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## Original Article

## Family empowerment and associated factors in Japanese families raising a child with severe motor and intellectual disabilities

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## ABSTRACT

**Objectives:** Family caregivers raising children with severe motor and intellectual disabilities (SMID) experience the enormous burden of care. The concept of family empowerment is one of the important assessment indexes of family nursing from the perspective of providing comprehensive support for these families. The objective of this study was to identify the factors associated with the empowerment of families raising a child with SMID in Japan.

**Methods:** We conducted a nationwide questionnaire survey involving 1659 primary caregivers raising a child with SMID through 89 special schools. We assessed the main outcomes using the Family Empowerment Scale (FES). We then conducted a multiple linear regression analysis to reveal the factors associated with family empowerment.

**Results:** In total, 1362 primary caregivers were included in our study. Our results show that factors contributing to high FES scores are higher age of the primary caregiver, higher education, greater recognition of regional support, lower childcare burden, higher utilization of home visit services, higher usage of a childcare institution, higher household income, and stronger family bonding.

**Conclusion:** Healthcare professionals should carefully assess the state of family empowerment of the primary caregivers who are younger and those who have low education, low household income, high childcare burden, and fragile bonding with the family. Second, they should encourage such families to use regional support resources for childcare. That is, policy makers should consider ways to promote home visits and institutional services for the care of children with SMID, aiming especially for the provision of well-coordinated care and services.

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## 1. Introduction

## 1.1. The situation of families raising a child with severe motor and intellectual disabilities

Since the 1970s, national policies in Japan have gradually come to focus on providing welfare services at home and community welfare centers [1]. However, some problems still remain. The number of children with severe motor and intellectual disabilities (SMID) in Japan is increasing, and about 70% of them live at home [2–4].

Children with SMID have serious physical disabilities and mental retardation [5]. In Japan, the term SMID is used for administrative purposes in child welfare and not as a medical diagnosis. These children require multiple forms of medical care and social services [4].

Family caregivers of children with SMID experience enormous physical and mental burden [6,7]. Specifically, it has been reported that many caregivers who are raising a child with SMID attending a special school experience pain in the lower back and mental exhaustion [8]. Additionally, the childcare burden tends to fall upon primary caregivers all day and night, despite their age and lack of support [4].

## 1.2. Empowerment of families raising a child with SMID

The concept of empowerment emerged in the field of health and

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social welfare science from the 1980s in the United States and the 1990s in the United Kingdom [9,10]. In 1999, empowerment was included in the Japanese guidelines (Basic Law for Persons with Disabilities) that address services and care for people with disabilities and their families [11].

In the field of family nursing, family empowerment is considered an assessment index that guides the support provided. In Japan, family empowerment is viewed as a holistic concept. To enable families to utilize services effectively and overcome child rearing problems, it is not only essential to enhance the quantity and quality of services, but it is also important that families possess the “strength” to cooperate with others while raising a child with severe disabilities. Globally, services have changed from a professional-oriented model, in which professionals are superior, to a “family-oriented” service model, in which the wishes of the parents are prioritized with cooperation between parents and professionals [12].

In the present study, based on definitions used in previous studies [13–17], family empowerment is defined as “the state or ability of families to cooperate with elements outside of their living scope by controlling their life for the purpose of raising a child with severe disabilities.” This concept of family empowerment can be assessed using the Family Empowerment Scale developed by Koren et al. [13]. The reliability and validity of the Japanese version of this scale have been confirmed [15]. The Japanese version of this empowerment scale consists of the following three equally important domains: family, service system, and social/political. The family domain represents the abilities of family caregivers to raise a child with SMID by themselves. The service system domain represents awareness of social services to assist childrearing. The social/political domain represents the capability of encouraging social action and change for other children with SMID. Only a few previous studies have examined empowerment [18,19], but this concept is crucial to the support needs of families raising children with special needs. By using the Family Empowerment Scale, we can quantify the concept of family empowerment and suggest ways to support these families better.

### 1.3. Aims of the present study

This study aimed to identify the factors associated with the empowerment of families raising a child with SMID in Japan. Based on this information, we considered ways to improve their family empowerment, including nursing approaches and collaboration with healthcare professionals. Our research questions were as follows:

- Is family empowerment related to the characteristics of primary caregivers, their child with SMID, and their whole family?
- Is the childcare burden of primary caregivers and family functioning associated with the empowerment of families raising a child with SMID?

## 2. Methods

We conducted a nationwide cross-sectional anonymous questionnaire survey from November 2015 to March 2016.

### 2.1. Participants

The participants were primary caregivers raising a child with SMID at home in Japan. Inclusion criteria were: 1) being primary caregivers raising a child with SMID going to a special school and 2) being able to read and write in Japanese. In the present study, a

primary caregiver was defined as the family member who mainly takes care of a child with SMID in the family unit. We did not limit participants based on whether they were the mother, father, or grandparent of the child with SMID, or whether they were a blood relative.

### 2.2. Recruitment procedure

First, we called and asked 212 special schools all over Japan, listed on the website of the Name of Organization [20], to cooperate with our research. The web list included elementary, junior high, and high schools for handicapped children aged 6–20 years. Subsequently, 89 head teachers in special schools agreed to cooperate with this study, and they provided information by telephone on the number of the children with SMID in each school. We then mailed our questionnaire to these 89 special schools. Teachers in the special schools handed the questionnaire out to the primary caregivers of children with SMID when they visited the school to drop off or pick up their children. Primary caregivers who agreed to answer the anonymous questionnaire filled it out, placed it in the envelope provided with the form, sealed it, and submitted it to the teachers. Finally, the teachers gathered the envelopes in each school and sent them to the university to which the researchers belong. The data collection period in each school was approximately one month.

### 2.3. Measures

The questionnaire consisted of the following: 1) attributes of primary caregivers, their child with SMID, and the whole family, and 2) family assessment indexes on childcare burden of primary caregivers, family functioning, and family empowerment. All the items were answered by the primary caregiver in each family unit.

#### 2.3.1. Attributes of the primary caregivers, children with SMID, and the whole family

Attributes of the primary caregivers included current age, education, occupation, hours of sleep per day, frequency of nocturnal awakening, marital status, number of people who provide support for childcare, and utilization of regional support. Specifically, regional support represented the general living resources in each area and community.

Attributes of the children with SMID were current age, severity score, change of living condition in the past one year (such as surgery), utilization of home visit services, utilization of institutional services, usage of an institution for childcare (e.g., local childcare support center, day services, ambulatory rehabilitation center, and family support center), and frequency of usage of short-term services for assistance with raising a child. The severity score of the child with SMID was assessed by the primary caregiver using a modified version of the checklist used by the Japan Welfare Association of Severe Motor and Intellectual Disabilities [21]. This checklist is generally used by medical professionals to assess the severity of SMID in children. Therefore, the description of each item needed to be simplified to aid understanding and ensure the consistency of answers provided by primary caregivers, who lack specialized medical knowledge. This checklist covers the following four areas of assessment: posture, respiratory care, feeding, and elimination care. The posture category score ranges from 0 to 6 points, and it assesses basic posture and the necessary frequency of position change. The respiratory care category score ranges from 0 to 26 points, and it assesses the use of a mechanical respirator, such as intubation and home oxygen therapy. The feeding category score ranges from 0 to 10 points, and it assesses the feeding method used, such as oral feeding, tubal feeding, or intravenous

hyperalimentation. The elimination care category score ranges from 0 to 20 points, and it assesses the need for urethral catheterization or colon irrigation, with or without artificial anus. Higher points on this checklist indicate higher severity of physical disability in children.

Attributes of the whole family included the number of adult family members living together, number of children living together, number of children who need special care, household income, and total duration of care given to a child with SMID at home.

### 2.3.2. Burden of primary caregivers

The childcare burden of the primary caregivers was evaluated using the 8-item short form of the Japanese version of the Zarit Caregiver Burden Interview\_8 (J-ZBI\_8). The J-ZBI\_8 has been validated, and it comprises 8 items that are rated on a 5-point Likert scale [22]. Higher scores on this scale indicate higher childcare burden.

### 2.3.3. Family functioning

Family functioning was assessed using the 16-item version of the Family Adaptation and Cohesion Evaluation Scale KG IV (FACESKG IV-16) [23]. This scale comprises dichotomous response options that assess adaptability and cohesion. Adaptability is the ability of the family to adapt to stressors. A higher score indicates lower adaptability. Cohesion is the emotional bonding with each family member that the respondent reports. A higher score indicates a stronger family bonding.

### 2.3.4. Family empowerment

Based on the definition used in a previous study [17], we defined family empowerment as “the ability of the family of a child with a disability and special needs to control their own lives independently, and the process involved in the same.” Family empowerment was assessed using the Japanese version of the Family Empowerment Scale (J-FES) [13]. This 34-item scale utilizes a 5-point Likert scale, and its reliability and validity have been confirmed [15]. It has the following three subscales: family (FA), service system (SS), social/political (SP). The score assessed by the primary caregiver represents the family empowerment of the family unit, with higher scores indicating higher family empowerment.

### 2.4. Data analysis

Questionnaires were included in the analysis if the J-FES was completed, and they were excluded if 10% or more of the other items were not completed. For the descriptive analysis, means, standard deviations, and weighted scores were calculated for each variable. No outlier was observed in any of the variables. We then conducted a multiple linear regression analysis by stepwise selection to reveal the factors associated with family empowerment. We set the J-FES score as the response variable and 23 factors as explanatory variables. We confirmed that there was no multicollinearity. IBM SPSS 24.0 for Mac (SPSS Japan Inc.) was used for all analyses, and the significance level was set at  $P = 0.05$ .

### 2.5. Ethical considerations

Participation in this study was voluntary, and the special schools and primary caregivers were assured that refusal to participate would not result in any disadvantages or negative consequences in their child's education or medical care. Additionally, participants could withdraw from the study at any time before they submitted the anonymous questionnaire. The special schools and participants were assured that their privacy would be strictly protected when

the study results are published. This study was conducted with the approval of the medical ethics review board of the University of Tsukuba (No. 1004).

## 3. Results

We sent 4707 questionnaires through the 89 special schools, and 1659 families participated in this study. Data obtained from 1362 primary caregivers were included in our final analysis as valid responses. The valid response rate was 34.6%.

### 3.1. Characteristics of primary caregivers, their children with SMID, and the whole family

Table 1 shows the attributes of primary caregivers. It may be seen that 61.8% of the primary caregivers were in their 40s, 97.1% of them had graduated at least from high school, and 55.9% were full-time housewives. Further, 62.9% reported nocturnal awakening for caring for a child with SMID, and 28.2% did so every night. The participants had a mean of  $3.2 \pm 1.7$  people who supported childcare, such as a spouse or partner or the senior siblings of the child with SMID.

Table 2 shows the attributes of the participants' children with SMID and those of their family. The mean age of the children with SMID was  $12.1 \pm 3.5$  years, and 53.0% of them attended special

**Table 1**

Attributes of the primary caregiver of the child with SMID ( $N = 1362$ ).

Attributes	<i>n</i> or <i>M</i> ± <i>SD</i>	% or range
Current age(year)		
20–29	11	0.8
30–39	313	23.0
40–49	842	61.8
50–59	178	13.0
60–69	13	1.0
N/A	5	0.4
Education		
Under high school	31	2.3
High school	556	40.8
Vocational school	154	11.3
College	337	24.7
University	235	17.3
Graduate school	20	1.5
Others	21	1.5
N/A	8	0.6
Occupation		
Full time housewife	761	55.9
Part time job	356	26.1
Full time job	238	17.5
N/A	7	0.5
Sleeping hours/day	$5.8 \pm 1.1$	1–10
<7	1060	77.8
≥7	289	21.2
N/A	13	1.0
Frequency of nocturnal awakening		
None	505	37.1
Few times a month	271	19.9
Few times a week	202	14.8
Every night	384	28.2
Marital status		
Single	187	13.7
Married	1171	86.0
N/A	4	0.3
Number of people who support her/him for childcare	$3.2 \pm 1.7$	0–8
Recognition of utilization of regional support		
Never	296	21.7
Seldom	334	24.5
Sometimes	479	35.2
Often	169	12.4
N/A	84	6.2

**Table 2**  
Attributes of the child with SMID and the whole family ( $N = 1362$ ).

Attributes	$n$ or $M \pm SD$	% or range
<b>Child with SMID</b>		
Current age (year)	$12.1 \pm 3.5$	6–19
<13 (elementary school)	722	53.0
13–15 (junior high school)	324	23.8
>15 (over high school)	313	23.0
N/A	3	0.2
Severity score	$11.1 \pm 6.7$	6–44
Change of living condition in the past one year*	$1.1 \pm 1.1$	0–5
Admission to a hospital	398	29.2
Surgery	141	10.4
Addition of medical care	94	6.9
Use of a pill-in-the-pocket medication	252	18.5
Increase of amounts of the medication	497	36.5
Others	77	5.7
Utilization of home visit service (hours/week)	$2.2 \pm 5.1$	0–70
Utilization of institutional services (hours/week)	$6.7 \pm 7.2$	0–55
Number of usage of institution for childcare	$3.2 \pm 1.6$	0–7
Frequency of usage of short-term services for assistance with raising a child		
None	882	64.8
Once a year	90	6.6
Once a few months	148	10.8
Once a month	136	10.0
Once a week	35	2.6
N/A	71	5.2
<b>Whole Family</b>		
Numbers of adult family members living together	$2.2 \pm 0.8$	1–7
Number of children living together	$2.1 \pm 0.8$	0–7
Number of children who need special care	$1.2 \pm 0.5$	1–4
Household income (million YEN)		
<3	257	18.9
3–<5	424	31.1
5–<7	320	23.5
7–<10	188	13.8
10–<13	62	4.6
≥13	34	2.5
N/A	77	5.6
Number of years of taking care of a child with SMID at home		
<1	31	2.3
1–<2	23	1.7
2–<5	70	5.1
5–<10	382	28.0
≥10	650	47.7
N/A	206	15.2

Note: \* Multiple answers allowed.

1 USD = 122.87 YEN (at the time of investigation).

elementary schools. Further, 29.2% of the children had been hospitalized in the past year. On average, they used home visit services  $2.2 \pm 5.1$  hours per week by a physician or nurse, or a care worker. With regard to the whole family, the mean number of adult family members living together was  $2.2 \pm 0.8$  persons, and that of children in one family unit was  $2.1 \pm 0.8$ . Further, 47.7% of the families had been taking care of their child with SMID for over 10 years.

### 3.2. Childcare burden, family functioning, and family empowerment

The mean score for childcare burden (J-ZBL\_8) was  $8.9 \pm 6.5$  points. With reference to family functioning (FACESKIV-16), the mean score for adaptability was  $0.8 \pm 2.2$  points and that for cohesion was  $3.2 \pm 3.2$  points. The mean score for family empowerment (J-FES) was  $101.5 \pm 17.4$  points, while those for the FA, SS, and SP subscales were  $37.4 \pm 7.1$ ,  $39.7 \pm 7.0$ , and  $24.4 \pm 5.5$  points, respectively (Table 3).

### 3.3. Factors associated with family empowerment

A multiple regression analysis was performed using the J-FES scores as the response variable. Table 4 lists the 23 factors that were

used as explanatory variables, including the attributes and assessment scores of the families.

Higher age of primary caregivers, higher education, recognition of more sufficient utilization of regional support, lower childcare burden, higher utilization of home visit services, higher usage of institution for childcare, higher household income, and stronger family bonding contributed to higher J-FES scores, as shown in Table 4.

## 4. Discussion

The current study is the first to report the actual situation of family empowerment in a large sample of families raising a child with SMID in Japan and to reveal the factors associated with their empowerment. In the following sections, we discuss our results pertaining to the characteristics of the family and primary caregivers of children with SMID in Japan, the family scores on the assessment indexes, and factors associated with family empowerment. The adjusted  $R^2$  was low. This could be caused by the diversity of the participants, who were recruited in this study all over Japan. And identification of the factors associated with the social context and individual-family outcome like “family empowerment” is so difficult to measure all the factors, in other words, we could have some hidden factors. However, in the present study, we had given exploration and identification of the factors associated with the family empowerment of families raising a child with SMID in Japanese contexts extra importance. Our results represent the common factors associated with the empowerment of families raising a child with SMID in Japan.

### 4.1. Characteristics of the primary caregivers, children with SMID, and whole families

The ratio of employed women with children in Japan was 65.7%, that of part-time workers was 34.9%, and that of full-time workers was 20.9% [24]. The occupational distribution in the present sample was similar to these national ratios. The mean sleep duration of the Japanese population is getting shorter, for which the two most common reasons are childcare and household duties [25]. In addition to sleep deprivation, we determined that over 60% of the primary caregivers of children with SMID woke up at night to care for their child with SMID. This result indicated that nocturnal awakening should be given more importance when assessing the physical burden of primary caregivers raising a child with SMID. As about half of the primary caregivers have been taking care of their child with SMID at home for over five years, they can be considered well-experienced caregivers. Home visit services are essential forms of support for families raising a child with SMID [26]. The number of children using home visit services and institutions providing such services is increasing in Japan [27]. Even though the primary caregivers' occupation ratio in the present study was lower than the national ratio of employed mothers, we believe that they could ensure the minimum utilization of childcare services owing to the public health insurance system of Japan. This could explain why 17.5% of the present participants were able to work full time while also taking care of their child with special needs. Nevertheless, families raising a child with SMID complained of a lack of childcare services, and they often faced difficulties in using the services for children with SMID [16]. Therefore, with respect to medical insurance, it is imperative to develop a system that facilitates the use of home visit services for a child with SMID.

### 4.2. Childcare burden, family functioning, and family empowerment

The scores for childcare burden in the present study were

**Table 3**  
Current status of childcare burden, family function, and family empowerment( $N = 1362$ ).

	No. of items	Score range	$M \pm SD$	Range
Score on J-ZBL_8	8	0–32	$8.9 \pm 6.5$	0–32
Score on FACESKGIV-16 adaptability	8	–8.0–8.0	$-0.8 \pm 2.2$	–8.0–7.5
Score on FACESKGIV-16 cohesion	8	–8.0–8.0	$3.2 \pm 3.2$	–8.0–8.0
Score on J-FES	34	34–170	$101.5 \pm 17.4$	44–158
Family (FA)	12	12–60	$37.4 \pm 7.1$	14–58
Service System (SS)	12	12–60	$39.7 \pm 7.0$	16–58
Social Politics (SP)	10	10–50	$24.4 \pm 5.5$	10–48

Note:J-ZBL\_8: The 8-item short form of the Japanese version of the Zarit Caregiver Burden Interview. Higher scores indicate a higher care burden.  
FACESKG IV-16: the 16-item version of the Family Adaptation and Cohesion Evaluation Scale KG IV. FACESKGIV-16 adaptability: Higher scores indicate lower adaptability in family function.  
FACESKGIV-16 cohesion: Higher scores indicate higher cohesion in family function.

**Table 4**  
Factors associated with the family empowerment of families with a child with SMID( $N = 1362$ ).

Explanatory variables	$B$	$SE$	95% CI	$\beta$	$P$
Recognition of utilization of regional support (1: Never; 2: Seldom; 3: Sometimes; 4: Often)	3.976	0.464	2.948,4.761	0.218	0.000
J-ZBL_8 score	–0.496	0.068	–0.616,–0.352	–0.184	0.000
Number of usage of institution for childcare	1.566	0.241	1.533,2.607	0.166	0.000
Household income (million YEN) (1: Less than 3; 2: 3 or more and less than 5; 3: 5 or more and less than 7; 4: 7 or more and less than 10; 5: 10 or more and less than 13; 6: 13 or more)	0.972	0.377	0.198,1.669	0.067	0.010
Current age of caregiver(1: 20–29; 2: 30–39; 3: 40–49; 4:50–59, 5: 60–69)	2.063	0.676	0.679,3.343	0.078	0.002
Score on FACESKGIV-16 cohesion	1.312	0.536	1.106,1.710	0.063	0.015
Utilization of home visit service (hours/week)	0.250	0.102	0.041,0.439	0.061	0.014
Education (1: Under high school; 2: High school; 3: Vocational school; 4: College; 5: University; 6: Graduate school)	0.787	0.344	0.067,1.410	0.060	0.022
$R^2$	0.172				
Adjusted $R^2$	0.167				

Note:Response variable: Family Empowerment (score on the J-FES).  
 $B$ : partial regression coefficient;  $SE$ : ( $B$ 's) standard error;  $CI$ : confidence interval;  $\beta$ : standardized partial regression coefficient.

similar to the scores of caregivers of the elderly who require nursing care, who experienced difficulties with caregiving (9.31 points), and it was higher than the score of caregivers who have no difficulties in caregiving (3.45 points) [22]. This indicates that the participants in the present study experienced high caregiving burden.

The score on the adaptability subscale of family functioning was higher in the present study than in a previous study that we conducted on a limited population ( $n = 34$ ) in the capital region of Japan (–1.31 points) [17]. As we mentioned in Section 2.3.3., the adaptability score is an oppositional score [23]. Thus, the adaptability of participants from the capital region may have been neutralized because the sample was localized, while the present sample comprised participants from all over Japan, including local regions. The score for cohesion in the present study tended to be slightly lower but not significantly different from that observed in the capital region (3.38 points) [17]. Cohesion represents family bonding; therefore, these findings may imply that family bonding is not influenced by regional differences.

Regarding family empowerment, the current score of 113.6 was lower than that observed in the capital region [17]. Similar trends were observed for the three subscale scores (FA, SS, SP); they were  $FA = 41.3$  points,  $SS = 43.2$  points, and  $SP = 29.1$  points in the capital region [17]. Compared to other countries, the score on SP was notably lower in the families raising a child with developmental disabilities in Japan [13,14,28]. This feature might be universal in Japan rather than being limited to families of children with developmental disabilities and SMID. Although it is assumed that the accessibility of services depends on each local government, SP empowerment should be improved in order to encourage families' social action for other children with SMID. In future, it would be beneficial for policy makers of local governments to examine the differences and features of SP in each region in Japan. It might be

useful to identify the appropriate form of support that is suitable for each area based on the characteristics of its residents.

#### 4.3. Factors associated with family empowerment

Higher educational level of parents was related to SP (community subscale) scores in families raising a child aged 0–9 years [29]. Additionally, previous research on family empowerment in families raising a child with intellectual disabilities has found that the better the economic status of the family, the higher the level of family empowerment [28,30,31]. Our results also confirmed that household income and family educational level were important factors associated with family empowerment among families raising a child with special needs. Additionally, the household incomes of participants in this study are generally representative of the Japanese population, for which the median household income was 3,500,000 yen (about 29,000 USD) at the time of the present study [32].

Regarding the utilization of home visit services, in addition to those discussed in Section 4.1, home visit services were found to be essential for families raising a child with SMID who needs medical care [33]. Previous studies revealed that social services could decrease the primary caregivers' stress of care and enhance the coping of parents [34,35]. However, there were some barriers to use social services, such as the lack of supporters to coordinate the utilization of home visit [36], inadequate institutional services [36], family members' disagreement with the use of services [37]. To promote the use of social services, professionals should address above issues.

A previous study conducted in one city in the capital area of Japan reported a compelling need for support from a number of institutions and specialists from multiple disciplines [38]. The utilization of regional support was the most influential factor

associated with family empowerment in the present study. This reflects the amount and quality of utilization of all forms of support for childcare in their residential area. In light of our results, medical professionals such as medical and health social workers should strive to empower families by introducing them to institutions and people who provide childcare support, as well as to parental organizations and regional parenting clubs.

Another notable finding based on the family assessment index used in the present study was that the cohesion subscale of family functioning (family bonding) contributed to family empowerment. To continue their family life raising a child with SMID at home, family members need to stick together and care for their child at any time of the day [39]. Thus, family bonding is the basis of their cooperation to maintain their daily life with a child with SMID, and it is one of the important positive factors of family empowerment.

#### 4.4. Limitations of this study and suggestions for future research

There are several limitations in this study. First, regardless of the cooperation of special schools, the response rate was low. A possible reason for this is that we decided the numbers of questionnaire sent to schools based on their school enrollments; however, not all children in these special schools had SMID. Second, some primary caregivers might have not cooperated in this study because our questionnaires had too many items and took a long time to complete. Thirdly, the present study was conducted in Japan by using a Japanese version of Family Empowerment Scale and therefore our results and conclusions might not represent the situation in other countries.

We suggest that the family empowerment of such families be investigated in more detail in future studies, with special reference to the compatibility of service providers, national and regional legal systems, and other family members' cognition of family bonding and family functioning. Future studies should focus on how the factors associated with the family empowerment of such families influence the family caregivers and other family members, and the relationship between the factors and the social support.

## 5. Conclusion

From the results of our multiple regression analysis with the J-FES score as a response variable, the following practical implications are drawn.

Regarding the assessment of families raising a child with SMID, it is necessary that we carefully assess the family empowerment of primary caregivers who are older and those who have low education, low household income, high childcare burden, and fragile bonding with the family.

With reference to interventions for such families, healthcare professionals should encourage them to use regional support resources for childcare, and we should provide easy-to-use home visit services.

With respect to policy, problems such as a lack of supporters to coordinate the utilization of home visit services and inadequate institutional services for childcare have to be addressed immediately. In other words, policy makers should consider ways to promote the utilization of home visit and institutional services for the care of children with SMID, aiming especially for the provision of well-coordinated care and services.

## Conflicts of interest

The authors declared that there is no conflict of interest.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijnss.2018.09.006>.

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