

**Quality of life in patients with
schizophrenia and bipolar disorder:
comparison of self-report and
proxy assessment**

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comparison of self-report and
proxy assessment**

Directed by Professor Hyun-Sang Cho

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Eunjoo Kim

TABLE OF CONTENTS

ABSTRACT.....	1
I. INTRODUCTION.....	3
II. MATERIALS AND METHODS.....	8
1. Participants and data collection.....	8
2. Instruments.....	9
3. Data analyses.....	12
III. RESULTS	
1. Characteristics of patients and proxies.....	13
2. The comparison of patients' and proxies' ratings of QoL.....	16
3. Patient and proxy reports: Intraclass correlation coefficient.....	18
4. Inter-rater agreement by subgroup.....	20
IV. DISCUSSION.....	21
V. CONCLUSION.....	29
REFERENCES.....	31
ABSTRACT (IN KOREAN).....	38

LIST OF TABLES

Table 1. Demographic and clinical characteristics of patients and proxies....	15
Table 2. Mean scores, standard deviations and mean differences of the four WHOQOL-BREF and SF-36 in patients and proxies.....	17
Table 3. Agreement between patients' and proxies' ratings on WHOQOL and SF-36.....	19
Table 4. ICC between patients' and proxies' ratings on WHOQOL-BREF and SF-36 according to different family member subgroups.....	21

ABSTRACT

Quality of Life in Patients with Schizophrenia and Bipolar Disorder: Comparison of Self-report and Proxy Assessment

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Objective: There is little data to indicate whether patients with chronic mental illness can provide self-report Quality of life (QoL) data or if informants' reports can substitute the patients' ratings. We evaluated patient-proxy agreement in patients with schizophrenia and bipolar disorder and compared levels of agreement according to the relationship between patient-proxies.

Methods: WHOQOL-BREF and SF-36, two of the most popular quality of life instruments were administered to 82 schizophrenia-proxy and 50 bipolar disorder patient-proxy pairs.

Results: Proxies of schizophrenia patients rated patients' QoL lower than patients themselves. Agreement between patients and proxies on each subdomains of QoL in WHOQOL-BREF and SF-36 was moderate to good. Moreover, the agreement between patients' and proxies' ratings was higher

when the proxy was a mother or spouse compared to father.

Conclusions: These findings suggest that proxy rating of QoL can be used as a reasonable estimate of the patients' rating of QoL in schizophrenia and bipolar patients, especially in Korea. Knowing which domains of QoL are affected in specific psychiatric disorders can help clinicians focus on particular QoL domains during the diagnostic process and to define adequate treatment goals. Therefore, the assessment of QoL may be an important part of the diagnostic process because it can give insight into the areas of functioning in which a patient is suffering the most.

Key words: Quality of life, proxy, schizophrenia, bipolar disorder

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I. INTRODUCTION

Quality of life (QoL) is defined as a multidimensional concept that captures a person's subjective functioning and objective indicators. Subjective functioning comprises the physical, emotional, and social functioning of the individual. The objective QoL indicators include living conditions, employment or school functioning .^{1,2}

Clinical trials in psychiatric populations have traditionally used objectively rated measures such as rates of relapse, hospitalization or symptom reduction to assess patient outcome. However, in recent years the concept of outcome in psychiatry has been widened beyond those clinical measures to include quality of life since sole reliance on symptomatic outcome measures may not detect more subtle changes in well-being and functioning of the patients.³

QoL is a well-established area of study with regard to chronic diseases

(rheumatology, oncology, and nephrology). Since most psychiatric illnesses also tend to persist, improvement in the quality of everyday life should be an important treatment goal.⁴ To fine-tune interventions, more knowledge is needed regarding the impact of psychiatric diseases on different aspects of QoL. However, only recently QoL of people with severe mental disorders has received more attention from researchers, policy makers and health care staffs.

The assessment of QoL in medical setting may be of value in several ways. While the reduction of symptoms may be the primary goal of the clinician, it may be that the patient places more emphasis upon restoring family relationships, or being able to engage in leisure activities. These individualized measures, although sometimes difficult to administer and interpret, put the patient at the centre rather than at the periphery of assessing the effectiveness of treatment interventions. QoL assessments can also help determine patient preference, allow comparisons of well-being between different conditions and detect subtle differences in response to treatment that may be missed by traditional outcome measures.⁵ Under these circumstances, it was particularly encouraging to see that some of the large pharmacological trials of treatment interventions for schizophrenia or bipolar disorder are now using QoL measures as important secondary outcome measures.³

By consensus, the primary source of information should be the patient, but there are circumstances in which patients are unable to provide adequate information. In

fact, QoL can be highly subjective and open to distortion depending on who the rater is. Especially, some basic and methodological issues have been raised when assessing the QoL of individuals with psychiatric symptoms⁶⁻⁸ due to (1) the problematic validity and reliability of patients' evaluation due to affective, cognitive, and reality distortion symptoms (2) the intrinsic difficulties in assessing QoL in people suffering from these disorders (3) the low life expectations, the restricted ranges of experiences and the downward drift on which individuals with mental disorders can base their comparisons that may lead patients to rate their QoL as high (the so-called 'disability paradox')^{3,7,9} In previous investigations conducted in schizophrenia subjects, there have been some reports that neuropsychiatric symptoms affect QoL significantly or total BPRS change scores accounted for the greatest percentage of the QoL scores variance.^{10,11} On the other hand, other studies reported that there have been little evidence for a relationship between positive symptoms and QoL but negative symptoms, general pathology, and mood disturbance were all found to have demonstrated relationship to QoL.⁶

With respect to schizophrenia patients, significant correlations were found between self-rated and expert-rated QoL in patients with good insight but not in patients with poor insight. Accordingly, diminished insight may limit the usefulness of self-reports for some individuals with severe schizophrenia.¹² On the other hand, in self-reports of patients with mild-to moderate schizophrenia, symptoms are

reported to be valid and reliable.¹² There is some evidences that it is indeed feasible to collect statistically reliable quality of life data from chronic mental patients, and that subjective quality of life assessments can be applied to such patients.⁴ Nonetheless, there still remains uncertainty about the validity of patients' judgement of their well-being and about how discrepancies between patients and clinicians could best be resolved.⁴

In bipolar disorder patients, the measurement of QoL is feasible in some patients. Some researches indicated that patients with mild to moderate manic symptoms can provide reliable descriptions of their symptoms.^{13,14} But the relationship between QoL and hypo/mania is less well understood and there exists a paucity of information about the ability of patients in the hypo/manic phase of their illness to reliably and accurately complete QoL measures.^{13,14}

In these situations, the importance of comparing the patient's subjective evaluation with an 'external' evaluation provided by an external rater or proxy is stressed.¹¹ It is reported that significant others can provide information on both subjective and objective QoL indicators³ and the use of a family caregiver as a proxy respondent is a reasonable option that can minimize informative missing data, increase the sample size, and improve external validity.^{6,11}

Even though there are many published studies comparing the QoL ratings in patients with cancer, dementia, and child psychiatric population, there have been

few studies comparing the QoL rated by schizophrenia or bipolar patients and proxies. In addition, previous studies have tended to use professionals rather than patients' family members as raters of patients' QoL.¹⁵ This approach may have given undue importance to the judgment of professionals and ignored the relative meaning and importance given to such roles by the patients' caregivers.¹⁵ Proximity with the patients and having advantage of possessing similar sociocultural norms may lead family members to give a more valid assessment of QoL than clinicians.¹⁶ However, studies specifically comparing QoL evaluations in patients with schizophrenia and their proxies suggest a low correlation between patients' and proxies' evaluations, although the reasons for this discrepancy are still unclear.¹⁷ In particular, it is unknown whether this lack of agreement depends to some extent on the relationship between the patient and the proxy.¹⁸ Additionally, different studies have used different measures of quality of life and little information comparing these measures is available.

Therefore, the purpose of the current study was to clarify this issue, and specifically to compare levels of agreement between patients and proxies in a population of patients with schizophrenia and bipolar disorder, and especially whether the levels of agreement between QoL ratings of patients and proxies depend on the patient-proxy relationship.

II. MATERIALS AND METHODS

1. Participants and data collection

Patient and proxy pairs were recruited to participate in this study at three university hospitals (Severance Mental Health Hospital, Severance Hospital, Hallym Sacred Heart Hospital at Pyungchon,) and one general hospital (National Health Corporation Ilsan Hospital.). Patients were comprised of clinically stable patients, that is, outpatients and day hospital patients. Psychiatrists diagnosed patients according to the DSM-IV criteria and medical record review. Proxies were equal number of healthy relatives of the patients, who are identified among those accompanying patients to outpatient visits or the caregivers of the day hospital patients living at home with the patients. Patients with other Axis I or II disorders and serious general medical condition were excluded because of the possible confounding effects of other disorders on quality of life. In total, 132 patients (82 schizophrenia, 50 bipolar disorder patients) were enrolled.

The WHO quality of life scale abbreviated version (WHOQOL-BREF) and 36-Item Short Form Health Survey (SF-36) were completed by patients and proxies. The patients were instructed to self-rate their quality of life, and the proxies were asked to choose the answers that best described the patient's situation. Questionnaires were completed in separate rooms in the hospitals and there was no

contact between patients and caregivers while they completed the questionnaire, to eliminate the possibility for discussion between patients and caregivers, which can become a potential confounding factor. This study was approved by the Institutional Review Board of the four hospitals participating in this investigation. After a complete description of the study, written informed consent was obtained from all subjects.

2. Instruments

We selected two widely used Quality of Life instruments, WHOQOL-BREF and SF-36 because these two scales measure different concepts of QoL, even though they measure similar ‘generic’ quality of life (as opposed to ‘disease-specific’ quality of life). Whereas WHOQOL-BREF is a more broad and general conceptualization of QoL, defining QoL as ‘individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’,¹⁹ SF-36 mainly deals with ‘Health-related quality of life (HRQoL)’, those aspects of an individual’s life that impact directly upon their health and the more economically-derived cost utility models of QoL.²⁰ HRQoL is a more specific and narrower concept than WHO definition, relating to the impact of physical and mental disorders and disability on the general well-being of a person.⁴ Since many studies reported

different results due to the difference of QoL instruments they incorporated, the use of two QoL scales with different characteristics may provide more objective picture of patients' QoL, compensating for the limitation of each scale.

QOL-proxy version of WHOQOL-BREF and SF-36 was basically the same as the version administered to each patient, making it easy to compare the responses of proxies to those of patients.

1) World Health Organization Quality of Life Scale

WHOQOL-BREF was developed by the WHOQOL for assessing a wide spectrum of psychological and physical disorders. It is a self-report instrument in the framework of a large international project: a generic multilingual and multidimensional instrument for cross cultural use and is patient-centered. This is a self-administered scale consisting of 26 questions scored in four domains.

(1) physical health, (2) psychological domain, (3) social relationships and (4) Environment. The physical domain has questions related to daily activities, treatment compliance, pain and discomfort, sleep and rest, energy and fatigue. The psychological domain assessed positive and negative feelings, self-esteem, body image and physical appearance, personal beliefs, and attention. The social relationship domain covers personal relationships, social support, and sexual activity. The environmental domain explores physical security, financial resource, health and social care and their availability, opportunities for acquiring new

information and skills, and participation in and opportunities for recreation and transport. All items are rated on a 5-point Likert-type scale. The WHOQOL-BREF is considered reliable, valid and sensitive to changes and it takes only 10-15 minutes to administer.²¹ Recent study on the reliability and clinical sensitivity of the WHOQOL in schizophrenic patients reported a good internal consistency with a Cronbach's α for the total scale of 0.94 and coefficients for the six domains and general quality of life ranging from 0.67 (social domain) to 0.87 (psychological domain).²² In this study, we used Korean version of WHOQOL-BREF and it showed high internal consistency.²³ (Cronbach's α 0.89)

2) 36-Item Short Form Health Survey (SF-36)

The Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) is a well-established, widely used, generic quality of life instrument developed in 1992.²⁴ It consists of 36 items grouped into the following eight scales: physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health. The score of each dimension (dimension score) is calculated and these 36 items are grouped and summarized into two broad 'summary scores' like physical composite score and mental composite score. It is a self-rated instrument, which can be completed in approximately 15 min. Scores range from 0 to 100, with higher values indicating higher quality of life. Since it was not specifically developed for schizophrenic patients, its reliability and validity in mentally ill

patients is investigated in some studies.²⁴ The eight scales demonstrated good reliability ($\alpha > 0.70$); Cronbach's α ranged from 0.71 (general health) to 0.89 (physical functioning and bodily pain). Korean version of SF-36 showed a good internal consistency with a Cronbach's α ranging from 0.60 to 0.90 in each eight domains.^{25,26} Given the breadth of existing data for the SF-36 in bipolar populations, the scales' acceptable psychometric properties and detailed normative data, this scale is recommended for the measurement of health related QoL in patients with schizophrenia and bipolar disorder.^{3,27}

3) Measuring symptoms and severity of illness

Patients' psychiatric illness severity was rated by the treating psychiatrist using Brief Psychiatric Rating Scale (BPRS), Clinical Global Impression-Severity (CGI-S) in patients with schizophrenia, and bipolar patients were rated using Young Mania Rating Scale (YMRS), Hamilton Rating Scale for Depression (HAM-D) and CGI-S.

3. Data analyses

Descriptive statistics were collected for patients' and proxies' demographic characteristics and we performed independent t-test and chi-square test to compare variables of schizophrenia and bipolar disorder patients. Differences in QoL area scores between patients and proxies were examined, and paired sample t-tests were

used to compare these differences.

An intraclass correlation coefficient (ICC) was calculated to estimate inter-rater reliability of patient and proxy responses to the WHOQOL-BREF subscale scores, the SF-36 total scores, and scores on each of the 8 domains. ICCs are analysis of variance-based estimates that compare true variance and total variance.²⁸ ICC values and their respective confidence intervals were obtained using ICC two way mixed model. Standards for interpreting ICC values are arbitrary, but there are published precedents.²⁹ The standards we used were: ICCs greater than 0.80 were classified as excellent agreement; good agreement was from 0.61 to 0.80; moderate agreement was from 0.41-0.60, and poor agreement was 0.40 or less. To delineate how the relationship of patient-proxy pair affects the rate of agreement in QoL ratings, we calculated ICCs based on the relationship between the patients and proxies. All statistical analyses were conducted with SPSS 13.0 (Chicago, IL, USA). All p values are two-tailed, and statistical significance was set at $\alpha=0.05$.

III. RESULTS

1. Characteristics of patients and proxies

A total of 132 patient-proxy pairs (82 schizophrenia, 50 bipolar disorder) participated in this study. Some participants did not respond to every item in the questionnaire packet. Therefore, as table 1 indicates, the sample size for study

measure varies slightly. The demographic and clinical characteristics of the patient and proxy participants are reported in Table 1. Independent t-test for continuous variables and chi-square test for categorical variables revealed that the demographic variables of schizophrenia and bipolar patient groups are not significantly different from each other, except marital status; more bipolar patients were in married state than were schizophrenia patients.

According to the results from independent t-test and chi-square test, the two proxy groups were not significantly different in most of the measured variables. However, in regard to the relationship with the patient, there existed a statistically significant difference between these two groups. Since more bipolar patients were married, 32.7% of the proxies were spouses in bipolar disorder groups, compared to the 9.8% of schizophrenia groups. In 52.4% of schizophrenia group and 42.9% of bipolar disorder groups, the proxies were the patients' mothers. Most proxies lived together with the patients, and possess the decision making capacity on the patient's treatment.

With respect to clinical characteristics, the mean BPRS scores for schizophrenia patients corresponded to the mild degree of severity (38.56 ± 9.73) of symptoms. HAM-D and YMRS ratings showed that the bipolar patients participated in this study were clinically stable euthymic patients. CGI ratings shows that schizophrenia patients (3.35 ± 1.10) were rated by psychiatrists to have more severe

symptoms than bipolar patients (1.80 ± 0.84).

Table1: Demographic and Clinical Characteristics of Patients and their proxies

variable	Schizophrenia (N=82)	Bipolar disorder (N=50)	Proxy: Schizophrenia (N=82)	Proxy: bipolar disorder (N=50)
Gender				
Male	36 (43.9)	21 (42.9)	28 (34.1)	19 (38.8)
Female	46 (55.4)	28 (57.1)	52 (63.4)	29 (59.2)
Age	32.16(9.97)	33.71 (3.40)	51.04 (SD 12.17)	47.16 (SD 10.92)
Education level				
Elementary school	2 (2.4)	3 (6.1)	6 (7.3)	5 (10.2)
Middle school	4 (4.8)	1 (2.0)	11 (13.4)	4 (8.2)
High school	40(48.2)	16 (32.7)	19 (23.2)	18 (36.7)
University	27 (32.5)	23 (47.0)	37 (45.2)	15 (30.6)
Graduate school	3 (3.6)	4 (8.2)	4 (4.9)	4 (8.2)
Marital status				
Single	64 (77.1)	25 (51.0)	6 (7.3)	2 (4.1)
Married	10 (12.0)	19 (38.8)	52 (63.4)	39 (79.6)
Divorced	1 (1.2)	1 (2.1)	2 (2.9)	1 (2.0)
Others	3 (3.6)	3 (4.1)	11 (13.3)	4 (8.1)
BPRS	38.56 (9.73)			
YMRS /HAM-D		2.80/5.82		
CGI	3.35 (1.10)	1.80 (0.84)		
Working status				
Employed			41 (50.0)	20 (40.8)
Unemployed			31 (37.8)	22 (44.9)
Relationship with the patient				
Father/mother			14(17.1)/43(52.4)	8(16.3)/21(42.9)
Spouse			8 (9.8)	16 (32.7)
Siblings			9 (11.0)	1(2.0)
Son/ daughter			4(4.9)/1(1.2)	1 (2.0)/1(2.0)
Cohabitant				
Yes			72 (87.8)	42 (85.7)
No			6 (7.3)	4 (8.2)
Tx. Decision making				
Yes			58 (70.7)	43 (87.8)
No			12 (15.0)	1 (2.0)

Mean±S.D.; BPRS, Brief Psychiatric Rating Scale; YMRS, Young Mania Rating Scale; HAMD, Hamilton Depression Rating Scale; CGI, Clinical Global Improvement

2. The comparison between patients' and proxies' ratings of QoL

Proxies' vs. patients' differences in mean scores for the four subscales of the WHOQOL-BREF are shown in Table 2. On average, proxies of the schizophrenia patients tended to rate patients' psychological ($t = 1.86$, $p = 0.06$) and social relationships areas ($t=1.72$, $p=0.09$) of QoL as poorer than patients did. On the other hand, proxies' ratings on physical and environmental area were very similar to patients' ratings. In contrast to the results from schizophrenia patient-caregiver pairs, no statistically significant differences were found on the ratings of bipolar patient-caregiver pairs in all the four areas of WHOQOL-BREF.

Table 2 also demonstrates proxies' vs patients' differences in mean scores for eight dimension scores and two summary scores of SF-36. No statistically significant differences were found on the ratings of schizophrenia patient-caregiver pairs in the ratings of SF-36. However, proxies of the bipolar disorder patients tended to rate patients' physical function ($t=2.79$, $p=0.01$) and physical composite score significantly lower than patients did ($t=2.03$, $p=0.05$). In contrast, proxies' ratings on mental composite score and other dimension scores were not significantly different from those of patients.

Table2. Mean scores, standard deviations and mean differences of the four WHOQOL-BREF areas and SF-36 scores in patients with schizophrenia,, bipolar disorder and their proxies.

	Schizophrenia				Bipolar disorder				
	Patient mean (SD)	Proxy mean (SD)	t	p	Patient mean (SD)	Proxy mean (SD)	t	p	
WHOQOL-BREF									
Physical	53.80 (16.72)	51.88 (15.10)	0.76	0.45	60.30 (16.77)	55.83 (15.70)	1.37	0.18	
Psychological	48.13 (18.24)	42.99 (16.69)	1.86	0.06	55.67 (17.00)	52.38 (16.04)	0.99	0.33	
Social	47.89 (17.40)	43.43 (14.81)	1.72	0.09	55.33 (15.13)	50.95 (15.83)	1.40	0.17	
Environmental	49.62 (17.58)	49.33 (16.76)	0.11	0.91	56.46 (16.90)	53.89 (11.82)	0.88	0.38	
SF-36									
Dimension scores									
Physical function	78.73 (24.71)	78.94 (31.80)	-1.34	0.18	89.49 (11.23)	82.05 (17.27)	2.79	0.01	
Role physical	52.82 (4.45)	49.30 (40.08)	0.67	0.50	68.42 (34.72)	66.45 (36.43)	0.35	0.73	
Bodily pain	72.08 (2.68)	70.93 (22.10)	0.40	0.69	79.46 (21.64)	77.67 (19.33)	0.69	0.49	
General Health	55.41 (20.02)	55.77 (19.15)	-0.13	0.90	61.72 (19.15)	58.51 (18.47)	0.94	0.35	
Mental Health	61.01 (19.24)	61.52 (18.80)	-0.21	0.83	68.10 (20.32)	67.28 (17.88)	0.25	0.80	
Role emotional	56.06 (39.04)	52.22 (5.18)	0.65	0.52	67.55 (38.40)	68.45 (40.99)	-0.14	0.89	
Social function	69.44 (22.39)	67.19 (23.78)	0.68	0.50	76.60 (25.52)	76.60 (23.15)	0.00	1.00	
Vitality	49.79 (19.53)	48.68 (20.02)	0.39	0.70	59.21 (20.52)	53.95 (15.73)	1.32	0.50	
Summary scores									
Physical	60.31 (18.01)	60.64 (18.33)	0.14	0.89	71.61 (15.42)	67.26 (14.69)	2.03	0.05	
Mental	58.28 (18.27)	57.05 (19.35)	0.46	0.65	70.12 (28.48)	64.55 (17.33)	1.40	0.17	

3. Patient and Proxy Reports: Intraclass Correlation Coefficients (ICC)

Inter-rater agreement between patients' and proxies' scores was evaluated by calculating ICCs. Table 3 reports ICC values and corresponding confidence intervals for four subscales of WHO-QOL BREF and eight dimension scores and two summary scores of SF-36.

In schizophrenia group, the ICC agreement between patients' and proxies' scores ranged between 0.44 for the physical area and 0.67 for environmental area in WHOQOL-BREF. In SF-36 ratings, ICCs were 0.55 for mental composite score, 0.61 for physical composite score. For both of QoL scales, ICC values above 0.60 were obtained, suggesting good agreement between patient and proxy reports for psychological and environmental subscale of WHOQOL-BREF and physical composite score of SF 36. In other subscales, ICCs above 0.4 were obtained, suggesting that at least moderate degree of agreement exists between patients' and proxies' reports for physical and social subscales of WHOQOL-BREF and mental composite score of SF-36.

In bipolar disorder group, ICCs in WHOQOL-BREF subscales ranged between 0.43 for psychological area and 0.69 for social relationship domain. In SF 36 ratings, ICCs were 0.58 for mental composite score, 0.75 for physical composite score. Similar to the result from schizophrenia patient group, at least moderate degree of agreement existed between patients' and proxies' reports in both

WHOQOL-BREF and SF-36.

Table 3. Agreement (ICC) between patients' and proxies' ratings on WHOQOL and SF-36.

	Schizophrenia			Bipolar disorder		
	ICC	Confidence interval	P-value	ICC	Confidence Interval	P-value
WHO-QOL BREF						
Physical	0.44	0.13-0.64	0.005	0.56	0.19-0.76	0.004
Psychological	0.61	0.40-0.75	0.001	0.43	-0.04-0.69	0.034
Social	0.47	0.16-0.67	0.004	0.69	0.65-0.90	< 0.001
Environmental	0.67	0.49-0.79	0.001	0.62	0.10-0.75	0.001
SF-36						
Dimension score						
Physical function	0.51	0.21-0.69	0.002	0.51	0.23-0.79	0.01
Role physical	0.52	0.34-0.74	0.001	0.69	0.31-0.81	< 0.001
Bodily pain	0.59	0.20-0.59	0.001	0.81	0.67-0.91	< 0.001
General health	0.45	0.12-0.66	0.007	0.53	-0.58-0.57	0.011
Mental health	0.61	0.37-0.76	0.001	0.59	0.21-0.78	0.003
Role emotional	0.51	0.21-0.69	0.002	0.64	0.48-0.86	< 0.001
Social function	0.42	0.08-0.64	0.011	0.83	0.67-0.91	< 0.001
Vitality	0.40	0.04-0.63	0.016	0.18	-0.58-0.57	0.28
Summary score						
Physical composite	0.61	0.38-0.76	0.001	0.75	0.53-0.87	0.19
Mental composite	0.55	0.28-0.72	0.001	0.58	0.21-0.78	0.41

ICC: Intraclass correlation coefficient

4. Inter-rater Agreement by Subgroup

The study population was divided into subgroups based on whether their proxies were mother, father, and spouses, and ICCs were calculated separately by subgroup. The results are shown in Table 4. Examination of the agreement between patient and proxy pairs grouped by the proxy category did not reveal definite patterns, but in general, mother (WHOQOL 0.06-0.70, SF-36 0.52-0.59) and spouses (WHOQOL 0.45-0.75, SF 36 physical 0.62) tended to show more agreement compared to that of patient-father pairs (WHOQOL 0.03-0.43, SF-36 0.32-0.33) in schizophrenia groups. In bipolar groups, mothers tended to demonstrate more agreement compared to other proxies. This result means that mothers and spouses of schizophrenia patients, and mothers of bipolar disorder patients can provide more reliable estimates of the patient's QoL ratings in WHOQOL-BREF and SF-36 than other proxies.

Table 4: ICC between patients' and proxies' ratings on WHOQOL-BREF and SF-36 according to different family member subgroups

	Schizophrenia : ICC (p-value)			Bipolar disorder: ICC (p-value)		
	Father (N=14)	Mother (N=43)	Spouse (N=8)	Father (N=8)	Mother (N=21)	Spouse (N=16)
WHOQOL-BREF						
Physical	0.16 (0.38)	0.06 (0.43)	0.45 (0.23)	0.84 (0.02)	0.44 (0.11)	0.64 (0.04)
Psychological	0.43 (0.51)	0.66 (0.001)	0.61 (0.12)	0.06 (0.52)	0.51 (0.07)	0.31 (0.26)
Social	0.30 (0.28)	0.40 (0.07)	0.73 (0.05)	0.71 (0.07)	0.82 (0.01)	0.33 (0.24)
environmental	0.03 (0.48)	0.70 (<0.001)	0.75 (0.06)	0.21 (0.59)	0.67 (0.01)	0.41 (0.18)
SF-36 summary scores						
Physical	0.33 (0.26)	0.59 (0.005)	0.62 (0.08)	0.68 (0.19)	0.82 (<0.001)	0.59 (0.08)
Mental	0.32 (0.67)	0.52 (0.02)	0.16 (0.40)	0.23 (0.41)	0.67 (0.01)	0.46 (0.16)

IV. DISCUSSION

The present study compared proxies' and patients' reports of quality of life using WHOQOL-BREF and SF-36. Even though a few studies comparing patients' and proxies' ratings in a sample of schizophrenia have been published, to our knowledge, this is the first study conducted on a sample of bipolar disorder patients that examined patient-proxy agreement of QoL ratings. Although this study has its own methodological limitation, it has demonstrated findings that could be of general

interest.

In terms of disease severity, schizophrenia patients included in this study were rated to have ‘mild to moderate’ degree of psychopathology in clinical ratings conducted by psychiatrists using the BPRS and CGI. The bipolar patients, on average, were rated to be ‘euthymic’ using YMRS, HAMD, and CGI, demonstrating that they did not show any clinically significant mood symptoms. Therefore, in line with the findings from other studies, the participants in the present study is considered to be able to report their quality of life reliably and adequately.^{9,10,11} However, many researchers recommend that patient’s ratings are to be interpreted with caution since there have been evidences that even subclinical and mild cognitive and affective symptoms can affect their judgement to a considerable degree.^{3,27}

1. The comparison of patients’ and proxies’ ratings of QoL

Our study indicates that proxies’ ratings tended to be lower than patients’ ratings in psychological and social areas of WHOQOL-BREF in schizophrenia ($p=0.06$), whereas two summary scores of SF-36 did not reveal significant difference between patients’ and proxies’ ratings. By contrast, the QoL ratings of proxies were similar to that of patients in bipolar disorder sample in WHOQOL-BREF. However, the

physical function subscale and the physical composite score of SF-36 showed that bipolar patients rated their physical well-being higher than their proxy counterparts.

Although our finding reached just a trend level of statistical significance, our result with schizophrenia patients is in line with the findings from studies conducted previously, which reported that caregivers provided a more negative evaluation of patients' QoL.^{17,30,31} There are several reasons why self and proxy reports of QoL in schizophrenia group might differ. The first reason may be the patients' lack of insight into their symptoms and limitations. Since this study did not measure insight level of participants, we were not able to delineate the association between QoL and insight in our schizophrenia patients. However, there have been many evidences that insight into their illness affects QoL ratings.^{32,33} Patients with greater insight into illness reported significantly lower QoL compared to patients with poor insight.³² On the other hand, other studies found that good insight into having a mental illness significantly related with better social functioning and expert-rated QoL,^{33,34} and therefore, the relationship between insight and QoL is not clearly clarified issue, yet. Second, the QoL rating is affected by the perceived stress by caregivers.^{35,36,37} Researches have been conducted on the extent of caregiver stress for patients suffering from schizophrenia or bipolar disorder.^{38,39,40} According to the results from these studies, the depressive symptoms are commonly reported up to 40% of caregivers of people with mental illness and

informant depression may distort their perceptions of patients' QoL.⁴¹ It is also possible that informants with greater depressive symptoms have more difficult caregiving or life circumstance, which may also be detrimental to the patients' QoL. In addition, caregivers may underestimate patients' QoL, possibly influenced by the stigma of mental disorder.⁴¹ Due to these caregiver factors, even some studies suggested that non-family members were better proxies because they more closely reflected the patients' opinion, except for assessment of clearly observable dimensions.⁴² Further research is needed to determine if depressive symptoms bias informant reports or are merely correlated with patient QoL due to the presence of a third factor. Third, the evaluation standards for QoL might differ between informants and participants. While going through chronic mental illness, compensatory mechanism may involve changing the relative importance of life goals to emphasize goals over which more control can be exerted. This may relate to an adaptive mechanism whereby the patients progressively adjust their perspective over time to tolerate a less than ideal situation.^{9,43} There is general evidence to support the phenomena of accommodation of evaluation standards in mental disorder patients.^{15,34}

This study also attempted to clarify whether the levels of agreement between QoL ratings of patients and proxies depend on the patient-proxy relationship (Table 4). Our finding revealed higher agreement in mother/spouse-patient pairs than in

father-patient pairs in schizophrenia patient groups, and in mother-patient pairs in bipolar disorder groups. These results are also in line with other studies conducted in non-psychiatric clinical samples.¹⁶ Significant others living in the proximity of patients seem to be more accurate assessors of patients' QoL. In Korean culture, mother and spouses tend to be a primary caregiver of the patients than fathers do.

In contrast to the results from schizophrenia patient-caregiver pairs, no statistically significant differences were found on the ratings of bipolar patient-proxy pairs in all the four areas of WHOQOL-BREF. In SF-36, proxies tended to rate patients' physical function ($t=2.79$, $p=0.01$) and physical composite score significantly lower than patients did ($t=2.03$, $p=0.05$). In contrast, proxies' ratings on mental composite score and other seven dimension scores were not significantly different from those of patients. The reason that our study revealed better agreement in WHOQOL-BREF in bipolar patients compared to patients with schizophrenia seems to be that the disease severity of the bipolar patients in this study is milder than that of patients with schizophrenia. In current study, the clinical ratings of patients' symptoms show that two groups are significantly different in CGI ratings (bipolar disorder 1.80), and mostly euthymic patients are included in bipolar disorder group, compared to patients with schizophrenia suffering from moderate degree of psychotic symptoms (CGI 3.36). Euthymic patients are likely to be less prone to the effects of mood symptoms or cognitive distortion than are

symptomatic patients. Manic subjects may overestimate their life satisfaction driven by subjective feelings of euphoria and excitement while inner feelings of worthlessness and pessimism might influence bipolar depressives to underestimate their aspects of QoL.^{8,13,42} Actually, the QoL studies with bipolar disorder patients were mainly conducted in euthymic outpatients so far to ensure the validity of their QoL ratings, and there exists a paucity of information about the ability of patients in the hypo/manic phase of their illness to reliably and accurately complete QoL measures.¹¹ However, some reports argue that even euthymic patients are not necessarily asymptomatic as many have mild sub-syndromal symptoms and several studies demonstrated that even residual depressive symptoms can be strongly associated with impaired QoL.¹³ Further study is needed to see the impact of mood state on the patient's ratings of QoL.

2. Patient and Proxy Reports: Intraclass Correlation Coefficients (ICC)

We found moderate to good agreement (ICC ranges 0.4-0.8) between patients' and proxies' QoL ratings in both WHOQOL-BREF and SF-36. That is, the agreement between patients with chronic mental disorders and proxy caregivers was within acceptable range. Substantial studies suggest that patient and proxy reports do not always agree.^{8,9,11,15} Patient-proxy agreement depends upon the type of HRQOL construct examined and the study confirms that agreement is higher for

physically based observable dimensions of health status such as self-care and ambulation than for less observable dimensions such as emotion and mental health.⁴³ Our result is a rather contradictory finding of the QoL study in the area of psychiatric disorders,^{15, 44, 45} although few studies have found close agreement.²⁷ In other words, the result of our study shows much greater agreement between patients' and proxies' ratings than those of other studies. Other study reported that the agreement between patients and proxies in QOL assessment in schizophrenia is modest, ICC ranging from 0.29 (psychological area) to 0.41 (physical area) compared to the range of our study (0.44 for physical area and 0.67 for environmental area). In bipolar disorder patients, ICC values above 0.60 were obtained for both the scales, suggesting good agreement between patient and proxy reports for psychological and environmental subscale of WHOQOL-BREF and physical composite score of SF 36. In other subscales, ICCs above 0.4 were obtained, suggesting that at least moderate degree of agreement exist between patients' and proxies' reports for physical and social subscales of WHOQOL-BREF and mental composite score of SF-36.

This finding seems to be interpreted in the context of the family culture in Korea. Compared to the West, where the independence of the each individual is highly valued and social security system provide more adequate care of the patients, a considerable amount of social support is still provided to the patients by their parents,

siblings or other family members in Korea. Actually, the percentage of proxies who cohabited with the patients are much higher than that of other Western countries where half of the caregiver were family members and the other half were nurse or social workers.¹⁵ Due to the proximity and more close family contact with patients and their caregivers, there is much greater knowledge of patients' problems than might exist in the western culture. Therefore, the degree of agreement between patients and proxies are higher in the present study. In the studies conducted in India, where the multigenerational family members cohabited at the same place, the agreement rate of QoL score was also higher than that of the Western countries.²⁷ Consequently, this study shows that cultural context may play an important role in the agreement of patient-proxy rating of QoL. With SF-36, the correlation between patient-proxy ratings was still moderately and substantially good ranging from 0.55 to 0.61. Our finding suggests that relatives can be used as a form of proxy rating in studying QoL in mild to moderate degree of chronic mental illness such as schizophrenia and bipolar disorder, especially in Korea.

Limitation

There are several limitations of this study. First, methodological shortcomings included small sample sizes and cross-sectional design. The selection of subjects is also a limitation as patients attending hospital outpatient departments or day

hospital are not likely to be representative of the patient population as a whole. More work is needed to see whether the findings of this study can be confirmed in a more representative sample of schizophrenia or bipolar patients, including inpatient samples. Besides, other factors, which were not measured in the present study, may influence the patients' QoL, such as current medication or medication side effects, length of illness, depressive symptomatology and measure of insight.¹¹ In addition, past studies demonstrated that the main differences in QoL depend on extra-psychiatric variables, principally marital status and income.⁴⁶ The above factors are reported to play complex interactions to affect the patients' quality of life.⁶ Furthermore, since the WHOQOL-BREF and SF-36 are generic QoL instruments, they do not assess specific aspects relevant to the subjective experience of patients with schizophrenia and bipolar disorder.

V. CONCLUSION

These findings suggest that proxy rating of QoL can be used as a reasonable estimate of the patients' rating of QoL in schizophrenia and bipolar patients, especially in Korea. As clinicians rely heavily on patients' subjective ratings of symptoms, we used patients' judgments of their quality of life as our standard against which to compare the proxies' judgment, given that their symptom level and functioning were sufficiently good to allow a reliable assessment. Knowing which

domains of QoL are affected in specific psychiatric disorders can help clinicians focus on particular QoL domains during the diagnostic process and to define adequate treatment goals. Therefore, the assessment of QoL may be an important part of the diagnostic process because it can give insight into the areas of functioning in which a patient is suffering the most.¹¹

Future investigators should carefully consider gathering QoL information from both informants and patients because they provide unique information regarding patient QoL and, to date, neither source of information has been established to be superior. These results suggest that a multi-rater assessment is desirable in QoL measurement in patients with psychiatric disorders.

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ABSTRACT (IN KOREAN)

정신분열병과 양극성 장애 환자의 삶의 질: 환자와 보호자
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연구목적: 최근 의학에서 삶의 질 향상은 중요한 치료 목표이자 지표로 간주되고 있다. 그러나, 여러 가지 정신병리로 인해 환자의 삶의 질에 대한 자기보고의 신뢰도에 대한 논란이 있어 왔으며, 따라서 삶의 질 측정을 위해 보호자로부터 얻는 정보가 매우 중요해지고 있다. 이 연구에서는 정신분열병, 양극성 장애 환자와 그 보호자들의 삶의 질에 대한 평가가 얼마나 일치하는지를 알아보고자 하였다.

연구방법: 82명의 정신분열병, 50명의 양극성 장애 외래 환자와 그 보호자를 대상으로 World Health Organization Quality of Life (WHOQOL-BREF), 36-Item Short Form Health Survey (SF 36 척

도)를 사용하여 삶의 질을 평가하였다. 환자 보호자간 평가 신뢰도 (interrater reliability)를 알아보기 위하여 Intraclass Correlation Coefficient (ICC)를 사용하여 분석하였다

연구결과: 양극성 장애 환자가 정신분열병 환자보다 삶의 질을 유의미하게 높이 평가하였다. 정신분열병 환자 보호자의 경우 삶의 질을 환자 본인보다 낮게 평가하는 경향성이 있었으나, 양극성 장애 환자, 보호자의 경우 삶의 질 평가에는 유의미한 차이가 없었다. 정신분열병환자의 경우, WHO QOL의 4가지 영역 (ICC=0.44-0.67) 과 SF 36 (ICC=0.55-0.64) 모두에서 환자와 보호자의 평가는 중등도(moderate) 내지 상당한 (substantial) 일치도를 보였다. 양극성 장애 환자에서는 두 스케일 모두에서 중등도 내지 상당한 정도의 일치도를 보였다.

결론: 서구에서 행해진 유사 연구와는 대조적으로, 본 연구에서는 정신분열병 및 양극성 장애 환자와 보호자의 삶의 질 평가가 상당한 일치도를 보였으며, 이는 국내에서는 보호자의 삶의 질 평가를 통해 환자의 삶의 질에 대한 신뢰성 있는 정보를 얻을 수 있음을 시사한다.

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핵심되는 말: 삶의 질, 보호자 평가, 정신분열병, 양극성장애