

## Factors Affecting Quality of Life and Family Burden among the Families of Patients with Schizophrenia

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**Objectives** : Study aimed to identify factors that may affect family burden and quality of life (QOL) of primary caregivers in schizophrenia family.

**Methods** : Among outpatients with schizophrenia undergoing treatment at the psychiatric department of a university hospital, 72 patients and their primary caregivers were investigated. Sociodemographic and clinical data were collected and analyzed.

**Results** : As a result of multiple regression of primary caregivers' family burden ( $R^2=0.284$ ), primary caregiver's income ( $p=0.001$ ) and patient's delusional symptoms ( $p=0.001$ ) significantly explained the total family burden of primary caregivers. In multiple regression on QOL ( $R^2=0.515$ ), primary caregiver's income ( $p=0.033$ ) and education level ( $p=0.006$ ), patient's sex ( $p=0.006$ ), treatment duration ( $p<0.001$ ), degree of disorganized speech ( $p=0.008$ ), negative drug attitudes ( $p=0.026$ ) and the attitude of overcoming stigma against mental patients ( $p=0.029$ ) all significantly explained the average QOL score.

**Conclusion** : Various factors determining primary caregiver's QOL, including Clinical symptoms such as patient's disorganized speech and clinically correctable factors such as negative drug attitude and insight into disease. Therefore, provision of education regarding drug and disease for patients and caregivers will be helpful to effectively reduce burden and improve the QOL of primary caregivers. (Korean J Schizophr Res 2016;19:78-88)

**Key Words** : Schizophrenia · Caregiver burden · Quality of Life.

### Introduction

Family are often the first diagnosticians and first decision makers of individuals with schizophrenia, and as providers of emotional and financial support, they play important roles in treatment and rehabilitation.<sup>1)</sup> However, if prejudices and stigma surrounding mental illness are strong, family members and patients alike face considerable social and physical threat.<sup>2)</sup> In particular, emotional responses including anxiety and depression not only exacerbate family pain and burden, but also negatively influence patient prognosis.<sup>3)</sup>

With the dehospitalization trend, beginning in the late 1960s, patients suffering from schizophrenia returned to society, and recent atypical antipsychotic medications decreased frequency of relapse and hospital admissions. However, as communities lack basic support services, responsibility

for patients' support has been relegated to families, and this is related to family burden.<sup>4)</sup>

Family burden refers to various psychological, social, and financial burdens borne while caring for patients. Hoenig and Hamilton<sup>5</sup> conceptualized this on subjective and objective levels. Objective burden refers to concrete sacrifices and losses suffered by the family because of mental disorders, and subjective burden refers to the level of pain subjectively experienced as a result of the burdensome situation. The definition introduced by Dillehay and Sandys<sup>6</sup> is often used, defining family burden as "the psychological status resultant from the combination of factors such as physical labor and emotional or social pressure."

Families caring for patients with schizophrenia face many burdens, but it is unclear which factors give rise to such burdens. There seems to be a degree of overlap regarding the connection to the patient's symptoms, with significant correlation between family burden and symptom severity.<sup>7-9)</sup> However, each symptom showed conflicting results or did not show a significant difference.

In much of the literature, the term family burden has a negative meaning, implying family burden directly or indirectly

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negatively influences the caregiver's life. Prior research stated that long-term family burden affects economic limitations and financial demand and can damage interpersonal relationships, career, and role performance in social activities.<sup>10,11)</sup> Moreover, family burden decreased quality of life (QOL) for the caregiver because of emotional stress, family conflict, and low satisfaction.<sup>12)</sup>

Prior research on family burden surveyed many factors, including both patients and caregivers, but factors influencing family burden were diverse. Furthermore, family burden itself may influence the life of caregivers of patients with schizophrenia directly and indirectly. This research more concretely investigated effects of various factors on family burden and caregiver QOL.

## Methods

### Research subjects and process

Subjects were recruited from patients receiving outpatient care in the neuropsychiatric department of a university hospital in Incheon, who were diagnosed with and receiving care for schizophrenia, based on diagnostic criteria of the DSM-5.<sup>13)</sup> Inclusion criteria were a visit to a neuropsychiatric department between September 1, 2014 and April 30, 2015 and symptoms of schizophrenia that showed no sign of worsening for at least 4 weeks prior to evaluation. Adult patients with schizophrenia aged between 19 and 70, capable of understanding the research procedure and cooperating, were selected as subjects, and both patients and primary caregivers participated. The primary caregiver was defined as the family member who spent the most time with the patient or was responsible for their financial support.<sup>14)</sup> Patients with a history of intellectual disabilities, epilepsy, or organic brain disorders or who had accompanying alcohol or drug use disorders were excluded.

Patients and their primary caregivers were given an explanation of the research, and consent was obtained only if the patient and one's caregiver agree on that. Patients and caregivers were administered a questionnaire in separate locations, with the assistance of a medical team.

This research was approved by the Inha University Hospital Institutional Research Ethics Board.

### Clinical scales

#### Attitude to drugs

The Korean version of the Drug Attitude Inventory-10

(KDAI-10),<sup>15)</sup> a self-report questionnaire evaluating subjective positive and negative feelings towards antipsychotic medication, was used. If the final score is positive, it signifies a positive subjective attitude towards medication, and if the final score is negative, it signifies a negative subjective attitude.

#### Internalized stigma

The Korean version of Internalized Stigma of Mental Illness scale (K-ISMI)<sup>16)</sup> was used. The 29 total items on the scale consist of 6 alienation items that evaluate a damaged identity or the respondent's subjective experiences of feeling that they are not a full member of society ; 7 stereotype endorsement items that evaluate the respondent's level of agreement to stereotypes of those with mental disorders ; 5 discrimination experience items that evaluate the respondent's perception of treatment by others ; 6 social withdrawal items that evaluate the socially intimidated degree of patients; and 5 stigma resistance items that evaluate the experience of resisting internalized stigma. The higher the final score, the higher the level of internalization of negative attitudes towards mental illness, and this signifies a negative attitude towards themselves.

#### Clinical symptoms and functional assessment

Clinical symptoms were assessed through semi-structured scales include DSM-5 Clinician-Rated Dimensions of Psychosis Symptom Severity (DSM-5 CRDPSS),<sup>13)</sup> Global Assessment of Functioning (GAF),<sup>17)</sup> and Clinical Global Impression-Severity (CGI-S).<sup>18)</sup>

Out of the 8 items in the DSM-5 CRDPSS, the items for depression and mania, which reflect mood disorders, were excluded, and the remaining 6 items, concerning hallucination, delusion, disrupted language, dysfunctional psychomotor actions, negative symptoms, and lost cognitive function, were used.

#### Awareness of illness

To evaluate disorder awareness, the Scale to Assess Unawareness of Mental Disorder-Korean version (SUMD-K)<sup>19)</sup> was used. This scale consists of 9 items, evaluating awareness of mental disorder, effectiveness of medicine, social results of mental illness, positive symptoms, and negative symptoms; the higher the score, the lower the awareness of mental disorder.

### Family burden

For caregiver burden, the Family Burden Scale (FBS)<sup>20)</sup> was used. In pilot research, this scale has shown superior reliability and validity. Fourteen of its items evaluated objective burden, and the remaining 22 items evaluated subjective burden. In each item, a higher score was interpreted as a higher family burden.

### Quality of life

The World Health Organization Quality of Life Assessment Instrument, abbreviated version (WHOQOL-BREF-Korean version) was used.<sup>21)</sup> This scale assesses overall QOL through self-reporting, with subscales in the general health, physical health, psychological, social relationships, and environmental domains. Although it is a 5-point scale, “pain and discomfort,” “dependence on medicinal substances and medical aids,” and “negative feeling” items are analyzed with an inverse operation. The scores for each subscale were added together, and a higher sum in each subscale signified better QOL. The average of the quality of life scores (QOL score) was the sum of all scores divided by 26, and a higher score meant better quality of life.

### Statistical analysis

Caregiver family burden and QOL were analyzed to determine correlation with each respective factor. Variables affecting primary caregiver family burden and QOL were analyzed with one-way ANOVA. Possible explanatory variables included patient sex, age, level of education, diagnostic period, treatment period, number of hospital admissions, number of outpatient sessions in the most recent 3 months, as well as caregiver age, sex, level of education, monthly income, KDAI-10, K-ISMI, K-SUMD, DSM-5 CRDPSS, CGI-S, and GAF scores. The FBS was divided into total family burden, objective family burden, and subjective family burden. The WHOQOL-BREF-Korean Version was divided into the physical health, psychological health, social relationships, environmental, and general domains and analyzed. In order to solve the problem of multicollinearity between the explanatory variables, variables were selected using stepwise selection, and a multivariate regression analysis was conducted.

All statistical analyses were undertaken using SPSS version 19.0 (SPSS Inc., Chicago, IL, USA). All statistical significance levels were set as 0.05 or less.

## Results

All 102 patients were asked to research, but 4 patients didn't visit hospital again and 9 caregivers refused to participate in research. A total of 89 patients (47 males and 42 females) and caregivers (43 males and 46 females) participated. Seventeen subjects were excluded because their content was either unreliable or insufficient, and the data from the remaining 72 underwent statistical analysis (Fig. 1).

### Socio-demographic and clinical distribution

The patient's father was the most common primary caregiver, followed by sibling, mother, partner, and children (Table 2). More than half of the patient group (N=37) had a diagnostic period of  $\geq 11$  years, and most patients also had a treatment period  $\geq 11$  years. Eighteen subjects had comorbid diseases, including diabetes, hypertension, and arthritis, in that order (Table 3).

### Characteristics by scale of patients and primary caregivers

Mean patient CGI-S score was 3.40, with mild to medium severity. GAF score averaged 52.44, with medium difficulties in social or professional functions. The KDAI-10 score (range : -10–10) in the patients with schizophrenia was 3.56, showing an overall positive attitude towards medication. The sum of K-ISMI (range : 4–91) was 39.51, and the score of SUMD-K (range : 0–27) was 17.81 (Table 3). Caregiver FBS

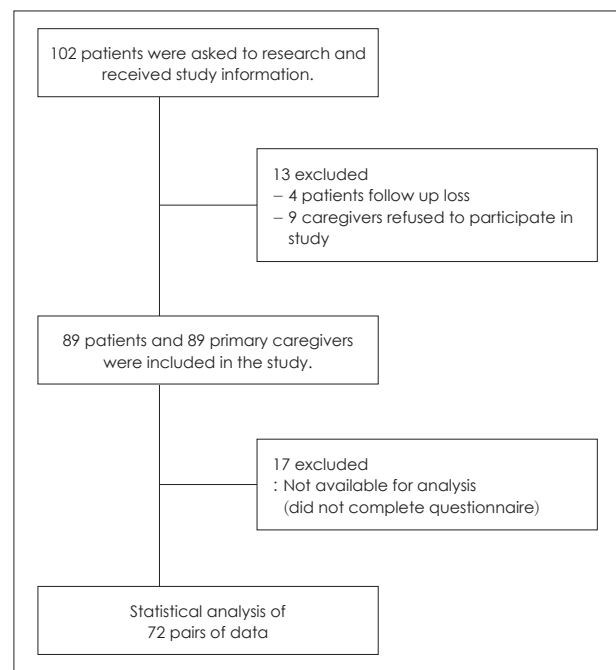


Fig. 1. Flow chart of study participants.

**Table 1.** Sociodemographic characteristics of the patients with schizophrenia

	Schizophrenia (N=72)
	N (%)
Sex	
Male	36 (50)
Female	36 (50)
Age	
≤ 29	15 (20.3)
30–39	16 (22.2)
40–49	16 (22.2)
50–59	17 (23.6)
≥ 60	8 (11.1)
Education	
High school graduate or less	35 (48.6)
Some college or more	37 (51.4)
Marriage	
Married	12 (16.7)
Never married	51 (70.8)
Others*	9 (12.5)
Employment	
Unemployed	56 (77.8)
Employed	16 (22.2)
Living arrangement	
Living alone	11 (15.3)
Living with someone†	61 (84.7)
Experience of community mental health program‡	
Yes	22 (30.6)
No	50 (69.4)

\* : cohabitation, divorce or widowed, † : living with family or residential psychiatric rehabilitation facility members, ‡ : community mental health center, family therapy or self-help group programs

score (range : 0–144) was 42.00, and the WHOQOL-BREF-Korean version had an average QOL score of 2.98 (Table 4).

### Variance analysis of family burden and quality of life by subject characteristic

Twelve factors from patients' socio-demographic and clinical attributes were considered possible explanatory variables in primary caregivers' family burden and QOL, and a variance analysis was conducted. No patient factors significantly explained total, objective, or subjective burden. However, patient sex, age, diagnostic period, and treatment period accounted for caregiver QOL and showed statistically significant differences (Table 5).

The variance analysis conducted on caregiver socio-demographic attributes, family burden, and QOL showed a statistically significant difference in total burden according to caregiver sex and monthly income. For objective burden,

**Table 2.** Sociodemographic characteristics of primary caregivers of patients with schizophrenia

	Primary caregiver (N=72)
	N (%)
Sex	
Male	35 (48.6)
Female	37 (51.4)
Age	
≤ 29	1 (1.4)
30–39	4 (5.6)
40–49	7 (9.7)
50–59	31 (43.1)
≥ 60	28 (39.4)
Education	
High school graduate or less	46 (63.9)
Some college or more	26 (36.1)
Marriage	
Married	47 (65.3)
Never married	10 (13.9)
Others*	15 (20.8)
Employment	
Unemployed	32 (44.4)
Employed	40 (55.6)
Total monthly income (Won)	
< 500,000	29 (40.3)
500,000–2,000,000	37 (51.4)
> 2,000,000	6 (8.3)
Relationship with patient	
Father	27 (37.5)
Mother	13 (18.1)
Spouse	9 (12.5)
Sibling	14 (19.4)
Offspring	9 (12.5)
Living with patient	
Yes	52 (72.2)
No	20 (27.8)
Experience of community mental health program‡	
Yes	20 (27.8)
No	52 (72.2)

\* : cohabitation, divorce or widowed, † : community mental health center, family therapy or self-help group programs

caregiver sex and monthly income, and for subjective burden, caregiver sex, educational background, and monthly income were statistically significant factors. For caregiver QOL, caregiver age, educational background, marital status, and monthly income showed a significant difference (Table 6).

### Multivariate regression analysis using stepwise selection

Multivariate analysis showed caregiver monthly income

**Table 3.** Clinical characteristics of the patients with schizophrenia

	Schizophrenia (N=72)
	N (%)
Duration of diagnosis (years)	
< 1 yr	7 (9.7)
1–5 yr	18 (25.0)
6–10 yr	10 (13.9)
≥ 11 yr	37 (51.4)
Duration of treatment (years)	
< 1 yr	9 (12.5)
1–5 yr	19 (26.4)
6–10 yr	12 (16.7)
≥ 11 yr	32 (44.4)
Number of admission	
None	8 (11.1)
1–2	38 (52.8)
3–5	17 (23.6)
≥ 6	9 (12.5)
Number of outpatient visit for 3 months past	
< 3	29 (40.3)
3–5	40 (55.6)
≥ 6	3 (4.2)
Number of comorbid physical illness	
Yes	18 (25.0)
No	54 (75.0)
	Mean (SD)
KDAI-10	
Subjective positive feeling	2.06 (3.75)
Subjective negative feeling	–1.50 (2.51)
FS (Final score)	3.56 (5.21)
K-ISMI	
Alienation	13.81 (3.56)
Stereotype endorsement	14.51 (2.85)
Discrimination experience	10.36 (2.45)
Social withdrawal	13.14 (3.17)
Stigma resistance	12.31 (2.64)
Total score	39.51 (9.94)
DSM-5 CRDPSS	
Hallucination	1.75 (0.90)
Delusion	1.97 (0.77)
Disorganized speech	1.53 (0.84)
Abnormal psychomotor behavior	1.18 (0.68)
Negative symptoms	1.85 (0.74)
Impaired cognition	1.85 (0.76)
CGI-S	3.40 (0.85)
GAF	52.44 (13.44)
K-SUMD	
Awareness of mental disorder	1.86 (0.68)

**Table 3.** Clinical characteristics of the patients with schizophrenia (continued)

	Schizophrenia (N=72)
	N (%)
Awareness of social consequences	1.97 (0.73)
Awareness of medication effects	1.78 (0.74)
Awareness of positive symptoms	5.99 (2.17)
Awareness of negative symptoms	6.21 (1.79)
Total score	17.81 (4.99)

KDAI-10 : Korean version of Drug Attitude Inventory-10, K-ISMI : Korean version of Internalized stigma of mental illness scale, DSM-5 CRDPSS : DSM-5 Clinician-Rated Dimensions of Psychosis Symptom Severity, CGI-S : Clinical Global Impression-Severity, GAF : Global Assessment of Functioning, K-SUMD : Korean version of Scale to Assess Unawareness of Mental disorder

**Table 4.** Clinical characteristics of primary caregivers of patients with schizophrenia

	Primary caregiver (N=72)
	N (%)
FBS	
Total score	42.00 (26.07)
Objective burden	12.44 (10.20)
Subjective burden	29.56 (17.30)
WHOQOL-BREF	
Physical health domain	21.97 (5.25)
Psychological domain	16.67 (3.78)
Social relationships domain	8.47 (2.51)
Environmental domain	21.71 (4.90)
Overall QOL domain	5.61 (1.42)
Total score	74.42 (14.76)
QOL score (Average)	2.98 (0.59)

FBS : Family Burden Scale, WHOQOL-BREF : World Health Organization Quality of Life Assessment Instrument abbreviated version

and patient delusory symptom subscore on the DSM-5 CRDPSS significantly explained caregiver total family burden. Factors significantly correlated with caregiver objective burden were the same as those for caregiver total family burden, but factors explaining caregiver subjective burden also included caregiver monthly income and sex and patient DSM-5 CRDPSS delusory symptom subscore (Table 7).

Caregiver monthly income and educational background, as well as patient sex, diagnostic period, disrupted language subscore of DSM-5 CRDPSS, negative subjective drug attitude, and attitude of overcoming stigma against mental patients all significantly explained total QOL (Table 8).

## Discussion

This research was conducted using outpatients monitored

**Table 5.** Effect of variables of patients with schizophrenia on the familial burden score and quality of life of primary caregivers

	FBS (Total score)		FBS (Objective)		FBS (Subjective)		QOL score	
	Mean (SD)	F	Mean (SD)	F	Mean (SD)	F	Mean (SD)	F
Sex								
Male	42.72 (27.57)	0.055	13.47 (11.12)	0.728	29.25 (18.14)	0.022	2.79(0.55)	7.481*
Female	41.28 (24.86)		11.42 (9.23)		29.86 (16.67)		3.16 (0.58)	
Age								
≤ 29	41.20 (29.78)	0.626	12.80 (11.23)	0.391	28.40 (19.06)	1.021	3.33 (0.44)	4.198†
30–39	44.69 (25.46)		11.00 (10.69)		33.69 (17.44)		2.73 (0.56)	
40–49	48.69 (31.00)		15.06 (11.88)		33.63 (19.89)		2.87 (0.57)	
50–59	34.88 (13.12)		11.53 (6.86)		23.35 (7.83)		3.18 (0.53)	
≥ 60	39.88 (32.12)		11.38 (11.16)		28.50 (22.24)		2.59 (0.65)	
Education								
≤ High school graduate	41.80 (23.29)	0.004	13.09 (8.91)	0.266	28.71 (15.60)	0.159	2.95 (0.60)	0.152
Some college or more	42.19 (28.78)		11.84 (11.37)		30.35 (18.95)		3.00 (0.60)	
Marriage								
Married	42.83 (22.42)	2.327	12.17 (7.91)	2.150	30.67 (15.48)	2.061	3.11 (0.68)	0.438
Never married	44.82 (27.69)		13.63 (11.05)		31.20 (18.16)		2.96 (0.60)	
Others‡	24.89 (13.00)		6.11 (4.46)		18.78 (10.77)		2.87 (0.38)	
Living Arrangement								
Living alone	40.67 (34.21)	0.037	11.75 (12.93)	0.066	28.92 (22.01)	0.019	3.11 (0.65)	0.695
Living with someone§	42.27 (24.48)		12.58 (9.69)		29.68 (16.42)		2.95 (0.58)	
Experience of community mental health program¶								
No	41.46 (26.44)	0.069	11.66 (10.36)	0.967	29.80 (17.57)	0.032	3.03 (0.59)	1.202
Yes	43.23 (25.80)		14.23 (9.83)		29.00 (17.06)		2.86 (0.58)	
Duration of diagnosis (years)								
< 1 yr	33.29 (7.06)	1.028	8.43 (4.11)	1.028	24.86 (5.64)	0.974	3.21 (0.52)	3.814*
1–5 yr	35.17 (27.62)		10.33 (10.52)		24.83 (17.78)		3.30 (0.47)	
6–10 yr	46.20 (36.35)		15.50 (12.71)		30.70 (24.26)		2.71 (0.75)	
≥ 11 yr	45.84 (24.16)		13.41 (10.04)		32.43 (16.25)		2.85 (0.55)	
Duration of treatment (years)								
< 1 yr	40.67 (16.31)	0.827	10.44 (5.50)	0.630	30.22 (11.98)	0.929	3.20 (0.48)	4.407*
1–5 yr	34.53 (26.99)		10.32 (10.22)		24.21 (17.50)		3.30 (0.45)	
6–10 yr	43.25 (33.09)		13.75 (12.08)		29.50 (22.09)		2.75 (0.76)	
≥ 11 yr	46.34 (24.94)		13.78 (10.56)		32.56 (16.45)		2.81 (0.54)	
Number of admission								
None	45.25 (23.47)	0.583	15.50 (8.40)	1.012	29.75 (16.18)	0.369	3.07 (0.56)	0.897
1–2	39.68 (27.92)		11.03 (10.63)		28.66 (18.44)		3.06 (0.60)	
3–5	40.41 (26.47)		11.94 (10.55)		28.47 (17.51)		2.83 (0.63)	
≥ 6	51.89 (19.82)		16.67 (8.78)		35.22 (14.09)		2.81 (0.53)	
Number of outpatient visit (for 3 months past)								
1–2	43.14 (26.05)	0.467	12.83 (9.88)	0.339	30.31 (17.99)	0.471	2.95 (0.53)	0.667
3–5	40.23 (24.90)		11.85 (10.00)		28.38 (16.19)		3.02 (0.64)	
≥ 6	54.67 (47.17)		16.67 (18.45)		38.00 (29.00)		2.63 (0.61)	
Comorbid physical illness								
No	44.96 (28.71)	2.863	13.69 (10.99)	3.299	31.28 (18.98)	2.176	2.98 (0.63)	0.001
Yes	33.11 (12.61)		8.72 (6.18)		24.39 (9.46)		2.97 (0.47)	

\* : statistically significant p value (<0.05), † : statistically significant p value (<0.005), ‡ : cohabitation, divorce or widowed, § : living with family or residential psychiatric rehabilitation facility members, ¶ : community mental health center, family therapy or self-help group programs



**Table 6.** Effect of variables of primary caregivers on the familial burden score and quality of life of primary caregivers

	FBS (Total score)		FBS (Objective)		FBS (Subjective)		QOL score	
	Mean (SD)	F	Mean (SD)	F	Mean (SD)	F	Mean (SD)	F
Sex								
Male	33.09 (19.78)	8.840†	9.66 (7.91)	5.400*	23.43 (13.60)	9.575†	3.04 (0.54)	0.698
Female	50.43 (28.65)		15.08 (11.46)		35.35 (18.56)		2.92 (0.64)	
Age								
≤ 29	31.00 (0.00)	0.393	9.00 (0.00)	0.080	22.00 (0.00)	0.820	3.32 (0.00)	4.713†
30–39	32.00 (20.69)		13.25 (10.08)		18.75 (10.69)		3.47 (0.61)	
40–49	41.29 (32.58)		13.00 (11.27)		28.29 (21.85)		2.88 (0.77)	
50–59	39.06 (26.13)		11.55 (10.30)		27.52 (16.50)		3.21 (0.46)	
≥ 60	45.29 (24.36)		32.89 (17.25)		32.89 (17.25)		2.67 (0.55)	
Education								
≤ High school graduate	46.30 (28.17)	3.599	13.67 (11.09)	1.873	32.63 (18.70)	4.206*	2.81 (0.57)	12.472†
Some college or more	34.38 (20.21)		10.27 (8.16)		24.12 (13.13)		3.28 (0.50)	
Marriage								
Married	37.79 (22.10)	2.676	10.70 (8.43)	2.185	27.09 (15.42)	2.761	3.13 (0.54)	7.403†
Never married	41.90 (30.27)		14.40 (10.73)		27.50 (20.16)		2.96 (0.62)	
Others†	55.27 (31.72)		16.60 (13.74)		38.67 (19.04)		2.51 (0.51)	
Employment								
Unemployed	46.88 (27.96)	2.043	13.69 (10.89)	0.854	33.19 (18.48)	2.596	2.85 (0.67)	2.714
Employed	38.10 (24.11)		11.45 (9.64)		26.65 (15.93)		3.08 (0.50)	
Total monthly income (Won)								
< 500,000	56.00 (31.33)	8.601†	17.03 (12.45)	5.825†	38.97 (20.14)	8.795†	2.68 (0.62)	7.961†
500,000–2,000,000	33.22 (17.46)		9.76 (7.26)		23.46 (12.39)		3.14 (0.49)	
> 2,000,000	28.50 (5.89)		6.83 (4.07)		21.67 (3.14)		3.41 (0.35)	
Relationship with patient								
Father	50.93 (27.74)	1.438	14.59 (11.16)	0.649	36.33 (17.70)	1.856	2.92 (0.58)	0.483
Mother	34.77 (27.20)		9.77 (9.79)		25.00 (19.82)		2.89 (0.64)	
Spouse	34.33 (6.78)		10.33 (3.81)		24.00 (4.64)		3.14 (0.55)	
Sibling	36.29 (19.04)		11.57 (9.10)		24.71 (11.96)		3.11 (0.59)	
Offspring	42.22 (36.21)		13.33 (13.84)		28.89 (23.06)		2.93 (0.65)	
Living with patient								
Yes	43.65 (27.13)	0.751	12.81 (10.33)	0.235	30.85 (18.14)	1.043	2.97 (0.63)	0.018
No	37.70 (23.18)		11.50 (10.06)		26.20 (14.80)		2.99 (0.47)	
Experience of community mental health program§								
No	41.91 (24.68)	0.003	11.60 (9.26)	1.915	30.32 (16.88)	0.525	3.00 (0.61)	0.398
Yes	42.33 (31.79)		15.67 (13.07)		26.67 (19.14)		2.89 (0.53)	

\* : statistically significant p value (<0.05), † : statistically significant p value (<0.005), ‡ : cohabitation, divorce or widowed, § : community mental health center, family therapy or self-help group programs

for schizophrenia as subjects, along with primary caregivers, and evaluated their socio-demographic factors and clinical scales, then analyzed patient and primary caregiver factors affecting the family burden and QOL of primary caregivers.

Patient sex influenced caregiver QOL; primary caregivers of males had lower QOL scores than those caring for females. In this study, admission times of male patients with schizophrenia were bigger than that of female patients. Generally, not only has early onset in male patients traditionally been

regarded as a factor in their poor prognosis, but these patients also are generally considered to have a greater number of negative symptoms, and worse treatment outcomes.<sup>22)</sup> Therefore, caregivers supporting male patients may have lower QOL than caregivers of female patients.

The patient's age also affected caregiver QOL; it was lowest if the patient was in his/her 60s, with an increasing trend between 30 and 50, and QOL was highest among primary caregivers of patients in their 20s or younger. As the majori-

**Table 7.** Caregiver burden of variable selection by stepwise

	Parameter Estimate	Standard Error	t value	p
FBS, total score ( $R^2=0.284$ )				<0.001
Caregiver, income	-15.022	4.115	-3.650	0.001
Patient, CRDPSS (delusion)	11.365	3.347	3.395	0.001
FBS, objective burden ( $R^2=0.218$ )				<0.001
Caregiver, income	-4.768	1.734	-2.750	0.008
Patient, CRDPSS (delusion)	3.111	1.428	2.178	0.033
FBS, subjective burden ( $R^2=0.322$ )				<0.001
Caregiver, income	-10.348	2.709	-3.820	<0.001
Patient, CRDPSS (delusion)	8.916	2.297	3.882	<0.001
Caregiver, sex (female)	2.127	0.979	2.174	0.033

FBS : Family Burden Scale, CRDPSS : DSM-5 Clinician-Rated Dimensions of Psychosis Symptom Severity

**Table 8.** Caregiver quality of life of variable selection by stepwise

	Parameter Estimate	Standard Error	t value	p
Average QOL score ( $R^2=0.515$ )				<0.001
Caregiver, income	0.203	0.093	2.181	0.033
Caregiver, education	0.322	0.112	2.870	0.006
Patient, sex (female)	0.304	0.108	2.821	0.006
Patient, treatment duration	-0.175	0.046	-3.776	<0.001
Patient, CRDPSS (disorganized speech)	-0.111	0.063	-1.756	0.008
Patient, KDAI-10 (negative)	-0.049	0.022	-2.273	0.026
Patient, K-ISMI (stigma resistance)	0.046	0.021	2.227	0.029
QOL-Physical health ( $R^2=0.508$ )				<0.001
Caregiver, education	2.478	0.953	2.599	0.012
Caregiver, sex (female)	-3.479	0.938	-3.708	<0.001
Patient, sex (female)	4.150	0.936	4.433	<0.001
Patient, treatment duration	-1.532	0.412	-3.718	<0.001
Patient, KDAI-10 (negative)	-0.555	0.182	-3.046	0.003
Patient, K-ISMI (stigma resistance)	0.496	0.177	2.804	0.007
QOL-Psychological ( $R^2=0.178$ )				<0.001
Caregiver, income	2.591	0.661	3.921	<0.001
QOL-Social relationships ( $R^2=0.276$ )				<0.001
Patient, diagnosis duration	-0.768	0.241	-3.189	0.002
Patient, CRDPSS (disorganized speech)	-0.649	0.313	-2.075	0.042
Patient, KDAI-10 (negative)	-0.308	0.104	-2.959	0.004
QOL-Environmental ( $R^2=0.352$ )				<0.001
Caregiver, education	3.896	0.977	3.987	<0.001
Patient, treatment duration	-1.865	0.440	-4.237	<0.001
Patient, K-SUMD (positive symptom awareness)	-0.668	0.224	-2.983	0.004

CRDPSS : DSM-5 Clinician-Rated Dimensions of Psychosis Symptom Severity, KDAI-10 : Korean version of Drug Attitude Inventory-10, K-ISMI : Korean version of Internalized stigma of mental illness scale, K-SUMD : Scale to Assess Unawareness of Mental disorder-short form

ty of primary caregivers were parents, they may be elderly themselves, with a loss of economic capability or diminished satisfaction with their own health, and may thereby have an overall lower view of their QOL. By contrast, most parents of patients in their 20s or younger enjoy vigorous social activity and maintain good physical health, and thus may have a rela-

tively more satisfied attitude towards life.

The length of patient's diagnostic and treatment period influenced caregiver QOL; caregivers of patients with 6–10 year diagnostic and treatment periods had the lowest QOL scores, followed by those with  $\geq 11$  year diagnostic and treatment periods. Caregivers of patients with  $\leq 5$  year diagnosis



and treatment periods had relatively high QOL scores. The patient's diagnosis or treatment may not greatly affect caregivers for the first 5 years, however, after patients in their late 20s and 30s, experience several relapses, families become cognizant of the chronic process of schizophrenia. The QOL scores for primary caregivers would be worst at approximately 6–10 years of treatment.

Objective, subjective, and overall burden were all higher if a primary caregiver was female. Also, if the primary caregiver's educational level was high school graduate or less, the subjective burden was larger than for those with a college degree or more, congruent with the findings of Gopinath et al.<sup>23)</sup> The increase in average QOL with increased educational level is similar to trends in the general population.

Caregiver QOL score significantly differed according to caregiver age, educational level, marital status, and monthly income. In particular, QOL score was lowest among primary caregivers in their 60s or older, followed by those in their 40s, 50s, 30s, and 20s, in that order. Similar to the trend mentioned above, as the caregiver age increased, financial burden increased and physical satisfaction decreased, leading to an overall decrease in QOL.

In multivariate regression analysis, as caregiver monthly income decreased and patient delusion subscore increased, or if the caregiver was female, burden felt by the caregiver increased. However, caregiver sex correlated only with caregiver subjective burden. If the primary caregiver was female, there was a higher level of subjective burden than males, consistent with Noh et al.<sup>24)</sup> As female caregivers tend to spend more time with a patient and feel greater responsibility, the primary caregiver's feelings of stress may be perceived as subjective burden.

Caregiver monthly income may have the strongest correlation with caregiver family burden and overall QOL. As monthly income decreased, objective, subjective, and overall burden all increased, and average QOL decreased. In research presented in the United Kingdom in 1984,<sup>25)</sup> caregiver socioeconomic position was not correlated with subjective burden, but a 2000 Korean study<sup>14)</sup> showed correlation between family burden and monthly income of the primary caregiver. Under financial pressure, hospital admission may be delayed, even if the patient's symptoms become more serious, so burden is influenced by caregiver monthly income. The different results between domestic and overseas studies may arise from differences in either the social support system or the culture.

Unlike other subscores, caregiver QOL score in the psy-

chological domain was only correlated with caregiver monthly income. According to the results of a survey in 2009 conducted on the QOL of primary caregivers of patients with schizophrenia, financial burden was an important factor that influenced caregiver QOL, usually related to pharmacotherapy or costs related to treatment. This had an even greater influence in developing countries.<sup>26)</sup>

Patient factors correlated to the burden felt by caregivers include delusion subscore, congruent with the prior research.<sup>9,27)</sup> Kwang et al.<sup>27)</sup> observed a relation between positive symptoms and subjective burden felt by primary caregivers, and Woltraus et al.<sup>9)</sup> found that delusions or hallucinations had more subjective burden than other symptoms.

Sibitz et al.<sup>28)</sup> stated that as patient attitude towards overcoming stigma strengthened, patient personal satisfaction regarding QOL also increased. Additionally, as the stigma surrounding patients with schizophrenia becomes more severe, caregiver burden increases and QOL decreases<sup>3)</sup>, and thus as the attitudes of patients with schizophrenia toward overcoming stigma of mental illness improved, caregiver satisfaction regarding their QOL increases. However, there are not yet sufficient data to support a direct connection between these results.

As a peculiarity of the environment domain of QOL, as patient awareness of positive symptoms decreased, caregiver QOL environmental subscore decreased. The survey questions included "how secure do you feel in everyday life?" and as patient awareness of positive symptoms decreased, there was a greater chance that they will behave unpredictably, and thus the caregiver may feel relatively more insecure.

We noted that "the lack of community support services might exacerbate family burden"<sup>25)</sup> and investigated whether social services such as community mental health programs influenced family burden and caregiver QOL, but no correlation was observed. Previous surveys on caregiver QOL mentioned lack of social support as a major factor in decreased caregiver QOL, unlike this research.<sup>26)</sup> However, among the results of these 34 itemized surveys, only 12 inquired into experiences with social services and connection to QOL, and each study showed conflicting results.

Limitations are, first, this study was based on a single center or single country and had relatively small sample size. Also, the current sample was restricted to clinically stable outpatients visiting a university hospital with their primary caregiver. These features limit statistical power and generalizability. Second, the DSM-5 CRDPSS assessment of patient's symptoms only reflects symptoms from the past week.

In addition, depression and manic subscales were excluded, but severity of these emotional symptoms might influence family burden. Third, early stage elimination rate was high. Subject consent was obtained by patients with schizophrenia, but consent could not be obtained from 9 of 13 primary caregivers who, upon reading the survey questions, suddenly became depressed or angry. These 9 primary caregivers were all mothers of patients. However, the 9 patients associated with the primary caregivers who refused to participate did not show statistically significant differences in terms of the severity of their symptoms, and so further research is needed into what factors led primary caregivers to display such different emotional reactions. Fourth, limitation of this study include the possibility of a type I error due to multiple comparisons in ANOVA analysis of family burden score and quality of life. Furthermore, 17 patient-caregiver pairs left most questions blank or had all identical answers to survey items and so were excluded from analysis. This may have been due to a high number of self-report questions. Finally, this study didn't find the correlation between experience of community mental health program and caregiver QOL. A limitation of the present study is its cross sectional design so that frequency and period of using community mental health program were not considered.

## Conclusion

Among the factors determining caregiver QOL were those that could be corrected clinically, such as patients' clinical symptoms, including disrupted speech, negative subjective drug attitudes, and insufficient awareness of positive symptoms. Moreover, as patient attitudes toward overcoming the stigma of mental illnesses grew stronger, caregiver QOL improved as well. Subsequently, our results indicate that it may be possible to decrease the family burden of primary caregivers of patients with schizophrenia and improve QOL with a positive combination of clinical and medicinal education programs geared towards patients with schizophrenia and their caregivers.

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