Original Article

Quality of Life and Explanatory Models of Illness in Patients with Schizophrenia

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ABSTRACT

Background: Patients with schizophrenia hold a variety of explanatory models of illness that influence different aspects of their life including their understanding of the disease, ability to cope and sense of well-being. **Aim:** To study the association of explanatory models and quality of life in patients with schizophrenia. **Materials and Methods:** One hundred and thirty consecutive patients with schizophrenia attending a psychiatric outpatient clinic were recruited in the study and administered the Positive and Negative Symptom Scale (PANSS), the modified Short Explanatory Model Interview (SEMI) and the World Health Organization Quality of Life-BREF (WHOQOL-BREF) Scale to assess severity of psychosis, explanatory models of illness, and quality of life. Sociodemographic and clinical details of patients were also recorded. Standard bivariate and multivariable statistics were employed. **Results:** Higher quality of life scores were associated with better socioeconomic conditions and lower scores on negative and general psychopathology subscales of PANSS. Quality-of-life scores were significantly higher in patients who did not perceive their illness to have negative effects on the different domains of their functioning. **Conclusion:** Explanatory models of illness are associated with perceived quality of life in patients with schizophrenia. There is a need to focus on attitudes, perceptions and functioning, rather than symptom reduction alone, to enhance the quality of life in schizophrenia.

Key words: *Explanatory model of illness, mental illness, quality of life, schizophrenia, short explanatory model of illness*

INTRODUCTION

Schizophrenia is often chronic and disabling. The impact of the illness and its treatment on the socio-occupational and interpersonal domains of life, as well as the stigma it carries, can significantly influence the individual's sense of well-being. Quality of life (QOL) has been defined as 'the individual's perception about his or her own position in life within the context of the culture and system of values in which the individual lives, as well as their own aims, expectations, standards and interests'.[1] Debate exists regarding whether QOL should be an objective measurement that assesses concrete and quantifiable aspects such as housing and frequency of social interactions,[2] or whether it should only focus on the patient's subjective feelings and reports of satisfaction.[3] This uncertainty is evident in the variety of instruments that are available for the

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assessment of QOL. It is now recognized that QOL is a multidimensional concept that should encompass both objective and subjective measures.[4] Studies on QOL in patients with schizophrenia in comparison with healthy subjects, patients with chronic physical illness and patients with other psychiatric syndromes have generally, though not universally, demonstrated a lower score on different aspects of functioning.[5,6] QOL in patients with schizophrenia is reported to be influenced by neurobiological, psychological, illness-related and sociodemographic factors.[7–10] Though research has been characterized by different definitions of QOL as well as different assessment tools,[11] factors that have been found to influence QOL in these patients include age, gender, marital status, level of education, chronicity of illness, levels of psychopathology, personality characteristics, insight as well as intervention strategies and supports available.[2,12]

Explanatory models (EMs), defined by Kleinman[13] as the notions about an episode of sickness and its treatment, are known to influence many aspects of the patient's life. The patient may simultaneously hold many and sometimes contradictory beliefs which are not fixed, and are influenced by factors such as culture, personality and response to treatment interventions.[14] The elicitation of EMs in clinical practice allows the clinician to have a better understanding of the patient's perspective regarding the illness, their fears and expectations from treatment. EMs regarding illness determine the patient's help-seeking behavior; they also allow individuals to make sense of their experiences and serve as a coping strategy.[15–18] The authors of this study attempted to assess the individual's EMs of illness and the association of these with the patient's perceived QOL.

MATERIALS AND METHODS

Study design and setting

The study employed a cross-sectional design. Patients were recruited from the outpatient clinic at the Department of Psychiatry, over a period of 12 months. This facility is a 122-bed tertiary care center which caters to about 500 outpatients a day and employs a multidisciplinary approach to treatment to manage a variety of mental and behavioral disorders in adults and children.

Sample

Consecutive patients attending the follow-up outpatient clinic who satisfied International Classification of Diseases-10 (ICD-10) diagnostic criteria for research diagnosis of schizophrenia[19] were screened for possible recruitment to the study. Subjects in remission (defined as PANSS items P1, P2, P3, N1, N4, N6, G5

and G9 ≤3),[20] above the age of 18 years and who spoke Tamil, were eligible to take part. Those with severe language, hearing or cognitive impairment were excluded, as were those with a primary mood disorder, substance use disorder or organic disorder. The details of the study were explained and written informed consent was obtained. The institutional review board and ethics committee approved the study protocol. Following recruitment, participants were interviewed at a single point in time. All patients received treatment as usual.

Assessment

The following instruments were used for assessment:

The Positive and Negative Syndrome Scale (PANSS)[21] is a standard scale to assess psychopathology. It consists of subscales to evaluate positive and negative symptoms and general psychopathology in psychosis. It is a scale that is widely used world over, as well as in India. Its concurrent and predictive validity and sensitivity to change have been established.

The Short Explanatory Model Interview (SEMI)[22] was used to explore the patient's perspectives regarding the nature of the illness, its perceived causes, help-seeking and the impact of sickness.[13]The tool is semi-structured with open-ended questions to encourage subjects to express themselves freely, and probes to explore the details. The SEMI is a simple and brief instrument with well-established face and content validity. It has been translated into many different languages and used among people of different cultures. It has also been used to elicit perspectives among Indian populations. The Tamil version was used in this study.[14,23]

World Health Organization Quality of Life-BREF (WHOQOL-BREF)[24] was used to assess the QOL. It comprises 26 items measuring the broad domains of physical health, psychological health, social relationships and environment. The domain scores have demonstrated good discriminant validity, content validity, internal consistency and test–retest reliability. Each answer is based on self-reported assessments using a 5-point Likert scale ranging from 1 (very dissatisfied/very poor) to 5 (very satisfied/very good). Scores are scaled in a positive direction with higher scores corresponding to a better QOL. The average score of items within each domain was used to calculate the domain score. Mean scores were then multiplied by 4 in order to transform them into a linear scale between 0 and 100 and make domain scores comparable with the scores in the WHOQOL-100.[25] The WHOQOL instruments were developed collaboratively in a number of centers worldwide, and have been widely field tested. The Tamil version of the scale was used.

Proforma for sociodemographic and clinical variables – Details regarding sociodemographic variables and clinical details, obtained from the patient, caregiver and medical records, were recorded in this proforma.

Statistical methods

The statistical software Statistical Package for Social Sciences version 21.0 (SPSS 21.0) was employed for the analysis of data. Mean and standard deviation were employed to describe continuous variables, while frequency distributions were obtained for categorical data. Data were found to be normatively distributed; therefore, parametric statistical tests were used. The Chi-square test and the Student's t-test were used to assess the significance of associations for categorical and continuous variables, respectively. The Pearson's correlation coefficient was employed to assess the statistical significance of the association between two continuous variables. Linear regression was employed as multivariate statistics with the dependent variable being the mean total domain score and independent variables being the type of house; substance use; PANSS negative, general psychopathology and total scores; and responses to the SEMI, which were significant on bivariate analysis. The sample size was calculated ($n = 130$) using the formula $4pq/d^2$, where P denotes the prevalence of non-medical EMs in schizophrenia, estimated to be 80%,[26], $q = (100 − p)$ and d is the expected difference between the two arms under study, taken as 7.

RESULTS

A total of 157 subjects who fulfilled eligibility criteria were contacted, of which 130 consented to participate, giving a percentage response rate of 82.8. There was no statistical difference in the age and gender of those who consented and those who did not. The sociodemographic and clinical characteristics are documented in Table 1. The majority of the sample were male, married, literate, employed and from the middle-class backgrounds. The mean age of onset of illness was 30 years while the mean duration of illness was 82 months. The majority were compliant with treatment.Side effects were reported in a large number, the commonest being extrapyramidal symptoms. Most patients did not have a history of substance use or medical comorbidity.

Responses to the SEMI are found in Table 2. When asked whether they had an illness or health problem, a little more than a third of respondents said that they had none. When asked to put a name to their problems, several descriptions from the local language were used to describe their psychological problem, including "manakashtam," "manathalarchi," and "manasorvu;"

Table 1: Sociodemographic and clinical characteristics of patients

Characteristic	Mean (SD)	Frequency (%)	Median (range)
Age (years)	35.2 (9.5)		33 (19-62)
Gender - male		69 (53.1)	
Literacy - read and write		120 (92.3)	
Education (years)	12.4 (3.9)		12.0 (0-21)
Marital status - married		66 (50.8)	
Housing - own		93 (71.59)	
Residence - urban		67 (51.5)	
Number of people living in the house	4.2 (1.5)		4 (2-10)
Monthly family income (rupees)	20,357.6 (33863.8)		10000 (500-300000)
Debt - no		74 (56.9)	
Amount of debt (rupees)	147,476.9 (355318)		0 (0-3000000)
Occupation - employed		57 (43.8)	
Substance use - present		17 (13.1)	
Physical illness - present		26 (20)	
PANSS positive score	7.00 (0.2)		7 (7-8)
PANSS negative score	7.5 (0.7)		7 (7-10)
PANSS general psychopathology score	17.9 (1.4)		18 (16-21)
Total PANSS score	32.5 (1.7)		32 (30-37)
Age of onset of illness (years)	30.0 (19.5)		27 (15-53)
Duration of illness (months)	82.0 (73.0)		60 (7-396)
Duration of treatment (months)	53.8 (55.6)		36 (6-384)
Duration of remission (months)	20.3 (25.5)		11.5 (4-192)
Subtype of schizophrenia - paranoid		86 (66.2)	
Side effects - yes		102 (78.5)	
Medication compliance - good		96 (73.8)	

SD – Standard deviation; PANSS – Positive and Negative Syndrome Scale

some also used the terms depression and schizophrenia. Most attributed their problems to a disease, though many also simultaneously explained their problems as secondary to black magic or punishment from God, karma or evil spirits. When asked about which aspect of the illness they most feared, symptoms of the illness such as aggression and suicidal thoughts as well as the effects on their future, family, social life and study were most prominent in the responses. While some denied any emotional response to their problems, sadness and fear were common emotional responses described. All domains of life were reported to be affected, including work, home life, relationships, mobility and social life. While the majority responded that the hospital was the first place they would seek help from, others mentioned religious places or magical treatments as their first choice. Many responded that in addition to medical help, they would also seek help from religious centers and try dietary modifications. Other strategies that were considered to be helpful included yoga and meditation as well as increased social interaction.

Factors associated with QOL: The mean QOL score for each domain is shown in Table 3. A higher QOL score was found to be significantly associated with being single, having a higher socioeconomic status and not using substances of abuse. The negative, general psychopathology and total PANSS scores were negatively correlated with the WHOQOL-BREF scores; however, there was no correlation with the positive subscale score. Among these sociodemographic and clinical factors, marital status lost its statistical significance when adjusted for age.

Patients who did not think they had an illness currently and those who reported a lack of fear about their problems had higher QOL scores. Those who did not perceive their illness to have affected them emotionally; restricted their mobility; or affected their social life, home life, relationships or work, had statistically significantly higher QOL scores than those who reported having problems in these areas. Patients who reported that the hospital had been the first place they had sought treatment from had a higher QOL score than those who had chosen other options [Table 4]. All these factors remained significant on adjusting for age on multiple linear regression [Table 5].

DISCUSSION

This study examined the relationship between EMs and perceived well-being and QOL among people with schizophrenia. The debate about whether patients with schizophrenia can reliably judge their subjective state is divided between the viewpoint that the lack of insight makes this impossible versus the idea that

Table 2: Explanatory models associated with schizophrenia

Characteristic	Frequency (%)
Reason for visit - non-specific complaints	46 (53.1)
Presence of health problem/illness - no	45 (34.6)
Personal contribution to illness - no	91 (70)
Seriousness of problems - moderate or severe	69 (53.1)
Cause of illness - disease	73 (56.2)
Black magic	44 (33.8)
Punishment from God	40 (30.8)
Difficulties caused by illness - no	34 (26.2)
Most feared aspect - none	17 (13.1)
Symptoms of illness	36 (27.7)
Effects on future	21 (16.2)
Domains affected - mobility	56 (43.1)
Social life	51 (39.2)
Home life	67 (51.5)
Relating to others	67 (51.5)
Work	79 (60.8)
Emotionally affected - no	32 (24.6)
Sadness	67 (51.5)
Fear	14 (10.8)
First help-seeking site - hospital	94 (72.3)
Religious place	24 (18.5)
Magical	11 (8.5)
Treatment option sought – doctor/nurse	127 (97.7)
Temple/mosque/church	87 (66.9)
Dietary measures	48 (36.9)
Traditional healers	21 (16.2)
Mantravadi	12 (9.2)
Yoga/meditation	11 (34,4)
Improved social interaction	6 (18.8)
Prayer	5 (15.6)

Table 3: Domain scores on WHOQOL-BREF

Domain	Physical health	Psychological	Social relationships	Environment	Mean total
Mean	64.1	59.3	64.0	63.1	62.6
(SD)	(16.2)	(16.0)	(22.2)	(16.5)	(14.7)
Median	63.0	56.0	69.0	63.0	61.8
(range)	(25-100)	(19-100)	(0-100)	(19-100)	(15.75-92.5)

WHOQOL-BREF – World Health Organization Quality of Life, abbreviated version of the WHOQOL-100; SD – Standard deviation

the patient's perspective is most important.[3] In this study, patients were in clinical remission, thus reducing the possibility that florid positive psychotic symptoms may have influenced their perceptions. The advantage of the study is the use of standard instruments for systematic assessment of the QOL and EMs. The limitations include the cross-sectional nature of the study which does not allow the drawing of inferences on the direction of causality or the precise nature of the association between the variables, the absence of blinding and the relatively small sample size.

The study documents that patients with schizophrenia perceived deficits in the quality of their life in

Table 4: Factors associated with QOL in people with schizophrenia-bivariate statistics

Variable	Quality-of-Life score (mean)	t/r value	Df	p
Marital status				
Single	66.1	2.027	128	0.045
Married	60.7			
Type of house				
Concrete	63.8	−2.572	128	0.011
Other	53.6			
Substance use				
Present	55.2	2.264	128	0.025
Absent	63.7			
PANSS negative score	7.5	−0.282	-	0.001
PANSS general psychopathology score	17.9	−0.210	-	0.017
PANSS total score	32.5	−0.287	-	0.001
Responses to SEMI:				
Belief of having an illness				
No	67.3	2.722	128	0.007
Yes	60.1			
First help-seeking site				
Hospital	64.7	2.611	128	0.010
Other	57.3			
Fears related to the problem		−2.046	128	0.043
No	69.3			
Yes	61.6			
Fears related to the future		2.60	128	0.010
No	55.1			
Yes	64.1			
Difficulties due to the problem				
None	72.8	−2.314	128	0.022
Present	61.8			
Emotionally affected				
No	68.6	2.718	128	0.007
Yes	60.7			
Mobility affected				
No	65.9	2.967	128	0.004
Yes	58.3			
Social-life affected				
No	65.1	2.412	128	0.017
Yes	58.8			
Family-life affected				
No	65.6	2.247	128	0.026
Yes	59.8			
Relationships affected				
No	65.6	2.247	128	0.026
Yes	59.8			
Work affected				
No	66.0	2.122	128	0.036
Yes	60.4			

PANSS – Positive and Negative Syndrome Scale; SEMI – Short Explanatory Model of Illness; t – t value on Independent t-test; r – Pearsons' correlation coefficient; df – Degree of freedom. Non-significant associations between QOL score and the following variables: Patient's age, gender, education, marital status, employment, monthly income, place of residence, family size, physical comorbidity, age of onset of illness, duration of illness, treatment and remission, medication side-effects and compliance, subtype of schizophrenia, causative belief models and treatment options sought

Table 5: Factors associated with QOL in people with schizophrenia-multivariate statistics adjusted for age

Characteristic	Linear regression	
	B (SE)	95% CI (p)
Marital status	−.12 (1.53)	−4.98 to - 1.07 (0.25)
Type of house	−.26 (3.28)	−16.74 to−3.73 (0.002)
Substance use	−1.95 (3.76)	−15.92 to−1.01 (0.026)
PANSS negative score	−.28 (1.76)	−9.42 to−2.43 (0 001)
PANSS general psychopathology score	−.216 (0 0.902)	−3.99 to −.376 (0.018)
PANSS total score	−.29 (0 0.69)	−3.82 to−1.07 (0 0.001)
Presence of illness	−.23 (2.65)	−12.36 to−1.87 (0.008)
First help-seeking site	−.23 (2.82)	−13.11 to−1.95 (0.009)
Fears related to the problem	0.21 (3.84)	1.36-16.57 (0.021)
Fears related to the future	−.22 (3.43)	−15.58 to−1.98 (0.012)
Difficulties due to the problem	0.21 (4.76)	1.707-20.55 (0.021)
Emotionally affected	−.23 (2.92)	−13.64 to−2.06 (0.008)
Mobility affected	−.26 (2.53)	−12.72 to−2.71 (0.003)
Social-life affected	−.22 (2.60)	−11.82 to−1.52 (0.012)
Family-life affected	−.20 (2.54)	−10.96 to −.89 (0.021)
Relationships affected	−.20 (2.54)	−10.96 to −.89 (0.021)
Work affected	−.196 (2.61)	−11.04 to −.69 (0.026)

PANSS – Positive and Negative Syndrome Scale; B – Regression coefficient; SE – Standard error; CI – Confidence interval

the different domains assessed. Previous studies have variably reported that these patients had a lower life quality in comparison with people with other psychiatric diagnoses[27] and the general population,[28] higher than that of patients with mood disorders, and similar to those with chronic physical illness.[29]

The literature on factors associated with QOL in schizophrenia includes studies that differ widely with respect to the definitions of QOL, methodology, assessment instruments and patient population. Being married has been variously reported to be unrelated to,[30,31] or enhancing the QOL in these patients.[32] In our study, single people were found to have a better QOL on bivariate analysis; however, this association did not persist after adjusting for age. Women were reported to have a higher QOL as compared to males in a study on unmedicated patients,[33] while others found no association with gender.[30,31] Age has been reported to have a negative,[30,31] or no[32] association with subjective life quality. The findings of this study support others that report a significant influence of housing and socioeconomic factors on QOL, emphasizing the need to focus on improving the environment and support systems for these individuals.[27,34] Though not replicated in this study, higher levels of education and unemployment have been reported to contribute to poor QOL significantly.[32] We found that higher the

negative symptom and general psychopathology scores, lower was the QOL score, similar to reports from other studies.[35] This highlights the need to provide adequate intervention to address the patient's non-psychotic symptoms which appear to have a significant influence on well-being, though they may not be as evident as the positive symptoms. Other clinical factors that have been reported to be associated with poor QOL are positive symptoms,[35] longer duration of symptoms and tardive dyskinesia.[30] This study found lower QOL scores in patients with substance abuse, as in earlier studies,[36] possibly explained by the fact that the comorbidity further impairs functioning and the ability to cope and adjust to the environment.

Many respondents in this study did not consider themselves as ill nor did they report being anxious or having difficulties in the different domains of life. While the cross-sectional nature of this study does not allow us to draw definite conclusions regarding the direction of the relationship, this may suggest that people who perceive themselves as well and healthy, feel better. A study of adults undergoing speech-language therapy noted that those individuals who reported themselves to be healthy had better QOL scores on the physical, psychological and environmental domains.[37] Similarly, Schuler[38] found that an individual's subjective perception of his/her health status was a significant predictor of their QOL rather than physical health, mental health, age and income. The presence of an actual physical or mental health problem or the severity of these was not found to be the best indicator, rather it was the perception of health status that influenced the QOL with positive health perceptions predicting a higher QOL.[38,39]

Studies in schizophrenia have reported that patients who have symptoms of anxiety and depression had lower QOL scores, suggesting that affective states alter perceptions regarding QOL.[40,41] It is possible that the group of patients studied here who were in remission with respect to their positive symptoms, had progressed to the point where they had adapted as best as possible to their problems, which was reflected in their EMs regarding their health and QOL. While it is clear that self-perception of health and QOL are subjective by nature,[42] ultimately an individual's subjective perspective influences satisfaction with life. As described by Beck, "people's emotions and behaviors are influenced by their perceptions of events. It is not a situation in and of itself that determines what people feel but rather the way in which they construe a situation."[43] The study highlights that focusing on attitudes, adaptive skills and functioning can help to improve the patient's sense of well-being.

CONCLUSION

In a chronic illness such as schizophrenia, pursuing treatment goals aimed at cure or complete remission may not be feasible; a more appropriate and useful approach may be to focus on factors that will enhance the quality of the patient's life and improve patient satisfaction.[44] The concept of QOL is therefore important for clinicians who should be aware of how it is impacted upon by the patient's environment, social adjustment and levels of functioning as well as by the subjective appraisal of symptoms and life problems.

The results of this study highlight the need for psychosocial interventions in individuals with schizophrenia in order to improve their functioning and socioeconomic stability; it also demonstrates that clinicians must pay attention to the individual's perceptions of their health status, all of which contribute to QOL. Given the variable course of schizophrenia, further research on the changes in QOL over time and the factors influencing these would enhance our understanding of this aspect of our patient's lives.

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There are no conflicts of interest.

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