Demystifying Human Milk Donation and Casual Informal Milk Sharing

Krista Sigurdson
PhD Candidate
Sociology, Department of Social and Behavioral Sciences
krista.sigurdson@gmail.com

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I am a medical sociologist

I study medicine, health and illness as social phenomena.

Dissertation Title: “Emerging Milk Exchanges: Human Milk Banking, Sharing and Technoscience”

I use the terms of the participants who I studied.

I invite audience contributions to understanding this phenomena!

I cannot give advice on best practices in milk sharing but can tell you what I have observed on the ground.
Ways milk is shared

Through in-person relationships

- Mom’s groups (e.g. play groups and lactation support groups)
- Between friends
- Between relatives
- Between co-workers
Ways milk is shared
Through parenting or neighborhood listservs

- Bay Area Home Birth Collective
- Bernal Heights Neighborhood Group
- Golden Gate Mothers Group
- Berkeley Parents Network
Ways milk is shared

Through referrals

- Lactation consultants
- Midwives
- Physicians
- Friends
Ways milk is shared

Through online platforms set up for milk sharing

- Milk Share
- Human Milk 4 Human Babies - Facebook
- Eats on Feets - Facebook
- Bay Area Breast Milk Cooperative - Facebook
Breastmilk Donation

MilkShare was formed in 2004 by Khadijah Kelley Cisse (formerly Kelley Faulkner), a home midwife and mother who is unable to produce enough breastmilk due to a congenital lack of glandular tissue. Knowing the significant benefits that only breastmilk can offer, she sought to provide the best possible nutrition for her children using donated breast milk. Thanks to more than 100 generous and loving nursing mothers, she has received approximately 30,000 ounces of donated milk over the last ten years for her three children. Her second and third son were exclusively breastmilk fed for the first year of life.

Khadijah’s passion for empowering families, includes educating families about the many benefits and the various options and considerations for sharing human breastmilk for the benefit of babies that might otherwise go without. She believes that breastfeeding is important for all infants and is dedicated to community awareness about the benefits of breast milk, options beyond milk banks, and the value of milk donation. Her vision is to improve the quality of human life through increased breastfeeding across the world...even when Mother Nature is seemingly uncooperative.
Friends and relatives should not make requests for breastmilk on behalf of someone else’s baby. Only parents/guardians should make requests for breastmilk on the Eats On Feet's network.

Eats On Feet - Northern California

Community

#4Pillars #DirectContact #InformedChoice

1,004 likes

Ajita Dorch likes this.

Invite your friends to like this Page.

ABOUT

Eats On Feet is a world-wide network for those who have made the informed choice to share breastmilk.

http://www.eatsongfeat.org/

Suggest Edits

PHOTOS

See a need, fill a need.

NOTES

Before we start

November 13, 2011
Friends, we have three babies in urgent need of milk. 6wx old, 7wx old and 9wx old. If you have extra milk or are willing to pump for them, please let us know or respond to the posted requests directly. Thank you so much! Keep checking the posts by others too to see offers and requests as they come up!

Moms Unite To Provide Breastmilk For Baby After His Mother's Sudden Death

Donors of breastfeeding mothers across Southern California have joined forces to provide milk for a baby whose mother died following a heart attack.
Ways milk is shared

- Considerable overlap between ways of making matches.
- Some sharing involves cross-nursing; more likely through in-person matches.
  - Tradition or babysitting arrangements
  - Taboos against cross nursing
- Milk sharing is not a new practice. Reflects old practices taking new forms through the facilitation of internet platforms.
Informal milk sharing versus selling

- For participants, sharing as opposed to selling meant:
  - Increased safety
  - Empathy and support for those struggling with breastfeeding
  - Some opposed milk selling but for others it just “wasn’t what we do” or it just isn’t expected in sharing communities.
Why recipients are using informally shared milk

- Why don’t recipients use a milk bank? (Gribble 2013)
  - Would not qualify as having a medical need
  - Cost prohibitive
- Debbie’s story.
Why recipients are using informally shared milk

- Adoption or Surrogacy
- Insufficient milk caused by:
  - Tongue tie (missed, caught late)
  - Separation from baby at birth
  - Painful/poor latch
  - Return to work causing supply drop
  - Low prolactin levels
  - Insufficient glandular tissue (IGT)
  - Prematurity or other birth complication
  - Multiple/unknown reasons
Narratives of breastfeeding leading to use of donated milk

Carina’s story – “This doesn’t happen.”
…when you’re being told by everyone, medical professionals included “This doesn’t happen. Women don’t just not make enough breast milk”. And being told by everyone, “oh it’s just your fenugreek, just drink more water, breast milk tea”. Jesus Christ. I drank more tea and potions and the only thing I didn’t do is acupuncture when it comes down to it. Literally the only thing I didn’t do…I mean’s it’s crazy making in a way, but like I said I needed to feel like I did everything I could and I had the resources and the support to do it…. In the moment you’re just doing what you can to get your kid to survive, but he was doing fine on formula. It wasn’t about that, it was about me wanting to fix what I saw as broken in myself, I guess. I felt like I had been betrayed by my body and I wanted to show it that it could do it and kind of to figure out what works.

Carina, recipient
Narratives of breastfeeding leading to use of donated milk

Lisa’s story

So I think for pretty much 6 months, I’d been taking herbs, pumping, power-pumping, nursing, pumping. And pretty much for the first 3 months almost, I couldn’t leave the house because I was either nursing him or I was attached to the pump. It was hell. It was just so miserable, I was in tears all the time because I just felt like I couldn’t feed my baby. You know that - there’s a bit of you that knows that this it’s hormonal, a lot of that sadness, but it just doesn’t help. And formula, I just felt like formula was poison. And I know it isn’t - I’m educated enough to know that it isn’t, but it’s just awful - I remember the first time we gave him a bottle when he was a few weeks old because he was desperate for food and I just sobbed, it was hideous. – Lisa, recipient
What are the characteristics of people who share milk? (Palmquist 2015)

- 95% white
- 69% college degree
- High income
- Breastfeed longer than the national average
- But differences found between donors and recipients:
  - Recipients lower income (still all relatively high)
  - Recipients more likely to have c-section or pre-term birth
  - Recipients had fewer lactation supports
“Our data suggest that **Internet milk sharing** operates within a hierarchy of social privilege that is largely constrained to an exceptional group of middle-income women who are highly motivated to breastfeed. While structural factors are associated with lactation insufficiency among recipients, these same women were able to rebound from lactastrophes, achieving high rates of breast milk exclusivity and duration in ways that are not possible without milk sharing.”

(Palmquist 2015)
What are the characteristics of people who share milk?

- Often mothers but also fathers.
- Diverse family arrangements, sexual orientations and gender identity. Lots of LGBTQ representation.
  - E.g. transgender men
  - Lesbian moms, Gay dads
  - Single moms
  - Single dads
Why donors are sharing milk informally

- “Wanted to help someone”, describing milk donation as an empathetic response to women with insufficient milk.
- Had excess milk. Did not want to waste it. Part of management of over-supply.
- Not wanting to waste milk.
- (Gribble 2014)

Why not donate to a milk bank?

- No banks local to them, did not qualify as donors, process to difficult, philosophical objections to milk banking, not knowing the recipient.
- (Gribble 2013)
Why donors are sharing milk informally

- For many not really a “decision”, just did what occurred to them first. Might not even know about milk banking.
- Extreme convenience
- Some misinformation about milk banks (e.g., thinking they are for-profit)
- Milk banks are not accessible to all that need milk or objection that parents have to pay for milk when not covered by insurance.
- Did not qualify for milk bank donation (e.g. for medication use, travel time in Europe or England that exceeds what is allowable).
Narratives of donation

Leah’s story
So I always had loads of milk. Then it was to the point where the lactation consultant was like “You know you are only allowed to store so much in the freezer. What do you want to do with the milk?” I’m like “What am I going to do with it?”… So she checked the milk bank to make sure the whole mad cow disease thing was true and it was. There was the Bay Area Breast Milk Coop. So Beth got in touch with me and was like “I find homes for homeless milk” which cracks me up..

Leah, donor
How safety is negotiated: Informed Milk Sharing

Human Milk 4 Human Babies

Informed Milk Sharing Network

Breastmilk, the biologically normal sustenance for humankind, is a free-flowing resource and mothers of the world are willing to share it. Milksharing is a vital tradition that has been taken from us, and it is crucial that we regain trust in ourselves, our neighbors, and in our fellow women.
Informed Milk Sharing

It means you find out what you need to know and you make the decisions, but we’re not taking responsibility and we’re not telling you it’s safe…If you’re not comfortable with that person, you don’t have to enter into a milk sharing relationship with that them. And don’t, we advise you not to. So you establish a level of trust and then you go onto the milk sharing with them. And we can’t take that on, because then we can’t guarantee safety. **We don’t want to guarantee safety, and these are just volunteer stay at home moms basically, that are running these pages. We just can’t ask that of them. We can never go there. That’s not a system that would work, so that’s why everything’s set up.**

Emma Kwasnika
How safety is negotiated: Four Pillars of Safe Milk Sharing

- Informed Choice
- Donor Screening
  - donor self-exclusion, health and lifestyle communication and blood testing.
- Safe Handling
  - proper handling techniques and follow generally accepted guidelines for storage of expressed milk.
- Home Pasteurization
  - Holder or Flash

The Four Pillars of Safe Breast Milk Sharing

Shell Walker and Maria Armstrong

Introduction
Since 1991, I have fostered milk exchanges between many families within my community and it is not uncommon for folks to call on me if their baby has a need for donor milk. As an organic response to this trusting calling, I established Eats on Eats in July of 2010.

A lot has changed in my milk sharing consciousness since I was a new mother living with my friends under the towering cypress-topped trees by the river. As Eats on Eats moved beyond my personal community, I was filled with endless questions (is milk sharing really safe? How should lactating women access this information so that they need it? Am I doing this being well served? Am I missing something?)

In November of 2000, I had the privilege of meeting Maria Armstrong, who became a founding member of Eats on Eats. We discovered that we had the same questions and considerations, and together we threw ourselves into the study of breast milk sharing. “The Four Pillars” are a result of our research and have been compiled from our “Reference for Informal Breast milk Sharing.”

The use of healthy donor milk is the best solution when a mother cannot provide her own milk for her baby. However, there are risks associated with feeding a baby breast milk outside of the closed bio-system of mother and child. It is our intention to provide evidence-based information for the safety of sharing milk.

These four pillars form a foundation from which parents can learn how to safely share breast milk. The four pillars are not only useful to parents, but also to pediatricians, midwives and those active in birth and parenting communities. By understanding these easy to implement principles, you too can help babies in these communities by supporting safe breast milk sharing.

The Four Pillars
1. Informed Choice
2. Donor Screening
3. Safe Handling
4. Home Pasteurization

Informed Choice
An informed choice is made by examining all available, verifiable and relevant information available and using it to carefully and objectively weigh options as well as potential consequences. When parents or professionals lack the information, in order to safely share breast milk or support breast milk sharing, it is important that M.L. and the information is taken into consideration, (just the same which supports personal decision in regards to breastfeeding) in order to make truly informed choices.

To date, milk banks have not the standard for milk sharing. Unfortunately, these standards are based on blood bank safety.
How safety is negotiated

- Screening
  - Filling out questionnaires, asking questions or volunteering info about lifestyle, diet, drug use, health conditions.
  - Asking to see bloodwork
  - “Not the kind of population you have to worry about”
  - Pregnant women have just had labs done

- Taking the plunge and getting used to it
- Pasteurization?
Bibliography


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