

## Understanding the Characteristics of Human Milk Sharing in Daerah Istimewa Yogyakarta: A Descriptive Quantitative Study

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### Abstrak

Donor ASI merupakan salah satu alternatif yang dapat dipertimbangkan sebagai asupan pengganti jika produksi ASI tidak mencukupi kebutuhan bayi. Namun demikian, donor ASI tanpa pasteurisasi oleh sesama ibu menyusui tidak direkomendasikan terkait alasan keamanan. Disisi lain, jumlah praktik donor ASI di Indonesia terus meningkat dan memungkinkan penularan penyakit melalui ASI jika dilakukan secara informal. Lebih lanjut, dengan terbatasnya data tentang karakteristik praktik donor ASI di Daerah Istimewa Yogyakarta (DIY), peneliti melakukan studi *cross-sectional* dengan sistem *online* ini untuk memberikan gambaran tentang karakteristik praktik donor asi di DIY meliputi pengetahuan dan praktik donor asi oleh ibu, proporsi ibu yang menyumbangkan dan menerima ASI donor, alasan, dan status menyusui. Dari 153 responden, 9,1% hanya menerima ASI donor, 19,6% mendonorkan ASI, dan 5,2% mendonasikan dan menerima ASI donor. Sebesar 43,1% ibu memiliki pengetahuan yang rendah, dan hanya 13,1% dari mereka mengetahui bahwa donor ASI tidak direkomendasikan dilakukan secara informal. Sebagian besar ibu mencari donor karena merasa ASI tidak mencukupi. Dengan banyaknya jumlah ibu yang melakukan praktik donor ASI, level pengetahuan mereka, dan jumlah praktik proses donor asi secara tidak tepat menggarisbawahi pentingnya dukungan menyusui, edukasi, dan regulasi donor asi untuk meminimalisir resiko kesehatan pada proses donor ASI secara informal.

**Kata Kunci:** Donor ASI, Menyusui Eksklusif, Penularan Penyakit, Pemberian Makan Anak, Kesehatan dan Gizi Anak

### Abstract

*Human milk donors (HMD) is one of the alternatives foods for the baby if the mother's breastmilk production is insufficient. However, unpasteurized and peer donor milk sharing is not recommended way due to safety concerns. On the other hand, the rate of HMD in Indonesia increased significantly and might be followed by its disease transmission risk by informal milk sharing. This cross-sectional study aimed to figure the HMD characteristics in Daerah Istimewa Yogyakarta (DIY), including the mother's knowledge and practices, the proportion of mothers who give and receive HMD, the reason, and their breastfeeding status. Among 153 participants, 9.1 % only received donor milk, 19.6% of them donated their breast milk (BM), and 5.2% did both receiving and donating BM. However, 43.1% of them have a lack of knowledge, and only 13.1% knows that they should not ask for HMD through informal way. Most of the mothers seek HMD because of the feeling of insufficient BM production. Concerning the rate of mothers who donated or received HMD, their level of knowledge, and the number*

*of inappropriate human milk sharing, we underline the importance of breastfeeding support, education, and regulation of HMD to minimize the health risk of inappropriate human milk sharing.*

**Keywords:** Human Milk Donor, Exclusive Breastfeeding, Disease Transmission, Child Feeding, Child Health and Nutrition

## Introduction

Human milk donors is one of the alternatives foods that could be considered for the baby if the baby mother's milk production is insufficient. However, the safety issue during its collecting, storage, and distribution process still need to be underlined. The donation process should be delivered through a tight screening procedure in a human milk bank to minimize the health risk. Also, donating human milk should be accompanied by a lactation counseling process. Conversely, human milk donor through the internet or direct sharing is not recommended and did not meet the standard safety criteria based on a risk of contamination of both bacterias, viruses, or drugs (American Academics of Pediatrics, 2017).

Healthcare providers have used HMD since 1900s in United States (American Academics of Pediatrics, 2017) and followed by several countries in the world (Ergin & Uzun, 2018) including Indonesia (Septyani & Umijati, 2018). In 2009, the Indonesian government enacted a law that stated that each baby should be breastfed or given a human milk donor through a human milk bank exclusively for six first months of the baby's life, exceptionally if there is another medical reason for not to do so (World Health Organization, 2014). If the health professional stated that the baby needs additional feeding beside the mother's breast milk, the mother could decide to give donor-human milk for their baby (Direktorat Gizi Kementerian Kesehatan RI, 2012). In this decision-making process, the health professional should provide several options besides milk donor sequally and truthfully. It is including the potential cost, the advantages, and disadvantages of each option. This process is called an informed decision-making process (Septyani & Umijati, 2018; Trilium Health Partners, 2013).

Previous data showed that the human milk donor utilization increased each year. In Indonesia, the demand for donor milk rose by 3-5 times throughout five years (2007-2012). This condition may have been due to the development of technology that allows the recipient candidates to seek milk donors available through the internet by themselves. However, as mentioned before, finding donors through the internet has a potential health risk because of its lack of regulation and improper health assessment (Septyani & Umijati, 2018).

Moreover, research and data provided about human milk donors in Indonesia and DIY are still limited. There were insufficient findings of the human milk sharing characteristics, including mother's knowledge, donor-recipients proportion in society, the reasons, and donor milk-recipient practices in seeking and handling the donated milk. These points highlighted the importance of this research to provide an overview of the human milk sharing characteristics that might be important as considerations for further human milk donor regulation and policy.

## Methods

The research was a cross-sectional, observational study conducted in Daerah Istimewa Yogyakarta (DIY), Indonesia. The participants were recruited using purposive sampling and followed by a snowball sampling technique. An online structured questionnaire was developed by using Google forms, with a consent appended to it. We posted the research announcement and the questionnaire link on several social media such as WhatsApp groups, Facebook, and Instagram. The participants were encouraged to roll out the survey to as many people as possible. The questions consist of the mother's knowledge of human milk sharing, donor-recipients status, the reason for giving human milk donor for the baby, and donor milk-recipient practices in seeking and handling the donated milk.

The study was approved by the Research Ethics Committee, Universitas Ahmad Dahlan (Approval Number 012101006). Only participants who have internet access could participate in the study. The inclusion criteria were: mothers of children aged 0-6 months and who lived in DIY. The data collection was started in December 2020 and closed on March 2021. The instruments have passed the standard as valid ( $r\text{-count} > 0.159$ ) and reliable instruments ( $\alpha\text{-Cronbach} > 0.6$ ). Data were analyzed using descriptive and frequency analysis.

## Results and Discussion

### *Socio-demographic Characteristics of Study Participants*

The participants of the study were 153. Table 1 explained the socio-demographic characteristics of study participants. Most of the participants were aged 19 to 40 years old and live in Sleman. The majority of the mothers graduated with a diploma or undergraduate degree. Moreover, their main occupation was as a housewife, and more than half of the participants had a child aged 3-6 months.

**Table 1. Socio-demographic characteristics of study participants**

No.	Variables	Frequency n= 153	Percentage
1	Mother's age		
	< 19 years	1	0.7 %
	19-40years	149	97.3 %
	>40 years	3	2.0 %
2	Mother's education		
	Elementary-Junior High School	4	2.6 %
	Senior High School	32	20.9 %
	Diploma & Bachelor	98	64.1 %
	Postgraduate	19	12.4 %
3	Mother's occupation		
	Housewife	90	58.8 %
	Civil servants/ Private Employee	37	24.2 %
	Private employee with shift	13	8.5 %
	Farmer/ Entrepreneur	12	7.8 %
	Freelance	1	0.7 %
4	Child's age		
	0-1 month	18	11.8 %
	1-3 months	49	32.0 %
	3-6 months	86	56.2 %
5	Residential area		
	Yogyakarta	40	26.1 %
	Sleman	57	37.3 %
	Bantul	47	30.7 %
	Kulon Progo	6	3.9 %
	Gunung Kidul	3	2.0%

### *Mother's Knowledge of Human Milk Sharing*

Table 2 shows that almost 60% of participants had good knowledge of human milk sharing, while the other participants had a lack knowledge of it. Further, only 13.1% had the true answer to this question: "If there is no human milk donor available from a human milk bank, it is permitted to search milk donor from the social media". The response of the question is shown in Table 3.

**Table 2. Mother's knowledge of human milk sharing**

Mother's knowledge	Frequency	Percentage
Lack	66	43.1 %
Good	87	56.9 %

**Table 3. Mother's knowledge of human milk sharing: the 5 lowest percentage of true responses**

Questions	Frequency	Percentage
If there is no human milk donor available from human milk bank, it is permitted to search milk donor from the social media	20	13.1 %
For baby whose the mother have passed away, human milk donor shall be given for long term use	22	14.4 %
Mother who once in a while consuming few amounts of alcohol, could donate their milk.	29	19.0 %
If there is no potential donor who has the same age baby with our baby, it is better to give formula milk rather than giving breast milk from mother with older baby (max 6 mo)	55	35.9 %
Mother who was received organ donor in past 12 months could not be a breast milk donor	71	46.4 %

**Donor-Recipients Status**

Donor and recipient status is shown in Table 4. Among 153 respondents, 57 respondents reported participating in peer breast milk sharing. The data consisted of 30 (19.6%) mothers as milk donors only, the other 14 (9.1%) persons as breast milk recipients only. Besides, 8 respondents (5.2%) stated as being both donors and recipients. However, 5 breast milk recipients (3.3%) didn't give a response about their donor status.

**Table 4. Human milk sharing status**

Human milk sharing status	Donor	Non-donor	Not confirmed (*)
Recipient	9 (5.2%)	14 (9.1%)	5 (3.3%)
Non-Recipient	30 (19.6%)	77 (50.3%)	18 (11.8%)

(\*) Participant's donor status could not be confirmed due to loss-contact

**Variables Related to Human Milk Donor Practices**

Various variables related to human milk donor practices were presented in Table 5. Twenty-seven participants stated that they receive human milk donors, and only 25 participants were willing to fulfill the follow-up questionnaire about human milk sharing practices. Further, most of the recipients seek human milk donors because of insufficient breast milk supply (44%). The second reason was the breast milk wasn't yet available on the baby's first day of life (24%). Majority of recipients most commonly reported receiving breast milk donors when their child's age was under a month old (72%), although several reported receiving breast milk donors in a period at the child's age between 1 to 6 months old. Among recipients, 76% reported receiving milk from their close friends or family, 8% from a stranger in social media, 4% provided by the hospital, and 12% receiving donors from several sources. None of them seek milk donor from a milk bank. Moreover, only 13 recipients (52%) reported doing appropriate donor milk sharing practice, while 12 recipients (48%) doing it inappropriately.

Table 6 shows the breast milk sharing practices among participants who gave breast milk donors to their babies. Only seven recipients (28%) sought donors from close family/friends whose health history is known before baby birth. Only a few of the participants asked the potential donors about their health history. Only 8 recipients (32%) asked about the organ transplantation status of their donors, only 11 recipients (44%) asked about the medical history of donors, and only 13 recipients (52%) asked about the drug consumption history of donors. Moreover, only 11 recipients (44%) had practical help from

lactation counselors to be able to do breastfeeding and only 13 recipients (52%) have been using other media than bottle-feeding (or pacifier) feeding to give their babies breast milk donors.

**Table 5. Characteristics of human milk donor recipient**

Variables	Frequency	Percentage
Mother's Reasons		
The feeling of their breast milk was not yet available	6	24.0 %
The feeling of insufficient breast milk	11	44.0 %
Working mom	4	16.0 %
Mother's health issue	2	8.0 %
Prematurity	1	4.0 %
Others	1	4.0 %
Child's age while receiving donor milk		
< 1 month	18	72.0 %
Between 1-6 months	6	24.0 %
Several months	1	4.0 %
Mother's Practices (*)		
Lack	12	48.0 %
Good	13	52.0 %
Donor sources		
Close friends/family	19	76.0 %
Social media	2	8.0 %
Hospital	1	4.0 %
Milk banks	0	0.0 %
More than 1 source	3	12.0 %

**Table 6. Mother's human milk sharing practices: the 5 lowest percentage of appropriate practice**

Questions	Frequency	Percentage
Mother looking for donors before baby birth from a close family/ friend who their health history is known	7	28 %
Mother asked donors candidate if she did an organ transplantation 12 months before	8	32 %
Mothers received a donor-milk by asking for donor's medical check-up results or other medical history	11	44 %
Mothers received a donor-milk with a lactation counselor accompaniment to be able to do direct breastfeeding	11	44 %
Mothers asked donor candidate for their drugs consumption history	13	52 %
Mothers giving a donor-milk using other media than pacifier or bottle feeding	13	52 %

### Discussion

Breast milk has known as the best food for babies. If the mother could not fulfill the baby's needs after being provided with lactation support, a pasteurized human milk donor indicated as a first alternative way to fill the gap (Tran et al., 2020). However, some mother seek a donor without a proper understanding and consideration of the requirements and its health risks (Direktorat Gizi Kementerian Kesehatan RI, 2012; Septyani & Umijati, 2018). This research result found that more than 40% of study participants have little knowledge about the human milk requirements and risks.

Moreover, only 1 of 10 mothers know that we should not seek donor milk through social media or the internet (informal milk sharing). This type of milk sharing commonly based on altruistic non-profit sharing of expressed breast milk between family, friends, or online social networks. These options come with varying levels of risks that increased with an unknown donor and lack of medical and lifestyle history. The report of the health test result of 1090 potential donors to a milk bank in California, that 3.3% of them had positive results on serological screening for either syphilis, hepatitis B, hepatitis C, HLTV, or



HIV(Perinatal Services BC, 2016). This explanation underlined the potential disease transmission that might be not detected through an informal milk sharing.

On the other hand, only 14.4% understand that donor milk is not for long-term use. The donor human milk (DHM) is characterized by temporary support if the mother faced milk-supply challenges in the first few days after the baby's birth (Johnson & Economides, 2019) or for the preterm and sick infant that didn't get access to their mother's milk.(Weaver et al., 2019) Furthermore, in the case that the mother is reachable, lactation support should be provided simultaneously (Israel-Ballard, 2019). In the case of babies who need long-term support due to maternal separation, illness, or death, in western society, DHM might be the option (Brandstetter et al., 2018). However, in the specific consideration of the concept of "Mahram" (Brotherhood based on breast milk sharing from the same mother) in Muslim society, the option available might be through donated expressed breast milk or wet-nursing from a foster mother (Hsu et al., 2012).

The human milk donor consists of the mother willing to donate their milk, the mother willing to use donated breast milk for their infant, and the sharing methods (Shared through human milk banks or peer sharing). Besides, some mothers did both give and received human milk. Mother's willingness to involving in these processes represents their acceptance of human milk sharing practices (Gelano et al., 2018). In this study, the number of mothers who donated their milk is greater than that of mothers who receive donor milk for their baby. Some receive donor milk on the first day after the baby's birth and give donor milk later after their supply was sufficient.

The previous study showed that the intention to donate milk was mostly based on altruism to help other mothers and excessive milk supply. On the other hand, this study results found that mothers seek donor milk because their breast milk was not yet available or insufficient to fulfill the baby's needs. This is also explained why the highest number of donor milk recipients was in the under 1-month child's age group. These donor-seeking reasons were the breastfeeding problems commonly found in the baby's early life: mothers worry about milk deficiency, thinking their baby is not satisfied, and or baby's inadequate weight gain. However, education, assistance, strong proactive lactation method, and social support were reported to effectively solve the problem (Karaçam & Sağlık, 2018). This is also explained why the highest number of donor milk recipients was in the under 1-month child's age group.

Almost half of the mothers have inappropriate human milk sharing. Based on previous research, there are several factors regarding human milk sharing practices including concern and perception about milk sharing risk and the presence of health care providers and in parent's decision making and milk sharing processes (Palmquist & Doehler, 2016). Similarly, this study found that 36% of human milk recipients didn't seek any support from health professionals or lactation counselors in the decision-making process including its potential risk and discussing safer milk screening and handling practices(Barbas et al., 2017). Moreover, 44% of them didn't get the support that allows them to breastfeed directly and independently(Thibeau & Ginsberg, 2018)

Human milk banks play a significant role in screening and recruiting breast milk donors and then collecting, processing, screen, storing, and distributing safe donor human milk (Olonan-Jusi et al., 2021). Interestingly, none of the subjects looking for donor milk through milk banks. They mostly prefer to seek donors from a close friend or family who had a similar baby's age. This is because the number of standardized human milk banks available in Indonesia is limited, then human milk donation from family or friends became the most acceptable way to get donor milk. Several previous research results also showed similar findings in which most of the mothers sharing their milk with relatives, family, or friends (Senol & Aslan, 2017).

On the other hand, In Malaysia, as a country with a predominantly Muslim society like Indonesia, the concept of "pooled donor milk" applied in Western milk banks was considered unethical. the human milk donation concept between mothers equipped with health screening, documentation, and the freeze-thaw process is considered an alternative

rather than pooled human milk banks (Hsu et al., 2012). This case was also found in Turkey, in which mothers hesitate to donate their breast milk to milk banks based on religious concerns (Ergin & Uzun, 2018). This is also underlined that the human milk sharing in Muslim majority country needs to be well managed by considering Sharia law (Zahar et al., 2019).

Furthermore, almost half of the mothers gave the donor milk using bottle-feeding. Infants' exposure to artificial nipples in bottle-feeding leads to breastfeeding problems such as nipple confusion and should be avoided (Kebebe & Assaye, 2017). The health care provider should explain to the mothers and family the risk of bottle feeding, pacifier, and teats in the lactation counseling (Vu Hoang et al., 2020). It including the use of bottle feeding both to give their own expressed breast milk or DHM.

In addition, the donor milk recipients didn't ask for the potential donor's health reports, organ and blood donation history, and drug consumption. However, these points determine the eligibility of the potential donors. Several points make mothers not eligible to donate breast milk: Consume medicine that's not an approved medication, smoke, drinks alcohol daily, use other drugs, received a blood transfusion in the past four months, received an organ transplant in the past 12 months, and a positive test for infectious disease or have a partner with HIV positive (American College of Nurse-Midwives, 2019).

Considering the requirements and risk of human milk sharing, further, a standardized regulation of human milk sharing should be arranged to provide safe and high-quality donor human milk. Furthermore, although DHM has benefits in reducing disease risk and other potential benefits, Mom's own milk (MOM) is more effective in reducing multiple morbidities and their costs and is less expensive to acquire than DHM. Health care providers must frame the argument that MOM still the best baby food, even in the NICU setting (Meier et al., 2017).

## Conclusion

Concerning the rate of mothers who donated or received human milk donors, their level of knowledge, and the number of inappropriate human milk sharing, we underlined the importance of breastfeeding support, education, and regulation of human milk donors to minimize the health risk of inappropriate human milk sharing.

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