Perinatal Services BC
An agency of the Provincial Health Services Authority

Informal (Peer-to-Peer) Milk Sharing: The Use of Unpasteurized Donor Human Milk

Practice Resource for Health Care Providers

July 2016

Practice Resource Guide:
INFORMAL (PEER-TO-PEER) MILK SHARING:
THE USE OF UNPASTEURIZED DONOR HUMAN MILK

Contents

EXECUTIVE SUMMARY AND KEY MESSAGES

Breastfeeding is the "normal and unequalled method of feeding infants and young children".[1] Breastfeeding — exclusively for the first six months and continued for up to two years or longer with appropriate complementary feeding — is important for the nutrition, immunologic protection, growth, and development of infants and toddlers. A mother's own milk for her own child is the biologic norm and the optimum nutrition under almost all circumstances. If a mother's own milk is unavailable despite significant lactation support, supplementation with pasteurized donor human milk (PDHM) from a regulated milk bank is recommended. However, in the current context of the limited availability of PDHM, some parents may decide to give their infant informally obtained unpasteurized donor human milk (UDHM) as an alternative to human milk substitutes (commercial formula). This decision may be based on their perception that the known benefits of human milk, even if it is milk that is informally shared, outweigh the potential risks of formula. Health Canada, the Canadian Paediatric Society (CPS), and the Human Milk Banking Association of North America (HMBANA) do not endorse the use of UDHM. Some of the reasons outlined are the:

- Potential risk for contamination of the milk with harmful substances both microbial and chemical
- Lack of control over proper collection and storage of the milk
- Lack of knowledge or understanding of the donor's health history

However, the right of parents to make informed decisions regarding the care of their children is generally respected within the context of Canadian law, even if the decision is contrary to medical advice.

Informal milk sharing is a practice that has occurred throughout history and across cultures, but one that has recently become more evident as a phenomenon due to increasing public awareness of the short- and long-term health benefits of human milk, and with the advent of social media platforms that facilitate informal sharing. A survey conducted in British Columbia reported that informally obtained UDHM occurs in neonatal intensive care units (NICU), maternity units, and communities across BC and Canada, often on a 'don't ask, don't tell' basis.[2] It is not the role of the health care provider to promote informal milk sharing, however they must be prepared to provide unbiased information on all infant feeding options based on the best available evidence. For the purpose of this discussion, it is important that HCPs understand the differences in potential risk between the purchase of milk from strangers, milk sharing between family or friends, and regulated milk banking. Informal milk sharing poses risks for all infants; particularly for the ill or vulnerable newborn. The online buying and selling of UDHM between strangers is generally recognized as the scenario involving the greatest risk. Possible risks include:

- Unreliability of informal screening of donors
- Difficulty in determining the donor's health and life style risks
- Impossibility of testing milk for contamination in the home environment to ensure it is safe for human consumption
- Unreliability of donor in-home heating methods is not reliable
- Possibility of dilution with water, cow's milk, or other substances
- Increased risk the greater the distance the milk must be transported

The alternative, human milk substitutes (formula), can also pose risks and should be discussed. Risks associated with human milk substitutes that have been noted in studies include:

- Formula offers nutrition, but does not provide the antibodies, enzymes, hormones, and stem cells contained in human milk.[3]
- Formula has been associated with an increased incidence of acute otitis media, non-specific gastroenteritis, severe lower respiratory tract infections, atopic dermatitis, asthma in young children, obesity, type 1 and 2 diabetes, childhood leukemia, sudden infant death syndrome (SIDS), and necrotizing enterocolitis in the preterm infant.[4,5,6]
- Increased environmental burden for disposal of formula cans and bottles; and increased energy demands for production and transport of artificial feeding products.
- Economic impact to both the family and larger society.[7]
- Powdered formula is not sterile and may be contaminated with bacteria, as can the water used for reconstitution.[8]
- Out-dated, recalled, and contaminated commercially prepared formulas may result in serious illness.[9]

HCPs should reframe the traditional risk/benefit discussion to acknowledge the risks of human milk substitutes (as opposed to focusing solely on the importance of breastfeeding).

Individual decision-making regarding milk sharing is based on a balancing of risks and benefits as perceived by each family. For the HCP, consideration of informal milk sharing involves both ethical principles and issues of legal rights and liability. Discussions involving informal milk sharing should be based on the guiding principles of patient-centered care, informed decision-making, shared decision-making, and harm reduction.

The purpose of this document is to provide the HCP with the essential knowledge and tools to facilitate an informed discussion and decision-making process. Included in this practice resource document are the following appendices:

- Infant Feeding Options Decision Support Tool (DST)
- Supplementation with UDHM – Talking Points
- Sample Policy on the Use of UDHM
- Sample Acknowledgement of Risk Form for the Use of UDHM
- Family Information Handout: Informal (Peer-to-Peer) Human Milk Sharing

Key Messages

1. Health Canada, the Canadian Paediatric Society, and the Human Milk Banking Association of North America do not endorse the use of unpasteurized donor human milk.
2. Recommended supplementation options in Canada are:[10]
   a. Mother's own expressed milk;
   b. Pasteurized human donor milk from a regulated milk bank; and
   c. Human milk substitute (commercial infant formula).
3. The right of parents to make informed decisions regarding the care of their children is respected within the context of British Columbian and Canadian law.
4. It is not the role of the health care provider to promote informal milk sharing, however they must be prepared to provide information on all infant feeding options based on the best available evidence.
5. If, following a process of informed decision-making, parents choose to provide UDHM to their baby against medical advice then the counseling and informed decision should be documented in the infant's health record.
6. The promotion of milk donation to the provincial milk bank and the development of milk depots across the province are recognized as a priority to increase the amount of available PDHM to all infants in need across the province.

1.0 INTRODUCTION

"Breastfeeding is the normal and unequalled method of feeding infants".[1] According to Health Canada, breastfeeding — exclusively for the first six months and continued for up to two years or longer with appropriate complementary feeding — is important for the nutrition, immunologic protection, growth, and development of infants and toddlers.[10] When every agency and health care provider working with expectant and young families offers evidence-informed care, such as those based on the WHO/UNICEF Baby-Friendly Initiative (BFI), families are more likely to meet their breastfeeding goals.[11]

A mother's own milk for her own child is the biologic norm and the optimum nutrition under almost all circumstances; supplementation with an alternative may be required in specific circumstances. There are well-defined infant and maternal medical indications for supplementation.[12,13] In addition, approximately 5–15% of breastfeeding women are unable to produce sufficient milk due to hormonal or anatomical/surgical reasons, or ineffective breastfeeding or milk expression technique.[14,15] There are also situations (such as adoption) in which the milk of an infant's own mother may not be available.

When a mother's own milk is not recommended, unavailable, or limited despite significant lactation support, pasteurized donor human milk (PDHM) from a regulated milk bank is the recommended supplement or replacement feeding.[4,10, 16] The BC Women's Provincial Milk Bank, is the only regulated milk bank in BC and is currently one of three Human Milk Banking Association of North America (HMBANA) facilities in Canada.* Due to significant demand and not enough donations to meet all the requests, PDHM is prioritized for the most vulnerable infants in Neonatal Intensive Care Units (NICU).†

Human milk carries a low risk of disease transmission even in the donor situation.[17] In the largest study to date of 1091 potential donors to a HMBAMA milk bank in California, 3.3% tested positive on serological screening for either syphilis, hepatitis B, hepatitis C, HTLV, or HIV.[18‡]

If PDHM is unavailable, a human milk substitute (commercial infant formula) is the next recommended and most widely-used alternative in Canada.[19] While the use of formula is considered to be an acceptable nutritional replacement for human milk, it is not without potential risk and is associated with adverse health outcomes at the population level for both mothers and infants.[4,6,10,20§]

Over the past 10 years, a growing body of research and related public health messaging regarding the significant benefit of human milk to the short- and long-term health of infants has resulted in an improved awareness in the value of breastfeeding. As a result, there has been a steady rise in breastfeeding initiation rates in Canada.[21] In the context of limited

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* The other HMBANA milk banks are the Calgary Mother's Milk Bank and the Rogers Hixon Ontario Human Milk Bank in Toronto.

† In 2014, the BC Women's Provincial Milk Bank established in 1974, processed over 2,396 liters of milk from 238 donors, providing milk to 3,000 infants (Jones, 2015). Currently, this milk is available to a limited number of NICUs provincially, though expansion plans are underway.

‡ Actual numbers were as follows: 6 syphilis, 17 hepatitis, B, 3 hepatitis C, 6 HTLV and 4 HIV. Note that a positive serological test does not equate directly to the presence of the virus in the breast milk, the transmission of the virus to the infant, nor the actual occurrence of disease in the infant.[18]

§ The research on human milk substitutes indicates a difference in health outcomes between babies exclusively fed human milk substitutes versus human milk. There is also evidence of a dose response relationship for many health outcomes, however there is a paucity of definitive research on mixed feeding.[4]

availability of PDHM from a regulated milk bank, some parents may decide to give their infant informally obtained unpasteurized donor human milk (UDHM) as an alternative to human milk substitutes.[22,23]

As a health care provider (HCP), there are a variety of situations where you may come into contact with families who are considering milk sharing, or who are already providing UDHM to their infant. Whether you are a physician working in a NICU or a public health nurse providing maternity support in the community, milk sharing could be occurring within your patient population.

The sharing of human milk outside of regulated HMBANA milk banks usually involves the altruistic not-for-profit sharing of expressed milk between family, friends, or more recently, online social networks that connect donors and mothers in need.[23] There is a growing availability of websites that promote the buying and selling of milk from strangers, and a relatively new option that involves the ability to purchase PDHM from a commercial milk processing company. All of these options come with varying degrees of risk, which logically escalate with an unknown donor and lack of medical and lifestyle history.

Individual decision-making regarding milk sharing is based on balancing the risks and the benefits as defined by each family, as well as how these stack up against the alternative, which is usually commercial infant formula. For the HCP, consideration of informal milk sharing involves both ethical principles and issues of legal rights and liability. Discussions involving informal milk sharing should be based on the guiding principles of patient-centered care, informed decision-making, shared decision-making,[24] and harm reduction.

This practice resource is intended to provide HCPs with information and tools to facilitate an informed discussion and shared decision-making process.

See the Definitions and Abbreviations section to understand the terms used throughout this document to address milk sharing as there are often different understandings as to what they mean. It is important for health care providers to speak the same language in order to eliminate confusion.

Definitions and Abbreviations

A Note on Gender Inclusion and the Language of this Document
Whereas breastfeeding is traditionally understood to involve an individual of the female sex and gender identity (cisgender) who also identifies as a woman and mother, it is important to recognize that there are individuals in a parenting and human-milk-feeding relationship with a child who may not identify as any of these (for example, trans* folks)*. Some parents may prefer to use the term 'chestfeeding' rather than breastfeeding.

Cooperative Nursing: Breastfeeding of a child by someone other than the biological mother, including:

- Wet-Nursing: when a lactating woman breastfeeds an infant other than her own, directly at the breast, historically often for pay.
- Cross-Nursing: the occasional nursing of another's non-biological child while the mother continues to nurse her own biological child, often in a child care situation.
- Co-nursing: two people in a relationship who both breastfeed their baby.

Donor Screening and Milk Screening: Regulated North American milk banks follow rigorous screening required by Human Milk Banking Association of North America (HMBANA). This includes screening donors verbally, in writing, and through serological testing. To increase safety, a potential donor's physician/midwife is contacted to confirm eligibility, and there is ongoing contact with the donor. In addition, careful handling and processing of the milk is required, precise heating and cooling requirements are followed, and donor milk is tested for bacterial and viral contamination after pasteurization to ensure the milk is safe to distribute.[25]

Flash Heating: Flash heating involves placing a measured amount of milk in a glass container that is then placed in a measured amount of water. The water is heated to a rolling boil before the jar is removed and allowed to cool. Flash heating has been found to inactivate HIV-1 present in human milk; however, this research is not conclusive, and the effect of flash heating on other viruses remains theoretical.[26,27,28]

Health Care Provider: In the context of this document, the term refers to nurses, midwives, physicians, dietitians, lactation consultants, and other allied health care professionals working with childbearing families.

Holder Pasteurization: Holder pasteurization (milk held at 62.5°C for 30 minutes) is the standard method adhered to by HMBANA milk banks. This method has been demonstrated to kill a wide variety of viruses and bacteria. A percentage of nutritional and immunological components normally present in human milk are destroyed by pasteurization; however, it retains many beneficial properties.[16,29,30]

Human Milk Banking Association of North America (HMBANA): HMBANA is a professional association for supporters of non-profit donor human milk banking. It promotes the health of babies and mothers through the provision of safe, pasteurized donor human milk and support of breastfeeding (hmbana.org).

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* Trans* is an umbrella term that refers to all of the identities within the gender identity spectrum. 'Folks' is a broad non-specific term preferred by the queer community. In discussion with families, do not make assumptions. Ask the person how they would like you to refer to them, and use gender neutral language when appropriate.

Human Milk Substitute: Any food marketed or otherwise presented as a partial or total replacement for human milk, whether or not suitable for that purpose.[31] In the context of this document, human milk substitute refers only to commercial infant formula.

Informal Milk Sharing: Informally obtained unpasteurized donor human milk (UDHM), including:

- Peer-to-Peer Informal Milk Sharing: the altruistic, not-for-profit sharing of UDHM between family, friends, or online social network sites dedicated to connecting donors to mothers in need.
- Purchased UDHM: the for-profit buying and selling of UDHM between strangers.

NICU: Neonatal Intensive Care Unit

Pasteurized Donor Human Milk (PDHM): Donor human milk from a regulated milk bank that has undergone pasteurization and has met the standards of screening, processing, handling, testing, and shipping set out by the Human Milk Banking Association of North America.

Perinatal Services BC (PSBC): Perinatal Services BC is an agency of the Provincial Health Services Authority and provides leadership, support, and coordination for the strategic planning of perinatal services in British Columbia. PSBC collaborates with the Ministry of Health, health authorities, and other key stakeholders and is central source in the province for evidence-based perinatal information.

Replacement Feeding: The infant receives something other than mothers own milk.

Supplementation: When infant is receiving an alternative, in addition to mother's own milk.

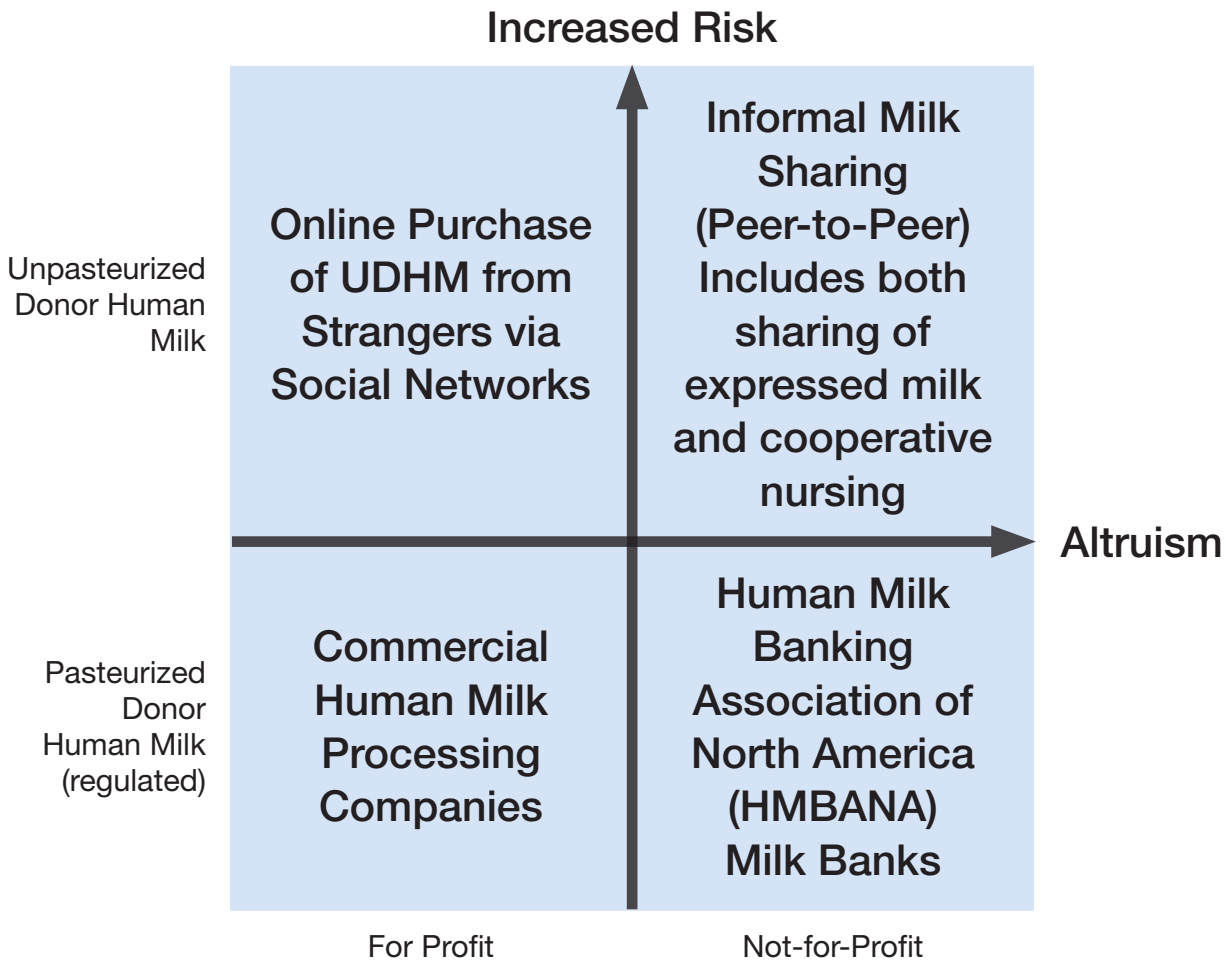
Unpasteurized Donor Human Milk (UDHM): Human milk donated or brought by a family member, friend, or stranger that has not undergone donor screening and pasteurization by a HMBANA regulated milk bank. It may be fresh, flash heated, refrigerated, or frozen.

2.0 INFORMAL MILK SHARING (Unpasteurized Donor Human Milk)

In conjunction with an increased awareness of the importance of breastfeeding and human milk, and the risks associated with human milk substitutes (formula), the advent of online social networking has contributed to the rise of altruistic informal peer-to-peer milk sharing.[32] One of the sites, Human Milk 4 Human Babies, hosts a global page as well as local community pages representing every state in the US and in 52 countries. There has also been a significant amount of traditional and social media attention recently, leading to an even greater awareness on the part of the parenting community of this type of movement.

Contributing to the complexity of our understanding of milk sharing are reports of diluted and contaminated human milk sold online, the trend of purchasing human milk for purposes other than feeding an infant (such as a nutritional supplement to boost athletic performance), and the development of commercial for-profit milk banks. It is important to recognize that the broader concept of human milk sharing can encompass four very different practices, each associated with different degrees of altruism and potential risk. Figure 1 shows a matrix of the types of human milk sharing in the context of the variables of risk and altruism.

Figure 1. Human Milk Sharing Matrix



Altruistic, not-for-profit, informal peer-to-peer milk sharing historically involved some form of cooperative breastfeeding. This practice continues today amongst family and friends, as does the sharing of expressed human milk, but because of the "behind closed doors" nature of these interactions, this type of "familial" milk sharing remains largely unexamined.[33] The altruistic sharing of expressed milk from one mother to another who is not already known to her is more readily apparent to observers, including HCPs, due to the public nature of the transactions, most often via an online community.

Altruistic informal milk sharing differs from the selling of human milk for profit both in its selflessness and the possible level of risk. **Altruism** is the unselfish regard for or devotion to the welfare of others, and it is a reasonable assumption that mothers giving their milk for free to another mother in need are doing so with the best of intentions.[34] When profit is a motivation, the purposeful dilution of human milk with cow's milk or water has been documented.[35]

Commercial human milk processing companies have introduced yet another complexity to the "sharing" of human milk. In the US, these companies are regulated by the Food and Drug Administration for the safety of their product (no bacterial, viral, or other contamination), but the ethics of the marketing of human milk for profit has generated considerable concern amongst a variety of organizations.[36,37,38]

Pasteurized donor human milk from a regulated not-for-profit HMBANA milk bank is recognized by health care authorities as the most recommended alternative when a mother's own milk is unavailable. It is considered safe, reliable, and cost effective. The per-ounce cost of HMBANA milk from the BC Women's Provincial Milk Bank is approximately $1.25/30 ml (in 2016), as opposed to as much as $125 for 20 ml from one of the US for-profit companies that sell their milk in Canada. Our Canadian health care system has been proudly built upon the concept of not-for-profit altruism in relation to the donation of blood and other human tissue, and there is concern about the possible erosion of this valued principle.[37]

It is estimated that in 2015, over 55,000 women worldwide posted on websites with the intention of providing or obtaining milk, either for free or for payment.[39] There is little data available on the prevalence of informal milk sharing in Canada. A US study conducted between April 2011 and March 2013 reviewed a total of 1,249 posts on two social networking pages that host not-for-profit milk sharing: Eats on Feets and Human Milk 4 Human Babies.[32] A review by the authors of the BC-specific pages of these same milk sharing social network sites revealed 26 separate requests for milk in six months (January–June 2015). Infants ranged in age from one week to nine months. The most common reasons for requests (when given) were low milk supply and multiples, with one infant in hospital at the time of the request. While this offers a glimpse into the online world of public milk sharing between strangers, the prevalence of the more common form of informal milk sharing that takes place between family and friends remains undetermined.

Initiating a discussion with parents and openly acknowledging altruistic milk sharing as a choice women and families are making can be an uncomfortable conversation for HCPs. Some of the reasons include:

- A lack of familiarity with the risks and benefits
- Uncertainty about the process of engaging in a shared decision-making conversation
- Uncertainty about their institution's or health authority's policy

- Knowledge of position statements by professional organizations that do not endorse informal milk sharing
- Belief that by acknowledging the possibility of the practice, they will be perceived as condoning it[2]

Despite the lack of formal data, indications are that informal milk sharing is increasing in many hospital and community settings.

The lack of clarity around informal milk sharing is also challenging for families. Parents are concerned that health care providers will not support (or will not 'allow') their decision to feed their child UDHM, with the result that parents may withhold information about their infant-feeding choices. When combined with the fact that HCPs are themselves not initiating this discussion with parents, it is not surprising that we find ourselves in a 'don't ask, don't tell' situation, in which potential opportunities for dialogue and respectful sharing of information are lost. The decision support tools and HCP and parent information resources in this resource have been developed to help support practitioners with this conversation.

It is not the role of the health care provider to promote informal milk sharing.
Health Canada, the Canadian Paediatric Society, and the Human Milk Banking Association of North America do not endorse the use of unpasteurized donor human milk.

3.0 ETHICAL AND LEGAL CONSIDERATIONS

When parents make an informed decision to provide their infant UDHM, contrary to medical or professional advice, it presents a practice challenge to the HCP and the institution or health authority where the care is being provided. “A bioethical dilemma is created when various solutions appear equally good or bad and priorities seem difficult, if not impossible, to set. Conflicts also arise when the people involved place significantly different values on the possible actions”.[40] Fortunately, whenever differing opinions exist related to the appropriate treatment/care of an infant, HCPs and families have a number of guiding ethical and legal principles that may assist in the decision-making process.

HCPs are required to ensure their practice conforms to their profession’s code of ethics and standards of care. The familiar bioethical principles of autonomy, beneficence, non-maleficence, and justice provide the basis for guiding most HCP professional practice and can be applied to the context of informal milk sharing.[41] The principle of **autonomy** reminds HCPs to provide infant feeding information to parents in an unbiased manner in order for them to make an informed decision and to not withhold information based on their personal values and beliefs. **Beneficence**, to benefit, entails doing what is in the patient’s best interest. In situations where what is in the best interest of the child is unclear, and/or differs based on different values and beliefs of the relative risks and benefits, the health care team should respect the parent’s wishes unless it is obvious that the child will suffer harm.[42] **Non-maleficence**, to do no harm (or to minimize risk), conveys to the HCP an ethical obligation to discuss risk reduction strategies when a family has made an informed decision to engage in informal milk sharing. **Justice** requires that individuals be treated fairly. PDHM from a regulated milk bank is necessarily prioritized to the most vulnerable hospitalized infants. Supply and distribution challenges mean that it is often not available equally across the province for all babies in need. Informally shared donor milk is most often distributed within a community and between individuals free of charge.

These principles offer only a partial framework for many health care decisions, including informal milk sharing. Concepts such as patient-centered care, informed decision-making, shared decision-making, and harm reduction offer additional, somewhat overlapping models to further guide HCP and family discussions regarding infant feeding decisions. See Concepts of Patient-Centred Care, Informed Decision-Making, Shared Decision-Making, and Harm Reduction section for a review of each of these concepts.

Bioethical conflicts often arise when the people involved, place significantly different values on the possible actions. In the case of informal milk sharing and the determination of what is in the best interest of the child, the conflict is generally a difference in the value placed on human milk and a different weighing of the inherent risks and benefits associated with informal milk sharing versus the use of commercial infant formula. According to guidance from the Canadian Paediatric Society (CPS), the values, preferences, beliefs, and expectations of the family play an important role in decision-making and should not be ignored when considering the best interests of the child. The CPS also cautions that a physician’s own values should not restrict or bias the options discussed with patients or families.[42]

The right of parents to make informed decisions regarding the care of their children is respected within the context of British Columbian and Canadian law, even if this decision is contrary to medical advice (Health Care [Consent] and Care Facility [Admission] Act, R.S.B.C. 1996, c. 181. 2; Health Care Consent Act, 1996, SO 1996, c 2, Sch A). The

right to determine what constitutes their child's best interest is honoured in all but the most extreme circumstances, when it is obvious that the decision places the child at a significant risk of serious harm.[42]

Human milk carries a low risk of disease transmission even in the donor situation.[17] In the largest study to date of 1091 potential donors to a HMBAMA milk bank in California, 3.3% tested positive on serological screening for either syphilis, hepatitis B, hepatitis C, HTLV, or HIV.[18]* The actual incidence of illness attributable to informal milk sharing is not yet known.

It is legal to share donor human milk in Canada. It is considered a food, and therefore, its sale and distribution is regulated under the Food and Drugs Act.[19] Donor human milk must adhere to sections 4 and 7 of the Act, which states: "No person shall sell an article of food that: (a) has in or on it any poisonous or harmful substance; (b) is unfit for human consumption; (c) consists in whole or in part of any filthy, putrid, disgusting, rotten, decomposed, or diseased animal or vegetable substance; (d) is adulterated; or (e) was manufactured, prepared, preserved, packaged, or stored under unsanitary conditions; and no person shall manufacture, prepare, preserve, package, or store for sale any food under unsanitary conditions."[43] Donors who are considering selling or sharing their milk informally should be made aware of these regulations.

HCPs are also required to follow their individual agency policies and guidelines. Refer to Appendix 3 for a **Sample Policy on the Use of UDHM**.

If parents choose to provide UDHM to their baby against medical advice, the counseling and informed decision should be documented in the infant's health record. Provincial Health Services Authority (PHSA) Risk Management and the provincial Health Care Protection Program (HCPP) have been consulted on the development of the Acknowledgement of Risk Form for the use of UDHM (Appendix 4) for risk management purposes. This form has not gone through a legal review. Individual organizations must still go through the vetting process (including legal review) to ensure it meets their own organizational requirements before using. Individual organizations may choose to develop their own Acknowledgement of Risk Form based on this template, or may instead advise careful documentation in the narrative notes (risk/benefit discussion on all supplementation options, parents'/caregivers' informed decision, and their acknowledgement of risk regarding the use of UDHM).

* Actual numbers were as follows: 6 syphilis, 17 hepatitis, B, 3 hepatitis C, 6 HTLV and 4 HIV. Note that a positive serological test does not equate directly to the presence of the virus in the breast milk, the transmission of the virus to the infant, nor the actual occurrence of disease in the infant.

Concepts of Patient-Centered Care, Informed Decision-Making, Shared Decision-Making, and Harm Reduction

This practice resource is based on the concepts of patient-centered care, informed and shared decision-making, and harm reduction, which offer somewhat overlapping models to guide health care provider and family discussions regarding infant feeding decisions.

Patient-Centered Care: This is one of the cornerstones of Canadian health care. "Care that is truly patient-centred considers patients' cultural traditions, their personal preferences and values, their family situations, and their lifestyles. It makes patients and their loved ones an integral part of the care team who collaborate with health care professionals in making clinical decisions. The core principles include dignity and respect, information sharing, participation, and collaboration".[44]

Informed Decision-Making: The right of parents to make a decision based on choice regarding the care of their children is respected within the context of Canadian law.[45,46] HCPs have an ethical responsibility to facilitate informed decision-making by collaborating with families and providing evidence-based information).[42,47,48] Any discussion on the risks of informal milk sharing must take place within the larger context of the risks and benefits of all infant-feeding options. Throughout childhood, parents make decisions regarding the nutrition of their child. These decisions may be influenced by their beliefs, values, understanding of the information and social circumstances.

Shared Decision-Making: Shared decision-making is a collaborative process that enables patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as patient values and preferences).[49] Shared decision-making honors the provider's expert knowledge, the parent's right to be fully informed, and ultimately their right to make a decision that they feel is in the best interests of their child.

Harm Reduction: "Harm reduction is a pragmatic response that focuses on keeping people safe and minimizing death, disease, and injury associated with higher risk behaviour, while recognizing that the behaviour may continue despite the risks".[50] The principle of harm reduction is most often associated with measures to reduce the harms of illicit drug and alcohol use; however, the same principles can be applied to other public health measures that aim to reduce risk, such as the practice of bedsharing and safe sleep.[51,52] HCPs recognize that informed, capable clients (or substitute decision-makers in the case of parents) have the right to be independent, live at risk, and direct their own care.[48,53,54] At times, patients may make choices that are not optimal in the eyes of the HCP, and in these situations, harm reduction strategies may be effective in reducing risk. A central tenet of harm reduction is respect for individual decision-making and responsibility.[55] In the context of UDHM, any strategy that aims to reduce the potential negative health consequences of informal milk sharing would be considered in keeping with harm reduction principles.

4.0 RISKS AND BENEFITS OF INFANT SUPPLEMENTATION OPTIONS

Once it has been determined that an infant requires supplementation, the HCP should review the recommended options with the parent(s), including risks and benefits of each.

Recommended options for supplementation in Canada are:[10]

1. Mother's own expressed milk
2. Pasteurized donor human milk from a regulated milk bank
3. Human milk substitute (commercial infant formula)

Refer to the **Infant Feeding Options Decision Support Tool** (Appendix 1).

4.1 HUMAN MILK SUBSTITUTES (commerical infant formula)

Public health messaging related to infant feeding alternatives is beginning to favour the use of language that identifies the 'risks of not breastfeeding' (i.e., using human milk substitutes), rather than the prevailing narrative of the 'benefits of breastfeeding'.[6] HCPs should therefore have an understanding of the potential risks associated with human milk substitutes in order to better understand the parents' perspective.[8]

The wholesale endorsement of the use of commercial infant formula as an equal substitute to mothers own milk for all babies all the time has ignored the growing research documenting the potential risks. The research on human milk substitutes indicates a difference in health outcomes between babies exclusively fed human milk substitutes versus human milk, as well as a dose response related to duration.[4] However there is a lack of research on mixed feeding.

Potential Risks of Human Milk Substitutes

- Formula offers nutrition, but does not provide the antibodies, enzymes, hormones, and stem cells contained in human milk.[3]
- Formula has been associated with an increased incidence of acute otitis media, non-specific gastroenteritis, severe lower respiratory tract infections, atopic dermatitis, asthma in young children, obesity, type 1 and 2 diabetes, childhood leukemia, sudden infant death syndrome (SIDS), and necrotizing enterocolitis.[4,5,6]
- Increased environmental burden for disposal of formula cans and bottles; and increased energy demands for production and transport of artificial feeding products.
- Economic impact to both the family and larger society.[7]*
- Powdered formula is not sterile and may be contaminated with bacteria, as can the water used for reconstitution.[8]
- Outdated, recalled, and contaminated commercially prepared formulas may result in serious illness.[9]

Potential Benefits of Human Milk Substitutes

- It is considered a medically and culturally acceptable infant feeding option.

* A 2012 study from UNICEF UK found that over £17 million (Canadian conversion 31829382.20) could be gained annually by avoiding the costs of treating four acute diseases in infants (GI, Respiratory, Ear infections and NEC).[7]

- It is an option for infants diagnosed with Galactosemia (a rare genetic metabolic disorder) where human milk is contraindicated.[12]
- It is an option for infants for whom breastfeeding is contraindicated due to maternal use of certain pharmaceuticals.
- There are situations in which human milk (mother's own milk or PDHM) is not available and human milk substitutes become a necessity.
- It is readily available.
- It provides families with a choice.

4.2 INFORMAL MILK SHARING

Individual decision-making regarding milk sharing is based on balancing the risks and the benefits as defined by each family, as well as how these stack up against the alternative, which is usually commercial infant formula.

Potential Risks of of Informal Milk Sharing

- Unreliability of informal screening of donors
- Difficulty in determining the donor's health and life style risks
- Impossibility of testing milk for contamination in the home environment to ensure it is safe for human consumption
- Unreliability of donor in-home heating methods is not reliable
- Possibility of dilution with water, cow's milk, or other substances
- Increased risk the greater the distance the milk must be transported
- Ethical, legal, financial, and other considerations

The level of risk of using unpasteurized donor human milk will vary depending on a number of known and unknown factors that could affect the safety of the milk.

Potential Reasons/Benefits of Informal Milk Sharing

- It provides an option when a mother or parent does not want to use human milk substitutes and is unable to provide her own milk or pasteurized donor milk is not available.
- Using UDHM avoids the possible negative effects of pasteurization. Holder pasteurization, while increasing the safety of the milk, unfortunately reduces the concentration and functionality of its bioactive components.[56,57]
- Informal milk sharing, especially cooperative nursing, may also be seen as a way to avoid the protein damage that can occur through the multiple freeze-thaw cycles associated with milk obtained via a formal milk bank.[58]
- It provides women who do not have the minimum volume of milk required by the milk banks the option of donating to a cause* and a means to connect with a supportive community network.

* BC Women's Provincial Milk Bank currently requires 4.2 L or more of donor milk to help offset the costs of screening.[59]

Inability to access PDHM occurs for a number of reasons (funding, logistics, and insufficient donors). Currently, PDHM is prioritized to the infants with the highest medical need, with limited access and availability for other infants. (The development of milk depots across British Columbia is recognized as a priority to increase the amount of available PDHM.)

4.3 INFANTS IN THE NICU

The benefits of human milk are particularly evident for preterm infants and include a reduction in the incidence of necrotizing enterocolitis, sepsis, retinopathy, and improved neurodevelopmental outcomes, among others.[60]

Mothers of preterm infants (or those with other medical health issues), are in particular need of skilled lactation support to enable them to provide their own milk for their own infants. In the absence of mother's own milk, PDHM is the preferred alternative. Formula should only be used when the above options are not available.

The possible risks associated with UDHM are amplified for medically fragile infants because of their increased risk for infections and other illnesses. The potential transmission of cytomegalovirus (CMV) via human milk to the preterm and vulnerable infant is of particular concern. Preterm infants are more vulnerable to CMV infection because of their immature immune systems. CMV is easily transmitted via human milk[61] and is highly prevalent — as many as 60–70% of women of reproductive age in Canada carry the virus.[62] Symptomatic disease may include neutropenia, thrombocytopenia, hepatitis, jaundice, and pneumonia, and more rarely, a severe sepsis-like syndrome. US research estimates that the rate of breast milk-acquired CMV infection among VLBW and premature infants is 6.5% in their population, with 1.4% of infants developing symptoms of severe sepsis.[63]

The Neonatal Program Nutrition Committee of BC Women's Hospital recommends against the use of UDHM in all babies, particularly in premature and ill babies in the NICU.[64]

Help decrease the need for the use of donor human milk by supporting mothers to get breastfeeding off to a good start. Become a Baby-Friendly Hospital or Community Health Facility. Ensure families get adequate support throughout the continuum of care.

5.0 MINIMIZING THE RISKS OF INFORMAL MILK SHARING

Health Canada recommends that Canadians consult their health care provider if they are considering obtaining human milk from an alternative source in order to determine if it is the best and safest option for their infant.[19]

There is no reliable evidence that following harm-reduction strategies eliminates all or any of the risks of unpasteurized donor human milk.

Information for HCP to Review in Harm Reduction Discussion

- The level of risk may be influenced on how well the recipient family knows the donor and their level of trust in the accuracy of the information provided, including the donor's lifestyle choices, travel history, and health history as well as their adherence to safety guidelines on milk handling, storage, and transport. If the donor and recipient are close relatives/friends, this may reduce the risk (though this is not a guarantee).
- Maintain ongoing contact with the donor, preferably meeting both her and her baby in person. Milk sharing with strangers (internet or otherwise) presents greater risks, as it is impossible to adequately assess risk, based on little or no contact.
- When human milk is sold for profit by individuals, the risk of intentional adulteration (e.g., with cow's milk) to increase profit exists.
- Limiting the number of donors may reduce the infant's exposure to possible infections and unsafe substances.
- Donor blood test results must be current and accurately interpreted by a HCP with current knowledge in milk-donor screening.[65]
- Home testing kits to examine the whether breast milk contain alcohol, prescription drug, or other substances are not reliable screening tools.

The patient information handout on the use of UDHM, **Informal (Peer-to-Peer) Human Milk Sharing** (Appendix 5) is available to assist the HCP in a discussion with parents who have decided to feed their baby UDHM, helping to address any gaps in their understanding of the risks and harm reduction strategies.

Purchasing milk from strangers is high-risk and not recommended.

Health and Lifestyle Questions to Ask a Potential Donor

Families should ask their potential donor questions about their health and lifestyle that may help the recipient family decide whether they wish to accept milk. Visit the BC Women's Provincial Milk Bank website at www.bcwomens.ca and search milk bank for the types of questions asked during their detailed donor screening process.

BC Women's Provincial Milk Bank is not able to counsel recipients or donors on screening of donors, or test or process milk for peer to peer milk sharing.

Screening questions and serology tests are a component of the process HMBANA milk banks use for donor screening. It is important to recognize that HMBANA donors and donor milk undergo additional screening steps:

- Skilled, trained personnel conduct the screening, interpret the results, and follow-up as needed.
- Medical approval by the donor's physician is required.
- The milk is tested following pasteurization to ensure safety.

NOTE: Regulated milk banks revise and update their tests and testing criteria on an ongoing basis.[66]

Safe Storage, Handling, and Transport

Human milk can be contaminated with bacteria due to improper handling of the milk or pumping and storage supplies.

Parents should be educated about proper hand hygiene and handling techniques and should follow the guidelines for safe storage and transport. HMBANA has published guidelines on the safe storage and handling of donor human milk.[67] Refer to *HealthLinkBC: Storing Breast Milk*.[68]

It can be difficult to determine if donor milk has been safely handled and stored, but the presence of foreign material in the milk or evidence of thawing/refreezing are indicators of the need to discard. It is important to ask the donor:

- Where the milk was stored?
- What temperature was the milk stored in, for how long and were there any power failures at any time during the period of storage?

Determining these details will help to identify factors that may have adversely affected the milk.

Flash Heating

If families choose to flash heat, information on the limitations of the procedure for heat treating milk in the home needs to be discussed.

Flash heating was developed for use in resource-poor countries by mothers with HIV to treat their own milk for their own babies when a safer alternative is not available. There has been no research indicating that flash heating is appropriate for use with donor milk in informal milk sharing situations in North America.[69] Due to the lack of a regulated process (including standardized equipment and environment), overheating or under heating is a possibility; either can impact the safety and quality of the milk.

Families should be informed that there is no evidence to support the safety of in-home flash heating of donor human milk in North America (refer to definition of flash heating for more detail) and that both over and under heating can be problematic.

A procedure developed for resource poor countries is available on milk sharing websites (e.g., Eats on Feets www.eatsonfeets.org).

Refer to your institution's policy on the use of Unpasteurized Donor Human Milk (UDHM).

6.0 DECISION SUPPORT TOOLS (DST)

In order to make an informed decision regarding infant feeding, parents must be aware of all the options. Health care providers need knowledge, skill, and support around delivering risk and benefit messages regarding all infant feeding options.[70] The following decision tools and HCP and parent information resources have been developed to support this process.

For the HCP

1. ***Infant Feeding Options DST*** (Appendix 1): This summarizes risks and benefits of all supplementation options with links to matching resources.
2. ***Supplementation with UDHM – Talking Points*** (Appendix 2): The talking points gives an example of the type of conversation a HCP might have with parents who have indicated a desire to use UDHM as the method of supplementation for their infant.
3. ***Sample Policy on the Use of UDHM*** (Appendix 3): This is a sample facility policy on the use of UDHM.
4. ***Sample Acknowledgement of Risk Form for the Use of UDHM in Health Care Settings*** (Appendix 4): PHSA Risk Management and HCPP were consulted on the development of the Acknowledgement of Risk Form for the use of UDHM. Individual organizations must still go through the vetting process (including legal review) to ensure it meets their own organizational requirements before using.

For the Parents

1. ***Family Information Handout: Informal (Peer-to-Peer) Human Milk Sharing*** (Appendix 5): This handout for parents summarizes the risks and potential benefits of the use of UDHM and harm reduction strategies, including donor screening, flash heating, and the safe collection, storage, and handling of human milk. Parents should be encouraged to take some time to consider their options, learn more, and ask questions before they decide.

7.0 FUTURE CONSIDERATIONS: A Need for Further Research and Guidance

This document offers tools to guide the health care provider in a shared decision-making process with families who are considering providing informally shared milk to their infants. While this practice is not a new phenomenon, anecdotal evidence suggests it is increasing.

The lack of lactation support in some health care facilities and in communities needs to be addressed to enable more mothers to succeed in breastfeeding their own children.

There is a need for further research to understand the prevalence of informal milk sharing, and to elucidate the potential risks and benefits of using unpasteurized donor human milk in its various contexts (e.g., the vulnerable preterm infant versus the healthy term infant), the appropriateness of techniques to mitigate risk (e.g., flash heating and milk testing), and the impact of informal milk sharing on the psychosocial well-being of both the donor and recipient. Finally, continued efforts to make pasteurized donor human milk via HMBANA milk banks freely available to all infants in need will mean that parents will have the preferred recommended alternative to a mother's own milk available to them.

Help decrease the need for the use of informally shared milk by supporting BC Women's Provincial Milk Bank: www.bcwomens.ca (search milk bank) and encourage women to donate their milk.

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APPENDIX 1: Infant Feeding Options DST

Expressed Milk from Infant's Mother Is Always the First Choice

- **Biological norm;** protects baby against short and long term health risks, including GI, respiratory infection, otitis media, SIDS, obesity; supports cognitive development; lactation protects mothers against maternal type 2 diabetes, certain breast and ovarian cancers; a mother's own milk is affordable and environmentally friendly
- **Risk free** (unless breastfeeding is contraindicated for a particular mother)

Determining the preferred option for supplementation involves a process of informed decision-making on the part of the parents, in consultation with their infant's primary health care provider (HCP). The HCP role is to ensure the parents have the best information available to make this decision. The parents' assessment of the relative risk and benefits for each choice, in the context of their personal values and preferences, is fundamental to the principles of shared decision-making.

Whenever supplementation is considered, a comprehensive breastfeeding assessment of the mother-infant dyad should be performed, and a support plan developed to optimize successful exclusive breastfeeding (should that be the mother's goal).

Based on the limited research available, **suggested intakes (per feeding) for *term healthy infants*** are as follows; feeding should be by infant cue to satiation (ABM, 2009):

1st 24 hours	2-10 ml (per feeding)
24-48 hours	5-15 ml
48-72 hours	15-30 ml
72-96 hours	30-60 ml
> 96 hours	by cue to satiation

All types of supplementation require attention to safe collection, preparation, storage, and administration to maintain quality and minimize the risks associated with contamination.

Medical Indications for Supplementation
and/or
Informed Decision by Parent/Caregiver to Supplement
If milk from an infant's mother is not available

Donor Human Milk from Human Milk Bank Is the Next Best and Next Safest Choice

- **Importance of human milk;** rigorous donor screening, Holder pasteurization and milk handling prevents transmission of pathogens and other substances (e.g., medications)
- **Limited availability;** pasteurization affects some components of human milk

Premature and medically vulnerable infants will normally be given priority for pasteurized donor human milk if supplies are limited.

When neither human milk from an infant's mother nor pasteurized donor human milk from a human milk bank is available, Health Canada recommends a human milk substitute (commercial infant formula).

Human Milk Substitute
(Commercial Infant Formula)

- **Readily available; accepted; considered safe**
- **Not biological norm;** not human milk; inferior composition; risk of contamination of product or during preparation
- **Increased short and long term health risks** including GI, respiratory infection, otitis media, SIDS, obesity; reduced cognitive development; expensive; not environmentally friendly; potential for contamination

Whenever interruption or cessation of breastfeeding is considered, the importance of breastfeeding should be weighed against the risks posed by the use of human milk substitutes and the need to intervene because of the presenting medical condition. Refer to Perinatal Services BC Guideline: Breastfeeding Healthy Term Infants and World Health Organization and UNICEF Acceptable medical reasons for use of breast-milk substitutes.

Health Canada and the Canadian Paediatric Society **do not endorse** the use of unpasteurized donor human milk; yet, parents may consider choosing unpasteurized donor human milk.

Unpasteurized Donor Human Milk
(Informal Milk Sharing)

- **Importance of human milk; readily available in comparison to milk processed by human milk banks**
- **Not recommended by Health Canada or the Canadian Paediatric Society**
- **Screening of donors/donated milk is not standardized/reliable;** no controls on handling processes; potential risk for transmission of pathogens and other substances (e.g., nicotine, alcohol, herbal supplements, medications, street drugs)

Resources

For the Health Care Provider

- Academy of Breastfeeding Medicine, Clinical Protocol #3: Hospital Guidelines for the Use of Supplementary Feedings in the Healthy Term Breastfed Neonate, Revised 2009 **www.bfmed.org**
- Infant Formulas for Healthy Term Infants Compendium Alberta Health Services (2014) **www.albertahealthservices.ca**
- Informal Milk Sharing: A practice resource for Health Care Providers: **www.perinatalservicesbc.ca**
  - Supplementation Script for the HCP
  - Donor Human Milk: Informal Milk Sharing Policy
  - Acknowledgement of Risk Form
- Perinatal Services BC Guidelines **www.perinatalservicesbc.ca**
  - Breastfeeding the Healthy Term Infant (2012)
  - Breastfeeding the Healthy Preterm Infant (2001)
  - Breastfeeding Multiples (2007)

For Parents

- Baby's Best Chance: **www.health.gov.bc.ca/library/publications/year/2015/babys-best-chance-2015.pdf**
- BC Women's Provincial Milk Bank Information: **www.bcwomens.ca** search milk bank
- PHAC *10 Great Reasons to Breastfeed Your Baby* and *10 Valuable Tips for Successful Breastfeeding:* **www.phac-aspc.gc.ca/hp-ps/dca-dea/stages-etapes/childhood-enfance_0-2/nutrition/reasons-raisons-eng.php**
- Healthy Families BC: Breastfeeding, Hand Expression and Pumping articles and videos: **www.healthyfamiliesbc.ca**
- Healthy Families BC: How to Choose, Prepare and Store Infant Formula: **www.healthyfamiliesbc.ca/home/articles/how-choose-prepare-and-store-infant-formula**
- Informal (Peer-to-Peer) Human Milk Sharing Information Handout (found in *Informal Milk Sharing: The Use of Unpasturized Donor Human Milk. A Practice Resource for Health Care Providers*): **www.perinatalservicesbc.ca**

APPENDIX 2: Supplementation with UDHM – Talking Points

This is an example of the type of conversation a health care provider (physician, midwife, nurse) might have when a mother's milk is not available or insufficient, and parents are considering what to feed their infant. The shared decision-making process involves an unbiased conversation with parents regarding the risks and benefits of a particular choice, supported by supplementary information tools (e.g., handouts) to facilitate an informed decision. Parents may wish (and in fact, if time permits, should be encouraged) to take some time to consider their options, learn more, and ask questions before they decide.

Checklist for Discussion

☐ First choice mother's own milk – ways to optimize milk production

Recommended options if alternative feeding or supplementation necessary:

- ☐ Pasteurized donor human milk from a milk bank – risks/benefits
- ☐ Human milk substitute (commercial infant formula) – risks/benefits

If pasteurized donor human milk is not available and parents may be considering using unpasteurized donor human milk:

- ☐ Informal milk sharing – not recommended – risks/benefits

- *I sense you may be considering other options for feeding your baby?*
- *Would you like to talk more about those options, so you have the information you need to make the best decision for you and your baby?*
- *The next best option (after your own milk) is pasteurized donor human milk from a regulated milk bank. It gives your baby most of the benefits of human milk, and it is very safe. Because there is a limited supply of PDHM, it can be difficult to get except for very sick babies, but we can find out what's available now if that's something you're interested in. Do you have any questions about this option?*
- *Commercially produced formula is the next recommended option. While it isn't human milk, it is very available, and is generally considered a safe choice when properly prepared and handled.*

When a parent does make a fully informed choice to use formula, provide individual counselling on the safe use, preparation, and handling of formula, as well as the importance of recognizing and following feeding cues, pacing feeds so baby doesn't take more than needed, and eye contact/holding baby close during feedings.

- *Do you have any questions about anything we've talked about so far?*

If the parent asks about informal milk sharing, ***or*** you determine that they may be considering this based on their individual circumstances, explore further.

- *What have you heard about informal milk sharing?*
- *Breastfeeding and human milk are very important to the health of babies, so I understand why you might consider informal milk sharing. Is it okay if we talk about the risks and ways to make informal milk sharing safer?*

- *It is very important that anyone who is giving you milk for your baby is screened for things such as HIV and hepatitis. Donors should also avoid nicotine, alcohol, herbal supplements, some medications, and street drugs. Even when you know someone very well, it's not always possible to know everything about their health and use of substances. If you don't know the donor at all or if they are very far away, it's even less likely that you will have the information you need to make safe choices for your baby.*
- *Donors also need to know how to express, store and transport milk safely so that it doesn't become contaminated before it gets to your baby.*
- *No one can tell you how risky milk sharing is because there are so many unknown factors. Every family has to decide for themselves the balance of risk and benefits for their particular situation.*
- *If you think you will be feeding informally shared milk to your baby, I advise you to explore how to do it safely. Consider testing, expressing, storage, and transportation.*
- *How do you feel about the options we've discussed? Is there anything else you'd like to know about…?*

(Refer to Appendix 1 for Parent Resources.)

APPENDIX 3: Sample Policy on the Use of UDHM in Health Care Settings

1.0 PURPOSE

Mother's own milk for her own child is the biologic norm and the optimum infant nutrition under almost all circumstances. In situations where mothers are unable to produce sufficient milk to meet a baby's needs and/or where there are well-defined medical indications for supplementation,[1] pasteurized donor human milk (PDHM) from a regulated milk bank is the recommended substitute for a mother's own milk. If PDHM is unavailable, a human milk substitute (commercial infant formula) is the next recommended alternative.[2]

Some parents may consider giving their infant informally obtained unpasteurized donor human milk (UDHM) as an alternative to human milk substitutes. The use of UDHM is sometimes referred to as 'informal' or 'peer-to-peer milk sharing'. Health Canada and the Canadian Paediatric Society do not endorse the use of UDHM.[3]

Health care providers (HCP) should not promote informal milk sharing. HCP should help parents to make an informed decision, therefore must be able to discuss with the parents evidence-based information on the risks and benefits of all infant-feeding alternatives.[4] The right of parents to make informed decisions regarding the care of their children is respected within the context of Canadian law.[5]

2.0 DEFINITIONS

Health Care Provider (HCP): A person who is licensed, certified, or registered to provide health care in BC under the *Health Professions Act*. In the context of this document, the term refers to nurses, midwives, physicians, dietitians, lactation consultants, and other allied health care professionals working with childbearing families.

Human Milk Banking Association of North America (HMBANA): HMBANA is a professional association for supporters of not-for-profit donor human milk banking. It promotes the health of babies and mothers through the provision of safe pasteurized donor milk and support of breastfeeding.

Shared Decision-Making: A shared decision-making approach enables patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as patient values and preferences.[6] Shared decision-making honors the provider's expert knowledge, the parent's right to be fully informed, and ultimately their right to make a decision that they feel is in the best interests of their child.

Most Responsible Provider (MRP): The physician or midwife currently responsible for an infant's care.

Pasteurized Donor Human Milk (PDHM): Donor human milk from a regulated milk bank that has undergone pasteurization and has met the standards of screening, processing, handling, testing, and shipping set out by the Human Milk Banking Association of North America.

Perinatal Services BC (PSBC): Perinatal Services BC is an agency of the Provincial Health Services Authority and provides leadership, support, and coordination for the strategic planning of perinatal services in British Columbia. PSBC collaborates with the Ministry of Health, health authorities, and other key stakeholders and is central source in the province for evidence-based perinatal information.

Unpasteurized Donor Human Milk (UDHM): Raw human milk that has not undergone pasteurization in a regulated milk bank and has been donated by a family member, friend, or stranger. The use of unpasteurized donor human milk is commonly referred to as 'informal' or 'peer-to-peer' milk sharing.

3.0 POLICY

3.1 HCPs will not actively promote the use of UDHM.

3.2 The HCP must be able to discuss with the parents evidence-based information on the risks and benefits of all infant-feeding alternatives, including the use of UDHM.

3.3 If parents decide to provide UDHM to their infant, the counseling and informed decision will be documented in the infant's health record. In hospital, it is recommended that an Acknowledgement of Risk Form also be signed by the parent and MRP.

3.4 UDHM will be handled and administered according to facility policy on expressed human milk.

4.0 PROCEDURE

4.1 When supplementation of an infant is medically indicated, the HCP should review the following options with the parents, including risks and benefits of each:

1. Mother's own expressed milk
2. Pasteurized donor human milk
3. Human milk substitute (commercial infant formula)

4.2 If the use of informally obtained UDHM is raised by the parent/s as a possible option, or the HCP determines that this is an option the parent/s may be considering, a shared decision-making discussion should take place.

4.3 Refer to the PSBC document *The Use of Unpasteurized Donor Human Milk: A Practice Resource for Health Care Providers*[7] (www.perinatalservicesbc.ca) for background and support tools including:

- Infant Feeding Options DST
- Supplementation with UDHM – Talking Points for the Health Care Provider
- Family Information Handout: Informal (Peer-to-Peer) Human Milk Sharing

4.4 The HCP documents counseling and the parent's informed decision to use UDHM in the infant's health record. In hospital, an Acknowledgement of Risk form should be signed by the parent or guardian and the MRP. (Refer to health authority or facility specific documentation policy. Either an Acknowledgement of Risk form should be completed [see PSBC sample form] or careful documentation in the narrative notes including risk/benefit discussion on all supplementation options, parents'/caregivers' informed decision, and their acknowledgement of risk regarding the use of UDHM).

4.5 The procedure for preparation, handling, and administration of UDHM is the same as for mother's own expressed milk or PDHM. Follow facility specific policies for preparation, handling, and administration of expressed human milk.

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APPENDIX 4: Sample Acknowledgement of Risk Form for the Use of Unpasteurized Donor Human Milk Not Issued by a Regulated Provincial Milk Bank

I UNDERSTAND and ACCEPT the following:

I, _____ (parent or guardian) have been advised by _____ (health care provider) that: _____ (name of facility/agency/or health care provider) does not recommend the use of donor human milk from any source other than a provincial accredited milk bank.

Health Canada and the Canadian Paediatric Society do not endorse the informal sharing of unpasteurized donor human milk due to the risks involved.

The risk of giving unpasteurized donor human milk to your baby includes the transmission of infectious diseases which may be present in human milk and can be passed to your infant. The donor mother may not be aware that she has infections which include but are not limited to:

- Human immunodeficiency virus (HIV)
- Human T-cell lymphotropic virus
- Hepatitis B and C
- Cytomegalovirus
- Human papillomavirus
- Tuberculosis
- Group B Strep
- Staphylococcus

Nicotine, alcohol, some medications (both prescription and over the counter), herbal supplements and street drugs that can be potentially dangerous to the baby can pass into the donor mother's blood and then into her milk.

If human milk is not handled properly, it can be contaminated with pathogens during collection, storage, transport and/or processing.

The above information was provided to me and I have had my questions answered to my satisfaction. However, I view unpasteurized donor human milk as an acceptable alternative to the baby's own mother's milk and preferable to formula. In spite of the risks outlined and with the approval of my spouse/partner (if applicable), I have made the decision that my baby be fed with unpasteurized human milk provided by myself.

I hereby agree to release _____ (name of facility/agency) and its employees, physicians, agents, successors and assigns from all claims, actions, causes of action, demands or proceedings ("Claims") that may result from or be related to the provision of unpasteurized donor human milk to my baby. I agree that I will not pursue any such Claims in relation to the provision of this material and I hereby agree to indemnify _____ (name of facility/agency) and its employees, physicians, agents, successors and assigns from all costs associated with any such Claims.

I will abide by _____ (facility/agency name) policies and procedures for the labeling, storage, transportation and handling of all human milk.

Print name	Signature of parent/legal guardian	Date (yyyy/mm/dd)
Print name	Signature of health care provider	Date (yyyy/mm/dd)

☐ Family information handout on Informal Milk Sharing provided ☐ File in baby's chart

APPENDIX 5: Family Information Handout: Informal (Peer-to-Peer) Human Milk Sharing

Your own milk is the best way to feed your baby. When your milk is not available, for whatever reason, pasteurized donor human milk from an official milk bank is the next best choice.

What is Pasteurized Donor Human Milk?

Human milk donated to an official milk bank. The milk is treated to kill any harmful bacteria or viruses. Donors are screened and the milk is tested before and after being treated to ensure safety

Due to a limited supply, milk from an official milk bank is usually only available for premature, ill, or high-risk infants. When milk from an official milk bank is not available, the recommended choice is infant formula.

What is Informal (Peer-to-Peer) Milk Sharing?

Some parents feel the benefits of breast milk outweigh the potential risks of formula. Informal milk sharing (sometimes called peer-to-peer milk sharing) is human milk that is:

- obtained from family members, friends, a milk-sharing website, or purchased online;
- usually is not treated to kill any harmful bacteria or viruses.

If you are thinking about giving your baby milk from an informal donor, talk with your health care provider first to discuss the risks and benefits of all feeding options.

Risks of Informal Milk Sharing

- It's difficult to know for sure that a donor's health and life style is safe for milk sharing.
- Viruses such as HIV, Hepatitis B and C, CMV, and human T-cell lymphotropic virus could be passed to your baby (the donor mother may not know that she has these).
- If human milk is not collected and stored properly, bacterial growth could make your baby sick.
- Smoking, alcohol, some medications (both prescription and over the counter), herbal supplements, and street drugs can all pass into human milk.
- Milk purchased online may be diluted with water or cow's milk, or something else may be added.

Health Canada, the Canadian Paediatric Society, and the Human Milk Banking Association of North America do not endorse the use of unpasteurized donor human milk.

Minimizing the Risks

- Know the donor's health and lifestyle; know who shouldn't donate milk.
- Know the donor's blood test results—donor blood tests should be recent and reviewed by a health care provider.
- Visit the BC Women's Provincial Milk Bank website for an understanding of their detailed donor screening process. BC Women's staff cannot provide counseling on milk sharing and cannot test milk.

- If the donor is a close family member or friend, this may reduce the risk (but not necessarily). Some mothers find it difficult to ask lifestyle questions of family members/ friends.
- Limit the number of donors.
- Have ongoing contact with the donor; face to face is best.
- Do not purchase milk online.
- Work with the donor to ensure the milk is handled, stored, and transported safely as possible.
- Be aware that in-home heat treatment, also known as flash heating, has not been studied or proven effective in informal milk- sharing situations.

For More Information

- BC Women's Provincial Milk Bank: www.bcwomens.ca search milk bank
- Health Canada – Safety of Donor Human Milk in Canada: www.hc-sc.gc.ca/index-eng.php
- Healthy Families BC – Safe Handling, Storage, and Transport of Human Milk and other breastfeeding topics: www.healthyfamiliesbc.ca

For more HealthLinkBC File topics, visit www.HealthLinkBC.ca/healthfiles or your local public health unit.

Click on www.HealthLinkBC.ca or call 8-1-1 for non-emergency health info.

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Perinatal Services BC (PSBC) would like to acknowledge the working group who created this practice resource for health care providers.

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We would also like to thank external reviewers Janet Murphy-Goodridge, Provincial Breastfeeding Consultant, Perinatal Program, NL, and Gillian Hanley, Health Researcher, Department of Obstetrics & Gynecology, Vancouver General Hospital. Consultation during development included representatives from nursing, midwifery, medicine, neonatology, trans gender community, BC Women's Milk Bank, BC Baby-Friendly Network, BC Women's Ethicist and PHSA Risk Management.

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