THE MILK GAP

Contextualizing Human Milk Banking and Milk Sharing Practices and Perceptions in Switzerland

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Abstract

Background and Aim: Beyond nutrition, human milk is a dynamic, lifesaving bio-fluid, full of biologically active compounds, gut microbiome support and immune factors that coalesce to meet the individualized and holistic needs of a developing infant. Breastfeeding is known to contribute to the short and long-term health of both mother and infant. When the biological mother's own milk is limited, then the WHO recommends donor human milk from a milk bank as an optimal alternative. Milk banks safely collect, process, store and dispense pasteurized donor human milk for premature and critically-ill neonates. As not all mothers can access milk banking services, they have consequently and increasingly been engaged in private milk sharing, often facilitated via the internet. The handling of human milk is not regulated by the law in Switzerland and the medical community discourages informal milk sharing as raw, unscreened and untested donor human milk can present a number of health risks to the receiving child. As human milk becomes a growing public interest, even among for-profit entities, stronger policies are needed to support breastfeeding, lactating women and their infants. Within this backdrop, the aim of the study, led by the Stillförderung Schweiz, is to examine current milk banking and milk sharing practices and perceptions, in order to address the needs, challenges and opportunities in relation to breastfeeding and use of human milk in Switzerland.

Materials and Methods: Following an in-depth literature review, interviews were conducted with lactation consultants from hospitals, five with and six without milk banks, throughout Switzerland. Then, following a review of the online human milk sharing and selling websites, interviews were conducted with five mothers who have engaged in milk sharing.

Results: Milk banks only exist in the German-speaking regions of Switzerland. Despite existing guidelines, milk banks are heterogeneous in practice and face a number of challenges, including donor human milk shortages. The obstacles for hospitals to establish new milk banks were found to be inadequate finances, infrastructure, protocol and support from hospital management. Online milk sharing and selling platforms were found to have inconsistent information, no safety controls and a lack of liability, which places users and their infants at their own risks. Interviewed mothers valued community and information exchange and perceived more of the benefits than risks of milk sharing, preferring raw human milk over commercial infant formula. All interviewed mothers resorted to informal milk sharing because they faced lactation or breastfeeding challenges, lacked support and were unable to access milk banks due to unfulfilled criteria.

Conclusion: The rise of milk sharing ultimately highlights systematic barriers to lactation support and access to safe donor human milk when needed. Milk banks need to be more standardized, accessible geographically and scaled-up to address the human milk gap. This can provide safer infrastructure and support to meet the needs of lactating and breastfeeding mothers. Health care professionals and policymakers must collaborate to prioritize breastfeeding, strengthen lactation education and expand the access of banked donor human milk to ensure the safety and health of all mothers and infants.

Keywords: breastfeeding, breast milk, donor human milk, milk banking, milk sharing

1 Introduction

Growing Demand for Human Milk

Human milk is a living food beyond nutrition. It is a biologically active fluid comprised of free amino acids, nucleotides, cells, enzymes, growth factors, hormones, probiotic bacteria and prebiotic oligosaccharides for the infant gut microbiome [1]. Human milk is antimicrobial, antioxidant, anti-inflammatory, immune boosting, in addition to containing the complete macro- and micronutrients required for the survival, growth and development of an infant [1]. Breastfeeding contributes to the overall health and well-being of both mother and infant. Breastfeeding protects mothers from breast cancer, reduces infant infection and is associated with higher child cognitive development [2,3]. The latest Swiss Infant Feeding Study (SWIFS) indicates that exclusive breastfeeding prevalence is 95% right after birth, 62% at the 3rd to 4th months and 26% at the 5th to 6th months [4].

Beyond the mother-infant dyad, the modern applications of human milk have expanded to donor human milk banking, online human milk trade and lactoengineered products made by for-profit companies [5]. Unlike blood or organs [6], the handling of human milk is not regulated by federal law in Switzerland. The risks, benefits, costs, legalities, perceptions and ethics with the contemporary uses of human milk have sparked national and international debates.

The World Health Organization (WHO) recommends 6 months of exclusive breastfeeding and the use of safe donor human milk from an established milk bank as an optimal alternative for infants when the biological mother's own milk is insufficient or unavailable [7].

In addition, the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) Committee on Nutrition recommend that the "full or exclusive breast-feeding for around 6 months is a desirable goal. In exclusively or partially breast-fed infants, complementary feeding, such as any solid or liquid food other than breast milk or infant formula and follow-on formula, should not be introduced to the diet of any infant before 17 weeks or delayed after 26 weeks of age" [7, p. 114]. Moreover, when the fresh mother's own milk is unavailable, then donor human milk from a human milk bank is the recommended alternative [9].

The Nutrition Commission of the Swiss Society of Paediatrics (SSP) agrees with the breastfeeding recommendations of the ESPGHAN [10]. The SSP's most recent set of recommendations for infant nutrition provide information related to breastfeeding, infant formula and complementary foods, but they do not include the use of donor human milk from Swiss milk banks as an alternative when breastfeeding is not possible or the mother's own milk is limited [10].

Milk banks screen donors, collect, process, pasteurize, store and distribute donor human milk intended for high-risk infants [11,12]. Historically, milk banking in Switzerland began as early as the 1940s in Basel. Milk banks closed worldwide in the 1980s during the rise of the HIV/AIDS epidemic. Due to the increase in scientific evidence supporting banked donor human milk for high-risk infants, milk banks in Switzerland have resurged since the late 1990s to early 2000s [13]. Currently in Switzerland, there are seven hospital-based milk banks located in Aarau, Bern, Basel, Chur, Luzern, St. Gallen Children's Hospital and St. Gallen Women's Hospital. Swiss milk banks widely reference "The Guidelines for the Organization and Operation of Milk Banks in Switzerland," [13] developed by milk banking specialists and endorsed by the Swiss Society of Neonatology [14]. These guidelines aim to establish uniform protocol for milk banking operations and quality assurance. However, Swiss milk banks nevertheless face a number of challenges, such as inconsistent donor human milk stocks [15], and without statutory standardization, each can vary how the guidelines are applied in real practice which could lead to diverse clinical outcomes. An observable, systematic challenge is that Swiss milk banks exist in only the German-speaking regions of the country and it is unclear as to why there are no milk banks in Romandie, Valais or Ticino. These challenges, in addition to the geographic, cultural and linguistic disparities, reveal that there are evident gaps as to how and where safe donor human milk can be accessed when needed.

In Switzerland, not all mothers can access a milk bank and those who face lactation or breastfeeding challenges are often given infant formula starting at the hospital after the birth. According to SWIFS, 20% of mother's own milk was reported to be supplemented with infant formula in the hospital and 16% of participating mothers indicated that they used free samples of infant formula in the hospital, which is in violation of the WHO International Code of Marketing of Breast-milk Substitutes [4,16]. As commercial cow milk-based infant formula lack the unique and diverse bioactive components found in human milk, research demonstrates that this can have implications on infant health and health care costs [17–22].

Mothers may encounter challenges and suboptimal support while reaching their lactation and breastfeeding goals. According to SWIFS, various factors such as employment, socio-economic characteristics, maternal exhaustion and migration were associated with lower compliance to breastfeeding guidelines [4]. In addition, 51% of participating mothers (n=689) reported to have stopped breastfeeding due to "having too little milk" [12, p.52]. Mothers of healthy, full-term babies, who experience lactation insufficiency or illness, are unable to access safe donor human milk from Swiss milk banks because milk banks only serve premature or critically-ill neonates. As a result, there has been a rise of informal milk sharing, arranged privately between families and facilitated by social media networks, where mothers have taken initiative to address their need for human milk, peer-to-peer support and sense of community via the internet [23–26]. Researchers, physicians and expert groups have discouraged online milk sharing or selling, including the American Academy of Pediatrics and a joint statement released by the European Milk Bank Association and the Human Milk Bank Association of North America, which delineate the risks of contamination and adverse consequences to the receiving child [27–29]. Overall, these challenges highlight that there is an increasing need for lactation support, information, access to safe donor human milk and improvements to the existing milk banking infrastructure in Switzerland. Furthermore, there are opportunities to form collaborations, involving all important stakeholders, mothers, health care professionals, researchers and policymakers, to ensure that breastfeeding, mother's own milk, all human milk is protected, promoted, and supported for all infants [30].

This report examines the use of human milk in formal and informal contexts and is the first study to analyze human milk banking and milk sharing in Switzerland. Within this context, the aim of this report is:

1. To examine human milk banking and milk sharing practices and perceptions and
2. To propose discussions with relevant stakeholders to address the needs, challenges and opportunities in relation to breastfeeding and use of human milk in Switzerland.

Firstly, the study examines current milk banking practices and perceptions of lactation consultants in hospitals, with or without milk banks, throughout Switzerland.

1. How do Swiss milk banks interpret and apply current milk banking guidelines?
2. What are the challenges that milk banks face and what are areas for improvement?
3. What are the obstacles and needs of hospitals without milk banks?

Secondly, the study investigates the motivations, experiences and impressions of mothers who have engaged in private milk sharing via online or other networks in Switzerland. Specifically, mothers who have recently either donated their milk or received another woman's milk to feed her own child. Further research examines the human milk market and networks that are available on the internet.

1. What are the motivations, experiences and impressions of mothers who have engaged in informal milk sharing?
2. What are existing websites where people can share or sell or purchase human milk? What are the liabilities, legalities, prices, who are the donors, receivers, and what are the quality or safety issues of breast milk from online sources?

2 Literature Review

2.1 Milk Banking

The Swiss milk banking guidelines, "Leitlinie zur Organisation und Arbeitsweise einer Frauenmilchbank in der Schweiz (2010)" developed by a collaboration of Swiss milk banking specialists, ensure the quality and safety of donor human milk intended for preterm or sick infants. The guidelines provide recommendations on the qualifications of milk bank employees, workflows, infrastructure, equipment, bacteriological requirements, hygienic handling of donor milk and documentation [13]. Potential human milk donors must be a healthy mother with excess milk, undergo a medical history evaluation, meet donor criteria (non-smoker, no drugs, no alcohol, caffeine, non-vegan, no new tattoos, piercings and acupuncture within the last 6 months) agree to serological blood testing and provide a written informed consent for voluntary donation without financial compensation. The guidelines are widely referenced by all Swiss milk banks; however, the guidelines are not legally obligatory and serve only as quality assurance recommendations and to support the homogeneity of milk banking operations.

Despite the growth of scientific literature on human milk and milk banking in recent years, there were no published studies found that examine milk banking in Switzerland. Currently, the following organizations or documents serve as important resources for milk banks in Switzerland:

- "Leitlinie zur Organisation und Arbeitsweise einer Frauenmilchbank in der Schweiz" [13]
- "Empfehlungen zur Förderung von Frauenmilchbanken in Deutschland, Österreich und der Schweiz (D-A-CH-Raum)", by the European Foundation for the Care of Newborn Infants [31].
- "Handbuch für die Errichtung und Organisation von Frauenmilchbanken," by the European Foundation for the Care of Newborn Infants [32].
- Stillförderung Schweiz
- European Milk Bank Association

Why donor human milk?

Human milk is associated with lower risks of mortality, infections, necrotizing enterocolitis, and positive effects on the neurodevelopment, compared to infant formula, among critically-ill or premature infants in the neonatology [19,33–38]. The evidence recommends that fresh mother's own milk should be prioritized and supported as it has shown to improve growth, reduce prematurity related morbidities and health care costs [39–45].

When mother's own milk is insufficient or unavailable, despite lactation support efforts, then donor human milk is the recommended alternative and adequate fortification may be necessary to meet the specific needs of preterm or very low birth weight (VLBW) infants [35,37,46,47]. The availability of donor human milk has been found to increase overall human milk feeding, decrease infant formula use, and to not impact mother's own milk feeding in hospitals [48]. In addition, the provision of mother's own milk, supplemented with banked donor milk, was followed by exclusive breastfeeding and economic savings on health care costs [22]. Compared to formula-fed infants, exclusive human milk-fed infants were found to be more protected against costly diseases such as necrotizing enterocolitis [20,49,50]. Researchers have demonstrated significantly higher rates of exclusive breastfeeding at discharge [51] and consumption of mother's own milk during hospitalization and at discharge [52] when VLBW infants had access to banked donor human milk in the neonatology.

To eliminate the pathogenic risk of donor human milk, milk banks conventionally use the Holder Pasteurization method, which heats the milk at 62.5°C for 30 minutes; however, this method has been found to reduce some nutritional and bioactive compounds [46]. For this reason, milk banks in Norway provide raw, unpasteurized donor human milk to preterm infants, which has shown beneficial health outcomes [53,54]. The Committee on Nutrition of the European Society for Pediatric Gastroenterology, Hepatology, and Nutrition (ESPGHAN) recommend that future research should evaluate the clinical impact of donor

human milk fortification and processing methods that retain the nutritional and bioactive properties of donor human milk, while maintaining microbiological safety [37]. Emerging pasteurization methods such as ultraviolet irradiation [55], ultrasonication [56], high-temperature-short-time [57] and high pressure processing [58] are methods being investigated experimentally; however, future research on clinical outcomes with these new methods are needed. Overall, investments and care should focus on prioritizing breastfeeding and mother's own milk, providing lactation support with skilled lactation specialists and access to donor human milk when needed.

Maternal perceptions: who are the donors?

The following section summarizes research on the characteristics and perceptions of human milk donors. A study in Spain found that the main motivations of women, who donated their milk to a milk bank, were feelings of altruism and having an oversupply of breast milk [59]. Interestingly, these mothers reported to also have sufficient social and institutional support and access to infrastructure which assisted in their milk donation experience [59].

In France, eight milk banks participated in a study that examined donor motivations, demographics and personalities of 103 women who donated their breast milk to milk banks [60]. The researchers found that the maternal motivations to donate their milk were mostly altruistic. Donors also had strong support at home and 50% of the participants were not working at the time of the study, but many had careers in the health and social services [60].

A study based in Italy looked at the awareness, motivations and attitudes of women on the topic of donating breast milk to milk banks [61]. The study found that 71.2% of women (n=153) were aware that breast milk can be donated, but only 7.2% knew how to donate their milk [61]. Respondents expressed a high level of interest on the topic of milk banking and those who had already donated to a milk bank reported an overall positive experience and stated that their main reasons were to help other babies and to not waste their breast milk [61].

In a quantitative study on maternal opinions about donor human milk and infant formula, researchers uncovered that donor milk was perceived as short-term, unfamiliar, costly, complicated, but "healthier", while formula was perceived as more long-term and familiar [62].

Overall, these studies reveal that donating breast milk to a milk bank is a topic of high relevance and interest among mothers; however, addressing barriers, increasing awareness and providing social and institutional support are critical factors that can help mothers throughout their donation process.

2.2 Milk Sharing

Internet-based human milk sharing and selling is increasing in popularity, controversy and ethical debates [24,26,63–70]. In a mixed-methods observational study of human milk sharing communities online, researchers found that thousands are engaging in the sharing of raw human milk via the internet [71]. Current active websites are Only the Breast, Eats on Feets, Human Milk 4 Human Babies (HM4HB), and MilkShare.

Human milk exchanges via the internet

Studies reveal that parents sharing milk online reported to engage in practices that should reduce the risks of contamination, such as donor screening, safe human milk handling and storage [72,73]. However, in a cross-sectional study examining online posts from an internet-based milk sharing network (n=254), the topic of donor screenings (e.g., inquiring donor health behaviours or health/disease status) was found to be not a major topic of discussion on the website postings [74].

A proliferation of scientific evidence reveals that breast milk from the internet contains numerous health and safety concerns. Cohen and colleagues found a significant positive screening serology of Hepatitis B and C, HIV, HTLV and Syphilis among potential human milk donors (n=1091), suggesting the significant risks associated with online milk sharing from unscreened donors [75]. Human milk samples purchased from the internet were found to have high counts of aerobic

bacteria, Gram-negative bacteria and Staphylococcus spp, which reflects poor hygienic handling, storing and transport [76,77]. Furthermore, tested milk samples from the internet had evidence of active smoking, secondhand smoke exposure, caffeine consumption and adulteration with cow's milk products, which can be especially harmful to vulnerable infants or those with an intolerance or allergy to dairy [78,79]. As recipients cannot simply validate the composition of donor milk, researchers warn about contamination, adulteration and online misrepresentation of donor behaviors, which expose risks to the receiving infants [80].

Maternal perspectives on milk sharing

Informal milk sharing is on the rise, despite its controversy. Mothers are challenging medical institutions, which fail to meet their needs, by taking charge over the exchange of human milk through their networks. It takes "self-help and female solidarity to new heights, illustrating how women are innovating to tackle breast milk scarcity and deny infant formulas as its default-substitute status" [24, p.1].

Researchers have studied the socio-demographics of women in the U.S. who have engaged in online milk sharing and found that participants were primarily middle-class, well-educated and employed, with donors reporting to have more support from partners, relatives, employers and health professionals [81]. According to the Moms2Moms Study, 77% of participating mothers (n=813) were aware of milk sharing and 4% donated milk among friends and relatives or received donor milk from a milk bank [82]. A study on maternal perceptions of human milk sharing revealed that most women are aware of informal milk sharing, many reported a willingness to donate compared to receiving milk from the internet, but they were more willing to exchange with a relative or close friend [83]. Furthermore, among the participants who had already shared milk, it was found that lactation consultants and midwives were involved in coordinating human milk exchanges between mothers [83].

Online milk sharing donors have been surveyed and their main motivations to donate were found to be altruism, empathy towards women with lactation insufficiency, the desire to not waste their own milk and overall satisfaction with their milk sharing experiences [84]. Studies have also found that receivers of human milk from the internet had insufficient knowledge of the risks and risk prevention strategies, such as safe donor milk handling or consulting with a health care professional [85,86].

3 Materials and Methods

3.1 Milk Banking

Interview invitation letters were sent by the Stillförderung Schweiz directly to lactation consultants working at six different milk banks (Aarau, Basel, Bern, Chur, Luzern and St. Gallen Children's Hospital) and seven neonatology departments without official milk banks (Bellinzona, Geneva, Lausanne, Mendrisio, Winterthur, Visp and Zurich). The timeline to recruit and conduct the interviews were from May 2017 to March 2018. Lactation consultants who agreed to be interviewed were instructed to contact the Stillförderung Schweiz to coordinate the interview date and location.

Prior to the interview, the interview questions were sent in German and French to the lactation consultants in advance. At the beginning of the interview, the objectives of the study were restated, the participants were informed about their anonymity and they were asked for their permission for the interview to be voice recorded for transcription and data analysis purposes. Interviews had the presence of a native German or French speaker to ensure the flow and coherence of the discussion. When an in-person interview was not feasible, then telephone or written responses were acceptable. The complete list of interview questions are available in the Supplementary Material section. With reference to the 'Leitlinie zur Organisation und Arbeitsweise einer Frauenmilchbank in der Schweiz' [13], the 40 interview questions were stratified by the following themes:

- *General milk banking operations*

Respondents were asked about their hospital's capacity for milk banking operations, such as staffing, infrastructure, equipment, safety and quality assurance procedures, documentation and financing.

- *Donors and donor human milk*

Questions included the criteria and recruitment process of donors, donor screening, donor human milk collection procedures (testing, pasteurization, storage, and distribution) and overall processing capacity.

- *Recipients of donor human milk*

The staff answered questions about the donor human milk recipient eligibility for milk, maternal requests and reactions regarding donor human milk, dispensing procedures and about the use of alternatives when donor human milk was not available.

- *Perceptions about milk banking and milk sharing*

Additionally, respondents were asked to share their perceptions about milk banking public awareness, organized promotional campaigns, their opinions about financial compensation to donors, and about their awareness and opinion about online human milk sharing platforms.

- *Milk bank needs, challenges and improvements*

Participants were asked how data is collected or evaluation methods are recorded, hospital needs to improve or start milk banking, areas to improve milk banking in Switzerland and their opinion about the regulation of human milk under Swiss law.

3.2 Milk Sharing

The Google search engine was used to identify online milk sharing and milk selling platforms. The following platforms were found and selected for this analysis: Eats on Feets, Human Milk 4 Human Babies, Only the Breast and MilkShare. These global platforms either had their own website or used Facebook groups to organize exchanges at the country level. A database was developed with the following information from these platforms:

- *Milk sharing or milk selling categorization*

Platforms were categorized as commerce-free milk sharing or milk selling with options to buy or sell human milk. Human milk market prices from these platforms were also reviewed.

- *Risk reduction information and safety measures*

We assessed if the websites had provided any resources, services or information to users on how to reduce the health risks to the receiving infant (e.g., infectious transmission, adulteration, contamination, nutrient deficiency, allergic reaction). The specific information assessed were about informed consent and full disclosure, how to screen donors, to inquire about donor behaviors (e.g., smoking, alcohol consumption, diet), to inquire about blood testing results, consultation with a health care professional, obtain a letter from a family doctor, share medical history, information about home pasteurization methods and safe storage, hygienic handling, shipping or transport and container use.

- *Conditions, liabilities and contracts*

The liability information, specifically who would be responsible or liable in the case of any harm done due to an exchange arranged through the platform was researched, and the availability of legal documents, such as 'Terms of Agreement' or contracts available for users.

- *Activity level in Switzerland*

The activity level was categorized (limited, moderate, active) based on the regular observation of milk exchange online posts by users based in Switzerland from May 2017 to March 2018.

Human Milk 4 Human Babies (HM4HB) Switzerland Facebook group was selected for this study analysis as the platform was found to have a regular activity level of commerce-free milk sharing with a community of over 800 followers in Switzerland. Administrators of the HM4HB Switzerland Facebook group were contacted by the study investigators, informed about the study objectives and asked to post in the group about the study to help recruit mothers to participate in an interview. Mothers were eligible if they were an active member of the HM4HB Facebook group and recently donated or received donor human milk.

Interested respondents were asked to contact the researchers directly to arrange the date and location of the interview. The timeline to recruit and conduct the interviews with the mothers were from June 2017 to August 2017. When an in-person interview was not feasible for the mother, then telephone or written responses were acceptable. The open-ended interview questions were stratified and analyzed according to the following thematic groups:

- *Reasons, motivations and perceptions*

Respondents were asked about their reasons and motivations for donating or receiving donor human milk. We asked the mothers to describe their perceptions of the subject matter and their opinion if sharing human milk should be donation-based or if mothers should be financially compensated for their time and efforts.

- *Milk sharing and milk banking experiences*

Mothers were asked to describe their milk sharing and milk banking experiences.

- *Concerns and risk reduction strategies*

Their main concerns about milk sharing were analyzed, their knowledge about the risks and the strategies they used to minimize the health risks to the receiving infant.

- *Improvements to meet maternal needs*

The mothers were asked about the current system in Switzerland and how it could be improved to better meet the needs of lactating and breastfeeding mothers.

The questions were open-ended to allow for the mothers to elaborate on their perceptions and personal experiences. At the beginning of an in-person interview, the goals and objectives of the study were restated, the participants were informed about their anonymity and permission from each mother was requested if the interview could be voice recorded for transcription and data analysis purposes.

4 Results

4.1 Milk Banking

Interviews with lactation consultants

11 out of 13 invited hospitals agreed to participate in the study (see Table 1). As demonstrated in Figure 1, five hospitals with milk banks (Aarau, Bern, Basel, St. Gallen, Chur) and six hospitals without milk banks (Bellinzona, Geneva, Lausanne, Mendrisio, Visp, Zurich) participated. In total, five interviews were conducted in-person (Basel, Bern, Lausanne, St. Gallen, Zurich), four by telephone (Bellinzona, Geneva, Mendrisio, Visp) and two interview responses were sent by email (Aarau, Chur). The interviews conducted by telephone and email were at the request or preference of the participants. Kantonsspital Winterthur and Luzerner Kinderspital declined to be interviewed.

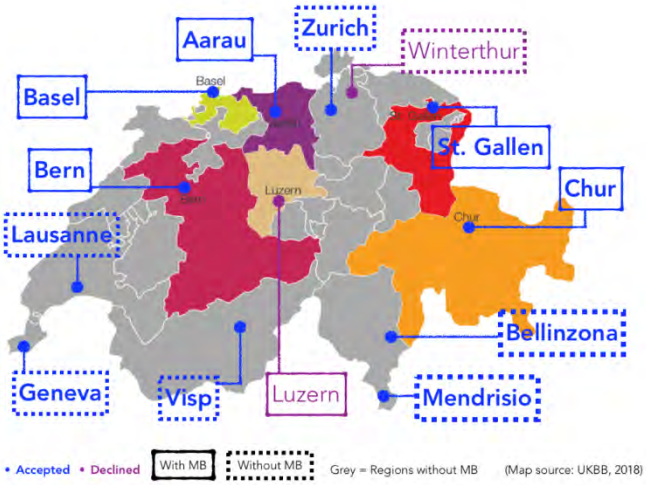

Figure 1: A map of participating hospitals in the study

- **General milk banking operations**

All milk banks reported to reference the Swiss guidelines for milk banking operations [13] have similar infrastructure of separate rooms designated for specific milk banking functions, e.g., pasteurization room, preparation room, dirty room, clean room for storage. All milk banks remarked having multiple refrigerators and freezers, pasteurization machines, cleaning equipment, accessories to process and store donor human milk. However, St. Gallen is the only milk bank that uses a MIRIS Human Milk Analyzer [87], which is a machine that tests the energy and nutritional composition of breast milk so that they can

precisely fortify the donor human milk with the necessary macronutrients (e.g., proteins, carbohydrates and fats) as needed.

The milk bank staffing capacity varied per site depending on the work load and time requirements. In Bern, twelve staff worked at the Milchnahrungszentrum, in St. Gallen there were two lactation consultants, five health workers and one physician, which was reported as sufficient, and Basel had five nurses, two nursing assistants; however, Basel reported that additional lactation consultants were needed.

All milk banks reported that their costs are covered by their corresponding hospitals. However, Bern reported that milk banking should be covered by the health insurance since donor human milk is beneficial and preventive for critically-ill infants.

All hospitals without milk banks (Bellinzona, Geneva, Lausanne, Mendrisio, Visp), except Zurich, lacked infrastructure, equipment, finances, hospital management and staff to do any milk banking operations. Zurich reported to have the capacity to pasteurize and store breast milk (in the refrigerator or freezer), but only the mother's milk for her own infant and not for larger scale milk banking.

- **Donors and donor human milk**

All milk banks recruit healthy lactating women with oversupply of breast milk according to the Swiss milk banking guidelines [13]. Donors donate voluntarily, give consent to be screened with a health questionnaire, undergo a blood test, have a consultation with a physician and agree to have samples of their milk tested–all are safety controls to reduce the risk of infectious transmission to the hospitalized infant.

Bern and Basel reported to prioritize unpasteurized mother's own milk. Bern and St. Gallen only collect preterm human milk from mothers with premature babies and high supply. Basel accepts breast milk from external donors and outpatients from other cantons without a milk bank. The other milk banks only accept donor milk from mothers who are in-patients who delivered their baby in the hospital. According to Bern and St. Gallen, mothers outside the hospital have wanted to donate to their milk banks, but they do not accept external donors. Basel, Bern and St. Gallen reported that donors can donate in the hospital or also express their milk at home.

None of the milk banks pool milk from multiple women. Basel separates each donor milk per day and conducts laboratory tests every fifth day. Bern separates donor milk every two to three days, and conducts laboratory tests every seventh day and St. Gallen separates and tests every three days.

- **Recipients of donor human milk**

Only hospitalized neonates receive donor human milk following a doctor's prescription. The hospitals had slight differences regarding the recipient requirements, which also greatly depends on the conditions of their donor human milk stocks. The usual requirements are as follows:

Aarau: birth weight <1500g
Basel: gestational age <32 weeks or birth weight <1800g (<1500g when donor milk stocks are low)
Bern: birth weight <1500g (<1250g when donor milk stocks are low)
Chur: gestational age <32 weeks or birth weight <1500g
St. Gallen: birth weight <2000g, premature or sick babies

Mothers react positively when they are informed that their child could benefit from receiving donor human milk from their milk bank. However, some mothers can be more hesitant to receive donor human milk due to religious reasons. All hospitals without milk banks use infant formula when the mother's own milk is limited.

- **Perceptions about milk banking and milk sharing**

All lactation consultants agreed that human milk should be donated commerce-free to milk banks. Lactation consultants expressed that human milk should not be commercialized to avoid adulteration (mixing donor milk with water or cow's milk) or situations where women are financially motivated to sell their milk and give infant formula to their own child instead of their breast milk.

None of the lactation consultants recommended online milk sharing to mothers. However, not all lactation consultants were aware of any online milk sharing platforms. When approached by mothers with questions about milk sharing, two lactation consultants informed mothers about the risks involved with milk sharing, such as the lack of testing of the milk, no background checks of the donors and no proof that the milk is not mixed with water, formula or cow's milk.

- **Milk banking needs, challenges and improvements**

The milk banks in Switzerland organize an annual meeting where challenges, improving standards and goals are discussed, best practices are shared and data is exchanged, regarding how much milk was donated and used during the year. One major challenge reported by most milk banks is the maintenance of sufficient donor human milk stocks and to address this issue requires logistical efforts and additional costs.

Another challenge reported by some milk banks are religious concerns surrounding human milk and the need to be culturally-sensitive and precautious when addressing the issue of donor milk with different patient groups.

Basel is actively involved in awareness activities to promote milk banking within and outside the hospital and both Basel and St. Gallen reported that milk banking was covered by the Swiss media.

Two hospitals without milk banks responded that there is a need for more education and promotion about milk banking in Switzerland.

The barriers faced by hospitals without milk banks is that there is insufficient information available on how hospitals can establish a new milk bank. In addition, the creation of a milk bank requires sustainable financing and priority from hospital management and the government. All lactation consultants interviewed reported that human milk should be regulated by the law in Switzerland. However, the question regarding how human milk should be regulated produced diverse responses including, human fluid, similar to blood, special food and medicine.

Table 1: A summary table of interviewed hospitals

City	Hospital	Milk Bank?	Response	Interview Method	Language
Aarau	Kantonsspital Aarau Kinderklinik, Muttermilchbank	Yes	Agreed	Email	German
Basel	Universitätsspital beider Basel, Frauenmilchbank	Yes	Agreed	In-person	German*
Bellinzona	Ospedale Regionale Bellinzona e Valli, San Giovanni	Yes	Agreed	Phone	German*
Bern	InselspitalUniversitätsklinik, Milchnahrungszentrum	Yes	Agreed	In-person	German*
Chur	Kantonsspital Graubünden, Muttermilchbank	Yes	Agreed	Email	German
Geneva	Hôpitaux Universitaires Genève, Unité de néonatologie	No	Agreed	Email	French
Lausanne	Centre hospitalier universitaire Vaudois, néonatologie	No	Agreed	In-person	French
Luzern	Luzerner Kantonsspital, Frauenmilchbank	Yes	Declined	---	German
Mendrisio	Ospedale Regionale di Mendrisio Beata Vergine	No	Agreed	Phone	German*
St. Gallen	Ostschweizer Kinderspital St. Gallen Milchbank	Yes	Agreed	In-person	German*
Visp	Spital Visp Pädiatrie, Früh-und Neugeborenenabteilung	No	Agreed	Phone	German*
Winterthur	Kantonsspital Winterthur, Geburtshilfe & Gynäkologie	No	Declined	---	German
Zurich	UniversitätsSpital Zürich, Klinik für Geburtshilfe	No	Agreed	In-person	German*

*Interviews with a native speaker to translate, as needed

4.2 Milk Sharing

Assessment of human milk sharing and selling online platforms

Only the Breast is a milk selling online platform where users can sell or buy breast milk at an approximate rate of 50-100 CHF per liter. Eats on Feets, Human Milk 4 Human Babies (HM4HB) and MilkShare are milk sharing platforms that function based on informed consent and do not support the sale of human milk. Eats on Feets and HM4HB use Facebook as their medium to coordinate exchanges at the country level, whereas Only the Breast and MilkShare have their own international websites. With reference to the safety controls from the Swiss milk banking guidelines [13], similar safety criteria were considered and evaluated for each of the milk sharing and selling websites, which are summarized in Table 2.

Only the Breast (onlythebreast.com) contains basic information regarding tips for donor screening, handling and home pasteurization; however, the website lacks further information about the risks associated to milk selling, if the donor is taking medications or on a vegan diet. They have no contracts available and the online 'Terms of Use' clearly notes that Only the Breast is "not liable for any harm resulting from user content, user conduct, your Only the Breast use or our representation." The activity level of this platform was found to be limited in Switzerland.

Eats on Feets (eatsonfeets.org) is a global network of milk sharing supporters that provide information and resources on their website including the "Breastmilk Sharing Resource Guide" which informs users about donating, receiving, handling milk, health considerations and breastmilk vs. substitutes. Another online informational resource is their "Four Pillars of Safe Breastmilk Sharing" detailing about informed choice, donor screening, safe handling and home pasteurization. There was no information found about the risks of adulteration. In the resource guide, it states that Eats on Feets "does not accept liability for outcomes associated with sharing breastmilk." There were no terms and conditions nor any contracts available and the activity level by users in Switzerland was found to be limited.

MilkShare (milkshare.forumotion.com) provides basic tips about donor screening, testing, pasteurization and handling, but lacks further information for donors about not to consume alcohol or drugs, be aware of certain medications and the risks of adulteration and contamination. Users must be a registered member of the MilkShare platform and each must agree to the 'Forum Terms of Service', which states that "the company does not guarantee accuracy of this information" posted on the forum and "the user is liable for damage of any kind." MilkShare also provides a "Breastmilk Donor Agreement" template contract for donors and receivers to use and sign. The majority of users on MilkShare are from the USA and none were found to be from Switzerland.

The HM4HB (hm4hb.net) global network website provides information to users about informed choice, safe social networking, full disclosures about medications, alcohol or drug use, sharing test results, consultation with a health care professional, home pasteurization, storage and proper hygiene to reduce the risk of contamination. The website did not provide information about the risks of adulteration, the issues of donors on a vegan diet nor safe shipping or transport of donor milk. There were no contracts found and the website states that the HM4HB "does not accept liability for the outcomes associated with sharing breastmilk". The HM4HB networks are organized through Facebook groups, where the group administrators post ads from both donors and mothers in need of donor human milk. Additional information in the posts may include the city where the mother lives, how much milk she can donate or needs, the age and health status of their infant and health behaviors of the donors. Those interested in a post can contact the mother directly through Facebook private messaging and afterwards they can arrange the exchange on their own. The HM4HB Facebook group was found to be the most active milk sharing online platform in Switzerland with almost 900 followers as of August 2018.

Table 2: Online human milk sharing and selling platforms assessed by available safety information, liability and activity level in Switzerland

Website	Category	Online Safety Information		Terms, Conditions, Liabilities, Contracts	Activity Level in Switzerland
Only The Breast www.onlythebreast.com	Milk selling (price range: 50-100 CHF per Liter)	Screen donor	✓	"Terms of Use" "We are not liable for any harm."	Limited
		Blood testing	✓		
		Doctor's note	✓		
		Share medical history	✓		
		No alcohol, drugs	✓		
		No adulterations	✓		
		Medications			
		Diet (i.e., vegan)			
		Home pasteurization	✓		
		Hygienic handling	✓		
		Freezing and storage	✓		
		Safe transport	✓		
		Risks using donor milk			
		Meet and communicate about lifestyle	✓		
Eats On Feets www.eatsonfeets.org	Milk sharing	Screen donor	✓	"Does not accept liability for outcomes associated with sharing breastmilk."	Limited
		Blood testing	✓		
		Doctor's note	✓		
		Share medical history	✓		
		No alcohol, drugs	✓		
		No adulterations			
		Medications	✓		
		Diet (i.e., vegan)	✓		
		Home pasteurization	✓		
		Hygienic handling	✓		
		Freezing and storage	✓		
		Safe transport	✓		
		Risks using donor milk	✓		
		Meet and communicate about lifestyle	✓		
Human Milk 4 Human Babies (HM4HB) http://hm4hb.net/ HM4HB Switzerland: https://www.facebook.com/hm4hbswitz/	Milk sharing	Screen donor	✓	"Does not accept liability for the outcomes associated with sharing breastmilk."	Active
		Blood testing	✓		
		Doctor's note	✓		
		Share medical history	✓		
		No alcohol, drugs	✓		
		No adulterations			
		Medications	✓		
		Diet (i.e., vegan)			
		Home pasteurization	✓		
		Hygienic handling	✓		
		Freezing and storage	✓		
		Safe transport			
		Risks using donor milk	✓		
		Meet and communicate about lifestyle	✓		
MilkShare http://milkshare.forumotion.com/	Milk sharing	Screen donor	✓	Forum Terms of Service "The user is liable for damage of any kind." Breastmilk Donor Agreement (contract template)	None
		Blood testing	✓		
		Doctor's note	✓		
		Share medical history			
		No alcohol, drugs			
		No adulterations			
		Medications			
		Diet (i.e., vegan)			
		Home pasteurization	✓		
		Hygienic handling	✓		
		Freezing and storage	✓		
		Safe transport	✓		
		Risks using donor milk			
		Meet and communicate about lifestyle	✓		

Interviews with mothers engaged in milk sharing

Five mothers from the Human Milk 4 Human Babies (HM4HB) Facebook group in Switzerland participated in the study. Three mothers were interviewed in-person and two provided their responses via email. Two mothers were donors and three mothers were recipients of donor milk.

- **Reasons, motivations and perceptions**

Both donors were aware of the benefits of human milk and wanted to donate their breast milk to babies who needed it. With regard to their reasons to donate, one donor had oversupply of breast milk and another mother wanted to donate her milk following the death of her baby. Both donors were disappointed that they could not donate their breast milk to a milk bank in Switzerland. One donor shared her opinion that it is easier to donate than receive donor milk. Each of the recipients of donor human milk experienced various breastfeeding challenges and lacked support, but all had the motivation to continue to feed their babies with human milk, rather than infant formula. Their specific reasons to engage in milk sharing included having a limited supply of breast milk, going back to work and being diagnosed with breast cancer. Table 3 highlights direct quotes from each of the mothers' perspectives. All recipients researched various alternatives but believed that HM4HB was a solution that met their needs to continue to feed their babies with human milk. Beyond the sharing of milk, one respondent expressed the value of information sharing within the group and fostering an empathetic community with mutual respect. All mothers who were interviewed, except one, believed that sharing milk should be commerce-free and human milk should be donated voluntarily based on informed choice. In their opinion, monetary incentives could lead to the exploitation of bodies and increase the risks for the babies. One donor reported that she was contacted on Facebook by an agent who was interested to buy her milk and worked for a lactoengineering company called Ammenpulver [88] based in Germany that resells modified donor human milk to hospitals. She did not sell her milk to this company, but in her opinion mothers should be compensated for their efforts if they give their breast milk.

Table 3: Direct quotes from participants about their milk sharing perspectives

Quotes from donors	"St Gallen milk bank rejected my milk since I did acupuncture. It was heartbreaking. So I googled and found the Facebook Group Human Milk 4 Human Babies. I felt amazing that I could feed 4-5 babies that are healthy and thriving."
	"When my second son died from brain damage…I felt that at least another child could profit from my loss. I think it was one important step in my grieving. I have met both mom and baby who received my milk and I consider her a friend. It was nice to see her child drink my milk and smile."
Quotes from receivers of donor milk	"I received milk from approximately 10 donors…Many of them I did develop trust with, but I assumed positive intentions from all of them. Everything happened so fast that I didn't know or even think about asking many of them health questions or think about anything negative happening. "
	"I first thought about milk sharing when my friend was breastfeeding her son next to me. I thought to myself…why am I struggling with formula when my friend produces so much excess milk and tips it down the sink?"
	"I was interested in donor milk when I had to go back to work and could only nurse from one breast. I don't see the risks with sharing milk, only benefits. I don't believe another woman will pump, store, freeze and reach out to other mothers to donate while she breastfeeds her child if she's taking drugs or alcohol."

- **Milk sharing and milk banking experiences**

All respondents approached a milk bank in Switzerland seeking support, but none of them could donate nor access milk from a milk bank. Common reasons for this were that there was no milk bank at their closest hospital or only hospital patients could access milk banking services. Both donors were refused to donate their surplus breast milk to a milk bank due to having acupuncture treatments within the last 6 months. Both donors searched online and joined the HM4HB Switzerland Facebook group, where they were both able to connect with other mothers in need of milk for their babies. With regard to the receiving side, one receiver connected to a donor through her midwife, the other two receivers searched and found HM4HB online– one arranged three to four donors and the other received milk from ten different donors. Relatives, friends or members of the Facebook group were reported to assist these mothers with the transport of donor milk.

- **Concerns and risk reduction strategies**

The initial donor concerns were to not waste their valuable breast milk, cultural taboos associated with milk sharing and discrimination against mothers who share breast milk. Regarding the receivers, prior to accepting donor milk, all experienced forms of mental, physical and emotional stress from feeling overwhelmed, guilt, shame, disappointment, anxiety, giving her child not her own but another woman's milk, initial gross factor, worry of judgement from others, stigma of milk sharing or hesitation from the spouse. All mothers applied a variety of risk reduction strategies, such as consulting with a midwife or doctor regarding milk sharing. A respondent with low supply was connected to another mother with oversupply by their midwife, who had access to their medical records, could confirm that the potential donor was healthy and she could also test the milk samples. Two respondents consulted their family physician and one doctor wrote a letter confirming that the mother was in good health and safe to donate her milk. Both donors made extra steps to provide proof that they were healthy, such as offering blood test results. All mothers reported to meet or make efforts to get to know the other mother whom they arranged exchanges with. Two receivers reported trying to develop relationships of trust with their donors and assumed only positive intentions from other mothers. However, one receiver who accepted milk from up to ten donors reported to not have enough time to ask detailed health screening questions or meet all the donors. None of the mothers reported to practice home pasteurization of donor milk as they argued that it destroys the benefits of raw breast milk. Their discussions about the risks and possible negative consequences related to human milk sharing was limited in detail.

- **Improvements to meet maternal needs**

Mothers reported that there is a need for more systematic support for lactating and breastfeeding mothers. For instance, one mother experienced lactation challenges and had to return to work. She could not pump enough for her baby in daycare and needed more milk. She indicated that the maternity leave of 14 weeks is not sufficient for mothers to meet the exclusive breastfeeding recommendations. Further, more general education is needed about breastfeeding, milk banking and milk sharing in Switzerland and there should be more promotion to increase the rates of exclusive and long-term breastfeeding. One mother stated that public breastfeeding and pumping is still stigmatized, sexualized and considered gross in society, where mothers are hidden and still breastfeed in public toilets. In her opinion, women are not given enough support for successful nursing in hospitals, where hospital staff do not have sufficient skillsets for breastfeeding and nutrition, mothers and their babies are separated and infant formula in bottles are given too easily. In addition, more awareness is needed about the benefits and risks of all infant feeding methods, including the risks associated with infant formula feeding. Many mothers supported the idea of a community-based, formalized process for milk sharing and a delivery system. There is a need for a breastfeeding center or community milk bank that

would not only support mothers experiencing breastfeeding difficulties, but also make milk sharing safer and more normalized and acceptable in society.

5 Discussion

5.1 Milk Banking

Milk banks were found to be heterogeneous in practice. This flexibility can allow for each milk bank to adapt the guidelines to meet their specific needs; however, unstandardized practices can also lead to challenges and possibly different clinical outcomes. For instance, the guidelines state that donor human milk should be fortified [11, p.33], but it does not detail specifically how milk banks should supplement donor human milk. Only the milk bank in St. Gallen has a MIRIS Human Milk Analyzer machine to analyze the milk's nutritional composition and can precisely supplement nutrients to the donor milk as needed. As hospitalized newborns have individual and case-specific health needs, human milk analysis and supplementation can ensure a more personalized nutrition to prevent nutritional deficiencies that may impede on the growth and development of the infant.
All milk banks expressed that their biggest challenges are the fluctuation of donor human milk stocks and major shortages. Milk banks can order additional donor human milk from another milk bank; however, this requires further logistics and can be expensive at the cost of the receiving milk bank. According to Basel, it is estimated that donor human milk in Switzerland costs approximately 100-140 CHF per liter. In addition, since there is no standardized milk delivery system, each milk bank must cover the high delivery costs, which are usually done by taxi or express shipping. Furthermore, donor human milk shortages pose higher risks for the critically-ill infants because hospital personnel may need to resort to lowering the birth weight criteria of the receiving infants (e.g., the birth weight threshold could be lowered from 1500g to 1250g during a period of donor milk shortages). By lowering this weight threshold, hospitalized infants, who would normally benefit from banked donor human milk, would likely be given infant formula instead. However, formula-fed preterm infants have been found to have a statistically significant higher incidence of necrotizing enterocolitis compared to donor human milk-fed preterm infants [33]. This indeed reflects the risks of donor human milk shortages and an ongoing challenge faced by all the milk banks that were interviewed.
Donor human milk shortages at milk banks could also be related to a low public awareness. Many lactation consultants stressed the need for more general education and health promotion campaigns about milk banking in Switzerland. However, little awareness activities have been carried out by the hospitals. Basel promotes milk banking within and outside the hospital and posts on their website when there is a need for donor milk. There were coverages on the Swiss television SRF Puls and a publication in the bz Basel newspaper when they had a donor milk shortage [15,89,90].
As a result from more promotional campaigns, more potential donors could be aware and may express their interests to donate. Lactation consultants are already facing some pressures from mothers outside their hospitals who are interested to donate their milk. Only Basel currently has the capacity to accept eligible external donors. The infrastructure and personnel capacities of all existing milk banks would need to expand, so they could handle more donations to increase the overall supply and reduce the risk of donor milk shortages. There is consensus from the interviewed lactation consultants that more milk banks are needed, especially in the Romandie and the cantons of Valais, Ticino and Zurich. Ideally, every major hospital with a neonatology department should have access to the network of banked donor human milk and an efficient distribution system. The scale-up and expansion of infrastructure that supports breastfeeding and milk banking in Switzerland would require initial investment. This could be viewed as costly, but optimal breastfeeding and availability of banked donor human milk can lead to significant public health benefits. The presence of milk banks and the use of donor human milk to supplement mother's own milk are associated with increased rates of exclusive breastfeeding at hospital discharge among VLBW infants and economic savings on health care costs [22,51]. Overall, there is limited research and

breastfeeding data, particularly to argue the cost-effectiveness of donor human milk and milk banking in Switzerland. Further economic analysis and research to demonstrate the short and long-term health and economic value of breastfeeding and human milk can lead to greater awareness, resources and political support for Baby-Friendly Hospital Initiatives, milk banking expansion and lactation trainings for hospital staff [91].

There were strong geographical and cultural differences observed between the German, French and Italian speaking regions of Switzerland with regard to milk banking. The current milk banks exist in only the German-speaking regions of the country. In the Romandie, there have been discussions about the need of a milk bank, but the hospital management have not prioritized this issue to move it forward. Lactation consultants in the Romandie have received milk banking inquiries from mothers, but they must refuse these requests since there is no milk bank nor any infrastructure to properly handle donor milk in west Switzerland. It was reported that mothers living in the French speaking region are tending to go to milk banks or 'lactariums' in France. This reflects a critical need for a milk bank in the Romandie so that lactating women would not need to travel across the border to seek milk banking services and resources. According to the lactation consultants in Bellinzona and Mendrisio, they would welcome a milk banking system; however, the low breastfeeding rates and low awareness in the canton of Ticino should first be addressed. There is no breastfeeding promotion campaign in the canton of Ticino and breastfeeding is not generally promoted as infant formula is seen as easier and cheaper among doctors. These regional differences reveal that there are evident gaps as to how and where donor milk and milk banking services can be accessed when needed. There is a strong need for political support among public health and legal authorities to ensure that breastfeeding is promoted and milk banks are accessible in all major languages and regions in Switzerland.

Human milk is currently not regulated by the law in Switzerland and the debate about how human milk should be regulated remains to be a contested issue [13]. According to the interviewed lactation consultants, there was a majority consensus that human milk should be regulated by the law in Switzerland, but their opinions as to how human milk should be regulated were diverse, e.g., similar as blood regulation, food or medicine.

The neighboring countries of France, Germany, Italy and Austria, all demonstrate some level of governmental involvement with relation to human milk banking. In France, human milk is regulated by public health law, which ensures public protection, accountability, traceability, quality management and the costs of donor human milk are reimbursed by health insurances [92]. The three German states of Bavaria, Saxony, Baden-Württemberg, in addition to Austria and Italy, regulate human milk as food [32,93,94]. These regulations are put in place to ensure the food safety standards, inspection and high quality assurance and to prevent the risks of an unregulated market of human milk. Ministries of Health in France, Italy and Austria (Ministry of Women's Health), are all governmental bodies that support, published and endorsed national human milk banking guidelines in their respective countries [93,95,96]. The Swiss milk banking guidelines published in 2010 were endorsed by only the Swiss Society of Neonatology [14] and no governmental authority. Perhaps for the next Swiss milk banking guidelines there could be a cooperation and endorsement from the Swiss government authorities so that policymakers could be more engaged to support and promote breastfeeding, donor human milk and milk banking.

Hospitals without milk banks need infrastructure, financing and support from hospital leadership to establish new milk banks. Perhaps an interdisciplinary team could establish a forum where hospitals, with or without milk banks alike, could work together to build a stronger milk banking network. This would ensure that every region has access to banked donor milk and a more efficient delivery system. In addition, collective support for research and promotional campaigns could make a stronger case for future financing, health insurance coverage, hospital management and health policies. Overall, these challenges highlight that there is an increasing need for human milk, there is room for improvement in the existing milk banking

infrastructure in Switzerland, there are opportunities to learn good practices from other countries and potential collaborations for policy and practice to ensure that breastfeeding, mother's own milk, all human milk is protected, promoted, and supported for all infants [30].

5.2 Milk Sharing

Milk sharing demonstrates a growing general awareness of the importance and value of human milk. However, milk sharing also highlights systematic gaps in policy, education and access that need to be addressed in order to provide for the needs of lactating mothers and their infants.

Policies must strengthen breastfeeding and mother's own milk. One interviewed mother had to return to work, after 14 weeks of maternity leave, but she did not have enough time nor could she express enough milk for her child during workhours so she resorted to online milk sharing. This sheds light on the issue of lactation support for working mothers and the right of paid lactation breaks during workhours. By Swiss federal law, lactating women are entitled to paid lactation breaks to breastfeed or express their milk during workhours [97]. Breastfeeding requires time investments [98]; however, it is unclear if the times allocated for mothers to breastfeed or express their breast milk during workhours are sufficient and if mothers and employers aware of these rights. Ongoing research by the Institut Universitaire de Médecine Sociale et Prévention at the University of Lausanne is already examining the barriers that mothers face to continue breastfeeding when returning to work, which includes the position of the employers [99]. According to the ESPGHAN Committee on Nutrition commentary on breastfeeding, they state that "societal standards and legal regulations that facilitate breastfeeding should be promoted, such as providing maternity leave for at least 6 months and protecting working mothers" [8, p. 123].

Indeed, policies should also protect breastfeeding and mother's own milk from economic motives and free markets that seek to commercialize human milk. The investigated online milk sharing and selling platforms were variable in scope, lacked detail, had limited reliable references and none of the websites provided liability for any harm or damages. There is a lack of clarity on the legal accountability and safety controls which places users and receiving infants at their own risks in exchanging raw breast milk. Furthermore, there are growing for-profit entities, such as Prolacta Bioscience [100], an American company that resells donor human milk as lactoengineered products to hospitals, that seek to aggressively enter the unregulated human milk market in Switzerland. One interviewed mother was contacted by an agent from another company based in Germany called Ammenpulver [88] and was interested to buy her milk. These forms of cross-country human milk trade can have implications that undermine breastfeeding and milk banking. Swiss policymakers and health care professionals must assess the efficacy of the evidence base and implications of these industries in order to protect breastfeeding from economic motives. The majority of interviewed mothers opposed monetary incentives for the exchange of breast milk. This shows that the participants believed in commerce-free milk sharing and placed value on peer-to-peer support, mutual respect and community building.

The narratives from the interviewed mothers reveal the need for better education on breastfeeding and the risks associated with milk sharing. Prior to or while engaging in milk sharing, all participating mothers experienced different emotional struggles from feeling guilt and shame, particularly for not being able to breastfeed their child as planned, anxiety over judgement or stigma, and disgust with using a stranger's milk for their infant. Donors also experienced worry over societal taboos of sharing milk with strangers, stress and disappointment for not being able to donate their milk to an official milk bank. These stressful emotions reveal the societal pressures and struggles that mothers face when attempting to reach breastfeeding expectations. Educational campaigns should empower parents to make informed choices and lactation support should be closely linked to mental health support when needed.

On the topic of acupuncture, both donors had undergone acupuncture treatments during pregnancy, which disqualified them from donating their milk to a milk bank. The donors were able to share their milk through HM4HB and were transparent

about their acupuncture treatments. All receivers either accepted milk from a donor knowing that the donor had acupuncture treatments or had the opinion that as long as the milk passes the microbiological tests, then the donor human milk should be acceptable. Acupuncture is a popular procedure sought by pregnant women because it is believed that acupuncture relieves various pregnancy related ailments, such as morning sickness, back ache, pain relief during labor and support healing after delivery, according to the British Acupuncture Council [101]. However, milk banks in Switzerland do not accept donor milk from mothers who have had acupuncture treatments within the last six months since there are risks for infection or disease transmission with the use of needles [13]. The issue of acupuncture during pregnancy and milk bank donation disqualification should be properly communicated to mothers before they seek these services.

All mothers perceived that the benefits of milk sharing outweighed the risks. However, their risk reduction strategies were not consistently carried out across participants. Despite feelings of hesitation prior to engaging in milk sharing, mothers in the study reported to communicate with other mothers online, meet in person to observe the hygienic handling of the milk, ask health screening questions, ask for blood test results, medical history and establish relations of trust and mutual respect prior to sharing milk. Mothers also reported to have consulted with a health professional and educated themselves by searching online about the risks and safety precautions prior to engaging in milk sharing. However, none of the mothers practiced home pasteurization. Furthermore, one mother accepted breast milk from ten different donors, but she was not able to ask donor health screening questions with all of them. This reveals that although mothers may be aware of the risks associated to milk sharing, many important steps that can reduce the risks of infectious transmission are not always applied in practice, which elevates the risks to the receiving infant.

There was consensus among the mothers in the study that there is a need for more accessible infrastructure and services to support breastfeeding and donor human milk. For instance, a public breast milk collection center or community milk bank could serve the needs of all infants and lactating women, particularly mothers with medical reasons, so they can access safe donor milk and avoid the risks of online milk sharing. These centers could also be more engaged in breastfeeding promotion activities and education. All mothers who were interviewed believe that there is room for improvement in terms of breastfeeding education and accessibility of information and services to support lactating and breastfeeding women.

According to the respondents, breastfeeding and milk sharing is, in their opinion, still stigmatized, sexualized, shamed, hidden, considered gross in society and certain participants in the study reported to have breastfed in public restrooms or were asked to leave a restaurant while pumping. More efforts for nationwide awareness campaigns and educational programs can support and normalize public breastfeeding. All mothers suggested to improve lactation education to better prepare parents for successful nursing and to ensure that hospital personnel are trained in lactation so they have the competencies to support mothers with breastfeeding challenges and not automatically resort to infant formula feeding.

Milk sharing should not be seen as a threat, but as an opportunity for leaders in the medical and political spheres to create an enabling environment to support breastfeeding and increase the accessibility of milk banks. Health authorities should conduct further research and disseminate evidence-based information about all forms of infant feeding, the risks associated and provide guidance on how to mitigate the risks. There is a need for further infrastructure to address the current milk gap and meet the current need for human milk in a safe way. The demand for human milk is high, as evident in the echoed experiences of the participating mothers. Therefore, as a shared responsibility, health care professionals, policy makers, organizations, employers, educators and individuals must work collectively–in the form of education, policy and practice–to prioritize breastfeeding and to ensure that milk banking and the availability of safe donor human milk is integrated into standard care in Switzerland.

6 Conclusion

The WHO states that donor human milk from a milk bank should be the next best alternative when the biological mother's own milk is limited. However, not all lactating women have access to a milk bank in Switzerland. As a result, more mothers are engaging in online milk sharing.

Led by the Stillförderung Schweiz, the aim of the report is to analyze the human milk gap in Switzerland by investigating milk banking and milk sharing practices and perceptions. This is the first study of its kind to contextualize the contemporary uses of human milk in Switzerland.

Donor human milk shortages are a major challenge for milk banks. This can lead to additional workload for staff, the need to arrange donor human milk from other milk banks, lowering the birth weight criteria or resorting to infant formula.

Hospitals without milk banks face numerous obstacles, such as a lack of equipment, infrastructure, defined budgets, support from hospital management and detailed protocol on how to establish new milk banks. Respondents agreed on the need for more milk banks, the regulation of human milk and more informational campaigns about breastfeeding and milk banking in Switzerland.

A review of milk sharing and milk selling platforms found inconsistent safety and quality information, missing reliable sources to information and no liability. The Human Milk 4 Human Babies Facebook group was found to be the most active milk sharing platform in Switzerland with nearly 900 followers. According to interviewed mothers engaged in milk sharing, donors had oversupply and altruistic intentions, but could not donate to a milk bank. Milk sharing receivers experienced low milk supply, illness or had to return to work. Overall, participants assumed no harm and positive intentions from other mothers and believed that the benefits outweighed the risks, preferring raw donor human milk over infant formula. However, their risk reduction strategies, such as screenings, medical background checks, blood tests and home pasteurization, were not consistently practiced by all the respondents.

These trending milk sharing behaviors demonstrate that there are systematic gaps in policy, education and access that hinder mothers from meeting their breastfeeding goals. Switzerland could establish public human milk collection centers or community milk banks, which provide a safe infrastructure for women to donate or access banked donor human milk when needed; thereby, avoiding the risks of sharing milk online or informally. Government officials in Switzerland must collaborate with essential stakeholders, prioritize funding, research, education and policy to support breastfeeding and sustainable infrastructure to urgently address the human milk gaps.

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9 Supplementary Material

Laktationsberaterinnen Interview-Fragen
Praktizierende Frauenmilchbanken

Arbeitsweisen Frauenmilchbanken

1. Seit wann existiert die Frauenmilchbank in Ihrer Neonatologie-Abteilung und weshalb wurde sie gegründet?
2. Wie viele und was für Fachkräfte arbeiten im Zusammenhang mit der Frauenmilchbank? Genügt das oder werden mehr Angestellte benötigt.
3. Was für Räumlichkeiten oder Einrichtungen haben Sie für die Frauenmilchbank (Lagerung, Pasteurisierung, Kontrolle, Verteilung)?
4. Wie funktioniert die Frauenmilchbank in Ihrer Neonatologie-Abteilung? Was sind die spezifischen Arbeitsabläufe?
5. Wie werden die Kosten von der Frauenmilchbank gedeckt? (Spital, Krankenkasse, Patienten, andere)

Über die Spenderinnen und die gespendete Frauenmilch

6. Wie finden Sie Spenderinnen? Stationäre Patientinnen, ambulante Patientinnen, Nicht-Patientinnen?
7. Kann jede Mutter Spendermilch beantragen oder braucht sie ein ärztliches Rezept?
8. Wie oft erhalten Sie Spendermilch?
9. Gibt es ein Screening-Verfahren? Wenn ja, was sind die Kriterien und das Verfahren? Werden die Informationen von Spenderinnen überprüft?
10. In welchem Fall würde eine Spende abgelehnt? Hat sich das ereignet?
11. Erklären Sie den Ablauf einer Frauenmilchspende in der Klinik.
    a. Wie wird Frauenmilch gespendet? Wird die Frauenmilch regelmässig freiwillig gespendet oder bei Bedarf bei anderen Müttern angefragt?
    b. Wird die Spendermilch in der Klinik abgepumpt oder besteht die Möglichkeit die Spendermilch Zuhause zu pumpen und dann dem Spital zu übergeben.
12. Werden Frauenmilchportionen gemischt, falls die gespendete Frauenmilchportion nicht ausreicht?
13. Wie wird die Spendermilch gelagert und was ist die maximale Lagerdauer?
14. Wie wird die Gefahrlosigkeit der Spendermilch garantiert?
15. Wird die Spenderin informiert, falls die überprüfte Spendermilch nicht als sicher betrachtet wird?
16. Wird die Spendermilch auf den Nährstoffinhalt geprüft?
17. Ist immer genügend Spendermilch vorhanden? Was ist das Vorgehen, wenn Frauenmilch benötigt wird, aber keine Spendermilch auf Lager ist?
18. Wie ist die allgemeine Resonanz bei Müttern auf Ihrer Abteilung die um Spendermilch ersucht werden?

Über die Abnehmer

19. Ersuchen Mütter selber um Spendermilch?
20. Erklären Sie den Ablauf wie die Spendermilch zu den Abnehmern gelangt?
21. Haben Mütter schon eine empfohlene Frauenmilchspende für ihr Kind abgelehnt?
22. Wie wird Spendermilch dem Säugling verabreicht? Und von wem-Pflegepersonal oder der Mutter?
23. Wer sind die Abnehmer von Spendermilch?
24. Haben Sie negative Reaktionen von Säuglingen im Zusammenhang mit gespendeter Frauenmilch beobachtet? Falls ja, was haben Sie unternommen?

Wahrnehmung von Frauenmilchbanken und Frauenmilch-Internetplattformen

25. Besteht Bedarf nach mehr Publizität von Frauenmilchbanken im Allgemeinen? Wie könnte diese aussehen?
    1. Hat ihre Abteilung eine Publizitätskampagne bezüglich Frauenmilchbanken organisiert (z.B. Radio, TV, Internet, Flyers)

26. Sollten Spenderinnen für ihre Spendermilch vergütet werden oder sollte die Spende unentgeltlich sein?
27. Kennen Sie Internetplattformen wo Mütter Frauenmilch vermitteln und beziehen? Empfehlen Sie Müttern diese Plattformen zu nutzen?
28. Kennen Sie Frauen die Frauenmilch im Internet gespendet oder verkauft habe?

Verbesserungen

29. Werden Daten bezüglich Frauenmilchbanken erhoben? Wie wird Ihre Frauenmilchbank evaluiert?
30. Wie viele Mütter haben über ihre Frauenmilchbank Spendermilch gespendet und erhalten?
31. Wo können Frauen sich in Ihrer Klinik zum Thema Frauenmilchbank informieren?
32. Wie kann ihre Frauenmilchbank verbessert werden?
33. Braucht es Ihrer Meinung nach eine nationale Vereinigung/Regulierungsbehörde für Frauenmilchbanken in der Schweiz?
34. Braucht es mehr Frauenmilchbanken in der Schweiz?
35. Sollten Frauenmilchbanken in allen Schweizer Spitälern praktiziert werden?
36. Sollten Frauenmilchspende/-verkauf durch das Schweizer Recht besser reguliert werden?
37. Sollte Spendermilch als Lebensmittel, Arzneimittel oder in einer anderen Kategorie reguliert werden? (Fakultativ)

Interview Fragen Spital (Keine Milchbank):

1. Obwohl es in _____ keine Milchbank gibt, sammeln Sie gelegentlich Muttermilch?
    a. Sammeln Sie Muttermilch von einer Mutter für ihr Kind? Pasteurisieren oder lagern Sie ihre Muttermilch in einem Kühlschrank oder Gefrierschrank?
    b. Sammeln Sie Muttermilch (Spendermilch) von einer Mutter, um sie einem anderen Kind zu geben? Pasteurisieren oder speichern Sie Spendermilch im Kühlschrank oder Gefrierschrank?
2. Haben Sie eine Mutter im Spital gebeten, ihre Milch für ein Frühgeborenes zu spenden (wenn die Mutter des Kindes keine oder zu wenig Muttermilch hatte)?
3. Wenn Frühgeborene Spendermilch erhalten, welches sind die Kriterien für das Kind (zum Beispiel: <1.500 g Gewicht)?
4. Wenn Frühgeborene keine Spendermilch erhalten, was wird ihnen dann gegeben, wenn die biologische Mutter nicht in der Lage ist, ausreichend mit Milch zu stillen oder zu pumpen? Hat Spital _____ Spendermilch von einem anderen Spital mit einer Milchbank verlangt?
5. Da es im Spital _____ keine offizielle Milchbank gibt, was könnte die Gründung einer Milchbank in _____ erschweren? Gibt es Diskussionen, eine Milchbank in _____ zu gründen?
6. Gibt es eine Nachfrage (von Müttern), eine Milchbank in _____ zu gründen?
7. Haben externe Mütter (nicht stationär) Ihre Spitalabteilung um Spendermilch gebeten? Haben externe Mütter gebeten, ihre Milch (bei zu viel Milch) in Ihrem Spital zu spenden?
8. Wenn eine Mutter (mit zu wenig Milch) anfragte, dass sie Spendermilch von einer anderen Mutter bekommen möchte (mit zu viel Milch), welchen Rat würden Sie ihr geben?
9. Kennen Sie Mütter, die ihre Muttermilch privat (zwischen Freunden oder Verwandten) oder im Internet teilen?
10. Sollte die Milchspende kostenlos sein? Oder sollten Spender bezahlt werden?
11. Sollten Frauenmilchbanken in allen Schweizer Spitälern praktiziert werden?
12. Was ist Ihre Meinung zu einer nationalen oder einigen regionalen Milchbanken?
13. Braucht es in der Schweiz einen größeren Bedarf an mehr Stillwissen / Bildung?
14. Muttermilch ist derzeit nicht durch das Schweizer Gesetz geregelt. Sollte Spendermilch als Lebensmittel, Arzneimittel oder in einer anderen Kategorie reguliert werden?

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