had the option to reject the milk if I wasn't comfortable with it (7)
_____ I know friends & family who have milk shared (8)	_____ I know friends & family who have milk shared (8)	_____ I know friends & family who have milk shared (8)	_____ I know friends & family who have milk shared (8)
_____ I believe breast milk is a resilient fluid (9)	_____ I believe breast milk is a resilient fluid (9)	_____ I believe breast milk is a resilient fluid (9)	_____ I believe breast milk is a resilient fluid (9)
_____ Historical context – humans have been milk sharing for centuries (10)	_____ Historical context – humans have been milk sharing for centuries (10)	_____ Historical context – humans have been milk sharing for centuries (10)	_____ Historical context – humans have been milk sharing for centuries (10)
_____ I had previous positive experience with milk sharing (11)	_____ I had previous positive experience with milk sharing (11)	_____ I had previous positive experience with milk sharing (11)	_____ I had previous positive experience with milk sharing (11)
_____ My healthcare provider presented it as a valid feeding option (12)	_____ My healthcare provider presented it as a valid feeding option (12)	_____ My healthcare provider presented it as a valid feeding option (12)	_____ My healthcare provider presented it as a valid feeding option (12)
_____ My healthcare provider supported milk sharing (13)	_____ My healthcare provider supported milk sharing (13)	_____ My healthcare provider supported milk sharing (13)	_____ My healthcare provider supported milk sharing (13)

Q7.55 How important was milk sharing as a strategy in helping you reach your infant feeding goals?

- Not important (1)
- A little important (2)
- Somewhat important (3)
- Important (4)
- Very important (5)

Q7.56 Did your baby ever have a noticeably different reaction to consuming shared milk (as compared to nursing parent's own milk)?

Examples might include upset tummy, obvious dislike of the taste, refusal to drink, diarrhea, etc.

- Yes (1)
- No (2)
- Don't know / uncertain (3)

Display This Question:
If Q7.56 = 1

Q7.57 If yes, please describe:

Q7.58 Did you ever have a negative experience with milk sharing?

- Yes (1)
- No (2)

Display This Question:
If Q7.58 = 1

Q7.59 If yes, please describe:

Q7.60 Did you ever reject milk from a potential donor?

- Yes (1)
- No (2)
- Don't know / uncertain (3)

Display This Question:

If Q7.60 = 1

Q7.61 If yes, why did you reject the milk?

Select all that apply.

- Donor was consuming a drug or medication that I wasn't comfortable with (1)
- Donor's medical records were not available (2)
- I was not comfortable with donor's medical history or health status (15)
- I was not comfortable with the donor's diet or lifestyle (3)
- The donor was not breastfeeding their own baby (5)
- The donor's baby's age wasn't close enough to my own baby (6)
- The donor wanted payment (7)
- The donor was unpleasant or rude (8)
- Difficulty communicating with donor or arranging for pick-up (9)
- I had a bad feeling about the donor or situation (10)
- The milk was too old (11)
- The donor had an insufficient quantity of milk (14)
- I already had enough milk (12)
- Other (13)

Display This Question:

If Q7.61 = 13

Q7.62 Other - please specify:

Q7.63 Did you ever consider feeding infant formula to your baby (or babies) who received shared milk (regardless of whether or not you ended up doing it)?

- Yes (1)
- No (2)

Skip To: Q7.65 If Q7.63 = 2

Q7.64 **When you were considering feeding infant formula, how concerned were you about the following issues?**

Please drag and drop the list of potential concerns into categories according to how concerned you were about them. Within each group, the ordering of concerns does not matter.

<i>Not at all concerned</i>	<i>Somewhat concerned</i>	<i>Very concerned</i>
_____ Formula is not as good as breast milk (2)	_____ Formula is not as good as breast milk (2)	_____ Formula is not as good as breast milk (2)
_____ Formula isn't natural (20)	_____ Formula isn't natural (20)	_____ Formula isn't natural (20)
_____ Contamination of the formula (e.g., with heavy metals or harmful bacteria) (3)	_____ Contamination of the formula (e.g., with heavy metals or harmful bacteria) (3)	_____ Contamination of the formula (e.g., with heavy metals or harmful bacteria) (3)
_____ Problems with specific ingredients (e.g., high fructose corn syrup) (4)	_____ Problems with specific ingredients (e.g., high fructose corn syrup) (4)	_____ Problems with specific ingredients (e.g., high fructose corn syrup) (4)
_____ Lacking important ingredients that breast milk has (5)	_____ Lacking important ingredients that breast milk has (5)	_____ Lacking important ingredients that breast milk has (5)
_____ Don't trust formula companies (11)	_____ Don't trust formula companies (11)	_____ Don't trust formula companies (11)
_____ Lack of regulation by the FDA (22)	_____ Lack of regulation by the FDA (22)	_____ Lack of regulation by the FDA (22)
_____ Feeding problems, such as hard to digest, constipation, or bad taste (6)	_____ Feeding problems, such as hard to digest, constipation, or bad taste (6)	_____ Feeding problems, such as hard to digest, constipation, or bad taste (6)
_____ Practicalities – inconvenient, difficult to mix and feed on the go (7)	_____ Practicalities – inconvenient, difficult to mix and feed on the go (7)	_____ Practicalities – inconvenient, difficult to mix and feed on the go (7)

_____ Short-term health risks associated with formula feeding (e.g., damage to the gut, higher risk of ear infection, allergies) (8)

_____ Long-term health risks associated with formula feeding (e.g., higher risk of obesity, asthma) (9)

_____ Lack of antibodies in infant formula, leading to a risk of lower immunity (14)

_____ Risk of lower IQ associated with formula feeding (19)

_____ Lack of bonding associated with formula feeding (13)

_____ Too expensive (10)

_____ Down-regulating mom's own milk supply (18)

_____ Baby developing a preference for formula over breast milk (15)

_____ Baby developing a preference for bottle over breast (16)

_____ Being judged negatively by family or friends (17)

_____ Short-term health risks associated with formula feeding (e.g., damage to the gut, higher risk of ear infection, allergies) (8)

_____ Long-term health risks associated with formula feeding (e.g., higher risk of obesity, asthma) (9)

_____ Lack of antibodies in infant formula, leading to a risk of lower immunity (14)

_____ Risk of lower IQ associated with formula feeding (19)

_____ Lack of bonding associated with formula feeding (13)

_____ Too expensive (10)

_____ Down-regulating mom's own milk supply (18)

_____ Baby developing a preference for formula over breast milk (15)

_____ Baby developing a preference for bottle over breast (16)

_____ Being judged negatively by family or friends (17)

_____ Short-term health risks associated with formula feeding (e.g., damage to the gut, higher risk of ear infection, allergies) (8)

_____ Long-term health risks associated with formula feeding (e.g., higher risk of obesity, asthma) (9)

_____ Lack of antibodies in infant formula, leading to a risk of lower immunity (14)

_____ Risk of lower IQ associated with formula feeding (19)

_____ Lack of bonding associated with formula feeding (13)

_____ Too expensive (10)

_____ Down-regulating mom's own milk supply (18)

_____ Baby developing a preference for formula over breast milk (15)

_____ Baby developing a preference for bottle over breast (16)

_____ Being judged negatively by family or friends (17)

Q7.65 Have you ever spoken to a healthcare provider about milk sharing?

Note: for this question "healthcare provider" is defined broadly to include anyone who might have been involved in your childbirth or your child's medical team and could include: midwives, lactation consultants, doulas, pediatricians, obstetricians, etc.

- Yes (1)
- No (2)

Skip To: Q7.69 If Q7.65 = 2

Q7.66 If so, what type of provider(s) did you speak to about milk sharing?

Select all that apply.

- Obstetrician (1)
 - Midwife (2)
 - Pediatrician (3)
 - Lactation Consultant (4)
 - Doula (5)
 - Specialist (e.g., endocrinologist, allergist, etc.) (6)
 - Other (7)
-

Q7.67 Has any healthcare provider ever offered resources or advice on how to practice milk sharing in a safe way?

Select all that apply.

- Obstetrician (1)
 - Midwife (2)
 - Pediatrician (3)
 - Lactation Consultant (4)
 - Doula (5)
 - Specialist (e.g., endocrinologist, allergist, etc.) (6)
 - Other (7)
 - None (8)
-

Q7.68 Has any healthcare provider ever connected you directly to a milk sharing donor or obtained shared milk directly from a donor to give to you?

Select all that apply.

- Obstetrician (1)
 - Midwife (2)
 - Pediatrician (3)
 - Lactation Consultant (4)
 - Doula (5)
 - Specialist (e.g., endocrinologist, allergist, etc.) (6)
 - Other (7)
 - None (8)
-

Q7.69 If there was ever a time when you withheld information from or avoided discussing milk sharing with a healthcare provider, what were your reasons for doing that?

Select all that apply.

- My provider(s) never asked me about milk sharing (1)
 - I didn't feel comfortable talking about milk sharing with my provider(s) (2)
 - I didn't feel the need to talk about milk sharing with my provider(s) (3)
 - I didn't view my provider(s) as educated or qualified enough to weigh in on the decision (7)
 - I felt like my provider(s) wouldn't understand or approve of milk sharing (4)
 - Not applicable (5)
 - Other reason (6)
-

Q7.70 Overall, how do you feel about your experience as a milk sharing recipient?



- Big Frown (1)
- Small Frown (2)
- Neutral (3)
- Small Smile (4)
- Big Smile (5)

Q7.71 Would you recommend milk sharing to a friend who was experiencing breastfeeding challenges?

- Yes (1)
- Maybe / it depends (2)
- No (3)

Q7.72 Would you milk share again in the future if you found yourself in a situation where you needed to supplement your child?

- Yes (1)
- Maybe / it depends (2)
- No (3)

Q7.73 What were the positive aspects of milk sharing that were important to you as a recipient?

Select all that apply.

- I felt supported by a community of other mothers/parents (1)
- I developed a friendship with my donor(s) (2)
- My stress or anxiety was significantly reduced (14)
- I was happy that another parent's milk didn't go to waste (5)
- I was able to provide more breast milk to my child (15)
- I was able to avoid feeding my child infant formula (6)
- I was able to reduce the amount of infant formula my child received (10)
- My child was able to receive immune benefits from other parent's milk (11)
- I had previously donated my milk and felt good about now being able to receive milk from other donors (13)
- Milk kinship (12)
- Other (8)
- None of the above (9)

Display This Question:

If Q7.73 = 8

Q7.74 If you selected "other," please specify:

Q8.1 The following questions specifically refer to your experience AS A DONOR in a milk sharing arrangement. Please answer these questions about your most recent milk sharing experience as a donor.

Q8.2 Referring to your most recent milk sharing experience: at the time you began milk sharing, how old was the child who was receiving your milk?

- 0-3 months (1)
 - 4-6 months (2)
 - 7-9 months (3)
 - 10-12 months (4)
 - 13-18 months (5)
 - 18-24 months (6)
 - >24 months (7)
 - Don't know / uncertain (8)
-

Q8.3 Referring to your most recent milk sharing experience: at the time you began milk sharing, how old was YOUR child (the one who you were producing milk for)?

- 0-3 months (1)
 - 4-6 months (2)
 - 7-9 months (3)
 - 10-12 months (4)
 - 13-18 months (5)
 - 18-24 months (6)
 - >24 months (7)
 - Don't know / uncertain (8)
-

Q8.4 Did you ever look into donating your milk to a milk bank?

- Yes (1)
- No (2)

Display This Question:

If Q8.4 = 1

Q8.5 If so, did you go through the donor screening process?

- I never got screened (3)
- I started the screening process but never finished (5)
- I went through screening but wasn't approved as a donor (2)
- I went through screening and was approved as a donor (4)

Display This Question:

If Q8.5 = 2

Q253 If you knew the reason you weren't approved as a donor, please share it here:

Display This Question:

If Q8.5 = 2

Q254 If you knew the reason you weren't approved as a donor, please share it here:

Display This Question:

If Q8.4 = 2

Or Q8.5 = 3

Q8.6 Why didn't you consider getting screened as a milk bank donor?

Select all that apply.

- I felt like it would be too time consuming and/or expensive (1)
 - The milk banks required a high minimum volume of milk to donate (11)
 - There wasn't a milk bank collection place close to me (2)
 - My milk had already been expressed (3)
 - Object to the costs charged by milk banks (4)
 - I preferred to donate my milk locally (5)
 - I wanted to know the family who was receiving my milk (7)
 - I was donating specifically to someone I knew (9)
 - I had concerns around milk kinship (6)
 - No reason in particular (10)
 - Other reason not listed above (8)
-

Q8.7 Where did you initially come up with the idea of donating your milk informally?

Select all that apply.

- Myself (8)
 - Someone in my BF support group (9)
 - Someone in an online community (10)
 - Online web search (13)
 - My doctor or my child's doctor (7)
 - Lactation consultant (3)
 - Midwife (4)
 - Doula (5)
 - Partner / significant other (1)
 - Friend or family member (2)
 - Other caregiver (12)
 - Other (11)
-

Q8.8 With your youngest child, did you have a freezer stash of your expressed breast milk?

- Yes (1)
- No (2)
- Don't know / uncertain (5)
- Not applicable (6)

Display This Question:

If Q8.8 = 1

Q8.9 With your youngest child, what was the largest amount of your own breast milk you ever had stored in your freezer? Please just give your best estimate.

- 0-24 ounces (1)
- 25-49 ounces (2)
- 50-74 ounces (3)
- 75-99 ounces (4)
- 100-249 ounces (5)
- 250-499 ounces (8)
- 500-999 ounces (6)
- 1,000+ ounces (7)

Q8.10 How many different families did you donate your breast milk to?

Please give your best estimate and only count repeat or ongoing recipients once.

- Number of different recipients: _____

Q8.11 Out of those recipient families, to how many did you give repeat or ongoing milk donations?

- Number of repeat recipients: _____

Q8.12 What type of milk did you donate?

- Surplus expressed milk originally intended to feed my own child (1)
 - Milk that I expressed specifically for donating (2)
 - Both surplus and milk expressed for donating (3)
-

Q8.13 Giving your best estimate, how many ounces of your expressed breast milk did you donate in total?

Please include donations to ALL milk sharing recipients but exclude any milk donated to milk banks.

- 0-24 ounces (1)
- 25-49 ounces (2)
- 50-74 ounces (3)
- 75-99 ounces (4)
- 100-249 ounces (5)
- 250-499 ounces (8)
- 500-999 ounces (6)
- 1000+ ounces (7)

Q8.14 How did you **initially connect** with families who were looking for shared milk?
Select all that apply.

- Online group (e.g., Eats on Feets or HM4HB Facebook group, breastfeeding listserv, etc.) (1)
- I already knew them (e.g., friend or family member) (2)
- Facilitated through a mutual friend / acquaintance (3)
- Facilitated through a midwife or doula (4)
- Facilitated through a lactation consultant (5)
- Other (6)

Display This Question:

If Q8.14 = 6

Q8.15 If you selected "other," please specify:

Display This Question:

If Q8.14 != 1

Q8.16 Did you ever use online resources to find a milk sharing recipient? Examples might include FB groups like Eats on Feets or Human Milk 4 Human Babies, BF support groups, mommy email listservs, etc.

- Yes (1)
- No (2)

Q8.17 Did you actively offer / post your milk, or did you respond to someone who was asking for shared milk?

- Offered only (1)
- Responded to someone who asked for milk only (2)
- Both offered and responded (3)



Q8.18 Who did you donate your milk to?

Select all that apply.

- Friend (1)
 - Family member (2)
 - Online acquaintance that you have met in person (3)
 - Online acquaintance that you have NOT met in person (4)
 - Someone you connected with through an intermediary (e.g., a midwife or lactation consultant) (7)
 - Someone you met in your local community offline (5)
 - Other (6)
-

Q8.19 Has any healthcare provider ever suggested that you consider donating your breast milk to a milk bank?

Select all that apply.

- Obstetrician (1)
- Midwife (2)
- Pediatrician (3)
- Lactation Consultant (4)
- Doula (5)
- Specialist (e.g., endocrinologist, allergist, etc.) (6)
- Other provider not listed above (7)
- None (8)

End of Block: SHORT DONORS - MILK SHARING PRACTICES [asked of D/Rs]

Start of Block: SOCIAL NETWORKS [asked of everyone]

Q9.1 **Now we'd like you to answer a few questions related to who else you know who has also milk shared.**

These questions are very important to the survey, so please read all of the question notes and think carefully before answering them.



Q9.2 Approximately how many DC-area parents with children under the age of 3 **who have received informally shared milk** do you know, who also know you? Please think only of milk sharing RECIPIENTS for this question.

Note: Knowing someone indicates that you have directly interacted with them in person or online and know their name. In turn, they would also need to know your name. This would include, but is not limited to, people who you personally shared milk with.

For example, someone who you “met” online and DM’d would count, but someone who you just saw posted on a milk sharing group such as Eats on Feets but who you did not directly interact with would NOT count.



Q9.3 Of those milk sharing recipients listed above, **how many of these have you had any type of contact with in the last 6 months?** This includes remote contact, such as email or telephone.



Q9.4 Approximately how many DC-area parents with children under the age of 3 **who have donated their milk informally** do you know, who also know you? Please think only of milk sharing DONORS for this question.

Note: Knowing someone indicates that you have directly interacted with them in person or online and know their name. In turn, they would also need to know your name. This would include, but is not limited to, people who you personally shared milk with.

For example: someone who you “met” online and DM’d would count, but someone who you just saw posted on a milk sharing group such as Eats on Feets but who you did not directly interact with would NOT count.



Q9.5 Of those milk sharing donors listed above, **how many of these have you had any type of contact with in the last 6 months?** This includes remote contact, such as email or telephone.

Q9.6 Do you know any milk-sharing parents (donors OR recipients) who are different from you in respect to race/ethnicity or socio-economic status?

- Yes (1)
- No (2)
- I don't know any other milk-sharing parents (4)
- Don't know / uncertain (3)

End of Block: SOCIAL NETWORKS [asked of everyone]

Start of Block: RISK PERCEPTIONS [for recipients]

Q10.1 Now we'd like to ask you some questions about your attitudes and beliefs about the positive and negative aspects of various infant feeding strategies.

Please answer as honestly as you can.

Q10.2 Do you view yourself as someone who generally trusts other people?

- Yes (1)
 - No (2)
 - Don't know / uncertain (3)
-

Q10.3 In general, how would you describe your level of comfort in taking risks related to your personal safety and health?

In answering this, please think about yourself as an individual and not specific to your role as a parent.

- Very comfortable taking risks (1)
 - Somewhat comfortable taking risks (2)
 - Somewhat uncomfortable taking risks (4)
 - Very uncomfortable taking risks (5)
-

Q10.4 **Specific to your role as a parent:** how would you describe your level of comfort in taking risks related to the personal safety and health of your child(ren)?

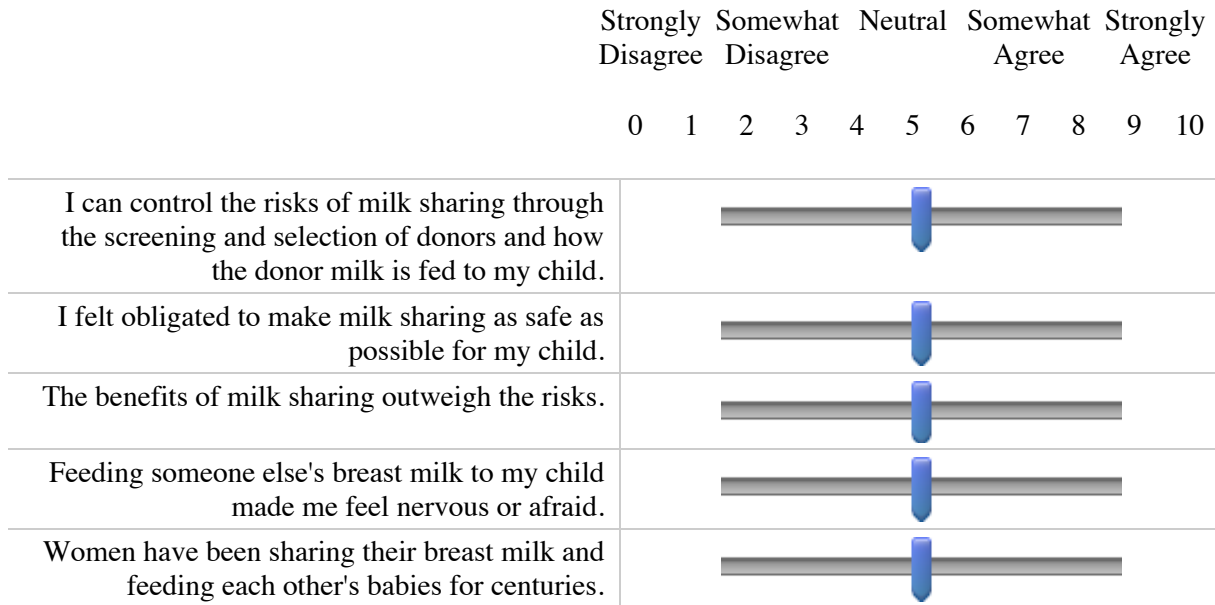
- Very comfortable taking risks (1)
 - Somewhat comfortable taking risks (2)
 - Somewhat uncomfortable taking risks (4)
 - Very uncomfortable taking risks (5)
-

Q10.5 What level of anxiety did you have in your role as a parent to an infant?

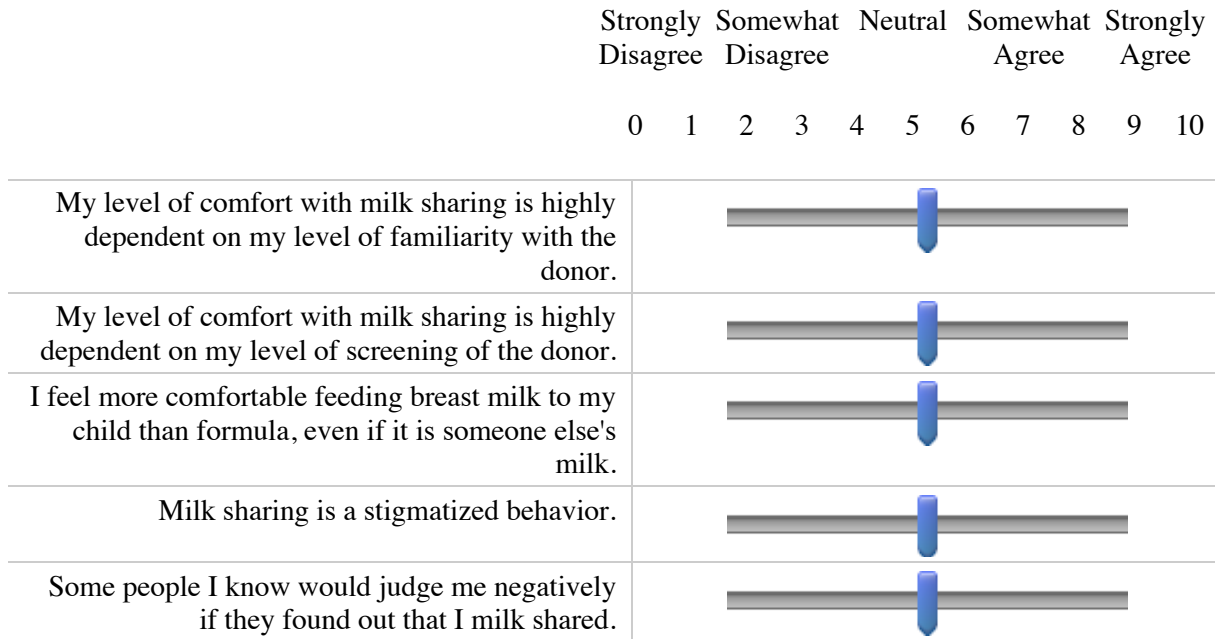
- Little or no anxiety (2)
 - Moderate anxiety (3)
 - Severe anxiety (4)
-

Page Break

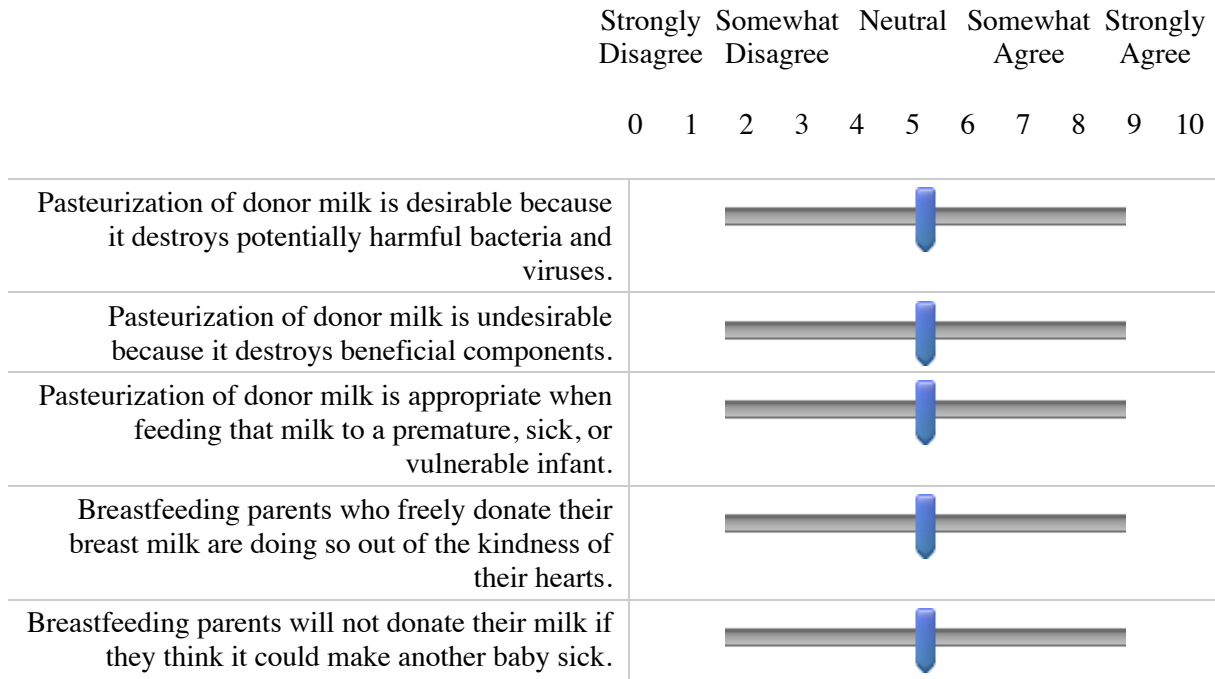
Q10.6 Please rate how strongly you agree or disagree with the following statements about MILK SHARING.



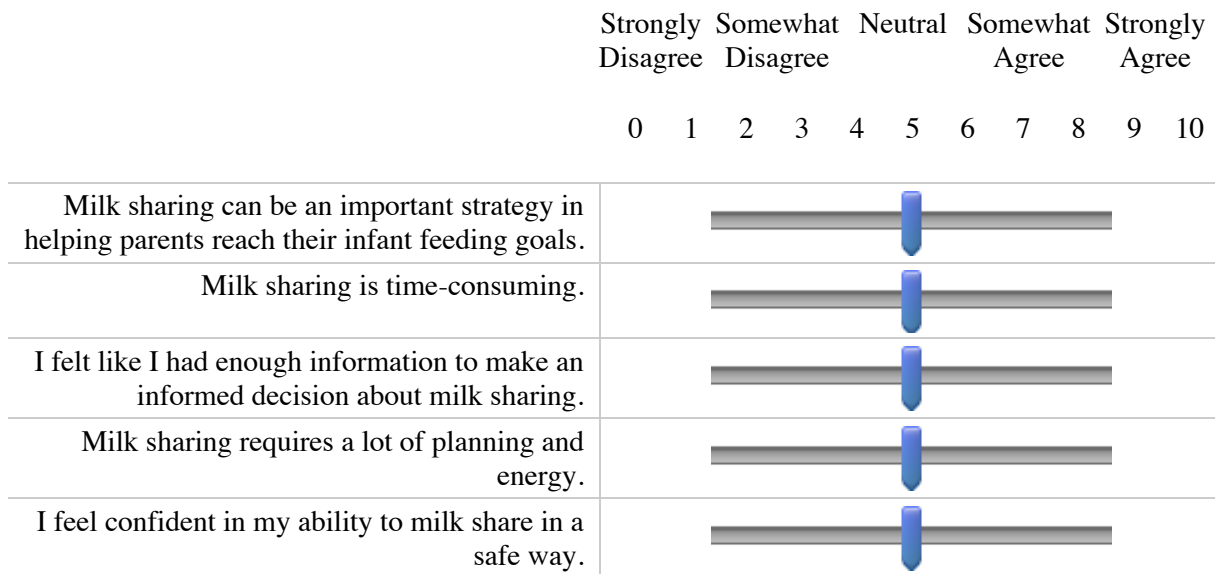
Q10.7 Please rate how strongly you agree or disagree with the following statements about MILK SHARING.



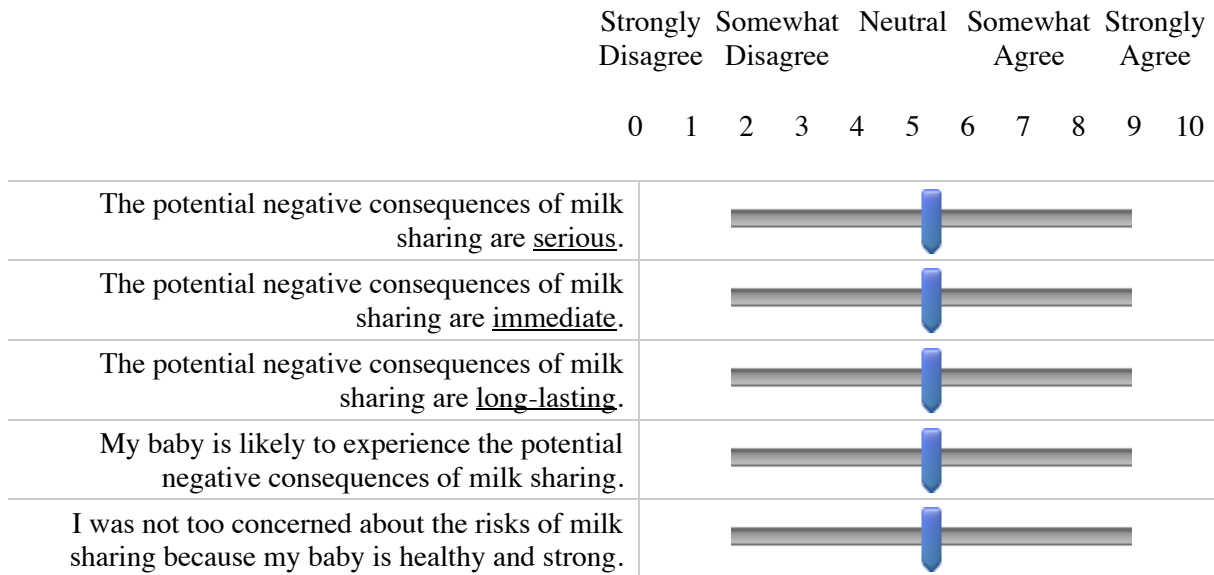
Q10.8 Please rate how strongly you agree or disagree with the following statements about MILK SHARING.



Q10.9 Please rate how strongly you agree or disagree with the following statements about MILK SHARING.

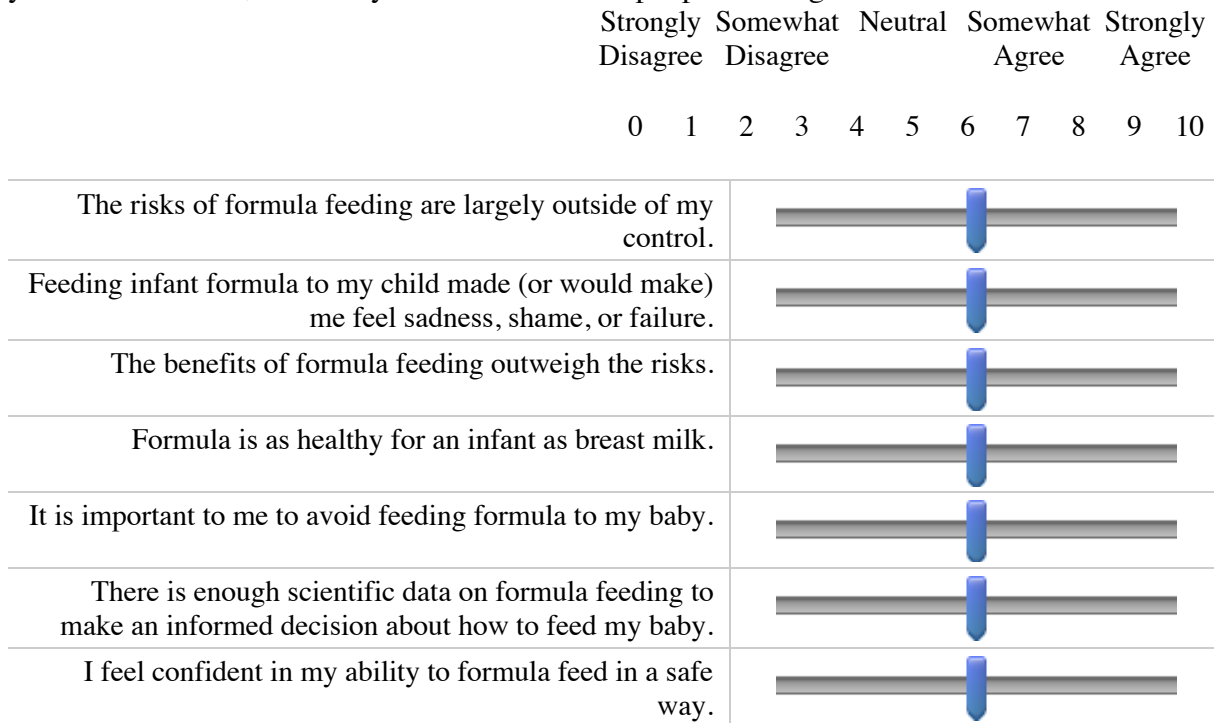


Q10.10 Please rate how strongly you agree or disagree with the following statements about MILK SHARING.



Q10.11 Please rate how strongly you agree or disagree with the following statements about FORMULA FEEDING.

When answering these questions, please think about your feelings toward formula feeding your own children, not how you feel about other people feeding formula to their children.



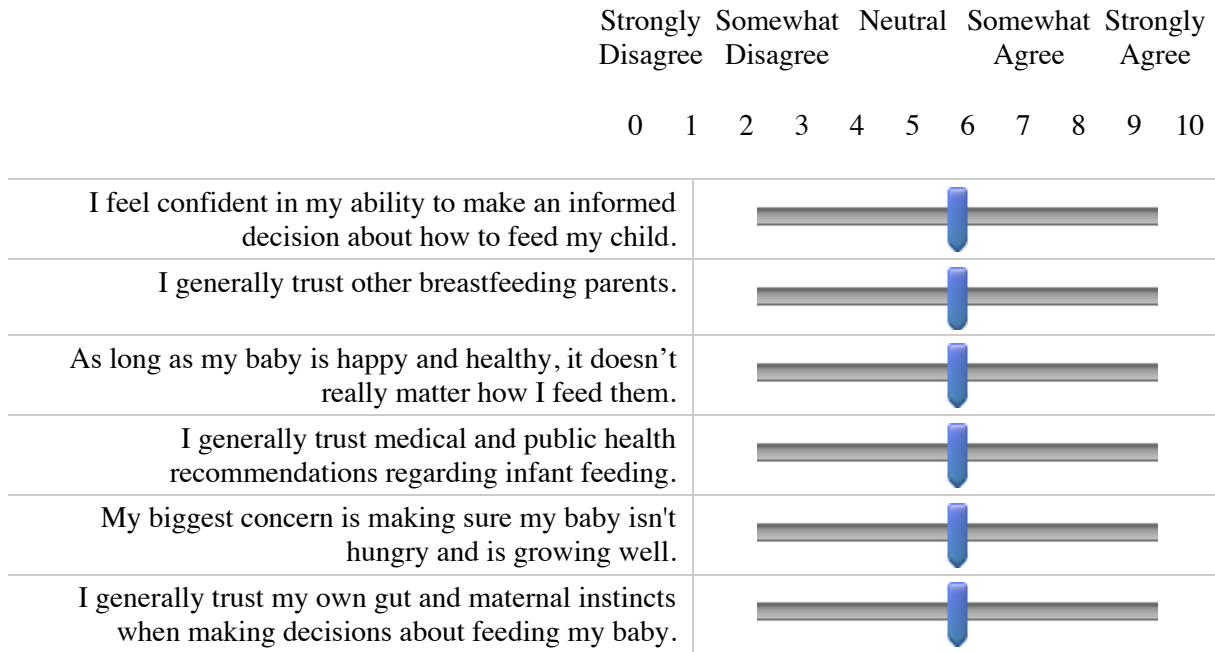
Q10.12 Please rate how strongly you agree or disagree with the following statements about FORMULA FEEDING.

When answering these questions, please think about your feelings toward formula feeding your own children, not how you feel about other people feeding formula to their children.

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree						
	0	1	2	3	4	5	6	7	8	9	10
The potential negative consequences of formula feeding are <u>serious</u> .											
The potential negative consequences of formula feeding are <u>immediate</u> .											
The potential negative consequences of formula feeding are <u>long-lasting</u> .											
I am not too concerned about the risks of formula feeding because my baby is healthy and strong.											
The potential negative consequences of formula feeding are more severe than those of milk sharing.											
My baby is more likely to experience potential negative consequences of formula feeding than those of milk sharing.											

Page Break

Q10.13 Please rate how strongly you agree or disagree with the following statements about INFANT FEEDING.



End of Block: RISK PERCEPTIONS [for recipients]

Start of Block: SOCIODEMOGRAPHICS [asked of everyone]

Q13.1 **We're almost finished! Thank you so much for your dedication, we know that was a lot of questions to answer!**

To wrap up, please just answer a few general questions about yourself and your household.

Q13.2 What gender identity best describes you?

- Female (2)
 - Male (5)
 - Non-binary (3)
 - Choose not to identify (4)
-



Q13.3 How many children do you have?

- 0 (0)
 - 1 (1)
 - 2 (2)
 - 3 (3)
 - 4 (4)
 - 5 (5)
 - 6 or more (6)
-



Q13.4 How old were you when you had your first child?

▼ 12 (12) ... 60 (60)



Q13.5 How many people live in your household? Please include yourself, and all adults and children who reside in the home at least half-time.

- 1 (1)
 - 2 (2)
 - 3 (3)
 - 4 (4)
 - 5 (5)
 - 6 (6)
 - 7 (7)
 - 8 or more (8)
-

Q13.6 What is your racial/ethnic background?
Select all that apply.

- African American (1)
 - American Indian / Native Alaskan (2)
 - Asian (3)
 - Indian (4)
 - Latino / Hispanic (5)
 - Middle Eastern (6)
 - Native African (7)
 - Native Hawaiian / Pacific Islander (8)
 - White (9)
 - Multi-racial (10)
 - Other (11)
 - I'd prefer not to say (12)
-

Q13.7 What is your marital status?

- Single / never married (1)
 - Married / domestic partnership / civil union (2)
 - Divorced (3)
 - Widowed (4)
-

Display This Question:

If Q13.7 = 2

Q13.8 What is the gender identity that best describes your partner?

- Male (1)
 - Female (2)
 - Non-binary (3)
 - Choose not to identify (4)
-

Q13.9 What is the highest level of education that you have completed?

- Did not complete primary / high school diploma (1)
 - Completed primary / high school diploma (2)
 - Some college/university with no degree (3)
 - Associate's degree, trade school, apprenticeship, or professional certificate (4)
 - Bachelor's degree (5)
 - Master's degree (6)
 - Doctoral level degree (PhD, MD, JD, etc.) (7)
-

Q13.10 What is your current employment status?

- Unemployed - looking for work (1)
 - Unemployed - full-time parent (5)
 - On parental leave with the intention to return to work in the next 6 months (2)
 - Employed part-time (3)
 - Employed full-time (4)
-

Q13.11 What is your estimated annual combined household income (in USD)?

- < \$25,000 (1)
 - \$25,000 - \$49,999 (2)
 - \$50,000 - \$74,999 (3)
 - \$75,000 - \$99,999 (4)
 - \$100,000 - \$149,999 (5)
 - \$150,000 - \$199,999 (6)
 - \$200,000 - \$249,999 (7)
 - \$250,000 - \$299,999 (8)
 - \$300,000 or more (9)
-

Page Break



Q13.12 Please provide your home zipcode.

Q13.15 Unfortunately, we can no longer give out e-gift cards due to problems with survey scammers.

However, we're happy to mail you the Amazon gift card at your DC/MD/VA home address. We will mail out the gift card within 48 hours after you have completed the survey.

Please provide the mailing address where you'd like to receive your Amazon gift card:

- Full Name (4) _____
- Street Address (5) _____
- Address 2 (6) _____
- City (7) _____
- State (8) _____
- Postal code (9) _____

Q13.16 May we contact you again via email if we have need any clarification or have follow-up questions for you?

- Yes (1)
- No (2)

Display This Question:

If Q13.16 = 1

Or Q13.17 = 1



Q13.13 Great! Please provide your email address so that we can contact you.

End of Block: SOCIODEMOGRAPHICS [asked of everyone]

APPENDIX B

SURVEY RECRUITMENT MATERIALS

Have you participated in peer breast milk sharing in the past 18 months?



Researchers at Cornell University are conducting an online research study to better understand the experiences of parents in the Washington, DC area who have participated in peer milk sharing, either as a donor or a recipient.

Study participants will be asked to complete a detailed online survey about their infant feeding and milk sharing experiences. They will then be asked to electronically recruit up to 3 other eligible people to participate in the survey.

Participation is confidential and voluntary.

Participants can earn up to \$42 in an Amazon gift card as a thank you for their time!

If you are interested in participating or would like more information about the study, contact:

Jenn Peregoy

jap455@cornell.edu

Email to be sent to potential recruiters/participants:

Dear XXX,

My name is Jenn Peregoy and I am a lactation researcher at Cornell University. I am conducting a research study to better understand the experiences of parents who have participated in peer milk sharing to feed their child – either as a donor or a recipient. Both men and women are eligible to participate, as long as they have been involved in peer milk sharing in the past 18 months as a way to feed their child.

Participation in the study will involve taking a detailed online survey about their milk sharing experiences and then recruiting up to 3 other people they know who have also milk shared in the past year. Participation is confidential and voluntary. Participants will earn \$12 for taking the survey and an additional \$10 for each participant they successfully recruit to complete the survey (for a max of 3 recruits).

I'm contacting you to see if you know anyone who might be eligible for this study. Please feel free to forward this email to them or have them contact me directly at jap455@cornell.edu.

Warm regards,
Jenn Peregoy

Study description to be posted on social networking websites:

Lactation researchers from Cornell University are conducting a study to better understand the experiences of DC-area parents who have recently participated in peer milk sharing. Study participants will be asked to complete a detailed online survey about their infant feeding practices and experiences with milk sharing, and then to recruit up to 3 other people from their social network who have also recently milk shared (either as a recipient or as a donor).

The survey takes about 25-30 minutes to complete and participants can earn up to \$72 as an Amazon gift card! If you are interested in participating or would like more information about the study, please contact Jenn Peregoy at jap455@cornell.edu.

Study description to be posted on social networking websites (NEW, v3 – no webRDS):

Lactation researchers from Cornell University are conducting a study to better understand the experiences of DC-area parents who have participated in peer milk sharing in the past 18 months. Participation involves completing a detailed online survey about your infant feeding practices and experiences with milk sharing.

The survey takes 20-30 minutes to complete and participants receive a \$20 Amazon gift card as a thank you for their time! If you would like more information about the study, please contact Jenn Peregoy at jap455@cornell.edu. Please click here if you would like to participate in the survey: https://cornell.qualtrics.com/jfe/form/SV_b9jcnw9fIa6mqh. Thank you!

APPENDIX C

ETHNOGRAPHIC INTERVIEW GUIDE

The interview guide provided below details the main themes/topics I want to cover. However, I do not intend to read these questions verbatim, but instead will use this as a rough template for the types of questions I want to ask while having a somewhat fluid, natural conversation with study participants. This interview guide is tailored to the experiences of women, but for male participants (e.g., same-sex couples who have participated in peer milk sharing) I will alter the questions as necessary (e.g., asking the breastfeeding questions about their wives or omitting them entirely, in the case of same-sex partners).

OPENING: I will begin by introducing myself and providing a detailed description of the study (from the informed consent form. I will give the participant an opportunity to ask any questions he/she might have. Then I will ask for them to sign the informed consent form before we begin the interview. Before asking any interview questions, I will request the participant's permission to (audio) record the interview.

Before I launch into the questions below, I'll ask the participant a warm-up question about his/her baby – how old is he/she? What's his/her name? Etc. The aim is to build rapport and get the participant feeling more comfortable with me. I also intend to use the baby's name throughout the interview (wherever it currently reads “your baby” or “your infant”).

A. Breastfeeding experience

1. Before your baby was born, what was your intention for feeding your infant? [*Probe: did you or your partner feel very strongly about this infant feeding option? Did you feel confident about this decision? Be sure to distinguish between feeding methods – feeding at the breast vs. pumping vs. formula*]
2. Please tell me about your breastfeeding experience so far. I'd like to know what the experience has been like from your perspective.
3. What have been your most significant BF challenges or barriers? [*Probe: Are there any others? Did you have a difficult time after leaving the hospital, how so? Have you had any physical pain or discomfort?*]
4. What factors have most helped you or supported your breastfeeding practice? [*to be asked of women who had some experience with breastfeeding*]
5. How are you currently feeding your baby? [*Probe for specifics: milk sharing, formula, feeding at the breast, pumping, etc.*] How is this working out for you?

B. Risk perceptions associated with infant feeding options

Now, I'd like to change topics. I'd like to better understand how you've thought through the decision of how to feed your baby. These days, parents are faced with so many options for how to feed their babies, I know it can be an overwhelming and complicated decision.

1. Let's start with an easy one. Thinking back to the time when you decided to XXX, can you tell me why you decided to XXX? *[Here I am referring to the infant feeding intention they initially made.]*
2. Were there any other reasons why you felt that XXX was the right thing for you to do? *[Here I'm specifically looking to understand the decision-making process, and all of the factors that were considered. I want to better understand the risk-benefit analysis that women are engaging in when they make this decision, so I will guide the conversation in such a way as to elicit this information as much as possible.]*
3. Did you discuss this decision with anyone else? *{I will only ask this if they didn't mention making the decision with a partner in Q C1). What about a nurse, doctor or lactation counselor?*
4. How did that discussion (those discussions) come out?
5. When you think about the other people you talked to, who do you feel helped you the most? Was there anyone whose advice you didn't like? Why was that?
6. Have you heard about any problems or concerns (risks) associated with XX *[infant feeding option]*? Have you heard about any problems with XX? What do you think about that?

C. Milk sharing experience

Now I'd like to talk to you about a sharing breastmilk, which is something some parents are doing these days.

1. Have you ever shared or donated any of your breast milk? That is, donating some of your milk to a milk bank or to another mom to feed to her infant?
2. Have you ever received donated milk – that is, milk from a milk bank or another woman to feed to your infant?
3. *[For women who said no to D1 and D2]* Have you known anyone who participated in milk sharing? Do you have any thoughts or opinions about milk sharing?
4. *[For women who said yes to either D1 or D2]* Can you please tell me about your experience with milk sharing? *[Potential probes: was it online or in-person? how did you find the donor/recipient? did you know them prior to exchanging milk? how many times did you exchange milk with this person? how far did you each travel to exchange milk? was any money or gifts exchanged for the milk?]*
5. Do you feel comfortable talking with friends or family about your milk sharing experience? Why or why not?

D. Motivations for milk sharing

1. What were the reasons you decided to share milk with other moms/parents?
2. *[For women who did informal milk sharing only]* Did you consider or attempt sharing milk formally through milk banks? Why or why not? *[Probe for type of milk bank]*
3. Did you have any concerns about informally sharing milk? What were they?
4. Only ask if the answer is yes: Did you do anything specific to alleviate your concerns? *[Probe for specific risk mitigation strategies, e.g., screening their donors,*

asking for health records, age-matching the milk to their infant, home pasteurizing the shared milk, etc.]

5. Do you know other women/parents who have shared milk? How common do you think milk sharing is?
6. Do you feel that other people are generally accepting of peer milk sharing, or do you think there is still some stigma around it?

E. Networks & study participation (to assess webRDS feasibility) – this section is not really part of the ethnographic interview *per se*, but I need to ask these questions to help me design a larger study and to know whether an online vs. in-person survey would be most appropriate.

Great! We're almost done. Now I just want to ask you a few questions that will help me design the research study I'm planning for the Spring. These should only take a few minutes and then we'll wrap up.

1. About how many other parents with children under the age of 2 do you know?
2. Of XX people [*provided in F1*], how many of these have you had contact with in the last 2 weeks?
3. What are the different ways in which you had contact with them? [*probe to distinguish between online vs. in-person contacts*]
4. Of XX people [*provided in F2*], approximately how many of them do you have contact with online (e.g., email, social media, etc.)?
5. Of XX people [*provided in F2*], how many of them have participated in milk sharing (that you know of)?
6. Of XX people [*provided in F2*], how many of them do you think spend time online on email, Facebook, etc.?
7. If I were to ask you to participate in a research study that involved taking a 15-minute online survey and electronically (via email) recruiting 3 of the people in your network to take the same survey, how much of a participation incentive do you think would be appropriate? [*Probe: I'm looking for both a dollar amount, and what formats of payment would be desirable, such as Paypal deposit, Amazon giftcard, etc.*]

CLOSING: Thank you so much for taking the time to speak with me. This has been great! I've learned so much from our conversation. Do you have any questions for me, or anything else you want to share with me that you believe would be relevant to this study?

APPENDIX D

CASE STUDIES IN HMS RECIPIENT DECISION-MAKING

Mothers discussed various perspectives on how they viewed safety and risk in the context of milk sharing. A case study approach will be used to understand how women viewed, analyzed, and navigated issues of risk involved in HMS. Here we present three different recipients' perspectives on HMS and describe how their perspectives and experiences influenced their practices.

Case Study #1: Lila, 33 years old, mother of 4 children. Lila was a birth doula, a strong proponent of breastfeeding, and viewed formula as a hazard to be avoided. She breastfed all four of her children and had a history of oversupply and overactive letdown. Over her years of breastfeeding experience, she had learned not to pump because pumping exacerbated her oversupply. She turned to milk sharing for her two youngest children because her oldest child was diagnosed with leukemia and she needed to spend a lot of time with him at the hospital as he underwent intensive treatments. Because she was very stressed during this time and did not have the capacity to add another thing to her plate, she opted not to pump for her daughters. Instead, she turned to her extensive network of friends to seek shared milk. Between her two youngest children, she had received milk from both familiar and unfamiliar donors. She fed S-HM to her younger daughters for their source of nutrition whenever she had to be separated from them. Otherwise, they were both exclusively fed at the breast. She also fed the S-HM to her four-year old son with leukemia to provide him with additional immune support.

It started with my third child. I reached out to people because I was worried about the stress of my, taking care of my son. My body

wouldn't do what it was supposed to. My body did, but there were a lot of situational things that I had to be away that she had milk, and then I was giving it to my son who had just been diagnosed as well. I wanted him to have milk from various moms for different antibodies. Immune support, skin support on sores, and stuff like that.

Interestingly, Lila was the only participant in this sample whose child was also cross-nursed by another woman. Lila didn't view cross-nursing as being substantially different from milk sharing. From her perspective, it was as simple as feeding a hungry baby, in whatever way you could at the time.

And then she [her 3rd child] wet nursed a couple of times too. I would drop her with a friend. And he was also breastfeeding. And there was even one time where she was with that friend and wouldn't take it. But then her other friend walked in and offered, and she took to my other friend...this is my like group of like doula birth worker type people. So they didn't even think twice to offer when they saw she was crying and I wasn't [available].

Lila viewed providing HM as a key responsibility in her role as a mother and was willing to make sacrifices to do so. Lila cut dairy and soy out of her diet because blood and mucus would appear in Alice's stool whenever she ate dairy.

When Alice was having the issues with milk [protein intolerance], he [her husband] said let's just give her some formula. She's clearly in pain. I was like, no, I'll change my diet. That's my job. Like I'm her mom. I will take care of it.

Throughout our conversation, Lila frequently cited scientific studies in her justification of both breastfeeding and milk sharing. She was clearly well educated on all the benefits of breastfeeding, as well as the risks of formula feeding. She was resolute in her refusal to feed infant formula to her children.

He [her husband] offered to go get some [formula] when she was in pain. I was like, nope. Or if like we have a date night out, which is

rare, I won't do it unless I find donor milk. He's like, let's just, and I'm like no, even one throws off their biome. Nope. Won't do it.

From Lila's perspective, given how well-established the science is on the benefits of breastfeeding, she viewed milk sharing as the obvious second choice when mother's own milk wasn't available. She found it both puzzling and infuriating that the western healthcare system was so opposed to milk sharing, when those are the same people who push mothers to breastfeed and regularly espouse the benefits of HM. She also expressed mistrust of medical providers and their motivations.

I mean, it's infuriating to me, honestly... I mean mainstream science supports breast milk. I mean, they've broken it down and evaluated every aspect of human milk. So you can't deny that. And even though the science backs it, I really don't find that obstetricians and pediatricians truly feel that breast is best...Because if they did, they would be encouraging moms to find human milk. But they don't. It's "here is a can." And obstetricians selling their information. Because how does that milk [infant formula] show up in my mailbox? I'm sorry, who gave that information? I mean, money talks, and the pediatricians definitely get a kickback. And so do obstetricians.

Lila's milk-sharing practice was based on a foundation of trusting other mothers. She contrasted her perspective of trust and maternal intuition to that of the biomedical perspective, which she portrayed as inherently risk averse and suspicious.

I would say with mainstream medicine folks, it's kind of like wait - how do you trust that? Why, it's not pasteurized? And the whole, how can that be safe if it's not, you know, how do you know it's sanitary? And again, it's just the pure trust of a mom to mom. Like, we're all down in these moms trenches together. There's no conniving like sneaky let me put some shadiness in this breast milk going on. Like there's not. But I feel like in the mainstream medicine providers, they are so hesitant to ever, I mean they never recommend it. They go straight for the milk bank. But who can, no one can afford that. I mean, it's exorbitant.

Because Lila felt so strongly about the superiority of human milk over infant formula, she was strongly motivated to feed human milk to her children and avoid infant formula, and her HMS practices reflected this preference. She didn't do much screening of her donors, she received S-HM from both familiar and unfamiliar donors, and she seemed to be equally comfortable with both types of donors. She viewed mothers who donate their surplus milk as a trusted source because they shared a mother-to-mother connection, they were also feeding this milk to their own children, and she didn't believe that any mother would have malice toward another mother's child. She also described herself as an intuitive person who relied on her instincts to make parental decisions.

It's just such a natural, genuine thing to me that just seems like easy peasy, you know? I'm also a pretty intuitive person and if I ever felt weird about a situation, I would never have gone through it. But I have yet to ever encounter someone who is being weird about it.

Lila's strong convictions about the value of human milk combined with her experience as a breastfeeding mother and her training as a birth doula provided Lila with a strong foundation for resisting social pressures to feed infant formula to her children when she encountered challenges. One example of such resistance is her experience in the hospital immediately postpartum with her youngest child, Alice.

Lila: *She was induced at 36 weeks and had issues with her sugars. And the hospital kept pushing formula, saying that I had to use formula to raise her sugars, and I said no. I'll bring another mom in here to nurse her before my milk fully comes in, and all of a sudden, they had donor milk at the hospital. So I used an SNS system to feed her extra. Well, she was on me and her sugars regulated fine.*

J: *So they didn't originally offer you donor milk as an option?*

Lila: *They did not. I was going to bring my own milk in, and they said, oh we can't allow that. So here's some other human milk from the NICU because she wasn't in the NICU...they were threatening to send her there if I didn't do formula type deal. But then, the*

donor milk appeared...You know, they literally made it seem that I would like get in trouble if I didn't give it [formula]. And like, yeah, it was pretty intense.

J: *So they were kind of trying to intimidate you?*

Lila: *[Nodding yes] That you have to give formula. And then I had my own, I knew about a different formula, if they were going to push me, for just that. And they said, oh no it has to be, we can't let you bring in stuff. I said, well I'm not giving her other stuff, so we're at an impasse here. And then all of a sudden, the donor milk appeared. Oh, like we DO have this. We don't typically do this. So it was not the first option. Similac was the first...*

This example clearly illustrates how resolute Lila was in her intention to exclusively feed her infant human milk, even in the face of strong pressure from the medical establishment to formula feed. Ultimately, Lila had only taken S-HM from one donor for her youngest child (who was four months old at the time of the interview) but intended to continue to milk share for as long as needed to supplement her youngest child with S-HM when they had to be separated.

Case Study #2: Samantha (#213), 35 yrs old, mother of 1 child, Sutton.

Samantha was a first-time mom who had a hospital vaginal birth with her son, Sutton. She intended to breastfeed and had taken a childbirth class that included some breastfeeding education. Samantha felt that breastfeeding was the best for infants and she wanted to avoid formula feeding if possible. In the hospital, she experienced delayed milk arrival (day 5 postpartum), during which time her son lost 13% of his body weight. She described having difficulty gaining access to helpful lactation support despite having numerous challenges with latch (she was later told that she had flat nipples, making it difficult for her son to latch). Because of the substantial weight loss experienced by her infant, the hospital “forced” her to

supplement with infant formula before they would discharge her. Her son continued to have insufficient weight gain for much of his first year of life, along with reflux and an overall reluctance to eat. Samantha struggled with low milk supply and was desperate to have a successful breastfeeding relationship. She described engaging in a series of efforts that can best be described as intensive and dedicated. She used nipple shields and a supplemental nursing system (SNS), did syringe feeding, took domperidone for 9 months to help increase her supply, and endured a rigorous and exhausting triple-feeding schedule⁷ for weeks at a time. Samantha was not happy about it, but she did supplement her son with formula in the first few months of life because he wasn't gaining sufficient weight.

Samantha's risk perspective at the time she participated in the study was that human milk is best for human babies, and if the mother can't produce enough, then donor milk was better than infant formula. She had concerns about infant formula not being natural and she strongly believed in the health benefits of human milk. However, Samantha wasn't always so comfortable with the idea of donor milk. She described an evolution in her perspective over time. When she was pregnant and had not yet begun breastfeeding, she described seeing messages about milk sharing and finding the idea repulsive. But over time, as she grew more comfortable with breastfeeding and then found herself in a situation of having inadequate supply and feeling desperate to feed her child, her perspective shifted to one of acceptance. Several times during the interview, she reinforced this notion that feeling desperate to feed your child is a very real stressor that changes your view of what is acceptable.

⁷Usually, a triple-feeding schedule consists of feeding at the breast, followed by pumping, and then feeding the pumped milk by syringe, bottle, or a supplemental nursing system (SNS). It is a rigorous, time-consuming, and exhausting schedule to maintain for any period of time.

I'll tell you that when people would offer up milk on the listserv I was grossed out by it. I thought it was gross. Why would you feed... it was one thing if you had some of the challenges you presented, which was, maybe they adopted and so they weren't producing milk. But the thought of giving another woman's milk to my child is like (makes a vomiting noise).. And then fast forward a couple months later and I'm presented with this problem that I'm not producing enough and my lactation consultant said, well you know so-and-so [someone in her breastfeeding support group] - she had your problem, she was successful in recovering her milk, she has a lot of excess. Ask her if she has some that you can have... At that point I was desperate..I was so defeated at that point, that, that I had been (getting choked up) essentially starving my son for a while at that point...(begins crying).

Samantha described being comfortable with receiving S-HM from mothers who were familiar to her because she felt like she could trust them. Her trust was primarily based on two factors; the donor mothers were also nursing their own children, and they were very upfront in disclosing details about their diet, medication use, and lifestyle that could affect their milk composition. She also mentioned that these were affluent, educated, breastfeeding women who were very unlikely to be abusing drugs or doing anything to jeopardize their own children's health.

I mean they're actively nursing women. They wouldn't be doing something that would harm their own child. So our child should be fine, you know. If they're a heroin user then they wouldn't be nursing their child... And all the donors I encountered would say, this is my diet. This is my prescription use or over-the-counter drug use of any... This is, you know, they would, they would share... And his dominant donor, who was just a woman who was in my group who had an oversupply and had to pump all the time - she'd text and say I had to take two Tylenol today. Do you want me to make sure he doesn't get that milk for a few days? No. That's fine. And I mean the reality is, again, I knew these women. We're in a middle class to upper class area of educated women. So my hope was that I wasn't encountering someone who was doing street drugs or sneakily wanting to hide their prescription medication.

In contrast, Samantha viewed sharing milk with a stranger, or someone who is “unfamiliar” to her, as being riskier than sharing with “familiar” donors. She decided for herself that she wouldn’t be comfortable receiving milk from a stranger she connected with through the milk-sharing websites. She chose to only receive milk from women she met through her real-life friends and social network, which felt much safer to her.

So I looked on the sites in the beginning. I knew it was there if... But for me, the not knowing the person was key. Because I also realized... at least with these women [her donors] I felt like I knew the lifestyle they were living. And they could have been lying to me, and I could have perceived incorrectly. But someone on Facebook who I don't know...Because I even read about one woman, she came into D.C. for a conference at the convention center. She pumped while she was here to get her milk removal in but she did not want to return home with it. Would anyone be willing to receive? So then I'm receiving milk from a woman who doesn't live in the area... and then she flies off into the night. And what if her milk was contaminated? What if I could never find her again? What if she did pass a bodily...you know, some sort of a transmittable disease over? That for me was the risk above what I was willing to take. I think if I got to that level, that's when I would have broken down and used formula.

Samantha also discussed her perspective on screening donors by comparing their practices to her own. She indicated that she wouldn’t hold her donors to a standard higher than she held herself to – meaning, that if she wasn’t always rigorous about cleaning her breast pump or was taking over-the-counter medications, then she wouldn’t screen her donors on those factors.

I mean I don't have a dirty house or a dirty environment but I'm by no means Mrs. Clean...I was taking over-the-counter medication to try and cope with my headaches. So Sutton was already receiving medicine from me. So far be it from me to say don't have Tylenol in your milk because I was doing that myself...

Ultimately, Samantha received milk from approximately 8 different donors over 10 months of milk sharing. She produced about half of Sutton's milk requirements and the rest came from donors. She said that milk sharing allowed her to avoid feeding infant formula and helped her son's growth improve, although he has always been on the smaller side. Samantha had a very positive experience with HMS and said she had recommended it to a friend who encountered unexpected breastfeeding challenges.

Case Study #3: Melinda (#139), 42 years old, mother of 1 child, Elise.

Melinda intended to breastfeed baby Elise, and strongly believed in the benefits of human milk for babies. Her mother was a big breastfeeding advocate and was active in La Leche League for years, and Melinda had always planned to breastfeed her children. After Elise was born, she became dehydrated and started losing weight. Melinda saw a lactation consultant who told her she had insufficient glandular tissue and would likely continue to have an inadequate milk supply. After about 5 days of trying to increase her milk supply and baby Elise still being hungry and dehydrated, the lactation consultant decided that it was time to supplement, so they began by feeding infant formula and discovered that Elise didn't respond well to it.

We tried formula. And I think we had 2 or 3 different kinds of formula...and it was just clear that she was uncomfortable with it, just like stomach pain-wise. And some of the formulas that we fed her, she seemed to react to, even just like physical, like rashes on her face. There was one formula that I was feeding her that when she would drink it, her eyes would swell like she had been in a fight, like she had swollen little eyelids. And I was like, that's not the formula! And then I fed it to her again, and it would crop right back up. So I was like, OK, that's obviously the formula! She was having some allergic reaction...she went from being this amazingly docile calm baby... But on the formula, she was becoming this baby that

*cried all the time. And it was just sad. That was the hardest thing to see, was her personality changing. Because she was in pain. **And, you know, she was better hungry than she was fed formula.***

After several weeks postpartum, Melinda said it became clear that she was going to need to supplement Elise on a long-term basis. Her lactation consultant asked if they wanted to supplement with formula or donor milk. Melinda described that initial decision as being a difficult one for her and her husband to make, in particular because they had been feeding Elise infant formula and she was having negative reactions to it.

Basically, my husband and I...um....we knew what the options were and we didn't know what the best choice was. And I wouldn't call myself religious, but the two of us, we prayed for, kind of, wisdom on what to do, on what was best for her. We were trying to make the formula work, and it was really discouraging to see what she was going through, just health-wise because of it....So basically we were in a position where like, I had my breast milk, we had donor milk in the freezer, but it was dwindling. It was becoming clear that formula might be our only choice. And then we're finding out that she just responded terribly to it.

Melinda and her husband carefully weighed the decision about how they were going to supplement Elise. This was not a decision they made lightly. They considered a wide variety of potential risks of both formula and S-HM, demonstrating their thoughtfulness in making this difficult decision. Melinda expressed numerous concerns about the safety of milk sharing and how to find donors they could trust.

I think that the highest concern was, I need to feed my baby. I mean, that was the overarching concern. But before we knew there was a formula problem, we were deciding between formula and donor milk, um, we were scared. We were scared that like, you know, that HIV could be transmissible in milk, that, um... I knew, like I'm pretty sure that hepatitis could be transferred, you know. I was concerned about, you know, hygiene, like how good was a mom with cleaning her supplies and like, microbial infection. And

concerned about, like, what drugs does a person take? Particularly because I've worked so hard during pregnancy to avoid things that contain BPA. It's like, does this mom do that? And then in addition to that, I really went through a tremendous amount of expense cleaning our house of things that had flame retardant chemicals in it. And so now, I just have to accept that a lot of other people haven't done that. And it's in the breast milk. And it is gonna be in the milk that she drinks, and it's part of the package. I mean, like, that was ALL there. That was all part of it...that made it a really hard decision.

Melinda did not consider herself to be “anti-formula,” but she did have a number of concerns about the quality of infant formula and its effects on infant health.

*So many formulas are comprised of corn syrup - I don't feel like that's something that humans really react well to, and I was concerned about the amount of, um, you know, processed sugar that's in formula. And I was concerned about the particular types of vitamins that they fortify formula with. Especially like, you know, they put folic acid in it, and I'm of the mind that folate should be taken rather than folic acid, um, just for the health concerns. And I was concerned about, you know, there's so much use of hydrogenated oils and I just think that they are incredibly harmful to health. Um, and I am concerned about, just contamination as far as pesticides with soybeans, and there's tons of soy in formulas. **So I was concerned about just health, and growing a human on stuff that I myself wouldn't consume.***

Ultimately, Melinda and her husband decided they really wanted to minimize the amount of formula Elise consumed because of the negative effects that formula was having on her. Thus, they proceeded to pursue milk sharing and feed a mix of mother's own milk, S-HM, and infant formula. It took some experimenting to find a combination and feeding schedule that worked well for them.

We actually stayed...I found that if she had under a certain threshold of formula, like if she only had 1 or 2 servings of formula a day, and she had some of my breast milk, and some donor milk, like if we did a mix, we could keep her out of the pain zone.

Melinda went to extraordinary lengths to source donor milk for her daughter. Over the six months that she had been milk sharing, she had received milk from approximately 25 donors, many of whom were unfamiliar to her. She used various avenues to find donors, including DC-area milk-sharing websites, breastfeeding support groups, and her lactation consultant's network. She described driving 2 and a half hours for 50 ounces of S-HM, which was only enough to feed her daughter for about a day and a half at that time. The process of finding donors, screening them, picking up the milk, and managing the donor milk supply was time-consuming. She found the constant risk analysis to be particularly challenging and exhausting, always being in a position where she had to decide if a donor was "safe." When asked if she would have milk-shared if her daughter had not reacted negatively to infant formula, she replied:

No, because there were huge hurdles in order to get the donor milk. Like, to collect it, and to network and identify who had it, and um, to worry about, like, you know, I haven't met this mom, you know. What do I do? How do I trust that she doesn't have a communicable disease? And that forced us into the Holder pasteurization, which is hard.

Among this sample of HMS recipients, Melinda was the only parent who regularly pasteurized the S-HM. They decided to pasteurize the milk once they realized that milk sharing was going to be a long-term infant feeding strategy for them. She described how they came to the decision to begin home pasteurizing the S-HM and how they operationalized that process at home.

It became clear that we wouldn't be able to use formula, and that we were going to have to rely on donor milk longer term. And then it was like, ok well we've got this established, we've now picked up the milk, we've fed it to her. We've got that, you know, we understand the process, and now we kind of have a responsibility

to, you know, make it as safe as we can. So we looked up the Holder pasteurization and we tried it on the stove and it was...um...you know you need to keep it at 145 degrees, and our stove would only go as low as 167. So it was moving it back and forth to keep it at the right temperature. My husband did it with my brother. I think I was swimming with the baby at that point, but apparently it was a half hour of cursing (laughing). He was like, this is impossible, grumble grumble. Then he was on the phone with one of his brothers complaining about how hard the pasteurization was. And his brother was like...I wonder if you could use a sous vide? And we're like, what's a sous vide...you know? So he described it to us and why it would work. And we ordered one that week and we got it, and we never had to try the stove pasteurization again. And so every day at our house, we'd do a round of sous vide (laughing)...145 degrees for 30 minutes, and you're good.

At the time of the interview, baby Elise had not experienced any negative reactions to the S-HM, was growing well and thriving. Melinda and her husband intended to continue milk sharing at least until Elise reached her first birthday.

Discussion

These case studies on parental decision-making revealed the different ways in which women conceptualized and managed risk related to HMS. All three of these recipients engaged in thoughtful analysis of the risk involved in feeding both formula and S-HM, but came to different conclusions, underscoring the individualized nature of infant feeding decisions. The degree to which each recipient viewed formula as a hazard to be avoided was an important factor in their risk-benefit analysis. Lila (CS1) felt strongly that even one serving of infant formula was enough to disturb the gut microbiome of a child, so she wouldn't allow HCP or her husband to feed their children any formula. The degree of trust placed in other mothers also emerged as an important factor in determining infant feeding practices. Lila (CS1) felt

like she inherently trusted other mothers and so she didn't feel the need to do much screening of donors. Samantha (CS2) was somewhat trusting of other mothers, but still felt that it was important to know her donors and wasn't comfortable with receiving milk from a stranger who she met online. These recipients are in contrast with Melinda (CS3), who didn't have an inherent trust of other moms, which was reflected in her practice of carefully screening potential donors and home-pasteurizing the S-HM before feeding it to her daughter.

APPENDIX E

RDS ABSTRACT AND POSTER PRESENTED AT ISRHML VIRTUAL RESEARCH CONFERENCE 2020

Title: Network Structure of Milk Sharing Parents: Novel Findings and Methodological Implications

Presenting Author: Jennifer A. Peregoy, Division of Nutritional Sciences, Cornell University

Co-Authors: Kathleen M. Rasmussen

Background: Peer-to-peer human milk sharing (HMS) is a difficult phenomenon to study because HMS families constitute a “hidden population,” meaning that they engage in a behavior that is stigmatized, are unlikely to disclose their status as a member of that population, and no sampling frame exists to reach them.

Objective: We conducted a proof-of-concept pilot study to test the usability of respondent-driven-sampling (RDS), a technique for sampling hidden populations, as a method to reach milk-sharing parents.

Methods: Email-based RDS was used to sample parents from the network of HMS families in the Washington, DC area. Participants were asked to complete a detailed online survey about their milk sharing experience, infant feeding attitudes and beliefs, and social network characteristics. After completing the survey, participants were asked to refer other HMS parents to the study.

Results: A total of 67 HMS parents (58% donors) participated in the study: 26 purposively selected “seeds” and 41 recruited through RDS peer referral. Both recipients and donors reported small mean network sizes (3.1 and 3.6, respectively). The peer-referral chains were short and died off before the target sample size could be reached.

Conclusions: Although the RDS sampling methodology was unsuccessful in this population, it revealed novel findings about the structure of the HMS network. Respondents reported a small mean network size, below the threshold recommended for RDS studies. The milk-sharing relationships in this sample were predominantly weak social ties, which has important implications for peer referral. The HMS network structure and density may not be adequate to support a peer-referral methodology.

Funding Source: NIH Training Grant (T32 HD087137)

WORD COUNT: 250 words (limit 250)

Network Structure of Milk Sharing Parents: Novel Findings and Methodological Implications

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INTRODUCTION

Peer-to-peer human milk sharing (HMS) is a difficult phenomenon to study because HMS families constitute a "hidden population," meaning that they engage in a behavior that is stigmatized, are unlikely to disclose their status as a member of that population, and no sampling frame exists to reach them.

OBJECTIVE

We conducted a proof-of-concept pilot study to test the usability of respondent-driven-sampling (RDS), a peer-referral technique for sampling hidden populations, as a novel method to reach milk-sharing parents.

METHODS

Email-based RDS was used to sample parents from the network of HMS families in the Washington, DC area. Initial "seed" participants were purposively recruited via DC-area milk sharing Facebook groups, birth-worker client referrals, and through DC area parenting listservs.

What is RDS?

- A specialized form of chain referral sampling method used to reach hidden populations
- A network-based approach
- Both a sampling and analytic method
- Provides representative estimates and confidence intervals for the network from which the sample is drawn

Participants were asked to complete a detailed online survey about their milk sharing experience, infant feeding attitudes and beliefs, and social network characteristics. After completing the survey, participants were asked to refer other HMS parents to the study.

RDS Parameters:

- Initial number of seeds: 10-14
- Primary incentive: \$12
- Secondary incentive: \$10 per successful recruit
- Coupons distributed: 3-6
- **Total incentive range: \$12-72 per participant**

RESULTS

A total of 67 HMS parents participated in the study: 26 purposively selected "seeds" and 41 recruited through RDS peer referral. Of those 26 seeds, 15 recruited 0 participants.

Peer Recruitment Tree

N = 67
28 recipients, 39 donors

Dots represent participants, lines represent recruitment relationships

Features:

- Short, stubby trees, barely any branching
- Few recruitment waves
- Many non-productive seeds

The peer-referral chains were short and died off before the target sample size of 175 could be reached.

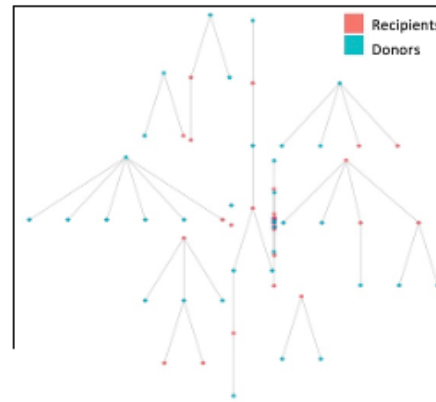


Fig. 1. Peer Recruitment Tree

Recruitment Homophily

A measure of how likely participants are to recruit other participants who are similar to them. The indicator (h) is interpreted similar to an odds ratio, with 1 being neutral.

- Donor/recipient status: $h = 0.604$
- Educational status: $h = 1.372$
- Income level: $h = 1.087$

Network Size

Both recipients and donors reported small mean network sizes (3.1 and 3.6, respectively). The minimum mean network size recommended for RDS studies is 5.

Network Size Metric	Recipients N = 27	Donors N = 39
Number of HMS recipients known	1.2	2.8
Number of HMS recipients interacted with in the last 6 months	1.1	1.9
Number of HMS donors known	3.0	2.2
Number of HMS donors interacted with in the last 6 months	2.0	1.7
Total number of other HMS parents known	4.2	5.0
Total number of other HMS parents interacted with in the last 6 months	3.1	3.6

Table 1. Mean network size characteristics of the sample

RESULTS

Reasons cited by participants for not recruiting peers to the study

In response to probing about challenges or difficulty with the peer referral process, respondents cited a number of factors that impeded their ability to recruit peers to the study. A variety of themes emerged:

Peers didn't meet the inclusion criteria:

"My personal donors don't qualify due to location."



"Two of the women weren't eligible because it had been 2 years since they donated."

Stress and anxiety:



"I have a newborn and am dealing with some PPD/PPA and just don't want any more things to deal with."

Weak social ties:

"The person I donated to also posted to this group in search of milk, and I had never met her before either; we just arranged a pick up time."

"I don't have the email information for the people I donated to."



"I do not know the recipient of my milk donation, a friend of hers collected the milk for her."

CONCLUSIONS

Although the RDS sampling methodology was unsuccessful in this population, it revealed novel findings about the structure of the HMS network. Respondents reported a small mean network size, below the threshold recommended for RDS studies.

The milk-sharing relationships in this sample were predominantly weak social ties, which has important implications for peer referral. The HMS network structure and density may not be adequate to support a peer-referral methodology.

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