Risk Abatement Practices of Recipient Participants in Private Arrangement Milk Sharing in the United States

by

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ABSTRACT

Exclusivity and duration of breastfeeding and the provision of human milk in the United States is suboptimal. In the absence of adequate banked donor human milk for distribution to all infants in need, many families choose to engage in the practice of Private Arrangement Milk Sharing (PAMS), partially facilitated through social media, to procure human milk for their infants. Evidence regarding the participant and infant characteristics and risk abatement practices is incomplete. This dissertation describes and explores the characteristics of recipient participants and infants, family constellation, donor screening practices, and related risk abatement strategies. Data was collected via on-line survey as a sub-group of a larger data set including donor participants and international participants. Binary logistic regression modeling of factors that contribute to consistent screening and risk abatement practices and important antecedents to engaging in PAMS was conducted. Results are contextualized within a tailored socioecological framework of factors affecting infant feeding practices. Tailoring was accomplished via qualitative descriptive analysis of participant responses applied to an existing breastfeeding framework. Participants in this sample were predominantly white, married, with a mean age of 32.9 years, with at least some college education and above median income. Risk abatement and screening practices were influenced by support of a healthcare provider during decision-making, college education, infant age and health status, having lactation support, birth type and birth attendant, and the duration and sources sought for learning about milk sharing.

DEDICATION

This dissertation is dedicated to the vulnerability, honesty, integrity, courage, and perseverance of the families who have trusted me with their stories. It is my hope that I have done justice to the complexity and nuance of their experiences.

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CHAPTER 1

INTRODUCTION

Introduction

Human infants are born with the developmental expectation of nutritional sustenance and continued growth and maturation of the gut via of human milk. Per the World Health Organization/UNICEF guidelines for infant and young child feeding, in the rare circumstances where the birth parent cannot or should not nurse the infant, the use of expressed milk from the parent, use of donor milk from a healthy wet nurse or milk bank are biologically congruent and developmentally supportive and preferable to the use of artificial infant milk (formula). Sharing human milk among family members and between families in immediate communities is a timeless practice with many cultural and historical social variations of formality. In the United States (US) there has been an increased governmental investment in Breastfeeding (BF) as a public health metric and life-course health consideration, and more families are aware of the well-established evidence regarding the health and mortality risks associated with formula feeding. The expansion in public policy and awareness has not resulted in meaningful increase in infrastructure, legislation, or program funding to reduce cultural and practical dependence on formula.

Widely recognized authorities on infant feeding, such as the American Academy of Pediatrics (AAP), and US Food and Drug Administration (FDA), and the American Academy of Nursing (AAN) acknowledge and endorse the use of banked donor milk (BDM) from human milk banks. The AAP and FDA advise against the use of milk from

a wet-nurse or private donor, citing hygiene and communicable disease risk. No evidence has been cited to support these advisories, and the statements have not been revised or revisited since 2010. The advisories also fail to acknowledge the shortage of human milk available to even the sickest infants from the Human Milk Banking Association of North America (HMBANA), the only endorsed milk banks in the US. By contrast, the AAN released a policy statement in 2016 acknowledging the need for professional support of the informed decision to use human milk outside the HMBANA system, and provide an analysis of the then-current state of knowledge regarding the associated practices for nurses to facilitate discussion (AAN, 2016).

In 2015, there were 16 active milk banks, serving 40 states, and 423 cities in the US. Access to HMBANA donor milk requires physician prescription, and all requests are subject to a distribution hierarchy. This hierarchy prioritizes hospitalized premature infants, and proceeds in descending order of consideration: healthy hospitalized preterm infants, hospitalized full-term infants, hospitalized older infants, home-dwelling infants with chronic conditions likely to respond to BDM, hospitalized older children with conditions likely to respond to BDM, adults with conditions known to respond to BDM, healthy home-dwelling infants who have been adopted or who have medical documentation of inability to receive milk from a parent, and all other requests (Sakamoto, 2010). It is rare for BDM to be available for infants not hospitalized (HMBANA, 2014). The cost of milk varies depending on shipping distance, and shipped quantity. Smaller hospitals, hospitals not in reasonable proximity to a milk bank, and individuals incur the greatest cost, with a cost ranging from $3.50-$9.00 per ounce, which

may or may not be covered by insurance (HMBANA, 2014). Because access to BDM is cost-prohibitive, many families of infants who qualify for access are unable to purchase it. It is also important to note that only infants with *conditions likely to respond* are eligible for HMBANA milk. As such, terminally ill children and infants not already receiving BDM may not qualify.

There are many reasons for shortages and costs associated with BDM. Operating costs for milk banks are high, supply is uncertain and highly variable, and there is a general shortage of eligible donors due to exclusion criteria and relatively low rates of BF in general. Donor exclusion criteria, supported by varying degrees of evidence, include but are not limited to: volume of milk insufficient to recover its own post-processing cost, use of any medication, use of megavitamins, lifestyle factors such as smoking and use of alcohol, having lived in Europe or the United Kingdom for longer than 3 months during the Bovine Spongiform Encephalopathy ("Mad Cow") crisis, and most recently travel to areas of Central and South America affected by the Zika virus. These restrictions leave otherwise healthy and socially acceptable donors with no institutionally recognized option for donation. Donor milk from milk banks where donors are anonymous and milk from several donors is pooled may be unacceptable based on the recipient family needs. Instances where milk donors and their children become religious kin, recipient infant dietary needs restrictions based on allergies or religious observance of vegetarianism are examples of pooled anonymous milk being incongruent and potentially unacceptable with respect to meeting cultural needs of the family.

The overwhelming majority of families raising infants not being breastfed face a significant geographic, economic, situational, or religious/philosophical barriers to accessing BDM. In the absence of available BDM, families face infant feeding choices consisting of feeding commercial or home-made formula, feeding raw animal or plant milks, seeking wet-nurses or purchasing human milk, or seeking milk through private arrangement. The current predominant mode of milk sharing, private arrangement milk sharing (PAMS), facilitated through social media, has grown exponentially since its inception with over 130,000 participants on the global networks (Perrin, 2014). PAMS is a grass-root, community-based social intervention created to address the shortage of accessible BDM.

PAMS, as most commonly discussed in the literature and pop media, originated with the organization Eats On Feets in 2010. The philosophy of PAMS advocated by this organization centers on the Four Pillars of Safe Breast Milk Sharing – Informed Choice, Donor Screening, Safe Handling, and Home Pasteurization (Walker & Armstrong, 2012). All other major PAMS networks have adopted some variation of these basic principles. Families seeking to donate or receive human milk through milk-sharing organizations negotiate all aspects of screening related to donors, recipients, milk handling, transportation, and reciprocation of storage devices. PAMS is a distinct practice from selling human milk via personal advertisement on the internet. PAMS includes directed donation within hospital settings, community based peer-to-peer sharing, and other informal arrangements provided that there is no exchange of goods, services, or currency for the milk.

Problem Statement

Inadequate support to families who are facing insufficient supply of or inadequate access to human milk results in cohorts of infants experiencing increased risk of serious adverse health events and chronic illnesses directly attributable to lack of human milk including otitis media, non-specific gastroenteritis, severe lower respiratory tract infections, atopic dermatitis, childhood onset asthma, obesity, type 1 and 2 diabetes, childhood leukemia, necrotizing enterocolitis, and sudden infant death (Ip et al., 2007). In 2012, 3.2 million infants born in the United States became a cohort at risk for significant health challenges, including preventable death, due to absence of exclusive breastfeeding (BF) for the first six months of life (Bartick & Reinhold, 2010, Centers for Disease Control and Prevention (CDC), 2014, 2016; Ip et al., 2007).

Current BF data indicate that while 79.2% of the 3.9 million births in the US per year include BF initiation, only 18.8% continue to exclusive BF at 6 months postpartum (CDC, 2014). Direct annual economic cost from lost parental productivity, preventable disease treatment, increased incidence of disease, and preventable deaths is estimated to be as high as $13.5 billion (US) per year due to absence of human milk for infants. This cost would be eliminated if 90% of births reached Healthy People 2020 goals for BF (Bartick & Reinhold, 2010; Department of Health and Human Services (DHHS), 2012).

In a culture where most health providers do not have the personal experience of lactation (Duke, Parsons, Snow, & Edwards, 2007), or dedicated training for lactation support (Steube, 2014), and commercial interests of formula manufacturers are valued above ethical marketing of human milk supplements (Walker, 2007), support for

providing privately obtained human milk is exceptionally difficult to garner. Some Internationally Board Certified Lactation Consultants (IBCLC), the only accredited dedicated lactation support professionals, have publically stated that professional code of conduct prohibits them from discussing PAMS, an assertion countered by then President of the International Lactation Consultant Association, Elizabeth Brooks (2014). Limited public policy has addressed concerns of PAMS, without consideration of evidence, and without update since 2010 (Food and Drug Administration, 2010). The American Academy of Pediatrics (2012) briefly mentions PAMS as an inadvisable practice. These policy statements are important, as families are denied support or consideration by care providers and lactation professionals under the guise of being prohibited from providing objective, evidence based care. Policy statement from the American Academy of Nursing Expert Panel on Breastfeeding published in 2016 marked an important step in acknowledging and counseling best practices that may reduce risks in PAMS (AAN, 2016).

Other factors contributing to early sharp declines in BF and limited provision of human milk include policies that minimize the value of paid parental postpartum leave in establishing healthy parenting and feeding patterns, institutional and systems barriers to accessing lactation support and limited resources for obtaining supplemental human milk (Surgeon General, 2011). Because many families are reported to place a high philosophical and practical premium on the ability to nourish infants with human milk (Gribble, 2012, 2013a,b), the absence of concerted advisories, professional health and lactation care provider, and public health policies and infrastructure that might enable the

provision of BDM in the absence of milk from a biological parent has led to the formation of a community around PAMS. Data describing the prevalence, frequency, and peculiarities of PAMS arrangements are limited. It is critical to public health and the provision of conscientious and culturally relevant support to determine the specific nature, benefits, and risks using a framework cognizant of individual, group, and social factors impacting PAMS participation. This study describes and explores the factors contributing to suboptimal breastfeeding, which lead to participation in PAMS, and the donor screening and risk abatement practices of US recipients participating in PAMS.

Theoretical Framework

Research of PAMS leveraging a well-defined and culturally specific framework ensures that the body of evidence builds systematically and meaningfully expanding upon previous research. Evidence for provider and lactation professional support must be able to clearly and concisely convey both the individual importance of meeting infant feeding goals in an informed manner, and describing/exploring pertinent public health impacts of increasing the number of infants sustained on human milk. In 2005, Hector and colleagues produced the Conceptual Framework of Factors Affecting BF Practices to examine the Individual, Group, and Society level factors that contribute to BF practices in the community (Figure 1). The Hector et al. framework facilitates research on and evaluation of five specific types of interventions, ranging from individual to environmental impacts: development of individual skills, orientation of health care systems to prioritize the dyad's needs, creating supportive environments, strengthening community action, and developing public health policy.

An essential extension of the Hector et al. framework in the exploration of infant feeding practices associated with PAMS recipient families is the consideration of culture. Here, culture reflects the definition used by the National Institutes of Health (2014). i.e. "the collective elements of personal identification, language, thoughts, communications, actions, customs, beliefs, values, and institutions, that are often specific to ethnic, racial, religious, geographic, or social groups." This extension to the framework applies directly to practices at the individual and group levels, and has the potential to provide additional insights that may guide effective, culturally-sensitive policy making. The use of this type of socio-ecological model is appropriate for a cross sectional exploration of (a) the scope of PAMS in the US, (b) interactions between donors and recipients in PAMS exchanges, and (c) antecedents of insufficient milk from a biological parent based on integrated consideration of factors that are and are not under the control of the affected families at all levels of the framework.

This extended socio-ecological framework is particularly well suited for the examination of individual and group level factors considered in the study reported here, specifically attributes of the recipient infant and family, features of the environment that have facilitated or restricted BF and/or the access of donor human milk, and the degree of involvement in the PAMS community can be considered in context of interrelationship within the SEM. This PAMS specific model of the associations among these factors and levels (Figure 2) is in progress (Bond, unpublished data).

Currently, research findings regarding PAMS focus on the experiences and reasons for participation and social factors influencing accessibility of BDM. Absent

from the body of knowledge are descriptors of the frequency and kinds of screenings used, intensity of participation as a component of infant feeding, antecedent factors of lactation insufficiency, and demographic characteristics regarding the home life, education, economic means, and partner decision makers of participants. These data are critical to inform further research on biological safety of exchanged milk, development of public health policy for education and support, and potential safety interventions. The data reported includes multiple measures of the key areas of absent data in the US and will provide first-of-its-kind analysis of intensity and frequency of screening and safety behaviors associated with PAMS in the United States.

This study describes and explores the problems contributing to suboptimal breastfeeding, and the donor screening and risk abatement practices of families in the US who turn to PAMS by addressing the following research aims and corresponding research questions via the survey responses of participant recipient families:

Aim 1. Describe a cross section of the PAMS recipient population in the US.

> **Research Question 1.** What are the participant-identified personal- and group-level characteristics of PAMS recipients in the US?

Aim 2. Identify the methods, prevalence, and intensity of donor screening, related risk abatement practices, resources sought, and the source of introduction to PAMS of recipient participants.

> **Research Question 2a.** What screening and heat treatment of milk protocols do participants use to maintain quality and safety of donated milk, if any?

Research Question 2b. How intensely do recipient participants screen donor participants for health and lifestyle factors that can affect milk safety?

Research Question 2c. How do recipient participants first learn about PAMS and how much time was spent considering this option?

Research Question 2d. What resources do PAMS recipients consult regarding milk sharing?

Aim 3. Identify antecedents of insufficient milk from the biological parent of the recipient infant.

Research Question 3a. What are the antecedent factors of insufficient milk?

Research Question 3b. What are the philosophical, religious, and human milk value beliefs and corresponding intensity, as reported by PAMS recipients?

Research Question 3c. What infant feeding options were considered prior to participating in PAMS?

Aim 4. Determine the Individual- and Group-level factors that may be predictive of screening and milk handling practices, specifically: infant health, parental characteristics, lactation support access, and human milk bank accessibility.

Research Question 4a. Do participant education, marital status, household income, family size, or ethnicity predict routine screening for HIV, HBV, HCV results, major lifestyle risk factors, or use of heat treatment?

Research Question 4b. Do custodial status, recipient infant age and health status, religious needs, or reported allergies/intolerance predict routine screening for HIV, HBV, HCV results, major lifestyle risk factors, or use of heat treatment?

Research Question 4c. Does the type of prenatal care provider, birth type or place, or the use of lactation support predict consistent screening for HIV, HBV, HCV results, major lifestyle risk factors, or use of heat treatment?

Research Question 4d. Does time spent researching PAMS, resources sought for PAMS participation, beliefs about formula safety, or religious necessity predict consistent screening for HIV, HBV, HCV results, major lifestyle risk factors, or use of heat treatment?

CHAPTER 2

REVIEW OF LITERATURE

Historical and Cultural Context

Humans are unique among mammals with respect to the frequency of births, parenting of multiple offspring concurrently, and historically dependence upon multiple generations of familial support to raise the young of the family unit (Kramer, 2010). This prolonged and intensive parenting creates a progressive developmental tension within the dyad, referred to as "kowakare", with the antagonism of the parent-offspring relationship being necessary to establish the psychological and social "otherness" of the infant without resulting in insufficient care and bonding with the infant (Negayama, 2010). Rearing of young by multiple caregivers, including the nursing of suckling of infants, frequently from women within the same family, is referred to in anthropology as "allomothering" or "alloparenting" in the case of absent gender restriction in infant care practices (Kramer, 2010). In order to minimize the antagonistic effects on both the parent and infant, alloparenting is practiced to provide respite for the parent and culturally normative socialization for the infant such that the end result is a progressive mutual autonomy of the dyad and familial/cultural companionship (Negayama, 2010). Western cultural values have progressively moved away from this model of alloparenting and mutualism of dyad to an individualistic model of care and perception of the dyad as immediately autonomous.

The current social norms regarding infant feeding are in flux in the United States, suggesting a return to practices of alloparenting. A marked increase in support for

physiologically normal infant feeding, that is to say nursing and the provision of human milk, can be noted from the early 1980's with the inclusion of breastfeeding as an objective to increase public health in The Surgeon General's Report on Heatlh Promotion and Disease Prevention (1979), and affirmed with the first Surgeon General's Call to Action to Support BF (2011). New emphasis placed upon BF metrics in the Healthy People 2010 and 2020 goals further the objectives of reaching optimal BF in the US. The shift from human milk to formula as the social norm for infant feeding began in the US in the early 1900's with the first commercially produced and marketed infant formula based on chemical analysis of several species of milk, promoted by pediatricians as "perfect food" for infants (Stevens, Patrick, & Pickler, 2009). By 1940, pediatricians and formula companies collaborated to instruct families on the scientific and proper feeding of infants, and BF declined steadily. In the 1970's, grass-root education campaigns began to slowly increase the initiation and duration of BF (Stevens et al., 2009). In 2014 in the US, 79.2% of births in the US per year include BF initiation; 18.8% continue to exclusive breastfeed at 6 months postpartum, and less than 10% of infants continue to receive breastmilk beyond the first year (CDC, 2014).

Current economic impact of formula marketing and sales is significant at individual and social levels. The default source of infant and young child nutrition in the absence of human milk is commercial formula in the US, thus at least 80% of infants in the US receive formula in their first year of life based on the rates of exclusive and any BF established in the Healthy People 2020 assessments. As a result of nearly half the children born in the US every year receiving nutritional assistance through the Special

Supplemental Nutrition Program for Women, Infants, and Children (WIC) services at the state level, the largest purchaser of infant formula is the WIC program. This estimated annual cost is $6.5 billion, and consumers contribute an additional $3.5 billion in income not including the income from follow-on formulae and maternal and child supplements (Oliveira, 2011). Marketing strategies for formula include use of healthcare providers, hospitals, and retail outlets for advertising, direct to consumer marketing through media and direct mail, and use of social media to elicit positive emotive attachment to brands by exploiting insecurity in lactation resulting from multiple social and individual barriers to meeting infant feeding goals (Kaplan & Graff, 2008) . Marketing and industry sponsored education to physicians and other care providers results in effective influence of prenatal infant feeding decisions toward formula feeding, and erodes the frequency and quality of lactation support provided in the antenatal and postpartum care setting (Brown, Raynor, & Lee, 2008; Kaplan & Graff, 2008).

Lack of paid parental leave postpartum, and limitations of 4-12 weeks of parental leave for most families in the US poses an additional barrier to the establishment and maintenance of lactation and the decision to initiate lactation (Brown, Raynor, & Lee, 2011; Kaplan & Graff, 2008; Mandal, Roe, & Fein, 2014). Social pressures against nursing infants in public, stigma of expressing milk in the work place, and cultural beliefs about the acceptable duration of nursing also provide significant barriers to meeting individual and Healthy People 2020 infant feeding goals. Policy changes to reduce the burden of lactation barriers in the workplace, such as provisions in the Affordable Care Act (ACA), have increased the number of employers providing paid parental leave and

improved access to lactation support and tools. However, limitations in the definitions of services and tools have reduced the practical impact of this legislation, leaving the majority of working parents with unaltered prospects for combining work and lactation. Families who persist in advocating for the use of human milk for their infants are directed by health and professional policy to the HMBANA milk banks (Section on BF, American Academy of Pediatrics, 2012). Infant need requirements, cost, geographic, and supply limitations make BDM through HMBANA banks an untenable solution. Thus, in the absence of effectively executed social policy and employer support for lactation, most families experiencing insufficient milk supply through parental lactation are left to seek alternative means of securing human milk or to turn to formula.

Allocation of human milk directly from donors to recipient families of infants in need has occurred throughout history, in a variety of contexts from altruism to religious rites to forced wet-nursing and the context continues to evolve with social and behavioral norms (Thorley, 2009). The specific form of milk exchange considered in this research is PAMS, defined as the exchange of expressed breast milk, with or without formal or semi-formal arrangement, between the lactating person and another family without exchange of money, barter, or other commerce for the expressed human milk (Bond, 2014). This definition encompasses several descriptions currently found in the literature, such as "peer-to-peer", "informal", and "casual" milk sharing (Akre, Gribble, & Minchin, 2011; Keim et al., 2014a; Keim et al., 2014b; Palmquist & Doehler, 2014; Perrin et al., 2014). Each of these descriptions is accurate for some segment of the milk sharing community,

but each of these descriptions lacks definition and implies social interactions that may or may not be present in the actual exchanges of milk via PAMS.

Potential Public Health Impacts and Risk Abatement

Human milk is adaptive, living, and microbially complex with utility as nutrition, medicine, as a contributor to growth regulation, and immunotherapy in the human infant. Well-established life-course risks for infants not fed human milk underpin public health efforts to reduce health disparities through lactation support and provision of human milk. Infant feeding is not without risk, and any deviation from an infant directly suckling from the birth parent introduces risks not associated with the "closed system" of parent and baby. Bacteria and yeast commonly found on the skin and in the duct system of the areola are found in all human milk, and parental viruses can be shed into milk, creating potential for infection (Fernández et al., 2013). This potential is increased when milk is expressed, as hand, equipment, and storage container become secondary sources of introduction of environmental microbes and other potential contaminants. Any additional handling and transfer of milk introduces additional points of potential risk for contamination.

To date, there is a single documented, published outbreak of illness attributable to a PAMS arrangement. Nakamura and colleagues (2016) describe 6 illnesses of health-fragile infants traced to a single donor within the Fukushima Medical University Hospital neonatal intensive care unit (NICU) in Fukushima, Japan in 2012. A single donor contributing unpasteurized milk to other families with infants admitted in the NICU was shedding extended-spectrum β-lactamase-producing *e. coli* due to subclinical mastitis,

contaminating milk expression equipment not properly sanitized between users that sickened one infant, and directly sickening 5 other infants including the donors from consumption of the bacteria containing milk. Because this practice was directed donation, as described by Martino and Spatz (2014), with the full knowledge and support of the medical team, culturing of the donor, equipment, respiratory fluids, and urine of the affected infants systematically and efficiently isolated the cause of the illness and subsequent discontinuation of use of the donor's milk within the NICU. It is unlikely that a clandestine donor situation, as is happening in many hospitals in the US currently, would have resulted in an immediate ability to isolate all potential sources of infant illness and respond efficiently.

Centralized human milk banks address concerns of microbial load and contamination differently across global banking systems. Not all banking systems pasteurize all milk before distribution, and donor screening protocols vary considerably. It is important to note that there has never been a reported incident of infant morbidity or mortality due to inherent microbial or other properties of the donor milk. From an integrative review of global milk banking methods (Bond, unpublished), consistent practices in donor screening were (1) assessments of lifestyle for high risk behaviors, (2) serological screening for infectious diseases, (3) microbiological analysis, and (4) milk handling education (Almeida & Dorea, 2006; Grovslien & Gronn, 2009; Lindemann et al., 2004; Osbaldiston & Mingle, 2007, Cohen et al., 2009; Landers & Updegrove, 2010; PATH, 2011). Tables 1 and 2 present the serological and bacterial strains screened for by microbiological and serological means in the European, Brazilian, United Kingdom,

South African, and North American milk banking models.

Each milk banking model employs heat treatment to some extent. All models except the PATH model employ Holder pasteurization, and HMBANA is currently validating ultraviolet pasteurization. The PATH model employs flash heating for donors not screened for HIV. This low-resource method of heat treatment is validated to kill HIV and deactivate three strains of pathogenic bacteria (Israel-Ballard et al., 2006). The Danish model uses Holder pasteurization only for donor milk that screens with more than 200,000 colony-forming units of non-specific bacteria, or distributed to infants less than 1500 g at birth (Grovslien & Gronn, 2009).

Wide variation in screening and processing standards presents challenges in discussing the minimum risk abatement strategies acceptable for relative safety of PAMS. At a minimum, based on global milk banking models, donor screening protocols should include questions regarding consumption of alcohol, tobacco, recreational drugs, and prescription medication and serological assays performed privately or through a health system for HIV, Hepatitis B, and Hepatitis C (Bond, unpublished). Donor education should include training on safe and hygienic expression and storage of milk, and the importance of self-disclosure of relevant lifestyle factors. Recipient education should include safe storage and handling of milk, importance of donor screening, and optional use of flash heating or Holder stove-top pasteurization if there is reasonable expectation that the infant will not be sickened by potential activation of spore-forming bacteria during heat treatment.

State of the Science Regarding PAMS Practices and Participants

Original research addressing specifically the practices and participants of PAMS is limited in scope, depth, and methodology. Several publications frequently cited as pertinent to PAMS were carried out with procedures and samples obtained from the completely anonymous, unstructured, and *privately purchased* human milk market where the milk may or may not have been of human origin (Geraghty, Heirer, & Rasmussen, 2011; Keim et al., 2014a, Keim et al., 2014b, Keim et al., 2015). PAMS networks, however, specifically *forbid the sale of human milk*, and require direct contact between donor and recipient for the exchange of milk in quantities necessary to meet the needs of infants, and uniformly advocate screening of potential donors. Research that is pertinent to and centered within the community of PAMS participation currently focusses on the beliefs, practices, demographics, involvement of health professionals and other support services, barriers and limitations of recipients and donors in accessing milk banks, and observation of social media exchanges.

Participant Characteristics. An important limitation to the current body of knowledge not specifically addressed with the current study is the over-representation of participants from the US. Both donor and recipient participants self-report above average income, rate of employment, and median income as compared to national averages, are predominantly non-Hispanic white, married or cohabitating with a partner, aged 30-35, with 2-3 living children (Gribble, 2013; Gribble, 2014a, b; Palmquist & Doehler, 2014). Donors and recipients self-identify as biological women as well as gender and sexual minorities sometimes using induced partner lactation, so it is indeed possible that

biological males are contributing human milk within the PAMS community (Palquist & Doehler, 2014). The majority of children receiving PAMS procured milk are the reported biological children of the recipient participants (Gribble, 2013; Palmquist & Doehler, 2014).

Support Seeking. Recipients frequently report seeking lactation support from multiple professional, community, familial, social, and medical sources familiar with (or presumed to be familiar with) lactation. In spite of these efforts, many participants still experience insufficient milk supply to exclusively meet the needs of their infant(s); which, at least in part, drives participation in PAMS (Gribble, 2014b, Palmquist & Doehler, 2014). Care providers and health and lactation professionals sought by PAMS participants include nurses, midwives, physicians, IBCLCs, and other professional and paraprofessional providers (Gribble, 2013; Gribble, 2014 a,b). Donors are more likely to have sought care from specialized lactation professionals and licensed care providers and to be equally or more satisfied with this support (Gribble, 2013; Palmquist & Doehler, 2014). Recipients are more likely to seek a variety of support, possibly indicating inability to find solutions, and report equal or less satisfaction with the support received (Gribble, 2014b; Palmquist & Doehler, 2014).

Safety and Risk Abatement Practices. Currently, there is no published research describing the specific methods of donor screening, milk handling, and heat treatment used by PAMS participants. This is a critical gap in knowledge that must be addressed before developing counseling strategies, health policies, and professional guidance for risk abatement. Examination of individual practices must be considered in the context of

the cultural and socio-ecological environment from which participants operate. Priority is placed upon the practices of PAMS recipient participants, as the infants receiving PAMS milk bear the burden of risk. In order to bridge this gap in knowledge focused on creating effective and community-centered practice information, the proposed PAMS framework has been developed based on the model framework for policy implementation of Hector et al. (2005) and tailored based on qualitative analysis of recipient experiences (Bond, unpublished).

PAMS Socioecological Framework

Hector et al. (2005) produced their Conceptual Framework of Factors Affecting Breastfeeding Practices in response to frequent mention within BF literature of the lack of systemic approach to BF research. In addition to inconsistent approaches and assessments, variables have not been clearly defined or considered in the larger socioecological and cultural contexts of infant feeding practices. As such, researchers have not clearly distinguished among risk markers for failure to initiate lactation, insufficiency of milk supply, early cessation of lactation and determination of actual direct antecedent or concurrent contributors to suboptimal BF (Hector et al., 2005; Binns & Scott, 1998). Expanding upon adaptations to SEMs of support and decision-making, the Hector and colleagues model further contextualizes the individual and dyad circumstances as described in the Ottawa Charter for Health Promotion (the "Ottowa model") (Tiedje et al., 2002; Ottawa Charter for Health Promotion, 1986). Five action areas for health promotion as described in the Ottawa model, are conceived of by Hector et al. as reciprocal factors affecting, directly and indirectly, the BF dyad. These five areas

for health promotion are developing personal skills, reorienting health services, creating supportive environments, developing public health policy, and strengthening community action. The resulting framework is useful for examining current practices as well as generating hypotheses underlying interventions aimed at addressing identified areas of risk within a socioecological context.

The utility of the Hector et al. framework for describing and contextualizing PAMS practices lies in the integrated approach to describing risk markers and antecedent factors of lactation insufficiency and behavioral decisions. The framework, however, also has limitations with respect to PAMS, including the assumption of mother-infant dyads. To address these limitations and tailor the current framework, a qualitative descriptive analysis was conducted using data collected in August 2013 from 116 recipient participants of PAMS in the US (Bond, unpublished). The three levels of the Hector et al. framework (Individual, Group, and Society) and the five action areas outlined in the Ottawa model were chosen as sensitizing concepts prior to initial coding of the data. In addition to the qualitative themes, practical considerations such as gender neutrality and removing assumptions of biological relationship and maternity have been incorporated based on published work with the PAMS community (Gribble, 2014a,b; Palmquist & Doehler, 2014, Perrin et al., 2015).

Data from responses to the prompt, “Is there anything else you feel is important to share about your milk sharing experience?” were used to develop this framework. Participants then described the critical components of their decision-making and participation experiences. Descriptive coding was completed for de-identified responses

at three levels of abstraction, beginning with primarily in vivo codes (labels or codes defined by the respondent's own words), moving to categorical coding (categorized in in-vivo coded segments based on sensitizing concepts), and grouping into themes associated with the levels of the Hector et al. framework. To ensure credibility of the coding, at the in vivo and categorical levels, two methodologically trained coding partners independently coded the same responses, and coding reconciliation resulted in the final coding of these levels. Verisimilitude of the resultant themes emerges from the verification of findings within the published literature, and triangulation with accompanying quantitative data collected concurrent to the qualitative responses.

Individual level alterations are gender neutrality of terms used to refer to the participant and non-assumptive reference to the relationship to the recipient infant. At the society level, specific inclusion of gender and sexual norms, family roles, and food systems provide context for the unique culture of PAMS participants in the US. Socioecological considerations for PAMS are uniquely interrelated within the basic framework provided by Hector and colleagues (2005). Participants described critical components of their decision-making and participation experiences. An essential alteration to the Hector and colleagues (2005) framework is the inclusion of a previously undescribed social process by which donors, by virtue of the PAMS specific relationship, cease to be part of a group and become intimately involved with the raising of the child, and integrated into extended recipient family. The final significant change is the inclusion of professional policy in the features of the environment, in addition to public health policy.

CHAPTER 3

RESEARCH METHODS

The exploration of components of the PAMS recipient community and participants in relation to risk abatement beliefs and practices leverages a tailored socioecological framework for examining the context of these beliefs and practices. The SEM framework facilitates contextual consideration of interdependent factors influencing or predisposing behaviors associated with safety practices in milk handling and donor screening within the PAMS community. This chapter serves as a description of the development of the instrumentation, data sub-set for analysis, limitations and methodological approaches to data analysis designed to preserve rigor.

Research Design

Human Subjects approval was issued by the Arizona State University Institutional Review Board Committee on Human Subjects Research in August of 2013 and data collection began immediately. The data collected have been securely stored on an encrypted hard drive, to be used for analysis in five distinct, but interrelated projects. The research reported here is a cross-section analysis using data consisting exclusively of recipient participants from the US, and data on selected quantitative variables drawn from a larger, multinational dataset describing beliefs, handling and risk abatement practices, and participant characteristics via qualitative and quantitative prompts. Data were collected using parallel, but role-specific (i.e., donor vs. recipient) self-report questionnaires provided in American English. Items on Donors and Recipients forms

were identical in content, but response options were tailored to the respondent's role in PAMS participation.

Setting

Questionnaires were completed at participants' convenience via a web-based survey hosting site. Participation required a computer or mobile device with internet access and a Facebook account to receive the questionnaire link. Letters of support were received from the online hosting communities on social media - Eats On Feets, Piripoho Aotearoa, and Modern Milk sharing. These three networks were the only hosts directly provided the link to the questionnaire; all other incidences of hosting were viral in nature, posted by individual pages as local administrators saw fit. The self-report web-based questionnaires included items with matrix, multiple choice, and text box responses. Portal use duration for completed surveys ranged from 9 minutes to 78 minutes.

Sample

Participant recruitment occurred through social media networks dedicated to PAMS participants and by word-of-mouth. Participants were donors and recipients who had participated in PAMS prior to taking the survey, or who were currently participating. Recruitment was not targeted with respect to gender, race or ethnicity, duration or intensity of participation, or other criteria beyond current or prior participation in PAMS. To participate in the survey, potential respondents were required to acknowledge having read a participant cover letter indicative of their expressed consent. All participants confirmed at the time of data collection that they were 18 years of age or older and provided informed consent by completion of the survey and submission of responses.

This was not an individually administered questionnaire, therefore tailoring – a finite degree of individualization- was used rather than complete individualization. The process for tailoring with the goal of creating a tool that is personally relevant to respondents was adapted from the processes for tailoring an intervention as described by Sidani and Braden (2011) as a four-step process. Tailoring processes in order of consideration are (1) identification of the characteristics suitable for tailoring, (2) assessment of characteristics of participants, (3) construction of tailoring strategies within the tool, (4) and development of an algorithm to determine delivery of tailored content.

Identification of characteristics. Tailoring elements come directly from the modified Hector et al. (2005) framework. At the Individual level, specific tailorable components are the parental role and gender identity of the participant, infant health status and relationship to the participant, considerations of the dyad, and potential relationship to the Donor(s) involved. Group level factors tailored to PAMS include prenatal, birth, and health services, PAMS network and community environments, and Public/Professional organization policies. Society level factors tailored include norms associated with human milk and child feeding, parental and guardianship roles, and infrastructure of formal milk allocation systems.

Assessment and construction of tailored responses. At the individual level, opportunities for non-binary gender identity were provided in demographic questions, sensitivity to deceased infants, and the use of supplemental feeding apparatus was included for dyads with complicated feeding needs. At the Group level use of prenatal care providers at home, in hospital, and at free-standing birth centers was acknowledged,

as were the major PAMS networks within the community. Openness to diversity in Social level factors was used to tailor responses relevant to this level by removing assumptions of parental roles, human milk norms, and inclusion spiritual/philosophical beliefs that may affect decisions and practices of PAMS. This openness is unusual in lactation and infant feeding research, but is necessary to the PAMS community which has a significant sub-culture of gender and sexuality variant participants, and highly varied family structures.

Algorithm to tailored content. The survey software used for delivery of this questionnaire enables "piping", the software defined process wherein the origin question has unique follow up questions based on the answer given, in this case, those who answered "Donor" were "piped" to donor-tailored questions and those who answered "Recipient" were "piped" to recipient-tailored questions. Participants who responded with their role when beginning PAMS as "Donor" were directed to questions pertinent only to Donor respondents. Participants responding as "Recipients" were directed to Recipient. This section included 3 additional questions compared to the Donor section, thus the unequal number of questions between groups. Upon completion of the role specific section, all respondents were piped to identical questions to complete the questionnaire.

Measurement

No pre-existing instruments regarding the sharing of human milk are currently available in the literature regarding lactation and milk banking. Development of this questionnaire draws heavily on the well-established BF tool, the Infant Feeding Practices

Survey II (CDC, 2005) and extensive observation of practices associated with PAMS. Recipient respondents were provided 88 questions; 19 multiple choice single-answer, 2 multiple choice multiple-answer, 3 text response options with stem prompt, and 65 multiple response 7-point Likert-type scale matrices anchored with “Always” and “Never”. Each question, response options, and level/aspect of the PAMS framework are presented in Table 3. The focus of this research centers on the individual and group-level factors of recipients, reflected in the 15 individual focused response options and 13 group level focused response options compared to two response options pertaining to society-level factors.

Within the individual-level-focused questions, four pertain to infant characteristics, two to the dyad, eight to the participant, and two to the donor(s) in the milk sharing arrangements. Within these questions, there are 8 responses specific to the attributes of the infant, 14 responses specific to the attributes of the participant, 4 responses specific to the attributes dyad, and 7 responses specific to the attributes of the donor(s). The attributes of the infant captured in the reported data are age of the infant at the start of participation, age at the time of the survey response, length of time the infant received human milk through milk sharing, how much of the diet was milk procured through PAMS, and whether infant health impacted the decision to seek human milk through PAMS. Questions capturing attributes of the participant regard demographics (e.g. age, gender, education, income), beliefs (e.g. value of human milk, religious or philosophical views), relationship to the infant, relationship to the birth parent (if not self), and antecedent factors of lactation insufficiency (e.g. psychological distress, painful

latch, insufficient supply, illness, use of drugs or alcohol, work or school incompatibilities). Attributes of the dyad were captured by illness of infant preventing latching, and insufficient weight gain of the infant (nearly always a combination difficulty of parent and child). Attributes of the counterpart, in this research the counterpart being the donor, assessed the relationship of the donor and recipient at the start of the arrangement, home life, health status of the donor's child, religious or philosophical beliefs, and heat treatment, freezing, or provision of raw human milk.

Group-level questions include a single inquiry each about home life and the pool of potential donors, two pertaining to the PAMS community, and five regarding health systems. Attributes of the hospital and health services were captured with 16 responses specific to place of birth, type of birth, birth attendant, use of lactation support persons or groups (lactation professionals, paraprofessionals, lay support, medical professionals, and family/friends), and healthcare providers involved with decision-making associated with participation in PAMS (recipient child's care provider, donor(s) care provider). Home, family, and friends attributes captured by 6 responses regarding whether or not the birth parent was living at the time of participation, size of the household, influence of family and friends in decision-making specific to PAMS, support for lactation from family and friends, intimate partner, household income, and education of intimate partner. The attributes of the work environment are examined with the responses regarding return to work or school as restricting the ability to provide milk from the biological parent of the recipient infant. Attributes of the milk sharing community were briefly explored with responses regarding the length of time spent researching PAMS as an infant feeding

option, and whether or not resources from the major milk sharing networks were consulted. Attributes of the pool of counterparts (potential donors) were captured by the 9 responses pertaining to health and lifestyle screening of potential donors (recent HIV, HBV, HCV screening, alcohol and drug use, family life). Attributes of public and professional policy were captured with the single response to the importance of policy statements or advisements regarding PAMS in the decision-making process.

Society-level factors were a peripheral consideration in the reported data. Attributes of cultural norms were assessed in two responses, and accessibility of BDM as a measure of accessibility of human milk banks was assessed in a single response. Cultural norms of infant feeding and nutrition were assessed by the response "biologically normal way of feeding babies" to the question "How important were the following reasons for choosing to participate in milk sharing?" Response options on a Likert-type scale ranged from "not at all important" to "very important". Accessibility of BDM as individually considered, was assessed with a response to the question, "Before choosing milk sharing, what other options did you consider?" with a response option of "Milk bank."

Content and face validity were established by content expert external review by two Internationally Board Certified Lactation Consultants (IBCLC) familiar with PAMS, and by two network administrators from the PAMS community. Specific criteria used to judge validity were clarity, jargon, length of questions, multiple ideas within questions, and face validity of the survey as a whole (Polit & Beck, 2012). Evaluator determination of validity was in agreement (Item Content Validity Index (I-CVI) of 0.80 or higher) for

82 of 85 questions provided to Donor respondents. The remaining three questions were modified per feedback from the expert reviewers to be congruent with the examined construct. Evaluator-determined validity was in agreement (I-CVI 0.80 or higher) for 84 of 88 Recipient respondent questions. Two prompts where modified to align with expert reviewer feedback. The remaining two prompts were questioned by the IBCLC reviewers for criterion significance, as the IBCLCs were not familiar with the terminology used within the community to refer to common practices, but were determined to be congruent by the network reviewers. After discussion with the expert reviewers, it was determined the questions were pertinent to the milk sharing community, and would remain in the questionnaire. Upon completion of the external review, 18 participants were asked to test the questionnaire for establishment of time to complete and ease of use. The testers provided no concerns.

Establishment of isomorphism of responses in an understudied population with a self-report, web-based questionnaire is difficult. Transitory personal factors, respondent bias, and instrument format across devices used to access the tool cannot be controlled (Polit & Beck, 2012). Piping respondents to donor- and recipient-specific questions addressed additional concerns of heterogeneity of respondents contributing the errors of measurement. To minimize participant burden, overlap of item content within Likert-type matrices was limited, despite the potential risk of decreased scale reliability.

Data Analysis

Data Processing and Management. The author imported data to SPSS version 21 directly from the survey host. Identifying data included from the survey software,

namely IP address of the respondent, were deleted immediately. Data collected via matrix format questions were transformed from 6 columns headed by each matrix response coded “0” for absent response and “1” for present response, the default collection options of the survey software, to a single column with coded responses 1-6 to correspond to the previous matrix headers. Missing data defaults of the survey software were “0” or blank cells. These missing data were changed to “999” for absent data or survey-generated blanks, “777” for responses that are not applicable for that prompt, and “888” for responses not relevant to the participant based on role in PAMS.

Data transformations. Most survey prompts offered a text box “other” option for participants to include options omitted for their individual situation. Each of these responses were evaluated for inclusive coding in existing data (e.g. “Family Practice Doctor” to existing option for “Medical Doctor”), or for inclusion as a new code (e.g. “Unassisted Birth or Free Birth” for “Birth Attendant”). For the analyses reported here, responses from each intensity of screening item and each milk shared-milk handling, storage, and heath treatment were transformed to create a new parallel variable for which responses of “Always” or “Almost Always” were classified as “Routine” (coded as 1) and “Never”, ‘Rarely”, or “Sometimes” were classified as “Not Routine” (coded 0).

Missing data. Each data category was tested for legitimacy of missing data, to determine data that are missing which should be missing, i.e. response not applicable to the respondent, compared to data that are missing because a respondent chose not to answer the question. Regression of missing values on relevant grouping characteristics (ex. missing data for income regressed on race/ethnicity) ensure that there was not

potentially a systematic bias or misrepresentation of a response for particular participants. Significance in these regression models required data to be analyzed as-is, or for case-by-case exclusion.

Research Aims

This study describes and explores the factors contributing to suboptimal breastfeeding, which lead to participation in PAMS, and the donor screening and risk abatement practices of US recipients participating in PAMS.

Aim 1. Describe a cross section of the PAMS recipient population in the US.

Research Question 1. What are the participant-identified personal- and group-level characteristics of PAMS recipients in the US?

Assessment of **RQ1** entailed descriptive analyses and generation of corresponding statistical tables, including category frequencies, and for quantitative measures, means and standard deviations. Data are presented using the original values and category labels whenever possible to preserve context and integrity. Income is presented as “low”, “middle”, and “high”, a condensation of data recorded in 10,000 USD increments from “less than 20,000” to “more than 200,000”. Education is presented as “less than diploma/GED”, “some college or vocational training”, “Bachelor’s degree”, “Master’s degree”, “Doctoral or Professional degree.” Race and ethnicity have been simplified from the current 13 provided options, to “White-not Hispanic” and “Non-White” due to the significant majority of participants who identify as “White” within the recipient group.

Aim 2. Identify the methods, prevalence, and intensity of donor screening, related risk abatement practices, resources sought, and the source of introduction to PAMS of recipient participants.

Research Question 2a. What screening and heat treatment of milk protocols do participants use to maintain quality and safety of donated milk, if any?

Frequencies of screening for HIV, HBV, HCV, alcohol, tobacco, prescription and recreational drug use, dietary supplement use, and caffeine consumption have been reported as a frequency table.

Research Question 2b. How intensely do recipient participants screen donor participants for health and lifestyle factors that can affect milk safety?

Frequencies and percentages of participants who engaged in serological screening, and screening for donor's self-reported current alcohol consumption, tobacco use, prescription and recreational drug use, dietary supplement use, and caffeine consumption are reported. For each item, a new parallel variable was created for which responses of "Always" or "Almost Always" were classified as "Routine" (coded as 1) and "Never", 'Rarely", or "Sometimes" were classified as "Not Routine" (coded 0) to report percent of routine screening. Intensity of screening is reported as a calculated variable summing "routine" (coded 1) responses, reported in a frequency table.

Research Question 2c. How do recipient participants first learn about PAMS and how much time was spent considering this option?

Frequencies and percentages of participants who engage in safe storage and handling practices pertinent to PAMS, specifically the use of heat treatment, is reported.

Research Question 2d. What resources do PAMS recipients consult regarding milk sharing?

For each handling variable, a new parallel variable was created for which responses of "Always" or "Almost Always" were classified as "Consistent" (coded as 1) and "Never", 'Rarely", or "Sometimes" were classified as "Not Consistent" (coded 0). Consistency is reported in frequency table with corresponding percentage.

Aim 3. Identify antecedents of insufficient milk from the biological parent of the recipient infant.

Research Question 3a. What are the antecedent factors of insufficient milk?

A frequency table with percentage of antecedent factors derived from the responses to the survey was created to determine the prevalence of physiologic and psychologic antecedents to lactation insufficiency.

Research Question 3b. What are the philosophical, religious, and human milk value beliefs and corresponding intensity, as reported by PAMS recipients?

A frequency table of antecedent factors and percentages of conditions proposed to affect the decision to participate in PAMS was constructed to determine the extent of philosophical, religious, and value impacts on the decision to engage in PAMS

Research Question 3c. What infant feeding options were considered prior to participating in PAMS?

A frequency table of considered feeding methods and sources of nutrition with appropriate percentages was constructed to determine how many options other than PAMS recipient participants considered in the decision-making process.

Aim 4. Determine the Individual- and Group-level factors that may be predictive of screening and milk handling practices, specifically: infant health, parental characteristics, lactation support access, and human milk bank accessibility.

Research Question 4a. Do participant education, marital status, household income, family size, or ethnicity predict routine screening for HIV, HBV, HCV results, major lifestyle risk factors, or use of heat treatment?

Research Question 4b. Do custodial status, recipient infant age and health status, religious needs, or reported allergies/intolerance predict routine screening for HIV, HBV, HCV results, major lifestyle risk factors, or use of heat treatment?

Research Question 4c. Does the type of prenatal care provider, birth type or place, or the use of lactation support predict consistent screening for HIV, HBV, HCV results, major lifestyle risk factors, or use of heat treatment?

Research Question 4d. Does time spent researching PAMS, resources sought for PAMS participation, beliefs about formula safety, or religious necessity predict consistent screening for HIV, HBV, HCV results, major lifestyle risk factors, or use of heat treatment?

Research questions 4a-4d were tested with multivariate logistic regression model. In table 4, dependent and independent variables are organized by research question, with each cell indicating and individual model for the corresponding independent variables of the row.

Study Assumptions

Survey research relies implicitly on the honesty of participants. Self-selection to participate, lack of compensation for participation, and altruistic nature of participants of PAMS support this assumption of honesty. Delivery of the survey via online portal assumes that the participant is familiar enough with technology and online software interaction to navigate the questions. This is a reasonable assumption as recruitment of participants took place on a social media platform where surveys, questionnaires, and functional internet and device proficiency are required for participation. Recruitment efficacy is assumed and cannot be reasonably tested, due to the anonymous nature of PAMS interactions. It is not possible to estimate many characteristics of the participant population, however, preliminary data analysis indicates that sample characteristics are congruent with published sample characteristics. Participants were assumed to be proficient in American English. All US PAMS networks conduct all page management in American English, and prompts and survey item responses were crafted to meet no more than an 8th grade reading fluency based on the Flesch-Kincade reading scale. Taken together, these facts make it unlikely that a survey in American English presented a significant barrier.

Study Limitations

The representativeness of the self-selected sample from the US exclusively is a limitation of the research. It is possible that those participating online or choosing to participate in an online survey of practices do not represent those seeking donors in the greater community and/or outside the US where infant feeding culture can be

significantly different. Cultural sensitivity is a potential limitation of the research. Multiple lactation professionals and PAMS network administrators examined the data collection tool prior to dissemination, however, these individuals may not reasonably represent cultures sensitive to sharing information about practices related to infant feeding. As a cross-sectional sample, there are limitations related to changes in practice and circumstances over time that cannot be captured.

CHAPTER 4

RESULTS

Results

Aim 1. Describe a cross section of the PAMS recipient population in the US.

Research Question 1. What are the participant-identified personal- and group-level characteristics of PAMS recipients in the US?

Recipient respondents from the US are predominantly white (not of Hispanic origin), with a mean age of 30.05 years at the time of participation in this research, identify as women, and are married or cohabitating with a partner with a mean household size of 4.85, have at least some college education, and a household income above the median ($50-52,000 USD) for the US. Their partners are predominantly identified as men with at least some college education (Tables 5 - 7).

The birth parent of two of the recipient infants included in this research are deceased. Within the recipient sample, infants were likely to be less than 6 months of age at the time of initiating PAMS participation, and received milk obtained through PAMS for less than 9 months. The majority of infants received less than 50% of their diet as donated milk from PAMS participation. Most of the participants in this research were the biological mothers of the infants receiving the milk, and provided milk to a single child in the home.

While the majority of recipient participants gave birth in a hospital, a quarter of the participants in this research gave birth out of hospital, compared to the US rate of out of hospital birth overall of 2% (Table 8). Participants were equally likely to have been

supported prenatally and at birth by a doctor or midwife. The rate of surgical birth (28.7%), planned or emergent, is less than the national average of 32%, perhaps related to the decreased likelihood of surgical birth with midwifery model of care and the disproportionately large percentage of births occurring out of hospital. Only 15% of the sampled participants did not seek some form of lactation support, and the support sought reflects seeking multiple types of support. Three quarters of participants reported seeking on-line resources regarding lactation support. The percent of infant diet reported to be from PAMS acquired milk has a bimodal distribution. Reports of infant diets from PAMS of less than 20% and more than 80% of the diet account for 26.2% and 26.5% of the sample, respectively, indicating that most continued to breastfeed but more than a quarter relied on PAMS to meet the majority of the needs of their infant.

Aim 2. Identify the methods, prevalence, and intensity of donor screening, related risk abatement practices, resources sought, and the source of introduction to PAMS of recipient participants.

Research Question 2a. What screening and heat treatment of milk protocols do participants use to maintain quality and safety of donated milk, if any?

Screening of donors was, overall, very low (Table 9). With the exception of HIV serological results within 12 months preceding donation, all serological screening occurred in less than 25% of milk sharing arrangements. Recipients were more likely to screen for common lifestyle factors such as prescription medication, use of tobacco and alcohol, and other supplements and treatment modalities. Questions regarding the health

of the donor's child and home life of the donor were asked by just over half of the responding recipient participants.

Research Question 2b. How intensely do recipient participants screen donor participants for health and lifestyle factors that can affect milk safety?

Routine screening of donors, reported as either "Always" or "Almost Always" by participating recipients was similarly low when compared to responses of ever having screened at all, with HIV results current within 12 months of donation being the most likely serological result sought (21.7%) (Table 10). Participants were most likely to screen for the use of medication (non-prescription 38.3%, prescription 46.2%), recreational drugs (36.1%), tobacco (40.5%) and alcohol consumption (38.7%), and the health status of the donor's child. Only 16% of recipients reported consistent use of heat treatment to address microbial content of donated milk.

Research Question 2c. How do recipient participants first learn about PAMS and how much time was spent considering this option?

Recipients were most likely to hear about PAMS from family or friends, and to spend less than a week learning about PAMS, with 25% reporting spending one day or less learning about PAMS (Table 11). It is possible that the degree of trust and social involvement of the introduction to PAMS as a practice of peers impacts the perceived need to research PAMS, and possibly the perceived need to screen potential donors. It is also possible that familiarity with donors increases confidence in the suitability of donors, or that this familiarity creates social taboos in asking for health and lifestyle suitability.

Research Question 2d. What resources do PAMS recipients consult regarding milk sharing?

Recipients were least likely to involve medical professionals in the decision-making process regarding PAMS, including the donor's doctor (4.5%) and recipient infant's doctor (22.6%) (Table 12). Participants were most likely to involve partners and caregivers in the decision-making process (79.1%). PAMS specific resources were very involved in about a third of recipient decisions (34.4-37.1%), including Eats on Feets Resource for Informed Breast Milk Sharing and the Human Milk 4 Human Babies FAQ, as well as general infant feeding blogs websites, or social media pages.

Aim 3. Identify antecedents of insufficient milk from the biological parent of the recipient infant.

Research Question 3a. What are the antecedent factors of insufficient milk?

The most frequent antecedent factors for seeking milk were insufficient milk from the lactating parent, slow infant weight gain, difficult infant latch, and recipient/parent illness or use of a medication not compatible with lactation (Table 13 &14). Serious infant health problems and/or congenital condition accounted for a small portion of the infants receiving PAMS milk.

Research Question 3b. What are the philosophical, religious, and human milk value beliefs and corresponding intensity, as reported by PAMS recipients?

Religious and philosophical beliefs were not common reasons for seeking milk through PAMS, cited as very important in only 18% of respondents (Table 14). Beliefs of biological normalcy and the right of babies to have human milk were important to well

over half of responding participants. While concerns about the safety of commercial formula were reported by a third of participants, only 21% had similar concerns about home-made formulas.

Research Question 3c. What infant feeding options were considered prior to participating in PAMS?

The majority of recipient PAMS participants considered formula prior to engaging in PAMS. Only 18% of participants reported even considering human milk banks (non-profit) as an option (Table 15). Wet-nursing and other milks were rarely considered. Additionally, 23.4% of recipients considered using a home-made formula.

Aim 4. Determine the Individual- and Group-level factors that may be predictive of screening and milk handling practices, specifically: infant health, parental characteristics, lactation support access, and human milk bank accessibility.

Research Question 4a. Do participant education, marital status, household income, family size, or ethnicity predict routine screening for HIV, HBV, HCV results, major lifestyle risk factors, or use of heat treatment?

Logistic regression was used to predict the probability of the intensity of screening (routine v. not routine) for recommended health and handling outcomes. Testing the complete model compared to an intercept-only model was statistically significant for the routine screening and handling outcomes of recreational drug use x^2 (4, N=351) = 15.28, p = 0.004 with an overall successful prediction of 61.7%, over-the-counter medication use x^2 (4, N=351) = 9.73, p = 0.045, with an overall successful prediction of 58.9%, supplement use x^2 (4, N=351) = 9.54, p = 0.049, with an overall

successful prediction of 68.3%, and Holder method pasteurization x^2 (4, N=351) = 16.87, p = 0.002, with an overall predictive success of 92.8%. Dependent variables are coded "1" to indicate "routine" screening based on participant responses of "always" and "almost always" and "0" to indicate "not-routine" based on participant responses of "never", "rarely", and "sometimes".

Table 16 shows the logistic regression coefficient, Wald test, odds ratio, and confidence interval for each predictor variable. Statistical significance for p is determined at 0.05. Employing this significance criterion, participant education had significant partial effects in predicting consistent screening for donor alcohol consumption, use of recreational drugs, over the counter medication, diet, and dietary supplements. The odds ratio for participant education indicates that when all other variables of the model are held constant, participants with an advanced degree had a lower likelihood to screen potential donors for use of alternative modalities (OR = 0.271, 95% CI [0.098, 0.748]) and that those with at least a Bachelor's degree had a lower likelihood to heat treat donor milk via Holder method pasteurization (OR = 0.212, 95% CI [0.055, 0.816]).

Research Question 4b. Do custodial status, recipient infant age and health status, religious needs, or reported allergies/intolerance predict routine screening for HIV, HBV, HCV results, major lifestyle risk factors, or use of heat treatment?

Testing the complete model for infant age, infant health, infant allergies, formula intolerance, parental status, and religious needs of the infant compared to an intercept-only model was statistically significant for the routine screening and handling outcomes of tobacco use x^2 (6, N=351) = 16.40, p = 0.012 with specificity of 90.5%, sensitivity of

18.6%, overall successful prediction of 60.9%, alcohol consumption x^2 (6, N=351) = 18.225, p = 0.006, with specificity of 82.6, sensitivity of 18.6, overall successful prediction of 62.1%, recreational drug use x^2 (6, N=351) = 21.83, p = 0.001, with specificity 95.8%, sensitivity 10.6%, overall successful prediction of 64.8%, over-the-counter medication use x^2 (6, N=351) = 18.86, p = 0.004, specificity 83.0%, sensitivity 36.1%, and overall predictive ability 64.6%, alternative modalities x^2 (6, N=351) = 14.94, p = 0.021, sensitivity 97.8%, specificity 8.7%, predictive ability 79.7%, and donor diet x^2 (6, N=351) = 29.13, p = 0.000, specificity 97.1%, sensitivity, 18.4%, with an overall predictive success of 92.8%.

Table 17 shows the logistic regression coefficient, Wald test, odds ratio, and confidence interval for each predictor variable (infant age, infant health, infant allergies, formula intolerance, parental status of the participant in relation to the recipient infant, and religious needs of the infant). Infant age of less than 6 months had significant partial effects predicting routine screening for recreational drug use (OR = 3.359, 95% CI [1.329, 8.491]). Formula intolerance had significant partial effects in predicting increased likelihood of routine screening of donors for over-the-counter medication use (OR = 1.991, 95% CI [1.185, 3.347]), and prescription medication use (OR = 1.674, 95% CI [0.999, 2.804]). Infant allergies had significant predictive partial effects that indicate greater likelihood of participant screening of donors for alternative modalities (OR = 4.370, 95% CI [1.788, 10.682]), diet (OR = 7.025, 95% CI [2.693, 18.32]), and donor use of dietary supplements (OR = 4.154, 95% CI [1.684, 10.246]).

Research Question 4c. Does the type of prenatal care provider, birth type or place, or the use of lactation support predict consistent screening for HIV, HBV, HCV results, major lifestyle risk factors, or use of heat treatment?

Testing the complete model for birth type, birth location, and birth attendant, compared to an intercept-only model was statistically significant for the routine screening and handling outcome of alternative modality treatments x^2 (6, N=351) = 12.94, p = 0.044 with overall successful prediction of 80.0%. Testing the complete model for lactation support compared to an intercept-only model was statistically significant for routine donor screening and donor milk handling outcomes of alcohol x^2 (3, N=351) = 11.08, p = 0.011, with an overall predictive success of 61.3%, recreational drug use x^2 (3, N=351) = 11.21, p = 0.011, with an overall predictive success of 63.9%, over-the-counter medication use x^2 (3, N=351) = 9.50, p = 0.023, with an overall predictive success of 61.7%, alternative modalities x^2 (3, N=351) = 11.23, p = 0.011, with an overall predictive success of 80.3%, supplements x^2 (3, N=351) = 15.95, p = 0.001, with an overall predictive success of 70.7%, and Flash heating x^2 (3, N=351) = 9.63, p = 0.022, with an overall predictive success of 89.7%.

Table 18 shows the logistic regression coefficient, Wald test, odds ratio, and confidence interval for each predictor variable (birth type, birth attendant, birth location, healthcare provider lactation support, IBCLC lactation support, and community lactation support). Participants with a CNM attended birth were significantly more likely to screen potential donors for HIV testing results recent within 6 months of the milk exchange (OR = 2.411, 95% CI [1.046, 5.557]). Seeking lactation support from a health care provider

was significantly more likely to result in donor screening for tobacco use (OR = 1.851, 95% CI [1.157, 2.964]), alcohol use (OR = 2.192, 95% CI [1.355, 3.547]), drug use (OR = 2.200, 95% CI [1.345, 3.596]), over-the-counter medication use (OR = 1.760, 95% CI [1.092, 2.836]), alternative modalities (OR = 2.068, 95% CI [1.115, 3.834]), use of dietary supplements (OR = 2.318, 95% CI [1.360, 3.950]), and heat treatment of milk via flash heating (OR = 2.633, 95% CI [1.083, 6.401]). Seeking lactation support from an IBCLC was significantly more likely to result in donor screening for alternative modalities (OR = 2.026, 95% CI [1.008, 4.073]). Using community-based lactation support was more likely to result in heat treatment of donor milk via Holder method (OR = 2.926, 95% CI [1.032, 8.297]). Giving birth via planned surgical birth significantly decreased the likelihood of donor screening for the use of supplements (OR = 0.319, 95% CI [0.114, 0.891]).

Research Question 4d. Does time spent researching PAMS, resources sought for PAMS participation, beliefs about formula safety, or religious necessity predict consistent screening for HIV, HBV, HCV results, major lifestyle risk factors, or use of heat treatment?

Testing the complete model for research duration, PAMS specific resources, and government statements regarding the safety of PAMS compared to an intercept-only model was statistically significant for the routine screening and handling outcomes of tests for Hepatitis B virus current within 12 months of donating milk x^2 (6, N=351) = 13.34, p = 0.038 with overall successful prediction of the model of 84.8%, hepatitis C virus tests current within 12 months of donation x^2 (6, N=351) = 13.45, p = 0.036 with

overall successful prediction of the model of 85.1%, donor use of tobacco x^2 (6, N=351) = 38.04, p = 0.000 with model specificity of 75.4% and sensitivity of 53.5% and overall successful prediction of 66.5%, alcohol consumption x^2 (6, N=351) = 34.57, p = 0.000 with specificity of 81.7% and sensitivity of 42.6% and overall successful prediction of 66.5%, recreational drug use x^2 (6, N=351) = 54.88, p = 0.000 with model specificity of 82.8% and sensitivity of 48.4% and overall successful prediction of 70.3%, OTC medication use x^2 (6, N=351) = 30.13, p = 0.000 with model specificity of 82.7% and sensitivity of 44.0% and overall successful prediction of 67.8%, prescription medication use x^2 (6, N=351) = 24.59, p = 0.000 with model specificity of 69.9% and sensitivity of 52.3% and overall successful prediction of 62.2%, alternative modalities x^2 (6, N=351) = 21.50, p = 0.001 with model specificity of 100% and sensitivity of 1.4% and overall successful prediction of 71.1%, diet x^2 (6, N=351) = 18.76, p = 0.005 with model specificity of 96.8% and sensitivity of 7.0% and overall successful prediction of 71.1%, and use of dietary supplements x^2 (6, N=351) = 37.59, p = 0.000 with model specificity of 95.5% and sensitivity of 13.6% and overall successful prediction of 71.3%.

Table 19 shows the logistic regression coefficient, Wald test, odds ratio, and confidence interval for each predictor variable (research duration, PAMS-specific resources used, and consultation of government statements). A participant who researched PAMS for up to one month was significantly more likely to screen potential donors for HIV testing within 6 months of the milk donation (OR = 2.457, 95% CI [1.034, 5.837]), hepatitis B virus testing within 12 months of donation (OR = 3.506, 95% CI [1.311, 9.379]), hepatitis C virus testing within 12 months of donation (OR = 3.365,

95% CI [1.255, 9.021]), tobacco use (OR = 2.552, 95% CI [1.403, 4.640]), alcohol consumption (OR = 2.557, 95% CI [1.393, 4.693]), recreational drug use (OR = 3.507, 95% CI [1.766, 6.968]), OTC medication use (OR = 1.822, 95% CI [1.014, 3.274]), prescription medication use (OR = 2.295, 95% CI [1.308, 4.027]), alternative modalities (OR = 2.642, 95% CI [1.161, 6.016]), diet (OR = 2.104, 95% CI [1.087, 4.072]), and use of dietary supplements (OR = 2.775, 95% CI [1.369, 5.626]).

A participant that spent more than one month researching PAMS was significantly more likely to screen potential donors for HIV testing within 12 months of donation (OR = 2.457, 95% CI [1.034, 5.837]), hepatitis B virus results within 12 months of donation (OR = 3.058, 95% CI [0.924, 10.125]), tobacco use (OR = 3.359, 95% CI [1.536, 7.346]), alcohol consumption (OR = 4.096, 95% CI [1.864, 9.001]), use of recreational drugs (OR = 5.324, 95% CI [2.258, 12.556]), use of OTC medications (OR =3.232, 95% CI [1.497, 6.980]), prescription medications (OR = 2.975, 95% CI [1.403, 6.309]), alternative modalities (OR = 3.869, 95% CI [1.433, 10.373]), diet (OR = 3.633, 95% CI [1.598, 8.260]), and use of supplements (OR = 5.214, 95% CI [2.195, 12.386]).

Participants who used the Eats on Feets Resource for the Informed Sharing of Human Milk were significantly more likely to screen potential donors for recreational drugs (OR = 2.487, 95% CI [1.311, 4.720]). Participants who used other online resources including blogs, social media pages, and support groups that are not specifically dedicated to PAMS were significantly more likely to screen donors for recreational drug use (OR = 2.007, 95% CI [1.182, 3.408]), alternative modalities (OR = 2.136, 95% CI [1.144, 3.985]), and the use of dietary supplements (OR = 1.850, 95% CI [1.068, 3.204]).

Participants who considered the FDA statement regarding the safety of sharing human milk were more likely to heat-treat donor milk via flash heating (OR = 8.678, 95% CI [1.661, 45.341]).

CHAPTER 5

DISCUSSION

Recipient participants of PAMS

PAMS participants in this research were characteristically consistent with the descriptions of prior research involving milk sharing and related practices. A relational diagram of these factors and screening outcomes is found in figure 3. The majority of participants identified as women in their early 30's, white (not of Hispanic origin), married or living with a partner, in a heterosexual relationship, and having at least a Bachelor's degree. Household income was median or higher for the US for most participants and average household size was 4.85 persons. Recipient participant partners had at least a Bachelor's degree in more than half of cases. The infant ultimately receiving the milk procured through PAMS was typically the biological child of the participant, and was 3-6 months of age at the start of the milk sharing relationship, lasting less than 9 months. Birth practices of recipient families are not typical of US birth statistics, where 98.5% of births occur in hospital, 84.8% attended by MDs, 8.0% attended by CNMs, and 32.2% by surgical birth (CDC, 2014). Recipient PAMS participants in this sample were attended out of hospital in 31.2% of the sample, by CNMs in 21.8% of cases, otherwise credentialed midwives in 19.8% of cases, and only 28.7% delivered via surgical birth (Figure 5). This deviation may be an extension of social privilege, result of cultural perceptions of birth and child rearing, exposure to diverse birth practices common in parenting social media groups, or some combination

thereof. These potential contributors will require further study to determine what extent they influence feeding decisions.

As with perinatal provider, birth location does not align with the overall birth environment in the US, with home birth and birth center birth being overrepresented in this sample. Homebirth by choice is associated with increased feelings of empowerment, satisfaction with birth, and greater feelings of control over their decisions as compared to those birthing in hospital, as are feelings of significant displeasure with a previous hospital birth experience stemming from lack of autonomy (Hildingsson, Radestad, & Lindgren, 2010; Ashley & Weaver, 2012 a,b). It is possible that birth decisions breaking from contemporary practice and location which may stem from poor experiences with medical professionals influences both the desire to avoid contemporary norms in infant feeding contextualized by paternalistic biomedical endorsement of artificial baby milk (formula) as equivalent to human milk, as well as the lower likelihood of seeking involvement of medical professionals in the decision-making process associated with PAMS (Kendall-Tackett, 2011; Nelson, 2006). Routine hospital birth practices negatively impact both the initiation and duration of breastfeeding, which may further contribute to early lactation difficulty predisposing the family to need supplemental milk as well as feelings of inadequate support by healthcare professionals (Lothian, 2005; Smith & Kroeger, 2010). This phenomenon may also explain the use of practitioners such as chiropractors and naturopathic medical practitioners by 15% of the participating recipients in this sample.

In line with alternative birthing and care provider tendencies within this sample, the use of home-made formulae was also prevalent within the sample. The use of home-made formulas has, to date, been given little attention in the US. These formulae are marketed to parents as "wholesome", "traditional", "organic", and "unprocessed" and therefore superior to commercial formulas. Health organizations in the US have not addressed the growing trend of home-made formulas comprised of ingredients ranging from nut juices to raw animal livers, to partially cooked eggs and bone broths, but Health Canada and the Department of Health of Western Australia in conjunction with the New South Wales Food Authority have issued strong warnings regarding the nutritional inadequacy, inconsistency, health risks associated with ingredients, and the potential toxicity of recommended vitamin and mineral additives (Health Canada, 2014; New South Wales Food Authority, 2015). In the extreme, organizations such as the Weston A. Price Foundation have posited that individuals not following a strict dietary regime (set forth by the foundation) should not attempt to breastfeed because the milk "provides no better nourishment for their infants than factory-made formula" (Weston A. Price Foundation, 2001). These statements fail to acknowledge the potential risks of home-made formula, and exacerbate evidence-devoid messages about human milk.

Low prevalence of screening and heat treatment

In this study, as a whole, screening of donors by recipient participants for potential acceptability or to minimize risk to the recipient infant was low. There is not a universal model of donor or human milk screening used globally. The common screening

practices among the major global models are serological results for HIV, HBV, and HCV recent within 6 or 12 months, general health of the donor and the donor's child, and potential lifestyle factors (such as diet and medication use) that may impact a health fragile infant (Biasini et al, 2013; Bond, unpublished; Brownell et al., 2013). The health status of the infants receiving milk via formal human milk banks is an important distinction. The entirety of the body of knowledge regarding milk banking and the safety practices necessary for optimal outcomes is focused on the unique and high risks of the health-fragile, typically premature, very low birth weight neonate often residing in neonatal intensive care. The necessity of intensive screening and handling, at the detriment of some live components and vitamins, has never been studied for otherwise healthy, home dwelling infants and young children which is the predominant infant population (80.6 – 88.3%) involved with PAMS. Regardless of the absent and necessary evidence specifically addressing donated human milk for otherwise healthy infants, a foundation of donor screening and milk handling for those elements of greatest concern is essential to minimizing risk to recipient infants.

Serological donor screening

For the banks affiliated with HMBANA, an HIV blood test result is required in order to accept milk within 6 months of the negative test results (HMBANA, 2016). There is currently no data regarding the sero-conversion of gestationally screened parents in the first year after birth, however, the risk of seroconversion for donor populations is low and a 12 month screening is accepted in smaller banking models, so an option for

serological results accepted up to 12 months has been included in this research (Bond, unpublished). Heavy media and governing body attention to the risk of HIV, as well as pervasive stigma associated with HIV, likely contributed to the relatively higher screening for HIV compared to HBV or HCV. Paradoxically, the stigma associated with HIV, and to a lesser extent HBV and HCV, may have contributed to feelings of embarrassment and violation of social mores regarding communicable disease and limited the likelihood of asking for recent results. It is also possible that recipient participants responded with their initiating the exchange of test results, and that this is artificially low due to donor's offering these results without solicitation.

Screening feasibility has been questioned in professional discussions of PAMS, and is addressed in limited context in the various PAMS-specific resources available to families and professionals online. Laboratory screening from conventional diagnostic facilities for HIV, HBV, and HCV range in cost individually from $38 - $49 USD and as a group from $83 - $147 (Any Lab Test Now, 2016; Pinkerton et al., 2010, Sonora Quest Laboratories, 2016). Non-conventional laboratories (such as Theranos labs) cost considerably less at $33-$35 as a group (Theranos Labs, 2016). Government subsidized screening offices, and online services vary in price but fall within these cost ranges. Considering the typical PAMS recipient family acquires milk from 6-8 donors, this potential cost to privately screen can range from $198 - $1,176 over the course of the PAMS participation. Indirect donor testing is, anecdotally, a common means of obtaining recent bloodwork. These methods of testing include donating blood, donating milk to a milk bank, routine physical examinations covered by donor insurance, and the use of

prenatal test results of the donor. It is probable that with the support of a healthcare provider, low-cost or no-cost donor serological results could be obtained by any one or combination of methods, providing the participants are willing to contribute this degree of effort.

Health and Lifestyle

Compared to serological screening, screening of potential donors for health and lifestyle behaviors was relatively higher, ranging from 14.5% for religious or philosophical beliefs to 54.1% for the health status of the donors child. At least one-third of the recipient participants reported screening potential donors for use of medication, alcohol and tobacco, diet and supplements, family life, and use of alternative therapies or modalities. This increase in the screening of donors for lifestyle factors is likely a combination of ease of discussing lifestyle in a congenial way compared to discussion of medical records and testing which are socially taboo, as well as greater knowledge of the potential importance of lifestyle factors compared to serious infectious disease. Higher intensity and consistency in this screening is desirable from the perspective of informed consent and risk abatement, but there is not a robust benchmark to compare these results to from within the formalized milk banking model, neither is there evidence from non-centralized banks to compare these results to.

Screening of this nature relies nearly exclusively on the honesty of the self-reporting donor and presumed altruism, supplemented by signature of a physician of the donor and the donor's infant in the case of many milk banks (Biasini et al., 2013). The

body of knowledge regarding human milk donor's motivation is consistent in both banked and shared populations, donors choose to donate to avoid disposal of the milk they have expressed, and because they wish to help another child (Gribble 2013; Osbaldiston & Mingle, 2007; Palmquist & Doehler, 2013). Less well documented is the efficacy of interview screening with supplemental documentation. Escuder-Vieco and colleagues (2016) validated the self-report records of donors via biochemical analysis for illegal drugs, caffeine, and nicotine. Of the 400 samples provided by 63 donors across lactation, a false-negative screen for legal or illegal drugs was not found, tobacco exposure/use was found in a single sample, and caffeine use/presence in milk had a range of specificity from 46-57%, and sensitivity from 46%-77% (with the exception of colostrum), depending on the stage of lactation. The screening itself is not a standard protocol among milk banks in the HMBANA, with at least 4 of the 13 active banks electing not to rescreen donors after 6 months, inconsistent definition of acceptable maturity of BDM, active resistance to transparency and consistency from a third of current milk banks (Brownell et al., 2013).

Overall use of heat treatment, either Holder method on the stove top or flash heating, was so low in the sample that it calls into question the reliability of results regarding this practice from this particular sample of recipients. It is, however, reasonable to say that heat treatment of PAMS acquired milk is a rare practice among recipient families. It is also unlikely that PAMS donors heat treat milk prior to freezing, as this is

not a practice that is recommended by the Academy of Breastfeeding Medicine Protocol 8 (2010), the standard milk expression and storage guidance in the US.

The HMBANA model employs Holder pasteurization to address microbial presence in distributed milk. Pre-screening of donor milk for bacterial load and specific pathogenic strains and post-screening for presence of bacteria is conducted, and all milk is discarded if a positive post-pasteurization screening occurs. The Danish milk banking model employs a pre-screening protocol for colony forming units (CFU), a non-specific measure of the overall bacterial load of milk per mL, and only Holder pasteurizes milk that has 200,000 CFU or more, or that will be distributed to infants of birth weight less than 2000 grams (Grovslien & Gronn, 2009). Post-heat treatment screening is essential for the detection of heat-activated spores that may be activated during low-heat pasteurization from the bacterial species *Bacillus* which can cause diarrheal illness (Kim & Unger, 2010). Human milk is not sterile, even in healthy donors, and a growing body of evidence suggests that the microbes in milk are beneficial to, and perhaps essential for, healthy development of the neonatal gut (Jost et al., 2015). In light of the lack of evidence that bacterial absence is universally protective, and the potential for spore activation that is not feasible to detect at home, it is difficult to recommend adherence to a heat treatment protocol for PAMS exchanges.

Antecedents of participation in PAMS

Recipient participants in this sample indicated that the predominant reason for seeking milk via PAMS was insufficient parental milk supply (87.1% either “Important”

or “Very Important”). Related to insufficient supply, 38.3% (“Important” or “Very Important”) of recipients indicated that infant weight gain was too slow. Infant weight gain is a key indicator of overall health and development and the primary topic of discussion in well-infant visits. Parents are asked to describe the infant eating and sleep patterns, at which point maternal concerns about perceived insufficient supply are discussed. Lack of provider and parental education about developmentally typical infant behaviors and expected periods of frequent eating and sleep disruption that coincide with growth and developmental milestones, combined with inappropriate or absent assessment of infant latch and transfer at a feeding and measures of infant milk transfer in a 24 hour period as a surrogate measure for daily production lead to inappropriate supplementation (Gatti, 2008). Exacerbating these factors are the frequent insistence on supplementation after a single assessment of growth, which is incapable of identifying tempo of infant growth, and recommendation to sleep train if infants are not “sleeping through the night” as early as 2 months of age, both contributing to perceptions of insufficient production and limitation of needed feeding sessions to maintain supply (Cole & Lanham, 2011; Gatti, 2008; Pizzi et al., 2014).

Reported parental illness or medication that is unsafe for breastfeeding was reported as “Important” or “Very Important” to the need that lead to seeking PAMS milk by 15.6% of recipient participants. Exceptionally few medications are absolutely contraindicated for use in conjunction with lactation for infant feeding (Davanzo et al., 2016). It is unclear whether the medical advisement to interrupt lactation was a temporary or permanent circumstance among the recipient participants based on quantitative

measures, however, qualitative responses to the question of medication use indicates that many were advised to discontinue any feeding (Bond, unpublished). The unnecessary advisement to interrupt infant feeding in this manner reflects a lack of understanding of lactation-specific pharmacology and failure to consult easily accessible resources for benefit-risk assessment (Davanzo et al., 2016; Hale, 2004). Even in the case of a temporary interruption, without proper lactation support, sequelae could lead to perception of or actual insufficient supply, further exacerbating the need for supplementation.

Significant concern has been expressed in commentary and publications regarding milk sharing, or other practices confused with milk sharing, result in health-fragile infants receiving milk presumed to be of high risk. Serious infant health problem and congenital anomaly were acknowledged by recipient participants in 13.8% and 8.0%, respectively, with significant overlap. This is certainly a minority of the recipient infant population, however, the extent to which PAMS milk may affect the infant condition, for better or worse, cannot be determined based on the data from the current sample. This is an area that will need specific and intensive further investigation.

Nipple pain as a result of poor latch is the second most frequently given reason for early cessation of nursing either for exclusive milk expression or other infant feeding method (Dennis, Watson, & Jo, 2014). A Cochrane review of interventions used to treat nipple pain beyond ensuring latch is appropriate indicates that treatment was ineffective in most cases, but that symptoms reduced or resolved if latching was continued for 7-10

days postpartum for the group most intensely affected by pain (Dennis, Watson, & Jo, 2014). Anticipatory guidance and advanced lactation support for persistent pain is recommended by Dennis and colleagues. In the current sample, recipient participants report nipple pain as “Important” or “Very Important” in only 8.3% of the sample. This may be related to the significant number of sources of support sought by recipient participants.

Factors explaining consistent screening and risk abatement

In order to simplify the presentation of complex results, Figures of the relationship between explanatory factors and the donor screening and risk abatement practices impacted have been created. Factors that were impacted such that recipient participants were more likely to consistently screen or use the risk abatement practice in question are indicated by a (+), and those less likely to be done or screened for consistently are indicated by a (-) within the figure. Figures (3-8) are grouped by related regression factors.

Serological screening. Recipient level of education, household size, ethnicity, household income, and participant age did not influence the consistency of screening and use of risk abatement practices. Similarly, recipient infant age, health status, allergies, formula intolerance, parental status, and religious needs that are specifically met via PAMS failed to significantly impact screening of donors for HIV, HBV, or HCV. It is possible that this lack of variation is due in large part to the significant homogeneity of the sample with respect to demographic and descriptive characteristics. The overall low

incidence of screening donors for serological results also likely contributes to the lack of variation of impact of these variables on screening behaviors.

Having a birth attended by a CNM resulted in more consistent screening of donors for HIV results current within 6 months, as compared to birth attendance by an Obstetrician, professional midwife, or other provider. The predominant perinatal care model in the US is hospital-based Obstetrician/Gynecologist (OB/GYN) care. Significant practice philosophy difference exist between the care models, with CNM care centering on the physiological typical nature of pregnancy and holistic support of the family compared to identification and intervention upon pathology with the OB/GYN model (Phillipi & Avery, 2014; Council on Resident Education in Obstetrics and Gynecology (CREOG), 2013). During prenatal visits, Paine and colleagues (2000) found that patients received more than 15 minutes of face-to-face time with their provider in 61.2% of visits with CNM providers compared to 31% with OB/GYN providers. Of those face-to-face minutes, 86% were spent providing counseling and education with CNMs and 47% for OB/GYNs.

The content of the postpartum visit is prioritized and allocated very differently for CNM compared to OB/GYN providers. Clinical practice guidance for CNMs and observation of these practices indicate that patients receive counseling about processing their birth, infant feeding (breast care, infant growth, and feeding behaviors), self-care including wound healing and involution, family adjustment, and anticipatory guidance for all members of the family, among other topics (Morten et al., 1991; Martin et al., 2013).

Clinical practice guidance and core curriculum for OB/GYNs focusses on bleeding, abdominal pain, wound healing, and postpartum mood (CREOG, 2013; Kacmar & Weitzen, 2004). Patients report significant frustration with the OB/GYN model of care, particularly when there are questions of care or questions pertaining to procedures that occurred during the birth, indicating that these questions are not addressed, addressed inadequately, or cannot be addressed due to lack of continuity of care (Martin et al., 2013). In light of the significant increase in focus of the CNM philosophy of care, and background in nursing, it is likely that the increase in HIV screening results from discussion and support that are lacking in the OB/GYN model. It is interesting to note that professional midwifery birth attendance, conducted with highly similar practice philosophy, and having a greater number of prenatal and postnatal visits, did not result in screening consistency. It is possible that a direct-entry professional midwifery education differently emphasizes the potential clinical significance of this kind of testing precaution, resulting in different priorities in consideration when counseling families. Similarly, lactation support from IBCLC, para-professional, and peer sources did not impact consistent screening of donors for serological results for HIV, HBV, or HCV, and may reflect differences in scope of practice and foundational education compared to nursing.

Time dedicated by the recipient participant to learning about PAMS greater than one week is associated with consistent screening for HIV results within 6 or 12 months of donation, HCV and HBV results within 12 months. Discussion in media and internet sources frequently address HIV specifically, and “communicable disease” more

generally. It is likely that frequent exposure to concerns about disease and transmission to recipient infants increases awareness and priority of screening. A relationship between the sources of information and consistency of screening did not exist, however, there was significant overlap in the sources recipient participants sought and considered important. The consideration of multiple sources and the inconsistency in information among sources may have minimized individual resource effects.

Donor lifestyle. Recipient participant screening of donors for lifestyle habits and practices that could potentially create complications for their infants was more common than any other kind of screening in this sample. Recipients more consistently screened potential donors for recreational drug use if the recipient infant was less than 6 months of age. Infants less than 6 months of age are the most sensitive to medications and other substances in human milk owing to the relative immaturity of liver function, regardless of health status, as discussed in frequently accessed parental resources such as the smart-phone applications "LactMed" and "Breastfeeding Answers Made Simple", as well as resources from the Infant Risk Center at Texas Tech University Health Sciences Center (infantrisk.com), and Kelly Mom (kellymom.com). Recipient participants who had reported an infant with allergies was associated with consistent screening of donors for the use of alternate modality therapies, diet, and the use of dietary supplements. This is a very expected outcome to guard against introduction of antigens via milk that can cause potentially life threatening reactions in the recipient infant. Recipient reported formula intolerance in the recipient infant was associated with more consistent screening of donors for over-the-counter and prescription medications. Pop-culture diagnosis of

formula intolerance by self-proclaimed experts (wellnessmama.org, mthfr.net as examples), acknowledged as differing from a bovine and related species casein allergy (Fiocchi et al., 2010), is hypothesized by the "experts" to be a result of enzymatic insufficiency, most often attributed to Methylenetetrahydrofolate reductase (MTHFR) mutation. Following this hypothesis, many online support groups, sans clinical evidence, recommend avoidance of any and all medications due to the altered pharmacokinetics and pharmacodynamics of individuals with diagnosed or presumed MTHFR mutation (wellnessmama.org).

Recipient participants who used a healthcare provider as a decision-making resource when considering PAMS were more likely to consistently screen potential donors for their use of tobacco, alcohol, recreational drugs, over-the-counter medications, alternative modality therapies, and dietary supplements. Seeking decision-making support while considering PAMS from an IBCLC resulted in recipient participants being more likely to screen for alternative modality therapies and dietary supplements. Both healthcare providers and IBCLCs are required to complete a minimum of collegiate level anatomy, physiology, biology, chemistry, child development, nutrition, and universal precautions (International Board of Lactation Consultant Examiners, 2013). While this foundation is consistent and provides essential understanding of fundamental health considerations for lactation and infant feeding, the practice environment and specificity of lactation training for IBCLCs may account for the difference in screening priorities. Lactation-specific education in medical, nursing, nutrition, and dietetics curricula in the US is acknowledged to be insufficient to adequately support families, and is estimated to

average between 6 and 18 hours of education regarding lactogenesis, lactation pharmacokinetics, infant feeding behavior, and support of lactation with no requirement of continuing education (Academy of Breastfeeding Medicine, 2011; Bozette & Posner, 2013; Ogburn et al., 2005, 2011; Theurich & McCool, 2016). For comparison, a WIC Breastfeeding Peer Counselor is required to have a minimum of 16 hours of lactation-specific education, with 8-15 hours per year of continuing education (Metallinos-Katsaras et al., 2015). The lack of lactation specific education, and culture of risk management common to the US medical system may contribute to a broader and potentially more comprehensive screening recommendation, whereas lactation specific practice mediates the areas of greatest emphasis for screening, based on known characteristics of human milk donors and milk banking among IBCLCs and the client-specific needs assessment.

Research regarding patient self-advocacy has established three key elements in ensuring patient activation and participation in decisions about their care: 1) "knowledge is power", meaning that patients are aware of the state of health, treatment options, and benefit/risk potential, 2) foundational education leads to assertiveness on one's own behalf, 3) knowledge and assertiveness support mindful non-adherence to provider-planned treatments based on rational and context-rich evaluation of their unique situation (Brashers et al., 1999; Pickett et al., 2012). It is possible that this phenomenon is responsible for the greater consistency in screening for lifestyle factors that may make potential donors unsuitable, while simultaneously choosing to forego screening for communicable disease within this sample. Research duration while learning about PAMS of at least one week was associated with more consistent screening of potential donors for

all lifestyle related risk factors. The specific use of the Eats On Feets Resource for Informed Breastmilk Sharing (EOF Resource) resulted in more consistent screening of potential donors for recreational drug use and dietary supplements. Consultation of blogs or non-PAMS related resources was associated with more consistent screening of potential donors for recreational drugs, alternative modality therapies, and dietary supplements.

Heat treatment of donor milk. The prevalence of heat treatment of PAMS acquired donor milk by recipient families was so low within the sample, that analysis of influences upon it from this sample are unreliable. Without validation of stove top Holder pasteurization and flash heating of PAMS acquired donor milk, it is perhaps better to have families forego it. Heat activated *Bacillus cereus* bacterial spores are capable of causing diarrheal illness in infants, and without post-heat treatment testing (particularly with Holder method), it is not possible to determine its presence. Milk that has been hygienically collected, stored, thawed, and heated in accordance with ABM protocol #8, the standard for working or exclusively pumping families, has not been linked to date to infant illness.

Conceptualizing risk abatement in PAMS via socioecological model

Families engaged in PAMS are part of a complex, and evolving practice. Socioecological models provide an adaptable framework for consideration and facilitate understanding on the movement and relational aspects of the elements within the model, illustrated for PAMS specifically in Figure 2. Recipient participant behaviors as they

relate to the society-, group-, and individual-level factors within this framework have been described and analyzed in some cases for predictive value. These steps are essential for progressing a body of knowledge and evidence regarding the specific practice of PAMS exclusive from other forms of human milk allocation, and for providing foundations for further exploration, conceptual description, and education for health care professionals and PAMS participants to minimize risks and address stigma.

Society-level factors. The existence of PAMS speaks to the cultural norms in the US shifting from formula-feeding toward human milk feeding, whether at breast/chest, via parental expressed milk, or from acquired human milk. Even with an evident shift in parental decisions regarding infant feeding, the overwhelming presentation of PAMS and related practices in the media, and even by health professionals, is one of exceptional risk, engaged in by uninformed and self-serving individuals (Carter, Reyes-Foster, & Rogers, 2015). Limited access to human milk banks, cost prohibitive nature of BDM, and need hierarchies employed by milk banks to ensure the needs of the most health fragile infants are protected exclude many families from accessing BDM. These limitations are acknowledged by the priority structure employed for distribution at HMBANA, and reality that only infants who have medical need of human milk are guaranteed distribution (Kim & Unger, 2010; Lauwers & Swisher pp. 514, 2011). Gendered expectations of parenting and social/peer judgement and bias against deviation from dominant gender roles create pressures internally and externally for families without sufficient milk from a biological parent to sustain their infant. Worthiness of parenthood is judged based upon the ability of the parent(s) to achieve optimal goals for the health

and well-being of their infant, without adequate support in many cases (Apple, 2012; Cross-Barnet et al., 2012; Martucci, 2015; Turner & Norwood, 2014).

Group-level factors. Birth and health services have important impacts on antecedent factors and PAMS risk abatement behaviors exhibited by recipient participants. Practice and philosophical differences between the midwifery model of care and the obstetric model of care facilitate different patient relationships. The greater satisfaction expressed by patients within the midwifery model of care, and greater emphasis on education and anticipatory guidance, centering of the dyad in care coordination, and facilitation of patient/parent care decisions seems to create an environment of information exchange and education that supports more consistent screening of potential donors. Lack of directives in the appropriate clinical management of infants suspected of inadequate weight gain may be resulting in infant supplementation and ultimately in sabotaged parental lactation, leading to PAMS participation when advanced and appropriate lactation support may have prevented need for supplementation. Regardless of the nature of the antecedent factors of PAMS participation, HCPs should be prepared to advise families objectively and pragmatically in context-specific risk abatement.

Public and professional policies regarding breastfeeding are inconsistent, resulting in education, practice, and for the purpose of this discussion work environment and parental leave practices, that do not facilitate meeting infant feeding goals. While not immediately impactful on individual feeding decisions, public and professional policy

form critical aspects of practice culture and provider decision-making frameworks. Following policy ensures consistency in care, ideally, but fails to protect autonomy and individually appropriate care. Until policy from public health, health care professions, education systems, health care payers, and nutrition programs reflect family-centered, evidence-based goals that are enforceable and objectively trackable, the environment of insufficient lactation support is unlikely to change.

The complexity of the milk sharing community and related pool of donors (counter parts within the conceptual framework) likely contribute most of the variation in screening behaviors. Qualitative responses from the recipients in this sample yielded themes of "Frustration with Infrastructure", "Inadequate Health and Lactation Support", "Supportive Community", and "Mothering Community". Each of these themes, when considered in relation to the quantitative data of this dissertation, explains potential effects of the unique nature of PAMS on recipient participant behaviors. Infrastructure frustrations stemmed from inaccessibility of BDM and significant resistance from hospital providers to respect the choice to use donor milk, frustration with the management of logistics of finding donors and acquiring milk, and navigation of "rules" of PAMS communities online that were evident but not explicit. Lack of support from healthcare providers regarding participation in PAMS, the advisement of discontinuation of breastfeeding not founded in evidence, and assertions of liability or breach of professional ethics where no such breaches or liabilities exist heighten emotional burden in the decision-making process. Absence of BDM, coupled with scarcity of donors via PAMS may create pressure on recipient families that influences the depth and importance

of donor screening. Fears of insufficient milk, difficulty in finding suitable donors due to cultural complexity, and use of formula may influence consideration of risk and benefits in a way that would not, perhaps, been the case without these pressures.

By contrast, support from the PAMS community and the reported feelings of communal mothering of recipient infants provide an environment of respect and validation, as described by participants in this and more recent research (Reyes-Foster, Carter, & Hinojosa, 2015). Sentiments of hope, redemption, peace of mind, and experience of caring and concern from fellow PAMS participants were themes consistent with the findings of Reyes-Foster and colleagues and used to construct the theoretical framework for this research (Bond, unpublished). Many of the first donors sought by recipients within this sample were friends or family, contrary to the popular view of PAMS as strangers on the internet. Donors were viewed as "milk moms" and credited as completely altruistic. Frequent repetition of recipient views that mothers/women can be inherently trusted to guard the well-being of infants. "If she is feeding her own baby, her milk is safe" is also a common sentiment, although there are many circumstances wherein the safety of feeding outside the closed system of the dyad may not be true. The on-line platform of milk sharing and related resources, coupled with the significant familiarity with donors existing prior to or formed because of the PAMS relationship is of great importance to the impact of decision making. Peer-lead education is a highly effective means of activating health advocacy, building feelings of empowerment, and delivery of peer-education to impact health behaviors via the internet is equally effective (Lau et al., 2015; Pickett, 2012).

Families seeking information about PAMS are doing so overwhelmingly via on-line resources. The primary contact on the milk sharing networks are peers. Resources created to support families in making decisions about PAMS are not consistent in content, and have not been systematically analyzed by an objective and knowledgeable third party for foundation in evidence and accuracy. Peer groups choosing one particular network philosophy or another will continue to perpetuate the prevailing view of safety and necessity of screening and milk handling practices, perhaps increasing potential risks to recipient infants. In-depth and critical evaluation of the resources and receptivity of recipients to changes in behavior to reduce infant risk should be priorities for future research.

Related to peer education and on-line platforms is the use and/or consideration of home-made infant formulas. Nearly a quarter of participants in this sample had used or considered home-made formula. Several participants in the current sample described these formulae as the only acceptable alternative to human milk for their infants. Some included recipes and ingredients in qualitative responses including raw chicken liver puree, coconut oils, raw cow or goat milk, and "custom" vitamin mixtures purchased online. The potential risks of creating small batches of this "formula", without means of assuring nutritional adequacy and safety in other respects are arguable far in excess of those associated with PAMS acquired milk.

Individual-level factors. The distinguishing features of infants receiving milk via PAMS with respect to risk abatement behaviors were age of the infant, specifically

infants less than 6 months of age, formula intolerance, and infant allergies. Younger infants made up the majority of infants receiving milk via PAMS, and younger infants were more likely to influence more screening behaviors of recipient participants. Participants seeking milk for infants with known or suspected allergies or formula intolerance were more likely to screen for diet-related donor risks of aggravating these conditions. No descriptive attributes of recipient participants were found to impact screening behaviors, although this could have been the result of significant homogeneity within the sample. Feeding difficulties associated with latch or transfer during nursing were disclosed by many recipients, indicating that at least in part, attributes of the dyad as a feeding unit contribute to the antecedent factors of participation in PAMS. Attributes of donors in PAMS relationships, whether actual or perceived on the part of the recipient participants interacting with them, resulted in many instances of intimate relationships forming around the exchange of milk. These relationships likely affect the perceived need of recipients to screen donors. This alteration in proximity from a relational perspective results in a movement of certain counterparts in the pool of potential donors into the Individual-level from the Group-level.

By examining the risk-abatement practices in the context of a socioecological model of infant feeding practices specific to PAMS, a foundation has been established for the types, intensity, and specifics of some key screening behaviors. From these quantitative data, further study of the relationship-specific changes associated with PAMS relationships with qualitative inquiry, and more detailed, specific examination of the practices, precautions taken in screening and milk handling, alternative feeding

choices, and the knowledge-base and risk perceptions associated with donor screening via quantitative methods can be designed. Critical examination of the quality and content of PAMS resources accessed by participants is essential for describing possible improvements in dissemination of best practices and adherence. In-depth mixed-method tracking of recipient infant health status following receipt of PAMS acquired human milk will establish essential information for evaluating infant outcomes as compared to formula feeding or feeding exclusively by the biological parent. Building this body of evidence is necessary before public health policy or discussion of regulation of PAMS and associated practices is undertaken.

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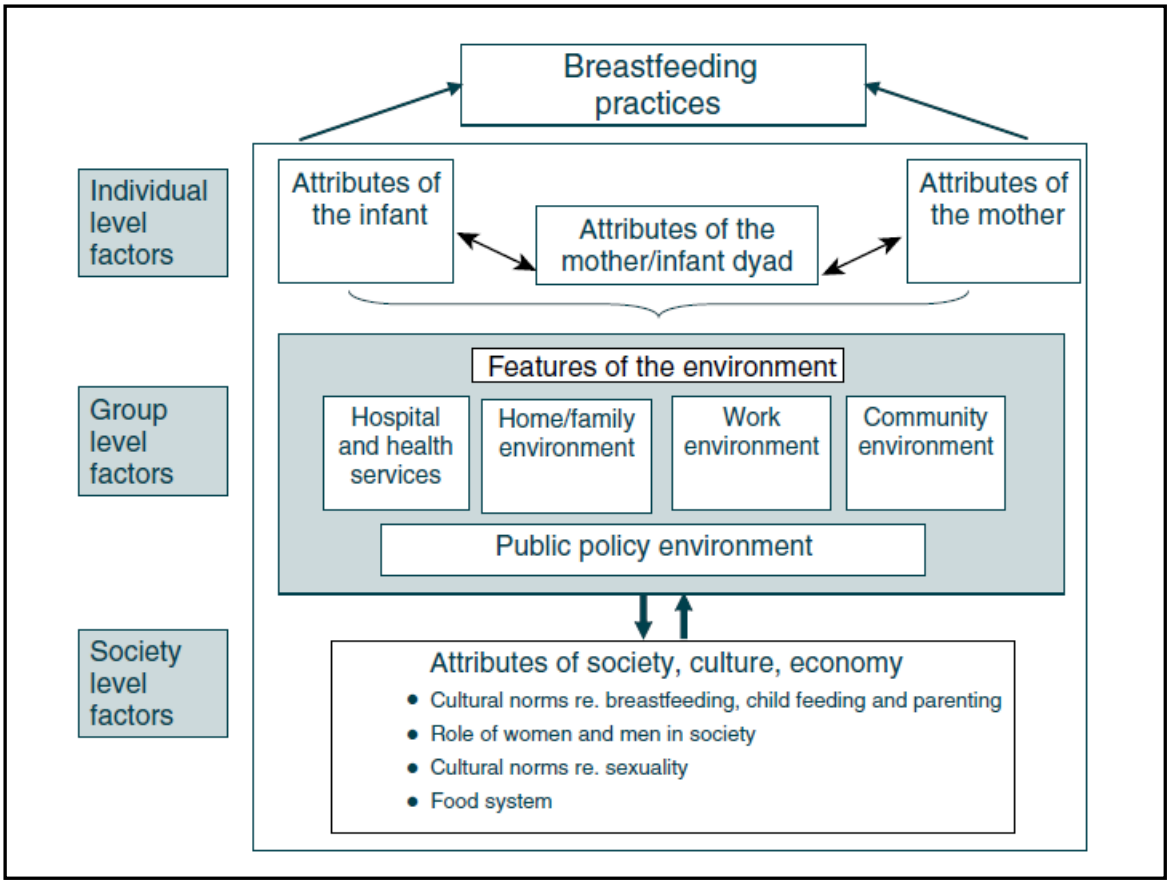
Appendix A

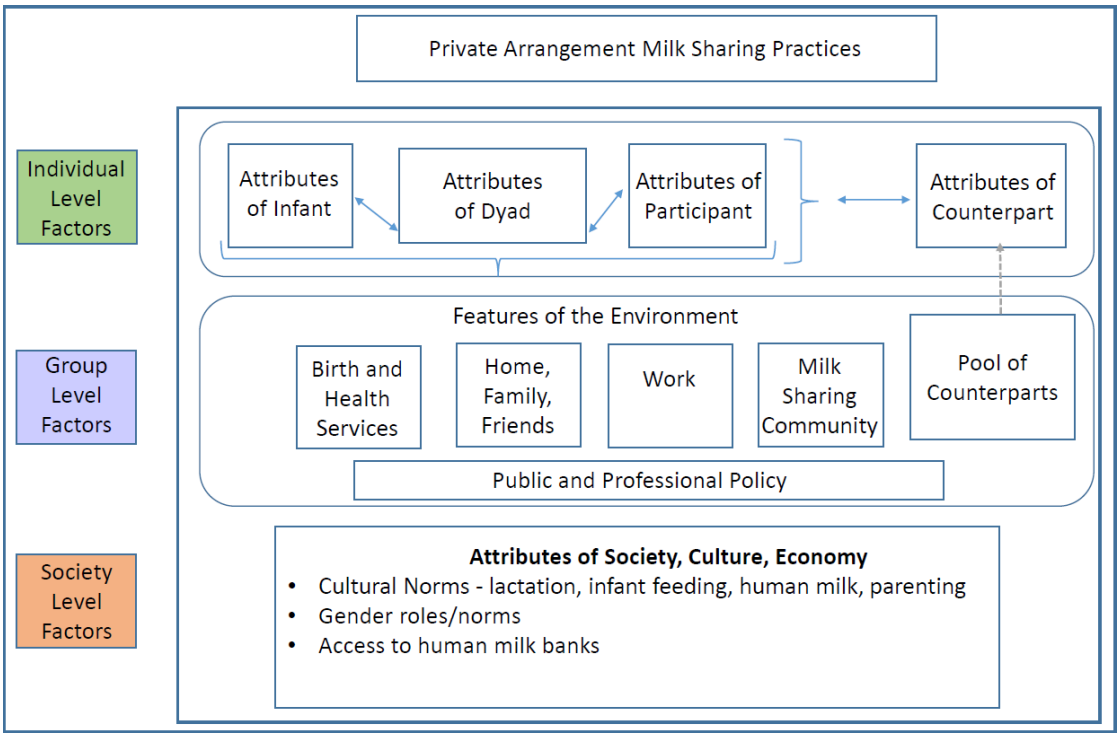
Figures

Figure 1. A conceptual framework of factors affecting breastfeeding practices (Hector et al., 2005)



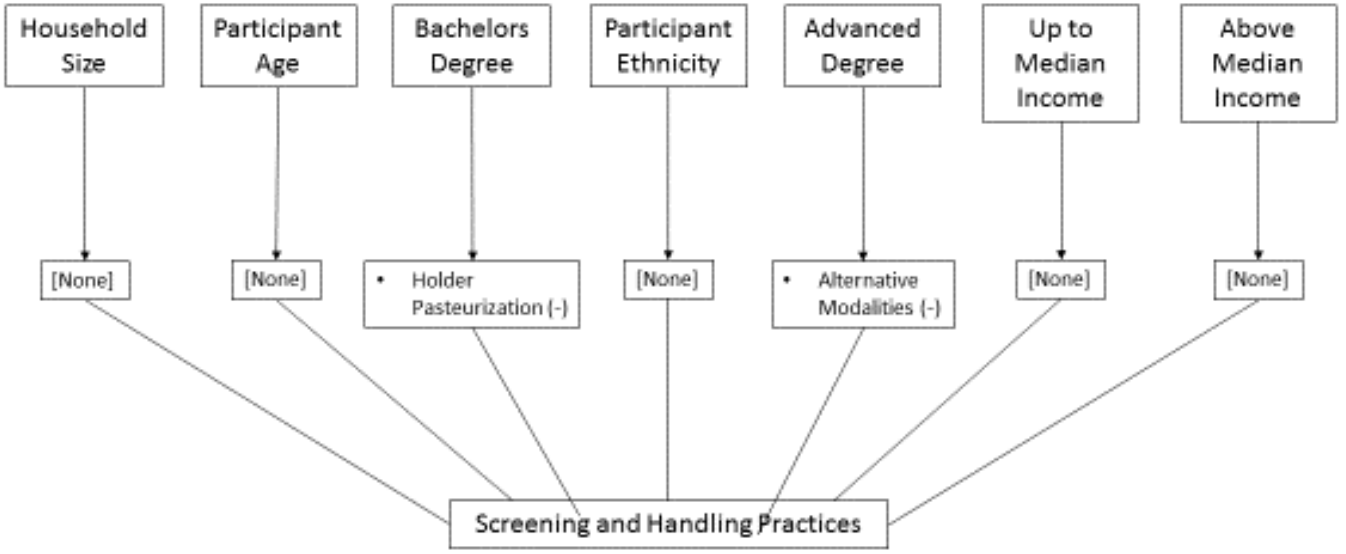
Socioecological relationship between factors known to impact the breastfeeding practices of contemporary mothers.

Figure 2. A conceptual framework of factors affecting PAMS practices.



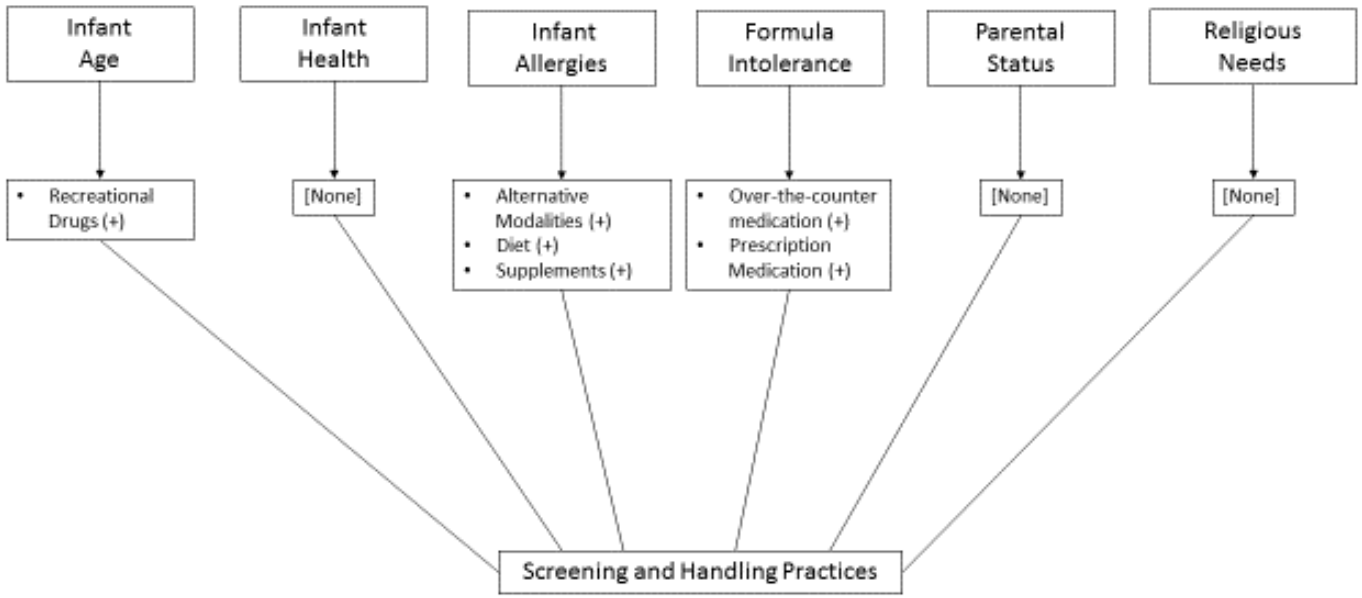
Socioecological model of factors affecting the practices associated with Private Arrangement Milk Sharing (PAMS). Theoretical framework tailored by qualitative descriptive analysis from a sample of US participants in PAMS from the foundational framework "A conceptual framework of factors affecting breastfeeding practices" (Hector et al., 2005).

Figure 3. Relationship between recipient participant characteristics and donor screening and risk abatement practices



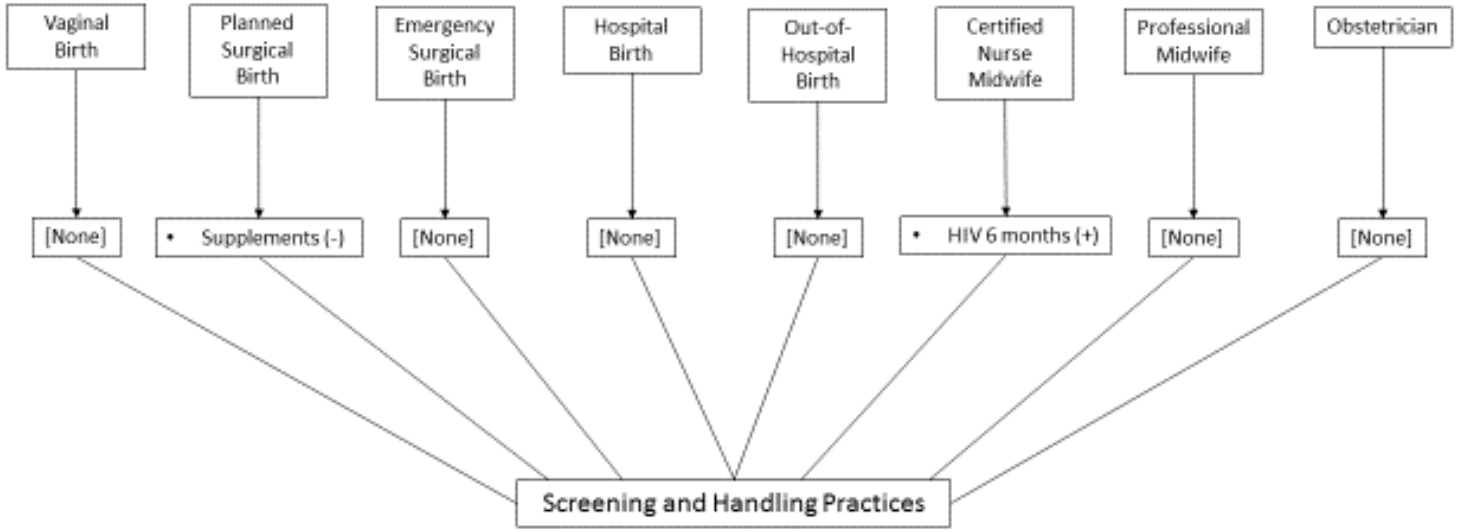
Participant completion of a college degree resulted in less likely screening for donor use of alternative modalities and use of Holder method pasteurization to address bacterial and viral load of the received donor milk. No other characteristics influenced donor screening and risk abatement practices.

Figure 4. Recipient infant characteristics and relationship to donor screening and risk abatement practices



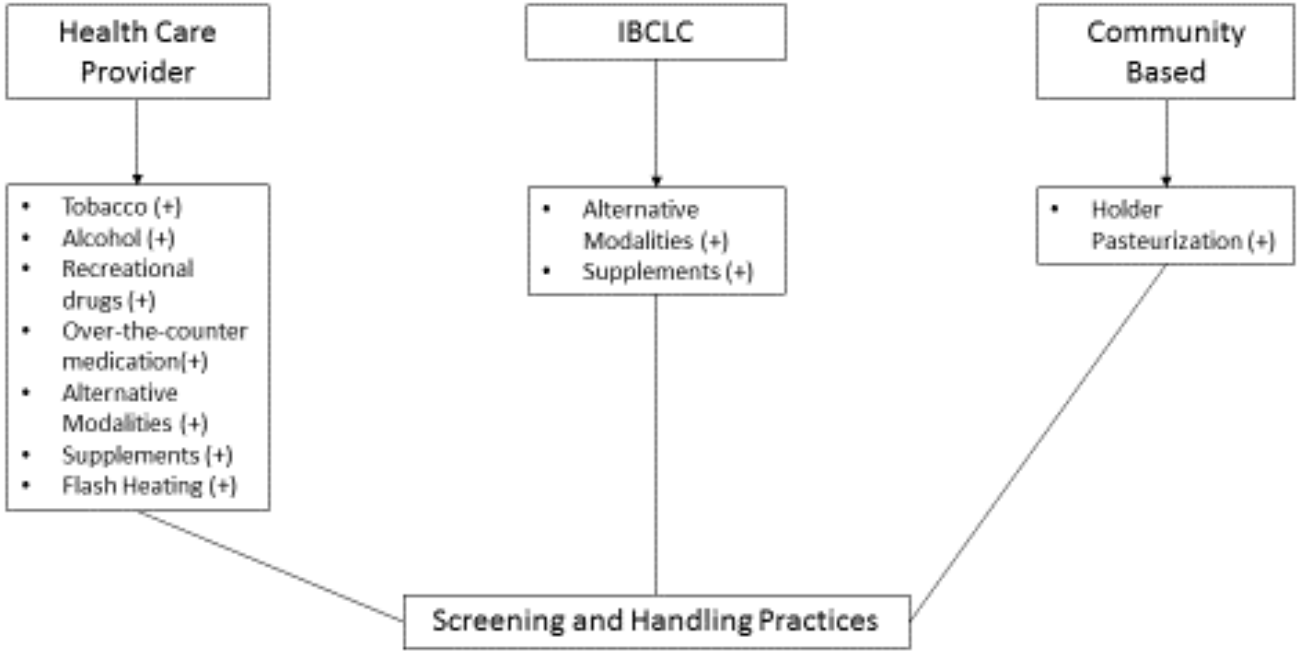
Infant age of less than 6 months resulted in more consistent screening of donors for the use of recreational drugs. Infant allergies were associated with more consistent screening of potential donors for use of alternative modality treatments, diet, and use of dietary supplements. Infants with formula intolerance resulted in more consistent screening of donors for the use of over-the-counter medications and prescription medications.

Figure 5. Recipient participant birth type, place and attendant in relation to donor screening and risk abatement practices



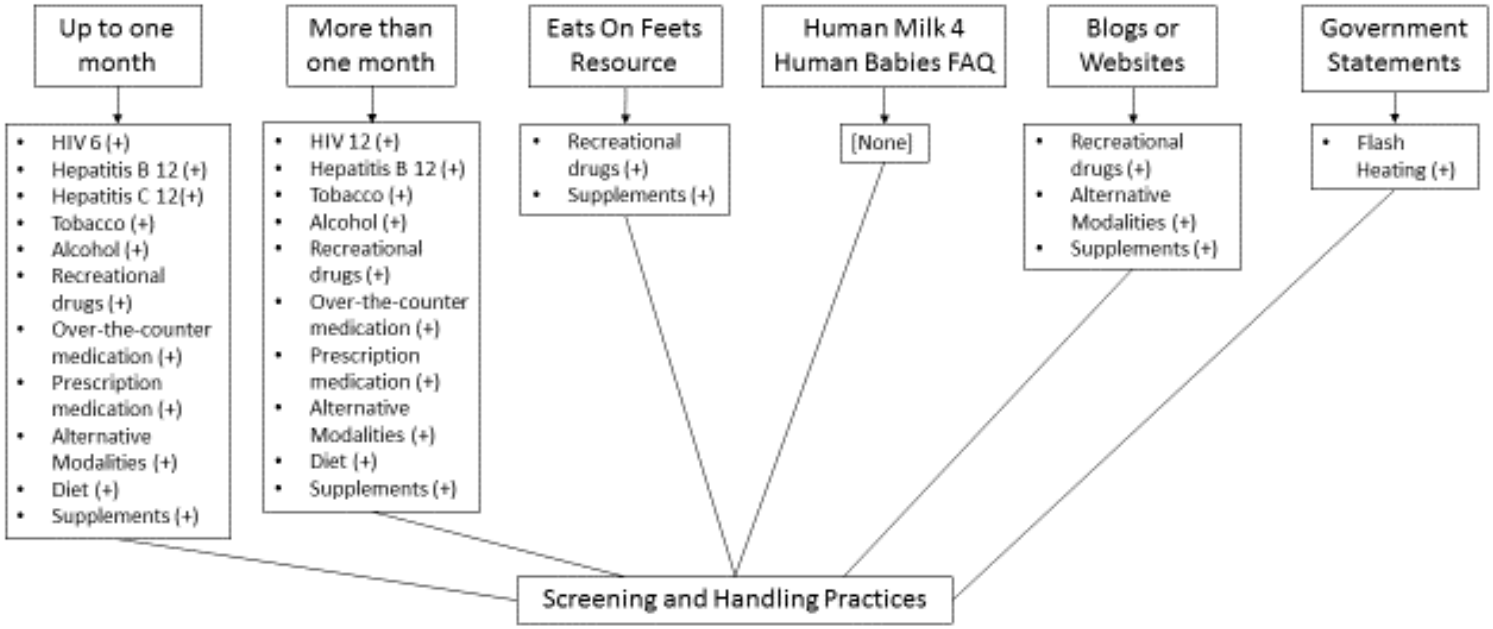
Recipient participants who gave birth via planned surgical birth were more consistent in screening potential donors for the use of dietary supplements.

Figure 6. Recipient participant lactation support and relationship to donor screening and risk abatement practices



Recipient participants who received lactation support from healthcare providers were more likely to consistently screen potential donors for use of tobacco, alcohol, recreational drugs, over-the-counter medications, alternative modality treatments, dietary supplements and to use flash heating to address potential pathogens in donated milk. Recipient participants who received lactation support from an IBCLC were more likely to consistently screen potential donors for use of dietary supplements and alternative modality therapies. Recipient participants who received lactation support from community-based sources were more likely to use Holder method pasteurization to address potential pathogens in donated milk.

Figure 7. Recipient participant research duration and resources and relationship to screening and risk abatement practices



Recipient participants who spent up to one month researching PAMS were more likely to screen donors for HIV blood tests within the last 6 months, hepatitis B and C testing within the last 12 months, use of tobacco, alcohol, recreational drugs, over-the-counter medications, prescription medication, alternative modalities, diet, and dietary supplements. Those who spent more than one month researching PAMS were more likely to consistently screen potential donors for HIV and hepatitis B results within the last 12 months, use of tobacco, alcohol, recreational drugs, over-the-counter medications, alternative modalities, diet, and dietary supplements. Those who used the Eats on Feets Resource for Informed Milk sharing were more likely to consistently screen for the use of recreational drugs and dietary supplements. Those who used blogs or websites not dedicated to PAMS were more likely to consistently screen for the use of

recreational drugs, dietary supplements, and alternative modalities. Participants who found the statements on milk sharing from government sources important were more likely to use flash heating to address potential pathogens in donated milk.

Table 1. Serological screening of potential human milk donors at milk banks

Pathogen Screened	Cohen	Groveslien	Lindemann
HIV	X	X	X
HTLV			
I	X	X	
II	X	X	
Hepatitis			
B	X	X	X
C	X	X	X
Syphillis	X		
CMV		X	X

Notes. HIV – Human Immunodeficiency Virus. HTLV – Human T-cell Leukemia Virus. CMV – Cytomegalo Virus

Table 2. Microbiology screening of banked human milk.

Species Screened	Landers	Lindemann	Almeida	Groveslien
Staphylococcus				
Coagulase negative	X			
aureus	X	X		
epidermidis	X	X		
Gram Negative Rods				
Lactose fermenting	X			
Non-lactose fermenting	X			
Oxidase positive	X			
Bacillus sp.	X	X		
Streptococcus	X			
Group B	X			
α hemolytic		X		
Enterrobacter sp.		X		
Diphtheroids	X			
Klebsiella sp.		X		
Escherichia coli		X		
Actineobacter sp.		X		
Serratia sp.		X		
Dornic Acidity			X	
Colony Forming Units				<100,000
BW <1500 g				<10,000

Note. Presence of "x" indicates the species was screened for in the model reviewed by the author.

Table 3. Questionnaire items, responses, and levels of the PAMS conceptual framework.

Questionnaire Item	Response Options	Level and Aspect of PAMS Conceptual Framework
How old is the child involved in milk sharing now?	0-3 months 4-6 months 7-9 months 10-12 months 12 or more months	Individual Level Factors – Attributes of the Infant
How old was the child during the milk sharing arrangement?	0-3 months 4-6 months 7-9 months 10-12 months 12 or more months	Individual Level Factors – Attributes of the Infant
How long was the child receiving milk from milk sharing?	0-3 months 4-6 months 7-9 months 10-12 months 12 or more months	Individual Level Factors – Attributes of the Infant
If the child received breastmilk PRIOR to milk sharing, how or from whom did you acquire the milk?	From the mother or birth parent From a milk bank From a wet nurse From a relative From a friend Other	Individual Level Factors – Attributes of Counterpart

How much of the diet was donor milk from milk sharing (by age)?	<20 % 21-40 % 41-60% 61-80% 80%>	Individual Level Factors – Attributes of the Infant
Are you the biological or birth parent of the child receiving milk through milk sharing?	Yes No	Individual Level Factors – Attributes of Participant
If you are not the biological or birth parent of the child receiving milk through milk sharing, what best describes your relationship?	Adoptive parent Legal guardian Other relative in custody Non-relative in custody Other (Please specify)	Individual Level Factors – Attributes of Participant
Are you the parent who gave birth to the child receiving milk through milk sharing?	Yes No	Individual Level Factors – Attributes of Participant
During the time of the milk sharing arrangement, was the mother or birth parent living?	Yes No	Group Level Factors – Attributes of Home, Family Friends
What type of birth did the child have?	Un-medicated vaginal birth Vaginal birth with epidural or other medication Induced vaginal birth Planned c-section Unplanned or emergency c-section Other (please specify) Unknown	Group Level Factors – Attributes of Birth and Health Services

What kind of birth professional attended the child's birth?	Professional, licensed, or community midwife Certified nurse midwife Obstetrician or Maternal Fetal Medicine Doctor Another kind of doctor (DO, FM, GP, NMD/ND etc.) No health care provider was present at the birth Unknown	Group level factors – Attributes of Birth and Health Services
Where was the child born?	At home At a birth center In a hospital Other (Please specify)	Group level factors – attributes of birth and health services
How often when meeting a new donor did you discuss the following:	HIV results within the last 6 months Hepatitis B results within the last 6 months Hepatitis C results within the last 6 months HIV results within the last 12 months Hepatitis B results within the last 12 months Hepatitis C results within the last 12 months Other communicable disease results Dietary needs or restrictions Dietary supplements	Group Level Factors – Pool of counterparts

		Medications (OTC, herbal, homeopathic, and prescribed) Caffeine consumption Alcohol consumption Tobacco use Recreational drug use Relationship and family life Health status of the baby Religion or philosophical beliefs Heat treatment of breastmilk Freezing of breastmilk Use of raw breastmilk	Individual Level Factors – Attributes of counterpart
	How important were the following reasons for choosing to participate in milk sharing? (Likert scale 1-5)	Religious or philosophical beliefs Beliefs about the rights of babies to have breast milk Baby was sick and could not nurse directly at the breast Sickness or needing to take medication not safe for BF Allergies to something in the mother or BF parent's diet Psychological or emotional distress BF was too painful The baby was intolerant of formula The baby did not gain weight fast enough The child had/has a serious health problem	Individual Level Factors – Attributes of the dyad

	The child had a birth defect or birth trauma Drug or alcohol abuse problem Mother/ BF parent did not have enough milk	Group Level Factors – Work and Milk sharing community Society Level Factors – Infant feeding norms
	A health professional advised not to breastfeed A health professional advised that BF would be best	
	Biologically normal way of feeding babies Safety concerns about formula Work or school made it impossible to meet the baby's needs	
What BF support, if any, was used at any point to make child feeding decisions? Select all that apply.	IBCLC in hospital or health organization IBCLC in private practice Another kind of lactation professional Community lactation support A doctor A nurse Midwife Family members Friends Other (Please specify) None	Group level Factors – Birth and health services

How much time did you spend researching private arrangement milk sharing?	Less than one day At least one day Several days At least a week At least a month Several months	Group level factors – Attributes of the milk sharing community
Before choosing milk sharing, what other options did you consider? Select all that apply.	Milk bank Wet nurse Commercial formula Home-Made formula Animal milk Other milk (coconut, almond, soy) Other (please specify)	Society Level Factors- Access to milk banks Cultural norms of infant feeding
How important were the following people in making the decision to participate in milk sharing?	Child's doctor Donor's doctor Other healthcare provider Public health worker or counselor Lactation consultant Peer BF support person	Group level factors – birth and health services
	Mother or birth parent Other biological parent Primary caregiver/partner Extended family or friends	Home, family, and friends
	Eats on Feets Resource Human Milk 4 Human Babies FAQs	Milk sharing community

	Other online BF resources	
	Government statements about milk sharing	Public and Professional Policy
How many people live in your household?	2 3 4 5 6 or more	Group level factors – attributes of home, family, friends
What year were you born?		Individual level factors – attributes of participant
What gender identity best describes you?	Woman Man Choose not to gender identify Other	Individual level factors – attributes of participant
What is your racial/ethnic background? (Select all that apply)	African American American Indian/Native Alaskan Asian Indian Latino/Hispanic Middle Eastern Native African Native Hawaiian/pacific islander White, not Hispanic More than one race Other indigenous (please specify) Other (please specify)	Individual level factors – attributes of participant

What is your marital status?	Single/never married Living wth partner Married Divorced Widowed	Individual level factors – attributes of participant
If in a relationship, what is the gender identity that best describes your partner?	Woman Man Choose not to gender identify Other (please specify)	Group level factors – attributes of home, family, friends
How many years of formal education have you completed?	Less than primary/high school diploma High/Primary School diploma Some college/university with no diploma Associates degree, professional certificate, apprenticeship, trade school Bachelor's degree Master's Degree Doctorate degree (PhD) Professional degree (MD, DVM, JD, DC etc)	Individual level factors – attributes of participant
How many years of formal education has your partner completed, if applicable?	Less than primary/high school diploma High/Primary School diploma Some college/university with no diploma	Group level factors – attributes of home, family, friends

	Associates degree, professional certificate, apprenticeship, trade school Bachelor's degree Master's Degree Doctorate degree (PhD) Professional degree (MD, DVM, JD, DC etc) Not applicable	
What is your combined household income (in USD)?	Less than 10,000 11,000-20,000 21,000-30,000 31,000-40,000 41,000-50,000 51,000-60,000 61,000-70,000 71,000-80,000 81,000-90,000 91,000-100,000 101,000-200,000 More than 200,000	Group-level factors – attributes of home, family, friends

Note. Individual-, Group-, and Society-level factors refer to the conceptual framework tailored to PAMS socioecological factors.

Table 4. Regression model variables

Independent Variables	Dependent Variables*
Parent education	HIV serology current within 6 months
Partner education	HBV serology current within 6 months
Marital Status	HCV serology current within 6 months
Family size	HIV serology current within 12 months
Household income	HBV serology current within 12 months
Ethnicity	HCV serology current within 12 months
Custodial status (adopted, surrogate, biological, guardian)	Tobacco Use
Infant age	Alcohol Use
Significant health complication of infant	Prescription drug use
Infant allergies (bovine milk proteins, soy, etc.)	Recreational drug use
Prenatal care provider	Dietary restrictions
Birth type	Nutrition supplements
Birth place	Caffeine consumption
Involvement of HCP in PAMS decision	Holder pasteurization
Use of lactation support	Flash Heating
Donor(s) were family or friends	
Donor(s) were unknown	

Time spent researching PAMS practices
Use of Eats on Feets resources
Use of Human Milk 4 Human Babies resources
Beliefs about commercial formula safety
Beliefs about home-made formula safety
Religious needs/beliefs about human milk

* Each cell is an individual model, each individual model run for all independent variables.

Table 5. Recipient participant, home, and recipient infant characteristics

Mean household size	4.85
Participant mean age	32.05
	n (%)
Birth parent deceased	2 (0.6)
Age of infant at start	
0-3 months	224 (64.6)
4-6 months	84 (24.2)
7-9 months	29 (8.4)
10-12 months	5 (1.4)
More than 12 months	5 (1.4)
Duration of feeding PAMS milk	
0-3 months	154 (44.1)
4-6 months	76 (21.8)
7-9 months	52 (14.9)
10-12 months	25 (7.2)
More than 12 months	32 (9.2)
Percent of recipient infant diet from PAMS	
Less than 20	90 (26.2)
21-40	62 (18.1)
41-60	56 (16.3)
61-80	38 (11.1)
81-100	91 (26.5)
Number of children receiving PAMS milk	
1	322 (92.8)
2	21 (6.1)
More than 2	4 (1.2)
Participant relationship to recipient infant	
Biological Mother	310 (89.9)
Biological Father	3 (0.9)
Adoptive Parent	21 (6.1)
Legal Guardian	3 (0.9)
Relative in custody	1 (0.3)
Non-relative in custody	7 (2.0)

Note. N= 351, missing 3

Table 6. Recipient participant demographic characteristics

Characteristic	Participants (n, %)
Race/Ethnicity	
African American	2 (0.6)
Asian (Not Chinese, Indian, Japanese)	1 (0.3)
Chinese	1 (0.3)
Indian	3 (0.9)
Latino/Hispanic	8 (2.5)
Middle Eastern	2 (0.6)
Native American/First Nation	5 (1.5)
Native Hawaiian/Pacific Islander	1 (0.3)
White, not Hispanic	281 (86.7)
More than one race	15 (4.6)
Other	4 (1.2)
Gender identity	
Woman	321 (99.1)
Man	1 (0.3)
Other/Non-binary	2 (0.6)
Marital/Relationship Status	
Single never married	14 (4.3)
Living with partner	34 (10.5)
Married	267 (82.4)
Divorced	6 (1.9)
Separated	3 (0.9)
Participant Education	
High School or less	22 (6.8)
Some college	59 (18.3)
Trade school or apprenticeship	14 (4.3)
Associate's Degree	36 (11.1)
Bachelor's Degree	105 (32.5)
Master's Degree	74 (22.9)
Doctorate or professional degree	13 (4.0)
Household Income	
Less than 30,000	45 (14.2)
31,000-50, 000	62 (19.6)
51, 000- 70,000	65 (20.5)
71,000-90,000	63 (15.2)
91,000-200,000	83 (26.2)
More than 200,000	14 (4.4)

Note. N=351, 34 missing

Table 7. Recipient participant partner characteristics

Characteristic	Participants (n, %)
Partner Gender identity	
Woman	12 (3.8)
Man	299 (95.5)
Other/Non-binary	1 (0.3)
Partner Education	
High School or less	39 (12.7)
Some college	68 (22.1)
Trade school or apprenticeship	23 (7.5)
Associate's Degree	20 (6.5)
Bachelor's Degree	101 (32.8)
Master's Degree	47 (15.3)
Doctorate or professional degree	10 (3.2)

Note. N = 351, 31 missing, 12 not applicable

Table 8. Recipient birth and lactation support

	n (%)
Birth Place	
Hospital	237 (67.7)
Free-standing birth center	24 (6.9)
Home birth	85 (24.3)
Hospital transport from planned home birth	3 (0.9)
Unplanned out-of-hospital birth	1 (0.3)
Birth Attendant	
Obstetrician or Maternal Fetal Medicine	158 (45.3)
Certified nurse midwife	76 (21.8)
Certified professional or licensed midwife	69 (19.8)
Lay midwife or community midwife	7 (2.0)
Other medical doctor	11 (3.2)
Multiple providers present	7 (2.0)
No provider or attendant hired	10 (2.9)
Delivery mode	
Vaginal	248 (71.1)
Planned surgical birth	37 (10.6)
Unplanned or emergency surgical birth	63 (18.1)
Unknown	1 (0.3)
Lactation Support	
Hospital-based IBCLC	198 (43.6)
Private practice IBCLC	122 (34.8)
Other lactation specialist	58 (16.5)
Community support group or organization	185 (52.7)
WIC representative	76 (21.7)
Doctor	120 (34.2)
Nurse	57 (16.2)
Nurse practitioner or physician assistant	44 (12.5)
Midwife	125 (35.6)
Doula	11 (3.1)
Family	137 (39.0)
Friends	221 (63.0)
Did not seek lactation support	15 (4.3)
Lactation resource used	
Books	6 (1.7)
On-line resources	286 (77.3)

Note. N = 370, 12 missing

Table 9. Donor screening and risk abatement practices ever used.

Practice	n (%)
Serological Screening	
HIV test within 6 months	74 (21.1)
Hepatitis B test within 6 months	73 (20.8)
Hepatitis C test within 6 months	71 (20.2)
HIV test within 12 months	97 (27.7)
Hepatitis B test within 12 months	71 (20.2)
Hepatitis C test within 12 months	70 (20.0)
Health and Lifestyle	
Dietary restriction or observance	125 (35.6)
Dietary supplements	128 (36.5)
Non-prescription medication	165 (47.1)
Herbal, homeopathic, or alternative modalities	96 (27.4)
Prescription medications	182 (51.9)
Tobacco use	163 (46.4)
Alcohol consumption	170 (48.4)
Relationship and family life	143 (41.0)
Recreational drug use	190 (54.1)
Health status of donor's child	163 (54.0)
Religious or philosophical beliefs	51 (14.5)
Milk Handling	
Frozen milk	275 (78.3)
Holder pasteurized	36 (10.3)
Flash heated	49 (14.0)

* N = 351, 33 missing or not applicable

Table 10. Routine screening and risk abatement practices.

Practice	n (%)
Health Screening	
HIV test within 6 months	54 (15.4)
Hepatitis B test within 6 months	52 (14.8)
Hepatitis C test within 6 months	50 (14.2)
HIV test within 12 months	76 (21.7)
Hepatitis B test within 12 months	53 (15.1)
Hepatitis C test within 12 months	52 (14.8)
Health and Lifestyle	
Dietary restriction or observance	100 (28.5)
Dietary supplements	103 (29.3)
Non-prescription medication	134 (38.3)
Herbal, homeopathic, or alternative modalities	69 (19.7)
Prescription medications	140 (46.2)
Tobacco use	142 (40.5)
Alcohol consumption	136 (38.7)
Relationship and family life	52 (17.2)
Recreational drug use	126 (36.1)
Health status of donor's child	164 (46.7)
Religious or philosophical beliefs	21 (6.0)
Milk Handling	
Frozen milk	260 (74.1)
Holder pasteurized	23 (6.6)
Flash heated	36 (10.3)

Note. N = 351, 4 missing or not applicable

Table 11. Introduction to and time spent learning about PAMS

	n (%)
Source	
Internet search	77 (22.1)
News or media	9 (2.6)
Sponsored advertisement on Facebook	10 (2.9)
Family or Friends	142 (40.8)
Lactation professional	31 (8.9)
Midwife	28 (8.0)
Doula	15 (4.3)
Birth circle or childbirth education class	9 (2.6)
Online – not Facebook	21 (6.0)
Breastfeeding support group in person	1 (0.3)
WIC	1 (0.3)
Medical Professional	3 (0.9)
Other	2 (0.6)
Time spent learning about PAMS	
Less than one day	88 (25.1)
At least one day	43 (12.3)
Several days, but less than one week	96 (27.5)
At least one week	73 (20.9)
At least one month	49 (14.0)

Note. N = 351, 9 missing

Table 12. Individuals and resources important to the decision making process to engage in PAMS.

Resources	Not involved n (%)	A little involved n (%)	Somewhat Involved n (%)	Involved n (%)	Very Involved n (%)
Mother or birth parent	37 (10.9)	4 (1.2)	2 (0.6)	1 (0.3)	286 (84.1)
Father or other biological parent	71 (20.9)	9 (2.6)	25 (7.4)	34 (10.0)	173 (50.9)
Partner/Primary care-giver	87 (24.8)	6 (1.8)	15 (4.5)	12 (3.6)	108 (32.0)
Family or friends	161 (47.4)	33 (9.7)	45 (13.2)	18 (5.3)	45 (13.2)
Recipient infant's doctor	215 (63.2)	27 (7.9)	23 (6.8)	11 (3.2)	16 (4.7)
Donor's doctor	256 (75.3)	7 (2.1)	5 (1.4)	2 (0.6)	1 (0.3)
Other healthcare provider	222 (65.3)	12 (3.5)	16 (4.6)	10 (2.9)	14 (4.1)
Public health worker or WIC	239 (70.5)	7 (2.1)	4 (1.1)	1 (0.3)	4 (1.2)
IBCLC	185 (54.4)	18 (5.3)	30 (8.8)	11 (3.2)	34 (10.0)
Other infant feeding support person	177 (52.2)	23 (6.8)	18 (5.3)	21 (6.0)	48 (14.2)
Government recommendations	236 (69.4)	13 (3.8)	7 (2.1)	2 (0.6)	5 (1.5)
Eats On Feets Resource	104 (30.6)	19 (5.6)	29 (8.5)	40 (11.8)	117 (34.4)
Human Milk 4 Human Babies	90 (26.5)	16 (4.7)	32 (9.4)	46 (13.8)	126 (37.1)
Modern Milk sharing	185 (54.4)	14 (4.1)	15 (4.4)	14 (4.1)	45 (13.2)
Infant feeding blogs, websites, or social media pages	95 (27.9)	29 (8.5)	41 (11.7)	45 (13.2)	104 (30.6)

Note. N = 351, 67 missing or not applicable

Table 13. Reasons for seeking milk through PAMS.

Reason	Not important/ Not Applicable n (%)	A little important n (%)	Somewhat Important n (%)	Important n (%)	Very Important n (%)
Infant illness made latching difficult	238 (67.8)	18 (5.1)	16 (4.6)	13 (3.7)	66 (18.8)
Insufficient milk from lactating parent	30 (8.5)	3 (0.9)	8 (2.3)	10 (2.8)	296 (84.3)
Induced lactation	319 (90.9)	3 (0.9)	6 (1.7)	2 (0.6)	21 (6.0)
Attempted re-lactation	315 (89.7)	3 (0.7)	6 (1.7)	2 (0.6)	18 (5.2)
Advised not to breastfeed	308 (87.7)	5 (1.4)	5 (1.4)	4 (1.1)	29 (8.3)
Illness/medication not safe	289 (82.3)	5 (1.4)	1 (0.3)	11 (3.1)	44 (12.5)
Infant allergy or sensitivity to parental diet	302 (86.0)	8 (2.3)	12 (3.4)	4 (1.1)	24 (6.9)
Infant weight gain too slow	185 (52.7)	11 (3.1)	20 (5.7)	30 (8.6)	104 (29.7)
Infant serious health problem	283 (80.6)	15 (4.3)	4 (1.1)	10 (2.9)	38 (10.9)
Congenital disorder or birth trauma	310 (88.3)	6 (1.7)	6 (1.7)	4 (1.1)	24 (6.9)
Drug or alcohol abuse	336 (95.7)	1 (0.3)	0	1 (0.3)	11 (3.1)
Work or school prevented maintaining adequate supply	293 (83.5)	6 (1.7)	11 (3.1)	12 (3.4)	28 (8.0)
Psychological or emotional distress	270 (76.9)	14 (4.0)	16 (4.6)	21 (6.0)	29 (8.3)
Latch was too painful	298 (84.9)	12 (3.4)	11 (3.1)	9 (2.6)	20 (5.7)

Note. N = 351, 3 missing

Table 14. Beliefs regarding human milk and importance to choosing PAMS.

Reason	Not important/ Not Applicable n (%)	A little important n (%)	Somewhat Important n (%)	Important n (%)	Very Important n (%)
Religious or philosophical beliefs	221 (63.0)	10 (2.8)	24 (6.8)	12 (3.4)	63 (17.9)
Rights of babies to have human milk	82 (23.4)	15 (4.3)	27 (7.7)	32 (9.1)	188 (53.6)
Biologically normal way to feed baby	38 (10.8)	7 (2.0)	20 (5.7)	40 (11.4)	240 (68.4)
Advised human milk best for baby	183 (52.1)	13 (3.7)	19 (5.4)	19 (5.4)	116 (33.1)
Safety concerns with commercial formula	80 (22.8)	13 (3.7)	29 (8.3)	38 (10.9)	190 (54.3)
Safety concerns about home-made formula	196 (55.8)	16 (4.6)	33 (9.4)	31 (8.9)	74 (21.1)

Note. N = 351, 3 missing

Table 15. Reasons for seeking milk through PAMS.

Reason	Not important/Not Applicable n (%)	A little important n (%)	Somewhat Important n (%)	Important n (%)	Very Important n (%)
Infant illness made latching difficult	238 (67.8)	18 (5.1)	16 (4.6)	13 (3.7)	66 (18.8)
Insufficient milk from lactating parent	30 (8.5)	3 (0.9)	8 (2.3)	10 (2.8)	296 (84.3)
Induced lactation	319 (90.9)	3 (0.9)	6 (1.7)	2 (0.6)	21 (6.0)
Attempted re-lactation	315 (89.7)	3 (0.7)	6 (1.7)	2 (0.6)	18 (5.2)
Advised not to breastfeed	308 (87.7)	5 (1.4)	5 (1.4)	4 (1.1)	29 (8.3)
Unsafe illness/medication	289 (82.3)	5 (1.4)	1 (0.3)	11 (3.1)	44 (12.5)
Infant allergy or sensitivity to parental diet	302 (86.0)	8 (2.3)	12 (3.4)	4 (1.1)	24 (6.9)
Infant weight gain too slow	185 (52.7)	11 (3.1)	20 (5.7)	30 (8.6)	104 (29.7)
Infant serious health problem	283 (80.6)	15 (4.3)	4 (1.1)	10 (2.9)	38 (10.9)
Congenital disorder or birth trauma	310 (88.3)	6 (1.7)	6 (1.7)	4 (1.1)	24 (6.9)
Drug or alcohol abuse	336 (95.7)	1 (0.3)	0	1 (0.3)	11 (3.1)
Work/school prevented maintaining adequate supply	293 (83.5)	6 (1.7)	11 (3.1)	12 (3.4)	28 (8.0)
Psychological or emotional distress	270 (76.9)	14 (4.0)	16 (4.6)	21 (6.0)	29 (8.3)
Latch was too painful	298 (84.9)	12 (3.4)	11 (3.1)	9 (2.6)	20 (5.7)

Note. N = 351, 3 missing

Table 16. Infant feeding options considered prior to participation in PAMS.

Feeding option	n (%)
Considered only PAMS	67 (19.1)
Human milk bank	63 (17.9)
Wet nurse	13 (3.7)
Home-made formula	82 (23.4)
Commercial formula	237 (67.5)
Animal milks	30 (7.2)
Plant or nut “milks”	20 (5.7)

Note. N = 351, missing 2

Table 17. Regression table – Individual-level descriptive characteristics

HIV 6 months	B	S.E.	Wald	df	Sig.	Odds Ratio	95% C.I. for Odds Ratio Lower	Upper
Education								
Less than BS	--	--	0.107	2	0.948	--	--	--
BS	0.043	0.427	0.010	1	0.920	1.044	0.452	2.411
Advanced Degree	0.154	0.491	0.099	1	0.753	1.167	0.446	3.052
Household Size	0.043	0.354	0.015	1	0.903	1.044	0.522	2.089
Ethnicity	0.104	0.522	0.039	1	0.843	1.109	0.399	3.086
Income	--	--	1.021	2	0.600	--	--	--
Median Income	0.318	0.450	0.500	1	0.480	1.375	0.569	3.325
Above Median	-0.055	0.590	0.009	1	0.926	0.947	0.298	3.011
Participant Age	0.016	0.032	0.238	1	0.625	1.016	0.954	1.081
Hepatitis B 6 months								
Education								
Less than BS	--	--	0.893	2	0.640	--	--	--
BS	-0.414	0.438	0.892	1	0.345	0.661	0.280	1.561
Advanced Degree	-0.254	0.497	0.260	1	0.610	0.776	0.293	2.056
Household Size	0.164	0.370	0.195	1	0.659	1.178	0.570	2.435
Ethnicity	-0.028	0.527	0.003	1	0.958	0.973	0.346	2.733
Income	--	--	2.893	2	0.235	--	--	--
Median Income	0.617	0.466	1.750	1	0.186	1.853	0.743	4.624
Above Median	0.000	0.638	0.000	1	1.000	1.000	0.286	3.495
Participant Age	0.024	0.032	0.552	1	0.458	1.024	0.962	1.091
Hepatitis C 6 Months								
Education								
Less than BS	--	--	0.449	2	0.799	--	--	--
BS	-0.243	0.435	0.312	1	0.577	0.784	0.334	1.841
Advanced Degree	-0.308	0.510	0.365	1	0.546	0.735	0.270	1.997
Household Size	0.247	0.376	0.431	1	0.511	1.280	0.612	2.676
Ethnicity	-0.057	0.529	0.011	1	0.915	0.945	0.335	2.663

Income	--	--	2.277	2	0.320	--	--	--
Median Income	0.551	0.468	1.390	1	0.238	1.736	0.694	4.341
Above Median	0.000	0.638	0.000	1	1.000	1.000	0.287	3.490
Participant Age	0.033	0.032	1.076	1	0.300	1.034	0.971	1.101
HIV 12 months								
Education								
Less than BS	--	--	0553	2	0.758	--	--	--
BS	-0.278	0.376	0.546	1	0.460	0.758	0.363	1.583
Advanced Degree	-0.202	0.442	0.209	1	0.648	0.817	0.343	1.944
Household Size	-0.296	0.316	0.875	1	0.350	0.744	0.400	1.383
Ethnicity	-0.280	0.431	0.422	1	0.516	0.756	0.325	1.759
Income	--	--	4.960	2	0.084	--	--	--
Median Income	0.386	0.387	0.993	1	0.319	1.470	0.689	3.139
Above Median	-0.586	0.559	1.100	1	0.294	0.556	0.186	1.664
Participant Age	0.019	0.028	0.448	1	0.503	1.019	0.965	1.076
Hepatitis B 12 Months								
Education								
Less than BS	--	--	0.391	2	0.822	--	--	--
BS	-0.079	0.431	0.034	1	0.854	0.924	0.397	2.149
Advanced Degree	-0.214	0.510	0.176	1	0.675	1.238	0.456	3.362
Household Size	0.268	0.370	0.523	1	0.469	1.307	0.633	2.698
Ethnicity	0.005	0.527	0.000	1	0.992	1.005	0.358	2.821
Income	--	--	3.687	2	0.158	--	--	--
Median Income	0.133	0.430	0.095	1	0.758	1.142	0.491	2.655
Above Median	-0.977	0.682	2.055	1	0.152	0.376	0.099	1.432
Participant Age	0.004	0.033	0.014	1	0.906	0.935	0.935	1.062
Hepatitis C 12 months								
Education								
Less than BS	--	--	0.406	2	0.816	--	--	--
BS	-0.081	0.431	0.035	1	0.851	0.923	0.397	2.145

Advanced Degree	0.217	0.509	0.183	1	0.669	1.243	0.458	3.370
Household Size	0.272	0.370	0.541	1	0.462	1.313	0.636	2.710
Ethnicity	0.008	0.527	0.000	1	0.988	1.008	0.359	2.829
Income	--	--	3.549	2	0.170	--	--	--
Median Income	0.130	0.430	0.092	1	0.762	1.139	0.490	2.648
Above Median	-0.958	0.680	1.982	1	0.159	0.384	0.101	1.456
Participant Age	0.003	0.033	0.009	1	0.924	0.997	0.935	1.063
Routine Tobacco Screening								
Education								
Less than BS	--	--	0.638	2	0.727	--	--	--
BS	0.056	0.313	0.033	1	0.857	1.058	0.573	1.952
Advanced Degree	-0.207	0.372	0.310	1	0.577	0.813	0.392	1.686
Household Size	-0.003	0.262	0.000	1	0.991	0.997	0.596	1.667
Ethnicity	-0.292	0.374	0.609	1	0.435	0.747	0.359	1.554
Income	--	--	1.676	2	0.433	--	--	--
Median Income	0.114	0.319	0.127	1	0.722	1.120	0.599	2.095
Above Median	-0.322	0.421	0.584	1	0.445	0.725	0.318	1.654
Participant Age	0.006	0.024	0.066	1	0.797	1.006	0.960	1.054
Routine Alcohol Screening								
Education								
Less than BS	--	--	1.529	2	0.465	--	--	--
BS	-0.131	0.314	0.173	1	0.677	0.878	0.475	1.623
Advanced Degree	-0.546	0.378	1.458	1	0.227	0.634	0.302	1.329
Household Size	-0.034	0.265	0.016	1	0.899	0.967	0.575	1.625
Ethnicity	-0.270	0.376	0.516	1	0.473	0.764	0.366	1.594
Income	--	--	0.644	2	0.725	--	--	--
Median Income	-0.050	0.320	0.024	1	0.877	0.952	0.508	1.781
Above Median	-0.305	0.423	0.519	1	0.471	0.737	0.322	1.690
Participant Age	-0.001	0.024	0.001	1	0.970	1.001	0.955	1.049
Routine Recreational Drugs								

Education								
Less than BS	--	--	0.407	2	0.816	--	--	--
BS	-0.146	0.321	0.207	1	0.649	0.864	0.461	1.120
Advanced Degree	-0.240	0.387	0.384	1	0.536	0.787	0.368	1.681
Household Size	0.287	0.273	1.107	1	0.293	1.332	0.781	2.272
Ethnicity	0.090	0.395	0.052	1	0.819	1.094	0.505	2.372
Income	--	--	3.181	2	0.204	--	--	--
Median Income	0.219	0.326	0.451	1	0.502	1.245	0.657	2.358
Above Median	-0.420	0.452	0.865	1	0.352	0.657	0.271	1.592
Participant Age	-0.042	0.025	2.722	1	0.099	0.959	0.959	1.008
Routine Over the Counter								
Education								
Less than BS	--	--	1.002	2	0.606	--	--	--
BS	-0.099	0.315	0.098	1	0.754	0.906	0.489	1.680
Advanced Degree	-0.364	0.375	0.941	1	0.332	0.695	0.333	1.450
Household Size	0.032	0.264	0.015	1	0.903	1.033	0.616	1.732
Ethnicity	-0.107	0.377	0.081	1	0.776	0.898	0.429	1.882
Income	--	--	0.959	2	0.619	--	--	--
Median Income	0.202	0.323	0.393	1	0.531	1.224	0.650	2.305
Above Median	-0.087	0.424	0.042	1	0.838	0.917	0.399	2.105
Participant Age	-0.022	0.024	0.860	1	0.354	0.978	0.933	1.025
Routine Prescription								
Education								
Less than BS	--	--	1.243	2	0.537	--	--	--
BS	0.012	0.312	0.002	1	0.968	1.012	0.550	1.865
Advanced Degree	-0.336	0.368	0.833	1	0.361	0.714	0.347	1.471
Household Size	0.074	0.260	0.081	1	0.776	1.077	0.647	1.793
Ethnicity	-0.220	0.374	0.344	1	0.558	0.803	0.386	1.672
Income	--	--	1.382	2	0.501	--	--	--
Median Income	0.283	0.319	0.791	1	0.374	1.328	0.711	2.479

Above Median	-0.021	0.414	0.002	1	0.960	0.980	0.435	2.205
Participant Age	-0.004	0.024	0.024	1	0.876	0.996	0.951	1.044
Routine Alternative Modalities								
Education								
Less than BS	--	--	6.734	2	0.034	--	--	--
BS	-0.207	0.362	0.328	1	0.567	0.813	0.399	1.653
Advanced Degree (8)	-1.307	0.519	6.352	1	0.012	0.271	0.098	0.748
Household Size	-0.209	0.322	0.423	1	0.515	0.811	0.432	1.524
Ethnicity	0.043	0.467	0.009	1	0.926	1.044	0.418	2.605
Income	--	--	0.493	2	0.781	--	--	--
Median Income	-0.010	0.371	0.001	1	0.979	0.990	0.479	2.049
Above Median	0.286	0.502	0.325	1	0.569	1.331	0.498	3.559
Participant Age	-0.029	0.030	0.906	1	0.341	0.972	0.916	1.031
Routine Diet								
Education								
Less than BS	--	--	0.432	2	0.806	--	--	--
BS	-0.175	0.336	0.272	1	0.602	0.839	0.435	1.620
Advanced Degree	-0.249	0.408	0.372	1	0.542	0.780	0.351	1.735
Household Size	0.242	0.287	0.710	1	0.399	1.274	0.726	2.237
Ethnicity	-0.343	0.397	0.744	1	0.388	0.710	0.326	1.547
Income	--	--	1.537	2	0.464	--	--	--
Median Income	0.194	0.340	0.324	1	0.569	1.214	0.623	2.365
Above Median	-0.263	0.471	0.311	1	0.577	0.769	0.305	1.937
Participant Age	-0.043	0.027	2.567	1	0.109	0.958	0.909	1.010
Routine Supplements								
Education								
Less than BS	--	--	0.180	2	0.914	--	--	--
BS	-0.034	0.332	0.010	1	0.919	0.967	0.504	1.854
Advanced Degree	-0.164	0.405	0.164	1	0.686	0.849	0.384	1.878
Household Size	-0.139	0.283	0.242	1	0.623	0.870	0.500	1.514
Ethnicity	0.094	0.412	0.052	1	0.820	1.099	0.490	2.463

Income	--	--	4.003	2	0.135	--	--	--
Median Income	0.247	0.338	0.532	1	0.466	1.280	0.660	2.483
Above Median	-0.520	0.476	1.193	1	0.275	0.594	0.234	1.512
Participant Age	-0.041	0.027	2.309	1	0.129	0.960	0.911	1.012
Routine Holder Pasteurization								
Education								
Less than BS	--	--	6.673	2	0.036	--	--	--
BS (4)	-1.551	0.688	5.085	1	0.024	0.212	0.055	0.816
Advanced Degree	-1.555	0.857	3.289	1	0.070	0.211	0.039	1.134
Household Size	-0.399	0.517	0.595	1	0.441	0.671	0.244	1.849
Ethnicity	1.031	1.064	0.940	1	0.332	2.805	0.349	22.566
Income	--	--	1.257	2	0.533	--	--	--
Median Income	0.194	0.552	0.124	1	0.725	1.214	0.412	3.581
Above Median	-0.998	1.155	0.747	1	0.387	0.368	0.038	3.543
Participant Age	-0.019	0.046	0.046	1	0.675	0.981	0.896	1.074
Routine Flash Heating								
Education								
Less than BS	--	--	2.876	2	0.237	--	--	--
BS (7)	-0.897	0.531	2.852	1	0.091	0.408	0.144	1.155
Advanced Degree	-0.497	0.636	0.611	1	0.435	0.609	0.175	2.116
Household Size	0.079	0.436	0.033	1	0.856	1.083	0.461	2.544
Ethnicity	-0.748	0.525	2.026	1	0.155	0.473	0.169	1.326
Income								
< Median	--	--	2.168	2	0.338	--	--	--
Median	-0.254	0.465	0.299	1	0.585	0.776	0.312	1.930
> Median	-1.274	0.866	2.163	1	0.141	0.280	0.051	1.528
Participant Age	-0.037	0.038	0.974	1	0.324	0.964	0.895	1.037

Note. Dependent variables are coded "1" to indicate routine screening defined as participant response of "Always" or "Almost Always" and "0" to indicate "not-routine" screening defined as participant responses of "Never", "Rarely", or 'Sometimes." Predictor variable "ethnicity" is dummy coded "0" for "Non-White" and "1" for "White."

Table 18. Infant health and parental status

							95% C.I. for EXP(B)	
HIV 6 months	**B**	**S.E.**	**Wald**	**df**	**Sig.**	**Exp(B)**	**Lower**	**Upper**
Infant Age > 6 months	.791	.623	1.610	1	.204	2.205	.650	7.482
Infant Health	-.139	.333	.174	1	.676	.870	.453	1.671
Infant Allergies	.144	.556	.067	1	.795	1.155	.388	3.437
Formula Intolerance	.379	.344	1.213	1	.271	1.460	.744	2.864
Parental Status	.457	1.075	.181	1	.671	1.580	.192	12.996
Religious needs	.037	.367	.010	1	.920	1.038	.505	2.132
Hepatitis B 6 months								
Infant Age > 6 months	.778	.625	1.550	1	.213	2.177	.640	7.412
Infant Health	.250	.327	.587	1	.444	1.284	.677	2.437
Infant Allergies	.516	.534	.935	1	.334	1.675	.589	4.766
Formula Intolerance	.069	.362	.036	1	.850	1.071	.527	2.176
Parental Status	-.377	.822	.211	1	.646	.686	.137	3.433
Religious needs	.018	.370	.002	1	.960	1.019	.493	2.105
Hepatitis C 6 Months								
Infant Age > 6 months	.720	.626	1.324	1	.250	2.054	.603	7.002
Infant Health	.091	.336	.073	1	.787	1.095	.567	2.117
Infant Allergies	.547	.534	1.047	1	.306	1.728	.606	4.925
Formula Intolerance	.159	.364	.190	1	.663	1.172	.574	2.394
Parental Status	-.431	.822	.276	1	.600	.650	.130	3.251
Religious needs	.093	.372	.062	1	.804	1.097	.529	2.275
HIV 12 months								
Infant Age > 6 months	.667	.501	1.775	1	.183	1.949	.730	5.202
Infant Health	.088	.285	.095	1	.757	1.092	.624	1.911
Infant Allergies	.054	.514	.011	1	.916	1.056	.385	2.893
Formula Intolerance	.113	.310	.133	1	.715	1.120	.610	2.055
Parental Status	.866	1.069	.656	1	.418	2.378	.293	19.326
Religious needs	-.269	.337	.634	1	.426	.765	.395	1.481
Hepatitis B 12 Months								
Infant Age > 6 months	.433	.553	.613	1	.434	1.542	.521	4.561

Infant Health	.057	.328	.030	1	.861	1.059	.557	2.015
Infant Allergies	-.077	.598	.016	1	.898	.926	.287	2.992
Formula Intolerance	.213	.352	.368	1	.544	1.238	.621	2.465
Parental Status	.446	1.071	.173	1	.677	1.562	.191	12.755
Religious needs	-.054	.375	.021	1	.885	.947	.454	1.976
Hepatitis C 12 months								
Infant Age > 6 months	.409	.553	.547	1	.459	1.506	.509	4.455
Infant Health	-.005	.333	.000	1	.987	.995	.518	1.911
Infant Allergies	-.002	.599	.000	1	.997	.998	.308	3.231
Formula Intolerance	.132	.359	.135	1	.713	1.141	.565	2.304
Parental Status	.420	1.071	.154	1	.695	1.523	.187	12.427
Religious needs	-.013	.376	.001	1	.973	.988	.473	2.062
Routine Tobacco Screening								
Infant Age > 6 months	.747	.395	3.572	1	.059	2.111	.973	4.582
Infant Health	.081	.245	.111	1	.739	1.085	.672	1.752
Infant Allergies	.771	.450	2.938	1	.086	2.162	.895	5.219
Formula Intolerance	.366	.266	1.895	1	.169	1.441	.857	2.425
Parental Status	1.921	1.082	3.151	1	.076	6.828	.819	56.949
Religious needs	-.207	.280	.544	1	.461	.813	.469	1.409
Routine Alcohol Screening								
Infant Age > 6 months	.656	.398	2.713	1	.100	1.927	.883	4.208
Infant Health	.028	.248	.013	1	.911	1.028	.633	1.671
Infant Allergies	.824	.449	3.363	1	.067	2.279	.945	5.495
Formula Intolerance	.504	.267	3.567	1	.059	1.656	.981	2.794
Parental Status	1.834	1.089	2.838	1	.092	6.261	.741	52.910
Religious needs	-.338	.287	1.384	1	.239	.713	.406	1.252
Routine Recreational Drugs								
Infant Age > 6 months	1.212	.473	6.555	1	.010	3.359	1.329	8.491
Infant Health	-.150	.255	.344	1	.558	.861	.522	1.420
Infant Allergies	1.023	.455	5.048	1	.025	2.782	1.140	6.794
Formula Intolerance	.402	.272	2.187	1	.139	1.494	.878	2.545
Parental Status	1.731	1.088	2.529	1	.112	5.647	.669	47.672
Religious needs	.020	.288	.005	1	.945	1.020	.580	1.792
Routine Over the Counter								

Infant Age > 6 months	.355	.381	.865	1	.352	1.426	.675	3.011
Infant Health	.178	.246	.521	1	.471	1.195	.737	1.936
Infant Allergies	.817	.454	3.238	1	.072	2.264	.930	5.516
Formula Intolerance	.689	.265	6.762	1	.009	1.991	1.185	3.347
Parental Status	1.077	.832	1.674	1	.196	2.936	.574	15.006
Religious needs	-.073	.281	.066	1	.797	.930	.536	1.615
Routine Prescription								
Infant Age > 6 months	.473	.368	1.647	1	.199	1.604	.779	3.302
Infant Health	-.005	.241	.000	1	.983	.995	.620	1.597
Infant Allergies	.519	.445	1.361	1	.243	1.681	.702	4.022
Formula Intolerance	.515	.263	3.822	1	.051	1.674	.999	2.804
Parental Status	1.209	.816	2.193	1	.139	3.350	.676	16.596
Religious needs	-.165	.274	.364	1	.546	.848	.495	1.450
Routine Alternative Modalities								
Infant Age > 6 months	.343	.479	.512	1	.474	1.409	.551	3.607
Infant Health	.259	.294	.777	1	.378	1.296	.728	2.308
Infant Allergies	1.475	.456	10.457	1	.001	4.370	1.788	10.682
Formula Intolerance	.030	.328	.008	1	.928	1.030	.541	1.960
Parental Status	.992	1.098	.817	1	.366	2.698	.314	23.188
Religious needs	.049	.333	.022	1	.882	1.051	.547	2.020
Routine Diet								
Infant Age > 6 months	.134	.415	.105	1	.746	1.144	.507	2.579
Infant Health	.079	.272	.085	1	.770	1.082	.636	1.843
Infant Allergies	1.950	.489	15.877	1	.000	7.025	2.693	18.329
Formula Intolerance	.398	.288	1.903	1	.168	1.489	.846	2.619
Parental Status	1.578	1.149	1.887	1	.170	4.844	.510	46.028
Religious needs	-.222	.317	.490	1	.484	.801	.430	1.491
Routine Supplements								
Infant Age > 6 months	.530	.434	1.490	1	.222	1.700	.725	3.982
Infant Health	.041	.265	.024	1	.878	1.042	.620	1.751
Infant Allergies	1.424	.461	9.558	1	.002	4.154	1.684	10.246
Formula Intolerance	.444	.281	2.510	1	.113	1.560	.900	2.703
Parental Status	1.569	1.104	2.021	1	.155	4.803	.552	41.798

Religious needs	.177	.296	.359	1	.549	1.194	.669	2.131
Routine Holder Pasteurization								
Infant Age > 6 months	-.194	.654	.088	1	.766	.823	.228	2.969
Infant Health	.469	.451	1.081	1	.298	1.599	.660	3.872
Infant Allergies	.339	.720	.222	1	.638	1.404	.342	5.761
Formula Intolerance	.378	.493	.589	1	.443	1.460	.556	3.834
Parental Status	-1.142	.838	1.858	1	.173	.319	.062	1.649
Religious needs	.343	.486	.499	1	.480	1.409	.544	3.652
Routine Flash Heating								
Infant Age > 6 months	.393	.635	.384	1	.535	1.482	.427	5.140
Infant Health	-.144	.391	.135	1	.713	.866	.403	1.863
Infant Allergies	.727	.578	1.581	1	.209	2.068	.666	6.421
Formula Intolerance	.162	.414	.153	1	.695	1.176	.522	2.650
Parental Status	-.824	.826	.994	1	.319	.439	.087	2.216
Religious needs	-.086	.435	.039	1	.843	.917	.391	2.154

Note. Predictor variables of infant age >6 months, medical condition, infant allergy, formula intolerance, parental status, and religious need are dummy coded “0” to indicate absence of the condition, and “1” to indicate presence of the condition.

Table 19. Birth and lactation support

HIV 6 months	B	S.E.	Wald	Df	Sig.	Odds Ratio	95% C.I. for Odds Ratio Lower	Upper
Birth type								
Vaginal Birth	--	--	3.069	2	.216	--	--	--
Planned Surgical Birth	.241	.558	.186	1	.666	1.272	.426	3.797
Emergency Surgical Birth	.698	.399	3.061	1	.080	2.010	.919	4.393
Hospital birth	.198	.380	.271	1	.602	1.219	.579	2.567
Birth attendant								
Obstetrician	--	--	4.680	3	.197	--	--	--
CNM	.880	.426	4.271	1	.039	2.411	1.046	5.557
CPM/LM	.374	.475	.618	1	.432	1.453	.572	3.687
Other birth attendant	.048	.593	.006	1	.936	1.049	.328	3.352
Lactation support								
HCP lactation support	.167	.326	.263	1	.608	1.182	.624	2.241
IBCLC	.492	.400	1.511	1	.219	1.635	.747	3.581
Community Lactation Support	.083	.311	.071	1	.790	1.086	.591	1.997
Hepatitis B 6 months								
Birth type								
Vaginal Birth	--	--	2.433	2	.296	--	--	--
Planned Surgical Birth	.432	.528	.670	1	.413	1.541	.547	4.338
Emergency Surgical Birth	.617	.407	2.299	1	.129	1.853	.835	4.113
Hospital birth	.068	.393	.030	1	.862	1.071	.496	2.313
Birth attendant								
Obstetrician	--	--	1.128	3	.770	--	--	--
CNM	.448	.446	1.009	1	.315	1.565	.653	3.753
CPM/LM	.268	.480	.313	1	.576	1.308	.511	3.349
Other birth attendant	-.026	.591	.002	1	.965	.974	.306	3.103
Lactation support	--	--						
HCP lactation support	-.031	.324	.009	1	.923	.969	.514	1.829

IBCLC	.261	.429	.370	1	.543	1.298	.560	3.010
Community Lactation Support	-.032	.314	.011	1	.918	.968	.523	1.791
Hepatitis C 6 Months								
Birth type								
Vaginal Birth	--	--	1.511	2	.470	--	--	--
Planned Surgical Birth	.387	.527	.540	1	.462	1.473	.524	4.139
Emergency Surgical Birth	.482	.415	1.349	1	.245	1.619	.718	3.651
Hospital birth	.082	.403	.041	1	.839	1.085	.493	2.390
Birth attendant								
Obstetrician	--	--	.365	3	.947	--	--	--
CNM	.213	.461	.214	1	.644	1.237	.501	3.055
CPM/LM	.236	.482	.240	1	.624	1.266	.493	3.255
Other birth attendant	-.043	.590	.005	1	.942	.958	.301	3.047
Lactation support								
HCP lactation support	-.093	.329	.080	1	.777	.911	.478	1.737
IBCLC	.510	.416	1.497	1	.221	1.665	.736	3.766
Community Lactation Support	-.204	.319	.406	1	.524	.816	.436	1.526
HIV 12 months								
Birth type								
Vaginal Birth	--	--	1.202	2	.548	--	--	--
Planned Surgical Birth	.472	.439	1.159	1	.282	1.604	.679	3.790
Emergency Surgical Birth	.186	.376	.246	1	.620	1.205	.577	2.517
Hospital birth	-.300	.333	.812	1	.368	.741	.386	1.422
Birth attendant								
Obstetrician	--	--	.390	3	.942	--	--	--
CNM	.142	.392	.130	1	.718	1.152	.534	2.486
CPM/LM	.052	.415	.016	1	.900	1.053	.467	2.374
Other birth attendant	.265	.465	.324	1	.569	1.303	.524	3.240
Lactation support								
HCP lactation support	.289	.285	1.029	1	.310	1.335	.764	2.334

IBCLC	-.154	.404	.145	1	.703	.857	.389	1.892
Community Lactation Support	.198	.273	.527	1	.468	1.219	.714	2.080
Hepatitis B 12 Months								
Birth type								
Vaginal Birth	--	--	.054	2	.973	--	--	--
Planned Surgical Birth	-.030	.549	.003	1	.957	.971	.331	2.845
Emergency Surgical Birth	.089	.430	.043	1	.837	1.093	.470	2.540
Hospital birth	-.250	.376	.442	1	.506	.779	.373	1.628
Birth attendant								
Obstetrician	--	--	1.550	3	.671	--	--	--
CNM	.190	.447	.180	1	.671	1.209	.503	2.905
CPM/LM	.077	.475	.026	1	.871	1.080	.426	2.738
Other birth attendant	.603	.499	1.458	1	.227	1.827	.687	4.860
Lactation support								
HCP lactation support	.148	.330	.200	1	.655	1.159	.607	2.215
IBCLC	.180	.430	.176	1	.675	1.197	.516	2.779
Community Lactation Support	.513	.321	2.546	1	.111	1.670	.890	3.134
Hepatitis C 12 months								
Birth type								
Vaginal Birth	--	--	.047	2	.977	--	--	--
Planned Surgical Birth	.005	.550	.000	1	.993	1.005	.342	2.952
Emergency Surgical Birth	.092	.431	.045	1	.831	1.096	.471	2.549
Hospital birth	-.189	.381	.246	1	.620	.828	.393	1.746
Birth attendant								
Obstetrician	--	--	1.535	3	.674	--	--	--
CNM	.124	.454	.074	1	.785	1.132	.465	2.755
CPM/LM	.115	.475	.059	1	.809	1.122	.442	2.844
Other birth attendant	.610	.499	1.497	1	.221	1.841	.693	4.895
Lactation support								
HCP lactation support	.124	.332	.139	1	.709	1.132	.590	2.171

IBCLC	.209	.430	.237	1	.627	1.233	.531	2.864
Community Lactation Support	.475	.323	2.160	1	.142	1.608	.853	3.030
Routine Tobacco Screening								
Birth type								
Vaginal Birth	--	--	.198	2	.906	--	--	--
Planned Surgical Birth	-.100	.388	.067	1	.796	.905	.423	1.934
Emergency Surgical Birth	-.131	.314	.173	1	.678	.878	.474	1.625
Hospital birth	.137	.287	.228	1	.633	1.147	.653	2.015
Birth attendant								
Obstetrician	--	--	1.526	3	.676	--	--	--
CNM	-.125	.327	.146	1	.703	.883	.465	1.675
CPM/LM	-.196	.346	.320	1	.572	.822	.418	1.619
Other birth attendant	-.509	.422	1.456	1	.228	.601	.263	1.374
Lactation support								
HCP lactation support	.616	.240	6.587	1	.010	1.851	1.157	2.964
IBCLC	-.055	.330	.028	1	.868	.947	.496	1.807
Community Lactation Support	-.018	.230	.006	1	.939	.983	.627	1.541
Routine Alcohol Screening								
Birth type								
Vaginal Birth	--	--	2.395	2	.302	--	--	--
Planned Surgical Birth	.326	.383	.722	1	.395	1.385	.653	2.936
Emergency Surgical Birth	-.336	.323	1.085	1	.298	.714	.379	1.345
Hospital birth	.156	.290	.288	1	.592	1.169	.661	2.064
Birth attendant								
Obstetrician	--	--	.789	3	.852	--	--	--
CNM	-.224	.333	.453	1	.501	.799	.416	1.535
CPM/LM	-.060	.348	.030	1	.863	.942	.476	1.863
Other birth attendant	-.279	.416	.450	1	.502	.757	.335	1.709
Lactation support								
HCP lactation support	.785	.246	10.220	1	.001	2.192	1.355	3.547

IBCLC	-.005	.331	.000	1	.989	.995	.520	1.906
Community Lactation Support	-.103	.233	.195	1	.659	.902	.572	1.424
Routine Recreational Drugs								
Birth type								
Vaginal Birth	--	--	.122	2	.941	--	--	--
Planned Surgical Birth	-.104	.405	.066	1	.797	.901	.408	1.992
Emergency Surgical Birth	-.096	.327	.086	1	.769	.909	.479	1.724
Hospital birth	.025	.294	.007	1	.932	1.025	.576	1.824
Birth attendant								
Obstetrician	--	--	4.118	3	.249	--	--	--
CNM	-.160	.340	.221	1	.638	.852	.437	1.660
CPM/LM	.369	.348	1.123	1	.289	1.446	.731	2.862
Other birth attendant	-.489	.449	1.189	1	.276	.613	.254	1.477
Lactation support								
HCP lactation support	.788	.251	9.877	1	.002	2.200	1.345	3.596
IBCLC	.019	.335	.003	1	.954	1.020	.529	1.964
Community Lactation Support	-.031	.236	.017	1	.896	.970	.610	1.541
Routine Over the Counter								
Birth type								
Vaginal Birth	--	--	1.371	2	.504	--	--	--
Planned Surgical Birth	-.258	.405	.408	1	.523	.772	.349	1.707
Emergency Surgical Birth	-.364	.330	1.220	1	.269	.695	.364	1.326
Hospital birth	.443	.298	2.209	1	.137	1.558	.868	2.794
Birth attendant								
Obstetrician	--	--	6.053	3	.109	--	--	--
CNM	.495	.331	2.239	1	.135	1.641	.858	3.139
CPM/LM	.137	.352	.152	1	.697	1.147	.575	2.288
Other birth attendant	-.706	.467	2.284	1	.131	.494	.198	1.233
Lactation support	--	--						
HCP lactation support	.565	.243	5.394	1	.020	1.760	1.092	2.836

IBCLC	.164	.329	.249	1	.618	1.178	.618	2.247
Community Lactation Support	.249	.232	1.151	1	.283	1.283	.814	2.023
Routine Prescription								
Birth type								
Vaginal Birth	--	--	1.770	2	.413	--	--	--
Planned Surgical Birth	.058	.385	.022	1	.881	1.059	.498	2.254
Emergency Surgical Birth	-.396	.318	1.547	1	.214	.673	.361	1.256
Hospital birth	.315	.287	1.201	1	.273	1.370	.780	2.404
Birth attendant								
Obstetrician	--	--	3.281	3	.350	--	--	--
CNM	.044	.326	.018	1	.893	1.045	.552	1.978
CPM/LM	.115	.343	.112	1	.738	1.122	.573	2.197
Other birth attendant	-.703	.433	2.631	1	.105	.495	.212	1.158
Lactation support								
HCP lactation support	.413	.235	3.099	1	.078	1.511	.954	2.394
IBCLC	-.167	.329	.258	1	.612	.846	.444	1.613
Community Lactation Support	.234	.226	1.070	1	.301	1.264	.811	1.969
Routine Alternative Modalities								
Birth type								
Vaginal Birth	--	--	5.021	2	.081	--	--	--
Planned Surgical Birth	-.873	.581	2.262	1	.133	.417	.134	1.303
Emergency Surgical Birth	-.854	.451	3.583	1	.058	.426	.176	1.031
Hospital birth	.173	.353	.241	1	.624	1.189	.595	2.374
Birth attendant								
Obstetrician	--	--	5.060	3	.167	--	--	--
CNM	-.166	.402	.171	1	.679	.847	.385	1.862
CPM/LM	.320	.403	.630	1	.427	1.377	.625	3.035
Other birth attendant	-1.349	.767	3.094	1	.079	.260	.058	1.167
Lactation support								
HCP lactation support	.727	.315	5.319	1	.021	2.068	1.115	3.834

IBCLC	.706	.356	3.926	1	.048	2.026	1.008	4.073
Community Lactation Support	-.080	.285	.079	1	.779	.923	.528	1.613
Routine Diet								
Birth type								
Vaginal Birth	--	--	1.529	2	.465	--	--	--
Planned Surgical Birth	-.276	.438	.399	1	.528	.758	.322	1.789
Emergency Surgical Birth	-.430	.364	1.391	1	.238	.651	.319	1.329
Hospital birth	-.240	.310	.601	1	.438	.787	.429	1.443
Birth attendant								
Obstetrician	--	--	3.701	3	.296	--	--	--
CNM	.077	.349	.048	1	.826	1.080	.545	2.139
CPM/LM	-.303	.381	.633	1	.426	.739	.350	1.558
Other birth attendant	-.844	.527	2.563	1	.109	.430	.153	1.208
Lactation support								
HCP lactation support	.439	.264	2.770	1	.096	1.551	.925	2.601
IBCLC	.276	.343	.646	1	.421	1.318	.673	2.581
Community Lactation Support	.294	.250	1.381	1	.240	1.342	.822	2.192
Routine Supplements								
Birth type								
Vaginal Birth	--	--	5.678	2	.058	--	--	--
Planned Surgical Birth	-1.143	.524	4.755	1	.029	.319	.114	.891
Emergency Surgical Birth	-.482	.355	1.835	1	.176	.618	.308	1.240
Hospital birth	-.084	.308	.074	1	.785	.919	.503	1.682
Birth attendant								
Obstetrician	--	--	2.781	3	.427	--	--	--
CNM	-.103	.348	.088	1	.767	.902	.456	1.786
CPM/LM	-.100	.367	.074	1	.785	.905	.441	1.858
Other birth attendant	-.880	.530	2.757	1	.097	.415	.147	1.172
Lactation support								

HCP lactation support	.841	.272	9.553	1	.002	2.318	1.360	3.950
IBCLC	.378	.338	1.247	1	.264	1.459	.752	2.831
Community Lactation Support	.213	.251	.719	1	.396	1.237	.757	2.021
Routine Holder Pasteurization								
Birth type								
Vaginal Birth	--	--	1.018	2	.601	--	--	--
Planned Surgical Birth	-1.081	1.074	1.014	1	.314	.339	.041	2.781
Emergency Surgical Birth	-.068	.614	.012	1	.911	.934	.280	3.113
Hospital Birth	-.727	.573	1.607	1	.205	.483	.157	1.487
Birth Attendant								
Obstetrician	--	--	1.573	3	.666			
CNM	-.832	.702	1.407	1	.236	.435	.110	1.721
CPM/LM	-.658	.694	.899	1	.343	.518	.133	2.019
Other birth attendant	-.313	.818	.146	1	.702	.731	.147	3.636
Lactation Support								
HCP lactation support	.626	.539	1.348	1	.246	1.870	.650	5.377
IBCLC	.248	.587	.178	1	.673	1.281	.405	4.051
Community Lactation Support	1.074	.532	4.074	1	.044	2.926	1.032	8.297
Routine Flash Heating								
Birth Type								
Vaginal Birth	--	--	.066	2	.967	--	--	--
Planned Surgical Birth	-.174	.680	.065	1	.798	.840	.222	3.184
Emergency Surgical Birth	-.017	.511	.001	1	.974	.983	.362	2.675
Hospital birth	.091	.470	.037	1	.847	1.095	.436	2.750
Birth Attendant								
Obstetrician	--	--	.813	3	.846	--	--	--
CNM	-.103	.543	.036	1	.849	.902	.311	2.614
CPM/LM	.203	.540	.140	1	.708	1.225	.425	3.532

Other birth attendant	-.494	.785	.396	1	.529	.610	.131	2.842
Lactation Support								
HCP lactation support	.968	.453	4.562	1	.033	2.633	1.083	6.401
IBCLC	.378	.464	.664	1	.415	1.460	.588	3.626
Community Lactation Support	.406	.385	1.113	1	.291	1.501	.706	3.194

Note. The predictor variable "birth type" references "vaginal birth in the statistical model as the comparator, coded as "1", with "planned" and "emergent" surgical birth coded as "2" and "3", respectively. "Hospital birth" is dummy coded such that "1" indicates an in-hospital birth and "0" indicates out-of-hospital birth, whether planned or unintentional. Birth attendant is coded with "obstetrician" as the comparative variable, coded as "1", with "CNM", "CPM/LM", and "other birth provider" coded "2"-"4", respectively. Lactation support providers were independently tested within the model as "health care provider", "IBCLC", and "community support".

T*able 20. Recipient participant research duration and sources used for research about PAMS.*

HIV 6 months	B	S.E.	Wald	df	Sig.	Odds Ratio	95% C.I. for Odds Ratio Lower	Upper
Research duration								
< one day	--	--	4.155	2	0.125	--	--	--
Up to one month	0.899	0.441	4.148	1	0.042	2.457	1.034	5.837
More than one month	0.779	0.560	1.932	1	0.165	2.179	0.727	6.535
Resources considered								
Eats on Feets Resource	0.288	0.409	0.495	1	0.482	1.333	0.598	2.973
HM4HB	-0.149	0.419	0.126	1	0.723	0.862	0.379	1.959
Online Blogs/Sites	0.244	0.341	0.513	1	0.474	1.277	0.654	2.492
Government Statements	-0.210	1.123	0.035	1	0.851	0.810	0.090	7.321
Hepatitis B 6 months								
Research duration								
< one day	--	--	1.682	2	0.431	--	--	--
Up to one month	0.515	0.408	1.591	1	0.207	1.673	0.752	3.722
More than one month	0.531	0.531	0.999	1	0.318	1.701	0.600	4.820
Resources considered								
Eats on Feets Resource	0.400	0.417	0.922	1	0.337	1.492	0.659	3.377
HM4HB	-0.280	0.423	0.437	1	0.509	0.756	0.330	1.733
Online Blogs/Sites	0.086	0.346	0.063	1	0.803	1.090	0.554	2.148
Government Statements	-0.139	1.118	0.015	1	0.901	0.870	0.097	7.784
Hepatitis C 6 Months								
Research duration								
< one day	--	--	1.277	2	0.528	--	--	--

Up to one month	0.425	0.411	1.070	1	0.301	1.530	0.684	3.423
More than one month	0.523	0.533	0.966	1	0.326	1.688	0.594	4.793
Resources considered								
Eats on Feets Resource	0.619	0.428	2.091	1	0.148	1.856	0.803	4.293
HM4HB	-0.341	0.432	0.621	1	0.431	0.711	0.305	1.660
Online Blogs/Sites	-0.080	0.352	0.052	1	0.820	0.923	0.463	1.841
Government Statements	-0.105	1.119	0.009	1	0.925	0.900	0.100	8.064
HIV 12 months								
Research duration								
< one day	--	--	5.001	2	0.082	--	--	--
Up to one month	0.704	0.369	3.648	1	0.056	2.022	0.982	4.163
More than one month	0.971	0.459	4.480	1	0.034	2.641	1.075	6.493
Resources considered								
Eats on Feets Resource	0.110	0.357	0.095	1	0.758	1.117	0.554	2.250
HM4HB	0.191	0.365	0.272	1	0.602	1.210	0.591	2.476
Online Blogs/Sites	0.159	0.299	0.285	1	0.594	1.173	0.653	2.105
Government Statements	-0.808	1.119	0.521	1	0.470	0.446	0.050	3.995
Hepatitis B 12 Months								
Research duration								
< one day	--	--	6.248	2	0.044	--	--	--
Up to one month	1.254	0.502	6.244	1	0.012	3.506	1.311	9.379
More than one month	1.118	0.611	3.349	1	0.067	3.058	0.924	10.125
Resources considered								
Eats on Feets Resource	0.509	0.418	1.478	1	0.224	1.663	0.732	3.777
HM4HB	-0.222	0.429	0.269	1	0.604	0.801	0.345	1.856

Online Blogs/Sites	0.310	0.346	0.803	1	0.370	1.363	0.692	2.684
Government Statements	-0.271	1.131	0.057	1	0.811	0.763	0.083	6.999
Hepatitis C 12 months								
Research duration								
< one day	--	--	5.830	2	0.054	--	--	--
Up to one month	1.213	0.503	5.814	1	0.016	3.365	1.255	9.021
More than one month	1.106	0.611	3.271	1	0.071	3.021	0.912	10.013
Resources considered								
Eats on Feets Resource	0.534	0.421	1.605	1	0.205	1.705	0.747	3.895
HM4HB	-0.198	0.432	0.209	1	0.647	0.821	0.352	1.914
Online Blogs/Sites	0.332	0.348	0.908	1	0.341	1.393	0.705	2.755
Government Statements	-0.291	1.131	0.066	1	0.797	0.748	0.081	6.862
Routine Tobacco Screening								
Research duration								
< one day	--	--	11.745	2	0.003	--	--	--
Up to one month	0.937	0.305	9.427	1	0.002	2.552	1.403	4.640
More than one month	1.212	0.399	9.209	1	0.002	3.359	1.536	7.346
Resources considered								
Eats on Feets Resource	0.348	0.306	1.290	1	0.256	1.416	0.777	2.580
HM4HB	0.495	0.312	2.526	1	0.112	1.641	0.891	3.021
Online Blogs/Sites	0.258	0.260	0.991	1	0.320	1.295	0.778	2.154
Government Statements	0.985	0.927	1.129	1	0.288	2.677	0.435	16.472
Routine Alcohol Screening								
Research duration								
< one day	--	--	13.681	2	0.001	--	--	--
Up to one month	0.939	0.310	9.188	1	0.002	2.557	1.393	4.693

More than one month	1.410	0.402	12.320	1	0.000	4.096	1.864	9.001
Resources considered								
Eats on Feets Resource	0.268	0.309	0.748	1	0.387	1.307	0.713	2.396
HM4HB	0.274	0.315	0.753	1	0.385	1.315	0.709	2.439
Online Blogs/Sites	0.422	0.260	2.637	1	0.104	1.525	0.916	2.539
Government Statements	1.058	0.928	1.300	1	0.254	2.882	0.467	17.777
Routine Recreational Drugs								
Research duration								
< one day	--	--	16.665	2	0.000	--	--	--
Up to one month	1.255	0.350	12.841	1	0.000	3.507	1.766	6.968
More than one month	1.672	0.438	14.596	1	0.000	5.324	2.258	12.556
Resources considered								
Eats on Feets Resource	0.911	0.327	7.774	1	0.005	2.487	1.311	4.720
HM4HB	-0.228	0.339	0.452	1	0.501	0.796	0.410	1.546
Online Blogs/Sites	0.697	0.270	6.645	1	0.010	2.007	1.182	3.408
Government Statements	1.113	0.981	1.287	1	0.257	3.043	0.445	20.812
Routine Over the Counter								
Research duration								
< one day	--	--	9.061	2	0.011	--	--	--
Up to one month	0.600	0.299	4.032	1	0.045	1.822	1.014	3.274
More than one month	1.173	0.393	8.922	1	0.003	3.232	1.497	6.980
Resources considered								
Eats on Feets Resource	0.299	0.307	0.948	1	0.330	1.349	0.739	2.462
HM4HB	0.487	0.312	2.434	1	0.119	1.628	0.883	3.003
Online Blogs/Sites	0.217	0.260	0.697	1	0.404	1.242	0.747	2.066

Government Statements	1.004	0.911	1.214	1	0.270	2.730	0.458	16.288
Routine Prescription								
Research duration								
< one day	--	--	10.556	2	0.005	--	--	--
Up to one month	0.831	0.287	8.380	1	0.004	2.295	1.308	4.027
More than one month	1.090	0.383	8.085	1	0.004	2.975	1.403	6.309
Resources considered								
Eats on Feets Resource	0.222	0.302	0.543	1	0.461	1.249	0.691	2.256
HM4HB	0.447	0.305	2.139	1	0.144	1.563	0.859	2.843
Online Blogs/Sites	0.050	0.256	0.039	1	0.844	1.052	0.637	1.737
Government Statements	0.250	0.826	0.092	1	0.762	1.284	0.255	6.480
Routine Alternative Modalities								
Research duration								
< one day	--	--	7.622	2	0.022	--	--	--
Up to one month	0.972	0.420	5.360	1	0.021	2.642	1.161	6.016
More than one month	1.353	0.503	7.230	1	0.007	3.869	1.443	10.373
Resources considered								
Eats on Feets Resource	0.614	0.380	2.607	1	0.106	1.848	0.877	3.895
HM4HB	-0.492	0.393	1.568	1	0.210	0.611	0.283	1.321
Online Blogs/Sites	0.759	0.318	5.683	1	0.017	2.136	1.144	3.985
Government Statements	0.003	0.903	0.000	1	0.997	1.003	0.171	5.892
Routine Diet								
Research duration								
< one day	--	--	9.595	2	0.008	--	--	--
Up to one month	0.744	0.337	4.880	1	0.027	2.104	1.087	4.072
More than one month	1.290	0.419	9.481	1	0.002	3.633	1.598	8.260

Resources considered								
Eats on Feets Resource	0.449	0.331	1.835	1	0.176	1.566	0.818	2.998
HM4HB	-0.115	0.340	0.114	1	0.736	0.892	0.458	1.736
Online Blogs/Sites	0.330	0.277	1.428	1	0.232	1.392	0.809	2.393
Government Statements	0.222	0.829	0.072	1	0.789	1.249	0.246	6.344
Routine Supplements								
Research duration								
< one day	--	--	14.214	2	0.001	--	--	--
Up to one month	1.021	0.361	8.011	1	0.005	2.775	1.369	5.626
More than one month	1.651	0.441	13.997	1	0.000	5.214	2.195	12.386
Resources considered								
Eats on Feets Resource	0.677	0.338	4.024	1	0.045	1.969	1.016	3.817
HM4HB	-0.326	0.350	0.867	1	0.352	0.722	0.364	1.433
Online Blogs/Sites	0.615	0.280	4.815	1	0.028	1.850	1.068	3.204
Government Statements	1.500	0.945	2.517	1	0.113	4.481	0.703	28.582
Routine Holder Pasteurization								
Research duration								
< one day	--	--	0.976	2	0.614	--	--	--
Up to one month	0.343	0.603	0.324	1	0.569	1.410	0.432	4.596
More than one month	0.714	0.725	0.970	1	0.325	2.042	0.493	8.450
Resources considered								
Eats on Feets Resource	0.166	0.608	0.075	1	0.785	1.181	0.359	3.884
HM4HB	0.034	0.625	0.003	1	0.956	1.035	0.304	3.526
Online Blogs/Sites	0.357	0.508	0.496	1	0.481	1.430	0.529	3.866
Government Statements	1.474	0.926	2.532	1	0.112	4.367	0.711	26.837

Routine Flash Heating

Research duration								
< one day	--	--	3.044	2	0.218	--	--	--
Up to one month	0.922	0.528	3.044	1	0.081	2.514	0.892	7.082
More than one month	0.756	0.661	1.307	1	0.253	2.129	0.583	7.777
Resources considered								
Eats on Feets Resource	-0.576	0.491	1.377	1	0.241	0.562	0.215	1.471
HM4HB	0.358	0.499	0.514	1	0.473	1.430	0.538	3.805
Online Blogs/Sites	0.069	0.420	0.027	1	0.870	1.071	0.470	2.440
Government Statements	2.161	0.844	6.560	1	0.010	8.678	1.661	45.341

Note.