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A Qualitative Study on Breastfeeding among Mothers with Intellectual Disabilities: Perspectives of Nurse-Midwives and Public Health Nurses

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ABSTRACT

Background: Breastfeeding is important for maintaining and promoting lifelong health and bonding between mothers and their children. Professional support in the early postpartum period is key to successful breastfeeding. Mothers usually learn parenting skills in the early postpartum period, but mothers with intellectual disabilities (IDs) require special consideration due to their learning disability. The views of nurse-midwives (NMWs) and public health nurses (PHNs) regarding breastfeeding among mothers with IDs in the early postpartum period need to be explored.

Purpose: We aimed to describe the perspectives of NMWs and PHNs on breastfeeding among mothers with intellectual disabilities (IDs).

Methods: Data obtained from semi-structured interviews with five NMWs and five PHNs with experience in caring for postpartum mothers with IDs were analyzed using a conventional content analysis approach.

Results: The analysis yielded two categories: "Determining whether breastfeeding is the best" and "Desire for strengthened support for establishing breastfeeding during postpartum hospitalization." The former comprised three subcategories: "Effects of complications and abnormal deliveries," "Evaluation of adaptability," and "Evaluation of the support person's capability." The latter consisted of "Focus on the advantages of breastfeeding," "Focus on the disadvantages of artificial feeding," and "Desire for NMWs' support during postpartum hospitalization to establish breastfeeding." The study found that NMWs had short-term perspectives that considered the physical trauma and fatigue sustained by mothers during childbirth; they tried to minimize mothers' physical and emotional burdens, whereas PHNs had long-term perspectives that considered the impact of breastfeeding on the children's future.

Conclusion: Successful breastfeeding by mothers with IDs requires a change in NMWs' awareness and the development of a system and instructional media that enable NMWs to perform their duties in accordance with the basic principles of breastfeeding. Additionally, policies are required to promote this practice.

Keywords: *breastfeeding; intellectual disability; mother; nurse-midwife; public health nurse*

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BACKGROUND

Breastfeeding is a beneficial practice for the long-term health of both mothers and their children. The composition of breast milk varies depending on the infant's sex, gestational age, and living environment. It provides the most suitable composition for the infant at the time and helps to prevent lifestyle-related ailments such as obesity, hypertension, and diabetes, as well as infectious diseases (Silfverdal et al., 2007; Hörnell et al., 2013; Galante et al., 2018; Kalbermatter et al., 2021; Gridneva et al., 2022). Breastfeeding is also correlated with lower rates of ovarian cancer, breast cancer, and diabetes (Luan et al., 2013; Gunderson et al., 2015; Babic et al., 2020; Qiu et al., 2022; Melov et al., 2022). Hence, successful breastfeeding is essential from the policy perspective of maintaining people's health and avoiding the financial burden of medical costs.

The World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) recommend breastfeeding exclusively for the first six months after childbirth, then introducing nutritionally adequate and safe complementary solid foods, and continuing breastfeeding until the age of two or beyond (WHO Regional Office for the Eastern Mediterranean, 2022). In 2012, the WHO approved a comprehensive implementation plan for maternal, infant, and young child nutrition in World Health Assembly Resolution 65.6, which set a goal to "achieve at least 50% breastfeeding in the first six months" by 2025 (WHO/UNICEF, 2014). In Japan, according to the Ministry of Health, Labour and Welfare's (MHLW, 2016) FY 2015 Infant Nutrition Survey, the exclusive breastfeeding rate for infants aged 1–2 months was 51.3%, which was 9.9% higher than that in the previous 2005 survey, and was 54.7% for infants aged 3–4 months, which was 16.7% higher compared to the 2005 survey (MHLW, 2006). Since the MHLW considers 5–6 months of age to be an appropriate time to start preparing for weaning (MHLW, 2019), no data on exclusive breastfeeding rates at six months of age are available in Japan. Nevertheless, Japan's exclusive breastfeeding rate at three months of age can be considered quite high. Further, the WHO recommends an annual increase in exclusive breastfeeding rates of 1.2% for countries that have already met the above mentioned goal (WHO/UNICEF, 2014).

According to the 2021 White Paper on Persons with Disabilities (Cabinet Office, 2022), institutionalized people account for 12.1% of the 1,094,000 individuals with intellectual disabilities (IDs) in Japan. The "Survey of difficulties in everyday life," conducted in 2016 (MHLW, 2018), indicated that among 764 people with IDs who voluntarily responded, 599 (78.4%) lived with someone else, 77 (10.1%) lived with their spouse, and 47 (6.2%) lived with their children. Contrastingly, in the same survey in 2011 (MHLW, 2013), 7.9% lived with their spouse, a slight increase, while 6.4% lived with their children, denoting minimal change. However, it is estimated that a considerable number of people in Japan are not certified as having IDs by their regional governments, despite actual limitations in intellectual capacity that hinder them in daily life.

Breastfeeding is also crucial from the perspective of preventing child abuse. In Japan, instances of parental abuse of children have been rising rapidly in recent years, with infants accounting for 65.3% of victims of abuse-related deaths, and mothers being the most common perpetrators (MHLW, 2022). Breastfeeding is associated with sensitivity from mothers towards their children and feelings of attachment security from babies towards their mothers (Britton et al., 2006; Tharner et al., 2012). However, people with IDs tend to find it difficult to acquire the necessary knowledge and skills during the

perinatal period. Therefore, the government has positioned parents with IDs as parents in particular need of support for childcare. From the early stages of pregnancy through the postpartum and childcare periods, health and medical welfare specialists work together to develop support plans for these parents, and to provide multiple opportunities for home visits and individual guidance by public health nurses (PHNs) and nurse-midwives (NMWs) (MHLW, 2013).

NMWs are the primary care providers for new mothers in the perinatal period, mainly at obstetric facilities, while PHNs primarily conduct home visits and collective infant health examinations. Furthermore, municipalities commission some NMWs on a freelance basis to conduct postpartum home visits, while other NMWs who manage midwifery centers provide care to mothers and their babies for a few weeks after childbirth. In Japan, hospitalization after childbirth generally lasts four to seven days. During this time, NMWs and nurses teach the mothers practical childcare skills for raising their children after discharge from the hospital.

Given the above, we aimed to explore the perspectives of NMWs and PHNs on breastfeeding for mothers with IDs.

PURPOSE

We aimed to describe the perspectives of NMWs and PHNs on breastfeeding among mothers with intellectual disabilities (IDs).

METHODS

Research Design

This study used a qualitative descriptive design to explore the perceptions of NMWs and PHNs regarding breastfeeding support for mothers with IDs.

Participant Selection and Data Collection

We carried out this study in a suburban part of Japan. Local government support for pregnant and nursing mothers with IDs in the study area was similar to existing support systems in many Japanese municipalities. Administrators of maternity hospitals and municipal health departments were asked verbally and in writing to participate in the study. Those interested contacted the researchers and requested information on the study. Snowball sampling was used to recruit participants, including those who knew the researchers as well as other participants. Participation criteria were having experience as an NMW or a PHN and in caring for postpartum mothers with IDs. A total of 10 participants were enrolled, all of whom were female. Five were NMWs: one in her 20s, one in her 30s, two in their 40s, and one in her 50s. Five were PHNs: one in her 30s, three in their 40s, and one in her 50s. The number of mothers with IDs the participants cared for, ranged between 1 and 32. Two midwives were affiliated with public hospitals, two with university hospitals, and one with a municipal hospital. All PHNs worked for municipalities (Table 1). The study objectives were explained to the participants in writing and orally, and written consent was obtained from them. We collected the data through semi-structured interviews held between April 2021 and March 2022 in person, through an online conferencing system, or over telephone. The first author carried out individual semi-structured interviews with all participants following an interview guide, which was developed based on the research question: “Is there a difference in the concept of breastfeeding support for mothers with IDs between hospital midwives, who provide breastfeeding care for new mothers during the early postpartum period, and public health nurses, who visit mothers at home after childbirth to provide childcare support?” Each

interview lasted for about one hour. The main interview question was “What do you think about breastfeeding support for mothers with ID?”

Table 1. Information about the participants (n=10)

Participant	Profession	Affiliation	Age	Years of experience caring for mothers with IDs	Number of mothers with IDs cared for (cases)
A	NMW	University hospital	30s	7	10
B	NMW	Municipal hospital	40s	10	32
C	NMW	Public hospital	40s	27	25
D	NMW	Public hospital	50s	14	20
E	NMW	University hospital	20s	1	1
F	PHN	Municipality	30s	1	3
G	PHN	Municipality	40s	9	10
H	PHN	Municipality	40s	4	5
I	PHN	Municipality	40s	5	5
J	PHN	Municipality	50s	15	4

Note: IDs: intellectual disabilities; NMW: nurse-midwife; PHN: public health nurse

Data Analysis

We examined the data using conventional content analysis, and recorded the interviews with the participants' permission and transcribed them. Next, we coded all textual data from the verbatim transcripts and divided them into the smallest sentences or paragraphs that reflected a single meaning. Subsequently, categories and subcategories were generated from the codes based on the commonalities in the perceptions of the NMWs and PHNs on breastfeeding by mothers with ID. We further structured, reorganized, and repeatedly merged the subcategories to increase the abstraction level, and performed the data analysis with two considerations to ensure trustworthiness. First, two researchers experienced in qualitative inductive research regarding the provision of care for persons with IDs in the perinatal period conducted the analysis. The results were confirmed by the participants.

Ethical Considerations

The research ethics committee of Nagoya Women's University (reference #2020-27) approved the study. Participants were informed, in writing and orally, regarding the management of data, ways of disclosing results, and their freedom to participate or withdraw from the study at any time. They were guaranteed anonymity and notified that data would not be used for any purpose except for the study, and their written consent was obtained.

RESULTS

Categories

The analysis elicited the following categories “Determining whether breastfeeding is the best” from the NMWs' interviews and “Desire for strengthened support for establishing breastfeeding during postpartum hospitalization” from the PHNs' interviews. Each category contained three subcategories.

Determining whether breastfeeding is the best

The category “Determining whether breastfeeding is the best,” extracted from the NMWs’ narratives, consisted of three subcategories: (1) effects of complications and abnormal deliveries; (2) evaluation of adaptability; and (3) evaluation of the support person’s capability (Table 2). We discuss each subcategory below in detail, along with narratives from the participants.

Effects of complications and abnormal deliveries

One NMW stated that women with IDs often suffer from psychiatric disorders and obstetric abnormalities and that artificial feeding is the only option to avoid the transfer of psychiatric drugs into breast milk. NMWs often bottle-feed the child and help the mother get enough sleep at night, as waking up in the middle of the night can exacerbate psychiatric symptoms and interfere with the mother’s recovery.

“A relatively large number of women with [IDs] have suffered from depression or other mental illnesses prior to pregnancy and are taking psychiatric medicines, making it impossible for them to breastfeed.” (A, NM, 30s)

“Lack of sleep worsens psychiatric symptoms, making night-time feeding impossible, so artificial nutrition is chosen from the beginning.” (B, NM, 40s)

Evaluation of adaptability

The NMWs asserted that it was difficult to communicate prevention measures and remedies for mastitis, breast, and nipple problems to mothers with IDs. Conversely, some NMWs stated that although the mothers faced difficulties with verbal understanding, such as numbers and concepts, they could easily imitate the maneuvers the NMWs demonstrated in response to the baby’s cries.

“We were talking about how difficult it is to evaluate how well she understands what we say or explain and to what extent she can do so.” (D, NM, 50s)

“We nurse-midwives have concerns that they might get mastitis. The baby was in the neonatal intensive care unit [NICU], and the mother was pumping and delivering breast milk, and we [NMWs] felt the greatest difficulty in that we had not had the opportunity to assess her ability to understand and perform how to prevent and deal with blisters and other nipple problems after she was discharged.” (E, NM, 20s)

“She breastfed her baby as if it were natural, and she didn’t get hung up on numbers, like how much weight her baby needed to gain, because she didn’t know the numbers, and she could feed her baby when he cried, change his diaper, and do it without thinking too much about it.” (C, NM, 40s)

Evaluation of the support person's capability

The NMWs remarked that key individuals, such as the mother's husband and her mother, should be assessed to determine whether they understood and could implement the childcare procedures the NMWs had taught, as well as how well they could support the mother.

"Her mother, who lived with her, and the baby's grandmother took care of everything, and we told her mother and instructed her how to do it and made sure she could do it." (B, NM, 40s)

"We asked her husband to come and explained [it] not only to her but to her husband [as well]. We would tell her husband everything and make sure he understood." (E, NM, 20s)

Desire for strengthened support for establishing breastfeeding during postpartum hospitalization

The category "Desire for strengthened support for establishing breastfeeding during postpartum hospitalization," extracted from the PHNs' narratives, consisted of three subcategories: (1) focus on the advantages of breastfeeding; (2) focus on the disadvantages of artificial feeding; and (3) desire for NMWs' support during postpartum hospitalization to establish breastfeeding (Table 2).

Table 2. Participants' perspectives

Category	Subcategory	Code
Determining whether breastfeeding is the best	Effects of complications and abnormal deliveries	Contraindications by underlying disease
		Consequence of abnormal delivery
	Evaluation of adaptability	Evaluation of tolerance for breast and nipple changes
		Evaluation of comprehension
		Evaluation of the ability to seek help
	Evaluation of the support person's capability	Evaluation of the primary support person's comprehension Evaluation of relationship with the primary support person Evaluation of the primary support person's parenting skills
Desire for strengthened support for establishing breastfeeding during postpartum hospitalization	Focus on the advantages of breastfeeding	Promoting bonding from the mother to the baby and attachment from the baby to the mother
		Immunological and nutritional benefits for the baby
		No tools needed
	Focus on the disadvantages of artificial feeding	Need to learn how to prepare formula Need for tools for preparing milk Curing costs

	Desire for NMWs' support during postpartum hospitalization to establish breastfeeding	Expectations for breastfeeding care provided by NMWs Requests for care in accordance with principles
<hr/>		
PHNs: Public health nurses		
NMWs: Nurse-midwives		
Note: PHNs, public health nurses; NMWs, nurse-midwives		

Focus on the advantages of breastfeeding

The PHNs noted the advantages of breastfeeding, such as attachment formation, the feeling that the child needs the mother, and not needing to use tools.

"I think breast milk has more advantages than formula. Attachment is formed through skin-to-skin contact." (J, PHN, 50s)

"With breast milk, you can give them advice on how to hold the baby and how to suckle the nipple, and they will understand it through the sensation of their bodies." (I, PHN, 40s)

"With breast milk, you feel that you can raise your child on your own and that your baby needs you." (G, PHN, 40s)

"When you go out, you do not need to carry much luggage and you do not need any special instruments." (G, PHN, 40s)

Focus on the disadvantages of artificial feeding

The PHNs remarked that the mothers with IDs did not understand the essentials of preparing formula and were doing so in a way that was detrimental to the growth and safety of their children. They also mentioned that formula required equipment and was expensive.

"The baby's weight was not increasing, so I asked her to show me how she was preparing the milk, and she said she was using the same amount of milk powder and only increasing the amount of water." (F, PHN, 30s)

"The way they give milk, they dilute it, or they give leftover milk that has been sitting at room temperature for hours." (H, PHN, 40s)

"They are already free to try to give milk that is still hot, or to put ice in the milk to cool it down, and so on." (F, PHN, 30s)

"With formula, you have to measure the amount, understand how to make it, how to give it to the baby, and how to sterilize the bottle...financially, artificial milk is expensive." (J, PHN, 50s)

Desire for NMWs' support during postpartum hospitalization to establish breastfeeding

The PHNs suggested that NMWs should assist mothers with IDs in the early postpartum period to implement recommendations for establishing breastfeeding.

"I think breastfeeding is probably easier, but it is hard to get the secretion going..." (I, PHN, 40s)

"You do not secrete breast milk right after giving birth, do you? If you give up on frequent breastfeeding right after giving birth, or if you switch to milk right away, then you will find that you are not secreting enough milk." (J, PHN, 50s)

"I would like the baby to be in the same room as the mother and do the basics of breastfeeding every time the baby cries." (G, PHN, 40s)

DISCUSSION

Based on the findings, one might conclude that NMWs have short-sighted perspectives on breastfeeding as they consider the physical damage and fatigue sustained by the mother during childbirth and try to minimize their physical and emotional burdens. However, PHNs have long-term views that consider the impact of breastfeeding on the children's future after the mother has recovered from the physical damage and fatigue of childbirth. The breastfeeding rate among women with IDs seems to be low (Goldacre et al., 2015; Hindmarsh et al., 2015; Guay et al., 2017). However, to the best of our knowledge, there are no studies on the breastfeeding rate of women with IDs in Japan. This is because Japan does not have a national system for centrally managing health administrative or disability welfare data. Hence, obtaining reliable data on perinatal care for people with disabilities is difficult. However, from the interviews in this study, one could infer that the breastfeeding rate among mothers with IDs is lower than that of those without IDs.

Expectedly, people with IDs have a higher prevalence of psychiatric disorders than those without IDs (Emerson et al., 2007), which was echoed by our interviewees. Weighing the risk of drug transfer to breast milk and the benefits of breastfeeding, the NMWs opined that the former is more important. In Japan, most psychiatric drugs used to be contraindicated or carefully administered to breastfeeding women. However, in 2019, the Pharmaceutical Affairs Law was revised, and currently, for many drugs, it is indicated whether to continue or discontinue breastfeeding in light of the therapeutic benefits of the drugs for the mother and the benefits of breastfeeding. Japan's Drug Information Institute in Pregnancy, run by the National Centre for Child Health and Development, provides correct information and consultation on drugs administered to pregnant women and breastfeeding mothers. NMWs should work with pharmacists and obstetricians to obtain accurate drug-related information and support mothers with IDs and their families in determining the best approach both for them and their babies.

We also found that concerns about psychiatric disorders becoming exacerbated due to night-time feeding would not be a sufficient reason to choose artificial nutrition from the outset. Given the various benefits of breastfeeding (Britton et al., 2006; Silfverdal et al., 2007; Tharner et al. 2012; Hörnell et al., 2013; Galante et al., 2018; Kalbermatter et al., 2021; Gridneva et al., 2022), a potential alternative could be mixed

nutrition with artificial feeding by someone other than the mother at night. In particular, colostrum, secreted in the early postpartum period, is crucial to prevent infections and to acquire immunity in the gastrointestinal tract and should be fed to newborns.

In a scoping review of studies on mothers' perceptions and experiences of breastfeeding from 2010 to 2020, Beggs et al. (2021) found that mothers (not limited to those with disabilities) tend to assume that breastfeeding is easy but have difficulties in dealing with breastfeeding problems, and that partner support, social networks, and advice from health professionals play a vital role in their breastfeeding decisions. Moreover, in supporting mothers with IDs, healthcare professionals must be sensitive to the characteristics of individuals with IDs. In judging the sufficiency of breast milk, weight gain and the number of times the child defecates are countable objective indicators, but the infant's desires, gestures, crying, and skin condition are also subjective indicators. Parents with IDs need support from others to make these assessments due to the nature of their disability, which includes poor reasoning and problem-solving abilities (Barr, 2019).

However, in Japan, there are virtually no opportunities for healthcare professionals to gain knowledge about the characteristics of people with IDs. Even in the United Kingdom (UK), where ID nursing¹ is a specialty and ID nurses are active, midwives' knowledge of people with IDs is inadequate. Educational opportunities for midwives to acquire knowledge are important, but reportedly, only 28.3% of acute obstetric institutes provide post-registration training. In Japan, the situation is even more serious, with virtually no opportunities to gain knowledge about people with IDs, either before or after graduation.

Even when mothers have the knowledge and motivation to breastfeed, social barriers (such as the environment and certain customs) hinder success (Desai et al., 2014; Mundagowa et al., 2019). In addition to maternal awareness, other factors that contribute to successful breastfeeding include support from health professionals, an environment where the mother and the child can be together throughout the day, and avoiding the easy use of formula (WHO, n.d.). In particular, support for mothers and their children from midwives in the early postpartum period is critical. However, midwives are becoming increasingly busy as more hospitals handling deliveries in Japan are adopting mixed wards. Under the circumstances of Japan's low birth rate and longevity, and consequently a rapidly aging population, 77.4% of delivery facilities in Japan are mixed wards (Japanese Nursing Association, 2017). This breakdown shows that 49.6% of the patients are in mixed departments, including neurosurgery and orthopedics, which have lower levels of independence during activities of daily living (ADLs) (Japanese Nursing Association, 2017). Moreover, 63.9% of hospitals indicated that they sometimes admit non-obstetric patients to obstetric wards if there are no beds available in their disease-relevant department (Japanese Nursing Association, 2017). This implies that midwives are simultaneously supporting childbirth and end-of-life care (Saito, 2018), or that they are simultaneously helping postpartum women during lactation and assisting older patients with dementia in the terminal stage. New mothers need midwives' support to cope with their babies' cries, as their sleep patterns differ from those of their newborns, with waking up more frequently during the night. However, under the mixed ward system,

¹ In the UK, the term "learning disabilities" is used instead of "intellectual disabilities," but in this study, we have used the latter.

midwives working the night shift are extremely busy. Hence, we assume that breastfeeding support for new mothers, especially at night, is inadequate.

An additional problem is the aggressive marketing of artificial milk companies to maternity facilities. As of October 2021, there were only 66 “baby-friendly hospitals” (Japan Breastfeeding Association, 2021) out of approximately 2,100 facilities for labor and delivery in Japan (Japan Society of Obstetrics and Gynecology, 2019). Baby-friendly hospitals are accredited by UNICEF as obstetric facilities that dependably implement the “Ten Steps to Successful Breastfeeding” (WHO, n.d.). In Japan, similar to the situation described in the WHO/UNICEF (2022) report, artificial milk companies generally dispatch their own nutritionists to many hospitals other than baby-friendly hospitals to instruct postpartum mothers on nutrition and formula use, distribute formula pamphlets, and gift them artificial milk.

These issues cannot be resolved solely through the efforts of midwives in the perinatal field, but must be viewed as a wider problem for society, closely intertwined with issues of securing and assigning nursing staff, as well as ensuring hospital management and patient safety. It is necessary to develop policies that will help Japanese society achieve its goals of controlling the declining birth rate and raising a healthy future generation.

Concerning the provision of easy-to-read perinatal information to people with IDs, 43% of maternity hospitals in the UK under the National Health Service trust provide information in formats comprehensible to pregnant women with IDs (Homeyard et al., 2018). However, this practice has not been implemented in Japan. To the best of our knowledge, only the family planning and contraception pamphlet depicted in easy-to-read Japanese manga for postpartum couples with IDs, produced by Sugiura and Fujisawa (2021), is provided in Japan. Johnson et al. (2022) reviewed English-language media only that provided information on infant nutrition, and found that little is known about the acceptability of such resources for mothers with IDs; there are a small number of acceptable resources, but they are largely inaccessible.

STRENGTHS AND LIMITATIONS

This study is significant because, to the best of our knowledge, it is the first to focus on the reality of breastfeeding among mothers with IDs in Japan. The first author is involved with multiple obstetric facilities as a faculty member, instructing nursing students during their training. This is seen as a contributing factor to the validity of the interpretation of the data. However, this study is not free from constraints. One participant was a midwife who only had experience supporting one mother with ID. However, this participant made an important contribution to the findings by providing thought-provoking narratives about breastfeeding care for mothers with IDs.

CONCLUSION

The results of our study suggest that successful breastfeeding by mothers with IDs requires a change in midwives’ awareness and the development of a system and instructional media that can enable midwives to follow the basic principles of successful breastfeeding; moreover, policies are needed to support this change. We are currently working on developing an informational medium for women with IDs in the perinatal period. As with the aforementioned pamphlet, we will aim to produce one that is easily understood by people with IDs by exploring their evaluations of the pamphlet.

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