

Japanese Parents' Explanations of Disabilities to Siblings of Children with Intellectual and Developmental Disabilities

Hiroki Yoneda, Kana Miura

University of Tsukuba, Japan
Email: hyoneda@human.tsukuba.ac.jp

Abstract: One form of support that has been demonstrated to reduce psychological burden in siblings of children with intellectual and developmental disabilities is an explanation of the disability. By clarifying the actual conditions in which parents explain their child's disability to siblings, the goal of this study is to support parents in promoting open communication in the family environment. A semi-structured interview was conducted with five parents of children with disabilities aged 2–6 years who were attending daycare or preschool at private educational institutions. Interviews were analyzed using a grounded theory approach. A primary reason for parents explaining their child's disability to siblings was their belief that siblings may already have known about the disability, and they wanted to answer any questions that may have arisen. After parents explained the disability, some mothers noticed no changes in the siblings, but others reported that siblings asked more questions about the child with disabilities and expressed a desire to help support them. It is recommended that Japanese parents of children with disabilities receive information on available support systems provided by educational institutions and government/administrative agencies.

Keywords: explanations of disabilities; parent; sibling; intellectual and developmental disabilities

INTRODUCTION

Children with disabilities (hereinafter referred to as 'child(ren) with intellectual and developmental disabilities' (IDD)) and their siblings often have different relationships with their parents and assume different family roles, which can lead to maladjustment and psychological burden for the siblings without IDD. Caring for children with IDD often requires considerable effort from parents, leaving them with relatively little time to spend with their other children. Research has found that siblings of children with IDD experience loneliness and dissatisfaction, as well as feelings of guilt over competition with their sibling for their parents' affections (Hayden et al. 2019; Lobato et al. 1987; Meyer and Vadasy. 2007). Furthermore, siblings of children with IDD often assume the role of a parent (McHale et al. 1989), or if the child with IDD is older, the age roles are reversed (Stoneman et al. 1991), resulting in an excessive burden for siblings that can lead to long-term maladjustment (Braconnier et al. 2018). Various factors have been shown to influence the psychological burden of siblings of children with IDD, including the type and degree of disability, birth order, gender of the sibling, parental attitude toward childrearing, and the family's socioeconomic status (Ferrari 1984; Hayden et al. 2019; Simeonsson and McHale, 1981). Based on the difficult circumstances experienced by siblings of children with IDD, researchers have highlighted the need for support tailored for them (Meyer and Vadasy. 2007; Marquis et al. 2019).

In Japan, the Ministry of Health, Labour and Welfare (2008) suggested that concrete measures be

taken to support siblings as part of family-inclusive, comprehensive support for raising children with IDD. One form of support that has been demonstrated to reduce psychological burden in siblings of children with IDD is an explanation of the disability. Nishimura and Hara. (1996) emphasized that siblings need an explanation that is developmentally appropriate for them. Kobayashi and Honma (2018) found that by the time children with IDD reached elementary school, their siblings were often conscious of their disability. Once siblings have this awareness, Kobayashi and Honma, (2018) suggested that they be provided with education and support. In a study on adult siblings conducted by Tsunakawa and Ikemoto, (2012), explanations concerning a sibling's disability were often provided by the mother or by both parents. In Yanagisawa's (2007) study, siblings were most likely to receive direct information about their sibling's disability from their parents at home, suggesting that siblings' understanding of the challenges faced by parents in caring for their sibling with IDD and their relationships with their parents were factors in the information they received. In Mori's (2015) survey, mothers of children with disabilities reported that providing siblings with an explanation of the disability enabled the former to support the latter, which may also have provided emotional support for their mothers.

However, Kawakami and Ushio. (2012) noted that siblings experienced difficulties with regard to the explanations of disabilities provided by their parents. According to the personal narratives of mothers, their explanations of disabilities included content that was difficult for siblings to understand (Kawakami and Ushio, 2012).

Table 1. Profile of children of participants

	Position of the child with IDD in the sibling relationship	Age of children with IDD and their school grade	Diagnosis	Position of the child without IDD in the sibling relationship	Sibling's age and school grade	Explanation to sibling about the disability
A	Younger sister	5 years old Day care	Pervasive developmental disorders	Older sister	9 years old 4th grade	Explained
B	Younger brother	2 years old	Intellectual disability	Older brother	5 years old 2nd year of preschool	Explained
C	Younger brother	5 years old Last year (3rd) of preschool	Autism Intellectual disability	Older sister	7 years old 2nd grade	Explained
D	Younger brother	3 years old Day care	Mild intellectual disability	older sister	6 years old 1st grade	Did not intend to explain but did
E	Older brother	6 years old Last year (3rd) of preschool	Autism Mild intellectual disability	Older sister	3 years old 1st year of preschool	Explained
F	Younger brother	3 years old Day care	Autism None	Older sister	6 years old 1st grade	Not explained
G	Younger sister	5 years old 2nd year of preschool	None (delay in motor skill development)	Older sister	11 years old 6th grade	Not explained

Abe and Kanna (2011) suggested that it may be necessary to provide support for parents, as many mothers raising siblings of children with IDD experience childrearing difficulties. In Nishimura and Hara (1996) study, mothers raising siblings of children with IDD worried that siblings may have felt the same burdens as the mothers. As a result, mothers felt guilt over the complexity of the circumstances, even as they were trying to treat their children as equally as possible.

Parents' explanations of their children's disabilities to siblings may be complicated by a variety of other feelings, including their own expectations for their children with IDD and their desire for their children to have a typical childhood. To alleviate the psychological burden siblings experience and reduce the likelihood of their long-term maladjustment, it is essential that primary caregivers embrace siblings' feelings toward the child with IDD, understand how to explain the disability in a way that is easily understood by siblings, and provide support for understanding the developmental stage of the child with IDD (Takura 2010) table 1.

To determine the kind of support that can help parents of children with IDD, it is necessary to clarify how parents explain these disabilities to their other children. In this study, we interviewed mothers to clarify the actual conditions surrounding parents' explanations of the disabilities of children with IDD to their siblings.

We focused on mothers specifically because in Japan mothers are children's primary caregivers. In Japan the division of labor is strongly gendered; 'the husband works outside, and the wife should protect the family' (Japanese Ministry of Health, Labour and Welfare 2017). In 2016, the average amount of time Japanese men spent on housework and childcare was less than half that spent by men from other Organization for Economic Co-operation and Development countries (Sasaki 2018). Moreover, Japanese men in their 30s worked the longest number of hours of all age groups and spent less than 0.8 hours on housework and childcare on any given weekday (Sasaki 2018).

METHOD

Sample

The sample consisted of parents of young children aged 2-6 who attended a private therapeutic and educational institution for children with IDD. Ten primary caregivers experiencing difficulties with sibling relationships were recruited, and a roundtable discussion was held. The final sample for the study comprised the seven primary caregivers who participated in the roundtable discussion and consented to participate in subsequent one-on-one interviews. The characteristics of the children with IDD and their siblings are displayed in Table 1.

Table 2. Interview guide

Principal motive	Please tell us what your principal motivation in giving the sibling an explanation about the disability was. Did you consult anyone about providing this explanation to the sibling prior to having the talk?
Content of explanation	How did you actually explain the disability to the sibling?
Reaction of sibling	How did the sibling react when you had the talk? How did you feel the sibling received the information? What comments or behaviour of the sibling made you feel so?
Change in sibling	How there would be changes of sibling before the talk? Please explain the changes specifically.
Self-evaluation by guardians	What were the positive outcomes of providing the sibling with an explanation? Please tell us if you feel like you should not have had the talk or if it made you feel confused.
Outlook for future talks about the disability	If you were to provide more details or talk another time, what do you think the occasion would be? Please tell us if there is any preparation or information you would like to have in order to continue having such talks.
Cases of siblings in 5th grade and up	What you just described, is it about the first time? Why did the exchange you described come to mind? May I ask about exchanges that happened prior to that time?
Cases where explanation had not taken place	Please tell us if you plan to give the sibling an explanation in the future. Please tell us if you currently have an idea of the kind of explanation you would like to give the sibling.

Roundtable discussion

First, a roundtable discussion concerning the siblings' relationships was held and attended by both parents and therapists. Ten parents participated: six in the first session, one in the second, and three in the third, with each session lasting no more than 1.5 hours. One parental training instructor acted as a facilitator for the roundtable discussion. There were four topics of conversation regarding children with IDD and their sibling(s): (1) their favorite/least favorite things, (2) difficulties they experienced, (3) things that work well between them, and (4) whether or not the disability had been discussed with the sibling(s). The roundtable discussions were recorded on a portable digital recorder with the consent of the participants. The researcher and one graduate student also made written records.

Parents were asked to fill out a face sheet, which included the age, gender, school, and diagnosis of the child with IDD; the sibling's age, gender, and grade in school; and whether or not the sibling had received an explanation of the child's disability.

Semi-structured interviews. Second, face-to-face semi-structured interviews were held with participants. The goal of the interviews was to clarify the explanations of disabilities provided by parents, the changes in siblings following the explanation, and parents' self-assessments of their explanations. Interviews were attended by one parent training instructor or staff member of the therapeutic and

educational institution. Each interview was conducted in a therapy classroom and lasted 30–40 minutes. Interviews took place between August and September 2016, were recorded with a digital recorder, and were subsequently transcribed, table 2.

Ethical considerations. In both the roundtable discussion and the semi-structured interviews, participants were informed of the purpose of the study, their right to refuse to participate at any time, and the protection of their privacy through the anonymization of the study results. All participants provided written informed consent to participate. It was believed that parents may experience anxiety post-interview. Parents gave consent to share their information with the staff member of the institution present at the interview(s), and a follow-up visit was provided to the caregiver by a clinician, as appropriate. This study was approved by the University of Tsukuba Human Research Ethics Committee: 28-81.

Instrument. An interview guide for the semi-structured interview was developed with reference to Mori (2015). The interview guide's validity was determined by five special education experts, including the authors, and some necessary corrections were made. The prepared interview guide is presented in Table 2. Based on the results of the roundtable discussion, individual interview guides were created for each participant and tailored to include the names of their children.

Methods of analysis, The Saiki-Craighill grounded theory approach (Saiki-Craighill 2008; Saiki-Craighill 2014) was used to analyse parents' interviews. This approach provides a methodology for the understanding of social phenomena that is not developed from existing theories and paradigms. In Japan, the Saiki-Craighill grounded theory approach has been used in studies on nursing, social services, and education.

Data analysis using the Saiki-Craighill grounded theory approach began with a question regarding parents' explanations of disabilities to siblings of children with IDD. The data were sectioned according to content. Subordinate concepts of property and dimension were extracted for each section and accordingly labelled and categorized. Categories were classified according to phenomena using the paradigm of situation, action/mutual action, and consequence. Category relationship diagrams were drawn linking multiple categories, the central phenomenon was formed using properties and dimensions, and storylines were created. Category relationship diagrams were created each time a case was examined, prepared according to each case study, and integrated into each relationship diagram.

The case study analysis was limited to siblings who did not themselves have IDD. Therefore, Case G, in which the sibling showed delayed movement development, and Case F, in which the sibling also attended therapy, were excluded from the analysis. Analysis was, therefore, conducted on five cases, namely, cases A–E.

FINDING AND DISCUSSION

Finding(s)

Using the paradigm, category relationship diagrams were created for each case and then integrated into the 15 categories shown in Table 3. Figure 1 shows an integration of the category relationship diagram for the core phenomenon category, 'explaining disabilities to siblings.' Detailed category relationship diagram integrations describing these dimensions have been divided into three categories: (1) 'before explaining disabilities to siblings,' (2) 'after explaining disabilities to siblings' and 'continuing anxieties,' and (3) 'ongoing concerns.'

Before explaining disabilities to siblings, The 'before explaining disabilities to siblings' category relationship diagram integration is shown in Figure 2. Prior to explaining disabilities to siblings, mothers saw the explanation as an opportunity for recognition and 'sibling awareness' of the 'present condition of the child with IDD.' In particular, 'sibling awareness' was cited as a factor with a significant influence on the decision to explain a child's disability. Awareness content included awareness of a delay in the words spoken by the child with IDD, awareness of differences

in lessons at the therapy and education institution for children with IDD, and awareness of the disabilities of children in therapy by siblings who accompanied them to therapy. Also, Case E revealed that younger siblings were aware they could do things that their older siblings with IDD were unable to.

Even if the mother had no knowledge of 'sibling awareness,' it was possible that it occurred if children with IDD attended special support classes at the same elementary school as their sibling(s). Furthermore, there were cases when the prospect of awareness led to a 'mother's anxiety,' and the explanation of disabilities was carried out by a father. When a father explained the disability but did not feel the sibling adequately understood, he consulted the parents of the mother regarding the explanation. Although there were no instances in this study in which support was received leading up to the explanation, in Case C, support was given during the explanation itself. There were also cases in which it was believed that it was too early to provide the explanation of disabilities considering the age of the sibling, but 'sibling awareness' led to an explanation of the child's disability. Overall, the results indicate that mothers provided an explanation of disabilities to siblings owing to 'sibling awareness' or the prospect of it.

After explaining disabilities to siblings, The 'after explaining disabilities to siblings' category relationship diagram integration is shown in Figure 3. Explaining disabilities to siblings included explaining the current situation for children with IDD to siblings to resolve their questions. It included Cases B, C, and D, in which primary caregivers explained to siblings that the child with IDD attended therapy to 'increase their abilities (what they can do).' In Case C, a sibling was actually shown the therapy facilities. Furthermore, there were cases in which primary caregivers requested support from the sibling. For example, in Case B, the primary caregiver stated, 'I want you to support your brother.' In Case A, in anticipation of 'sibling awareness,' primary caregivers shared information about the sibling with IDD enrolling in the school already attended by the sibling, using the name of the school's special support class, and including information on class size (Figures 1–3: A & D).

In 'changes in sibling after explanation,' mothers felt that siblings came to support the child with IDD. In Case C, the sibling told her mother that she felt lonely when she was unable to give the child with IDD sufficient attention. In Case D, the sibling began to ask more questions about the child with IDD, and began showing a desire to come along to therapy. Regarding 'change in sibling relationships,' Cases C and D involved siblings who were trying harder to control their emotions during difficult interactions with the child with IDD.

However, Case A involved a mother who felt that there were no changes in the sibling after explanation, or no change in sibling relationships. Some mothers noted receiving support from fathers for adjusting sibling relationships and devising methods to show greater consideration for siblings. In Cases B and C, primary caregivers consciously tried to communicate their gratitude to siblings when they provided support. In Cases C and D, primary caregivers were conscious of communicating to siblings of children with IDD that they did not have to endure a circumstance with their sibling that they did not enjoy.

There were cases in which support was provided by the mother's parents, primary caregivers of the sibling's friends, or other primary caregivers involved in treatment. For cases in which parents believed that siblings were already aware of the disability, they felt 'satisfaction regarding the decision to explain the disability' when siblings' questions were successfully resolved. When mothers provided them with an explanation of disabilities, siblings made statements of cooperation and were happy to provide support to the children with IDD.

The consequences of 'continuing anxieties' are shown in table 3. Caregivers continued to question siblings' degree of understanding following the explanation. There was also anxiety regarding the impact on siblings when mothers were unable to devote enough time to them and anxiety about whether siblings were performing a mothering role and assuming too much responsibility for the children with IDD.

As all children with IDD had yet to enter school, their enrollment was a factor with significant influence on 'future prospects for explanation of disability.' Mothers saw prospects for 'sibling awareness' both prior to and following school enrollment.

Ongoing concerns. The 'ongoing concerns' category relationship diagram integration is shown in Figure 3. Caregivers felt that explanations of a child's disability became necessary when younger siblings became able to do things their older siblings with IDD could not. In Case D, primary caregivers wanted to be able to provide explanations for any questions the sibling might have. Regarding 'continuing anxiety' for the future, mothers were concerned about each life stage of the siblings, and especially about bullying and teasing regarding their siblings with IDD during their school years. Therefore, there were cases in which mothers expected that an explanation of disabilities may be necessary for siblings depending on whether problems arose at school. In Case C, the possibility that a school would not provide support if children with IDD and their siblings were to be bullied led the mother to feel anxious.

Mothers also had general anxiety regarding the influence of their circumstances on siblings throughout their adolescence, adulthood, and after their parents' death, as well as in their future relationships. In cases in which younger siblings were able to do more than their older siblings with IDD, there was anxiety over the importance of the relationship status between younger and older siblings and how to explain disabilities to younger siblings.

As part of preparing for future explanations about disabilities, parents noted their 'hopefulness about seeking support from primary caregivers with previous experience.' Parents hoped to prepare for future explanations of disabilities by referencing the stories of experienced parents with families who had already experienced that stage of life in the same region or with the same sibling order.

Discussion(s)

One factor that led mothers to explain disabilities to siblings included sibling awareness or the possibility of it. When children were aware that their sibling had a disability, parents wished to resolve any questions they might have had regarding disabilities. This finding is consistent with those of Meyer and Vadasy. (2007) and can be interpreted as parents unknowingly providing explanations that reduce the psychological burden for siblings that can stem from a lack of accurate information about disabilities.

Vatne et al. (2015) underscore the importance of ensuring that parents have adequate knowledge of any rare disorders their child may have and providing the support they need to communicate with children about their sibling's diagnosis. In Miyauchi and Funabashi (2014) study, adult participants reported that even if they were aware of their sibling's disability when they were both children, they may have subconsciously felt unable to ask their parents questions, which may have increased their psychological burden. Ichikawa and Funabashi. (2014) found that many children had few questions for their primary caregivers regarding their sibling with a disability, suggesting that children may be worried that such questions might cause their parents pain. Reports also indicate that if parents thoroughly explain a child's disabilities to their siblings and the siblings possess adequate knowledge of the disability, the sibling relationship is relatively positive and the siblings are more adaptive (Williams et al. 2002).

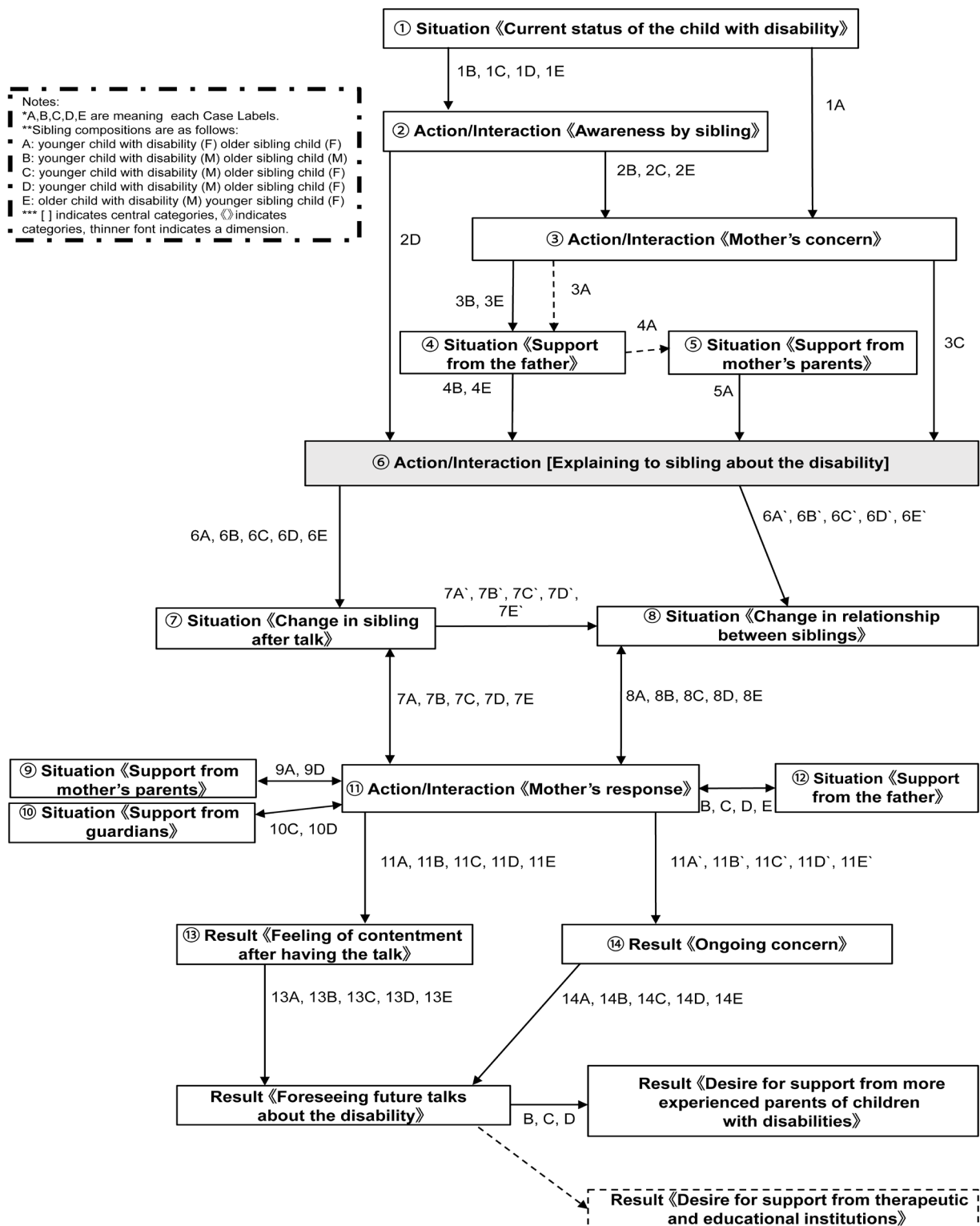


Figure 1. Flowchart of categories in the phenomenon of explaining the disability to the sibling.

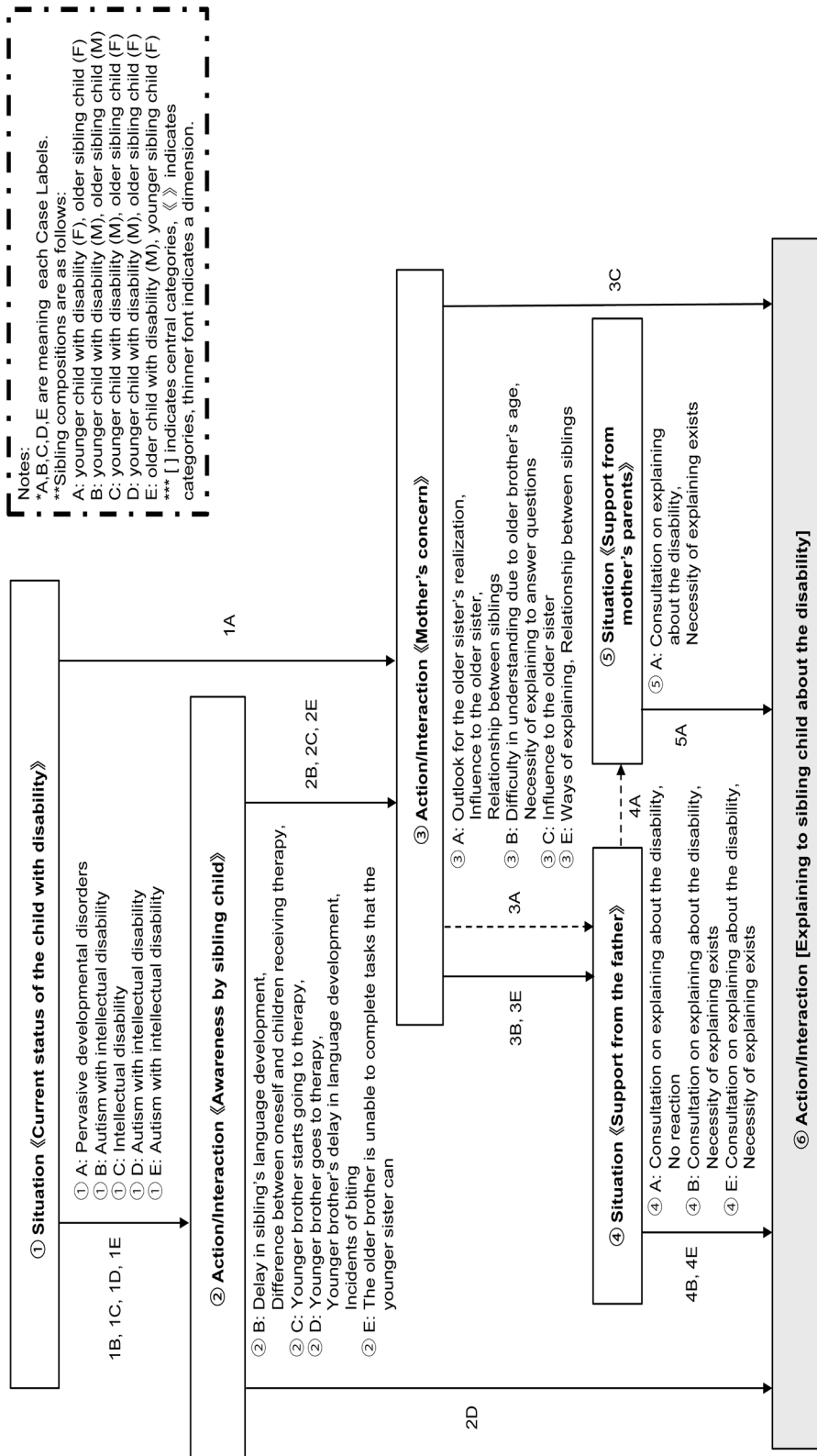


Figure 2. Flowchart of categories before reaching the event of explaining the disability to the sibling.

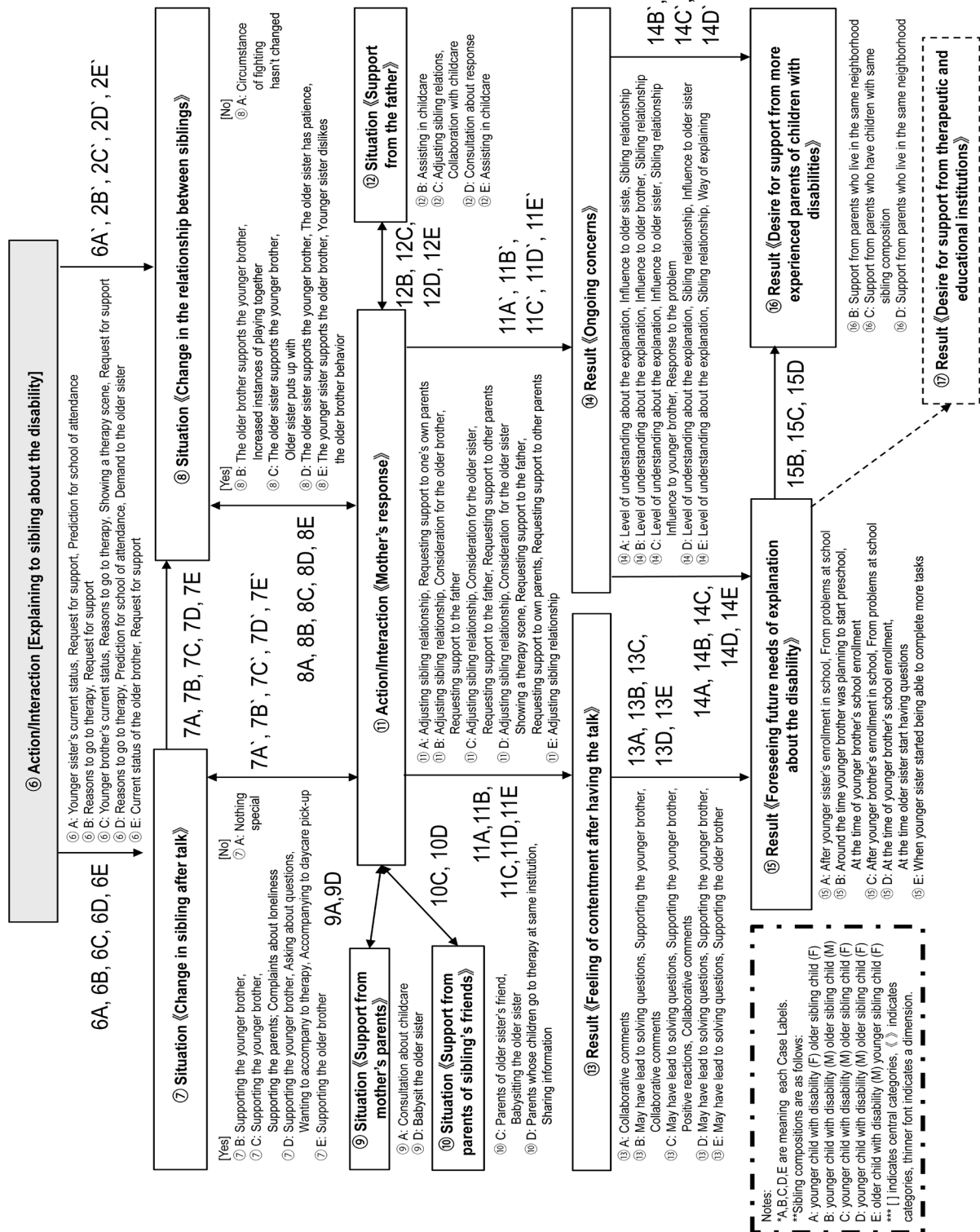


Figure 3. Flowchart of categories after the event of explaining the disability to the sibling.

In this study, mothers mentioned seeing a change in the questions children without IDD asked, such as about what their sibling with IDD was thinking, as part of the changes observed after receiving an explanation of the concerned IDD. Therefore, to reduce and prevent siblings' psychological burden, it is essential to provide them with explanations of disabilities in order to resolve their questions and create a family atmosphere where parents and siblings can talk about the child with IDD.

Caregivers in this study expressed a desire for support from other experienced primary caregivers. It is believed that parents participated in the roundtable meeting because they wanted support from the therapeutic and educational institution, although none explicitly stated this desire. However, they did state a desire for support from other experienced primary caregivers and were told that the institution could arrange a space for them to receive support from experienced caregivers.

However, we were unable to identify any educational institutions - such as kindergartens and schools - interested in providing support to the parents of children with IDD. This lack of interest may indicate that parents attempt to obtain information regarding the school support system from experienced primary caregivers, or that despite the vague worry that children with IDD and their siblings will be bullied once the child enters school, parents do not have a concrete idea on how they can be supported by educational institutions and administrative agencies. Abe and Kanna (2015) as well as Halstead et al. (2018) found that building social support through parental interventions, especially in families of children with behavioral and emotional problems, may improve the well-being of mothers of children with IDD.

Recommendations

Based on this study's findings, we recommend that information be provided to parents of children with IDD on avenues through which they can receive support from experts in educational institutions and governmental/administrative agencies. Also, Kobayashi (2008) states that there is a need for advice regarding the types of institutions that can be found in residential areas and the types of support parents can receive from them.

As mentioned above, mothers in this study commonly expressed anxiety over the possibility that their children with IDD and those without IDD could become the subject of bullying when the former enrolled in school. Therefore, it is important to create an environment where parents and children can easily seek advice about their problems from school counselors and school committees. However, the experience levels of special education teachers vary widely (Kojima et al. 2011; Yonezawa et al. 2011), and

it is expected that support will also vary considerably across schools. Therefore, parents need to be provided with enough information and access to the services of local administrative offices of school education, as well as high-quality special education support.

Yoshikawa (2001) and Tateyama et al. (2003) found that children felt guilt and disgust that led to self-criticism and a decrease in self-esteem if they were unable to prevent their siblings with IDD from being bullied or felt unable to respond appropriately when their friends discriminated against people with IDD. A survey of adult siblings conducted by the Commemoration of International Year of Disabled Persons Nice Heart Foundation (2008) details that 'other people's remarks and confusion over how to respond' and 'bullying/teasing due to disabilities' were specifically mentioned as troubles experienced by siblings while in school. At school, siblings may feel the psychological effects of attitudes toward their siblings and other people with disabilities and bullying owing to their siblings' disabilities. Tsunakawa and Ikemoto, (2012) found that the presence of an understanding teacher was a significant source of support for siblings during their time in elementary school.

As noted by Shoji and Hirano, (2008) and Matsui et al. (2016), for parents and siblings to recognize schools as sources of support, it is important to promote teachers' understanding of 'the special education and the support needs of siblings of children with IDD.'

Our second recommendation is for parents to be provided with opportunities to share their difficulties and information with each other and serve as an important source of support for one another. In this study, caregivers expressed hope for support from experienced primary caregivers.

Along these lines, Halstead et al. (2018) suggest that building social support through parental interventions, especially in families of children with behavioral and emotional problems, may result in improved well-being for mothers of children with IDD. Kugisaki and Haramaki, (2005) found that having a group of primary caregivers with similar experiences who serve as consultation partners allowed parents to 'understand similar situations,' 'listen to useful experience stories,' and 'exchange information.'

However, Fukunaga et al. (2000) found that informational exchange between parents is a powerful source of information, and in an environment where information from other parents cannot be obtained, there is a possibility that parents will rely on incomplete or limited information. Takakura and Yamada. (2007) note that there were few opportunities to meet parents in similar situations, and felt it was necessary to create a space for parents to have such opportunities in kindergarten. The same is true for primary caregivers

who do not belong to a parents' association, whose children do not receive therapy at a therapeutic and educational institution, and whose children with IDD currently attend a typical public school.

Takahashi (2010) notes the importance of encouraging parents to meet other parents with similar experiences. Therefore, one of the major challenges is to identify who will set up the opportunities for parents to share their concerns with one another. In this study, primary caregivers requested the support of experienced caregivers living in the same region. Therapeutic and educational institutions, kindergartens and schools, and local governmental agencies should help parents of children with IDD to meet other parents and, moreover, help them create mutually beneficial self-help groups.

Group-based parental training is thought to be an effective form of peer counseling (Matsui et al. 2016; Miyazaki et al. 2015; Zen et al. 2011). The parent-mentor system promoted by the Japanese Ministry of Health, Labour and Welfare (2011) and the provision of information on regional consultation organizations and their locations may also be important. Providing opportunities for parents with similar difficulties to speak with each other, as well as making information on existing resources available to them, will help create an environment in which parents can select the support resources they find most suitable.

Limitations. Our study involved some limitations. Our study was designed to identify the actual conditions in which parents explain disabilities to siblings of children with IDD; however, participation was limited to parents of children receiving therapeutic and educational services at a private institution. Moreover, the study was based on a small sample and limited participation from fathers. As there was a bias in the positional relationship of siblings in families that participated, we were unable to examine differences owing to birth order or gender. Although we focused on the first time a primary caregiver explained disabilities to their child, such explanations may be repeated depending upon the family situation and development stage. It is necessary to study the explanations of disabilities over time and any changes that occur with repeated explanations, and any difficulties experienced at each developmental stage. Future studies should attempt to recruit a larger number of participants across a wider variety of settings. Furthermore, we were unable to sufficiently determine the kinds of support parents wanted from educational institutions and administrative organizations. Therefore, future studies are required to further explore the types of support that would most benefit parents.

CONCLUSION

A primary reason for parents explaining their child's disability to siblings was their belief that siblings may already have known about the disability, and they wanted to answer any questions that may have arisen. After parents explained the disability, some mothers noticed no changes in the siblings, but others reported that siblings asked more questions about the child with disabilities and expressed a desire to help support them. It is recommended that Japanese parents of children with disabilities receive information on available support systems provided by educational institutions and government/administrative agencies.

REFERENCES

- Abe, N. & Kanna, M. (2011). Research on worries and troubles of parents raising siblings of children with disabilities. *Memoirs of the Faculty of Human Development, University of Toyama*, 6, 63–72.
- Abe, N. & Kanna, M. (2015). Evaluation of a support program for siblings and parents of children with disabilities. *The Japanese Association of Special Education*, 52(5), 349–358.
- Braconnier, M.L., Coffman, M.C., Kelso, N. and Wolf, J. M. (2018). Sibling relationships: Parent-child agreement and contributions of siblings with and without ASD. *Journal of Autism and Developmental Disorders*, 48(5), 1612–1622.
- Commemoration of International Year of Disabled Persons Nice Heart Foundation. (2008). Investigative Report into Siblings of People with Disabilities (in Japanese).
- Ferrari, M. (1984). Chronic illness: Psychosocial effects on siblings—I. Chronically ill boys. *Journal of Child Psychology and Psychiatry*, 25(3), 459-476.
- Fukunaga, I., Tatsumi, J., Momotani, E., Hashimoto, M., Tamai, M., Naoshima, J. and Jitsunari, F. (2000). On problems in child care for parents with disabled children: Questionnaire survey for parents of children with Down syndrome (in Japanese). *Journal of Shikoku Public Health Society*, 45, 137–140.
- Halstead, E. J., Griffith, G. M., & Hastings, R. P. (2018). Social support, coping, and positive perceptions as potential protective factors for the well-being of mothers of children with intellectual and developmental disabilities. *International Journal of Developmental Disabilities*, 64(4-5), 288-296.
- Hayden, N. K., Hastings, R. P., Totsika, V., & Langley, E. (2019). A population-based study of the behavioral and emotional adjustment of older siblings of children with and without intellectual disability. *Journal of abnormal child psychology*, 47(8), 1409-1419.

- Ichikawa, M. & Funabashi, A. (2014). A study of siblings of children with handicapped who accompany the location of rehabilitation (in Japanese). *Bulletin of Aichi University of Education*, 63, 29–37.
- Japanese Ministry of Health, Labour and Welfare. (2011). *Annual report on health, labor and welfare*. Tokyo, Japan: Ministry of Health, Labour and Welfare. Available at: < <https://www.mhlw.go.jp/wp/hakusyo/kousei/11/> > [Accessed 1 October 2019].
- Japanese Ministry of Health, Labour and Welfare. (2017). *White paper on gender equality 2017*. Tokyo, Japan: Ministry of Health, Labour and Welfare. Available at: < <https://www.mhlw.go.jp/wp/hakusyo/kousei/17/> > [Accessed 1 October 2019].
- Kawakami, A. & Ushio, R. (2012). Mothers' feelings towards healthy siblings of autistic children. *Japanese Journal of Research in Family Nursing*, 17, 126–133.
- Kobayashi, H. & Honma, S. (2018). Actual state and request support for siblings of people with developmental disabilities. *Bulletin of the Faculty of Education, Kanazawa University*, 10, 119–128.
- Kobayashi, M. (2008). Viewpoints for understanding parents raising infants with disabilities. *Bulletin of the National Institute of Special Needs Education*, 35, 75–88.
- Kojima, M., Yoshitoshi, M., Ishibashi, Y., Hiraga, K., Kataoka, M., Korenaga, K., Maruyama, K. and Mizuuchi, T. (2011). Structure of elementary and junior high school teachers' consciousness regarding special needs education in regular classrooms. *The Japanese Journal of Special Education*, 49, 127–134.
- Kugisaki, R. & Haramaki, S. (2005). Study of a support system for parents who have children with autism: survey of a parent's support group. *Bulletin of Seinan Jo-Gakuin University*, 9, 72–82.
- Lobato, D., Barbour, L., Hall, L. J., & Miller, C. T. (1987). Psychosocial characteristics of preschool siblings of handicapped and nonhandicapped children. *Journal of abnormal child psychology*, 15(3), 329–338.
- Marquis, S. M., McGrail, K., & Hayes, M. V. (2019). A population-level study of the mental health of siblings of children who have a developmental disability. *SSM-population health*, 8, 100441.
- Matsui, A., Okochi, A., Tadaka, E., Arimoto, A. and Shiratani, K. (2016). The process of enhancing affirmative feelings towards childrearing in the members of self-help groups of mothers of children with developmental disabilities. *Journal of Japan Academy of Community Health Nursing*, 19, 75–81.
- McHale, S. M., & Gamble, W. C. (1989). Sibling relationships of children with disabled and nondisabled brothers and sisters. *Developmental Psychology*, 25(3), 421.
- Meyer, D. J., & Vadasy, P. F. (2007). *Sibshops: Workshops for siblings of children with special needs, revised edition*. Baltimore: Paul H. Brookes.
- Miyauchi, A., & Funabashi, A. (2014). An examination for the view of disorder and barrier that talking of adult siblings: For the ideal method of siblings support. *Bulletin of Special Education and Welfare*, 10, 41–45.
- Miyazaki, M., Miyazaki, M., & Inoue, M. (2015). Sibling troubles on developmentally disabled children and the effects of the parents training method. *Psychiatria et Neurologia Paediatrica Japonica*, 55, 129–142.
- Mori, Y. (2015). Study of the way disease notification is given to children with developmental disorders and their siblings. *Bulletin of Center for Clinical Psychology*, 15, 49–59.
- Nishimura, B., & Hara, K. (1996). Siblings of disabled children (2). *Japanese Journal on Developmental Disabilities*, 18, 150–157.
- Saiki-Craighill, S. (2008). *Applied grounded theory approach (in Japanese)*. Tokyo: Shinyo-sha.
- Saiki-Craighill, S. (2014). *Grounded theory approach - Analysis workbook 2nd edition (in Japanese)*. Tokyo: Japanese Nursing Association Publishing Company.
- Sasaki, S. 2018. Determinant factors for time spent on housework by men at the era of work-life balance in Japan. *Journal of Household Economics*, 47, 47–66.
- Shoji, H., & Hirano, Y. (2008). Supports for siblings of people with disabilities: Interviews with teachers. *Bulletin of the Faculty of Education, Ibaraki University*, 57, 181–190.
- Simeonsson, R. J., & McHALE, S. M. (1981). Review: Research on handicapped children: Sibling relationships. *Child: Care, Health and Development*, 7, 153–171.
- Stoneman, Z., Brody, G. H., Davis, C. H., Crapps, J. M., & Malone, D. M. (1991). Ascribed role relations between children with mental retardation and their younger siblings. *American Journal of Mental Retardation*, 95, 537–550.
- Takahashi, M. (2010). About the problem of the regional life support of the developmental disorder child: From the consciousness survey of the parents in a local core city, "A" city. *Japanese Journal of Disability Sciences*, 34, 189–204.

- Takakura, S., & Yamada, J. (2007). An investigation for family support of children with special needs on early stage focusing on consulting place and person. *Japanese Journal on Developmental Disabilities, 29*, 40–49.
- Takura, S. (2010). The current situation and problems of sibling support for children with developmental disabilities (in Japanese). *Asp Heart, 9*, 12–19.
- Tateyama, K., Tateyama, J., & Miyamae, T. (2003). Notable signs observed in the growth process of “siblings” of handicapped children: Their cause and mother’s care of “siblings”. *Journal of Health Sciences, Hiroshima University, 3*, 37–45.
- Tsunakawa, M., & Ikemoto, K. (2012). A study on the needs of siblings of children with disabilities and the support by teachers in elementary school period. *The Technology in Education, Utsunomiya University Bulletin of the Integrated Research Center for Educational Practice, 35*, 125–132.
- Vatne, T. M., Helmen, I. Ø., Bahr, D., Kanavin, Ø., & Nyhus, L. (2015). “She came out of mum’s tummy the wrong way”(Mis) conceptions among siblings of children with rare disorders. *Journal of genetic counseling, 24*(2), 247-258.
- Williams, P. D., Williams, A. R., Graff, J. C., Hanson, S., Stanton, A., Hafeman, C., ... & Sanders, S. (2002). Interrelationships among variables affecting well siblings and mothers in families of children with a chronic illness or disability. *Journal of behavioral medicine, 25*(5), 411-424.
- Yanagisawa, A. (2007). Problems of siblings of people with disabilities and support strategies for them. *The Japanese Journal of Special Education, 45*(1), 13–23.
- Yonezawa, T., Okamoto, M., & Hayashi, T. (2011). Consciousness of teachers at elementary school toward special support education. *Bulletin of Center for Educational Research and Development, 20*, 337–342.
- Yoshikawa, K. (2001). Self-help group for siblings of the physically and/or mentally challenged: Their own problems and concerns. *The Bulletin of the Faculty of Sociology, Toyo University, 39*, 105–118.
- Zen, Y., Yuge, M., & Iwasaka, H. (2011). Evaluation of effectiveness of the family support class in the public health center using the technique of parent training. *The Journal of Child Health, 70*, 669–667.