

## Original Article

## Human milk sharing practices in the U.S.

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## Abstract

The primary objective of this study is to describe human milk sharing practices in the U.S. Specifically, we examine milk sharing social networks, donor compensation, the prevalence of anonymous milk sharing interactions, recipients' concerns about specific milk sharing risks, and lay screening behaviors. Data on human milk sharing practices were collected via an online survey September 2013–March 2014. Chi-square analyses were used to test the association between risk perception and screening practices. A total of 867 (661 donors, 206 recipients) respondents were included in the analyses. Most (96.1%) reported sharing milk face-to-face. Only 10% of respondents reported giving or receiving milk through a non-profit human milk bank, respectively. There were no reports of anonymous purchases of human milk. A small proportion of recipients (4.0%) reported that their infant had a serious medical condition. Screening of prospective donors was common (90.7%) but varied with social relationship and familiarity. Likewise, concern about specific milk sharing risks was varied, and risk perception was significantly associated (P-values = 0.01 or less) with donor screening for all risk variables except diet. Understanding lay perceptions of milk sharing risk and risk reduction strategies that parents are using is an essential first step in developing public health interventions and clinical practices that promote infant safety.

**Keywords:** human milk, breast milk, infant feeding decisions, social, factors, public health.

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## Introduction

Human milk sharing is a rapidly growing infant feeding practice in the U.S. (Keim *et al.* 2014a,b; Palmquist & Doehler 2014; Reyes-Foster *et al.* 2015). The term milk sharing refers to the commerce-free practice in which a donor gives expressed breast milk directly to a recipient family for the purpose of infant feeding or breastfeeds a recipient infant. Recent studies have shown that milk sharing donors and recipients use both online and offline social networks to facilitate these practices (Thorley 2012; Gribble 2014a,b; Reyes-Foster *et al.* 2015). Milk sharing provides parents with an alternative to infant formula and Holder pasteurized banked donor milk (BDM) when mother's own milk (MOM) requires supplementation or is not available, following World Health Organization (WHO) infant feeding guidelines (WHO 2003). Online social networking has been instrumental to the growth of milk sharing communities across the globe (Akre *et al.* 2011; Geraghty

*et al.* 2011; Cassidy 2012a). While there are a multitude of reasons that people share breastfeeding and human milk, a majority of parents seeking shared milk online in the U.S. are breastfeeding mothers who have initiated breastfeeding and have experienced lactation insufficiency (Palmquist & Doehler 2014).

Controversies surrounding milk sharing emanate from concerns about the potential risks involved in feeding an infant with human milk donated by individuals who are not systematically screened by a trained health professional (Geraghty *et al.* 2011; Gribble & Hausman 2012; Nelson 2012; Brent 2013; Jones 2013; Landers & Hartmann 2013; Keim *et al.* 2014a,b). These risks include transmission of disease, exposure to medications and substances, and microbial contamination associated with storage and handling practices (Golding 1997; U.S. Food and Drug Administration, 2010; Walker & Armstrong 2012; Brent 2013; Landers & Hartmann 2013; Martino & Spatz 2014). Other tensions have arisen around the potential negative impact

of milk sharing on the supply of donor milk to non-profit human milk banks (Jones 2003; Updegrave 2013a,b). Currently the American Academy of Pediatrics (AAP) only endorses BDM that has been processed by a Human Milk Banking Association of North America (HMBANA) affiliated milk bank (Gartner *et al.* 2012).

Even with public health recommendations cautioning against it, milk sharing appears to be commonplace in the U.S., notably among middle-income, college educated women who self-identify as Caucasian/white (Keim *et al.* 2014a,b; Palmquist & Doehler 2014; Reyes-Foster *et al.* 2015). In a study of 499 postpartum women, 77% were aware of the option to share human milk, 25% had considered sharing their milk and 4% had shared milk with either a family or friend, or donated to a milk bank (Keim *et al.* 2014a,b). A recent survey of members of the Academy of Breastfeeding Medicine (ABM) revealed that 21% of the 67 physician-respondents with breastfeeding experience reported milk sharing (Taylor & Labbok 2015).

Lack of access to BDM explains, at least in part, growing interest in milk sharing (Akre *et al.* 2011). Although HMBANA continues to expand its network of milk banks, the demand for human milk exceeds what they are currently able to provide (Updegrave 2013a). Burgeoning commercial markets for human milk, ranging from peer-to-peer sales to large corporations and cooperatives that pay for expressed milk, have generated competition for potential milk bank donors (Fentiman 2009; Swanson 2014). Structural barriers further limit access to BDM in the U.S. (Arnold 2006).

Despite the scrutiny and extensive attention that online human milk sharing has received in both the popular media and scholarly literature, there are substantial gaps in knowledge regarding how parents

conceptualize the risks of milk sharing and navigate these risks. Hence, the primary objective of the present study is to assess the relationship between perceptions of various types of milk sharing risk with lay screening behaviors. To this end we examine milk sharing social networks, donor compensation, the prevalence of anonymous milk sharing interactions, recipients' concerns about specific milk sharing risks, and lay screening practices. This is the first study to describe these aspects of human milk sharing practices using a robust sample drawn from people across the U.S. with milk sharing experience. Findings from this study may be used to better inform public health efforts to reduce the potential risks of milk sharing, expanding universal access to safe donor human milk for infants, and designing future research.

## Participants and methods

### Recruitment and survey instrument

This study is one component of an multi-sited, mixed-methods anthropological study of human milk sharing in the U.S. Data were collected via an anonymous online survey. A detailed description of study recruitment has been published previously (Palmquist & Doehler 2014). In brief, after receiving ethics approval by the Elon University Institutional Review Board, the link to an open-access, online survey was posted on several social networking sites that facilitate milk sharing connections. Participation was voluntary, and no incentive was provided. Respondents were eligible for the study if they were at least 18 years of age. Only respondents who were residing in the U.S., had ever participated in milk sharing, and were milk sharing for the purpose of infant feeding are included in the present analyses.

### Key messages

- Online human milk sharing is a growing and controversial infant feeding practice.
- A high demand for human milk is associated with a desire to avoid formula feeding, barriers to accessing banked donor human milk, and lactation insufficiency among breastfeeding mothers.
- This is the first study to describe milk sharing social networks, compensation, risk perception and screening behaviors among a robust cross-sectional sample of mothers engaged in online human milk sharing in the U.S.

Recipients were asked to indicate their relationship to the child for whom they were seeking breast milk and to report any infant conditions that were related to their most recent milk sharing experience. All respondents provided information about their social ties to people with whom they have shared milk (family member, friend, local community member, and online acquaintance).

Both donors and recipients answered several items about donor compensation, the contexts in which they have given or received milk (milk sharing only, both milk banking and milk sharing), milk storage (fresh or frozen), geography of milk pick-ups and drop-offs (face-to-face, shipped frozen milk), and if they had ever flash heated donor milk prior to feeding.

Recipients' risk perception was measured using variables to measure concern (extremely concerned, somewhat concerned, very little concern or no concern) for each of the following milk sharing screening items (MSSI): age of donor's baby, donor's alcohol use, diet, disease history, tobacco use, and use of medications.

Milk sharing screening was defined as 'asking questions about medical history, lifestyle and other relevant background information' as well as asking for specific types of information (the age of a donor's nursing, alcohol use, diet, illicit drug use, medical history, medications, pregnancy records, serological tests and tobacco use) in making their decision to give milk or to accept shared milk. All respondents reported general screening practices by social relationship (screen everyone, screen only strangers but not family or friends, screen some people but not all regardless of familiarity, do not screen anyone). Additionally, recipients reported screening practices by individual MSSI.

## Analyses

Univariate analyses were used to generate descriptive data for the aforementioned variables. Survey items regarding concern with discrete MSSI were dichotomized (high concern or low concern). Likewise, variables for screening by individual MSSI were dichotomized (screened, did not screen). Chi-square analyses were conducted to test for associations between concern about a MSSI and screening donors for the corresponding MSSI. Because concern with illicit drugs was only

included as a screening variable, this item was omitted from the chi-square analyses. All analyses were executed in SAS v.9.3 (SAS Institute, Cary, NC, 2011).

## Results

A total of 867 (661 donors, 206 recipients) respondents met the eligibility criteria for the study. Socio-demographic characteristics of respondents are reported elsewhere (Palmquist & Doehler 2014). Table 1 summarizes milk sharing social networks and general screening by type of social tie. Most recipients were mothers seeking milk for a baby to whom they had given birth. Recipients listed a variety of infant conditions that were associated with their decision to seek donor milk (Table 1). A small number of recipients ( $n=8$ , 4.0%) reported that their baby had a serious medical condition.

Sharing milk with family, friends, and community members was not mutually exclusive with sharing milk with online acquaintances (Fig. 1). A relatively small proportion of respondents indicated that they were milk sharing exclusively with friends or family. Rates of reported screening varied with donor-recipient social ties. Among recipients who reported a serious infant condition, all shared milk with donors they had screened or met face-to-face.

Respondents provided information on the estimated frequency with which various forms of reimbursement and compensation for milk occurs as well as attitudes about the importance of such compensation (Table 1). Recipients placed greater importance on all forms of remuneration than the donors did. Only 2.0% of donors and 8.7% of recipients reported ever being paid for milk or purchasing milk, respectively. Of the 18 recipients who purchased milk, one reported procuring milk from a milk bank. All recipients who reported purchasing milk also reported screening or meeting their donors in person.

Milk sharing donations were generally made using frozen expressed milk that was delivered face-to-face, although many respondents indicated that they had also shipped milk (Table 1). Of the respondents who reported ever having shipped milk, 52.3% (23/44) always screened donors, 25.0% (11/44) screened some but not all donors regardless of familiarity, 18.2% (8/44)

**Table 1.** Milk sharing social networks, infant conditions and donor compensation

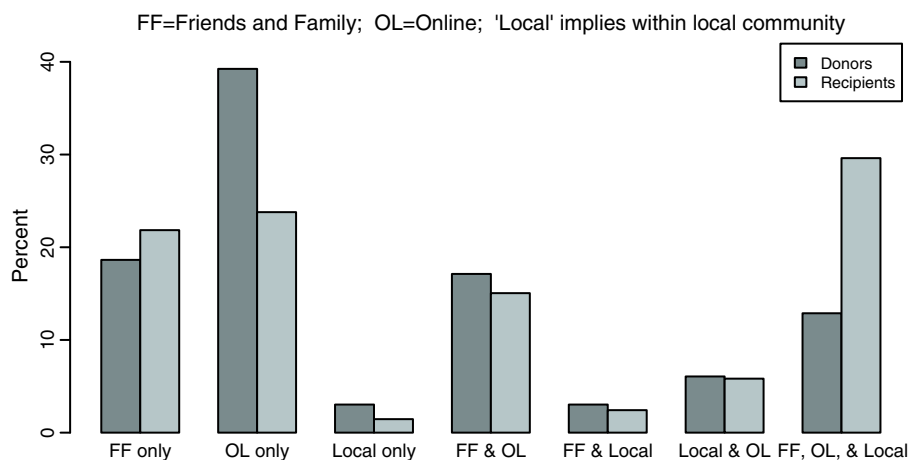
Survey item	Prevalence, <i>n</i> (%)	
	Donors	Recipients
Please indicate your relationship to the child for whom you are seeking milk	—	<i>n</i> = 206
child to whom I gave birth	—	195 (94.7)
child by surrogacy	—	1 (0.5)
adopted or stepchild	—	9 (4.4)
foster child	—	1 (0.5)
Do you screen prospective donors/recipients, including family or friends?	<i>n</i> = 651	<i>n</i> = 205
screen everyone	92 (14.1)	80 (39.0)
screen only strangers, not friends or family	161 (24.7)	53 (25.9)
screen some people, but not all, regardless of familiarity	89 (13.7)	53 (25.9)
do not screen anyone	309 (47.5)	19 (9.3)
Do you only share milk with friends or family members?	<i>n</i> = 660	<i>n</i> = 206
Yes	114 (17.3)	42 (20.4)
No (please select all options that may apply) <sup>a</sup>	546 (82.7)	164 (79.6)
online acquaintance that you have met in person	305 (46.2)	132 (64.1)
online acquaintance that you have not met in person	306 (46.4)	75 (36.4)
someone you met through people in your local community offline	159 (24.1)	79 (38.3)
friend	202 (30.6)	93 (45.1)
family member	78 (11.8)	16 (7.8)
Infant conditions related to most recent search for breast milk <sup>a</sup>	—	<i>n</i> = 199
adopted child born addicted to drugs	—	2 (1.0)
breast refusal	—	23 (11.6)
cleft lip/palate	—	3 (1.5)
dehydration	—	2 (1.0)
dysphagia and aspiration	—	1 (0.5)
failure to thrive	—	28 (14.1)
food allergy/sensitivity	—	20 (10.1)
formula intolerance	—	3 (1.5)
jaundice	—	1 (0.5)
laryngomalacia	—	1 (0.5)
prematurity that interrupted lactation	—	10 (5.0)
reflux/GERD	—	1 (0.5)
slow weight gain	—	2 (1.0)
tongue tie/lip tie	—	41 (20.6)
torticollis	—	2 (1.0)
poor latch/weak suck	—	5 (2.5)
none	—	84 (42.2)
serious medical condition that interrupted lactation	—	8 (4.0)
blood disorder (unspecified)	—	1 (0.5)
brain injury at birth and unable to breastfeed	—	1 (0.5)
cerebral palsy	—	1 (0.5)
Cornelia de Lange Syndrome (CdLS) with a variety of gastrointestinal issues	—	1 (0.5)
Hirschprung's Disease	—	1 (0.5)
maxillary tumor	—	1 (0.5)
multiple severe disabilities	—	1 (0.5)
neonatal myasthenia gravis	—	1 (0.5)
Have you ever bought or sold breast milk?	<i>n</i> = 661	<i>n</i> = 206
Yes	13 (2.0)	18 (8.7)
No	648 (98.0)	188 (91.3)
How often are donors compensated for costs, either through reimbursement or supplies?	<i>n</i> = 659	<i>n</i> = 206
at least half of the time	261 (39.6)	140 (68.0)
rarely or never	398 (60.4)	66 (32.0)

(Continues)

**Table 1.** (Continued)

Survey item	Prevalence, <i>n</i> (%)	
	Donors	Recipients
How important is compensating donors for mileage/travel costs?	<i>n</i> = 658	<i>n</i> = 196
at least somewhat important	142 (21.6)	83 (42.3)
not important	516 (78.4)	113 (57.7)
How important is compensating donors for milk storage supplies	<i>n</i> = 659	<i>n</i> = 204
at least somewhat important	340 (51.6)	164 (80.4)
not important	319 (48.4)	40 (19.6)
How important is compensating donors for shipping expenses?	<i>n</i> = 648	<i>n</i> = 201
at least somewhat important	292 (45.1)	93 (46.3)
not important	356 (54.9)	108 (53.7)
How important is compensating donors through gifts?	<i>n</i> = 654	<i>n</i> = 198
at least somewhat important	52 (8.0)	100 (50.5)
not important	602 (92.0)	98 (49.5)
Rates of giving/receiving milk through milk sharing and milk bank		
milk sharing only	590 (89.3)	187 (90.8)
both human milk banking and milk sharing	71 (10.7)	19 (9.2)
Milk storage <sup>a</sup>		
fresh/refrigerated expressed breast milk	167 (25.3)	45 (21.8)
frozen expressed breast milk	642 (97.1)	197 (95.6)
Milk delivery <sup>a</sup>		
local, face-to-face drop-off/pick-up	636 (96.2)	197 (95.6)
shipped frozen milk	97 (14.7)	44 (21.4)
Flash heat milk prior to feeding		
screen everyone	—	7 (3.4)
screen only strangers, not friends or family	—	2 (1.0)
screen some people, but not all, regardless of familiarity	—	7 (3.4)
do not screen anyone	—	2 (1.0)

<sup>a</sup>Total of column percentages may >100 for items where respondents could select more than one option.



**Fig. 1.** Figure illustrates the relational composition of people with whom donors and recipients reported sharing milk.

screened strangers only and 4.5% (2/44) did not ask donors screening questions. Breastfeeding a recipient baby and also expressing milk for donation were

reported by 11.9% (78/657) of donors, and 23.1% (18/78) of these donors exclusively shared milk with a family member or friends. A very small proportion

of donors (0.6%, 4/657) indicated that their milk sharing experience was limited to nursing a recipient baby.

Less than 10% of recipients reported flash heating (*cf.* Israel-Ballard *et al.* 2007) donor milk prior to infant feeding (Table 1). Most of these recipients reported sharing milk with some combination of family members (11.1%, 2/18), friends (61.1%, 11/18), a donor whom they met in their local community (50.0%, 9/18), and online acquaintances (61.1%, 11/18). However, two recipients reported sharing milk with a family member or friend only (11.1%, 2/18). Approximately 55.6% of recipients who flash heated milk (10/18) gathered information regarding serological tests as part of their donor screening. A high concern with the risk of disease was reported among 88.9% (16/18) of recipients who flash heated milk.

Recipients indicated highest concern with exposure to medications, alcohol, tobacco, and disease and relatively lower rates of concern with age of a donor's baby and diet, although concern for these latter two MSSIs was reported by >65% of recipients (Table 2). The prevalence of milk sharing screening was 90.7% (186/205) among recipients and 52.5% (342/651) among donors, respectively. Recipients who reported purchasing milk also reported asking donors screening questions at relatively high rates for most MSSIs (Table 2).

There was a significant relationship between recipients' concern for a specific MSSIs and the likelihood that they would ask a donor screening questions (Table 3). For all eight MSSIs that were examined, the proportion of recipients who asked screening questions was higher for individuals with high concern as compared with individuals with low concern. Donors frequently were screened about diet regardless of recipients' concern level. Rates of screening donors for disease were lower than for other MSSIs, regardless if a recipient indicated they had high or low concern.

## Discussion

MOM is the ideal source of human infant nutrition, but it is not always available. Human milk banking was founded on the premise that donor human milk provides the closest possible approximation to MOM (Golden 2001; Wolf 2001; Jones 2003; Swanson 2009, 2014; Bar-Yam 2010; Updegrave 2013a,b). This

**Table 2.** Recipients' milk sharing concerns and screening of donors

MSSI	Prevalence, <i>n</i> (%)	
	Concerned	Not concerned
All recipients		
Age of infant <i>n</i> = 205	135 (65.9)	70 (34.2)
Alcohol <i>n</i> = 205	175 (85.4)	30 (14.6)
Diet <i>n</i> = 203	135 (66.5)	68 (33.5)
Diseases <i>n</i> = 204	167 (81.9)	37 (18.1)
Medications <i>n</i> = 205	186 (90.7)	19 (9.3)
Tobacco <i>n</i> = 205	175 (85.4)	30 (14.6)
Recipients who purchased milk		
Age of infant <i>n</i> = 18	11 (61.1)	7 (38.9)
Alcohol <i>n</i> = 18	15 (83.3)	3 (16.7)
Diet <i>n</i> = 18	10 (55.6)	8 (44.4)
Diseases <i>n</i> = 17	15 (88.2)	2 (11.8)
Medications <i>n</i> = 18	16 (88.9)	2 (11.1)
Tobacco <i>n</i> = 18	12 (66.7)	6 (33.3)
	Asked screening questions	Did not ask screening questions
All recipients		
Age of infant <i>n</i> = 201	133 (66.2)	68 (33.8)
Alcohol <i>n</i> = 203	143 (70.4)	60 (29.6)
Diet <i>n</i> = 205	140 (68.3)	65 (31.7)
Diseases:		
Blood tests <i>n</i> = 201	54 (26.9)	147 (73.1)
Prenatal records <i>n</i> = 201	29 (14.4)	172 (85.6)
Medical history <i>n</i> = 199	53 (26.6)	146 (73.4)
Illicit drugs <i>n</i> = 204	142 (69.6)	62 (30.4)
Medications <i>n</i> = 201	142 (70.6)	59 (29.4)
Tobacco <i>n</i> = 205	148 (72.2)	57 (27.8)
Recipients who purchased milk		
Age of infant <i>n</i> = 18	13 (72.2)	5 (27.8)
Alcohol <i>n</i> = 18	13 (72.2)	5 (27.8)
Diet <i>n</i> = 18	13 (72.2)	5 (27.8)
Diseases:		
Blood tests <i>n</i> = 18	5 (27.8)	13 (72.2)
Prenatal records <i>n</i> = 18	3 (16.7)	15 (83.3)
Medical history <i>n</i> = 18	5 (27.8)	13 (72.2)
Illicit drugs <i>n</i> = 18	12 (66.7)	6 (33.3)
Medications <i>n</i> = 18	15 (83.3)	3 (16.7)
Tobacco <i>n</i> = 18	14 (77.8)	4 (22.2)

fundamental principle informs the WHO recommendations for infant feeding in which the unpasteurized milk of a healthy donor is promoted as an appropriate, and often preferred, alternative to breast milk substitutes when BDM and MOM are not available (WHO



**Table 3.** Recipients' concern about MSSl by donor screening variables

MSSI ( <i>N</i> = 206)	High concern		Low concern		95% CI <sup>c</sup>	Chi-square  <i>P</i>
	Asked screening questions	Did not ask screening questions	Asked screening questions	Did not ask screening questions		
	<i>n</i> (%) <sup>a</sup>	<i>n</i> (%) <sup>a</sup>	<i>n</i> (%) <sup>b</sup>	<i>n</i> (%) <sup>b</sup>		
Age of infant <i>n</i> = 200	52 (80.0)	13 (20.0)	81 (60.0)	54 (40.0)	(7, 33)	0.005
Alcohol <i>n</i> = 202	96 (78.0)	27 (22.0)	46 (58.2)	33 (41.8)	(7, 33)	0.003
Diet <i>n</i> = 202	57 (76.0)	18 (24.0)	82 (64.6)	45 (35.4)	(-1, 24)	0.090
Diseases:						
Blood tests <i>n</i> = 199	37 (34.6)	70 (65.4)	17 (18.5)	75 (81.5)	(4, 28)	0.011
Prenatal records <i>n</i> = 199	23 (21.3)	85 (78.7)	6 (6.6)	85 (93.4)	(5, 24)	0.003
Medical history <i>n</i> = 197	40 (37.7)	66 (62.3)	13 (14.3)	78 (85.7)	(12, 35)	<0.001
Medications <i>n</i> = 200	109 (80.1)	27 (19.9)	33 (51.6)	31 (48.4)	(15, 43)	<0.001
Tobacco <i>n</i> = 204	109 (79.6)	28 (20.4)	38 (56.7)	29 (43.3)	(9, 36)	<0.001

<sup>a</sup>These percentages reflect the proportion of high concern responses for each MSSl.

<sup>b</sup>These percentages reflect the proportion of low concern responses for each MSSl.

<sup>c</sup>This CI represents the difference in screening percentages calculated as (high concern – low concern).

2003). It is also one of the most commonly cited reasons that parents choose to engage in human milk sharing (Gribble 2013, 2014a,b; Palmquist 2014).

Milk sharing continues to grow because it is a highly accessible way for parents to feed their infants with human milk as recommended by the WHO and AAP when it would otherwise not be possible (Akre *et al.* 2011). In fact, milk sharing recipients in the U.S. report higher rates of exclusive breast milk feeding 0–6 months and longer duration of any breastfeeding/breast milk feedings than the national averages (Palmquist & Doehler 2014).

While milk sharing typically involves gifts of expressed milk from donor to recipient, it is often practiced alongside shared breastfeeding (i.e. allomaternal nursing, co-feeding or cross-nursing/cross-breastfeeding, which may or may not be reciprocal) (Shaw 2004, 2007; Thorley 2008, 2009, 2012, 2014; Reyes-Foster *et al.* 2015). Various types of milk sharing practices are found in communities where there are bonds of trust between infant caregivers (Thorley 2012). Islamic milk kinship is one example of a longstanding cultural milk sharing practice (Altorki 1980; Khatib-Chahidi 1992; Zuhur 1992; Carsten 1995; Parkes 2007; Thorley 2014). Sharing of breastfeeding and breast milk is described as a form of caregiving cross-culturally (*cf.* Boyer 2010; Cassidy & El Tom 2010; Cassidy 2012b; Gribble 2014a,b; Hewlett & Winn

2014; Palmquist 2014). Accordingly, the social and relational contexts of care, and not simply the benefits of human milk, are essential to parents' engagement with milk sharing and sharing breastfeeding (Shaw 2003, 2007; Gribble 2014a,b; Palmquist 2014). Moreover, these social relationships potentially shape the ways that milk sharing risks are conceptualized and milk sharing practices are enacted (Shaikh & Ahmed 2006; Cassidy & El Tom 2010; Thorley 2012, 2014; Gribble 2014c).

The relative risks and benefits of human milk sharing have been the subject of numerous editorials, commentaries and a growing scientific literature (Arnold, 2009; Cohen *et al.* 2010; Landers & Updegrave 2010; Akre *et al.* 2011; Geraghty *et al.* 2011; Gribble & Hausman 2012; Nelson 2012; Brent 2013; Geraghty *et al.* 2013; Keim *et al.* 2013, 2015; Landers & Hartmann 2013; Updegrave 2013a,b; Gribble 2014c; Keim *et al.* 2014a, b; Martino & Spatz 2014; Carter *et al.* 2015). Debates on the risks of contemporary milk sharing remain highly contentious because of anxieties regarding parents' ability to reduce the risk of harm by exercising informed choice and self-directed screening of prospective donors and recipients. People who share milk online have reported a lack of healthcare provider guidance in making informed milk sharing decisions (Gribble 2014c). Research directed at understanding

parents' perceptions of milk sharing risks, actions they are taking to attempt to reduce perceived risks, and reasons that motivate them to share milk despite recommendations against it is needed to inform more effective public health policy and practice. The present study contributes to the growing literature on milk sharing and public health.

Our findings add evidence-based perspectives to concerns that have been raised in the public health discourses of human milk sharing. One concern has been that shared milk is being sought primarily for critically ill infants (Geraghty *et al.* 2011; Nelson 2012; Keim *et al.* 2013; Keim *et al.* 2014a,b). Two studies, in which the content of online requests for milk were examined, found that parents commonly indicated they were seeking milk for an infant with 'a poor birth outcome or other medical condition, which may put them at increased infection risk' (Keim *et al.* 2013) or child health problems ranging from 'mild including colds and general immunity, to more severe problems, including necrotizing enterocolitis complications and terminal illness' (Perrin *et al.* 2014). These studies relied on online posts to draw broad conclusions about milk sharing practices, without accounting for the fact that these public postings are merely an entry point for private milk sharing interactions. In practice, milk sharing donors and recipients report exchanging a great deal of information in the interval after an online post is made and the act of giving or receiving milk (Gribble 2014a, 2014c; Palmquist 2014). Thus, online posts may not fully reflect the current health status of a particular child, the screening information that is gathered by recipient parents, nor how parents are weighing the risks and benefits of milk sharing relative to formula feeding or BDM.

Among respondents in the present study, only 4.0% reported seeking milk for a critically ill infant. Approximately 83% of recipients reported that their babies were born at full-term, and the average age of a milk sharing recipients' child was 7.1 months (Palmquist & Doehler 2014). The majority of infant conditions associated with recipients' decisions to seek donor milk are common conditions that often coincide with or exacerbate lactation insufficiency (Mannel *et al.* 2013) not indicators of serious underlying health issues. Moreover, 42.2% of recipients reported that they

experienced lactation insufficiency apart from a specific infant condition, and only 9.2% had procured milk from a milk bank. Thus, our findings add weight to previously published qualitative studies, which have described milk sharing as a practice that largely meets the needs of mothers with relatively healthy babies, but who are facing lactation insufficiency and, for a variety of reasons, may not have been able to access BDM (Thorley 2012; Gribble 2013, 2014a,b, c; Palmquist 2014; Palmquist & Doehler 2014).

Another issue is that human milk sharing is often conflated with anonymous online interactions that may or may not involve the purchase of milk (Nelson 2012; Geraghty *et al.* 2013; Landers & Hartmann 2013). The terms milk sharing and milk selling are often used interchangeably, underscoring a commonly held misconception that these two practices are enacted in similar ways and carry equivocal risks (Geraghty *et al.* 2013; Keim *et al.* 2013; Keim *et al.* 2014a,b). Our data contained no instances of anonymous milk sharing. The anonymous purchase of milk was also not reported among recipients; all 18 recipients who reported buying milk also indicated that they had screened their donors, met their donors in person or procured BDM. These results are consistent with findings from a recent survey conducted in central Florida in which milk sharing was highly localized, involving online and offline interactions, multiple types of social relationships and sharing of expressed milk simultaneously with cross-nursing (Reyes-Foster *et al.* 2015). The social networks and screening interactions reflected in these studies are discordant with the type of anonymous interactions reported in studies of human milk purchased online (Geraghty *et al.* 2013; Keim *et al.* 2013, 2015; Keim *et al.* 2014a,b). Hence, the risks associated with the anonymous sale of human milk, including microbial contamination and tampering with bovine milk, may not be broadly applicable to commerce-free milk sharing practices in which social relationships are familiar, localized, and donors and recipients make decisions to give or receive milk using lay screening practices (Reyes-Foster *et al.* 2015). Further research is needed to assess the risks and benefits of milk sharing empirically.

Milk sharing screening practices appear to be highly contextual and dependent upon the nature of



donor–recipient social relationships and not simply parents' perceptions of risk. For example, recipients reported screening online acquaintances at a higher rate than friends, family, and people they met through local community connections. Perceptions of risk were also lower when social ties were more familiar. Parents' screening practices and assessment of risks and benefits may also vary depending on the age and health status of their child. Longer-term milk sharing relationships have the potential to transform online acquaintances into friends, and so the temporal aspect of milk sharing is important to consider when interpreting these results. We explored whether a recipients' duration of total milk sharing, measured as the difference between their most recent milk sharing experience and the date of their first milk sharing experience, was associated with level of concern for each MSSSI. Specifically, we considered three categories for length of sharing: less than 6 months, at least 6 months but less than 1 year, and more than 1 year. MSSSI items were characterized as some level of concern or no concern. However, none of the chi-square tests indicated a significant association ( $P > 0.10$ ). This suggests that the formation of risk perception may be influenced more heavily by social ties than by time, or perhaps that complex interactions between these and other variables are relevant to the formation of milk sharing risk perception. All of these factors must be considered when attempting to elucidate the relational contexts of milk sharing risk and parents' decision-making processes.

The mixed associations between concern about risk and donor screening observed in our data are likely a function of the types of social relationships within a recipients' milk sharing networks. These findings are consistent with other studies in which mothers reported having gathered information they felt was necessary to make informed decisions regarding feeding their baby shared breast milk, including observing prospective donors breastfeeding their own babies and developing relationships of trust, without asking prescriptive types of screening questions (Shaw 2003, 2007; Shaw & Bartlett 2010; Thorley 2012; Gribble 2014a, 2014c). Wording of the survey item was problematic, because it implied that information gathered during screening was primarily initiated by recipients. Respondents ( $n = 93$ ) added comment for this survey

item indicating that donors typically offer screening information before recipients have a chance to ask screening questions. Thorley (2012) cautions healthcare providers to exercise care when asking parents if they have 'screened their donors,' because this prompt often elicits a much different response than asking parents if there are 'any circumstances in which they would not accept' shared milk. Recipients may not consider their decision-making processes as a screening process, *per se*, despite employing specific criteria in assessing whether or not to accept shared milk. Thorley goes on to note that, 'Women are usually very clear about whom they would never choose and why and from this it can be deduced that lifestyle and health screening are taking place (2012: 11).' The fact that some recipients did not report asking donors screening questions about certain MSSSI should, thus, be interpreted with caution.

There is risk of contamination whenever human milk is expressed and handled, but the extent to which handling of milk contributes to risks of contamination and negative health outcomes remains unclear. A study of milk sharing practices among an international sample of donors found that they did not always follow recommended practices for safe milk expression and handling (Gribble 2014c). While donors' milk expression and handling practices were not fully assessed in the present study, 99.2% (599/604) of donors reported breastfeeding/expressing milk for their own baby during the time in which they were sharing their milk (Palmquist & Doehler 2014). To put this in context, most U.S. breastfeeding mothers reported following Academy of Breastfeeding Medicine recommendations (ABM 2010) for expression and storage of milk (Labiner-Wolfe & Fein 2013). More research is needed to assess storage and handling practices among milk sharing families and microbial composition of shared milk. The present study provides a solid framework for the types of milk sharing interactions that should be approximated in future investigations.

Flash heating of milk was reported among a small proportion of recipients who reported a high concern with disease transmission. The risks and benefits of heating human milk to inactivate the human immunodeficiency virus have been established (Israel-Ballard *et al.* 2007; Gribble & Hausman 2012; Landers & Hartmann 2013). However, it is unknown whether

parents using this method have made an informed decision to flash heat milk.

Healthcare providers have an ethical responsibility to give their patients evidence-based information regarding the risks and benefits of all types of infant feeding practices, and to assist parents in weighing risks with benefits (Jones 2003; U.S. Food and Drug Administration, 2010; Gribble 2012). Yet, there is a wide range of opinions regarding how best to engage the issue of milk sharing ethically with patients. Many simply discourage it. Some have suggested that healthcare providers address these gaps by working closely with parents to assist them in making informed milk sharing decisions (Gribble 2012). Others have established ways to provide families with instrumental milk sharing support led by trained healthcare professionals (Walker & Armstrong 2012; Martino & Spatz 2014). For example, community-based organizations like Get Pumped! ([getpumpedonline.org](http://getpumpedonline.org)) and Mothers' Milk Alliance ([www.mothersmilkalliance.org](http://www.mothersmilkalliance.org)) coordinate the screening and serological testing of donors, provide information regarding safe donor milk expression, handling, storage and infant feeding, and distribute shared milk to local families in need. They work side-by-side with local milk banking advocates, other healthcare providers and families to promote the work of HMBANA, assist recipient families in making informed decisions, and actively advocate for breastfeeding in their communities. In the absence of guidance from healthcare providers, parents may employ a wide array of practices that may or may not reduce the risks, as exemplified by our data.

Findings from the present study bring into focus some of the key public health challenges of milk sharing, including what role healthcare providers may play in assessing whether parents' milk sharing practices are sufficient to reduce risk of harm to their infants. The USFDA statement on the use of donor human milk notes that human milk obtained directly from individuals or through the internet may come from donors who are not 'adequately screened' (U.S. Food and Drug Administration, 2010) but what constitutes adequate screening remains contentious. More to the point, recipients' lay perceptions of risk and definitions of 'adequate screening' strongly influence their milk sharing behaviors, as do their relationships to

prospective donors. The fact that many milk sharing donors and recipients do not seek guidance from healthcare providers reflects variations in the degree to which milk sharing is considered a practice that requires medical surveillance and oversight (Palmquist 2014). Understanding how parents conceptualize the risks of milk sharing is fundamental to developing guidelines that healthcare providers might use to discuss milk sharing in clinical settings. This work is also essential to designing health communication strategies that are effective and do not alienate or stigmatize parents who are milk sharing (Gribble 2012; Carter *et al.* 2015). Healthcare providers have an opportunity to also assist parents by monitoring the health of infants who are fed with shared milk. Such efforts are only possible if a health provider is aware that parents are milk sharing. An evidence-base is needed to ascertain the effects of milk sharing on infant health, and clinician-led documentation may be an expedient way to establish one.

### Limitations

This study is cross sectional. The survey instrument was an unrestricted self-selected online survey, making it difficult to ascertain the generalizability of results. Study findings may not pertain to other forms of milk sharing that rely less heavily on online social networking or to settings outside of the U.S. The extent to which milk sharing screening practices reported in this study may result in reduction of absolute risks is unknown.

### Conclusion

Milk sharing continues to grow despite public health recommendations against it. Study findings demonstrate that parents are concerned about milk sharing safety and actively negotiate risks using the resources available to them. The striking variability in perceptions of risk, screening practices and milk sharing social networks is likely tied to the absence of healthcare providers in parents' decision-making processes and milk sharing practices. The demand for human milk in the U.S. remains largely unmet through non-profit milk banks, and competition for donors will only intensify

as commercial markets for human milk grow (Pollack 2015). Dramatically improving breastfeeding rates and expanding universal access to human milk for all infants in need should be considered a major national health priority (Arnold 2006; WHO 2008, 2014; U.S. Department of Health and Human Services 2011) following the lead of other nations (Pires 2014). There are many aspects of milk sharing that merit further study, including the health outcomes of infants who are fed with unpasteurized donor milk as compared with infant formula, BDM, or exclusively MOM. Future studies of the risks of milk sharing should more closely approximate the milk sharing practices reported herein.

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### Conflicts of interest

The authors declare that they have no conflicts of interest.

### Contributions

AP drafted the first version of the manuscript. No grants, honoraria or other form of payment was given to anyone to produce the manuscript.

AP conceptualized and designed the online survey instrument, delineated statistical analyses to be conducted, assisted in analyzing statistical data, drafted the initial manuscript and approved the final manuscript as submitted.

KD executed the statistical analyses, assisted with drafting the manuscript and approved the final manuscript as submitted.

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