

Making “Milky Matches”

Globalization, Maternal Trust and “Lactivist” Online Networking

One of the most recent, and global breastfeeding activist or lactation activist movements was launched on the Internet in 2010. This mother-to-mother, sometimes called peer-to-peer, milk sharing Internet based networking does not support the selling of breastmilk, but facilitates, on a global scale, the establishment of local relationships. Issues of trust and exchange are key, as are questions of medicalization or biomedicalization, secrecy about cross-nursing, as well as the historical pejorative demonization of the lactating body. Discourses from government authorities, media outlets, and breastfeeding organizations have often created a sense of antagonism between this type of milk sharing, and the older form of donor human milk banking. However those who study these two visions argue for a synergy between the global Internet based milk sharing community and the donor human milk banking community as an important next step within the global culture of breastfeeding, and that synergy is not only possible, but necessary to ensure the primary interests of mothers and infants. As the mother of two infants, one of whom received donor human milk, while the other developed a fatal disease linked to lack of exclusive breastmilk feeding, I am particularly in favour of a world where all infants have the right to breastmilk, and that this right is not the sole responsibility of a single maternal body. Arguing that in the ideal world, we recognize it takes a village to feed that child.

Breastfeeding or lactation activism is a quintessentially local movement enjoying global features, with “lactivists”¹ networking across the world. One of the most recent global frames within this movement has been facilitated by the Internet and online human milk sharing communities, some of which are linked to the buying and selling of breastmilk online, while other versions are linked to establishing relationships of trust and exchange between mothers in

order to realize an ideal world of infants having access to breastmilk without individual mothers being the sole maternal body producing this milk. This movement is intimately linked to the “normalization” of breastmilk feeding which Australian advocates have argued for rather than its reification as some kind of precious metal (Gribble; Berry and Gribble). As part of this normalization it has been additionally argued that the natural sharing of human milk would become a ‘normal’ and immediate choice available for all infants whose mothers are unable to produce milk for them, citing the increasingly recognized century old global, but often medically controlled, donor human milk banking system. The continuing battle for legitimacy that the international donor milk banking community continues to fight, clearly has contributed to the spread and advocacy of a non-medically controlled human milk banking exchange system. These mother-to-mother human milk exchanges were helped to become global through the use of new digital technology.

The global Internet-based human milk sharing movement is designed to encourage sharing, not selling, breastmilk, and therefore establishing maternal relationships of trust between mothers who were (often) originally strangers, although living within reach of each other. In a commentary about the global Internet based mother-to-mother human milk sharing network, three underlying dynamics have been identified (Akre, Gribble and Minchin). Firstly, there is the long history of suspicion regarding women willing to give their milk which is invariably linked to the pejorative and stereotypical historical identifications with the profession of “wet nurses,” a topic which has been discussed extensively by historians in a number of countries. Secondly, there is the phenomenon of the Internet undermining and challenging medical authority, challenges that were developing long before the World Wide Web. Finally there have been arguments made that this global network threatens the perceived “limited” supplies of donor human milk for banks. As a personal and professional advocate of donor human milk banking (Cassidy and El Tom), I became interested in this global Internet based human milk sharing from the earliest days, making contact with its originator shortly after the message about going global was made public.

Disclosing My Story

Disclosure in medical research is generally reserved for research bias in relationship to economic support from non-biased corporations. However, autoethnography recognizes that all research has an investment in the topic being explored, and that it is best to make the disclosure part of the research endeavor itself (Anderson; Denzin; Wall).

My story about breastmilk sharing begins with a wish, progresses through a nightmare, and ends with hopeful visions of the future. My first son was born ten weeks prematurely, and I was unable to make breastmilk to feed him, either because of the interruption in my pregnancy or because of the difficulties surrounding his birth. The medical personnel in the hospital in Canada where he was born told me it was very important for him to have breastmilk, but since I had a family history of long-term breastfeeding, I was personally positively predisposed to the provision of breastmilk as primary nutrition for infants. But despite my best intentions I was not able to produce more than a few mils for my son, and the same medical personnel made the decision to aggressively give him formula, knowing and expecting that he would develop a fever and that his health would be compromised. I however kept trying to produce milk for him.

It seemed to me as if every time I went into the room to express milk for my son, I ran into another mother in the unit, a mother of twins, who seemed to me to be producing copious amounts of breastmilk. I often thought I wish I could ask her for some of her milk, but as far as I knew at that time this was something which one never did. It never occurred to me to ask my sister who was still feeding her three-year-old if she would give me some of her milk for my son.

Sixteen days after his birth, my son was rushed to another hospital to have surgery for a condition they told me was Necrotizing Enterocolitis (NEC). But the disease had progressed too far, and he died in my arms.

When I was able to think again, and as a medical sociologist/anthropologist I looked up NEC, and discovered its links with prematurely born infants, in particular with those not being fed breastmilk exclusively. When I asked the question about what was to be done when mothers were medically unable to produce enough breastmilk, I quickly found links to donor human milk banks, a topic I have discussed in greater detail elsewhere (Cassidy and El Tom).

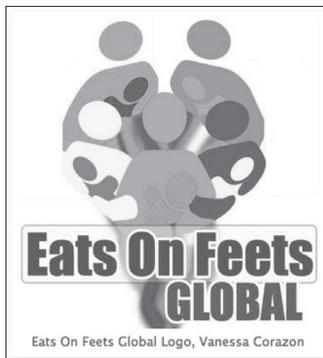
Less than a year later, armed with this new knowledge about a form of medicalized breastmilk sharing, my second son was born, also ten weeks prematurely and in many ways under even more traumatic circumstances. However when I was again not able to produce enough breastmilk, my partner and I were supported by the Dublin, Ireland based medical staff to get donor human milk. He thrived on this milk combined with whatever milk of my own I was able to produce, and was released from hospital after only five weeks. Because we were in Ireland, he received milk from the only community based donor milk bank in the UK, and a cross-border health exemplar that served the island of Ireland as a whole. He continued to receive donor human milk until he was almost two months corrected (around four months of age).

My partner and I were trying to help the Northern Ireland donor human milk bank to acquire more donors, and appeared, with the director and my son,

on television to tell our story. At that time my son weighed over eleven pounds, despite having been under three pounds (1500 grams) at one stage. We were able to increase the supplies for the donor milk bank, but they were still very limited and infants in greater physical need were given priority over my son. However the director of the donor milk bank told me if I were able to find a mother who was willing to help me by giving me milk for my son she would help to make sure it was as safe as that which I had received through her bank. Unfortunately I had no idea where to look for such a mother. Despite the fact that I was actively involved with a number of online breastfeeding mothers groups, it never occurred to me to ask for help to feed my son directly from the maternal online community.

Global Networking of Human Milk for Human Babies

My second son was four and half years old when, on October 30, 2010, a tweet went out from EatsOnFeets saying “Eats On Feets is a GLOBAL project to get donor breastmilk to babies in need through women-to-woman donation!” A week later a press release appeared on Facebook which said that a Canadian online breastfeeding activist named Emma Kwasnica, launched *Eats on Feets Global*, “the world’s largest human milk sharing network.”



The press release goes on to tell us that *Eats on Feets* started in July 2010 as a local Facebook page by a Phoenix based midwife, Shell Walker (Pevytoe). Walker reports that in 1991 she said to a friend/colleague “*Hey, why don’t we just become wet-nurses? Instead of Meals on Wheels, we can call ourselves ‘Eats On Feets.’*” She began using Facebook to help local women in July 2010, and thus joined the Facebook breastfeeding activist genre. In October she had been approached by Kwasnica who Walker said had been helping others

internationally through her private Facebook group “Informed Choice: Birth and Beyond” which she told me she had started shortly after joining Facebook.

A mother of three, Emma has long been involved with Facebook and breastfeeding activist issues, having been one of the early members on the open Facebook group “Hey, Facebook, breastfeeding is not obscene!” I also learned about this group shortly after it formed in 2007 by a San Diego mother Kelli Roman (Calhoun; Ibrahim). As *Time* magazine reported (Calhoun) in an article entitled “Facebook’s War on Nipples,” the “Hey Facebook” group receives Internet support from the Topfree Equal Rights Association (TERA),

a Canadian based group which continues to post the images that Facebook removes. TERA posted a number of Kwasnica's breastfeeding pictures that Facebook had removed, as notes her Facebook account deleted on January 1, 2009, saying "Emma is a major force for women's, mothers', and breastfeeders' rights."

A later *Time* magazine article says it occurred to Kwasnica that "the global breast-feeding community could use social media to organize real-world, offline "lactivism," in the form of milk sharing" (Block). This high profile article appeared weeks after the launch of the global network under the title, "Move over milk banks: Facebook and milk sharing," thus setting up an unnecessarily (as I will argue) antagonistic tone between women-to-women or peer-to-peer milk sharing and an older, medicalized system of donor human milk banking.

Regulating and Medicalizing Human Milk for Human Babies

Just as so much media attention was being directed to the new global network, government agencies started to add their voices. Since the network began in Canada, I want to concentrate on the Canadian discourse associated with this issue, beginning with the Canadian Paediatric Society (CPS) Nutrition and Gastroenterology committee position statement on "human milk banking," which was published on November 2010 (Kim and Unger). This strongly positive statement about human milk banking occurred when there was only one human milk bank in Canada. Despite this clearly positive human milk banking statement only one more human milk bank has opened in Canada, very recently, in Calgary, Alberta, in April 2012. In August of this year, it was reported that the Toronto milk bank was still months away from completion (healthzone.ca). It is also important this statement talks about the use of donor human milk banks in neonatal intensive care units (NICUs). They also state under the title Parental Choice that,

In this era of informed consent, it is of utmost importance for parents to be fully informed of all treatment options available for their children. Parents must thus be made aware of the possibility for their children to receive human donor breast milk along with all of the perceived benefits and potential risks. They must also be made aware of the health advantages of human breast milk compared with bovine milk. They may then make an informed decision as to the best feeding plan for their baby.

It is also important to note that the CPS statement does not mention human milk sharing on the Internet or otherwise. Perhaps this is because Health

Canada released a statement on November 25, 2010, against “the sharing of unprocessed human milk,” recommending that “Canadians consult their health care professional should they have questions about breastfeeding or if they are considering purchasing human milk or acquiring it through the Internet or directly from individuals.”

Dr. Sharon Unger, one of the authors of the CPS position statement on human milk banks, gave one of twelve presentations given to the American FDA Pediatric advisory committee meeting on December 6, 2010. Prior to this, on November 30, 2010, the FDA endorsed donor human milk banking, while at the same time including the following negative statement about the use of the Internet to obtain breastmilk:

FDA recommends against feeding your baby breast milk acquired directly from individuals or through the Internet.

When human milk is obtained directly from individuals or through the Internet, the donor is unlikely to have been adequately screened for infectious disease or contamination risk. In addition, it is not likely that the human milk has been collected, processed, tested or stored in a way that reduces possible safety risks to the baby.

FDA recommends that if, after consultation with a healthcare provider, you decide to feed a baby with human milk from a source other than the baby’s mother, you should only use milk from a source that has screened its milk donors and taken other precautions to ensure the safety of its milk.

Since the Canadian physician was argued to be the parent’s advisor, the *Canadian Medical Association Journal* (published an article on the issue in February 2011 under the emotive title “Milk Sharing: Boon or Biohazard?” (Vogel). Beginning with a statement regarding the demise of Canadian milk banks due to the public health concerns regarding HIV transmission, this article then said that, “regulators, medical professionals and mothers remain divided on the safety of sharing breast milk.” This article goes on to quote Dr. Unger as saying,

Sharing unprocessed breast milk is dangerous. There’s a reason infant mortality has dropped, and a lot of it has to do with current public health practices. I have faith in those practices, and for all formula may not be as good as mother’s own milk, it is safe. (qtd. in Vogel)

The relative safety of formula is however a debatable point, certainly for

mothers of premature infants. This article also pointed out that Dr. Unger says that one of the reasons that Canadian hospitals were slow in adopting donor human milk banks was because formula companies provide formula for free, and thus “public funding for milk banks requires proof that there are health benefits and costs efficiencies to be achieved from using donor milk” (Vogel). She then discussed a five-year study Canadian Institutes of Health Research (CIHR) funded study that is due to release preliminary results soon.

Lactation Surrogacy, Trusting Strangers and Discouraging Secrecy

Lauren Vogel points out that for some mothers waiting five years is too long, and they turn, therefore, to alternative sources. She quotes Kwasnica, who “agrees that purchasing milk from an unknown mother is risky but argues that the risk is mitigated when mothers are able to meet in person and provide testing results” (qtd. in Vogel). In this same article, Kwasnica goes on to point out that “formula feeding may be just as risky, if not more so,” and describes a constipated infant with blood in their faeces, a description reminiscent of my first son’s symptoms.

Kwasnica argues that the network builds maternal trust as women are encouraged to meet each other. The linking of the global with the local. These relationships between strangers establish trust, and these women give of themselves without payment. These dyadic trust relationships have been extensively studied by game theorists, and contrary to their expectations, “is widespread and it is reciprocated” (Wilson). Karen Cook has argued trust is social because “it develops from the social bonds or social identification with a group, organization, society” (Cook 288). The social bonds of mothers helping mothers is a key component underlying this global network of human milk sharing. The dyadic maternal exchange is based on mothers meeting and developing a relationship of trust, helping them to make the recommended informed decisions, and for many around the world the benefits of human milk for their infants outweighs the risks.

“Infact Canada,” a widely recognized “non-governmental organization that works to protect infant and young child health as well as maternal well-being through the promotion and support of breastfeeding and optimal infant feeding practices” (Sterken) notes that the “Health Canada advisory flies in the face of the recommendations by both UNICEF and the World Health Organization, that when a mother is unable to provide her own breastmilk, the milk of another mother is safer than the use of an infant formula.” Infact Canada then asks the question “When mothers need a breastmilk replacement how does Health Canada consider the use of commercial infant formula products to be safer than the use of peer-to-peer informed milk sharing?”

Le Leche League International (LLLI) has a long history of talking about these issues, and has been on the receiving end of dismissive treatment by physicians in the 1980s for similar radical practices (Akre et al.). A 1995 article from their magazine *Leaven* said that the full incidence of cross nursing may never be known, and it would be very common for leaders to come across examples, regardless of their own position (Minami). Well before the current events, in 2005 LLLI issued a statement in light of “recent reports of sharing or even buying and selling human milk informally over the Internet or among friends,” saying:

A mother who is unable to use a human milk bank is encouraged to use the services of a doctor who is knowledgeable about managing human milk donations. The doctor will order the necessary testing for the donor mother, and make sure that the mothers involved in the donation are given the correct management information about human milk expression, storage and transportation

This policy statement was updated in March 2011, and specifically listed the benefits and risks of milk sharing:

Benefits include, but are not limited to: optimal nutrition, easy digestibility, and immunologic protection. Risks can include, but are not limited to: transmission of certain infectious agents, like bacteria or viruses, some of which may be found in milk expressed by asymptomatic women; drugs; possibly some environmental contaminants, and potentially unhygienic storage and handling of unprocessed donated milk. Milk from a qualified milk bank will require donors meet specific health requirements before accepting their donated milk, which eliminates many of those risks. Each country sets its own standards for milk donors and these screening criteria are available by contacting the milk banks directly.

This statement again advises mothers to speak with their health care providers, which is reminiscent of Health Canada statement.

Statements such as these are encouraging women to hide their breastfeeding work, in opposition to the underlying advocacy associated with the global movement in the first place (Shaw, 2004). It is to be recalled that the whole movement exploited the catalyst of the visibility of breastfeeding, pictures on Facebook, ultimately reinforcing the fact that this is all about the visibility of women.

Human Milk for Human Babies

Four months after the initial network was formed, on March 2, 2011, it was announced that the global milk sharing network launched a new name: “Human Milk 4 Human Babies.” The original press release quotes Emma Kwasnica as saying:

Human Milk 4 Human Babies illustrates our mission clearly and effectively, and will be both culturally appropriate and easy to translate around the world. Breast milk is not a scarce commodity. It’s a free-flowing resource, and we were dumping it down the drain. There is clearly a need for a global network to connect donors and recipients, a network that is easy to use, free of charge, and free from influence or coercion. Families can consider the risks and benefits and can make an informed choice to share their milk in a safe, ethical manner.

The release pointed out that at that time there were 120 active chapters in this global network, working in 38 different countries. The press release also points out there are no fees associated with this organization, nor do they support the sale of human milk.

In March 2011 there was a difference of opinion between Shell Walker and Emma Kwasnica, and in a commentary published six months after the beginning of the global network in the open access *International Breastfeeding Journal*, “mother-to-mother milk sharing should be viewed as complementary to donor-milk banking and not as its competitor” (Akre et al.).

Increasingly the discourse among both mother-to-mother breastfeeding organizations and health care agencies advocates donor human milk banks as the safer and preferred option. Human milk banks have been criticized, inappropriately, as hindering maternal infant breastfeeding relationships (Modi; Weaver). Increasingly cross-cultural evidence has suggested the direct opposite, namely that human milk banking contributes to increased breastfeeding, an important component in the ideal vision of a global culture of breastfeeding.

In December 2011, the European Milk Banking Association (EMBA) Board of Directors issued the following statement:

The worldwide increasing support for and credibility of human milk banking and breastmilk sharing will be undermined in the event of adverse consequences derived from uncontrolled and informal utilisation of breastmilk and as a reaction the increased use of artificial milk could result. That is why EMBA strongly recommends that donor breastmilk should be obtained from human milk banks which

follow quality guidelines for donor screening, breastmilk handling and processing.

Furthermore, at the most recent Human Milk Banking Association of North America (HMBANA) conference, which was held in conjunction with the 4th International Milk Banking Association congress, on April 23-24, 2012 in Las Vegas, Nevada, the relationship between banking and sharing was one of the topics discussed both in a plenary paper (Spence) and at a breakout session. Calls for some form of “synergy,” and ideas of building bridges between the mother-to-mother or peer-to-peer networking with the global not for profit human milk banks resonated with my own thinking on this issue, championing a perspective which had been voiced shortly after the second wave of the Facebook global milk sharing networks emerged.

Connecting Babies and Breastmilk: A Perfect Match

Mothers of premature infants are sometimes actively discouraged from using Internet based milk sharing networks, thus encouraging mothers to keep secrets, and to quietly try to do things to help our babies. I would instance the story Emma Kwasnica tells about a mother who was not able to produce enough milk, and instead sneaked in human milk she had been given by a friend. But as I noted earlier, with the support of a human donor milk bank such mothers, in particular those with older babies, can continue to provide the vital help human milk affords their offspring. However, one might argue that the recognition of the life saving potential which breastmilk affords the prematurely born has helped the global breastfeeding cause.

Individuals like Karleen Gribble, whose YouTube Australian Breastfeeding Association talk criticizing the notion of breast not being “best,” but the norm, has been extensively quoted and linked to by Internet based activists. She specifically stated that in a global culture of breastfeeding it would be normal to provide breastmilk to infants who are in medical need, or who have mothers whose medical circumstances inhibit their giving their infants their own milk. A global culture of breastfeeding is argued to make breastfeeding not the “gold standard” but instead the norm around which all other standards are judged. In connection to this, the WHO recently (Berry and Gribble) commissioned the construction of detailed weight charts for which medical personnel globally might just individual infant growth.

As part of this global movement, in 2006 the popular American-based *Mothering* magazine held a competition to search for a winning design to International Breastfeeding Icon (breastfeedingsymbol.org). Below winning image, by Matt Dailge, is below:



HM4HB Global network, and the first version of Eats on Feets Global Network used a multi-coloured series of the image below representing breast-feeding women and their infants from all colours and backgrounds helping each other. Connected with this image is the imagining of what the Internet can offer this network within the collage of words, including notions of informed choice, generosity, solidarity, and thinking globally while sharing locally.



The earlier Internet-based milk sharing communities (largely based in the U.S.) which LLLI alluded to were however more locally situated, although sometimes linked to urban or statewide communities, that is until the publicity associated with the most recent global network. For instance, a Nebraska-based group is called Milk Share, formed in 2004 by Kelley Faulkner, “a mom who is unable to produce enough breastmilk due to a congenital breast abnormality.”

Milk Share continues to help “empower families” to share “human breastmilk for the benefit of babies that might otherwise go without.” Milk Share does however ask for donations, and asks people seeking donors to pay a one off fee of \$20. They point out that as of August 2008 they helped 16,000 families engage in private milk donation.

On their home page, Milk Share says they were inspired by Jean Connel, whose link is no longer active on the Internet. On this website, we are told Jean Connel’s heart-breaking story of finding out she has breast cancer while pregnant with her first child in the summer of 2002. She went on to have a



double mastectomy. She tells us how she had a physician’s prescription to receive donor milk from the Denver Mother’s Milk Bank, and how she looked into nursing systems which will allow her infant to experience the bonding of breastfeeding, although the milk will be from other women. She then tells her reader that her problem is that her insurance company will not pay for the donor human milk. She says she wishes to feed her baby from anywhere between three weeks to six months, the minimum for health benefits. She tells us that the cost is \$3.25/ounce meaning a typical baby will go through \$104 a day. So she has set up an account at the Denver Milk Bank, and people can donate to the bank on her behalf.



In a later update on her website we are told:

We also had MANY offers of privately donated breast milk, which after careful consideration I decided to accept! I spoke with my Doctor and we decided that as long as any donors were willing to go through the same blood tests and health history screening that is required by the milk bank that I would accept their generous donations. I purchased a home pasteurizer and have been busy collecting and processing milk for Grayson! He has been exclusively breastfed since day one and with any luck I will be able to feed him breast milk until well over a year! I couldn’t have done this without of the support of my wonderful husband, caring family and friends old and new! THANK YOU TO ALL!

She then tells us about her having a second child in 2004, whom she also fed on donated milk from private donations as she describes above. Her website disappears in 2007, but clearly influenced many others, although it did not directly feed other infants.

Liquid Modernity, Glocalization and Breastmilk Sharing

This story has brought us full circle. We began with global Internet milk sharing which was seen by some (not all) to be contra-indicated with donor human milk banking, back to the original Internet human milk sharing which was directly supported and encouraged both by a local donor human milk bank, and also by local physicians. Milk banks have fought long and hard to establish

medical credibility and recognition and are therefore all the more defensive and cautious about distinguishing their efforts from less formal and professionally and institutionally accredited forms of milk exchange. However, dialogue and exchange of practical experiences between these endeavours seems the best means of serving the best interests of the primary stakeholders, mothers and infants themselves.

The mantra of thinking locally and acting globally underlies the exchanges of human milk for human babies around the world. Without forgetting the mothers involved, the fact that these exchanges recognize that breastmilk production can and should be understood as a social, collective enterprise serves to liberate the breastfeeding debate from the narrowly individualistic and capitalist onus of individual maternal moral responsibility. Julia Kristeva has written about the ambiguity and negativity associated with the separation of self and other for the mother, which begins with pregnancy and continues after birth. This ambiguity Kristeva feels is directly responsible for the pejorative visions of maternal bodily fluids including breastmilk, which may help to understand some of the culturally based so-called “yuk” experiences (Shaw 2004) indicated with public/social displays of breastmilk feeding. In cultures where communal infant feeding of breastmilk is the norm such exchanges have larger implications for society, mothers and infants (Cassidy and El Tom). However we must remember that mothers are all different, and even if a mother is in favour of breastfeeding she may experience very different perceptions regarding the fluid boundaries between herself and her infant which provokes “deeply-felt emotions and sensations” (Schmied and Lupton). Not only is it impossible to construct a category of “mothers” as a stable or coherent identity or interest group, it is impossible to delimit any one individual “mother” as a discrete and delimited identity. Not all of the mothers involved in the human milk banking and sharing world consider themselves to be maternal activists, although their actions and exchanges increasingly frame global lactivist rhetoric.

¹A portmanteau of “lactation” and “activism,” lactivist is in neither *Oxford English Dictionary* or in the *Webster Dictionary*. However, a definition can be found on Dictionary.com that says, “a person, especially a woman, who advocates strongly the breast-feeding of children, and is opposed to bottle-feeding.” Other less gendered usages of the term can be found at urbandictionary.com. Some prefer “lactavist” to “lactivist,” a choice that privileges lactation over activism.

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