

**Development of a scale of difficulties
experienced by parents of children with hikikomori syndrome**

ひきこもり青年の親の困難感尺度の開発

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〔原 著〕

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Abstract:

Objective: Hikikomori (social withdrawal) has received considerable attention as a community mental health problem in Japan. The present study aimed to develop an assessment scale of the difficulties faced by parents of children with hikikomori, and to test its reliability and validity.

Methods: A 42-item scale with 4-point response options called "The Parents' Difficulties Scale" was extracted from previous research and derived from constructs identified in other family difficulty literature. Data were collected from 176 parents of children with hikikomori (response rate = 26.9%). Both exploratory and confirmatory factor analysis were conducted to test factor-based validity. To assess criterion-related validity, Family Difficulties Scale scores were compared with CES-D and QOL scores, and the variables related to withdrawn children by correlation coefficient. Internal consistency was assessed using Cronbach's alpha. All participants were made fully aware of the study purpose and procedures and informed consent was obtained from all participants. A university ethics committee approved the research protocol before starting the study.

Results: A three-structured scale was established and corresponded to difficulties in marital cooperation (five item scale), psychological conflict with the the child (seven item scale), and difficulties in support resource utilization (six item scale). A secondary structural model showed that a three-factor model fit best (SEM: GFI = 0.851, AGFI = 0.806, RMSEA = 0.08), although the goodness-of-fit criteria were not sufficient. The total score was significantly and negatively correlated with WHO/QOL score and positively with CES-D score. Internal consistency (Cronbach's α coefficient) was acceptably high (0.858).

Conclusion: The results suggest that the newly developed Parents' Difficulties Scale is reliable and valid.

Key words: Hikikomori, family support, scale development, parents' difficulties

I. Introduction

Hikikomori Syndrome (social withdrawal) has had considerable attention paid to it in community mental health in Japan. It is defined as a state of almost complete withdrawal from social interaction, limiting the lives of sufferers to their homes mainly for 6 months or longer.¹⁾ Hikikomori usually starts by late 20's, and it is estimated that 260,000 families in Japan have a child with Hikikomori.²⁾

Hikikomori has also been evidenced abroad. It

does not have an English translation, but is occasionally referred to as 'acute social withdrawal' or 'primary social withdrawal'. Generally, it is considered a problem unique to Japan, although there are some case reports of Hikikomori in Oman.³⁾

Hikikomori is considered to be a culture bound trait unique to Japan and linked to the closed nature of traditional Japanese society and the value placed on the nobility of solitude.⁴⁾ The fourth edition of the Diagnostic and Statistical Manual (DSM-IV) has in-

cluded a cultural formulation and a glossary of culture bound syndromes.⁵⁾ Alarcón et al.⁶⁾ said that with diagnostic terms: DSM-IV, acknowledges the difficulties of locating these cultural aspects and characteristics in the conventional nosology and realizes the non-pathological nature of some of them, as well as the value of their local explanations. Thus far, although young people with Hikikomori bear similarities to social phobia, personality disorder, anxiety disorder and depression, specialists pointed out important differences between them. Watts⁷⁾ reported that Hikikomori reflects as much on Japanese society as on the individuals concerned.

Providing professional support for families — especially parents — with Hikikomori children is important, because the parent has a central role in consultations with professionals about their child with Hikikomori, and because the parent often faces many difficulties.⁸⁾ The psychological distress of the family members is also reported to be greater than in the general population.⁹⁾ Support for family decreases their anxiety, and helps the family to see their child with Hikikomori positively.¹⁰⁾

In addition to supporting the family emotionally, it is also important to strengthen the family function. Some reports point to a possibility that Hikikomori and the family function are related. For instance, the family that has a child with Hikikomori tends to have lower adaptability and cohesion.¹¹⁾ Moreover, Suwa¹²⁾ suggested that the onset mechanism for Hikikomori is not merely a problem of the withdrawn person themselves alone, but includes the problems of family relationships. Support for family prevents the family members from being socially isolated, and being excessively involved in the problems of their child with Hikikomori. By supporting the family members, it is expected that stress at home will be relieved and family relations changed.

Helping the family leads to support of their withdrawn child indirectly. Some studies indicate that support for family makes a positive impact on withdrawn children. Kurita et al.¹³⁾ reported that support for family has improved withdrawn children's condition; scope of activity; communication inside the family, and

problematic behavior. Twenty percent of children with Hikikomori, whose families received support from mental health professionals, undertook social participation after one year.¹⁴⁾

Consequently, we need evidence to plan, implement and evaluate the support for families of children with Hikikomori. Kondo¹⁵⁾ emphasized the necessity of examining the actual condition, effectiveness and limitation of support services for Hikikomori. The difficulties for parents of children with Hikikomori are one of the most important indicators for the assessment of support for family. In support for family with people with health problems, some study assessed caregiver difficulties or burden which affect their QOL and mental health as outcome indicators.^{16,17)}

There are some scales which assess the difficulties or burden for families caring for children with some type of disability, but not any scales for parents of children with Hikikomori. A scale which assesses the difficulties for families of people with schizophrenia includes difficulties relative to treatment of mental illness such as "concern about sudden changes in psychological symptom and relapse", "difficulties of support for continuous medication" and "a difference of opinion with doctor".¹⁸⁾ These scales cannot be applied to children with Hikikomori, because they do not have mental and/or physical disorders and because their daily living and functional activities are not impaired. It is needed to develop newly scale which can assess difficulties specific to parents whose children with Hikikomori.

The present study aimed to develop a scale to assess the difficulties faced by parents of children with Hikikomori, and to test the psychometric properties (validity and reliability) of this assessment scale.

II. Methods

1. Definition of term

Hikikomori was defined as a condition characterized by socially withdrawal regardless of the cause of it in the present study. We did not distinguish clearly between parents whose children have a mental disorder and those whose children do not. This was partly

because parents with undiagnosed children still encounter difficulties and need help, and partly because it had to be borne in mind that - among those who have used services for Hikikomori - 35.7% have had a psychiatric disorder diagnosed,¹⁾ and - among those who have experienced Hikikomori - 54.5% had also experienced another psychiatric disorder in their lifetime.²⁾

Family difficulties was operationally defined as distress experienced by parents of children with Hikikomori in emotional and physical wellness, social life, and economic situation. Difficulties was regarded as one of the factor influencing QOL and mental state.

2. Data collection

Participants and procedure

We researched among parents who have been receiving support for their children with Hikikomori. Participants who have a child with Hikikomori were recruited through support organizations to which they belong. Mental and Welfare Centers from three adjoining prefectures in the Japanese Tokai region and four regional, incorporated, nonprofit organizations conducting self-help groups for parents with socially withdrawn children participated in this investigation.

Parents were asked to complete the questionnaires anonymously and mail them to the University. Parents gave their demographic information, their data on family difficulties, quality of life and depression, via self-reporting questionnaires. In addition, they provided demographic information about their children with Hikikomori.

Measures

A parents' difficulties instrument was newly developed because, to the investigators' knowledge, no known questionnaires exist for assessing parents' difficulties relative to children with Hikikomori. The items of the parents' difficulties were derived from the results of our qualitative study¹⁹⁾ and the other previous research of families with children with Hikikomori.²⁰⁾ Our previous interview study found that parents need marital cooperation because they fell into feelings of gloom and guilt,

and their mental condition became unstable.¹⁹⁾ Narabayashi et al.¹⁰⁾ reported parents of a Hikikomori child have feelings of anxiety, helplessness, impatience, fatigue, exhaustion and self-condemnation. Amagaya et al.²⁰⁾ stated that a family whose child has Hikikomori have many difficulties related to "communication with the child", "the child's future prospects", "economic anxiety", "frustration with the child", "depressed feeling", and "concern with appearances".

In addition, items were derived from the constructs identified in other family difficulties literature, from studies of families caring for people with schizophrenia and mothers of children with cerebral palsy. A family difficulties scale of people with schizophrenia which has been previously mentioned includes difficulties of "relationship with the patient", "prejudice of mental illness", "restrictions on freedom", and "financial burden" in addition to difficulties relative to treatment of mental illness.¹⁸⁾ A mother's needs scale of children with cerebral palsy consists of "need for information", "need for support", "explaining for others", "community services", "financial needs", and "family functioning".²¹⁾

The initial Parents Difficulties Scale for families coping with Hikikomori, which was used in our study, consisted of 42 items describing eight difficulties related to¹⁾ community human resource;²⁾ information utilization;³⁾ financial difficulties;⁴⁾ understanding Hikikomori;⁵⁾ relationship with the child;⁶⁾ psychological conflict;⁷⁾ marital cooperation, and⁸⁾ mental health professional support. All items were scored on a four-point Likert scale ranging from 1 ('strongly agree') to 4 ('strongly disagree'). High scores were indicative of there being difficulties.

Quality of life was assessed with the short form of the Japanese version²²⁾ of the World Health Organization Quality of Life scale (WHO/QOL-26).²³⁾ WHO/QOL-26 includes four subscales: Physical Domain; Psychological Domain; Social Relationships, and Environment. All items are scored on a five-point Likert scale. High scores are indicative of high QOL.

Depression was assessed with the Japanese version²⁴⁾ of the Center for Epidemiologic Studies Depression Scale (CES-D).²⁵⁾ All items are scored on a four-point

Likert scale. Depression is suspected if the CES-D score is 16 or higher. If the new scale can assess the family difficulties validly, it will have a negative correlation with the WHO/QOL score and a positive correlation with the CES-D score.

Ethical considerations

All participants were informed in writing about the study purpose and methods. They were assured that neither they nor their places of work would be identified. They were also informed that participation in the study was voluntary and that they could terminate it at any time if they were unhappy with any aspect of it. Consent from participants was confirmed by their filling out the questionnaires. A university ethics committee approved the research protocol before the study began.

3. Data analysis

Data analysis was conducted using the Statistical Package for the Social Sciences, Version 15, and Amos, Version 7. Significance level was set as $p < 0.05$ (two-sided).

Item analysis

Item analysis was conducted by sampling the fathers' and mothers' responses and comparing them with samples from the total of parents' responses. Some items in the initial Parents' Difficulties Scale, which had significant bias in score distribution, were excluded from later analysis. The criterion of exclusion was $(\text{mean}-\text{SD}) < 1$ (floor effect) or $(\text{mean}+\text{SD}) > 4$ (ceiling effect).

Exploratory factor analysis

An exploratory factor analysis of The Parents' Difficulties Scale items was conducted in order to assess if any items in the scale were measuring aspects of the same underlying dimensions or factors. Exploratory factor analyses were also conducted according to gender in order to examine whether or not the extracted factors can be found for fathers and mothers, respectively.

A least-square method without weighting analysis,

with quantimax rotation, was used. A scree plot was used to determine a number of factors, with the criteria having eigenvalues greater than 1. A solution was deemed acceptable based on the following criteria:¹⁾ all items load substantially on only 1 factor;²⁾ all items have a factor loading of at least 0.40; and ³⁾ the items cluster together in a meaningful fashion. Scale scores were subsequently derived for each subject by computing the mean of the items comprising each factor.

Confirmatory factor analysis

Structural equation modeling (SEM) methods as implemented by AMOS²⁶⁾ were used to test various models simultaneously.

Reliability analysis

Internal consistency was assessed using Cronbach's alpha. Alpha coefficients were computed for the total scale and then every subscale.

Construct-related validity analysis

To assess criterion-related validity, Family Difficulties Scale scores were compared with CES-D and QOL scores, and the variables related to withdrawn children by correlation coefficient.

In addition, to examine the possibility of the effect of the presence or absence of mental illness on The Parents' Difficulties Scale in Children with Hikikomori scores, it was compared between parents whose children have a mental disorder and those whose children do not, using t-test.

III. Results

1. Participants

The sample comprised all 176 parents (116 families, response rate = 26.9%), of whom 72 were fathers (40.9%) and 104 were mothers (59.8%). Table 1 shows socio-demographic characteristics of the parents. The average age was 60.8 years ($SD = 7.1$). Of the 176 parents, 124 (70.4%) participated in this study as couples (62 couples). Almost 80% of them have received family support. The average number of type of family services

was 2.2 (SD = 1.6), for the previous year.

The sample included two families with two withdrawn children. The sample concerned a total of 119 children: 96 (80.7%) were male and the average age was 30.2 (SD = 6.7). Although about 70 percent of the children did not have a mental disorder leading to

Hikikomori, they had been socially withdrawn for an average of 9.7 years each (SD = 5.9). Table 2 describes the condition of children with Hikikomori for the month prior to this research. Nearly half (41.2%) of the children were able to go out freely but didn't participate in any social activity. In their attitudes to their families, those with Hikikomori who rejected at least one other

Table 1 Socio-demographic characteristics of parents (N = 176)

	mean (SD; range)	
Age in years (n = 174)	60.8 (7.1; 37-81)	
	n	%
Relationship to child with Hikikomori		
father	72	40.9
mother	104	59.1
Number of children with Hikikomori		
1	169	96.0
2	7	4.0
Working styles (n = 174)		
not working	78	43.8
full-time job	39	21.9
part-time job	57	32.0
Marital status (n = 173)		
married/ living together	153	86.0
married/ separated	9	5.1
divorced	4	2.2
widowed	7	3.9
Participants in family support ^a (n = 174)		
medical setting	73	41.0
home visiting care	34	19.1
ambulant counseling	71	39.9
self-help group	98	55.1
telephone counseling	20	11.2
e-mail counseling	5	2.8
lecture meeting	89	50.0
Number of services received ^a (n = 175)		
0	30	16.8
1	37	20.8
2	35	19.7
3	34	19.1
4	15	8.4
5	22	12.4
6	2	1.1

Notes: ^a = over the past year

Table 2 Socio-demographic characteristics of children (N=119)

	mean (SD; range)	
Age ^a (n = 118)	30.2 (6.75; 14-49)	
Age when Hikikomori started ^a (n = 115)	20.4 (5.77; 10-37)	
Period of Hikikomori ^a (n = 114)	9.7 (5.97; 0-32)	
Age when family first ^a visited support organization (n = 113)	21.9(7.39; 8-45)	
	n	%
Gender		
male	96	80.7
female	23	19.3
Geniture		
first child	52	43.7
(no sibling)	(9)	(7.6)
second child	56	47.1
third child	10	8.4
fourth child	1	0.8
Prevalence of mental disorder (n = 115)	31	26.1
Fulfilling guideline of Hikikomori (n = 111)	55	46.2
Experience of school refusal (n = 116)	65	54.6
Problematic behaviors (n = 117)		
disrupted sleep patterns	47	39.5
self-injury	1	0.9
violence in the home	5	4.3
destructive behavior	15	12.6
compulsive behavior	15	12.6
disorderly diet	28	23.5
authoritative attitude in the home	15	12.6
Number of problematic behaviors (n = 117)		
0	44	37.0
1	37	31.1
2	23	19.3
3	9	7.6
4	2	1.7
5	2	1.7
Scope of activity over the past month (n = 111)		
participating in social activities	3	2.5
going out freely, excluding social activities	49	41.2
going out with reservations	30	25.2
being freely limited in home	22	18.5
keeping in one's room	7	5.9
Attitude to family over the past month (n = 111)		
not rejecting family members	66	55.5
rejecting some of the family members	30	25.2
rejecting all of the family members	15	12.6

Notes: ^a = years

Table 3 Means and deviations of the initial Parents' Difficulties Scale 42 items

	Parents (N=176)		Fathers (n=72)		Mothers (n=104)	
	mean	SD	mean	SD	mean	SD
1 I have friends who I can consult about Hikikomori.	2.38	1.12	2.04	0.99	2.61	1.15
2 I am supported by other families whose children suffer from Hikikomori.	2.15	1.09	1.95	1.04	2.28	1.12
3 I have someone who I can talk to freely concerning my ideas and feelings about Hikikomori.	2.63	1.14	2.23	1.13	2.90	1.09
4 I feel lonely because I don't have anyone I can talk to freely about Hikikomori.	2.91	1.00	2.84	1.10	2.97	0.94
5 I know the support resource which I will be able to use in the future.	2.39	1.03	2.11	1.00	2.57	1.02
6 I know the support resource for Hikikomori which I can use now.	2.68	1.00	2.44	1.04	2.84	0.93
7 I know the future progress of my child's condition.	2.07	0.86	1.85	0.82	2.22	0.87
8 I have heard the experiences of people who recovered from Hikikomori.	2.95	1.13	2.68	1.15	3.17	1.06
9 I have heard the condition of families whose children recovered from Hikikomori.	3.16	0.95	2.21	1.07	3.29	0.85
10 I have heard the experiences of families whose children recovered from Hikikomori.	2.71	1.12	2.55	1.13	2.82	1.12
11 I don't know what information is useful.	2.50	0.98	2.59	1.05	2.44	0.94
12 I need financial support for the daily life of child with Hikikomori.	2.08	1.02	2.15	1.10	2.04	0.98
13 I need financial support for the future life of my child with Hikikomori.	1.70	0.87	1.76	0.90	1.66	0.80
14 I need financial support to be able to use the services for children with Hikikomori.	1.89	0.93	1.89	0.96	1.89	0.93
15 I need financial support to prepare my child with Hikikomori to hold a job or attend school.	1.83	0.89	1.81	0.96	1.83	0.85
16 I understand the anguish of children with Hikikomori.	3.31	0.73	3.14	0.84	3.42	0.62
17 I respect the need to be patient with children suffering from Hikikomori.	3.27	0.72	3.22	0.80	3.31	0.67
18 I am eager for my child with Hikikomori to attend school or hold a job.	1.79	0.91	1.68	0.86	1.87	0.94
19 I compare children with Hikikomori to others of the same age without it.	2.14	0.92	1.93	0.92	2.30	0.89
20 I talk to my child with Hikikomori about hobbies and news.	2.57	1.04	2.33	1.05	2.75	1.01
21 I have a joke with my child with Hikikomori.	2.36	1.07	2.07	1.01	2.56	1.08
22 I often have a quarrel with my child with Hikikomori.	3.13	0.86	3.21	0.84	3.06	0.87
23 I always talk down to my child with Hikikomori	3.15	0.83	3.20	0.82	3.13	0.83
24 I get involved in the problems of my child with Hikikomori.	2.68	0.93	2.80	0.97	2.58	0.89
25 I don't know how to communicate with my child with Hikikomori.	2.32	0.87	2.20	0.83	2.41	0.89
26 I feel anger and frustration with my child with Hikikomori.	2.38	0.83	2.34	0.85	2.41	0.82
27 I am worried about my child with Hikikomori.	2.41	0.91	2.48	0.98	2.37	0.86
28 I caused my child to suffer from Hikikomori.	2.42	0.78	2.39	0.84	2.41	0.72
29 Care for my child with Hikikomori drains me physically and emotionally.	2.49	0.81	2.58	0.76	2.42	0.85
30 I worry that my status within the local community will be affected by my child.	2.34	0.88	2.33	0.96	2.33	0.84
31 I feel anxious and rushed about the future of my family.	1.83	0.77	1.86	0.80	1.81	0.76
32 I always share knowledge and information about Hikikomori with my partner.	2.76	0.92	2.96	0.76	2.64	0.99
33 I can discuss Hikikomori freely with my partner.	2.86	0.95	3.16	0.79	2.68	0.99
34 I handle the problems of Hikikomori differently to my partner.	2.56	0.81	2.46	0.72	2.61	0.85
35 I and my partner support each other emotionally.	2.70	0.92	2.82	0.82	2.64	0.98
36 I participate in lecture meetings and consultations about social withdrawal together with my partner.	2.40	1.10	2.54	1.08	2.34	1.11
37 I deal with Hikikomori in collaboration with my partner.	2.78	0.92	2.96	0.78	2.69	0.97
38 I have specialists who I can consult about Hikikomori.	2.57	1.10	2.30	1.00	2.74	1.13
39 My child with Hikikomori was examined by a psychiatrist.	2.28	1.09	2.19	1.03	2.31	1.13
40 I have heard from specialists about the mental problems related to Hikikomori.	2.75	1.08	2.43	1.14	2.96	0.99
41 I have heard from specialists about communication with children with Hikikomori.	3.04	0.95	2.85	1.03	3.16	0.89
42 I have heard from specialists about children with Hikikomori preparing to hold jobs or attend schools.	2.72	1.01	2.64	1.03	2.77	1.00

Table 4 Factor structure and correlation for The Parents' Difficulties Scale in Children with Hikikomori

Factors	Factor scale name	Factor loadings			Correlation		
		parents N=176 ($\alpha = .858$)	father n=72 ($\alpha = .727$)	mother n=104 ($\alpha = .860$)	1	2	3
1	Difficulties in marital cooperation	($\alpha = .888$)	($\alpha = .808$)	($\alpha = .795$)			
	32 I always share knowledge and information about Hikikomori with my partner.	.913	.876	.951			
	33 I can discuss Hikikomori freely with my partner.	.881	.850	.861			
	37 I deal with Hikikomori in cooperation with my partner.	.817	.776	.878	1	.045	.191*
	35 I and my partner support each other emotionally.	.742	.539	.805			
	36 I participate in lecture meetings and consultation about social withdrawal together with my partner.	.565	.572	.549			
2	Psychological conflict with the child	($\alpha = .831$)	($\alpha = .762$)	($\alpha = .899$)			
	27 I am worried about my child with Hikikomori.	.809	.809	.803			
	24 I get involved in the problems of my child with Hikikomori.	.653	.653	.691			
	26 I feel anger and frustration with my child with Hikikomori.	.646	.646	.768			
	29 Care for my child with Hikikomori drains me physically and emotionally.	.608	.608	.601		1	.305*
	30 I worry that my status within the local community will be affected by my child.	.601	.601	.587			
	25 I don't know how to communicate with my child with Hikikomori.	.599	.599	.548			
3	31 I feel anxious and rushed about the future of my family.	.539	.539	.579			
	Difficulties in support resource utilization	($\alpha = .813$)	($\alpha = .825$)	($\alpha = .825$)			
	5 I know the support resource which I will be able to use in the future.	.814	.900	.796			
	6 I know the support resource for Hikikomori which I can use now.	.807	.765	.889			
	7 I know the future progress of my child's condition.	.675	.752	.638			1
	3 I have someone who I can talk to freely concerning my ideas and feelings about Hikikomori.	.603	.558	.412			
	38 I have specialists who I can consult about Hikikomori.	.538	.633	.446			
	10 I have heard the experiences of families whose child recovered from Hikikomori.	.471	.522	.388			

Notes: α = Cronbach's alpha coefficient, * $p < 0.05$

member of their family amounted to almost 40%. More than 60% of children evidenced at least one problematic behavior, the most common being "disrupted sleep pattern", four out of ten suffering with this.

2. Item analysis

According to the score distribution in the initial Parents' Difficulties Scale (Table 3), seven items had a floor effect and five items had a ceiling effect. These 12 items were excluded from later analysis.

3. Factor analysis

Based on eigenvalue graphing, a three-factor solution was extracted with eigenvalues of 2.8, 3.5 and 5.9, which together explained 41.3% of the variance.

After several refinements, three structures were established and corresponded to difficulties in marital cooperation (five item scale), psychological conflict with the child (seven item scale), and difficulties in support resource utilization (six item scale). The first factor was named 'Difficulties in marital cooperation'. It included, for example, questions such as 'I always share knowledge and information about Hikikomori with my partner', and 'I can discuss Hikikomori freely with my partner'. The second factor was named 'Psychological conflict with the child'. Its questions included, for example: 'I am worried about my child with Hikikomori', and 'I get involved in the problems of my child'. The third factor was named 'Difficulties in support resource utilization'. The factor loadings and factor structure are shown in Table 4, and the descriptive statistics of items are shown in Table 5. The fathers' and mothers' samples had almost the same factor structure as the total sample.

The correlated three-factor model of The Parents' Difficulties Scale was tested to the fit of a one-factor model which assumes that all items load on one single underlying dimension. The results of confirmative factor analysis (CFA) showed that the three-factor model (SEM: GFI = 0.851, AGFI = 0.806, RMSEA = 0.08), fit to the data better than the one-factor model (SEM: GFI = 0.528, AGFI = 0.402, RMSEA = 0.198). The correlation among these three factors was low (Table 6).

4. Reliability

Cronbach's alpha coefficient of the total scale was 0.88, and for each subscale was 0.88, 0.83, and 0.81, for marital cooperation, psychological conflict and support resource utilization, respectively.

5. Relationship with other variables

Table 6 shows the scores of CES-D, QOL, and The Parents' Difficulties Scale.

Table 7 shows the correlation between Family Difficulties, QOL, depression and child condition. The scale had negative correlation with the WHO/QOL scores and positive correlation with the CES-D scores. The scale also had positive correlation with children's condition, meaning that parents, whose child had much problematic behavior and was more socially withdrawn and more rejective towards their family, were more likely to report family difficulties.

Table 8 shows comparison of the score of CES-D, QOL, and The Parents' Difficulties Scale between parents whose children have a mental disorder and those whose children do not. There were no significant differences in The Parents' Difficulties Scale.

IV. Discussion

1. Validity and reliability

The present study aimed to develop an assessment of the difficulties faced by parents of children with Hikikomori, and to test the psychometric properties (validity and reliability) of this assessment scale, The Parents' Difficulties Scale in Children with Hikikomori. Internal consistency (Cronbach's α coefficient) of both the total score and all the subscales was high and acceptable (> 0.800). Both exploratory and confirmatory factor analyses showed an acceptable degree of factor-based validity. A secondary structural model showed that a three-factor model fit best (SEM: GFI = 0.851, AGFI = 0.806, RMSEA = 0.08), although the goodness-of-fit criteria were not sufficient. The total score was significantly and negatively correlated with the WHO/QOL score and positively with the CES-D score. It is suggested that parents who have greater difficulties

Table 5 Descriptive statistics of the final Parents' Difficulties Scale 18 items

Factors	Items	parents (N=176)				father (n=72)				mother (n=104)			
		Strongly Disagree	Disagree	Agree	Strongly Agree	Strongly Disagree	Disagree	Agree	Strongly Agree	Strongly Disagree	Disagree	Agree	Strongly Agree
		n (%)				n (%)				n (%)			
MC	32 I always share knowledge and information about Hikikomori with my partner.	20 (11.4)	41 (23.3)	77 (43.8)	38 (21.6)	2 (2.8)	16 (22.5)	36 (50.7)	17 (13.9)	17 (16.5)	24 (23.3)	41 (39.8)	21 (20.4)
	33 I can discuss Hikikomori freely with my partner.	17 (9.7)	42 (23.9)	66 (37.5)	51 (29.0)	1 (1.4)	14 (19.7)	29 (40.8)	27 (38.0)	15 (14.6)	27 (26.2)	37 (35.9)	24 (23.3)
	37 I deal with Hikikomori in cooperation with my partner.	20 (11.4)	36 (20.5)	82 (46.6)	38 (21.6)	3 (4.2)	13 (18.3)	39 (54.9)	16 (22.5)	15 (14.6)	23 (22.3)	43 (41.7)	22 (21.4)
	35 I and my partner support each other emotionally.	22 (12.5)	43 (24.4)	77 (43.8)	34 (19.3)	5 (7.0)	16 (22.5)	37 (52.1)	13 (18.3)	16 (15.5)	26 (25.2)	40 (38.8)	21 (20.4)
	36 I participate in lecture meetings and consultation about social withdrawal together with my partner.	48 (27.3)	45 (25.6)	45 (25.6)	38 (21.6)	15 (21.1)	18 (25.4)	21 (29.6)	17 (23.9)	31 (30.1)	27 (26.2)	24 (23.3)	21 (20.4)
	27 I am worried about my child with Hikikomori.	28 (15.9)	68 (38.6)	58 (32.9)	22 (12.5)	13 (18.3)	20 (28.2)	27 (38.0)	11 (15.5)	15 (14.6)	46 (44.7)	31 (30.1)	11 (10.7)
PC	24 I get involved in the problems of my child with Hikikomori.	16 (9.1)	63 (35.8)	56 (31.8)	41 (23.3)	6 (8.5)	22 (31.0)	21 (29.6)	22 (31.0)	10 (9.7)	41 (39.8)	34 (33.0)	18 (17.5)
	26 I feel anger and frustration with my child with Hikikomori.	23 (13.1)	78 (44.3)	59 (33.5)	16 (9.1)	11 (15.5)	29 (40.8)	25 (35.2)	6 (8.5)	12 (11.7)	47 (45.6)	34 (33.0)	10 (9.7)
	29 Care for my child with Hikikomori drains me physically and emotionally.	17 (9.7)	73 (41.5)	68 (38.6)	18 (10.2)	5 (7.0)	24 (33.8)	36 (50.7)	6 (8.5)	12 (11.7)	48 (46.6)	31 (30.1)	12 (11.7)
	30 I worry that my status within the local community will be affected by my child.	28 (15.9)	77 (43.8)	52 (29.5)	19 (10.8)	14 (19.7)	26 (36.6)	22 (30.9)	9 (12.7)	14 (13.6)	51 (49.5)	28 (27.2)	10 (9.7)
	25 I don't know how to communicate with my child with Hikikomori.	29 (16.5)	76 (43.2)	54 (30.7)	17 (9.7)	12 (16.9)	37 (52.1)	16 (22.5)	6 (8.5)	17 (16.5)	38 (36.9)	37 (35.9)	11 (10.7)
	31 I feel anxious and rushed about the future of my family.	63 (35.8)	83 (47.2)	24 (13.6)	6 (3.4)	25 (35.2)	32 (45.1)	11 (15.5)	3 (4.2)	38 (36.9)	49 (47.6)	13 (12.6)	3 (2.9)
SR	5 I know the support resource which I will be able to use in the future.	46 (26.1)	39 (22.2)	65 (36.9)	26 (14.8)	26 (36.6)	14 (19.7)	26 (36.6)	5 (7.0)	20 (19.4)	24 (23.3)	39 (37.9)	20 (19.4)
	6 I know the support resource for Hikikomori which I can use now.	30 (17.0)	34 (19.3)	76 (43.2)	36 (20.5)	19 (26.8)	12 (16.9)	31 (43.7)	9 (12.7)	11 (10.7)	21 (20.4)	45 (43.7)	26 (25.2)
	7 I know the future progress of my child's condition.	49 (27.8)	74 (42.0)	43 (24.4)	10 (5.7)	27 (38.0)	27 (38.0)	15 (21.1)	2 (2.8)	22 (21.4)	45 (43.7)	28 (27.2)	8 (7.8)
	3 I have someone who I can talk to freely concerning my ideas and feelings about Hikikomori.	42 (23.9)	33 (18.8)	51 (28.9)	50 (28.4)	25 (35.2)	17 (23.9)	17 (23.9)	12 (16.9)	17 (16.5)	15 (14.6)	33 (32.0)	38 (36.9)
	38 I have specialists who I can consult about Hikikomori.	39 (22.2)	43 (24.4)	51 (29.0)	43 (24.4)	18 (25.4)	21 (29.6)	23 (32.3)	9 (12.7)	21 (20.4)	19 (18.4)	30 (29.1)	33 (32.0)
	10 I have heard the experiences of families whose child recovered from Hikikomori.	35 (19.9)	38 (21.6)	48 (27.3)	55 (31.3)	18 (25.4)	12 (16.9)	25 (35.2)	16 (22.5)	17 (16.5)	24 (23.3)	23 (22.3)	39 (37.9)

MC=Difficulties in marital cooperation, PC=Psychological conflict with the child, SR=Difficulties in support resource utilization

Table 6 Means and deviations of Parents' Difficulties Scale, WHO/QOL-26, and CES-D (N = 176)

	mean (SD; range)
Parents' Difficulties Scale in Children with Hikikomori	
Total score (18 items)	44.9 (8.5; 22-67)
Difficulties in marital cooperation (5 items)	13.4 (3.9; 5-20)
Psychological conflict with the child (7 items)	16.4 (4.1; 7-26)
Difficulties in support resource utilization (6 items)	15.0 (4.4; 6-24)
WHO/QOL-26 average	
Total score	3.1 (0.5; 1.8-4.7)
Physical Domain	3.4 (0.7; 1.7-8.2)
Psychological Domain	3.1 (0.6; 1.5-4.5)
Social relationships	3.0 (0.5; 1.0-4.0)
Environment	3.1 (0.5; 1.2-4.2)
CES-D	16.0 (9.9; 0-54)

Table 7 Correlation between Parents' Difficulties, QOL, depression and child condition (N = 176)

Family Parents' Scale in Children with Hikikomori	Total score		MC ^a		PC ^a		SR ^a	
	r	r	r	r	r	r	r	r
Child condition								
Number of problematic behaviors	0.165 *	0.004	0.227 **				0.095	
Scope of activity ^b (n = 164)	0.223 **	0.113	0.234 **				0.101	
Attitude to family ^c (n = 163)	0.172 *	0.109	0.234 **				0.014	
WHO/QOL-26 Total	-0.550 **	-0.328 **	-0.499 **				-0.281 **	
Physical Domain	-0.391 **	-0.268 **	-0.322 **				-0.200 **	
Psychological Domain	-0.530 **	-0.261 **	-0.506 **				-0.295 **	
Social relationships	-0.449 **	-0.243 **	-0.399 **				-0.259 **	
Environment	-0.527 **	-0.347 **	-0.496 **				-0.224 **	
CES-D	0.309 **	0.136	0.386 **				0.101	

r = Pearson's product-moment correlation coefficient

^aMC = Difficulties in marital cooperation, PC = Psychological conflict with the child, SR = Difficulties in support resource utilization

^b0 = participating in social activities, 1 = going out freely excluding social activities, 2 = going out with reservations, 3 = being freely limited in home, 4 = keeping in one's room

^c1 = not rejecting the family members, 2 = rejecting some of the family members, 3 = rejecting all of the family members

*p < 0.05, **p < 0.01

Table 8 Comparison between parents whose children have a mental disorder and those whose children do not

Morbidity of mental disorder	yes		no		t-value	p
	mean (SD)	n	mean (SD)	n		
Parents' Difficulties Scale in Children with Hikikomori		n=37		n=107		
Total score (18 items)	46.7 (9.5)		43.6 (7.8)		1.904	0.080
Difficulties in marital cooperation (5 items)	13.7 (3.9)		12.8 (3.7)		1.260	0.845
Psychological conflict with the child (7 items)	17.4 (4.7)		16.2 (3.8)		1.576	0.170
Difficulties in support resource utilization (6 items)	15.4 (4.7)		14.5 (4.3)		1.031	0.398
WHO/QOL-26 average		n=36		n=105		
Total score	3.2 (0.5)		3.1 (0.5)		1.456	0.148
Physical Domain	3.4 (0.6)		3.3 (0.7)		1.003	0.317
Psychological Domain	3.2 (0.6)		3.0 (0.5)		1.125	0.263
Social relationships	3.2 (0.5)		3.0 (0.5)		2.225*	0.028
Environment	3.2 (0.5)		3.1 (0.5)		1.201	0.232
CES-D		n=37		n=107		
	17.4 (9.8)		12.7 (9.1)		-2.547*	0.010

*p < 0.05

with their withdrawn child feel lower QOL and more severe depression. There is a report in which parental caregiver burden with children with disabilities has also negatively correlated with the QOL and positively with the depression.²⁷⁾ Parents, whose total score on The Parents' Difficulties Scale was higher, recorded their children as having much problematic behavior, being more socially withdrawn and being more rejective of their family. Thus, the criterion-related validity of The Parents' Difficulties Scale in Children with Hikikomori was supported. Moreover, the fathers' and mothers' samples showed the same factor structures and acceptable consistency. Consequently, the results indicate that the newly developed Family Difficulties Scale is reliable and valid.

The final Parents' Difficulties Scale concerned characteristics of difficulties among parents whose children have Hikikomori, in contrast with our initial scale, regarding the following four aspects. (Incidentally, three subscales consisting of 18 items were eventually extracted as The Parents' Difficulties Scale). First, marital cooperation; this was retained after factor analysis. Second, some difficulties in the families of people with schizophrenia and cerebral palsy, which parents were unrelated to those of families with children with Hikikomori, were removed. Third, the final Parents' Difficulties Scale evaluated difficulties which were not the effect of mental disorder, given that there were no significant differences in The Parents' Difficulties Scale between parents whose children have a mental disorder and those whose children do not. Fourth, parental responses; this scale is appropriate for measuring parental difficulties, especially among parents, given that the responses in the present study were all those of mothers and fathers.

The Parents' Difficulties Scale in Children with Hikikomori consists of three subscales as a result of factor analysis. Marital Cooperation is an especially original concept among the three factors. On the other hand, it has been recognized that families who have children with mental problems have difficulties related to social support and psychiatric distress. For instance,

McCubbin et al.²⁸⁾ reported four strategies: acquiring social support; seeking community resources; reframing, and seeking spiritual support, which parents would think of when coping with problematic child behavior. Marital Cooperation was extracted by factor analysis because the content of this scale includes the items which arose from earlier qualitative research into parents' experiences.^{19,20)} Difficulties in marital cooperation may be particular and notable difficulties in studies of parents with withdrawn children.

2. Clinical Implications

The Parents' Difficulties Scale in Children with Hikikomori is the first scale that can quantitatively measure the difficulties of families with Hikikomori children. Thus, it is useful both to professionals providing family support and to families with Hikikomori children.

Providing professional support for families with Hikikomori children is important, as children with Hikikomori rarely seek help on their own. The families play a central role in obtaining professional help, and families of children with Hikikomori often face many difficulties which support services can assist with. To date, we have had difficulties in obtaining information and gaining knowledge with which to properly support families with children who have Hikikomori; and, we need such information and knowledge - as evidence - with which to plan, implement and evaluate our services. Information about family difficulties is one of the most important outcomes in family support. The Parents' Difficulties Scale in Children with Hikikomori may contribute usefully with care providers to evaluate the effectiveness of their family support.

It is also important for parents to perceive their own difficulties related to their Hikikomori children. Parents can understand their level of difficulty easily and objectively using this Family Difficulties Scale.

3. Study Limitations

First, in respect of the study's limitations, we would like to note that the sample is small and the

response rate is low. Second, a majority of the respondents had accessibility to support services and the data collected in this study was obtained from parents who had already received family support. Third, the difficulties of the participants in the present study could be reflected in the quality of the family support which they have received, because the data were collected from parents who belonged to seven organizations providing support for families with Hikikomori children. The instrument needs further testing and evaluation with a larger sample.

It should be noted that there are two sub-scales of The Parents' Difficulties Scale in Children with Hikikomori: Difficulties in support resource utilization, and Difficulties in marital cooperation. They don't have a significant correlation with parents' depression and child condition. We need to use the scale carefully and note that the results of the sub-scales were measured independently.

While King & Bernstein²⁹⁾ reported that school refusal cases require comprehensive assessment and treatment, and advances have been made in the treatment of school refusal, additional controlled studies evaluating interventions in school refusal are needed. It is expected that The Parents' Difficulties Scale developed in the present study will assist a number of professionals in such related fields. Our newly developed Scale can be utilized easily in clinical practice; however, it cannot evaluate difficulties related to mental disorders.

V. Conclusion

The present study reported the development of an instrument for the assessment of family difficulties regarding children with Hikikomori: The Parents' Difficulties Scale in Children with Hikikomori, and confirmed its validity and reliability. It is useful in assessing the need for support for families of children with Hikikomori.

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Appendix: The Parents' Difficulties Scale in Children with Hikikomori

「ひきこもり青年の親の困難感尺度」

現在のひきこもり青年の親のとしてのあなたの状況についてお尋ねします。各々のことごとについて、A~Dのうち一つだけを選択し、アルファベットを○でかこんでください。

		当てはまらな 全く	どちらかと 当てはまらな い	どちらかと 当てはまる	よく当てはまる
1	ひきこもりに関する知識や情報を夫婦で常に共有している	A	B	C	D
2	ひきこもりについて夫婦間で自由に話し合うことができる	A	B	C	D
3	ひきこもりについて夫婦で協力して取り組んでいる	A	B	C	D
4	夫婦で精神的に支えあっている	A	B	C	D
5	ひきこもりに関する講演会や相談などには夫婦一緒に参加している	A	B	C	D
6	自分の気持ちのやり場がない	A	B	C	D
7	ひきこもり青年に巻き込まれる	A	B	C	D
8	ひきこもり青年に対して欲求不満や憤りを感じる	A	B	C	D
9	ひきこもり青年の世話で心身ともに疲れる	A	B	C	D
10	子どもがひきこもっていることは世間体が悪く、気苦労を感じる	A	B	C	D
11	ひきこもり青年と普段どのように関わったら良いかわからない	A	B	C	D
12	家族の将来設計が立てられない不安や焦りがある	A	B	C	D
13	現在利用できるひきこもり青年を支援するサービスについて知っている	A	B	C	D
14	ひきこもりの状態の今後の見通しについて知っている	A	B	C	D
15	ひきこもりについての自分の考えや気持ちを自由に話せる人がいる	A	B	C	D
16	ひきこもりについて相談できる専門家がいる	A	B	C	D
17	ひきこもりからの回復を果たした家族の体験談を聞いたことがある	A	B	C	D
18	将来利用できるひきこもり青年を支援するサービスについて知っている	A	B	C	D

ⓈA=4点, B=3点, C=2点, D=1点 Ⓢ6,7,8,9,10,11,12は反転

夫婦間の協力：1~5, ひきこもり青年に対する心的葛藤：6~12, 社会資源の活用：13~18