

[Original Article]

## The Meaning of 'Assertion' for Mothers of Children/Persons with Severe Motor and Intellectual Disabilities at Home from School-Age to Young Adulthood

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The purpose of this study is to elucidate what 'assertion' means to the mothers of children/persons with severe motor and intellectual disabilities (SMID) at home during the period from school-age to young adulthood. The study was targeted at a group of ten mothers who live with children/persons with SMID at home. Referring to the method of content analysis, a qualitative factor exploratory analysis method was utilized to create verbatim records, which were then used for coding and extraction of categories.

The analysis extracted the following six categories: Resolution to Self-Disclose Their Hesitation as Mothers; Expressing the Gratitude Originating from Sympathy; Realization of Alternative Methods of Self-Expression Originating in Hardship; Mutual Understanding through the Transmission of Knowledge and Experience; Preparation of Foresighted Development of Family; and Clue to Socialization through Connection with the Local Community. In addition, fifteen other subcategories were extracted. The mothers' resolution to self-disclose their honest feelings could be the foundation of assertion. Through actions such as expressing their gratitude to the people they met, realizing alternative methods of self-expression, or deepening mutual understanding and sympathy through expressing their feelings, mothers were able to accelerate the formation of the relationship of mutual trust. Also, through the transmission of knowledge acquired from their experience, mothers were able to find peers and connect with them. Moreover, by conducting 'assertion,' they were at the same time conducting foresighted preparation of the prospected development of their family. 'Assertion' for mothers accelerated their connection with the local community and helped them to find a clue to socialization.

The results also suggested a few necessary factors involved when providing support for these mothers, including: to support in such way to strengthen the ability mothers originally have; to coordinate the environment where they feel accepted by both the place and the people when they express their honest feelings; and to redirect them to professionals, such as appropriate supporters or groups, whom they can consult with about their anxiety for the future when they need to.

**Key words:** assertion, children with severe motor and intellectual disabilities, mother

### I. Introduction

With the diffusion of the principle of normalization in addition to advancements in medical service and promotion from the administration, a switch-over to home-care has been encouraged, which resulted in the increase of the number of

children/persons with severe motor and intellectual disabilities (written as 'SMID' hereafter) (Ministry of Health, Labour and Welfare, 2013). Although it is evident that the further improvement in medical service and more promotion of administrative measure will increase the ratio of the children/persons with SMID at home, in many cases they have various physical difficulties, such as paralysis, deformation, contracture and strain. Therefore a more comprehensive support that addresses not

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only the physical difficulties but also such psychological factors as communication disorders will be essential, in interrelation to the complications unique to persons with SMID (Kitazumi, 2016). Especially, the children/persons with SMID in the age group of puberty to young adulthood following their early school years are in a period in which they will experience various distinguished changes that accompany their physical growth. It coincides with the changes in their living environment such as entering the compulsory education period or graduation from it, as well as the decline in the family member's ability provide nursing care due to their aging. This period could greatly affect all family members. Therefore, it is necessary to take a long-term view when providing support for children/persons with SMID in their post-school, puberty-to-young adulthood period, in order to include their family as the subject of support.

It is naturally speculated that mothers of the homebound children/persons with SMID must have been making effort to improve their self-expression to communicate their feelings in situations such as when accepting the handicap of their children when first discovered, when the condition of the handicap worsens and when required to make decisions for treatment selections after the condition worsens. However, in many cases, mothers of children/persons with SMID did not know that there are places where they can go for consultation, or in some worse cases, that they were even allowed to consult on such issues. Their decisions were therefore influenced only by the information and knowledge they had at hand. They often felt negative emotions related to the fact that there is a disparity in the transfer of support (Hioki, 2009). Not all mothers of children/persons

with SMID can honestly express their distress, especially when they are carrying their burden and responsibility by themselves, shutting up their emotions in order to endure the hardship of their lives (Yamamoto, 2011). It is also true in the actual field of nursing, that not all mothers are capable of expressing their thoughts and feelings honestly, and it is important to provide support that encourages them to express their own feelings. therefore 'assertion' is drawing attention as the method of developing smoother communication (Tamase, 2003).

Moreover, the trend regarding both the Japanese and international study on the 'assertion' of the family with homebound children/persons with SMID weighs more on the 'assertion training,' and there is little to no research that addresses "the family of the handicapped" focusing on the feelings of mothers from the viewpoint of 'assertion.' Clarifying the meaning of 'assertion' for mothers could lead to the suggestion of supporting the family, including mothers. This paper seeks to elucidate the meaning of 'assertion' for mothers while focusing on the mothers of homebound children/persons with SMID, and aims to provide suggestions for the ideal way to support the family of children/persons with SMID, including mothers.

## II. Method

### 1. Definitions of Terminology

**Assertion:** Expressing one's own feelings, thoughts and beliefs while respecting each other's standpoint and opinion, with an equitable frame of mind, honesty and straightforwardness, and with a method that is appropriate to the situation.

**Children/persons with severe motor and intellectual disabilities:** children/persons who fall under

the classes 1 through 4 of Oshima's classification who are bedridden or keep sitting a chair with intelligence quotient under 35 (Oshima, 1998).

The meaning of 'assertion' for mothers of children/persons with severe motor and intellectual disabilities at home: The intention and purpose put into 'assertion' by the mothers of children/persons with severe motor and intellectual disabilities who live at home, or how the mothers capture the reason and significance of making 'assertions.'

## 2. Research Participants

Mothers who live with and take daily care of children/persons with SMID during the period from their puberty to young adulthood, who fall under classes 1 thru 4 in Oshima Classification.

## 3. Data Collection Method

A semi-structured interviewing method was employed. Utilizing a semi-constitutive questionnaire sheet made uniquely out of examinations on research materials and literature (Hiraki, 2015; Robert, Michael, 2009), an inquiry was made on the participants' feelings. For instance, when did you need the assertions during their lives at home with the children/persons with SMID, how to make the assertions and how do you understand the assertions by yourself.

Interviews were arranged on convenient dates and time for the research participants, in a room they requested, or at a provided location where privacy can be afforded. The content of the interview were recorded onto an IC recorder upon gaining prior consent from the participant. Time required for the interview was anywhere from 30 minutes to an hour and 10 minutes (average of 44 minutes), and was conducted only once per participant. Data collection took place during the period of March to July of 2016.

## 4. Analysis Method

Verbatim records were made from the contents of the recorded interviews. Utilizing Krippendorff's content analysis method as reference, coding and analysis was processed through qualitative factor exploratory analysis method (Krippendorff, 2003). For each narration on the meaning of 'assertion' given by mothers of children/persons with SMID at home, each piece of data was divided, while paying attention to the context and meanings of the expressed words, so that each individual sentence would constitute a single meaning and cell. Then with the increased abstraction level, categories and subcategories were generated. During the process of analysis, three specialists of qualitative research provided supervision to make the examination sufficient, in order to achieve adequate levels of credibility and validity.

## 5. Ethical Considerations

Upon selecting participants, researchers provided written explanation on the summary of the research and its ethical considerations to the facilities and groups that are accessed by children/persons with SMID at home, and a request was made after obtaining their consent. The following facts were explained in written form to the participants who agreed to join the research prior to getting their consent: Participation in this research is based upon their free will and deciding not to cooperate will not result in any disadvantage for either the facility or the individual; the data acquired will not be used for any other purpose than the purpose of this research; the collected data will be treated with extreme care. This research was reviewed by the ethics committee of Kawasaki University of Medical Welfare, and was conducted upon their approval (approval no. 15-087).

Table 1. Summary of Participants

Cases	Mothers		Severely Handicapped Children/Persons			Household Structure (including children/persons with SMID)
	Age	Age	Sex	Oshima's Classification	Main Medical Care	
A	late 30s	under 10	Male	1*	gastrosoma suction	Parents with 2 children
B	late 40s	under 10	Male	1	gastrosoma suction	Parents with 3 children
C	late 40s	late 10s	Female	1	gastrosoma suction tracheotomy ventilator	Parents with 3 children
D	early 50s	late 20s	Male	1	gastrosoma suction tracheotomy ventilator	Parents with 3 children
E	early 50s	early 20s	Female	2**	none	Parents with 3 children
F	late 40s	early 20s	Female	2	none	Parents with 3 children
G	late 50s	early 20s	Male	2	none	Parents with 2 children
H	early 50s	late 20s	Male	1	none	Parents with 2 children
I	early 50s	early 20s	Female	1	gastrosoma suction	Parents with 1 child
J	late 50s	early 20s	Male	1	gastrosoma suction tracheotomy ventilator	Parents with 3 children

\* children/persons who are bedridden and IQ under 20.

\*\* children/persons who sit a chair and IQ under 20.

### III. Results

#### 1. Summary of Participants

There were ten participants, all of whom were mothers living with their children/persons with SMID at home. The age topography consisted of one woman in her thirties, three in their forties, and six in their fifties. The average age was 50.0 years old, with the median 52.0 years old. As for their family circumstances, all of them were nuclear families, with 9 out of 10 children/persons with SMID having brothers and/or sisters. The age range of the children/persons with SMID spanned from 7 to 26 years old. The average age was 19.8 years old, with the median of 22.5 years old. There were 6 children/persons with SMID who needed medical care (see Table 1).

#### 2. The Meaning of 'Assertion' for Mothers of children/persons with severe motor and intellectual disabilities from School Age to Young Adulthood

For the meaning of 'assertion' for mothers of children/persons with SMID in their school age to young adulthood periods, 6 categories and 15 subcategories were extracted. In the following, categories will be put in between [ ], and subcategories in [ ]. The raw data from participants will be written with *Italic*, and where supplementary explanations are necessary, it will be described in ( ). The providers of raw data will be labeled with alphabets.

Based on the content analysis method, the surrounding contexts and contents of the narrative were typified and categorized. As a result, along with the fifteen subcategories described in Table 2, the following six categories were extracted: [Reso-

Table 2. The Meaning of 'Assertion' for Mothers of children/persons with severe motor and intellectual disabilities at home from School-Age to Young Adulthood

Categories	Sub categories
Resolution to Self-disclose Their Hesitation as Mothers	Self-disclose the puzzlement about the handicap Continue to express feelings while accepting the handicap Never give up on expressing intention to change the situation
Expressing the Gratitude Originating from Sympathy	Appreciating the cooperation in overall support Being understood through sympathy To stand close to children's minds and make them smile
Realization of Alternative Methods of Self-Expression Originating in Hardship	Become aware of the immaturity of self-expression To devise communication methods according to people and situation
Mutual Understanding through the Transmission of Knowledge and Experience	To support each other with peers through sharing of worries and information Transmission of empirical knowledge leading to stability
Preparation of Foresighted Development of Family	Availability of facilities limited by the intervention of medical care To adjust lifestyle according to the assumption of the aging of parents generation To not desire giving burdens to brothers/sisters
Clue to Socialization through Connection with the Local Community	Connection with local community broadens the view Connection to the local community brings confidence and accelerate socialization

lution to Self-Disclose Their Hesitation as Mothers]; [Expressing the Gratitude Originating from Sympathy]; [Realization of Alternative Methods of Self-Expression Originating in Hardship]; [Mutual Understanding through the Transmission of Knowledge and Experience]; [Preparation of Foresighted Development of Family]; and [Clue to Socialization through Connection with the Local Community].

1) [Resolution to Self-Disclose Their Hesitation as Mothers]

A mother commented that, "I was not ready at all to accept (the child's handicap), and thought it was impossible to take home (snip). There were various things I was to experience for the first time, so I was puzzled, or anxious . . . or something close to that." (C), indicating her puzzlement and anxiety. Moreover, after going through experiences of distress repeatedly, another mother expressed that "When my child was hospitalized, I had a chance to meet other parents of (children with a handicap of) similar severity. Just the fact that I had someone I could talk to, that I could talk about

my feelings, was a relief for me." (H), exhibiting the changes in the state of her mind towards [self-disclosing the puzzlement for the handicap]. In addition, after several experiences of having a hard time in expressing her own feelings, she became aware of the importance of [continuing to express feelings while accepting the handicap], and came to believe firmly that her feelings and requests would not be understood unless she verbalized them. And through saying that, "we must keep on saying, without giving it up, without thinking to yourself that it's no use, even though you might get depressed, if you want it to be understood." (C), she expressed her will to the people around her, believing with conviction that [never giving up on expressing intentions in order to change the circumstance]. 'Assertions' for mothers exist in the middle of a series within a process, and are based on their combination with their resolution to honestly express their hesitation as mothers. The meaning of 'assertions' for mothers can be defined as [Resolution to Self-Disclose Their Hesitation as Mothers].

2) 【Expressing the Gratitude Originating from Sympathy】

While living the life of a homebound nurse, mothers started to have the feeling of [gratitude towards cooperation in overall support] towards the people who support their lives as someone providing homebound nursing, namely doctors, visiting nurses and therapists. One mother expressed that, “(the visiting) nurse, the helpers and everybody (snip) each of them must be (thinking about) what’s good for (child’s name), what’s easy for (child) so that he can smile (when supporting him).(cry).” (A). She perceived them as people who [sympathize and understand feelings], and recognized them as people who share the same goal of [drawing close to the child and making him smile]. In this category, ‘assertions’ for mothers meant 【Expressing the Gratitude Originating from Sympathy】.

3) 【Realization of Alternative Methods of Self-Expression Originating in Hardship】

A mother said that, “maybe I was not doing enough (self-expression). Now that I think back, I was not saying or doing much. But if I had said more, I can’t help but think about the possibility of being able (to go to school) within the community. On the other hand, I think I can (say it) now.” (F). It indicates that she had realized that her own method of self-expression was not articulating her feelings and was inadequate for the task, which is the experience of [realizing the immaturity of her self-expression]. Moreover, another mother mentioned that, “I arbitrarily think that maybe it is easier for the people (on the service side), if I did (my self-expression) in a reserved manner. (snip) I think I would pull back if I didn’t want people to feel unpleasant, or if I wanted them to treat (child) pleasantly. I think taking a step back and ask them

may be a better way.” (A). This indicates that mothers are learning the importance of [devising ways to communicate depending on the person and situation] through their experiences of failing to communicate their feelings, in addition to learning about opportunities to come in contact with other mothers’ method of self-expression. ‘Assertions’ for mothers in this category reflects the 【Realization of Alternative Methods of Self-Expression Originating in Hardship】.

4) 【Mutual Understanding through the Transmission of Knowledge and Experience】

A mother expressed that, “As we sent to day care centers, we met with children with similar handicaps, and their mothers, who taught us about a lot of things. The thing that saved me the most was this encounter with the parents of children who had similar handicaps (snip) that really helped us get through.” (I). She had the experience of [being supports for each other through sharing concerns and information with friends], by honestly communicating about the difficulties and anxieties in facing her child’s handicaps to mothers of other children with similar handicaps, whom she considered as her friends. And she continued saying, “I would like to get information ahead of time from parents of older children with SMID. Up to compulsory education, or even to high school, we could manage through Schools for Special Needs Education or visiting nurses. But after that, we had no idea what may come, and that’s the kind of information I wanted. (snip) When I tell them what was bothering my mind, they’d go, it works this way.’ it may be the visiting nurse or therapists, or even other mom-friends.” (B). It indicates that not only the professionals, but also mothers of elder children could be the source of helpful advices coming from their experience. Thus, the transmission of empiri-

cal knowledge took place, and she experienced the [transmission of empirical knowledge leading to the state of peace], acquiring mutual understanding as parents of children with handicaps and helping each other keeping the peace of mind. Assertion for mothers in this category means **【Mutual Understanding through the Transmission of Knowledge and Experience】**.

5) **【Preparation of Foresighted Development of Family】**

A mother of a child with SMID tells that, "*since my child needs a lot of medical care, it puts him out of (the candidate for acceptance into the care facility), narrowing the options down a great deal, leaving us with very little (facilities) to choose from.*" (C) It indicates her anxiety for the future, caused by the present situations where they have hard time choosing facilities they can utilize during long vacations, after school, or after graduating from the support school due to [the limitation of available facilities due to medical care intervention]. In addition, another mother mentioned that, "*my parents try to give so much for us, and even though I am very grateful, if we continued on like this, it will ruin their own lives. I mean, they are only going to get older, and if I felt comfortable there, if I decided to rely on them, it'll become impossible for me to live without them.*" (H) It indicates her fear that arises as she and her parents get older, for the possibility of not being able to continue on with the life with a homebound child with SMID. She was also aware of the necessity to prepare for [adjusting lifestyle according to the assumption of the aging of her parents generation], and had started expressing her intentions at early stage. Moreover, there was another mother who told, "*I don't think my younger child can comprehend why his big brother is this way yet. I don't*

*want to put too much pressure on him when he is not capable of understanding the present situation.*"

(D). It indicates that she considers for the feelings of the brothers/sisters of the child with SMID with just the same intensity, so that she hopes to [free brothers/sisters from the stress]. Assertion for mothers in this category meant **【Preparation of Foresighted Development of Family】**

6) **【Clue to Socialization through Connection with the Local Community】**

A mother mentioned that, "*I believe I was given a child with handicap by fate, and now I am starting to feel the desire to do everything I can do as a parent, not only for my child but also for all of the children with serious handicaps. (snip) Raising a child sure is hard, but as far as my feelings go, I think now I have a broader vision, with which I can watch over not only my own child but also the entire picture.*" (J) It indicates that if a mother could express her own feelings and connect with the society, it results in [visions widened by the connection with the society], which in addition produced another result of [improved socialization and self-confidence through the connection with local community]. Assertion for mothers in this category meant **【Clue to Socialization through Connection with the Local Community】**.

#### IV. Consideration

When analyzing the assertions in the communication made by the mothers of in-home severely handicapped children/persons in their late-childhood to adolescence, four types of meaning were found to be associated with those assertions. They are: 1) the foundation of the assertion; 2) promoting a structure for a relationship of mutual trust; 3) preparing for the anticipated future development

of the family; and 4) path for socialization. First, the determination on the part of the mothers to self-disclose their honest feelings was a strong enough foundation for their assertion. The establishment of the relationship of mutual trust was promoted through the mothers' expression of their appreciation to the people they met and their realization of the different methods of self-expression, and through the deepening of mutual understanding and sympathy by expressing their feelings. Moreover, through the handing-down of the knowledge acquired through their experience, mothers connected with those around them and gained peers. Furthermore, the mothers' assertions also acted as a means of preparing for the anticipated development of the family in the future. Assertions by mothers also accelerated their connection to the community, eventually becoming a path to their socialization. Based on these facts, this thesis intends to consider these four meanings of assertion.

#### 1. The foundation of the assertion

It has become clear that what is important for mothers of homebound children/persons with severe motor and intellectual disabilities (SMID) in their first step of making "assertions" is to incorporate the [resolution to self-disclose the confusion they have as mothers] into the meaning of their "assertions." The main caregivers who nurse homebound children/persons with SMID in a family are usually their parents, among whom mothers account for 95% (Ozawa, Kanda, Kishi et al., 2011). Mothers are informed of the disability of their children in the early period around childbirth, and are expected to take the role of mothers of children with SMID (Uehara, Narama, 2016). Moreover, especially in the case of children with SMID who need medical treatment, mothers are

held responsible for sustaining their children's lives after they are discharged from the hospital. From the narratives of mothers collected for this research, there were many cases in which they said that, "in addition to the child being with SMID, experiencing childbirth and childcare for the first time left me clueless, and I spent every-day in anxiety and confusion." Mothers of infants with SMID tended to feel emotions such as unarticulated anxiety, superficial understanding of the notification, and isolation from the people around, until they acquire confidence as a parent (Miyazaki, 2002). This research also witnessed mothers gaining the experience of [self-disclosure of their confusion over disabilities] though feeling anxiety and confusion, facing and overcoming countless ordeals involved in tackling issues, such as the care unique to children with SMID or the life-support care for children who require medical care. Likewise, though little by little and with hesitation, mothers became conscious of [continuing to express their feelings while accepting the disability], and thus they were able to cultivate their determination as mothers of children with SMID. Generally speaking, the acceptance that something it true is called "belief." For mothers to have a strong belief that they will [never give up on expressing their intention to change the situation] is one of the essential factors of making "assertions." An "assertion" is a candid way of self-expression based on respect for others and the self (Hiraki, 2015). In terms of respecting their own feelings, it is essential for mothers to have a determination to candidly self-disclose the anxiety they feel while facing various ordeals, in addition to being able to properly chose the methods of self-expression. Moreover, just as Albertini & Emmons emphasized "assertion" as a human right, stating that



“anyone has the right to be assertive” and “it’s OK to be assertive,” (Robert, E. A, Michael, L. E., 2009) mothers of children with SMID have the right to make “assertions” in order to be respected for their human rights. The author believes that the mothers’ ability to express themselves and make “assertions” will lead them to cultivating their own self-respect, and eventually to protecting their human rights and mental health. Therefore, it is necessary for mothers to know the methods and process of self-expression. It is also necessary to provide occasions and people with whom mothers can freely let out their hardships and worries.

## 2. Promoting a structure for a relationship of mutual trust

It is clear that the formulation of relationships based on mutual trust is accelerated when both mothers and supporters recognized their own roles, and mothers expressed their feelings of profound gratitude towards the expertise, roles and capabilities of their supporters, therein **【expressing a gratitude born out of sympathy】**. Today, as the home care for children/persons with SMID has become possible, it is important to prepare a system that will allow for the long-term continuation of home care through choosing necessary support. To this end, mothers of children/persons with SMID must express themselves to communicate their feelings to their supporters and to form relationships based on mutual trust. Many of mothers’ narratives also thankfully indicated that the utilization of day care and visiting services provided them some leeway, both mentally and physically. Moreover, the mutual relationship with the visiting nurses and doctors can be another type of mental support different from their family. Though the promotion of home healthcare attach-

es importance to regional cooperation, in reality, it is difficult to keep a tight connection between different professions. However, if this challenge was overcome and they succeeded in providing support based on an understanding in the mothers’ requests expressed in their intention, and on the cooperation between professionals providing the service, mothers tend to feel gratitude such as **【appreciating the cooperation in overall support】**, resulting in their mutual trust relationship getting deeper. Thus, the mothers’ expression of gratitude will promote the formation of these relationships. In addition, the formation of relationship with other mothers is important (Arimoto, Yokoyama, Nishigaki et al., 2012). It is essential to have someone who will **【sympathize with and understand their feelings】**, as well as someone who will **【stand by their feelings and make their children smile】**, while thinking with them about the best life for their children and providing support for the common goal. Overseas research also points out that the essential factors that accelerate the use of “assertions” are experience, mutual trust with their friends, and healthy communication (Reese, Simmons, Barnard, 2016). It suggests the necessity of the support to form a trusting relationship through the accumulation of sympathetic understanding and cooperation with other mothers.

Moreover, mothers followed the steps of **【recognizing alternative methods of self-expression originating in hardship】** through the process of responding to a crisis in their family, by **【becoming aware of the immaturity of their self-expression】** and acquiring the ability to **【devise a way of communicating according to the person and situation】**. Mothers testify that there were countless occasions in their lives, in which they felt difficulty and faced a crisis. A “crisis” is defined as a circum-

stance in which a person faces a turning point in which he/she wonders whether it will be possible to maintain his/her life. A crisis in a family indicates a circumstance in which a family faces a situation that cannot be coped with through their conventional lifestyle, and their failure to respond properly could mean that it would become difficult to maintain the family (Morioka, Mochizuki, 2016). The life of a family with children/persons with SMID is indeed a series of crises. Families that succeeded in responding to these crises will eventually recover their mental stability. Mothers who participated in this research told of their experiences responding to crises while keenly feeling social stigmas. While experiencing conflicts and ordeals that arise in each life-cycle of the family, mothers tried to adjust the family function and overcome it through self-expression towards administrative officers, school teachers, hospitals, facilities and visiting service providers. This coincides with the concept of “family empowerment,” (Nojima, 2007) in which, when there is an emerging problem, a family tries to improve the situation through fulfilling their potential, recognizing the situation they are in, acknowledging the issue and proactively tackling the health issue. Self-expression can be categorized into three types: assertive, aggressive and non-assertive (Hiraki, 2015). The majority of mothers’ narratives provided in this research stated that their “self-expression is immature and insufficient,” which suggested that they were aware that their self-expression was non-assertive. However, there were a few mothers who expressed their feelings while taking into consideration the circumstances and standpoints of each of their supporters, namely their doctors, nurses and administration. Those mothers were capable of being considerate and devising methods

of self-expression according to the situation and person. There were also mothers who learned from their experience of witnessing other mothers’ aggressive ways of self-expression fail to bring desirable results. Moreover, while the concept of “assertion” was cultivated in western culture and therefore requires extra consideration when applied in Japan (Tamase, Baba, 2003), there were mothers who intentionally put it into practice in order to keep their human relations healthy. Therefore, this suggests the necessity of supporting the empowerment that will allow mothers to become aware of various methods of self-expression and encourage their process of selection, and that will allow them to fulfill the potential they possess in concert with others.

In addition, upon understanding what “assertion” is and by passing on the knowledge they learned from experience to others, mothers encourage [mutual understanding through the transmission of their knowledge and experience] and cultivate new relationship. Parents of children/persons with SMID tend to share stronger senses of solidarity and affinity with other parents in the same situation, compared to parents without SMID children, and the interaction between those parents favorably impacts them, both mentally and physically (Ushio, 2014). The deepening of human relations beyond the ordinary association between parents is an essential factor in improving the quality of life (Ushio, 2014). “Resilience” is often mentioned as the ability to recover from distress and to better cope with ordeals experienced in life (Rutter, 1985). In order to manifest their capacity for “resilience” under difficult circumstance, the existence of a peer is considered to be highly effective (Takemura, Tsushima, Tomari, 2015). In this research, many narratives suggested that to

be able to share the worries and difficulties with other mothers of children with the same disability and to become peers to each other were a great help in coping with challenges and ordeals. For mothers to meet with other mothers of children with similar disability in facilities and hospitals, to deepen their relationship through expressing concerns and anxiety, and eventually to build a relationship of sympathy for each other were all great ways of providing mental support, resulting in [supporting each other by sharing worries and information among peers]. Moreover, by building relationship with mothers who had more experience, they acquired wisdom and tools from their experience. This helped to make the nursing life at home with SMID children more peaceful from the previously experienced state. It produced favorable results such as the [transmission of empirical knowledge leading to peace]. In order to achieve such results, it was thought necessary to provide support that will create an environment in which mothers can be informed at the proper moment and to introduce family meetings and other mothers to each other who can share the same experience.

### 3. Preparing for the anticipated future development of the family

One of the purposes of “assertions” for mothers was to make [preparation for family development with an eye to the future]. The nursing of children with SMID starts from the moment they are diagnosed with the disability. Therefore, cooperation with various specialized fields and building of support for the family is important (Fujiwara, 2015). However, the support for the persons with disabilities in their later adulthood is insufficient due to a lack of a support system for home care as well as the facilities to which they can be ad-

mitted (Fujiwara, 2015). Moreover, though the number of the homebound children who need medical care is on the increase, availability of facilities and services is still insufficient (Iwasaki, 2014). Narratives of mothers in this research also indicated that one of their major concerns was their anxiety over the present situation in which the [facilities available for medical intervention are limited], which is especially notable for many SMID children. Furthermore, mothers continuously feel anxiety over the aging of both persons/children with SMID and their own parents, as well as their life after the passing of the parents. It is essential to carry out some life adjustment in preparation for the expected changes in the life cycle of the family in the future. It is important to express their intention for the adjustment in services to the providers such as administrations, prior to the expected changes in the life of the family in the future, so that they will be [prepared for the life adjustments expected due to the aging of the parents' generation]. Moreover, mothers expressed that they [do not wish to impose a burden on other siblings] in the future. They feel a sense of guilt for their insufficient performance as a mother toward other siblings during their childhood (Nishihara, Yamaguchi, 2016). They hope to watch over and support how other siblings of the children/persons with SMID will confront their sisters/brothers with disabilities (Nishihara, Yamaguchi, 2016) Furthermore, mothers hoped for a system that would lighten the burden after the marriage of the siblings of children with SMID or after the death of the parents (Komiyama, Miyatani, Koide et al., 2008). It is suggested that for mothers to be able to frankly self-express their concerns about the siblings of children/persons with SMID, and to properly utilize the social resource for lightening

the burdens imposed on the siblings, health professionals must provide information not only from the viewpoint of children/persons with SMID but also of the entire family, and execute an environmental adjustment in which mothers feel comfortable when requesting support.

#### 4. Path for socialization

For mothers to practice “assertions” to connect with society is one of the vital methods for enriching the life of the family, including mothers and the children, and is a [path to socialization through connections to the local community]. Today’s society promotes an increase in the level of academic achievement for both females and males alike, and with the enactment of the August 2015 law to promote female participation in working life (Female Participation Promotion Law), the social progress of women was promoted as a national policy (Gender Equality Bureau Cabinet Office, 2016). However, the life style of mothers who have given birth to and raise children with SMID is assumed to require many hours providing care for their children, strongly increasing the possibility that their lives will lack social contact. Mothers of children with SMID are expected to not only take care of their children in their daily life, but also to accompany them to and from school and during classes. With the life of children after school and during long vacations not being guaranteed, it is very difficult for mothers to be employed (Tanaka, 2015). Especially for mothers of SMID children/persons who need medical care, their opportunity to come in contact with the local society is extremely limited since the medical treatment to sustain life is necessary at all times. Many of the mothers of children who need medical care, who participated in this research also indicated that, “after giving birth to children with SMID, they felt their life was dissoci-

ated from society...” On the other hand, there were mothers who stated that, “Though they spent their lives just for the children at the beginning, now they wish to participate in social activities that could help other children with SMID as much as possible.” In cases of mothers who succeeded in building a new relationship through “assertions,” they were able to accumulate the experience of [further socializing by connecting with the society and becoming more confident], and by being appreciated and needed. Furthermore, the social participation of mothers was further promoted through [their horizons being broadened by their connections with the local community]. Mothers connected with their community through practicing “assertions,” and in order to improve the family’s surrounding environment, they utilized it as the path to their socialization creating smooth relationships with society. Thus, the results of this study emphasized the importance of adjusting the environment so mothers would be encouraged to make “assertions,” allowing their socialization to be accelerated and them to gain more confidence in their own lives.

## V. Conclusion

This research elucidated the meanings of assertion for mothers of homebound children/persons with SMID at school-aged to adolescence period, through conducting interviews to them, and analyzing their intentions and purposes in assertions made while raising children/persons with SMID, as well as their thoughts on how they perceived the reasons and significances of making assertions.

There is a necessity to support their natural strength to help them live their lives with confidence, as well as to adjust the environment so

that they can have places/people where/to whom they can express their straightforward feelings. Also, it suggested the importance of supporting them with long-term viewpoint, namely by introducing them to the family association or the professionals to whom then can consult their future anxieties at the appropriate timing.

## VI. Limits and Problems of the Research

The participants for this research were selected from group of people who do not feel pain in talking about their experience regarding assertions, based on the viewpoint of ethical consideration, which, as a result, provided mostly positive opinions about it. Also, data was possibly biased to a certain degree, since it was collected from users of facilities and organizations located in only one prefecture, and because most of the participating mothers had children in the age group of adolescence. For the future research, the existence of difference due to regional characteristics needs to be verified, along with examination based on the characteristics of each age group of participants. Furthermore, interviewing family members other than mothers in order to attempt more comprehensive intervention towards each family member will be necessary, so that the higher precision in selection of analysis and analysis utilizing triangulation can be achieved.

(Received August, 21, 2017)  
(Accepted May, 17, 2018)

### Acknowledgments

I thank mother and staff who cooperated with a research.

This report is a partially revised and edited version of a master's thesis submitted to the Graduate School of Medical Welfare Department at Kawasaki University of Medical Welfare in 2017.

### Author Contributions

Y.T. contributed to the conception and design of this study, conducted the qualitative research, and drafted the manuscript; K.M. supervised the entire study process. Both authors read and approved the final manuscript.

### Conflict of Interest

The authors declare no conflict of interest.

### References

- Arimoto, A., Yokoyama, Y., Nishigaki, K., et al: Viewpoints of visiting nurses to support mothers caring for children with special health-care needs, *Journal of Japan Academy of Community Health Nursing*, 14(2): 43-51, 2012
- Fujiwara, R: Special difficulties faced by families of children with disabilities and necessary support. *Japanese Journal for Problems of the Handicapped*, 42(4): 250-257, 2015
- Gender Equality Bureau Cabinet Office: (Cited 2 January 2017) Available from URL [http://www.gender.go.jp/policy/suishin\\_law/](http://www.gender.go.jp/policy/suishin_law/), 2016
- Hioki, M: An analytical study using active support: The significance and suggested support to children, young people and their families facing home and communal difficulties. *The Annual Report of Research and Clinical Center for child Development*. 3: 45-53, 2009
- Hiraki, N. (ed): *A Revised Edition Assertion Training (4th edn)*, 15-30. Kaneko Shobo, Tokyo, 2015
- Iwasaki, Y.: Juushoushinshinshougai nikansuru iryou sien no genjyou, *The Journal of Child Health*, 73(2): 240-242, 2014
- Kitazumi, A.: Juushoushinshinshougai eno genzai kako mirai—kouken to kadai nituite kangaeru—, *Journal of Severe Motor and Intellectual Disabilities*, 41(1): 3-7, 2016
- Komiyama, H., Miyatani, M., Koide F., et al: Mothers' perception of difficulties and their ways of coping with the siblings of children with severe motor and intellectual disabilities in home care, *Journal of Japanese Society of Child Health Nursing*, 17(2) 7: 45-52, 2008
- Krippendorff, K./Mikami, S., Shiino, N. & Hashimoto, Y., *Technique of the message analysis invitation to a content analysis (1st edn)*, Keiso Shobo, Tokyo, 2003
- Ministry of health, Labour and Welfare: (Cited 31 December 2016) Available from URL: [http://www.mhlw.go.jp/toukei/list/dl/seikatsu\\_chousa\\_c\\_h23.pdf](http://www.mhlw.go.jp/toukei/list/dl/seikatsu_chousa_c_h23.pdf), 2013
- Miyazaki, F: An analysis of mothers' experiences of caring for children with disabilities, *The Journal of Child Health*, 61(3): 421-427, 2002
- Morioka, K., Mochizuki, T. (eds): *Atarasii kazokusyakaigaku. (4th edn)*, 78-88, Baifukan, Tokyo, 2016
- Nishihara, M., Yamaguchi, K.: Mothers' involvement in the family following school enrollment of their children with

- disabilities, *Japanese Journal of Research in Family Nursing*, 21(2): 118-131, 2016
- Nojima, S.: *Kazoku no tikara wo sasaerukango* (Nojima, S., Watanabe, Y.) (eds), Family nursing, 6-12, Japan Nursing Association publication society, Tokyo, 2007
- Oshima, K.: Children with severe motor and intellectual disabilities classification—Oshima's classification—, *Journal of Severe Motor and Intellectual Disabilities*, 23(1): 14-19, 1998
- Ozawa, H., Kanda, M., Kishi K. et al. : *Tyou Juushouji no jittutai to iryou no renkei*, *Journal of Severe Motor and Intellectual Disabilities*, 36(1): 47-51, 2011
- Reese, J., Simmons, R., Barnard, J.: Assertion practices and beliefs among nurses and physicians on an inpatient pediatric medical unit, *Hospital pediatrics*. 6(5): 275-281, 2016
- Robert, E. A., Michael, L. E. (eds)/Suganuma, K., Jarrett, J. (eds): *Your Perfect Right: Assertiveness and equality in your life and relationships* (1st edn), 46-53, Tokyo Tosho, Tokyo, 2009
- Rutter, M.: Resilience in the face of adversity, protective factors and resilience to psychiatric disorder, *British Journal of Psychiatry*, 147: 598-611, 1985
- Takemura, J., Tsushima, H., Tomari, Y.: Nursing support for resilience recognized by mothers of children with severe motor and intellectual disabilities facing treatment selection for secondary impairments, *Osaka Medical College Journal of Nursing Research*, 5: 28-35, 2015
- Tamase, K., Baba, H.: A Study of the influence of field cognition on students' assertion, *Bulletin of Center for Educational Research and Development of Nara University of Education*, 12: 43-50, 2003
- Tanaka, T.: Where is the border between bringing up children and caring for children with disability?, *The Japanese Association on Disability and Difficulty*, 42(4): 26-33, 2015
- Uehara, A., Narama, M.: Experiences of parents whose children require home medical care: The meaning of being a parent and a sense of self, *Journal of Japanese Society of Child Health Nursing*, 25(1): 43-50, 2016
- Ushio, R.: Quality of life of parents who have patients with severe motor and intellectual disabilities at home, *Journal of Severe Motor and Intellectual Disabilities*, 39(3): 441-446, 2014
- Yamamoto, M.: Mothers who do not voice their toilsomeness—How nurses of severely retarded children observe such mothers' circumstances and reach out to help—, *Journal of Japan academy of Human Care Science*, 4(1): 19-28, 2011

〔原 著〕

## 学童期から青年期にある在宅重症心身障害児・者の 母親にとってのアサーションの意味

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### 要 旨

本研究の目的は、学童期から青年期にある在宅で暮らす、重症児・者の母親にとってのコミュニケーション時におけるアサーションの意味を明らかにすることである。在宅で重症児・者と暮らす母親10名を対象とし、内容分析の手法を参考に質的因子探索的分析法を用いて逐語録を作成してコード化を進め、カテゴリーを抽出した。

分析の結果、【母親としての逡巡を自己開示する覚悟】、【共感から生まれる感謝を意思表示】、【試練から異なる自己表現方法の気付き】、【知識や経験の伝承を通じた相互理解】、【家族発達の将来を見越した準備】、【地域との縁合による社会化への糸口】の6カテゴリーと15サブカテゴリーを抽出した。母親が自分の率直な思いを自己開示する覚悟をもつことで、アサーションの基盤と成り得ていた。母親が出会った人々に感謝を意思表示すること、異なる自己表現方法に気付くこと、自己の思いを伝えて共感や相互理解を深めることで、信頼関係の構築を促進していた。また、母親は、経験から得られた知識の伝承を通して仲間と繋がり、ピアとなる存在を得ていた。さらに、母親がアサーションを行うことで、想定される家族発達の将来を見越した準備がなされていた。母親にとってのアサーションは地域との縁合を促し、社会化への糸口となるといった意味を見出していた。

支援の際には、母親が本来持っている力を支え、思いを率直に表出することのできる場所や人といった環境の調整を行い、必要な時期に適切な支援者やグループの紹介をするなど、将来への不安が相談できる専門職へ繋ぐ必要性があると示唆された。

キーワード：アサーション、重症心身障害児・者、母親