

# Quality of Life (QoL) and Its Associated Factors Among Caregivers of Patients with Schizophrenia

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## ABSTRACT

**Background:** Schizophrenia is a chronic, severely disabling psychiatric illness involving a complex set of disturbances in thinking, perception, affect and social behavior resulting in physical, psychological and social problems related to the disease and the side effects of medication which put immense amount of physical, emotional and financial distress on the family members of patients leading to poor quality of life.

**Aim and Objectives:** To assess the quality of life (QoL) among caregivers of patients with schizophrenia.

**Methodology:** A quantitative cross sectional research design was used. 246 caregivers were selected by using purposive sampling technique. Standardized self-administered questionnaire by WHO QoL BREF scale and Multidimensional scale of perceived social support (MSPSS) were used to assess the QoL and perceived social support of the caregivers respectively.

**Results:** The study result shows that out of 246 caregivers, mean value in physical (50.84±11.36), psychological (55.47±15.12), social (57.74±19.00) and environmental (52.25±14.86) domain. There was a significant association between the QoL domains and caregiver's age, education and relationship with patient. A significant positive correlation was found between WHO QoL BREF scale and MSPSS (<0.05).

**Conclusion:** The caregivers had good QoL in social, psychological and environmental domains and poor QoL in physical domain. The mean QoL in this study was lower than that found in studies from India (Cuttack) and Malaysia. This difference can be attributed to overburdened caregiving task, cultural differences, caregiver's perception of their own wellbeing, expectation for the government to assume responsibility to reduce society's mental health burden.

**Key words:** Schizophrenia, caregiver, WHO QoL BREF scale, MSPSS

## INTRODUCTION

Schizophrenia is a major group of mental disorders involving a complex set of disturbances in thinking, perception, affect and social behavior. It is a chronic, severely disabling psychiatric illness.<sup>1-3</sup> It affects 21

million people worldwide about 1 in every 285.<sup>4</sup> In India, where nearly 1.1 billion people live, the prevalence of schizophrenia is about 3 in every 1000 individuals.<sup>5</sup> It results in physical, psychological and social problems related to the disease and the side

effects of medication which put immense amount of physical, emotional and financial distress on the family members. QOL is an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to the goals, expectations, standards and concerns, comprising of different dimensions such as an individual's physical, psychological and social well-being, and environmental relationships.<sup>6-7</sup> Caregiving is an act of giving free support and care to all family members. Over the past few decades, there has been an emphasis on the de-institutionalization of psychiatric care with a focus on community care. This creates an emphasis on the role of primary caregivers in treatment of the patients. In Asia there is a strong family involvement in caring for mentally ill persons where more than 70% of patients with schizophrenia depend on their families, in contrast to about 25–50% in Western countries.<sup>8-10</sup> In India, the family takes the role of taking care of the ill relative, staying with the patient round the clock when admitted to hospital, is acutely ill, agitated or suicidal. Additionally family is expected to take the role that was previously performed by the patient, bear financial expenses of the treatment, supervise treatment and engage the patient in meaningful activities. All this leads to significant burden and poor QOL in caregivers. Various data also suggest that many caregivers suffer from psychological morbidity as a result of their caregiver role. Studies have shown the importance of caregiver's QoL on the patient's health as caregivers' negative experience may hamper in their ability to care for the patients. Researchers have found that the level of QoL in caregivers of mentally ill is found to be lower than that of a general population, when a significant burden is being experienced. Even though caregivers play a major role in caring for the patients, lack of counseling, training or support for them has been rarely highlighted. Hence, there is a need to explore about the caregiver's quality of life. This study had investigated the quality of life

among the caregivers of patients with schizophrenia.

## **PROBLEM STATEMENT**

Quality of life (QoL) and its associated factors among caregivers of patients with schizophrenia.

## **OBJECTIVES OF THE STUDY**

1. To assess the QoL among caregivers of patients with schizophrenia.
2. To identify the association between QoL among caregivers of patients with schizophrenia with the selected socio-demographic and clinical variables.
3. To identify the association between the QoL and its associated factors among caregivers of patients with schizophrenia with Multidimensional perceived social support.

## **MATERIAL AND METHOD**

A cross-sectional descriptive design was used for the study. 246 caregiver of patients with schizophrenia attending the inpatient and outpatient services of department of psychiatry, Jawaharlal Institute of Post Graduate Medical Education and Research (JIPMER), Puducherry were taken as the sample for the study. Formal consent and permission from the authorities of JIPMER was taken prior to the data collection procedure. The tools used for the study were socio-demographic proforma and standardized questionnaire such as WHO QoL BREF scale (26 questions which measures the individual's perception of quality of life on four domains of physical health, psychological, social relationships and environment of the individual on a scale of 1-5.) and Multidimensional Perceived Scale of Social Support (MDPSS) questionnaire (7 point Likert scale consisting of 12 self-administered questions). Differential and inferential statistics were used to analyse the data. The distribution of categorical variables (socio-demographic variables) was expressed as frequencies and percentage and continuous variables were expressed as mean with standard deviation.

Association between the socio-demographic variables and quality of life was done by t-test and chi-square test for comparing normally distributed data. Mann-Whitney test was used with non-normal distributions for data. Correlation was done using spearman's rho correlation coefficient (r). Statistical analysis was carried out at 5% level of significance and p value <0.05 was considered significant.

## DESCRIPTION OF TOOLS

The tool used for the study consisted of three sections, it includes:

**Section A:** Socio-demographic variables.

**Section B:** WHO-QoL BREF Scale consist of 26 questions which measures the

individual's perception of quality of life on four domains of physical health, psychological, social relationships and environment of the individual on a scale of 1-5.

**Section C:** Multidimensional Scale of Perceived Social Support is a 12 item self-administered questionnaire designed to measure the perceived adequacy of social support from three sources: family, friends and significant other on a 7 point Likert scale.

## RESULTS AND DISCUSSION

### Section A: Description of the socio-demographic variables.

**Table 1: Frequency and percentage wise distribution of socio-demographic variables among caregivers of patients with schizophrenia. (n=246)**

Variables	Categories	n(%)
Age	≤30	81 (32.93%)
	31-40	53 (21.54%)
	41-50	45 (18.29%)
	51-60	44 (17.89%)
	>60	23 (9.35%)
Gender	Male	113 (45.93%)
	Female	133 (54.07%)
Education	Illiterate	25 (10.16%)
	Primary	19 (7.72%)
	High school	110 (44.71%)
	Graduation	68 (27.64%)
	Post-graduation	24 (9.75%)
Occupation	Student	20 (8.13%)
	Unemployed	82(33.33%)
	Self employed	91 (36.99%)
	Government employee	40 (16.26%)
	Private employee	13 (5.28%)
Marital status	Single	62 (25.20%)
	Married	150 (60.97%)
	Divorced	24 (9.76%)
	Widowed	10 (4.07%)
Relationship with patient	Parent	68 (27.64%)
	Children	75 (30.49%)
	Sibling	63 (25.61%)
	Spouse	40 (16.26%)
Residence	Urban	104 (42.28%)
	Rural	121 (49.19%)
	Semi urban	21 (8.54%)

Table- 1 depicts that out of 246 caregivers, 81 were ≤30years, 53 belonged to 31-40 age group, 45 belonged to 41-50 age group, 44 belonged to 51-60 age group and 23 belonged to >60 age group. The sample constituted of 113 (45.93%) male and 133 (54.07%) female. Distribution according to educational status demonstrated that 25 (10.16%) were illiterate, 19 (7.72%) studied

up to primary education, 110 (44.71%) studied up to secondary education, 68(27.64%) studied up to graduation, 24 (9.75%) studied up to post-graduation. According to marital status results showed that 62 (25.20%) subjects were single, 150 (60.97%) subjects were married, 24 (9.76%) were divorced and 10 (4.07%) subjects were widowed. Distribution according to

occupational status demonstrated that 20 (8.13%) were students, 82(33.33%) were unemployed, 91 (36.99%) were self employed, 40 (16.26%) were government employee and 13 (5.28%) were private employee. According to the type of relationship with patient, 68 (27.64%) were

parents, 75 (30.49%) were children, 63 (25.61%) were sibling and 40 (16.26%) were spouse. Among 246 subjects, 104 (42.28%) subjects were residing in urban area, 121 (49.19%) were residing in rural area and 21 (8.54%) were residing in Semi urban area.

**Table 2: Frequency and percentage wise distribution of socio-demographic variables among patient with schizophrenia. (n=246)**

Variables	Categories	n(%)
Age	≤30	120 (48.78%)
	31-40	42 (17.07%)
	41-50	33 (13.42%)
	51-60	35 (14.23%)
	>60	16 (6.50%)
Gender	Male	103 (41.87%)
	Female	143 (58.13%)
Education	Illiterate	22 (8.94%)
	Primary	61 (24.80%)
	High school	133 (54.06%)
	Graduation	29 (11.79%)
	Post-graduation	1 (0.41%)
Occupation	Student	37 (15.04%)
	Unemployed	135 (54.88%)
	Self employed	67 (27.23%)
	Government employee	6 (2.44%)
	Private employee	1 (0.41%)
Duration of illness	< 10 years	135 (54.88%)
	≥10years	111 (45.12%)
Onset of illness	<25 years	168 (68.29%)
	≥25years	78 (31.71%)
Number of hospitalizations	≥4	96 (39.02%)
	<4	150 (60.98%)

Table-2 depicts that out of 246 patients, 120 were ≤30years, 42 belonged to 31-40 age group, 33 belonged to 41-50 age group, 35 belonged to 51-60 age group and 16 belonged to >60 age group. Distribution according to gender is 103 (41.87%) male and 143 female (58.13%). Distribution according to education status were, illiterate 22 (8.94%), primary 61 (24.79%), high school 133 (54.06%), graduation 29 (11.79%) and post-graduation (0.41%). According to occupation, 37 (15.04%) were students, 135 (54.88%) were unemployed, 67 (27.23%) were self-employed, 6 (2.44%) were government employee and 1 (0.41%) was

private employee. Distribution according to duration of illness, 135 (54.88%) were ill for < 10 years and 111 (45.12%) were ill for ≥10years. According to onset of illness, 168 (68.29%) patients were diagnosed with schizophrenia <25 years and 78 (31.71%) patients were diagnosed with schizophrenia ≥25years. Distribution according to number of hospitalization, 96 (39.02%) were hospitalized ≥4 times and 150 (60.98%) were hospitalized <4 times.

**Section B: Assessment of the quality of life and associated factors among caregivers of patients with schizophrenia.**

**Table 3: Mean and standard deviation of quality of life (WHO-QoL BREF) in caregivers of patients with schizophrenia. (n= 246)**

WHO quality of life (QOL) BREF scale	MEAN ± S.D.
Physical domain	50.84 ±11.36
Psychological domain	55.47 ±15.12
Social domain	57.74 ±19.00
Environmental domain	52.25 ±14.86

Table 3 depicts that mean value in physical domain was 50.84±11.36, psychological domain 55.47±15.12, social domain 57.74±19.00 and in environmental domain 52.25±14.86

**Table 4: Frequency and percentage wise distribution of level of perceived social support of caregivers of patients with schizophrenia. (n = 246)**

Multidimensional scale of perceived social support	n(%)	Mean ±S.D
Significant other		4.59 ± 1.36
Low support	34 (13.82%)	
Moderate support	121 (49.19%)	
High support	91 (36.99%)	
Family		4.90 ± 1.34
Low support	22 (8.94%)	
Moderate support	102 (41.46%)	
High support	122 (49.59%)	
Friend		4.01 ± 1.31
Low support	58 (23.58%)	
Moderate support	136 (55.28%)	
High support	52 (21.14%)	

Table 4 depicts that majority of the caregivers reported moderate support from significant other 121 (49.19%), high support from family 122 (49.59%) and moderate support from friend 136 (55.28%). The mean value of

the level of perceived social support was 4.59 ± 1.36, 4.90 ± 1.34 and 4.01 ± 1.31 in significant other, family and friend respectively.

**Table 5: Association between the quality of life of caregivers of patients with schizophrenia with their selected demographic variables (n = 246)**

Domains	Caregiver's age					f value	p value
	<30 years	31-40 years	41-50 years	51-60 years	>60 years		
Physical domain	56 (19.69)	56 (31.88)	56 (25.69)	44 (19.75)	56 (19.81)	12.305 at 4 df	.015*
Psychological domain	54.33 (14.23)	58.13 (16.40)	55.36 (13.78)	52.07 (14.70)	60.09 (14.43)	1.636	.166
Social domain	59.99 (18.83)	59.66 (16.64)	56.33 (20.61)	52.39 (16.79)	58.43 (24.21)	1.370	.245
Environmental domain	53.02 (15.24)	54.34 (14.31)	52.87 (14.03)	45.64 (15.23)	56.17 (12.88)	3.011	.019*
Caregiver's education	N		Mean with standard Deviation			6.002	<0.001**
Illiterate	25		13.40	+5.75			
Primary	19		14.05	+5.06			
High school	110		15.62	+5.32			
Graduation	68		17.07	+4.77			
Post-graduation	24		19.37	+3.24			
Domain	Relationship with patient						
	Parent	Sibling	Children	spouse			
Social domain	57.54 (19.38)	59.76 (18.00)	58.16 (17.34)	53.65 (22.46)	0.912	0.912	
Environmental domain	49.65 (14.50)	54.28 (14.45)	55.11 (14.48)	48.38 (15.76)	0.912	0.912	

\*Significant at p <0.05  
\*\*significant at p <0.01

Table 5 depicts that the demographic variables caregiver's age, caregiver's education and relationship with patient had shown statistically significant association with the domains of WHO QoL BREF scale

at p <0.05 level and p <0.001 level. The other demographic variables had not shown statistically significant association with the domains of WHO QoL BREF scale.

**Table 6: Association between perceived social support in caregivers of patients with schizophrenia with their selected socio demographic variables. (n = 246)**

Domains	Caregiver's age					f value	p value
	<30 years	31-40 years	41-50 years	51-60 years	>60 years		
Significant other	17.47 (5.34)	19.64 (5.62)	17.91 (5.01)	17.75 (5.82)	20.52 (5.15)	2.463	.046*
Family	19.05 (5.09)	20.79 (5.46)	19.38 (5.42)	19.16 (5.53)	20.26 (5.73)	1.046	.384
Friend	17.88 (4.39)	15.79 (4.78)	14.89 (4.85)	15.57 (5.65)	13.30 (6.93)	5.036	.001**

Domains	Caregiver's occupation						
	Student	Unemployed	Self employed	Govt. employee	Private employee		
Significant other	16.80 (5.95)	19.62 (5.65)	17.54 (5.22)	18.32 (4.86)	18.54 (5.49)	2.08	0.08*
Family	19.00 (5.21)	20.38 (5.69)	18.92 (5.45)	19.65 (4.46)	20.54 (5.59)	0.95	0.95
Friend	17.90 (4.06)	14.64 (5.39)	16.06 (5.33)	17.82 (4.62)	17.52 (5.20)	3.38	0.01**
Domain	Caregiver marital status						
	Single	Married	divorced	Widowed			
Friend	17.77 (4.45)	15.22 (5.14)	16.71 (6.42)	16.00 (6.00)		16.00 (6.00)	0.012*
Domain	Relationship with patient						
	Parent	Sibling	Children	Spouse			
Significant other	18.72 (5.24)	18.57 (5.27)	17.27 (5.39)	19.02 (6.05)		1.185	0.316
Family	19.56 (5.43)	20.28 (5.15)	18.76 (5.27)	19.82 (5.84)		0.934	0.425
Friend	14.84 (5.05)	17.05 (5.26)	17.24 (4.70)	14.30 (5.54)		4.930	0.002**
Domains	Patient's gender		Z value	p value			
	Male	Female					
Family	19.47 (5.91)	19.73 (4.97)	-0.376	0.708			
Friend	15.11 (5.40)	16.71 (5.03)	-2.397	0.017*			

\*Significant at p <0.05  
\*\*significant at p <0.01

Table 6 depicts that the demographic variables caregiver's age, caregiver's occupation, marital status, relationship with patient and patient's gender had shown statistically significant association with multidimensional scale of perceived social support at p <0.05 level and p <0.001 level.

Other demographic variables had not shown statistically significant association with the domains of multidimensional perceived social support scale.

### Section C: Correlation between the domains of WHO QOL BREF and MSPSS.

Table 7: Correlation between the domains of WHO QOL BREF scale and MDPSS scale.

Domains	Physical domain	Psychological domain	Social domain	Environmental domain	Significant other	Family	Friend
Physical domain	1.000	.537**(.000)	.495**(.000)	.674**(.000)	.443**(.000)	.390**(.000)	.156*(.014)
Psychological domain		1.000	.369**(.000)	.561**(.000)	.623**(.000)	.625**(.000)	.006(.924)
Social domain			1.000	.561**(.000)	.346**(.000)	.359**(.000)	.272**(.000)
Environmental domain				1.000	.473**(.000)	.422**(.000)	.228**(.000)
Significant other					1.000	.776**(.000)	.024(.703)
Family						1.000	.090(.160)
Friend							1.000

\*\* Correlation is significant at the level of 0.01 (2-tailed).  
\* Correlation is significant at the level of 0.05 (2-tailed).

Table 7 depicts that a significant strong positive correlation was found between physical domain with significant, family (<0.01) and moderate positive correlation between physical domain with friends' domains of MSPSS (<0.05). The psychological domain showed a significant positive strong correlation with significant other and family domains of MSPSS (<0.01).

A significant strong positive correlation was found between the social and environmental domains of WHO QoL BREF scale and the significant other, family and friends' domains of MSPSS (<0.01).

### DISCUSSION

The findings of the present study revealed that among 246 participants in the WHO QoL

BREF scale, mean value reported were physical domain  $50.84 \pm 11.36$ , psychological domain  $55.47 \pm 15.12$ , social domain  $57.74 \pm 19.00$  and in environmental domain  $52.25 \pm 14.86$ . The findings of the study was consistent with the findings of Geriani et al. and Boateng et al in which participants showed higher level of satisfaction on environmental, social and psychological domains, while lower QoL was perceived in physical domain. The mean QoL in this study was lower than that found in studies from India (Cuttack) and Malaysia. This difference can be attributed to overburdened caregiving task, cultural differences, caregiver's perception of their own well being, expectation for the government to assume responsibility to reduce society's mental health burden.

The study found that there was a significant statistical association between caregiver's age, caregiver's education and relationship with patient with QoL of caregivers with schizophrenia at  $p < 0.05$ . The findings of present study were consistent with the results of the studies done by Zamzam et al. Ribe et al. and Boateng et al. This association can be attributed to the fact that higher education status leads to greater understanding, acceptance and mental illness awareness.

Out of 246 subjects, majority of the caregivers reported moderate support from significant other 121 (49.19%), high support from family 122 (49.59%) and moderate support from friend 136 (55.28%). The mean value of the level of perceived social support was  $4.59 \pm 1.36$ ,  $4.90 \pm 1.34$  and  $4.01 \pm 1.31$  in significant other, family and friend respectively. The present study showed a significant statistical association between caregiver's age, caregiver's occupation, marital status, relationship with patient and patient's gender with caregiver's multidimensional perceived social support at  $p < 0.05$ . The findings of the study was supported by Lök et al.

There is a significant strong positive correlation between the physical, psychological, social and environmental domains of the WHO QOL BREF scale with

the significant other, family and friend domains of Multidimensional scale of perceived social support at  $p < 0.05$ .

## CONCLUSION

With the above results, there arises a need to conduct regular screening to identify vulnerable caregivers at risks. Teaching adaptive coping strategies and psycho-education counseling and assistance of support groups can be helpful in reducing caregivers burden, thereby improving their QoL and thus, helping in provision of better recovery environment for the patients with schizophrenia.

### *Declaration by Authors*

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