

# Burden on Family Members of the Mentally Ill: A Naturalistic Study in Japan

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People with mental disorders often cause distress among their family members. We examined a total of 25 pairs of newly referred psychiatric patients and their family members to investigate the correlations between family burden and patient diagnosis (using the Structured Clinical Interview for DSM-III-R [SCID] axis I disorders), symptomatic severity (Positive and Negative Symptoms Scales [PANSS]), global function (Global As-

essment of Functioning [GAF]), and the general level of family function (Family Adaptability and Cohesion Evaluation Scale [FACES]). The subjective and objective burdens on the family were assessed by self-report. The subjective and objective burdens were significantly predicted only by the GAF score.

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NUMEROUS STUDIES<sup>1-8</sup> have focused on the burden of care experienced by family members living with individuals with severe mental disorders. Family members face financial problems, difficulty enjoying leisure activities, and various degree of distress while trying to understand the behavior of psychiatric patients living at home. Family members may report strong emotions such as fear and anxiety regarding the patient's symptoms and the cost of treatment. The burden of care imposed on a family may be negatively linked to the overall level of family function.<sup>5</sup> However, there have been few empirical studies concerned with the burden on family members living in Japan with disturbed adult psychiatric patients. The aim of this study is to examine the demographic and clinical predictors of objective and subjective burden on family members.

## METHOD

### Subjects

Consecutive psychiatric patients newly referred to Kita Hospital, a Prefectural mental hospital in Yamanashi, Japan, from November 1996 to March 1998, were asked to participate in the present study, provided they were 18 years of age or older and had an axis I disorder classified in the DSM-IV<sup>6</sup> other than organic brain disorders and mental retardation. A total of 79 patients met these criteria: 38 males and 39 females. We then solicited the participation of the core family members of these patients by explaining the purpose and nature of the study. Of 79 patients, 25 family members (seven men and 18 women; parent,  $n = 16$ ; spouse,  $n = 5$ ; sibling,  $n = 1$ ; child,  $n = 2$ ; and other,  $n = 2$ ) agreed to participate. Their mean age was 52.5 years ( $SD = 10.6$ ). The patients whose family members agreed to participate can be stratified into three diagnostic groups: (1) psychotic group, including schizophrenia ( $n = 11$ ) and delusional disorder ( $n = 1$ ); (2) depression group ( $n = 9$ ); and (3) miscellaneous group, including alcohol dependence ( $n = 1$ ), alcohol abuse ( $n = 1$ ), amphetamine dependence ( $n = 2$ ), eating disorder ( $n = 1$ ), and adjustment disorder ( $n = 1$ ).

We found no significant differences between the patients with

( $n = 26$ ) and without ( $n = 53$ ) the participation of family members in terms of demographic and clinical variables except for the patient's age (mean age of patients with participating family members = 39.0,  $SD = 15.0$ ; mean age of patients without participating family members = 41.9,  $SD = 20.9$ ;  $F = 7.9$ ,  $P < .01$ ).

### Measurement

*Family burden scale.* We used a 21-item modified version of the Burden Assessment Scale (BAS)<sup>3</sup> to measure the burden perceived by the family on a five-point scale from "not at all" (1) to "a lot" (5). BAS has two subscales: subjective (nine items) and objective (10 items) burdens. We added one subjective ("family members' concern about the patient possibly committing suicide") and one objective item ("patient's violent behavior directed at family members") to the original BAS.

*Structured Clinical Interview for DSM-III-R.* The patient version of the Structured Clinical Interview for the Diagnostic Statistical Manual of Mental Disorders, 3rd Edition Revised (SCID-I/P)<sup>7</sup> was used.

*Global Assessment of Functioning.* The Global Assessment of Functioning (GAF)<sup>8</sup> is a measure of overall psychological, social, and occupational functioning of patients. The scores on the GAF range from 1 to 100, with lower scores reflecting greater levels of disability.

*Positive and Negative Symptoms Scale.* The Positive and Negative Symptoms Scale (PANSS)<sup>9</sup> is a semistructured clinical interview. This scale is constructed according to a series of positive symptoms, negative symptoms, and general psychopathology.

*Family Adaptability and Cohesion Evaluation Scale.* The Family Adaptability and Cohesion Evaluation Scale (FACES

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III) was developed by Olson<sup>10</sup> to examine the circumplex model of family functioning. It consists of two subscales: adaptability and cohesion.<sup>14</sup> In this study, we used a modified, short version of FACES III because the items that related to children on the original FACES III were not suited to adult subjects and also because our questionnaire did not allow sufficient space to print the full-version scale. The chosen items were selected from among those that showed the highest correlation with the total score.<sup>12</sup>

### Procedure

After a doctor's interview with a patient, the patient and his or her family members were asked to take part in the present study. The interviewer explained the purpose and nature of the study and written informed consent was given prior to the interview.

After the interview (SCID, GAF, and PANSS) had been conducted, the interviewer handed a patient version of the questionnaire to the patients and a family version of the questionnaire to the family members. If a patient came to the hospital unattended, we requested that the patient give the family version of the questionnaire to one of his or her family members. Both the family member and the patient had the option of returning the questionnaire free of postal charges.

The questionnaire for the patient included demographic variables (age, sex, occupation, level of education, economic status, duration of illness, and information regarding whether or not he or she lived with the family of origin, etc), FACES III, and other information.

The questionnaire for the family members included demographic variables (age, sex, occupation, level of education, economic and social status, information about whether or not he or her lived with the patient, his or her relationship to the patient, information about the duration of illness, etc), Family Burden Scale (FBS), FACES III, and other information.

## RESULTS

As regards the relationships between the FBS subscale scores and the demographic variables scores, the patient's age correlated negatively with the subjective burden ( $r = -.48, P < .05$ ), whereas the objective burden score did correlate with the duration of illness ( $r = .42, P < .05$ ). We found no other significant associations between the demographic variables and the FBS subscale scores.

In terms of subjective burden score, there was a significant difference between the diagnostic categories ( $F = 5.39, P < 0.5$ ). The subjective burden was the highest in the psychotic group (mean = 35.9, SD = 5.5). The second was the depression group (mean = 26.8, SD = 11.5). The miscellaneous group was the lowest (mean = 21.2, SD = 10.6). To strike a balance between committing type I and type II errors, a conservative (i.e., Tukey honestly significant difference [HSD]) post-hoc analysis was applied to the diagnostic group's main effect. This analysis revealed that the psychotic

**Table 1. The Two FBS Subscale Scores and Clinical Variables**

Predictor Variables	FBS Subscales	
	Subjective	Objective
Diagnostic group		
Psychotic	35.9 (5.5)*	28.8 (11.5)
Depression	26.8 (11.5)*	21.3 (8.1)
Miscellaneous	21.2 (10.5)*	29.6 (14.4)
Recurrence of episode		
First episode (n = 10)	29.1 (12.1)	20.9 (6.6)
Recurrence (n = 14)	30.3 (9.6)	29.9 (9.5)
Duration of illness	-.08	.42*
Positive syndrome	.59†	.36
Negative syndrome	.11	.11
General psychopathology	.33	.27
GAF	-.67‡	-.42*
Family adaptability	-.14	-.22
Family cohesion	-.12	-.12

NOTE. SD in parentheses.

\* $P < .05$ .

† $P < .01$ .

‡ $P < .001$ .

group significantly differed from the other group ( $P < .05$ ). Among the PANSS subscales, the positive syndrome score correlated with the subjective burden (Table 1). The GAF score moderately and negatively correlated with the subjective burden.

In terms of objective burden score, no significant differences were found between the diagnostic categories ( $F = 1.44, P = .26$ ). The objective burden score was significantly higher among those with past episodes of illness (recurrent) than among those without recurrence (initial episode). The objective burden score significantly correlated with the duration of illness. It failed to show any significant correlation with the PANSS symptomatology scores. However, it correlated moderately and negatively with the GAF score.

We found no significant correlations between the FACES III subscale and the two FBS subscale scores.

Since the GAF score, the positive symptom score, the patient's diagnosis, and the patient's age significantly correlated with the subjective burden score in the bivariate analyses, we performed a series of multiple regression analyses using a set of these predictor variables. The demographic variable (patient's age) contributed significantly to a prediction of the subjective burden ( $R^2 = .232, F(1,22) = 6.65, P < .05$ ) with a significant  $\beta$  value ( $-.220, P < .05$ ). Next the three clinical indices—GAF, diagnosis, and positive syndrome—were included in the equation. The clinical indices signif-

icantly predicted the subjective burden score ( $R^2$  increase = .368;  $F(4,19) = 7.13$ ,  $P < .005$ ); only the GAF score demonstrated a significant  $\beta$  value (-.448,  $P < .05$ ). Finally, we entered the interaction terms of the demographic variable and the clinical indexes (GAF  $\times$  diagnosis, GAF  $\times$  positive syndrome, and positive syndrome  $\times$  diagnosis). They did not add significantly to the prediction of the subjective burden score ( $R^2$  increase = .030,  $F(7,16) = 3.90$ , not significant [NS]).

Similarly, a hierarchical regression analysis was performed using the objective burden score as the criterion variable. In this analysis, the demographic variables (duration of illness and recurrence/first episode) were entered first, followed by the clinical index (GAF), and then by the interactional terms of the demographic variables and the clinical index. The demographic variables significantly predicted the objective burden score ( $R^2 = .275$ ,  $F(2,22) = 4.18$ ,  $P < .05$ ), but none of the two demographic variables had a significant  $\beta$  value. The clinical index (GAF) contributed significantly to the prediction of the objective burden score ( $R^2$  increase = .160;  $F(3,21) = 5.40$ ,  $P < .05$ ), with a significant  $\beta$  value (-.401,  $P < .05$ ). The demographic and clinical interactional terms did not significantly predict the objective burden score ( $R^2$  increase = .072,  $F(6,18) = 3.09$ , NS).

## DISCUSSION

Among the many variables used in this study, only the GAF scale demonstrated the capacity to predict the subjective and objective burden experienced by family members. Cornwall and Scott<sup>1</sup> also reported that both the subjective and objective burdens correlated with the GAF score. The GAF scale includes the functional impairment, symptoms, and the needs of care by others, listed on a continuum. The GAF scale reduced the predictive power of the positive symptoms and the diagnostic categories in terms of each of the two burden scales in our analyses. Thus, variables such as social, psychological, and occupational functioning heavily influenced the burden perceived by a caretaker. Platt<sup>2</sup> concluded that the severity of subjective burden was related to the extent of observed problems of a patient. Family members living with a person with severe impairment had to take care of such patients more than did family members of a patient with milder impairments. The relatives' concerns about patients were linked to subjective burden.<sup>14</sup>

Certain limitations of this study should be considered when interpreting the present results. We were unable to find any correlation between the demographic variables and family burden, in contrast to other studies.<sup>4,15</sup> The small sample size limited the present study's statistical power and ability to control for the demographic variables. The low participation of the family members (32%) was of another concern. Although we found no significant differences between those who participated and who did not in terms of demographic and clinical variables, we should be cautious about possible variables that caused this low participation rate. For example, strongly stigmatized attitudes of Japanese people toward the mentally ill and psychiatric services may deserve further consideration. Moreover, our research was conducted only at the time of admission and did not provide follow-up evaluations of the patients and their families. The predictive variables regarding the burden to caretakers may not be sufficiently precise. These limitations may be difficult to overcome when using a naturalistic method rather than a prospective data collection method. However, it is of note that a family member's perceived burden could be predicted by the objective observations of psychiatric professionals as regards the patient's psychiatric state, regardless of the diagnosis.

Psychiatric professionals often view the family members of a patient as people of support; family members can act as informants regarding the patient and they can act as cotherapists at home. However, the family members themselves are facing difficulties due to the patient's behaviors and symptoms. Reduced function of one family member contributes to the perceived burden of other members and this in turn leads to other family members assuming a critical attitude towards the patient. Moreover, such criticism can perhaps lead in some cases to a relapse of the illness. Careful assessment of a patient's functional ability, in addition to symptomatology, deserves more attention in daily practice, as it has been shown to correlate with perceived burden on the part of caregivers. Hopefully, such research will provide a step forward towards better care given to both patients and their family members alike.

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## REFERENCES

1. Cornwall PL, Scott J. Burden of care, psychological distress and satisfaction with services in the relatives of acutely mentally disordered adults. *Soc Psychiatry Psychiatr Epidemiol* 1996;31:345-348.
2. Platt S. Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales. *Psychol Med* 1985; 15:383-393.
3. Horowitz AL, Reinhard SC. Ethnic differences in caregiving duties and among parents and siblings of persons with severe mental illnesses. *J Health Soc Behav* 1995;36:138-150.
4. Mors O, Sorensen LV, Therkildsen ML. Distress in the relatives of psychiatric patients admitted for the first time. *Acta Psychiatr Scand* 1991;85:337-344.
5. Grad J, Sainsbury P. Mental illness and the family. *Lancet* 1963;1:544-547.
6. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. Ed. 4 (DSM-IV). Washington, DC: Author, 1994.
7. Spitzer RL, Williams J, Gibbon M, First MB. *Structured Clinical Interview for DSM-III-R Patient Edition (SCID-P, Version 1.0)*. Washington, DC: American Psychiatric Press, 1990.
8. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. Ed. 3, Rev. (DSM-III-R). Washington, DC: Author, 1987.
9. Kay SR, Opler LA, Fiszbein A. Significance of positive and negative syndromes in chronic schizophrenia. *Br J Psychiatry* 1986;149:439-448.
10. Olson DH. Circumplex model VII: validation studies and FACES III. *Fam Process* 1986;25:337-351.
11. Olson DH. Circumplex model of marital and family systems: I. Cohesion and adaptability dimensions, family types, and clinical applications. *Fam Process* 1979;18:3-28.
12. Sadaki T, Kayano J, Enkan moderu ni yoru kaozku kino no asesumento [The assessment of family functioning based on the Circumplex Model of marital and family system: a study of clinical usefulness of FACES scales]. *Arch Psychiatr Diagn Clin Eval* 1997;8:125-135.
13. Greenberg JS, Kim HW, Greenley JR. Factors associated with subjective burden in siblings of adults with severe mental illness. *Am J Orthopsychiatry* 1997;67:231-240.
14. Bulger MW, Wandersman A, Goldman CR. Burdens and gratifications of caregiving: appraisal of parental care of adults with schizophrenia. *Am J Orthopsychiatry* 1993;63:225-265.