

Regular article

Burden and coping strategies in mothers of patients with schizophrenia in Japan

(running title: Burden in mothers of patients with schizophrenia)

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Abstract

The study was conducted to identify factors contributing to burden of care in 57 mothers caring for patients with schizophrenia. Members of the Federation of Families of People with Mental Illness in Nagasaki Prefecture were evaluated using well-validated scales to evaluate burden of care (the 8-item short version of the Japanese version of the Zarit Caregiver Burden Interview: J-ZBI-8), general health status (General Health Questionnaire 12-item version: GHQ-12), difficulty in life, coping strategies, emotional support, and understanding of mental illness and disorders. Burden of care was significantly associated with general health status and difficulty in life. Multiple regression analysis revealed that “social interests” and “resignation”, both of which are the subscales of coping strategies, exerted significant and independent effects with respect to burden of care.

Key words: schizophrenia, burden, mother, coping strategy

Introduction

Since the introduction of community-based rehabilitation services, research has been intensively conducted on the burden of care in families of patients with schizophrenia in order to identify factors in both patients and families that contribute to burden of care. Patient-related clinical and psycho-sociological factors reported in the literature include clinical characteristics of illness, severity of positive symptoms, number of hospital admissions¹⁻⁴, duration of illness⁵, social behaviors¹, social functioning^{4,5}, and occupational status⁵. In contrast, family-related psycho-sociological factors include living with the patient³, frequent care needs^{1,3}, expressed emotion⁶⁻⁹, coping strategies¹⁰, recognition of the disease¹¹, insufficient social resources¹², and assistance from professionals and social support^{1,5,13,14}. Several reports have described that the burden of care depends on the family relationship of the carer to the patient (i.e., parent vs. spouse) and the carer's gender^{7,11,15}; however, many other factors may also be contributing to burden of care.

In Japan, mothers are generally the carers of patients with schizophrenia. Compared to other family carers, mothers reportedly express their emotions more strongly, are more likely to expect patients to act productively, and are more negative towards patients' leisure activity^{16,17}. However, no studies have investigated the association of burden of care with other factors such as coping strategies, emotional support, and understanding of mental illness and disorders in mothers who generally undertake caring responsibilities. In this study, mothers living with patients with schizophrenia were investigated to identify factors contributing to burden of care.

Method

1. Subjects

The purpose and method of the study were explained in advance at the general meeting of the Federation of Families of People with Mental Illness in Nagasaki Prefecture. During the meeting, 11 of 30 local family groups for mutual support in Nagasaki Prefecture agreed to participate in the study. The research group visited the members of the 11 local family groups to directly inform them of the purpose and method of the study both orally and in writing before obtaining formal agreement and written consent. Eventually 123 family members gave consent for participation. The study was conducted during the period from October 2003 to March 2004

after being approved by the ethics committee of Nagasaki University Graduate School of Biomedical Sciences (Approval No. 15111258).

The subjects of the study were limited to 57 mothers living with patients who were diagnosed with schizophrenia according to ICD-10 diagnostic criteria and who were currently under outpatients' treatment. If a mother was caring for 2 or more patients, she was asked to fill out the questionnaire in relation to the patient for whom she had the greatest burden of care.

2. Evaluation scale

For the purpose of the study, the question items concerning demographic information were categorized into 2 groups as follows: 1) patient-related information: patient's age in years, gender, age of disease onset, total duration of hospitalization in psychiatric facilities, total number of hospital admissions, current treatment status (outpatient or inpatient) and the best social involvement experienced during the previous year (part-time/sheltered employment, workshop/day-care center, able to help around the house, or unable to help around the house); and 2) mother-related information: mother's age in years, domestic relationship to the patient (living with them or not), number of family members living together and their relation to the patient, presence of alternative carer(s), participation in family support group meetings during the previous year (all or almost all meetings, more than half the meetings, or occasionally) and any advantage from participation in family group meetings.

Six reliable and validated scales were used for evaluation of burden of care, difficulty in life, general health status, coping strategy, emotional support, and understanding of mental illness and disorders.

1) The 8-item short version of the Japanese version of the 22-item Zarit Caregiver Burden Interview (J-ZBI-8)^{18,19} was used to rate burden of care. This is a self-administered questionnaire that rates each of 8 items into one of 5 grades (from "never" (0) to "nearly always" (4)); a higher score indicates higher burden of care.

2) A 12-item scale developed by Oshima¹⁴ was used to evaluate the degree of difficulty in life of family members attributed to living with patients with mental disease. This is a self-administered questionnaire with a 3-point scale; a higher score indicates higher degree of difficulty in life.

3) The 12-item General Health Questionnaire (GHQ-12)²⁰⁻²² was used to rate general health

status. The GHQ-12 is an established self-administered questionnaire for screening of psychoneurotic symptoms with 4 options for each question item and a rating system using 0 or 1. A higher score indicates poorer health status.

4) The 23-item Family Coping Questionnaire (FCQ-23)²³ was used for rating coping strategies. This scale consists of 7 subscales of information acquisition, positive communication, social interest, coercion, avoidance, resignation, and patient's social involvement. It is a self-administered questionnaire with a 4-point scale; a higher score indicates better coping strategies.

5) A 10-item rating scale developed by Munakata²⁴ was used for rating emotional support. This is a self-administered questionnaire with a 2-point scale. A higher score indicates a better maintained emotional support network.

6) The 15-item Mental Illness and Disorder Understanding Scale (MIDUS)²⁵ was used for rating the degree of understanding of mental illness and disorders. This is a self-administered questionnaire with a 5-point scale; a higher score indicates poorer understanding of mental illness and disorders.

3. Statistical analysis

Burden of care was compared between different socio-demographic characteristics using a t-test (for comparisons between 2 groups) and analysis of variance (for comparisons among 3 or more groups). The relationships between burden of care and other factors were investigated using multiple regression analysis with burden of care as the dependent variable after deriving Spearman's rank-order correlation coefficients. SPSS 12.0J for Windows was used for statistical calculation. Statistical level of significance was set at less than 5%.

Results

1. Socio-demographic characteristics of the subjects (patients and their mothers)

Regarding mothers' age, 17 were in their 50s (29.8%), 17 were in their 60s (29.8%) and 16 were in their 70s (28.1%) and the remaining 7 (12.3%) were in other age groups. Thirty-three mothers (57.9%) reported alternative carers. Regarding frequency of participation, 33 (57.9%) mothers participated in "all or almost all" meetings of their local family support group during the previous

year; this was the most common level of participation. Family support groups held regular meetings approximately once per month.

Male patients (n=37, 64.9%) outnumbered female patients. Regarding age, 19 patients (33.3%) were in their 30s, 15 were in their 40s, and 15 were in their 20s (26.3% for each age group). Age of disease onset was 10–19 in 29 patients (50.9%). Thirteen patients (22.8%) had no history of hospitalization. Of the remaining 44 who had been hospitalized, the most common duration of hospitalization was less than one year (n=18, 31.6%). The most common level of social involvement over the previous year was utilization of workshops/day-care centers (n=29, 50.9%).

2. Evaluation of burden of care using the J-ZBI-8

Table 1 indicates the distribution of response scores for each item. Responses with higher average scores included “Do you feel embarrassed over your relative’s behavior?” (2.05), “Do you feel strained when you are around your relative?” (1.93) and “Do you feel uncertain about what to do about your relative?” (1.84). Responses with lower average scores included “Do you feel that your social life has suffered because you are caring for your relative?” (1.09) and “Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?” (1.21). For the J-ZBI-8, Cronbach’s alpha was high at 0.88. J-ZBI-8 score ranged from 1 to 32 and the average score was 12.5 (SD=7.7). The correlation between J-ZBI-8 and difficulty in life and that between J-ZBI-8 and GHQ-12 were significantly related, with values of $r=0.73$ ($P<0.001$) and $r=0.48$ ($P<0.001$), respectively.

3. Comparison of J-ZBI-8 average score by each socio-demographic characteristic of the subjects

Average J-ZBI-8 score was compared for each socio-demographic characteristic of the subjects (Table 2). J-ZBI-8 average score had no significant association with age, gender, age at disease onset, total years of hospitalization, total number of hospital admissions, or best social involvement. Regarding mothers’ attributes, J-ZBI-8 average score had no significant association with age or frequency of participation in family support group meetings, but those who reported an alternative carer had significantly lower J-ZBI-8 scores than those who did not

($P < 0.05$).

4. Correlation between J-ZBI-8 score and coping strategy, emotional support, and MIDUS

The correlation between J-ZBI-8 score and factors such as coping strategies, emotional support, and MIDUS is summarized in Table 3. Significant correlations with J-ZBI-8 score were observed for the total score of coping strategy ($r = -0.47$, $P < 0.01$), individual scores for the subscales of coping strategies [social interests ($r = -0.48$, $P < 0.001$), coercion ($r = -0.40$, $P < 0.01$), avoidance ($r = -0.61$, $P < 0.001$) and resignation ($r = -0.57$, $P < 0.001$)] and MIDUS ($r = 0.28$, $P < 0.05$).

5. Multiple regression analysis using J-ZBI-8 scores as dependent variables

Multiple regression analysis was performed using variables that were significantly associated with mothers' burden of care (having an alternative carer, social interests, coercion, avoidance and resignation subscales of coping strategies, and understanding of mental illness and disorder) as independent variables and burden of care as the dependent variable. The results of the analysis are summarized in Table 4. Burden of care was significantly associated with social interests ($\beta = -0.31$, $P < 0.01$) and resignation ($\beta = -0.39$, $P < 0.01$).

Discussion

1. Scale for evaluating burden of care

The J-ZBI-8 was used to evaluate burden of care in this study. Although the 22-item Zarit Caregiver Burden Interview (ZBI-22)²⁶⁻²⁸ was first developed by Zarit to evaluate burden of care in the family members of patients with dementia, it has recently been applied to the family members of patients with schizophrenia^{29,30}. Guitierrez-Maldonado et al²⁹ used the ZBI-22 to investigate the burden of care among 65 family members living with patients with schizophrenia. Regarding the reliability and validity of the ZBI-22, its internal consistency has been reported to be high (alpha 0.91), as has its test retest reliability (0.86). In addition, convergent validity with GHQ was 0.63. They reported that in a multiple regression the number of hospitalizations in the previous three years and kinship (mothers/fathers/others) remained significant predictors of burden.

In the present study, the mean J-ZBI-8 score was 12.5 (SD=7.7). Among families providing homecare for elderly requiring care, the mean J-ZBI-8 score was 9.31 (SD=7.19) for families

reporting “difficulties with care” (n=36) and 3.45 (SD=4.57) for families reporting “no difficulties with care” (n=421). Therefore, the burden among the present subjects was higher than that among the subjects in Arai et al¹⁸’s study. We hope to clarify the reasons for the high scores among our subjects in the future.

In the present study, an alpha coefficient of 0.88 was obtained for J-ZBI_8, indicating an adequate internal consistency. In addition, J-ZBI_8 was significantly associated with difficulty in life as well as GHQ12. However, no relationships were observed between J-ZBI_8 and patient-related factors. These findings suggest that J-ZBI_8 is useful to some extent for evaluating the subjective burden and difficulties experienced by families of patients with schizophrenia.

2. Correlation between burden of care and socio-demographic characteristics of subjects

None of the socio-demographic characteristics was identified to be associated with burden of care. Regarding the best social involvement experienced during the previous year, J-ZBI-8 scores were generally higher when social functioning was lower, but this correlation was not significant. This finding might have resulted from selection bias (all study subjects were members of local family support groups) and this may need to be further investigated in the future. Considering family factors, J-ZBI-8 scores were significantly lower for those who had alternative carers (33 subjects); the alternative carer was most often the “the patient’s father” (27 subjects) followed by “the patient’s siblings”. This suggests that it would be a great help for mothers caring for patients with schizophrenia if fathers (or mothers’ partners) could act as alternative carers. However, multiple regression analysis indicated that existence of alternative carers was not a significant predictive factor of J-ZBI-8 scores.

3. Correlation between burden of care and coping strategies

The study identified that “social interests” and “resignation” (both coping strategy factors) significantly exerted independent effects with respect to burden of care, independently from other factors. Magliano et al. have indicated that coping strategy factors such as “social interests”, “resignation”, “talking with friends” and “avoidance” also exert significant effects on burden of care¹⁰. Therefore, low “social interests” and high “resignation” were thought to

be important factors related to high burden. However, in the present study, no causal relationships could be confirmed between these factors. We hope to elucidate causal relationships in the future.

Since the subjects included in our study were the members of local family support groups, they were asked to relate the advantages of participating family group meetings. More than half the subjects agreed with responses such as “I was able to share my feelings with others who have the same problems” (73.7%) and “I have obtained some information about the disease and treatment methods” (59.6%). However, few agreed with responses such as “I have learned an appropriate way to cope with the patient” (29.8%), “I have learned how to reduce my mental burden” (28.1%), “I have obtained hints to prevent the patient having a relapse” (17.5%), and “I have learned how to improve relationships between family members” (3.5%). This suggests that, although carers can share their feelings with other families and obtain information about the disease and treatment methods through local family support group meetings, further improvement of coping strategies and coping skills remains as a future issue. Magliano et al. reported that one-year psychoeducational intervention based on cognitive behavioral therapy significantly improved coping strategies such as “social interests”, “resignation”, and “positive communication”³¹. Therefore, in consideration of the above findings, psychoeducational programs aimed at improving skills such as family communication skills and problem-solving skills may be of great importance.

4. Limitations of the study and future research issues

In order to investigate factors influencing burden of care, we recruited mothers who were members of the Federation of Families of People with Mental Illness in Nagasaki Prefecture. Although our target population is not representative of the general population, the study findings may be useful to identify factors influencing burden of care of the target population and to develop and practice further effective support programs. Further investigation is required to develop methods of intervention using psychoeducational programs based on cognitive behavioral therapy. In addition, cross-sectional and longitudinal research is also needed in areas with different socio-cultural and natural environmental conditions and different social resources for mental health and welfare, such as isolated islands or remote areas and urban areas. Future

research will include investigation into influences of interactions between family members on burden of care by means of assessment scales for family functions.

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Table 1 Responses to J-ZBI-8 (n=57)

Item	Never No.(%)	Rarely No.(%)	Sometimes No.(%)	Quite frequently No.(%)	Nearly always No.(%)	Mean (SD)
1) Do you feel embarrassed over your relative's behavior?	4(7.0)	18(31.6)	14(24.6)	13(22.8)	8(14.0)	2.05(1.19)
2) Do you feel angry when you are around your relative?	12(21.1)	18(31.6)	15(26.3)	7(12.3)	5(8.8)	1.56(1.21)
3) Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	22(38.6)	18(31.6)	5(8.8)	7(12.3)	5(8.8)	1.21(1.32)
4) Do you feel strained when you are around your relative?	11(19.3)	11(19.3)	15(26.3)	11(19.3)	9(15.8)	1.93(1.35)
5) Do you feel that your social life has suffered because you are caring for your relative?	22(38.6)	20(35.1)	6(10.5)	6(10.5)	3(5.3)	1.09(1.18)
6) Do you feel uncomfortable about having friends over because of your relative?	19(33.3)	16(28.1)	6(10.5)	7(12.3)	9(15.8)	1.49(1.47)
7) Do you wish you could just leave the care of your relative to someone else?	26(45.6)	6(10.5)	11(19.3)	7(12.3)	7(12.3)	1.35(1.47)
8) Do you feel uncertain about what to do about your relative?	9(15.8)	13(22.8)	18(31.6)	12(21.1)	5(8.8)	1.84(1.19)

Cronbach's alpha = 0.88

Table 2 J-ZBI-8 scores in various groups

	NO.	%	J-ZBI-8		<i>P</i>	
			Mean	SD		
Patient						
Gender						
Male	37	64.9	12.2	8.0	$t=-0.412$	$P=0.682$ ¹⁾
Female	20	35.1	13.1	7.1		
Age						
10-19	2	3.5	13.5	4.9	$F=0.838$	$P=0.529$ ²⁾
20-29	15	26.3	14.6	7.8		
30-39	19	33.3	12.0	9.3		
40-49	15	26.3	10.9	6.1		
50-59	4	7.0	9.3	5.0		
60-69	2	3.5	19.5	4.9		
Age at disease onset						
10-19	29	50.9	13.3	8.1	$F=0.359$	$P=0.700$ ²⁾
20-29	26	45.6	11.6	7.4		
30-39	2	3.5	13.5	3.5		
Total years of hospitalization						
0	13	22.8	11.2	7.0	$F=0.972$	$P=0.431$ ²⁾
<1	18	31.6	11.9	7.5		
<3	11	19.3	10.8	8.7		
<5	9	15.8	16.3	6.8		
<10	5	8.8	15.4	10.0		
NA	1	1.8	-	-		
Total number of hospital admissions						
0	13	22.8	11.8	7.2	$F=1.988$	$P=0.097$ ²⁾
1	17	29.8	14.3	6.2		
2	5	8.8	7.2	8.4		
3	12	21.2	14.2	9.8		
4	5	8.8	6.0	4.1		
5+	4	7.0	17.5	6.1		
NA	1	1.8	-	-		
Best social involvement						
Part-time & Sheltered employment						
	5	8.8	11.4	8.0	$F=0.58$	$P=0.631$ ²⁾
Workshop & Day care						
	29	50.9	11.9	6.9		
Able to help around the house						
	12	21.1	12.1	8.5		
Unable to help around the house						
	11	19.3	15.3	9.0		
Mother						
Age						
40-49	4	7.0	11.5	6.6	$F=0.133$	$P=0.940$ ²⁾
50-59	17	29.8	12.0	7.0		
60-69	17	29.8	13.5	10.4		
70+	19	33.3	12.4	5.9		
Presense of alternative carer(s)						
Yes	33	57.9	10.8	6.0	$t=-2.107$	$P=0.043$ ¹⁾
No	22	38.6	15.5	9.3		
NA	2	3.5	-	-		
Participation in family support group meetings during the previous year						
All or almost all	33	57.9	11.3	8.2	$F=1.230$	$P=0.301$ ²⁾
More than half	12	21.1	13.6	5.0		
Occasionally	11	19.3	15.3	8.4		
NA	1	1.8	-	-		
Total	57		12.5	7.7		

¹⁾t-test, ²⁾ANOVA

Table 3 Correlations between J-ZBI-8 and other scales

	No.	Mean	SD	r
J-ZBI-8	57	12.5	7.7	–
FCQ total score	51	66.8	7.8	–0.468 **
1)Information	56	5.5	1.4	0.180
2)Positive communication	56	12.9	3.5	0.055
3)Social interests	55	10.8	2.4	–0.479 ***
4)Coercion	56	15.4	3.1	–0.403 **
5)Avoidance	57	10.7	1.7	–0.605 ***
6)Resignation	55	6.1	1.8	–0.574 ***
7)Patient's social involvement	56	5.4	1.5	0.100
Emotional support	56	6.8	3.5	–0.247
MIDUS	55	10.9	8.5	0.278 *

*P<0.05, **P<0.01, ***P<0.001(Spearman)

J-ZBI-8,the 8-item short version of the Japanese version of the Zarit Caregiver Burden Interview;

FCQ,Family Coping Questionnaire; MIDUS, Mental Illness and Disorder Understanding Scale

Table 4 Results of the multiple regression analysis for J-ZBI-8
as a dependent variable (n=49)

Independent variable	J-ZBI-8		
	β	t	P
Alternative carer (Yes=1, No=0)	-0.136	-1.315	0.196
Social interests	-0.312	-3.072	0.004 **
Coercion	-0.133	-1.238	0.222
Avoidance	-0.201	-1.867	0.069
Resignation	-0.393	-3.657	0.001 **
MIDUS	0.094	0.880	0.384
R		0.785	
R ²		0.616	

**P<0.01; β , standardized regression coefficient; t, t-value; R, multiple correlation coefficient;
MIDUS, Mental Illness and Disorder Understanding Scale