

# Human Milk Donor Motivation and Engagement

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## ABSTRACT

This paper will review the literature around how new mothers use technology and why, how the public health sector and NGOs can use social media for user engagement, and the technology used for motivating blood donation. The literature around these three topics all relate to a less researched topic of the intersection of breastmilk donors and technology. Those topics will come together to analyze how technology can be used to motivate breastmilk donation and engage donors. Social media and how mothers behave online are the focus of the review, as they are important tools for breastmilk donor engagement and motivation.

## KEYWORDS

Human Milk Bank, Peer-to-Peer Milk Sharing, Social Networks, Blood Donation, Donor Mothers, Donor Engagement.

## 1 INTRODUCTION

Human milk is defined by the World Health Organisation (WHO) as a vital medical resource and the best source of food and nutrition for infants [23,2]. This is due to the positive influence it has on the health of infants. Benefits of human milk include its immunological properties which strengthen a newborn's immune system [37,38], it has anti-inflammatory properties essential to babies [39], and not all infants can tolerate formula (manufactured baby food), making human milk the most suitable form of sustenance and protection for infants [23]. Victoria et al. argue for the benefits of breastfeeding, stating that by scaling up breastfeeding to a near-universal level can prevent 823000 annual deaths of infants [38].

It would be ideal if every mother could breastfeed their children; however, for various reasons, some mothers can not produce human milk or only partially produce it [27]. Mothers are unable to produce breastmilk due to specific medications, lactation problems, sickness during maternity, and other complications [27,5]. These mothers must replace human milk by formula, or they must receive human milk from somewhere else. The most popular forms of donating breastmilk are human milk banks [5, 2], and peer-to-peer milk sharing, which has been on the rise due to the internet and social media facilitating engagement between mothers [27]. The demand for human milk often surpasses the supply, so to get breastmilk from a milk

bank, a doctor's prescription is normally necessary [27,28]. Breastmilk is crucial for Preterm babies and newborns in the Neonatal Intensive Care Units (NICUs), as they often can not intake any other form of nutrients, and need the health benefits of human milk [40].

Countries such as Brazil have streamlined processes in place to support milk banks and motivate mothers to donate their excess milk [8,15]. In contrast, countries like the United States neglect milk banking services, resulting in an increase in milk sharing among peers along with its risks, as well as less overall donated human milk [27]. Milk banking in such countries are done mostly by Non-governmental Organizations (NGOs), and they need a way to find donors, motivate them, and engage them [5].

The aim of this paper is to evaluate how Information and Communication Technologies (ICTs) can be used to motivate the donation of breastmilk to milk banks and donor engagement. There is a lack of literature on the intersection between breastmilk donation and technology, so this paper will focus on literature that can be linked to this topic. I will focus on the behavior of breastfeeding mothers and donors on the internet, on strategies used to engage and motivate donation in areas of public health, and on social network donation strategies.  
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### 2.1 Why Human Milk?

The health benefits of breastfeeding are evident in literature. Breastmilk can alter its composition to adapt to the infant's need for passive protection; it can stimulate development in the baby's host defenses, which continue protecting the baby after it has stopped being breastfed, and it protects the baby against allergies. Breastmilk is highly regarded for its anti-inflammatory properties as newborns are more susceptible to infections [23,2]. These benefits make human milk extremely important for premature infants, as their systems are underdeveloped and can not tolerate formula, which causes complications and can lead to death [26, 29]. Besides babies, breastfeeding can also decrease the chance of breast cancer in mothers [39].

### 2.2 Donation Terms & Types

Mothers who do not produce breastmilk, or have a shortage of it, have different places they can look for donations. Some of

the reasons why a mother can't provide their own milk for their child are, adoption, lactation problems, maternal illness, death, or specific medication they take [27]. There is a lack of information for mothers searching for human milk and a lot of concerns revolving milk donation. Health professionals have concerns with milk sharing, and mothers are sometimes concerned with milk banking [23,37]. This is an obstacle in moving forward with milk donation.

There are three main methods of milk donation that people can seek, which two are widely used. The first method and recommended by health professionals, is human milk banks [5,27,29,26]. The second method is increasing in popularity due to the ease of communication in social media, that is peer-to-peer milk sharing [6,12]. The last method is wet nursing, which is when a mother breastfeeds the child in need of milk [27]. The different methods have their benefits and complications, the first two methods will be discussed below, as they are the most used.

#### *2.2.1 Human Milk Banks*

Milk banks are commonly non-profit organizations that accept milk donations from mothers with an excess supply, and distribute it to infants with medical needs [2,26,5]. This is the option recommended by professionals in the area and by the Food and Drug Administration [27]. This is due to the strict screening process donors have to go through, and it ensures the pasteurisation process is done correctly [2]. Most milk banks give their milk exclusively to hospitals or to individuals with a prescription from a medical professional. The first in line for the milk are babies in the NICUs [26, 39] as they need it the most. This method of distribution is because the demand for milk from the banks are high in comparison to supply.

Literature has argued the benefits a country can have from successfully uplifting and giving continuous support to milk banking. Pimenteira Thomaz et al. investigates the motives of breastmilk donors in Brazil, the country leading milk banking currently. The two main reasons are altruism, and recommendations and support from their health care providers [29]. The benefits in terms of health and the economy are also shown in Brazil's milk banking system. The human banking system supplies human milk to over 170000 infants, and saves Brazil an estimated US\$540 million per year due to reduced medical costs [26].

#### *2.2.2 Peer-to-Peer Milk Sharing*

Milk sharing is the practice of sharing human milk directly between the donor mother and recipient [28,31], due to the altruistic nature of breastmilk donation, literature agrees that most of milk sharing is free of charge. This method is becoming popular due to two main factors. One is the creation of online communities on the internet, connecting donors and recipients outside their networks[27,28,31]. The second factor is the availability of cheap and easy to use pasteurization devices[6]. This method of milk donation is frowned upon by the health sector. There is a risk of pathogen transmission, and sometimes the milk is in inadequate condition to be donated [27,6].

## 2.5 Donor Motivation

Donor motivation in literature can be divided into three sections. General breastmilk donation, donations to milk banks, and milk sharing. Most people donate breastmilk for the same reasons, altruism, and the hope that someone would do the same for them [29,27,28,25]. However, people have different motives for the way they donate.

General breastmilk donations are mostly philanthropic [29,27,5]. Research has agreed on some of the factors that influence milk donation. Some of those factors are, testimonials of people who were helped by human milk, the social responsibility of donating surplus milk, and a significant factor is knowing an infant in need of human milk[29]. Some mothers donate with the hope that someone would do the same for them[28].

Breastmilk donors tend to prefer donating through milk sharing over milk banks [28,25,11]. There are a lot of variables influencing mothers' donating habits. There are logistical and emotional reasons, as well as misconceptions that lead to this. The two main misconceptions around milk banks are: That milk banks sell the donated milk for a profit and that the milk donated is just a source of food for the babies, instead of a medical resource [2]. Milk bank administration and operation can be costly, and they need the money to be able to operate. In regards to the emotional aspect of donating, mothers want to know who their milk is going to. They value their milk as it is food for their babies [28,11]. Often mothers will choose to donate to someone they want, and they see the tangible benefit. Lastly, there is a long process involved with being able to donate to a milk bank. Mothers must meet requirements and go through a strict screening process to be considered a donor [40]. It is often easier for mothers to engage in milk sharing rather than donating to banks.

## 2.6 Milk Matters & Previous Work

Milk Matters is a non-profit human milk bank based in the Western Cape, South Africa. Milk Matters has a small team whose activities comprise of sourcing donor milk from donors, pasteurizing the milk, and distributing it to local NICUs [40,19]. Milk Matters tends to have around 20 active donors at any one time, and they communicate with them through a mailing list [40,19]. In the past, they had a mobile application in the Play Store, but it is no longer there.

Chelsea Wardle and Mitchell Green worked with Milk Matters in the past to co-design the mobile application with the donor mothers [40]. This research uses their work as a start, by looking at their project, and as the sources they used. I found the rest of the literature by using a snowballing method, of using sources cited in papers. I also used credited search engines and the University of Cape Town's library.

## 3 BREASTMILK DONORS & ICT

There is a gap in research when it comes to the intersectionality between breastmilk donors and technology. By looking at new mothers, what they do online, and what they want, we get some insight into possible ways technology can influence them. Breastmilk donors are mothers of newborn babies, so they go through the same process as mothers do in the early postnatal timeframe [36,3,30]. The parallels between new mothers and breastmilk donors can help to understand what can motivate breastmilk donation and how to engage donors.

### 3.1 Mothers & Technology

Mothers of newborn babies have to go through a very stressful period while raising their child. In Dizon's research, all the mothers reported a disconnection with 'the outside world' and the 'world outside their bubble' in early motherhood [9]. They also spoke of their identities shifting with their child. There are many factors that influence the early days of motherhood. The literature revolving around new mothers and technology usually focus on the ability of technology to support mothers, and the community creation effect that social media has for them. Mothers go on the internet for many things, to look for information on raising a baby, they go looking to maintain social connections and make new ones through social networking, to entertain themselves when they can fit it into their erratic schedule, and they look for surety and support in a chaotic time in their lives [9,21,3].

Mothers' internet activity tends to increase after they have a child [21]. They use the internet for a variety of activities, some of the most frequent responses of what services they use are: Social networking websites, such as Facebook [36], websites and forums which contain information and communities for mothers such as, Netmums. There are a lot of applications tailored toward newborns, such as MyBabyToday and BabyGaga. Mothers reported using this technology on a smartphone, as they usually only have one hand free since the other one is busy with their child [9,40]. There is great importance in making technology that is easily accessible and easy to use with one hand for it to be useful to mothers. Many mothers complained that most forums are impossible to navigate on a smartphone, so they turn to social media baby groups for information instead [9]. The importance of the internet and smartphones is constantly growing in everyday life, and literature seems to agree they can play a important role in supporting mothers in their parenting journey [9,21,3,36].

### 3.2 Why Mothers Seek Online Support

One of the biggest and most impactful event of a person's life is having a child. Their life changes completely in a short time, while everyone around them moves on with life [9,21]. A mother's life ends up revolving around her baby, and it can be emotionally and physically exhausting. Many mothers have people close to them for support, but in our day and age of the internet and social media, many mothers are finding their support on the web [7,30,3]. Since Web 2.0, the internet became

an interactive place, the rise of social networks started, and social interaction online started growing, with many different communities finding their 'online space' [3,11,18]. It is no different for mothers, there are many reasons why mothers are using the internet more frequently, and how the internet is engaging and supporting them.

New mothers suffer from the physical and emotional exhaustion of their new life, fatigue associated with the demands of motherhood, and the uncertainty and constant learning they go through [9]. Often mothers will feel like they are failing as a mother, they compare themselves to others, and they are afraid of asking embarrassing questions because they do not want to seem incompetent [9,3]. Mothers also go through a period of social isolation, due to being consumed in taking care of their babies. Since their social circles comprise of work colleagues, friends and family, they feel excluded, as they do not have the shared experiences needed in feeling normalcy [30,9]. Motherhood can leave a person isolated, insecure, uncertain, and exhausted; these are the reasons why new mothers turn to the internet for help.

Two main themes are surrounding what new mothers want, according to Dizon. The need to improve confidence as a mother, and the need to be more than 'just' a mother [9]. Online support helps to empower mothers. Social networks are a great example of empowering mothers [3]. They can retain social connections, find answers to their questions, and preserve their identity by sharing their thoughts instead of focusing on sharing a 'baby diary' [9]. Social networks also help mothers find communities where there are people who share their experiences of being a new mother. By seeing other people having the same struggles and insecurities, mothers no longer feel insufficient. It also gives them a safe space to ask embarrassing questions [30]. The internet is also able to provide mothers with the ease of mind knowing they can find the information they need even at early hours of the morning [9,3,21].

Mothers are turning to the internet to find empowerment and confidence. By connecting with other mothers, having easy access to information, retaining social interactions, and preserving their sense of self, the mothers are turning the internet into a valuable support tool.

### 3.3 Breastmilk Donors & ICT

Breastmilk donors and new mothers use the internet for similar reasons. Most new donors get insecure about breastfeeding, for reasons such as not having as much milk as some of the other donors [40,3]. Breast milk donors look for a community they can find help, and comfort when it comes to their insecurities, as well as a space with people they can relate to [9,30]. One aspect of donation that is very important for donor mothers is acknowledgement [40]. For milk banks, acknowledgement is usually not available for donors due to scarce resources. This is frustrating for donors. In turn, social media helps to give that feedback to mothers, as they receive it from other donors [30,9,3]. For the most part, breastmilk donors use technology to help with milk sharing in a peer-to-peer

manner. There is not a lot of literature around milk donors and ICTs, but by linking what motivates and engages new mothers, to donor mothers, a strategy to engage donors can be created.

The online environment can be critical in influencing donors to continue donating; research indicates that support and encouragement from others reflect on mothers starting and continuing to breastfeed [30,7]. The use of trained mothers to play the role of encouraging and supporting has worked to provide emotional support and chances to ask questions about breastfeeding [9,30]. Mothers valued empathy and research found that a woman's experience with support during the breastfeeding stages, had them breastfeeding for six months or longer [30]. However, there are also bad experiences for mothers online. Many mothers complained about feeling judged for using formula, felt insecure around polarized debates around infant feeding, and had problems with the lack of regulation on who can answer questions and give advice [3,9]. A mother's online experience has an impact on their breastfeeding; therefore, it is important to create safe spaces for mothers to be in online.

### 3.4 NGOs, Public Health, and Donor Engagement

This literature is important because it can be linked to donor engagement of donor mothers, and milk bank NGOs. The literature surrounding the public health sector and engagement, agree that communication is vital for successful health promotion and disease prevention. Social networks have been a space where public health organizations broadcasted information, but it is continuously heading toward a direction where communication is needed, not just broadcasting [1,14]. It is hard to tell how well current public health organizations are using social media to engage their audiences, as there is little evidence of it [14].

Social media can enable many benefits for public health organizations, such as targeting new and diverse audiences, listening and collecting feedback in real-time, and increasing direct engagement [14,20]. This provides the users with acknowledgement, and the feeling of empowerment, as they feel like they are a part of the conversation [17]. This can be extended to creating opportunities for users to engage with each other and with the organization. These small acts of support can cause a ripple effect to increase user engagement [17,14].

User engagement should be a short and long term goal for NGOs and public health organizations, however there are concerns that need to be addressed and resolved. There is a risk of loss of message control with open conversations and engagements. Liability and reputational problems arise with this, unintended messages from users, and wrong information can give credence and credibility to 'junk science' [14]. The other problem, which would impact small NGOs greatly, is the resource allocation involved in having social media engagement at a desired level. The monetary and personnel expenditure is something that needs to be taken into account when engaging social media [14].

## 4 BLOOD DONATION & TECHNOLOGY

The intersection of breastmilk donation and technology is not widely researched, that is why I will use literature on using technology to motivate blood donation as it has been researched extensively. Due to the nature of the donations being similar, by analyzing blood donations, the results can be linked to breastmilk donation.

Blood donors and human milk donors are required to go through rigorous screening processes and meet various requirements to be eligible as a donor [35,41]. The motivations of donors also overlap as altruistic reasons; they are similar due to both being a public health matter and have the potential to save lives. They can both be viewed as vital medicine [39,16,10]. The main difference between blood donors and human milk donors are the demographic – breastmilk donors are solely mothers with newborn children. When analyzed, the percentage of women who donated blood for philanthropic reasons was the highest motivation given, which correlates to breastmilk donation motivations [13,22]. For these reasons, it is reasonable to analyze the use of technology to motivate blood donations in the context of human milk donation.

### 4.1 Technology Motivation on Blood Donation

The target demographic of potential blood donors is much larger than that of breastmilk donors, so there is a lot more technology and literature-based around blood donation. The most relevant technology to overlap with donor mothers would most likely be mobile applications, as mentioned previously, mothers seem to have a preference for their smartphones [9].

There are various media which NGOs and public health organizations tend to contact their user base through, such as emails, SMSs, and more recently through social media and mobile applications [24,22]. Users showed a preference for email communications when asked [22], and most of the donors were open to using a mobile app focused on blood donation [41].

Many blood donation mobile applications exist, and they fall under three different categories. According to Foth et al., these categories are social media, data visualizations, and personal services [10]. Donors preferred applications that empowered them and gave them information, such as news and updates from organizations and appointment scheduling [41,10]. Some applications offered users functionality to share their blood donation and encourage their social network to donate. Others offered blood donation tracking, to be able to record information of the last blood donations [41]. Even though users did not prefer the tracking and social media aspects of the applications, research indicates that the social media features are the most likely to influence people to continue donating, and recruiting new donors [22,41].

There were aspects of gamification included in some of the blood donor applications, but gamification, like money incentives, are discouraged in breastmilk donation [5,6]. This is because gamification may make donor mothers feel like they are

no producing enough milk, and monetary incentives can lead to donors neglecting their infants to sell milk [5].

## 5 DISCUSSION

This paper discussed topics related to the intersection of breastmilk donors and technology since there is a lack of literature on the topic. The topics explored involve mothers and ICT, the public health sector and NGOs use of social media for engaging with their audience and, the use of technology to motivate blood donation. Through linking these three topics, they can give some insight on technologies to motivate breastmilk donation, as well as donor mothers engagement and its importance. The importance of social media and engagement to attract and retain donors is prevalent through the paper. It shows that moving forward, NGOs need to invest in technology that allows for user engagement.

The application needs to create a social environment where donor mothers and Milk Matters can be engaged, where mothers can be acknowledged and receive feedback and praise for their donations. Meanwhile, Milk Matters must be able to mediate what happens as there are main concerns over engaging with users through social media. There need to be social networking features that allow donor mothers to share information, and achievements, to encourage donor recruitment.

## 6 CONCLUSIONS & FUTURE WORK

The benefits brought by human milk consumption are crucial for the healthy development of newborn babies, especially for preterm babies who can not tolerate any other form of nutrition. The infants in NICUs depend on human milk banks to survive, and the high demand for milk in regards to the supply milk banks have, is alarming. Milk sharing is increasing in popularity. However, there are concerns about peer-to-peer milk sharing. There is a need for people to shift their mindsets, more breastmilk donors are needed, and the stigma towards human milk banks needs to change.

Technology, more specifically, social networking and communication technologies need to be implemented and adopted by NGOs to attract new donor mothers and retain current ones for longer. The use of mobile applications, along with social networking features, with an aim to support the needs of new mothers, can lead to increased motivation and engagement of breastmilk donors. Donors need to be acknowledged for their deeds and be assured they are contributing. They also need a space where they can find support from people going through the same experiences. The challenge lies in being able to balance out the requirements of donor mothers and what the organization is allowed and able to do.

## ACKNOWLEDGMENTS

I would like to thank Melissa Densmore for meeting with my team every week and providing essential papers and feedback required to start this literature review. I would also like to thank Milk Matters, especially Jenny, as she took time out of her busy schedule to meet with us. I look forward to working with Milk Matters in the near future. I would also like to thank Chelsea Wardle for making herself available to help us, and investing so much in Milk Matters. Lastly I would like to thank Dino and Gerry, for being my team members and sharing resources with me, peer editing work, and for their dedication.

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