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Original article

Family empowerment and quality of life of parents raising children with Developmental Disabilities in 78 Japanese families

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ABSTRACT

Objectives: The families of these children experience distress both at the time of diagnosis and afterward. A top priority is to understand family empowerment, family function, and family members' quality of life (QoL) and to effectively support these families in Japan. The objective of this study was to assess the actual conditions of families living with children having DDs and to explore the factors associated with family empowerment and parents' QoL.

Methods: We surveyed ninety-three parents (78 mothers, 15 fathers) from 78 families which lived with children with DDs in the capital region of Japan. We assessed two main outcomes using the Japanese versions of the following instruments: Family Empowerment Scale (FES), World Health Organization Quality of Life 26 (WHOQOL26), and other six outcomes. Correlation and multiple regression analyses were conducted.

Results: No medication, cooperation with child rearing, assistance from a developmental support center, solved problems related to child rearing, and higher scores in Problem Solving contributed to higher FES scores. Higher WHOQOL26 scores were related to being a full-time housewife, higher self-esteem, no developmental support, a broad emotional support network, higher scores in Problem Solving and Role Function, and lower scores in Affective Reaction and General Function.

Conclusions: We revealed that family empowerment and QoL of parents rearing children with DDs in Japan were affected by various subscales of family function and other family attributes. Effective interventions for improving family empowerment and QoL should be researched in the future.

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1. Introduction

The Act on Support for Persons with Developmental Disabilities (DDs), which was enacted in Japan in April 2005, defines DDs, including autism and Asperger syndrome (AS), as conditions that usually develop at an early age [1]. Hiraiwa quantitatively defined DD as “a disorder that typically causes behavior, communication, and social adjustment problems during the development process” [2].

The Japan League on Developmental Disabilities reported a steady increase in the number of children with DDs in the country

[3]. Despite their high prevalence, DDs remain insufficiently understood in Japan. Furthermore, the social support for children with DDs and their families remains inadequate because of the “traditional prejudice among Japanese people against children/persons with DDs” and the delayed support from the government [4].

The parents and families of children with DDs experience distress during and after the diagnosis. Specifically, those parents who are caring for children with DDs face great distress [5]. Children with DDs cause or involve themselves in problems in the community or at school [6]. The parents of these children are primarily responsible for these problems; accordingly, these parents experience higher child-rearing stress than other parents [7,8] and face great pressure in child rearing [9,10]. Although most of these parents adjust to raising children with DDs, those who fail to adapt have a high risk of abusing their children [10]. Previous studies show that raising a child with DDs can increase stress in the family.

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Children with DDs and their mothers have received lower quality of life (QoL) scores than their normal control group peers [11]. Inada reported that both the psychological and social QoL of adults with pervasive DDs were significantly lower than that of the general population [12]. Markowitz et al. also revealed that the QoL of caregivers of children with autism spectrum disorder was already impaired before the diagnosis [13]. The multiple regression analysis results emphasized the importance of “the presence of the mother to provide support” in increasing the psychological and social QoL of adults with pervasive DDs. Previous studies identified eight factors that were associated with the impaired QoL of mothers rearing children with DDs and attending a developmental support center [14]. These factors included “feeling confused when thinking about the infant,” “showing higher concern about child rearing at present than before diagnosis,” and “disagreeing with the child rearing philosophy of the family” [14]. Dardas et al. developed a QoL questionnaire specifically for the parents of children with autism [15]. In sum, the QoL of parents raising children with DDs has received worldwide attention.

Miyauchi reviewed the literature on the families of children with DDs and reported that most of these studies focused on QoL, family function, and other outcomes [16]. However, most of these studies reported only the actual condition of their QoL instead of proposing effective interventions or examining family empowerment and the factors associated with QoL/family empowerment.

When raising children with DDs, families must be empowered in several ways, such as promoting collaboration within the family, among several families, and between families and specialists or local governments [17]. Empowerment refers to the attitude or action through which individuals achieve their goals by interacting with others [18,19]. “Family empowerment” has been identified as an important indicator for both children with DDs and their families in other countries [20–22].

Understanding the family empowerment and QoL of parents rearing children with DDs has been prioritized in Japan along with the exploration of factors associated with these outcomes. Therefore, this study aims to evaluate qualitatively the current status of the abovementioned outcomes using validated scales and identify the contributions to each outcome from the standpoint of medical and welfare professionals. However, as the research title implies, the findings of this study do not reflect the status of Japan as a whole because the participants were recruited through convenient sampling.

2. Methods

2.1. Participants

The participants included parents raising children with DDs within 10 years from their diagnosis. After informing them of the purpose of the study, 78 families were recruited from a developmental disability/psychosomatic disorder diagnosis and treatment department at a university hospital, a welfare medical center for children, a rehabilitation center, and a general hospital.

We included those parents who were raising children with DDs under 18 years and were living in the two prefectures of the Kanto region, a capital region in Japan. We excluded those parents who were physically and psychologically unable to answer the questionnaire within 30 min as assessed by the treating physicians. All participants were recruited through convenient sampling.

2.2. Procedures

The treating physicians recruited eligible subjects following the aforementioned inclusion and exclusion criteria. Those subjects

who consented to participate in the survey were provided with detailed information about the study and were asked to complete the questionnaire. The subjects answered the questionnaire at home and were asked to mail their responses from the nearest post office to the affiliated institution of the researchers.

2.3. Measures

The questionnaire comprised two parts. Part 1 focused on the attributes of children and their parents (Table 1), while part 2 focused on the perceptions on family empowerment, QoL of parents, and six other related outcomes (Table 2). We used two scales to assess family empowerment and QoL.

Family empowerment was assessed using the Japanese version of the Family Empowerment Scale (FES), which was developed to measure family empowerment [17]. The FES has been used in about 30 studies all over the world to measure the empowerment of families taking care of children with emotional, behavioral, and DDs [23]. The Japanese version of the FES (J-FES), which comprised 34 items rated on a five-point Likert scale, was tested for its reliability and validity [24]. Three subscales were adopted, including Family, Service System, and Social Politics. The primary caregiver was asked to complete the J-FES. A higher score indicates a higher family empowerment.

The QoL of parents was assessed using the World Health Organization QoL 26 (WHOQOL26) scale. WHO defines QoL as “an individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” The WHOQOL Group developed the WHOQOL100 from which the shortened form, WHOQOL26, was derived [25]. A Japanese version of the WHOQOL26 was also developed [26]. This scale assesses the QoL of an individual using 2 items as well as their physical health (daily activities and sleep), psychological state (body image and negative emotion), social relationships (personal relationships and social activities), and environment (living environment, safety, and security) using 24 items.

The six other related outcomes were assessed using six different scales. Specifically, family function was evaluated using the Japanese version of the Family Assessment Device (FAD) [27], caregiver burden was evaluated using the short Japanese version of the Zarit Caregiver Burden Interview_8 (J-ZBI_8) [28], childcare burden was evaluated using the Parenting Strain Index [29], emotional support from people around parents was evaluated using the Emotional Support Network scale [30], and the other outcomes were evaluated using the Self-Esteem [31] and Self-Efficacy scales [32]. We obtained the approval of the original developers to use these scales. Table 2 lists the viewpoints of each scale.

The primary caregivers answered all scales, and the spouses were asked to complete the WHOQOL26 and the scales for the other outcomes.

2.4. Data analysis

Only those questionnaires that were more than 90% complete were included in the analysis. The distributions, means, and standard deviations of each variable were calculated in part 1, while family empowerment, QoL, and other outcomes were calculated in part 2.

Before performing a multivariate analysis on the factors associated with family empowerment and QoL of parents, a univariate analysis was performed on the scores of the FES, WHOQOL26, and each of the associated factors. Spearman’s rank correlation coefficients were used for the continuous variables. If no multicollinearity was found among the related factors, then a multiple

regression analysis was performed using the scores of FES and WHOQOL26 as dependent outcome variables and the possible associated factors as explanatory variables.

The statistical analysis package SPSS 21.0 for Mac (SPSS Japan Inc.) was used for the analysis. The significance level was set at 5%.

2.5. Ethical considerations

Verbal and written consent were obtained from all participants. The ethical considerations included the following: 1) the participation of the subjects in the survey was completely voluntary; 2) the subjects were assured that their refusal to participate would not result in any disadvantages or changes to the medical care or treatment of their children; 3) the subjects were informed that their consent to participate could be withdrawn at any time during the study; and 4) the subjects were assured that their privacy would be strictly protected after the publication of the study results. The study was conducted with the approval of the medical ethics review board of the University of Tsukuba (No. 859).

3. Results

3.1. Attributes of children with DDs, their parents, and their entire families

A total of 93 parents (78 mothers and 15 fathers) living in the two prefectures of the Kanto region answered the questionnaires. Table 1 shows the attributes of the children with DDs, their parents, and their entire families.

The children with DDs had a mean age of 7.45 years, and 46 of them were diagnosed with autism spectrum disorders. One quarter of these children kept a rehabilitation notebook, which allows an intellectually disabled person to obtain services easily in Japan. All 78 parents answered the questionnaire about their attributes and those of their children. Both the mothers and fathers were facing some problems related to child rearing, and only half of the participating fathers received counseling about child rearing. In contrast to the mothers, none of the fathers thought that the cooperation system was poor.

With regard to the families, 59 and 18 of them were living in the Ibaraki and Chiba prefectures, respectively. Each family had an average of four members.

3.2. Current status of family empowerment, QoL of parents, and other outcomes

Table 2 shows the current status of family empowerment, QoL of parents, and other outcomes. No significant differences were observed between the mothers and fathers in terms of their QoL and other outcomes.

3.3. Factors associated with family empowerment and QoL of parents

Significant positive correlations were observed between the mean J-FES and WHOQOL26 scores ($r = 0.496$, $P < 0.01$). No multicollinearity was observed in the multiple regression analysis results.

3.3.1. Factors associated with family empowerment

A multiple regression analysis was performed using the J-FES scores as outcome variables. Table 3 lists 27 factors that are used as explanatory variables, including demographic characteristics and other possible relevant factors. Not taking medication (standard partial regression coefficient [sb] = 0.392, $P < 0.01$), assistance in

Table 1
Attributes of the DDs child, each parent, and the whole family.

	n/M±SD	%/range
Children with DDs (N = 78)		
Current age	7.45 ± 3.16	2–16
under 7 years old	30	38.5%
over 7 years old	46	59%
N/A	2	2.5%
Gender		
Boy	62	79%
Girl	14	18%
N/A	2	3%
Diagnosis (multiple answers allowed)		
Autistic spectrum disorders	46	59%
Learning disabilities	30	38.5%
Attention Deficit/Hyperactivity Disorder	24	30.8%
Pervasive developmental disorder	24	30.8%
Mental retardation (including mild MR)	9	11.5%
Developmental coordination disorder	7	9%
Anxiety disorder	4	5.1%
Epilepsy	4	5.1%
Asperger syndrome	3	3.8%
Attachment disorder	2	2.6%
Dissociative disorder	2	2.6%
Adjustment disorder (truant)	1	1.3%
Behavior disorder (self-injury)	1	1.3%
Nocturnal enuresis	1	1.3%
Obsessive-compulsive disorder	1	1.3%
Tic disorder	1	1.3%
Tourette disorder	1	1.3%
Number of times visiting a hospital per year	10.51 ± 12	1–50
Medication		
with	35	45%
without	40	51%
N/A	3	4%
School		
attending	72	92.3%
regular class	42	58.3%
special class	30	41.7%
not enrolled	6	7.7%
Developmental support center		
undergo	41	52.6%
not undergo	37	47.4%
Rehabilitation Notebook		
with	20	25.6%
without	58	74.4%
Mothers (N = 78)		
Age		
20's	1	1%
30's	39	50%
40's	33	42%
50's	2	3%
60's	1	1%
N/A	2	3%
Occupation		
full time housewife	37	47%
part time job	25	32%
full time job	12	15%
N/A	8	10%
Time to spend with children (hours)		
on weekdays	6.99 ± 3.62	1–16
on weekends	13.48 ± 4.45	2–24
Problems related to child rearing		
currently	64	82%
previously	10	13%
N/A	4	5%
Conselor about child rearing		
with	70	90%
without	8	10%
Degree of cooperation within the family		
Very good	20	26%
Good	23	29%
Normal	12	15%
Not good	10	13%
Bad	11	14%
N/A	2	3%
Fathers (N = 15)		

Table 1 (continued)

	n/M±SD	%/range
Time to spend with children (hours)		
on weekdays	2.43 ± 1.42	1–4
on weekends	10.33 ± 3.85	3–15
Problems related to child rearing		
previously	5	33%
currently	10	67%
Conselor about child rearing		
with	7	47%
without	8	53%
Degree of cooperation within the family		
Very good	2	13%
Good	3	20%
Normal	7	47%
Not good	3	20%
Bad	0	0%
Whole Family		(N = 78)
Resident area		
Ibaraki	59	75.6%
Chiba	18	23.1%
N/A	1	1.3%
Numbers of family members living together	4.21 ± 1.25	2–8
Numbers of siblings	0.97 ± 0.93	0–5
0	21	26.9%
1	41	52.6%
2	11	14.1%
5	2	2.6%
N/A	3	3.8%
Current age of siblings	7.24 ± 4.54	0–18
Siblings' Perception of their siblings with DDs		
with	31	39.7%
without	47	60.3%
Primary Caregiver		
mothers	70	90%
others	8	10%
Assistance with child rearing		
with	56	72%
without	22	28%
Welfare Service		
usage	33	42%
no usage	45	58%
Degree of household economy		
Sufficient	7	9%
Slightly sufficient	4	5%
Nomal	43	55%
Slightly insufficient	20	26%
Insufficient	3	4%
N/A	1	1%

child rearing ($sb = -0.212$, $P < 0.05$), assistance from a developmental support center ($sb = -0.295$, $P < 0.01$), solving problems related to child rearing ($sb = -0.215$, $P < 0.05$), and successful problem solving function ($sb = -0.473$, $P < 0.01$) contributed to the high J-FES scores ($F = 15.974$, $P < 0.01$) as shown in Table 3.

3.3.2. Factors associated with QoL

A multiple regression analysis was performed using the WHOQOL26 scores as outcome variables. Table 4 lists the 27 factors that are used as explanatory variables, including demographic characteristics and other possible relevant factors. The high WHOQOL scores ($F = 48.525$, $P < 0.01$) were attributed to being a full-time housewife ($sb = -0.249$, $P < 0.01$), having high self-esteem ($sb = 0.521$, $P < 0.01$), receiving no assistance from a developmental support center ($sb = 0.224$, $P < 0.01$), having a broad emotional support network ($sb = 0.622$, $P < 0.01$), having successful problem solving and role functions ($sb = -0.426$ and $sb = -0.346$, $P < 0.01$), and having unsuccessful affective reaction and general function ($sb = 0.224$, $P < 0.01$ and $sb = 0.596$, $P < 0.05$).

Table 2

Current status of Family Empowerment, Parents' QoL, and other outcomes.

	No. of items	Score range	M±SD	range
				(N = 77)
Scores of the Japanese version of Family Empowerment Scale	34	34–170	89.23 ± 21	46–137
Family (FA)	12	12–60	34.36 ± 9.34	18–52
Service System (SS)	12	12–60	34.86 ± 8.8	14–51
Social Politics (SP)	10	10–50	20 ± 5.16	11–36
				(N = 84)
Scores of the Japanese version of WHOQOL26	26	1.0–5.0	3.22 ± 0.53	2–4.35
physical health	7	1.0–5.0	3.35 ± 0.6	2–4.29
psychological state	6	1.0–5.0	3.19 ± 0.71	1.33–4.67
social relationship	3	1.0–5.0	3.26 ± 0.71	1.33–4.33
environment	8	1.0–5.0	3.14 ± 0.53	2.13–4.25
2 items for total QoL	2	1.0–5.0	3.06 ± 0.79	1.5–5.0
				(N = 91)
Scores of the Japanese version of Family Assessment Device				
Problem Solving (PS)	6	1.0–4.0	2.19 ± 0.5	1.17–3.33
Communication (CM)	9	1.0–4.0	2.18 ± 0.44	1.22–3.44
Role (RL)	11	1.0–4.0	2.2 ± 0.45	1–3.55
Affective Reaction (AR)	6	1.0–4.0	2.08 ± 0.56	1.17–3.5
Affective Intervention (AI)	7	1.0–4.0	2.31 ± 0.47	1.57–3.71
Behavioral Control (BC)	9	1.0–4.0	2.21 ± 0.49	1.11–3.33
General Function (GF)	12	1.0–4.0	2.15 ± 0.42	1.33–3.11
				(N = 93)
Scores of J-ZBI_8	8	0–32	16.44 ± 7.06	0–29
Scores of Parenting Strain Index	16	0–64	18.6 ± 11.84	0–44
Scores of Emotional support network scale	10	0–10	6.76 ± 3.64	0–10
Scores of Self-Esteem scale	10	10–50	30.72 ± 9.39	0–46
Scores of the Japanese version of the Generalized Self-Efficacy scale	23	23–115	69.9 ± 17.06	0–103

Family Assessment Device: Higher scores indicate a lower family function.

J-ZBI_8: It is a short version of the Japanese version Zarit Caregiver Burden Interview_8. Higher scores indicate a higher careburden.

Parenting Strain Index: Higher scores indicate a higher burden of childcare.

Emotional support network scale: Higher scores indicate that a questionee can perceive emotional support from around people more.

Self-esteem scale: Higher scores indicate a higher self-esteem.

Self-efficacy scale: Higher scores indicate a higher self-efficacy.

4. Discussion

4.1. Attributes of children with DDs, their parents, and their entire families

This study focused on family empowerment as one of the important factors of the entire family.

A previous study reported that the behavioral problems of children with DDs affected the mental health of their mothers, who are at high risk of having impaired mental wellbeing [33]. The mothers were more likely to perceive child rearing problems than the fathers, which could be attributed to the longer time that mothers spend with their children with DDs. With regard to child rearing problems, a previous study reported that parents often compared their children with DDs with their healthy siblings, and that husbands or relatives did not understand the distress of mothers about rearing children with DDs [34]. Asano reported that mothers and fathers held different perceptions toward DDs [35], thereby affecting their perceptions toward child rearing problems. Around 56% of the families in Japan include parents who are both working, and this proportion continues to increase every year [36]. Raising children with DDs would discourage mothers from working because only 15% of the families in this study had mothers who were working full time.

Table 3
Factors associated with Family Empowerment of families with DDs child ($N = 77$).

Objective variable	Explanatory variables	sb	P	
Family Empowerment	Age of DDs child	–0.009	0.940	
	Gender of DDs child	1: Boy, 2: Girl	0.006	0.956
	Number of times visiting a hospital per year		–0.074	0.471
	Medication	1: with, 2: without	0.392	0**
	School	1: enrolled, 2: not enrolled	–0.131	0.177
	Facilities for handicapped	1: undergo, 2: not undergo	–0.295	0.005**
	Rehabilitaion Notebook	1: with, 2: without	–0.042	0.702
	Age of parents	1: 20', 2: 30', 3: 40', 4: 50', 5: 60'	0.199	0.078
	Occupation	1: full time housewife, 2: part time job, 3: full time job	–0.052	0.620
	Time to spend with children on weekdays		–0.071	0.567
	Time to spend with children on weekends		0.046	0.669
	Problems related to child rearing	1: previously, 2: currently	–0.215	0.038*
	Conselor about child rearing	1: with, 2: without	–0.038	0.747
	Degree of cooperation within the family	1: Bad, 2: Not good, 3: Normal, 4: Good, 5: Very good	–0.023	0.851
	FAD score			
	Problem Solving (PS)		–0.473	0**
	Communication (CM)		0.237	0.080
	Role (RL)		0.023	0.871
	Affective Reaction (AR)		0.192	0.306
	Affective Intervention (AI)		0.004	0.974
	Behavioral Control (BC)		0.093	0.523
	General Function (GF)		0.169	0.319
	J-ZBI_8 score		0.096	0.485
	Parenting Strain Index score		–0.113	0.408
	Emotional Support Network score		–0.050	0.698
	Self-esteem score		0.088	0.410
	the Japanese version of the Generalized Self-Efficacy scale score		0.14	0.235
	Numbers of family members living together		0.033	0.757
	Numbers of siblings		–0.37	–0.062
	Current age of siblings		0.391	0.066
	Siblings' Perception of their siblings with DDs	1: with, 2: without	0.006	0.001
	Assistance with child rearing	1: with, 2: without	–0.212	0.046*
	Welfare Service	1: with, 2: without	–0.111	0.301
	Degree of household economy	1: Insufficient, 2: Slightly insufficient, 3: Normal, 4: Slightly sufficient, 5: Sufficient	0.176	0.092
		R^2	0.689	
		adjusted R^2	0.646	

sb: the values are standardized partial regression coefficients.*: $P < 0.05$ ** : $P < 0.01$.

#: reference category.

4.2. Current status of family empowerment, QoL of parents, and other outcomes

The families of children with DDs in Japan (92.5 points, $P = 0.12$), the U.S. (119.43 points, $P < 0.01$), and Australia (108.45 points, $p < 0.01$) had lower mean J-FES scores than the families of children with severe motor and intellectual disabilities (113.6 points, $p < 0.01$), families of children with inherited metabolic diseases in Japan (101.53 points, $P < 0.01$), and families receiving telemental health treatment for the attention-deficit hyperactivity disorder of their children (115.25 points, $P < 0.01$) [4,37–40]. The families in this study had low family empowerment and were struggling in rearing their children with DDs. Our mean score for the Service System of FES was lower than those in previous studies [39], which indicated that the families in this study did not have enough information about the services related to rearing children with DDs.

The mean WHOQOL26 score was lower than the national average scores of the Japanese people (3.23 points, $P = 0.81$), the parents of children with severe motor and intellectual disabilities (3.28 points, $P = 0.26$), and the parents of children with food allergy (3.42 points, $P < 0.01$) [4,26,41], but was higher than the score of mothers of children with inherited metabolic disease (3.11 points, $P = 0.73$) [38]. The QoL of parents of children with DDs was generally lower than that of parents rearing children with other diseases or conditions at home. This finding could be partly attributed to the low family empowerment of these parents as reflected in the multiple regression analysis results.

The mean J-ZBI_8 score was higher than the scores of parents of children with DDs aged above 18 years (12.8 points) and those of primary caregivers of adult dementia patients in hospitals (11 points) and homes (12.9 points) [42–44]. Honda et al. associated secondary disability and high degree of livelihood support with the caregiver burden of parents raising children with DDs [45]. A previous study using J-ZBI_8 ranging from 10 points to 20 points revealed a moderate degree of caregiver burden [28]. Therefore, those parents rearing children with DDs had a higher caregiver burden than adult caregivers caring for dementia patients in hospitals. This difference could be attributed to the living situation of these individuals. Specifically, patients with dementia are hospitalized and attended to by medical professionals. Therefore, the roles of their family members clearly differed from those of parents of children with DDs, who had to stay at their homes. The latter also had to manage the issues related to their children all by themselves.

The mean Parenting Strain Index of the parents of children with DDs was higher than that of caregivers rearing disabled children who were attending a nursery school for disabled children (11 points) [29] and that of mothers who joined child developmental support projects (12.3 points) [42], but was lower than that of caregivers of children with physical (19 points) or intellectual disabilities (21.3 points) [46]. However, those mothers who were rearing infants had a similar mean Parenting Strain Index (18 points) [47]. The Parenting Strain Index is structured into two sub-concepts, namely, developing negative feelings for children and restricting the social activities of mothers through child rearing

Table 4
Factors associated with Parents' QoL with DDs child ($N = 84$).

Objective variable	Explanatory variables	sb	P	
Parents' QoL	Age of DDs child	0.085	0.163	
	Gender of DDs child	1: Boy, 2: Girl	-0.003	0.956
	Number of times visiting a hospital per year		-0.072	0.219
	Medication	1: with, 2: without	-0.030	0.603
	School	1: enrolled, 2: not enrolled	-0.030	0.570
	Facilities for handicapped	1: undergo, 2: not undergo	0.224	0.001**
	Rehabilitaion Notebook	1: with, 2: without	-0.067	0.272
	Age of parents	1: 20's, 2: 30's, 3: 40's, 4:50's, 5: 60's	0.050	0.498
	Occupation	1: full time housewife, 2: part time job, 3: full time job	-0.249	0**
	Time to spend with children on weekdays		0.072	0.318
	Time to spend with children on weekends		0.077	0.383
	Problems related to child rearing	1: previously, 2: currently	-0.012	0.836
	Conselor about child rearing	1: with, 2: without	-0.064	0.368
	Degree of cooperation within the family	1: Bad, 2: Not good, 3: Normal, 4: Good, 5: Very good	0.064	0.386
	FAD score			
	Problem Solving (PS)		-0.426	0**
	Communication (CM)		-0.017	0.888
	Role (RL)		-0.346	0.001**
	Affective Reaction (AR)		0.191	0.142
	Affective Intervention (AI)		0.224	0.016*
	Behavioral Control (BC)		-0.064	0.526
	General Function (GF)		0.596	0**
	J-ZBI_8 score		0.089	0.235
	Parenting Strain Index score		-0.030	0.668
	Emotional Support Network score		0.622	0**
	Self-esteem score		0.521	0**
	the Japanese version of the Generalized Self-Efficacy scale score		-0.174	0.129
	Numbers of family members living together		0.042	0.515
	Numbers of siblings		-0.097	0.165
	Current age of siblings		-0.039	0.547
	Siblings' Perception of their siblings with DDs	1: with, 2: without	0.051	0.351
	Assistance with child rearing	1: with, 2: without	-0.035	0.610
	Welfare Service	1: with, 2: without	0.018	0.772
Degree of household economy	1: Insufficient, 2: Slightly insufficient, 3: Normal, 4: Slightly sufficient, 5: Sufficient	0.062	0.507	
	R^2	0.926		
	adjusted R^2	0.907		

sb: the values are standardized partial regression coefficients. * $P < 0.05$ ** $P < 0.01$.
#: Reference category.

[29]. Children with DDs are facing communication difficulties, thereby triggering the negative feelings of their parents. However, these children usually have a higher degree of autonomy than infants. Therefore, the social activities of patients of children with DDs would not be as restricted as those of parents rearing infants, but the parenting strain of the former would be approximately similar to that of the latter. Overall, rearing children with DDs requires much time and effort as reflected in the measured parenting strain.

The parents of children with DDs received a lower mean score in the Emotional Support Network scale than the parents of type 2 diabetic patients (7.1 points) [48]. The Emotional Support Network scale assesses the cognitions of emotional support from people surrounding these parents by asking several questions, such as "Is there a person with whom you can share your true feelings and secrets?" Investigating the presence and amount of emotional support may yield interesting results. The parents of children with DDs also received a lower mean score in the Self-Esteem scale than the nursing students at a university in Japan (33 points) [49], but received a higher mean score than thirtysomething mothers who were rearing a child (21.4 points) [50]. These parents also received a lower mean score in the Self-Efficacy scale than the community residents aged between 13 years and 93 years (76.45 points) [32] and the female students at a nursing university (72.4 points) [51].

Only few studies measured self-esteem and self-efficacy using these scales, thereby preventing us from differentiating our study from the other related literature. However, the self-esteem of parents in this study was lower than that of the samples in other studies.

A higher FAD score indicates a lower family function. No significant differences were observed between the mothers and fathers in terms of their FAD scores. No other study examined the FAD scores of mothers and fathers and the differences in the FAD scores of parents of children with and without DDs. No significant differences were observed in the mean family function scores of mothers and fathers. A previous study reported that the positive relationships between mothers and children with DDs and between fathers and children with DDs were the same [52]. However, Katayama and Naito revealed that the mothers of children with and without DDs had the same ability to deal with family bonds and cope with family crises [53], but the same case was not observed among fathers. Therefore, the family function of mothers and fathers depends on their roles within their families. In this case, the family functions of both parents must be assessed. Nishimura reported that the family function in the families of children with DDs affected the lives of siblings and the relationships between parents [54]. Therefore, studies on family outcomes must assess the family functions of both mothers and fathers.

4.3. Factors associated with family empowerment and QoL of parents

This study identified five factors associated with family empowerment and eight factors associated with the QoL of parents rearing children with DDs. Receiving assistance for child rearing has an important role in family empowerment. A previous study reported that a higher social support corresponded to a higher family empowerment [39]. Parents rearing children with DDs should seek assistance and social support from individuals outside of their family units. With regard to the finding that the solutions to problems were related to child rearing, we found that the problem solving function had a circular relationship with family empowerment. Given that those families with high family empowerment are highly able of solving their child rearing problems, these families may already have solved their problems.

Role function is another factor associated with QoL. A higher role function indicates that each family member has clear goals and is working well within their families. Therefore, the QoL of parents is affected by their family members. Interestingly, a lower affective intervention function corresponded to a higher QoL of parents. A previous study showed that communicating and interacting with children with DDs required a high amount of energy [16] and could lead to mental stress for the parents. Therefore, as an effective intervention function, parents must distance themselves from their children with DDs. The relationship between general function and the QoL of patients could not be easily explained. General function is created by gathering items from the other subscales because these items lowered the independence of each subscale during the development of the main scale [27]. However, we assigned each item of general function to other subscales because of its definition. Eight of the 12 general function items matched the affective reaction and affective intervention categories. The regression analysis results (Table 4) showed similar directions of association from affective reaction, affective intervention, and general function to QoL, although the association between QoL and affective reaction was not significant. Therefore, the affective intervention and general function of the parents of children with DDs must be maintained at low levels.

Despite the significant correlation between family empowerment and QoL, attending a developmental support center was related to high family empowerment and low QoL. This result represents a limitation of this study, and highly specific future studies must clarify this contradiction.

4.4. Limitations and future directions

In this study, we hypothesized that family function may influence the QoL of parents living with children with DDs, and that both parents and siblings may feel stressed under this situation. Kao et al. found that Latino siblings were concerned that having brothers or sisters with DDs would restrict their social activities [55]. Karst and Van Hecke reported that raising a child with DDs would result in high levels of stress for the entire family [9]. We could not assess the stress and QoL of all family members because we only recruited parents for this study. We related our findings to those of previous studies on family empowerment, QoL, and other health outcomes. However, for some health outcomes such as emotional support network, self-esteem, and self-efficacy, we could not compare our results with those of previous studies because the scales for these three outcomes were not used properly in the literature, thereby limiting our comparisons. We also considered our convenient sampling technique as another limitation because adopting such technique would generate results that could only reflect the status of a certain area or population in Japan.

In our future research, we aim to focus on the relationships among the QoLs of each family member living with children with DDs while considering the situation of the domestic cooperation system and the utilization of social support services for the family. We also aim to design support programs and systems that effectively maintain and improve the QoL of these family members as well as to establish the role of outpatient nurses, health nurses, and multidisciplinary local care teams in such systems.

5. Conclusion

This study emphasized the roles of family empowerment and QoL of parents rearing children with DDs in Japan. The participating parents generally had low scores for family empowerment and QoL, high caregiver burden, and low emotional support network, self-esteem, and self-efficacy. The multiple regression analysis results emphasize the importance of supplying appropriate medication for children with DDs, assisting in family functions, and solving problems related to child rearing in improving family empowerment and QoL.

Conflict of interest

The authors declare no conflict of interest.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.ijnss.2016.12.004>.

References

- [1] Ministry of Health, Labour and Welfare, Japan. Establishment of the support law for people with developmental disorders. 2005 [cited 2016 Jun 30]; Available from: <http://www.mhlw.go.jp/english/wp/wp-hw2/part2/p2c8s2.pdf>.
- [2] Hiraiwa M. A statement about children's mental and behavioral issue. *J Child Health* 2009;68:330 [Original work published in Japanese].
- [3] Japan League on Developmental Disabilities. Hattatsu shougai hakusho. Tokyo: Akashi Shoten; 2013 [Original work published in Japanese].
- [4] Wakimizu R. Survey on empowerment of families of children with special care needs: comparison between children with severe physical and intellectual disabilities and children with developmental disabilities. *J Ambul General Pediatr* 2012;15:25–30 [Original work published in Japanese].
- [5] Yamada A, Suzuki M, Kato M, Suzuki M, Tanaka S, Shindo T, et al. Emotional distress and its correlates among parents of children with pervasive developmental disorders. *Psychiatry Clin Neurosci* 2007;61(6):651–7. <http://dx.doi.org/10.1111/j.1440-1819.2007.01736.x>.
- [6] Takahashi S. School maladjustment and problems of educational support for students with mild developmental disabilities: a survey of resource rooms for students with emotional disturbances in elementary and lower secondary schools in Tokyo. *Jpn J Spec Educ* 2008;45:527–41 [Original work published in Japanese].
- [7] Anderson LS. Predictors of parenting stress in a diverse sample of parents of early adolescents in high-risk communities. *Nurs Res* 2008;57(5):340–50. <http://dx.doi.org/10.1097/01.NNR.0000313502.92227.87>.
- [8] Nachshen JS, Minnes P. Empowerment in parents of school-aged children with and without developmental disabilities. *J Intellect Disabil Res* 2005;49(12):889–904. <http://dx.doi.org/10.1111/j.1365-2788.2005.00721.x>.
- [9] Karst JS, Van Hecke AV. Parent and family impact of autism spectrum disorders: a review and proposed model for intervention evaluation. *Clin Child Fam Psychol Rev* 2012;15(3):247–77. <http://dx.doi.org/10.1007/s10567-012-0119-6>.
- [10] Raina P, O'Donnell M, Schwellnus H, Rosenbaum P, King G, Brehaut J, et al. Caregiving process and caregiver burden: conceptual models to guide research and practice. *BMC Pediatr* 2004;4:1. 1186/1471-2431-4-1.

- [11] Furusho J, Kubagawa T, Satoh H, Shibata R, Nemoto Y, Matsuzaki K, et al. Study of the kid-KINDL questionnaire scores for children with developmental disorders in normal classes and their parents. *No To Hattatsu* 2006;38(3):183–6 [Original work published in Japanese].
- [12] Inada N. Subjective QOL of high-functioning pervasive developmental disorder adult and related factors. 2009 Health and Labor Sciences Research Grant, Report of the Disability Health and Human Services Research Promotion Program. 2009 [cited 2016 Jun 30]; Available from: <http://www.dinf.ne.jp/doc/japanese/resource/kousei/h21houkoku/katuyou01.html> (Original work published in Japanese).
- [13] Markowitz LA, Reyes C, Embacher RA, Speer LL, Roizen N, Frazier TW. Development and psychometric evaluation of a psychosocial quality-of-life questionnaire for individuals with autism and related developmental disorders. *Autism* 2016;20(7):832–44.
- [14] Nishii M, Yamada K, Morioka I. Factors affecting Quality of Life of mothers rearing the infant commuting to a developmental support center. *J Child Health* 2015;74(6):948–58 [Original work published in Japanese].
- [15] Dardas LA, Ahmad MM. Validation of the world health Organization's quality of life questionnaire with parents of children with autistic disorder. *J Autism Dev Disord* 2014;44(9):2257–63.
- [16] Miyauchi T. Families with children with developmental disorders: review of the literature on psychosocial and social problems. *J Child Health* 2012;71(2):282 [Original work published in Japanese].
- [17] Koren PE, DeChillo N, Friesen BJ. Measuring empowerment in families whose children have emotional disabilities: a brief questionnaire. *Rehabil Psychol* 1992;37:305–21. <http://dx.doi.org/10.1037/h0079106>.
- [18] Dunst C, Trivette C, Starnes A, Hamby D, Gordon N. Building and evaluating family support initiative. Baltimore: Paul H Brookes; 2004.
- [19] Conger JA, Kanungo RN. The empowerment process: integrating theory and practice. *Acad Manag Rev* 1988;13:471–82.
- [20] Gutstein SE. Empowering families through relationship development intervention: an important part of the biopsychosocial management of autism spectrum disorders. *Ann Clin Psychiatry* 2009;21:174–82.
- [21] Luong J, Yoder MK, Canham D. Southeast Asian parents raising a child with autism: a qualitative investigation of coping styles. *J Sch Nurs* 2009;25:222–9.
- [22] Neely-Barnes S, Graff JC, Marcenko M, Weber L. Family decision making: benefits to persons with developmental disabilities and their family members. *Intellect Dev Disabil* 2008;46:93–105.
- [23] Herbert RJ, Gagnon AJ, Rennick JE, O'Loughlin JL. A systematic review of questionnaires measuring health-related empowerment. *Res Theory Nurs Pract* 2009;23(2):107–32.
- [24] Wakimizu R, Fujioka H, Furuya K, Miyamoto S, Iejima A, Yoneyama A. Development of the Japanese version of family empowerment scale (J-FES). *J Health Welf Statistics* 2010;11:33–41 [Original work published in Japanese].
- [25] World Health Organization Group. Study protocol for the world health organization project to develop a quality of life assessment instrument (WHO-QOL). *Qual Life Res* 1993;2:153–9. <http://dx.doi.org/10.1007/BF00435734>.
- [26] Tasaki M, Nakane Y. WHOQOL26 manual improved edition. Tokyo: Kaneko shobou; 2007 [Original work published in Japanese].
- [27] Saeki T, Asukai N, Miyake Y, Miguchi M, Yamawaki S. The reliability and validity of family assessment Device (FAD) Japanese version. *Arch Psychiatr Diagn Clin Eval* 1997;8:181–92 [Original work published in Japanese].
- [28] Tokunaga A, Hanyu M. Analysis of caregivers burden in family using the Japanese version of the Zarit caregiver burden interview_8: modeling of the care burden feeling factor. *Yamaguchi Econ Rev* 2011;60(3):219–53 [Original work published in Japanese].
- [29] Nakajima K, Saito Y, Okada S. Development of mother's scale of burden of childcare. *J Health Welf Statistics* 1999;46(3):11–8 [Original work published in Japanese].
- [30] Munakata M. Health and illness from the perspective of behavioral sciences. Tokyo: Medical Friend Co. Ltd.; 1996 [Original work published in Japanese].
- [31] Yamamoto M, Mastui Y, Yamanari Y. The structure of perceived aspects of self. *Jpn J Educ Psychol* 1982;30(1):64–8 [Original work published in Japanese].
- [32] Narita K, Shimonaka Y, Nakazato K, Kawai C, Sato S, Osada YA. Japanese version of the generalized self-efficacy scale. *Jpn J Educ Psychol* 1995;43:306–14 [Original work published in Japanese].
- [33] Suzumura S. Quality of life in mothers of preschoolers with high-functioning pervasive developmental disorders. *Pediatr Int* 2015;57(1):149–54.
- [34] Ishizuka Y. Support for mild developmental disorder infants and parents with child-rearing problems. *Bull Tenshi Coll* 2007;7:39–46 [Original work published in Japanese].
- [35] Asano M. Family strengths in families living with children who are resistant epileptics; case studies using narrative approach. *J Jpn Soc Nurs Health Care* 2003;5(1):17–23 [Original work published in Japanese].
- [36] Gender Equality Bureau Cabinet Office. Gender equality white paper. Chapter 1 the situation of the formation of the gender equality society. 2016 [cited 2016 Jun 30]; Available from: <http://www.gender.go.jp/whitepaper/h24/zentai/html/zuhyo/zuhyo01-03-17.html> [Original work published in Japanese].
- [37] Vander SA, McCarty CA, Zhou C, Rockhill CM, Schoenfelder EN, Myers K. The children's attention-deficit hyperactivity disorder telemental health treatment study: caregiver outcomes. *J Abnorm Child Psychol* 2016. <http://dx.doi.org/10.1007/s10802-016-0155-7>.
- [38] Yamaguchi K, Wakimizu R, Kubota M. The questionnaire survey of quality of life of children with inherited metabolic disorders and their family members. *Mol Genet Metab* 2016;117(3):294–5.
- [39] Wakimizu R, Fujioka H, Yoneyama A, Iejima A, Miyamoto S. Factors associated with the empowerment of Japanese families raising a child with developmental disorders. *Res Dev Disabil* 2011;32(3):1030–7.
- [40] Dempsey I, Dunst CJ. Help-giving styles as a function of parent empowerment in families with a young child with a disability. *J Intellect Dev Disabil* 2004;29:50–61. <http://www.coastfraseridpscd.ca/wp-content/uploads/2014/10/Helpgiving-Styles-Parent-Empowerment-Dempsey-and-Dunst-2004-flattened.pdf>.
- [41] Akishika K, Yamamoto Y, Taketani K, Kurosaka F, Kamesaki S. Quality of life in the mothers of children with food allergy. *Jpn Soc Pediatr Allergy Clin Immunol* 2015;29(2):169–80 [Original work published in Japanese].
- [42] Seki M, Hasegawa M, Deguchi Y. Parenting Strain Index and the related factors of mothers raising children who join the child developmental support project. *J Jpn Nurs Assoc* 2016;46:47–50 (Original work published in Japanese).
- [43] Fujita A, Kokubo M, Kanda T, Saito R, Yazaki S. The living situation of aged patient with dementia in recovery ward in this hospital and the care burden of primary caregiver. *Bull Yachiyo Hosp* 2015;35:45–7.
- [44] Kajiwaru K, Nakatani H, Ono M, Miyakoshi Y. Positive appraisal of in-home family caregivers of dementia patients as an influence on the continuation of caregiving. *Psychogeriatrics* 2015;15(2):26–31.
- [45] Honda H, Saito E. The related factors of caregiver burden of patients with developmental disabilities. *Jpn J Public Health*;63(5):252–259. [Original work published in Japanese]
- [46] Okada S. The study parenting strain index and information needs of caregivers rearing children with physical and mental disabilities [cited 2016 Jun 30]; Available from: <http://oshika.u-shizuoka-ken.ac.jp/outline/research/004/upimg/20080306111010843259504.pdf>; 2008 [Original work published in Japanese].
- [47] Iwabuchi S, Okuzawa S, Kamikawa Y, Kawasaki Y, Nakanishi M, Nie Y, et al. Assessment of child-care stress in mothers. *Shinshu Med J* 2009;57(5):155–61.
- [48] Tsutsui H, Oshida Y. A study of management in social support network to diabetic patients: the result of questionnaire in peculiarity of behavior for type 2 diabetic patients. *J Jpn Diabetes Soc* 2006;49(6):459–63.
- [49] Tone Y, Sugita R, Onodera S, Ohkubo A, Shinohara Y, Mochizuki C. Relation to the recognition of the commitment to the marital relationship of parents and self-esteem of nursing college student. *Mejiro J Health Care Sci* 2014;7:45–52 [Original work published in Japanese].
- [50] Zukawa N, Kitayama A. Effectiveness of group program for mothers with child-rearing problem: from the viewpoint of the change of mothers and their family relationship. *J Child Health* 2011;70(3):371–9 [Original work published in Japanese].
- [51] Ohto A, Nakashima F. The actual state of “interpersonal anxiety (shyness)” and the “generalized self-efficacy” in nursing students. *Jpn Health Med Assoc* 2015;23(4):266–71 [Original work published in Japanese].
- [52] Mitchell DB, Hauser-Cram P. Early childhood predictors of mothers' and fathers' relationships with adolescents with developmental disabilities. *J Intellect Disabil Res* 2010;54(6):487–500.
- [53] Katayama R, Naito N. Family function of mothers and fathers raising babies and support of the child care. *Jpn Soc Psychosom Obstetrics Gynecol* 2012;15(3):294–304 [Original work published in Japanese].
- [54] Nishimura B. Psycho-social development of siblings who grew up with children with developmental disabilities. *Jpn J Child Adolesc Psychiatry* 2004;45(4):344–59 [Original work published in Japanese].
- [55] Kao B, Romero-Bosch L, Plante W, Lobato D. The experiences of Latino siblings of children with developmental disabilities. *Child Care Health Dev* 2012;38(4):545–52.