Difficulties that Healthcare Professionals and Welfare Professionals Perceive in Mothers with Intellectual Disabilities, and Related Characteristics of Intellectual Disability

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Abstract

This study aimed to identify what healthcare professionals and welfare professionals perceive as difficult for mothers with intellectual disabilities (ID) who are rearing infants, what characteristics of ID cause such difficulties, and what strategies the professionals use when providing care. An analysis of data collected from semi-structured interviews with 13 participants generated the following results. Fifteen characteristics of mothers with ID as perceived by the participants were extracted. They consisted of 12 characteristics in the cognitive domain, including "difficulty understanding abstract things," two in the psychomotor domain, including "difficulty with manual dexterity," and two in the affective domain, including "difficulty controlling expression of pain." Difficult situations for mothers with ID as perceived by the participants consisted of three categories and eight subcategories, including "nutrition" and "safety." Strategies of caring for mothers with ID consisted of nine categories, including "repeatedly explaining" and "sharing designated goals with the mothers." Items the participants considered necessary to improve the care for mothers with ID were "specific instruction tools for mothers with ID," and "collaboration between social welfare, health, and medical systems." We concluded that further interdisciplinary and interprofessional systematic actions should be implemented to improve the care for mothers with ID.

1. Introduction

In April 2016, the "Act for Eliminating Discrimination against Persons with Disabilities" was implemented to eliminate discrimination against persons with disabilities and to realize a society where all people respect human rights and lifestyles without discrimination on the grounds of disability. According to the law, administrative bodies and companies must adopt measures to provide "reasonable accommodation" in order to eliminate discrimination based on disability (Adjustment and Preparing Correspondence of Appropriate Assistance for Various Disabilities). To date, various actions have been carried out with the

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aim of establishing an inclusive society. However, although many people with ID wish to get married and create their own homes and families, the marriage rate of persons with ID is lower than that of persons with physical disabilities and mental disabilities[1]. Several researchers have claimed that if people with ID had access to the appropriate support, they would be able to acquire parenting skills and raise children[2-5]. However, today in Japan, we do not have a sufficient support system for people with ID who wish to create a family. As a first step towards the establishment of such an environment, the present study aimed to identify what healthcare professionals and welfare professionals perceive as difficult for mothers with ID who are rearing infants, what characteristics of ID cause such difficulties, and what strategies these professionals have devised to overcome those difficulties.

2. Methods

2.1 Research design, participants, and data collection

We conducted a qualitative study with a content analysis approach for data collection and analysis. We sent oral and written requests to participate in the study to administrators of maternity hospitals, healthcare divisions of municipalities, and social welfare service facilities. We asked them to inform potential participants of the study, who then made contact with the researcher. We also recruited participants via snowball sampling, which allowed inclusion of participants who knew the researcher or other participants. Inclusion criteria were being a healthcare or welfare professional and experience in caring for mothers with ID rearing infants. After explaining the study purposes and obtaining written consent from the participants, data were collected through 30-90 min semi-structured interviews in a personnel room. Interviews were conducted from January 2017 to December 2019. The principal interview questions were as follows: "Please feel free to talk about difficult experiences you observed while caring of mothers with ID," "What characteristics of ID do you think caused the situation?", "What strategies did you use when caring for the mother?" and "What do you think is necessary to improve the care for mothers with ID?".

2.2 Analysis

All the interviews were recorded and transcribed. The data were analyzed in a two-step process, from an individual analysis to an overall analysis, based on Krippendorff's content analysis method[6]. In the individual analysis, remarks regarding the objectives of the study were abstracted from the transcripts and coded. In the overall analysis, the codes were classified into categories based on the similarity of the contents. In the analysis of difficult experiences and characteristics of ID, we extracted the episodes that the participants encountered and labeled each of them, and then classified them into themes, categories, and subcategories. Persons with ID have certain limitations with respect to learning ability.

Therefore, we divided the characteristics of ID into three areas using three learning domains as proposed by Bloom et al.[7], Anderson and Krathwohl[8], and Krathwolh et al.[9].

2.3 Ethical approval

The objectives and methods of the study were explained to the participants orally and in writing. We informed them that their anonymity would be guaranteed, that participation was voluntary, and that refusal to participate would not result in any negative consequences. The institutional ethics committee of Kawasaki University of Medical Welfare (ref. no.16-83, 17-71) and the research ethics committee of Nagoya Women's University (ref. no. 2019-12) approved this study.

3. Results

The participants comprised five public health nurses in their 20s to 50s, four nurse-midwives in their 20s, 40s or 50s; two social workers in their 30s and 40s; one nurse in her 60s; and one nursery teacher in her 50s. All participants were female. The number of mothers with ID ranged from 2 to 40 (Table 1). Of the 17 characteristics of mothers with ID extracted from the participant interviews, 13 were in the cognitive domain, two were in the psychomotor domain, and two were in the affective domain (Table 2). Difficult situations of mothers with ID abstracted from the transcripts consisted of three themes, "taking care of a

baby," "preparation for both the mother and baby," and the "mother controlling herself." Eight categories and 15 subcategories condensed from a total of 87 codes were obtained from the transcripts (Table 3). The findings are summarized below, and are supported by quotations from the participants. We identified 17 codes and nine categories as strategies of caring for mothers with ID (Table 4). Table 5 indicates what the participants thought was necessary to improve care for mothers with ID, as contained in 18 codes and three categories.

Table 1　Participant information (n=13)

No.	Profession	Affiliation	Age (decade)	Length of experience caring for people with ID (years)	Number of mothers with ID cared for (cases)
1	Nurse-midwife	Municipal hospital	40s	8	30
2	Nurse-midwife	Obstetric clinic	40s	8	40
3	Nurse-midwife	Municipal hospital	50s	33	3
4	Nurse-midwife	University hospital	20s	5	4
5	Public health nurse	Municipality	50s	34	4
6	Public health nurse	Municipality	40s	1	2
7	Public health nurse	Municipality	50s	31	8
8	Public health nurse	Municipality	30s	4	5
9	Public health nurse	Municipality	20s	1	2
10	Social woker	Child and family support center	40s	13	3
11	Social woker	Self-reliance support center	30s	19	3
12	Nurse	Infant home	60s	2	5
13	Nursery teacher	Child and family support center	50s	35	4

ID: intellectual disabilities

Table 2　Characteristics of mothers with ID

Domain	Characteristic
Cognitive	・Difficulty understanding abstract things ・Difficulty understanding numbers, counting, and calculations ・Difficulty explaining things ・Difficulty stating they do not understand something ・Difficulty asking questions ・Difficulty mastering new things ・Difficulty anticipating things ・Difficulty making plans ・Difficulty assessing the situation ・Difficulty making judgments ・Difficulty behaving in a way that matches the situation ・Difficulty finding out how to do things ・Difficulty solving problems
Psychomotor	・Difficulty adjusting to changes in power ・Difficulty with manual dexterity
Affective	・Difficulty controlling expression of pain ・Difficulty noticing things

Table 3　Themes, categories, and subcategories of difficult situations for mothers with ID

Theme	Category	Sub-category
Taking care of a baby	Nutrition	Bottle-feeding
		Breast-feeding
		Formula
		Weaning foods
	Safety	Preventing accidents
		Tidying up the house
	Cleanliness	Bathing
		Changing clothes
		Changing diapers
		Keeping the skin clean
	Crying	When the baby cries
	Sickness	When the baby is sick
Preparation for both the mother and baby	Preparation for both the mother and baby	Preparing for child-birth and child-rearing
Mother controlling herself	Contraception	Contraception
	Expression of pain	Expression of pain

Table 4　Categories and codes of strategies used to care for mothers with ID rearing infants

Category	Code
・Repeatedly explaining	・Repeatedly explaining ・Repeatedly explaining how to change diapers or how to hold a baby
・Sharing individually designated goals with the mothers	・Setting individual goals with the mothers ・Promising to attain the individual goals with the mothers
・Providing timely support corresponding to the mother's needs	・Explaining infant and child behavior and helping mothers build an attachment to the baby ・Making home visits early after discharge ・Providing timely support ・Frequently checking the baby's body weight
・Making individual instruction tools for the mothers	・Making individual teaching materials for the mothers ・Individual counseling for the mothers at an outpatient clinic ・Following the mothers by using a child-rearing diary ・Writing and drawing on a small whiteboard to help teach mothers important information
・Instructing the mothers in an actual home environment	・Making home visits and instructing the mothers in an actual home environment
・Instructing the mothers by showing them how to do things using their hands	・Instructing the mothers by showing them how to do things using their hands
・Collaborating with social welfare, health, and medical systems	・Collaborating with social welfare, health, and medical systems during pregnancy and after birth
・Providing lifelong support based on family-centered care	・Providing lifelong support based on family-centered care
・Maintaining a good relationship with the mother and her family	・Maintaining a good relationship with the mother and her family

ID: intellectual disabilities

Table 5 Categories and codes of items that are necessary to improve care for mothers with ID

Category	Code
・Specific instruction tools for mothers with ID	・Instructive pamphlets that correspond to the individual ・A manual that explains how to care for persons with ID ・A tool to assess ID level ・A checklist of what to do when caring for persons with ID
・Collaboration between social welfare, health and medical systems	・Collaboration between representatives of social welfare, health, and medical systems ・Conferences between social welfare, health, and medical systems ・Sharing of the support target and measures between support staff ・Home visits by public health nurses after discharge ・Instructions for family members or support staff before the mothers' discharge ・Enhancement of postnatal care
・Regarding the mothers' views as important	・Mothers with ID being given the opportunity to evaluate the service provided ・Regarding the mothers' views as important ・Building a relationship with the mother ・Providing mental support to mothers ・Viewpoint of supporting everyday life ・Reinforcement of instruction on the viewpoint of independent support ・Family-centered care ・Regarding preventive care as important

ID: intellectual disabilities

3.1 Taking care of a baby

3.1.1 Nutrition

Mothers with ID have difficulty counting, calculating and understanding numbers and abstract things. The healthcare professionals developed methods and ways of helping mothers corresponding to the situations they faced.

"*'She could not understand how to measure the amount of liquid, so I put tape on the surface of a bottle to show how much hot water to add to make formula milk.*" (nurse-midwife)

"*'They cannot calculate the number of scoops of powdered milk needed to make a formula according to their baby's age.*" (nurse-midwife)

"*'She could not distinguish what was acceptable or unacceptable as weaning foods for her baby. She gave her baby chocolate the other day.*" (nurse)

Every new mother receives instructions on child care skills from nurse-midwives or nurses before discharge from the maternity hospital for 4-5 days after a vaginal child-birth, or for 7-10 days after a cesarean birth. Mothers with ID had difficulty in mastering things new to them, and healthcare professionals explained and repeatedly demonstrated how to do things by using their hands:

"*She could not get accustomed to using a new bottle with a different shape from an old bottle and could not bottle-feed her baby well.*" (nurse-midwife)

The following transcription indicates the mothers' difficulty in behaving in a way that matched the situations and their difficulty anticipating things. "*Doing something on an ad hoc basis seems to be hard for them. The other day, when the mother was bottle-feeding her baby, the baby suddenly defecated, and then she panicked and froze because she did not know what she should do.*" (nurse-midwife)

"*She was still giving the baby the same amount of milk as she was told for the first time in the maternity hospital even though the baby was several days old.*" (public health nurse)

3.1.2 Safety

Mothers with ID could neither assess the situation nor anticipate what might occur.

"*When I visited her home for the first time, it was messy. There was too muuch stuff, including small stuff, on the floor and piled up here and there.*" (public health nurse)

3.1.3 Cleanliness

Mothers with ID had difficulty noticing things before assessing the situations or what was the matter.

"*She did not notice the rash on her baby's neck until I found it and pointed it out.*" (social worker)

Regarding the psychomotor domain, the participants indicated that mothers were awkward.

"*She could not tie a string in the shape of a butterfly when she changed her baby's kimono type newborn baby clothes.*" (public health nurse)

"*She could not hold the baby well to meet the gaze.*" (public health nurse)

3.1.4 Crying

When their baby was crying, mothers with ID could not determine how to handle it by themselves.

"*They could follow somebody's direction, but they could not try another way and find out how to do it themselves.*" (nurse-midwife)

3.1.5 Sickness

Mothers with ID could neither make a judgment nor anticipate what was going to happen later.

"*She could not follow the directions on giving antipyretics to the baby, and gave the baby a fever suppository 3 hours late.*" (nurse)

3.2 Preparation for both the mother and baby

Mothers with ID had difficulty imagining and anticipating things; hence the participants made an effort to provide timely support.

"*She seemed not to be able to imagine how her life was going to change after she gave birth.*" (public health nurse)

"*She attended a childbirth preparation class, but she could not understand what the instructor said. Thus, I made an effort to give timely support.*" (nurse-midwife)

3.3 The mother controlling herself

3.3.1 Contraception

Contraception is abstract and complex; thus, even for people without ID, it can be difficult to understand. Mothers with ID have difficulty in understanding, explaining, and asking questions. Those traits caused the failure of contraception.

"*How to use contraception seemed to be difficult for her. She nodded, and appeared to have understood. However, she got pregnant soon after that.*" (nurse-midwife)

"*She quickly forgot what I had taught her about contraception. So, we should have reminded her from time to time.*" (nurse-midwife)

3.3.2 Expression of pain

Puerperant women usually experience pain during childbirth or breastfeeding; however, these expressions of pain seem to be exaggerated in mothers with ID.

"*She cried and claimed that she had very severe pain in the pubic area. She could not get out of bed even 2 days after childbirth.*" (nurse-midwife)

4. Discussion

4.1 Difficulties the participants perceived in mothers with ID

A survey-based study[10] of public health nurses in charge of maternal and child health in local municipalities revealed that "preparing meals for children" and "maintaining children's safety and health" were regarded as considerably tricky for mothers with ID. In the present study, "nutrition," "safety," "sicknesses," and "cleanliness" emerged as subcategories of severe difficulties as well.

4.2 Characteristics of mothers with ID and strategies for care

The Ministry of Health, Labour, and Welfare defines ID as limitations of intellectual function originating before the age of 18. An IQ-test score of lower than 70 is accepted as a limitation of intellectual functioning. Because the limitation of intellectual ability can cause troubles in daily life, exceptional support is necessary

for those who experience difficulty. The American Association on Intellectual and Developmental Disability describes intellectual functioning as general mental capacity, such as learning, reasoning and problem-solving. The characteristics of mothers with ID that the participant narrated correspond to the definitions of intellectual disability shown above; however, the descriptions from our study participants are much more realistic and practical. In the United Kingdom, "learning disability[†1] nursing" is its own nursing field (a century old), and LD nurses practice at some National Health Service hospitals. Deinstitutionalization and desegregation of people with ID in Japan began about three decades later than in the United Kingdom. Today, the system for social inclusion of people with disabilities is still insufficient in Japan. Therefore, even healthcare professionals are not familiar with persons with ID. Furthermore, in Japan, until 1996, the Eugenic Protection Law legalized the sterilization of people with ID, mental disorders, or hereditary diseases to prevent births of what were deemed to be "inferior" offspring. Thus far, healthcare professionals have seldom encountered parents with ID. The results of this study can provide proper guidance for caregivers to better understand persons with ID in perinatal clinical settings.

In recent years, research on the relationship between working memory and intellectual or developmental disabilities has greatly progressed. Limitations of working memory can explain the characteristics of persons with ID shown in the results of this study[11].

The participants used several strategies to provide proper care to mothers with ID. Those strategies are consistent with the interventions for students with limitations of working memory in several preceding studies[12,13]. However, in addition to the efforts contrived by our study participants, systematic actions by the government are needed. Contraception is a typical abstract topic for people with ID because they have difficulty remembering, planning, and anticipating. Several modern contraceptive methods prevalent in foreign countries have not yet been approved in Japan, such as contraceptive implants, injections, and patches.

4.3 Issues to be addressed in the future

"Specific instruction tools for the mothers with ID" was mentioned as necessary to provide adequate care to persons with ID. In the United Kingdom and Sweden, easy-to-read literature is prevalent as "reasonable accommodation," targeting the intellectually or mentally disabled persons, people with aphasia or dyslexia, and the elderly. Fujisawa introduced the "Lättläst (LL) book," which is a Swedish easy-to-read picture book for adults with ID, to Japan[14]. She and her colleagues also produced "A guideline for providing easy-to-read information to people with ID[15]." There are few easy-to-read instructional materials providing useful information to parents from pregnancy to the child-rearing period, even in maternal and child health records published by the Ministry of Health, Labour, and Welfare.

Several organizations in the United Kingdom reported that people with LD have worse health than people without LD[16,17]. That is due to the inequalities and inadequate standards of care that people with LD had be subject to. In addition, several studies have demonstrated that many barriers prevent people with ID from obtaining good healthcare[18]. Some of those barriers were also revealed in the present study, such as "collaboration with social welfare, health and medical systems" and "regarding the mothers' views as important." Nowadays in Japan, along with policies, municipalities have been establishing "comprehensive support centers for families with children" in order to prevent child abuse, especially infant abuse. These centers are the nucleus of seamless interprofessional support from pregnancy to the child-rearing period. Professionals should pay particular attention to parents with ID as vulnerable people as well as persons with mental disorders, poor people, teenagers and foreigners. Several researchers in the United Kingdom, Canada, and Australia have led progress in the field of parenting and people with ID. Since the start of research in the field in the 1940s, the focus has shifted from genetic inheritance[19] to psychosocial factors and psychoeducational factors[20]. Recently, research into the effect of psychoeducational approaches is encouraged, and parenting skill instruction programs have been developed by incorporating several educational techniques, for example, visual depictions of each step of a task, the use of multiple exemplars to encourage skill generalization, and repetition of material with varying presentation methods. In 2018,

Tanaka introduced a parenting program of the Parenting Research Centre in Melbourne, Australia, to Japan[21]. That was the first step of a systematic parenting training program for people with ID in Japan.

5. Concluding comment

Exploring better healthcare for people with ID is an interdisciplinary theme; hence, integrating knowledge in other related fields into nursing should be beneficial. Interdisciplinary research collaboration and interprofessional practical collaboration are needed to improve healthcare for people with ID.

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Declaration of conflict of interest

The authors reported no potential conflict of interest.

Note

† 1) The term "learning disability" in the United Kingdom has a similar meaning to "intellectual disability."

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