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Relevance statement

This paper is relevant to mental health nursing practice as the revised Japanese Family Empowerment Scale for use with parents of adults with mental health issues and we studied whether it can serve as a useful evaluation measurement of a new goal of family interventions.

Accessible summary

What is known on the subject?

- Empowerment for family caregivers of adults with mental health issues has been getting focused among mental health nurses in Japan and has been recognized as a new goal of family interventions.
- The Family Empowerment Scale (FES) is originally developed to measure empowerment status for parents of children with emotional disorders and used for broader heatlh issues.

What this paper adds to existing knowledge?

- We developed a Japanese version of FES for family caregivers of adults with mental health issues (FES-AMJ) and examined the validity and reliability for parents. As results, FES-AMJ had acceptable concurrent validity and reliability, however, insufficient construct validity.

What are the implications for practice?

- In nursing practices, to clarify family caregivers’ needs and roles in service use may be important before development of FES-AMJ.

Abstract

Introduction: The Family Empowerment Scale (FES) was originally developed for parents of children with emotional disorders and applied to family caregivers of adults with mental health issues. In Japan, family empowerment is getting focused on and can be a goal of nursing interventions.

Aim: To develop a Japanese version of the FES for family caregivers of adults with mental health issues and study the validity and reliability for parents.

Method: We translated the FES into Japanese, employed a self-report questionnaire, analysed 275 parents.

Results: The multitrait scaling analysis revealed acceptable convergent validity and insufficient discriminant validity among all subscales. Especially, all items of Service system subscale had insufficient discriminant and/or convergent validity. Each subscale significantly correlated with the indicator of empowerment. The intraclass correlation coefficients of each subscale were 0.855-0.917. Cronbach’s alpha of each factor ranged from 0.867 to 0.895.

Discussion: The Service system subscale may not linearly reflect family empowerment, and instead may depend on unclear roles of family caregivers in service use of the adults rather than children, the disorder severity, or insufficient services.

Implications for Practice: In nursing practices in Japan, to clarify family caregivers’ needs and roles in service use may be important before scale development.

Keywords: empowerment, families, Japanese, mental disorder, mental illness, scales and assessment

Introduction

Empowerment is a core concept of the World Health Organization (WHO)'s vision of health promotion. In the mental health field, empowerment is recognized as a key priority of the WHO Mental Health Declaration for Europe (World Health Organization, 2005) and the WHO European Mental Health Action Plan (Regional Committee for Europe, 2013) for persons with mental health (MH) issues and their family caregivers. Althogh there is no one clear definition, empowerment is commonly defined as a process which enables people to gain greater control over their own lives and decision shape their lives (Herbert *et al.*, 2009; Nojima, 1996). Empowerment has been conceptualized as a state as well as a process and a multi-level construct to individual, organizations, and community (Nojima, 1996; Schulz *et al.*, 1995). The concept of empowerment emerged in MH field in 1980s as an alternative from a perspective of persons with MH issues in the medical model as having problems and deficits (Clark & Krupa, 2002; Kieffer, 1984).

In Japan, the concept of empowerment has been introcuded into nursing field first and applied widely to persons with a varitey of illness and their family caregivers since 1990s (Amagai, 2006; Nojima, 1996). Empowerment for family caregivers of adults with MH issues has been getting focused on since around 2000 (Amagai, 2006). A traditional important goal was Expressed Emotion as a clinical aspect reflecting persons with MH issues. However, empowerment focused on family caregiver themselves has emerged as a new goal of family interventions that include not only communication with the person and management of day-to-day situation but also finding their social roles through interaction with other family caregivers and activities on advocacy issues (Kageyama *et al.*, 2015). For example, the goal in a Japanese version of family psychoeducation program is empowerment of family caregivers as well as relapse prevention of persons with MH issues (Fukui, 2011) and the goal of a recent family peer-education program developed in 2007 is also empowerment of family caregivers

(Kageyama *et al.*, 2015).

In the background of empowerment of family caregivers has been focused on, MH nurses have increasingly recognized within last decade that they should support for family caregivers. One of the reasons was introduction of family support system (e.g. the Carers Act, carer's assessment) in the U.K. which was reported as special issues of several journals in Japan (Kageyama, 2013). MH nurses have been getting involved with family caregivers including giving individual consultation in home visiting services (Toyoshima & Matsuda, 2010) and Assertive Community Treatment (Sono *et al.*, 2012). In some reports, a partner of family caregivers as a new role of MH nurses is recommemded (Amagai, 2006; Kageyama, 2013). Empowerment of family caregivers may be getting more focused on and can be a good goal of nursing interventions.

Even though increasing awareness of necessity of family support, there are limited family interventions in Japan (Kageyama, 2013). When we develop and evaluate nursing interventions for family caregivers, mesurements of family empowerment can be useful in evaluation of family interventions. Among limited mesurements of family empowerment, the Family Empowerment Scale (FES) (Koren *et al.*, 1992) is most used in many countries for broader health issues including physical disabilities, intellectual disorders, autism, mental disorders, and dementia, as well as broader caregiver types and only measurement is applied to family caregivers of adults with MH issues (Herbert *et al.*, 2009). FES was developed to measure the status of family empowerment for parents whose children have emotional disabilities (Koren *et al.*, 1992) and developed its Japanese version (Wakimizu *et al.*, 2010). The FES was used in previous research for family caregivers of adults with MH issues (e.g.

schizophrenia) (Chiu *et al.*, 2013; Dixon *et al.*, 2011; Vandiver *et al.*, 1992). However, we have not found any reports of the validity and reliability of the FES in any language for use with family caregivers of adults with MH issues.

When the original FES apply to family caregivers of adults with MH issues (FES-AM), we think that some modifications are needed. Respondents are parents of children in original FES while family caregivers of adults in FES-AM. Given this difference, wording should be modified in relationship (e.g. child to person, parent to caregiver) and service systems (e.g. special education law to law related to disorder). These wording has been changed in previous research for caregivers of adults with MH issues (Dixon *et al.*, 2011). Beside wording issues, roles of family caregivers for adults and parents for children may be different. Parents for children are custodial guardians who have responsibilities to protect their children. On the other hand, family caregivers are not usually legal guardians. In Japan, each adult with MH issues should have a legal guardian under law until 2014. Therefore, family caregivers may feel responsibilities to care for adults even though they no longer guardian. Other problems are that respondents could be multiple caregivers per adult with MH issues, and that they may be not only parents but also spouses, siblings, other family members. The diversity in relationship to the adult with MH issues of respondents who have different caring experiences and roles may affect on validity of FES. Even though there are such potential issues when apply to FES to adults with MH issues, there is no report about such issues in previous research (Chiu *et al.*, 2013; Dixon *et al.*, 2011; Vandiver *et al.*, 1992).

We aimed to develop a Japanese version of the FES for family caregivers of adults with mental disorders (FES-AMJ), and to test its validity and reliability for parents. In order to avoid potential issues of multiple respondents and diversity of relationships to the adult, we focused on one parent per adult with MH issues.

Methods

General Description of the FES

The FES is a 34-item self-reported instrument designed to measure empowerment as a status rather than a process. Status is not necessarily assumed to be constant, but rather changeable over time in response to experiences, new conditions, or evolving circumstances (Koren *et al.*, 1992). The FES is based on a two-dimensional definition of empowerment. The first dimension refers to levels of empowerment, such as family, service system, and community/political. The other dimension refers to how empowerment is expressed in the form of attitudes, knowledge, and behaviours (Koren *et al.*, 1992).

Each item is rated on a Likert-type scale, ranging from 1 (not true at all) to 5 (very true). The FES produces scores for three subscales based on level of empowerment: Family (12 items), Service system (12 items), and Community/Political (10 items). Family is the immediate situation at home and primarily involves the parent’s management of day-to-day situations. Service system refers to professionals and agencies providing services to the child; this primarily involves parents’ working with the service system to obtain adequate services for their children. Community/Political refers to legislative bodies, policy makers, agencies, and community members, and primarily involves parent advocacy for the related population.

The mean of each subscale score is calculated by summing scores for the subscale items and dividing by the number of questions. Although all subscale scores can be summed to obtain an overall score ranging from 3 to 15, the scoring guide recommends using each subscale rather than an overall score, because each subscale addresses different topics.

Development of the FES-AMJ

We developed a Japanese version of the FES with reference to the following guidelines for the translation and adaptation of psychometric scales (Wild *et al.*, 2005): (1) Preparation: The first author contacted the developer of the FES and obtained permission to develop a Japanese version for family caregivers of adults with MH issues; (2) Forward translation: Four authors translated all items from English to Japanese independently; (3) Reconciliation: Authors met and reached a consensus on a draft Japanese translation that best reflected the literal and conceptual content of the original, was a more suitable expression for family caregivers of adults with MH issues, and fit within Japanese culture and service systems; (4) Cognitive debriefing: Nine Japanese family caregivers of adults with MH issues tested the Japanese version to assess alternative wording and to check understandability, interpretation, and cultural relevance of the translation; (5) Review of cognitive debriefing results: The authors reworded phrases repeatedly until a consensus was reached among authors and lay family caregivers; (6) Back translation: A native English speaker, who did not know about the original English version, implemented a back-translation of the Japanese version into English; (7) Back translation review and finalization: The original FES developer and authors reviewed the back translations against the source instrument and ensured literal and conceptual equivalence of the translation. Phrases that were changed from the original version are shown in Table 1.

Wording regarding relatinship was changed: ‘child’ to ‘the person’, ‘children’ to ‘people with disorders’and ‘parent’ to ‘family (meaning family caregiver)’. Wording for children was changed for adults: ‘grow and develop’ to ‘recovery’, ‘special education laws’ to ‘the law related to the disorders’ (item 24). Wording of roles by parents of children was changed to family caregivers of adults: ‘approve (all services)’ to ‘express my opinion on’ (item 1), ‘make good decisions’ to ‘understand fully’ (item 11). Regarding cultural issues, we were concerned about using the term ‘legislator’ in items 8 and 22 because few Japanese have the opportunity to meet legislators. However, we retained the word because only one lay family caregiver out of nine expressed concern regarding use of the term.

There are no instructions in the original FES. Therefore, we created instructions for this version in Japanese and the original developer confirmed an English translation of these instructions. The instructions for this version are as follows: The following questionnaire asks how you feel about your current situation. Please choose the response alternative that is most applicable to you and circle its number. There are 34 items in total. Please circle a number for all items. ‘I’ in the items refers to ‘you’ as a family caregiver, while ‘the person’ refers to ‘the person with disorders’ that you are supporting.

[Insert Table 1]

Survey to Assess Validity and Reliability

We examined the validity and reliability of the FES-AMJ as part of a larger survey “Japanese Family Violence and Mental Illness” (Kageyama et al. 2015b). The larger cross-sectional survey aimed to examine difficulties experienced by family caregivers who care for adults with MH issues. Participants were selected from a prefecture-level association of a national family group association for relatives with MH issues in Japan. The prefecture-level association included 866 households from 27 affiliate family groups. Based on the judgment of group leaders, questionnaires were distributed to 768 households. Questionnaires were not provided to 118 households due to potential respondents’ current health condition or family issues. Of the 482 returned family caregiver questionnaires, 463 were valid. Of the 463 respondents, 369 completed all items of FES-AMJ and 352 were parents from 275 households. To avoid multiple respondents each household, we selected randomly a parent per household. Finally, 275 parents from 275 households were this study samples. Required sample size was calculated using G*power (Faul *et al.*, 2007) for t-test for examing concurrent validity with effect size d=0.8 by reference to previous research using FES for children (Wakimizu *et al.*, 2010). The calculation showed 84 parents (42 each group).

To assess the test-retest reliability of the FES-AMJ, a second copy of the questionnaire was distributed at a board meeting of the prefecture-level association. This way of distribution was recommended by board leaders. They were afraid that the distribution of second copy may make general family caregivers confused. 50 family caregivers who expressed cooperation were participants. These second questionnaires were completed and returned one week after completion of the first questionnaires. Of 50 family caregivers, 43 second questionnaires were returned.

To test concurrent validity, we used the K6 as an indicator of powerlessness and the Family Attitude Scale (FAS) as an indicator of effective communication with patients in daily life regarding Family subscale. The K6, a short 6-item screening questionnaire, was developed as a screening scale for non-specific psychological distress (Kessler *et al.*, 2002). The reliability and validity of the Japanese version of the K6 has previously been confirmed; the best cut-off point has been estimated as 4/5, corresponding to 100% sensitivity and 68.7% specificity for the screening of mood/anxiety disorders (Furukawa *et al.*, 2008). The FAS is a 30-item self-report measure that evaluates criticism and hostility dimensions of Expressed Emotion (Amaresha & Venkatasubramanian, 2012). The total score ranges from 0 to 120. Higher scores indicate higher criticism or hostility. In Japanese samples, the cut-off with the highest sensitivity and specificity was 59/60, and the reliability and validity of the Japanese version of the FAS has been confirmed (Fujita *et al.*, 2002). In addition, we examined the following activities as behavioural indicators of Community/ Political subscale by reference to original FES: Participation at awareness events in the past three years (Yes/No) and experiences of negotiation with government officers on advocacy issues in the past three years (Yes/No). Although the original FES did not measure indicators of Service system subscale, we measured the patient's use of welfare services (Yes/No) because Service system involves parents' working to obtain adequate services for their adult children.

Data Analysis

First, we checked basic score distributions to assess floor and ceiling effects. These effects are considered to be present if the mean plus standard deviation (SD) > the highest possible score or mean minus SD < the lowest possible score (Ojio, 2005).

Next, we checked correlations between the three subscales and examined construct validity by using through the multitrait scaling analysis. The convergent validity was analysed correlation between a item and own subscale (corrected for overlap) using Spearman correlations ≥0.4 (Ikegami *et al.*, 2012). Discriminant validity was supported when a item had higher correlation with own subscale (corrected for overlap) than with other subscales. We did not conduct factor analysis in terms of construct validity because the factor analyses of the original scale did not show clear factors for level of empowerment and/or method of expression (Koren *et al.*, 1992; Singh *et al.*, 1995). Concurrent validity was examined using a *t*-test with K6, FAS, and activities as three behavioural indicators of empowerment and mean scores of subscales.

Test-retest reliability was assessed using the intraclass correlation coefficients (ICC; ideally>0.07) (Fayers & Machin, 2007) of each subscale over a one-week period. Internal consistency reliabilities were checked using Cronbach's alpha.

All analyses were conducted using SAS version 9.4 (SAS, North Carolina, United States), with the exception of ICCs, which were analysed using SPSS version 20 (IBM, SPSS for Windows, New York, United States).

Ethical Considerations

The Faculty of Medicine, the University of Tokyo, Research Ethics Committee approved the study (February 24, 2014; No. 10415). All participants were informed of the study's aim and that their participation was voluntary. Informed consent was implied through questionnaire completion and return. We ensured confidentiality and anonymity because we did not use identification numbers or any code that could be linked to a household or individual respondent's name.

Results

Subject Demographics

Of 275 parents, 118 (68.4%) were mothers. Their average age was 68.2 years old (*SD*=7.6). 228 parents (83.5%) were living with the family member. The family members were an average of 39 years old (*SD*=8.0), 250 (91.6%) of them were with a diagnois of schizophrenia, and 240 (87.9%) were outpatients. 142 (52.8%) family members did not use rehabilitation services.

[Insert Table 2]

Score Distributions

As shown in Table 1, the means of items were in the range of 1.99–3.47. There were no items indicating a ceiling effect and a floor effect. The mean−SD of item 8 was 1.02 and item 22 was 1.05, which were lowest two scores. The means for each subscale were as follows: *M*=2.99,*SD*= 0.59 for Family, *M*=2.81, *SD*= 0.61 for Service system, and *M*=2.55, *SD*= 0.70 for Community/Political.

Construct Validity

As shown in Table 3, all Spearman correlation coefficients between subscales were moderate to high (rs=0.696–0.930). In the multitrait scaling analysis (Table 4), the convergent validity of almost all items was acceptable ($rs \geq 0.4$) except for 3 items (item 9, 1, 32). However, the discriminant validity was not supported in many items among all subscales. The following items did not have higher correlations with their own subscales than with other subscales: item 16, 27 and 31 in Family, item 32, 5, 13 and 28 in Service system, item 10 and 14 in Community/Political. Moreover, the following items had only slightly higher correlations (difference $rs \leq 0.05$) with other subscales: item 26 in Family, item 18, 11, 12, 23, 30, 6 and 19 in Service system, item 3, 17 and 24 in Community/Political. All items of Service system were insufficient in the discriminant and/or convergent validity.

[Insert Table 3]

[Insert Table 4]

Concurrent Validity

As shown in Table 5, each subscale and the total scores were significantly positively related to all indicators of empowerment as expected. K6 was significantly related to Family as expected, $t(262)=5.68$, $p<0.001$, as well as FAS, $t(264)=5.52$, $p<0.001$. Patient's use of welfare services was significantly related to Service system, $t(270)=2.77$, $p<0.01$. Participation at awareness events was signigicantly related to Community/Political, $t(263)=6.82$, $p<0.001$, as well as negotiation with government officers on advocacy issues, $t(270)=8.03$, $p<0.001$.

[Insert Table 5]

Reliability

As shown in Table 3, the ICC of each subscale between the two times the test was completed ranged from 0.855 to 0.917. The Cronbach’s alpha of each subscale ranged from 0.867 to 0.895.

Discussion

Score Distributions

The score distributions showed near a floor effect for item 8 and 22. These two items included the word ‘legislator’; however, many Japanese do not have chance to meet these individuals. The degree of political interest among the general public in Japan is quite low; one reason for this is the attitude that politics and politicians cannot be changed (Kiso, 2012). Such attitudes may lead to low scores on items including the word ‘legislator’. However, when scores are compared to those obtained from other countries, use of the same term will permit direct comparison. Therefore, we do not recommend changing the term ‘legislator’.

Validity and Reliability

Regarding the concurrent validity of the FES, each subscale significantly correlated with the indicator of empowerment. Regarding construct validity, the multitrait scaling analysis revealed acceptable convergent validity of almost all items, however, insufficient discriminant validity among all subscales. Especially, all items of Service system were insufficient in the discriminant and/or convergent validity. There are several possible reasons for this. First, subject differences between this version and the original may have played a role. The current version is for family caregivers of adults rather than children. Service use in this group is often determined by the adult with MH issues. In particular, adults who are not severely disabled may obtain information, discuss with professionals, and determine service use by themselves. In this case, family caregivers may not necessarily know service details, express their own opinions, or take action to get better service. Thus, the Service system subscale may not linearly reflect family empowerment for family caregivers, but rather depend on the severity of the disorder or medical condition. In addition, services are not sufficient in Japan (Oshima *et al.*, 2007). With such characteristics of adults with MH issues and/or insufficient community services, attitude, knowledge and behaviours of the Service system may not contribute to actual service use by persons with MH issues. Finally, while family caregivers are recognized as partners in treatment and service planning in Europe (WHO Regional Office for Europe, 2010), in Japan, 66% of family caregivers find it takes over a year to obtain sufficient information about illness and 58% of family caregivers were not well satisfied with explanation by professionals about illness and prospect of recovery (Minna-Net, 2010). Most MH nurses in Japan do not recognize family caregivers as partners. Thus, even if family caregivers gain knowledge, they may not feel comfortable asserting their right to procure services for adults with MH issues. Insufficient practice to collaborate of MH nurses with family caregivers about service use may be make difficult to understand what status are promoted empowerment status in Service system.

Limitations and Further Research

There are some limitations in this study. First, we found inadequate construct validity. Further studies need to modify the scale and test the validity and reliability, especially with respect to the Service system subscale. Second, this study focused on parents. We have not examined other relationships (e.g. spouse or sibling). Such caregivers may have different caring experiences and roles that may affect on their empowerment. We should be careful to use FES-AMJ to all family caregivers. Third, study samples belonged to family self-help groups. Therefore, they were more likely to have knowledge of mental disorders and the service system, and to be active in community and policy. Although it is difficult to conduct a survey among isolated family caregivers who do not belong to family groups, these types of samples are better for the generalization of the scale. Fourth, this study was conducted only in Japan. Therefore, we do not know how differences between countries may affect the validity of the scale. In future research, studies should be conducted in other countries to develop a cross-culturally relevant FES for family caregivers of adults with mental disorders.

Implications for Practice

MH nurses need mesurements of family empowerment when they develop and evaluate nursing interventions for family caregivers. We found that using FES-AMJ by only simple modification of FES was not enough in terms of construct validity. Especially roles of family caregivers in service use were not clear. In Japan, MH nurses do not assess family caregivers' needs in many cases, nor make a support plan before dischage from psychiatric hospital. In nursing practices, to clarify family caregivers' needs and roles in service use may be important before development of FES-AMJ. If MH nurses recognize needs and roles of family caregivers, we can see what status is ideal on empowerment in terms of service system. Before modification of Service system in FES-AMJ, clarifyication of ideal family empowerment status in service system through discussion among MH nurses and family caregivers may be important.

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Table 1. Distribution of each item score (n=275)

Subscale			Response alternatives					FES-AMJ			
Dimension	Item No.	Original item statement (revised portion indicated with underlining and new text in parentheses)	1	2	3	4	5	Mean	SD	Mean -SD	Mean +SD
					n, %						
Family											
Attitude	4	I feel confident in my ability to help my child grow and develop (the person's recovery).	11 4.0	93 33.8	122 44.4	41 14.9	8 2.9	2.79	0.85	1.94	3.64
Attitude	9	I feel my family life is under control.	28 10.2	65 23.6	114 44.5	51 18.6	17 6.2	2.87	1.03	1.84	3.90
Attitude	21	I believe I can solve problems with my child when they happen (the person).	33 12.0	68 24.7	129 46.9	36 13.1	9 3.3	2.71	0.95	1.76	3.66
Attitude	34	I feel I am a good parent (family member).	11 4.0	55 20.0	128 46.6	67 24.4	14 5.1	3.07	0.90	2.17	3.96
Knowledge	7	I know what to do when problems arise with my child (the person).	12 4.4	65 23.6	129 46.9	57 20.7	12 4.4	2.97	0.89	2.08	3.86
Knowledge	16	I am able to get information to help me better understand my child (the person).	18 6.6	67 24.4	129 46.9	48 17.5	13 4.7	2.89	0.93	1.97	3.82
Knowledge	26	When I need help with problems in my family, I am able to ask for help from others.	24 8.7	56 20.4	109 39.6	65 23.6	21 7.6	3.01	1.05	1.96	4.06
Knowledge	33		4	36	129	86	20	3.30	0.84	2.46	4.14

		I have a good understanding of my child's disorder (the person's).	1.5	13.1	46.9	31.3	7.3				
Behaviours	2	When problems arise with my child, I handle them pretty well (the person).	6	60	149	51	9	2.99	0.79	2.20	3.78
			2.2	21.8	54.2	18.6	3.3				
Behaviours	27	I make efforts to learn new ways to help my child grow and develop (the person's recovery).	22	47	129	56	21	3.03	1.00	2.02	4.03
			8.0	17.1	46.9	20.4	7.6				
Behaviours	29	When dealing with my child, I focus on the good things as well as the problems (the person).	4	24	112	110	25	3.47	0.83	2.63	4.30
			1.5	8.7	40.7	40.0	9.1				
Behaviours	31	When faced with a problem involving my child, I decide what to do and then do it (the person).	21	78	115	52	9	2.82	0.94	1.88	3.76
			7.6	28.4	41.8	18.9	3.3				
Score average								2.99	0.59		
Service system											
Attitude	1	I feel that I have a right to approve all services my child receives (express my opinion on, the person).	15	48	101	81	30	3.23	1.04	2.19	4.27
			5.5	17.5	36.7	29.5	10.9				
Attitude	18	My opinion is just as important as professionals' opinions in deciding what services my child needs (the person).	16	69	111	57	22	3.00	1.01	1.99	4.01
			5.8	25.1	40.4	20.7	8.0				
Attitude	32	Professionals should ask me what services I want for my child (the person).	31	79	80	57	28	2.90	1.16	1.74	4.06
			11.3	28.7	29.1	20.7	10.2				
Knowledge	5		18	77	118	53	9	2.85	0.92	1.93	3.77

		I know the steps to take when I am concerned <u>my child</u> is receiving poor services (the person).	6.6	28.0	42.9	19.3	3.3				
Knowledge	11	I am able to <u>make good decisions</u> about what services <u>my child</u> needs (understand fully, the person).	15 5.5	86 31.3	124 45.1	45 16.4	5 1.8	2.78	0.85	1.93	3.63
Knowledge	12	I am able to work with agencies and professionals to decide what services <u>my child</u> needs (the person).	23 8.4	73 26.6	108 39.3	59 21.5	12 4.4	2.87	0.99	1.88	3.86
Knowledge	23	I know what services <u>my child</u> needs (the person).	32 11.6	75 27.3	120 43.6	39 14.2	9 3.3	2.70	0.96	1.74	3.66
Knowledge	30	I have a good understanding of the service system that <u>my child</u> is involved in (the person).	13 4.7	84 30.6	126 45.8	45 16.4	7 2.6	2.81	0.85	1.96	3.67
Behaviours	6	I make sure that professionals understand my opinions about what services <u>my child</u> needs (the person).	34 12.4	88 32.0	114 41.5	31 11.3	8 2.9	2.60	0.94	1.66	3.55
Behaviours	13	I make sure I stay in regular contact with professionals who are providing services to <u>my child</u> (the person).	69 25.1	99 36.0	67 24.4	34 12.4	6 2.2	2.31	1.05	1.26	3.35
Behaviours	19	I tell professionals what I think about services being provided to <u>my child</u> (the person).	54 19.6	101 36.7	84 30.6	29 10.6	7 2.6	2.40	1.01	1.40	3.40
Behaviours	28		8	34	129	83	21	3.27	0.88	2.39	4.15

		When necessary, I take the initiative in looking for services for my child and family (the person).	2.9	12.4	46.9	30.2	7.6				
Score average								2.81	0.61		
Community/Political											
Attitude	3	I feel I can have a part in improving services for children in my community (people with disorders).	13 4.7	54 19.6	117 42.6	65 23.6	26 9.5	3.13	0.99	2.14	4.13
Attitude	17	I believe that other parents and I can have an influence on services for children (families, people with disorders).	23 8.4	100 36.4	100 36.4	39 14.2	13 4.7	2.71	0.97	1.73	3.68
Attitude	25	I feel that my knowledge and experience as a parent can be used to improve services for children and families (a family, people with disorders).	25 9.1	69 25.1	118 42.9	49 17.8	14 5.1	2.85	0.99	1.86	3.84
Knowledge	10	I understand how the service system for children is organized (people with disorders).	12 4.4	68 24.7	137 49.8	48 17.5	10 3.6	2.91	0.86	2.05	3.77
Knowledge	14	I have ideas about the ideal service system for children (people with disorders).	36 13.1	79 28.7	103 37.5	44 16.0	13 4.7	2.71	1.04	1.67	3.74
Knowledge	22	I know how to get agency administrators or legislators to listen to me.	92 33.5	109 39.6	43 15.6	27 9.8	4 1.5	2.06	1.01	1.05	3.07
Knowledge	24		42	109	84	38	2	2.45	0.94	1.51	3.39

		I know what the rights of parents and children are under the special education laws (the people and families, the laws related the disorders).	15.3	39.6	30.6	13.8	0.7				
Behaviours	8	I get in touch with my legislators when important bills or issues concerning children are pending (people with disorders).	99 36.0	106 38.6	48 17.5	17 6.2	5 1.8	1.99	0.97	1.02	2.97
Behaviours	15	I help other families get the services they need.	41 14.9	84 30.6	98 35.6	42 15.3	10 3.6	2.62	1.03	1.59	3.65
Behaviours	20	I tell people in agencies and government how services for children can be improved (people with disorders).	79 28.7	120 43.6	49 17.8	24 8.7	3 1.1	2.10	0.95	1.15	3.05
Score average								2.55	0.70		

Table 2. Demographics of sample

n=275

		Mean±SD, n (%)
Subjects themselves		
Sex	Male (Father)	87 (31.6)
	Female (Mother)	188 (68.4)
Age (yrs)		68.8±7.6
	Under 60	30 (11.2)
	60–69	112 (41.6)
	70–79	102 (37.9)
	80 or over	25 (9.3)
Living with the person	Yes	228 (83.5)
	No	45 (16.5)
Persons with mental health issues		
Age (yrs)		38.7±8.0
Sex	Male	165 (60.9)
	Female	106 (39.1)
Main diagnosis	Schizophrenia	250 (91.6)
	Other	23 (8.4)
Treatment	Outpatient	240 (87.9)
	Inpatient	20 (7.3)
	No regular treatment	13 (4.7)
Rehabilitation	Under rehabilitation	127 (47.2)
	No rehabilitation	142 (52.8)

Numbers in the table do not include missing data.

Table 3. Spearman correlation coefficients between factors and reliability

	Spearman correlation between factors				
	Family	Service system	Community/ Political	Cronbach's alpha	ICC
Family				0.873	0.872
Service system	0.696			0.867	0.855
Community/ Political	0.698	0.804		0.895	0.917
All	0.867	0.910	0.930		

ICC: intraclass correlation coefficient

Table 4. Multitrait scaling analysis

n=275

Subscale			Item-scale correlation		
Dimension	Item No.	Revised item statements	Family	Service system	Community/ Political
Family					
Attitude	4	I feel confident in my ability to help the person's recovery.	0.542	0.343	0.353
Attitude	9	I feel my family life is under control.	0.386	0.179	0.261
Attitude	21	I believe I can solve problems with the person when they happen.	0.603	0.409	0.479
Attitude	34	I feel I am a good family member.	0.579	0.421	0.336
Knowledge	7	I know what to do when problems arise with the person.	0.613	0.557	0.538
Knowledge	16	I am able to get information to help me better understand the person.	0.600	0.630	0.615
Knowledge	26	When I need help with problems in my family, I am able to ask for help from others.	0.505	0.463	0.507
Knowledge	33	I have a good understanding of the person's disorder.	0.580	0.511	0.460
Behaviours	2	When problems arise with the person, I handle them pretty well.	0.438	0.342	0.309
Behaviours	27	I make efforts to learn new ways to help the person's recovery.	0.506	0.538	0.558
Behaviours	29	When dealing with the person, I focus on the good things as well as the problems.	0.564	0.468	0.400
Behaviours	31	When faced with a problem involving the person, I decide what to do and then do it.	0.629	0.644	0.622

Service system					
Attitude	1	I feel that I have a right to express my opinion on all services the person receives.	0.191	0.285	0.191
Attitude	18	My opinion is just as important as professionals' opinions in deciding what services the person needs.	0.441	0.519	0.484
Attitude	32	Professionals should ask me what services I want for the person.	0.288	0.364	0.366
Knowledge	5	I know the steps to take when I am concerned the person is receiving poor services.	0.576	0.570	0.627
Knowledge	11	I am able to understand fully about what services the person needs.	0.570	0.600	0.599
Knowledge	12	I am able to work with agencies and professionals to decide what services the person needs.	0.453	0.581	0.577
Knowledge	23	I know what services the person needs.	0.494	0.556	0.553
Knowledge	30	I have a good understanding of the service system that the person is involved in.	0.649	0.652	0.648
Behaviours	6	I make sure that professionals understand my opinions about what services the person needs.	0.460	0.572	0.542
Behaviours	13	I make sure I stay in regular contact with professionals who are providing services to the person.	0.398	0.533	0.544
Behaviours	19	I tell professionals what I think about services being provided to the person.	0.465	0.634	0.612
Behaviours	28	When necessary, I take the initiative in looking for services for the person and family.	0.608	0.532	0.527

Community/Political					
Attitude	3	I feel I can have a part in improving services for people with disorders in my community.	0.547	0.491	0.571
Attitude	17	I believe that other families and I can have an influence on services for people with disorders.	0.496	0.586	0.598
Attitude	25	I feel that my knowledge and experience as a family can be used to improve services for people with disorders and families.	0.522	0.614	0.673
Knowledge	10	I understand how the service system for people with disorders is organized.	0.580	0.632	0.588
Knowledge	14	I have ideas about the ideal service system for people with disorders.	0.513	0.668	0.657
Knowledge	22	I know how to get agency administrators or legislators to listen to me.	0.497	0.566	0.675
Knowledge	24	I know what the rights of the people and families are under the the laws related the disorders.	0.545	0.588	0.613
Behaviours	8	I get in touch with my legislators when important bills or issues concerning people with disorders are pending.	0.329	0.405	0.497
Behaviours	15	I help other families get the services they need.	0.542	0.553	0.646
Behaviours	20	I tell people in agencies and government how services for people with disorders can be improved.	0.460	0.632	0.711

Numerals in the Family, Service system, and Community/Political rows are item-scale Spearman's correlations (corrected for overlap).

Double-underlined coefficients refer to insufficient convergent validity between the item and own subscale (*rs*<0.4).

Single-underlined coefficients refer to insufficient discriminant validity of lower correlation with own subscale than with other subscales.

Dashed-underlined coefficiend refer to insufficient discriminant validity of slightly higher correlations (difference *rs*≤0.05) with own subacale then with other subscales

Table 5. Concurrent validity

	Subscales of FES-AMJ (each range: 1–5)									Overall (range: 3–15)		
	Family			Service system			Community/ Political					
	Mean	SD		Mean	SD		Mean	SD		Mean	SD	
K6												
High-distress (K6 ≥ 5) (n=158)	2.84	0.56	***	2.77	0.62	n.s.	2.48	0.68	*	8.09	1.72	**
Low-distress (K6 ≤ 4) (n=106)	3.24	0.56		2.89	0.61		2.67	0.72		8.80	1.75	
FAS												
High score (FAS ≥ 60) (n=69)	2.68	0.51	***	2.74	0.59	n.s.	2.42	0.68	n.s.	7.84	1.66	**
Low score (FAS < 60) (n=197)	3.11	0.58		2.84	0.62		2.60	0.71		8.56	1.79	
Patient's use of welfare services												
No (n=189)	2.94	0.58	*	2.75	0.61	**	2.48	0.68	**	8.16	1.73	**
Yes (n=83)	3.11	0.62		2.97	0.61		2.73	0.72		8.81	1.79	
Participation at awareness events in past three years												
No (n=105)	2.83	0.58	***	2.53	0.53	***	2.20	0.56	***	7.56	1.51	***
Yes (n=160)	3.09	0.59		2.99	0.59		2.76	0.70		8.84	1.76	
Negotiation with government officers on advocacy issues in past three years												
No (n=133)	2.82	0.59	***	2.57	0.55	***	2.24	0.56	***	7.63	1.54	***
Yes (n=139)	3.15	0.55		3.03	0.59		2.85	0.70		9.04	1.69	

t-test, n.s. = not significant, $*p<0.05$, $**p<0.01$, $***p<0.001$