

Quality Of Life Satisfaction Among Caregivers Of Schizophrenic Patients

Rahat Usman¹, Anum Haider², Zoobia Ramzan³, Shafi Mansoori⁴

Abstract

Objective: This study is aimed to determine the Quality of Life (QOL) satisfaction among caregivers of schizophrenic patients attending Outpatient department of Psychiatry, Abbasi Shaheed Hospital, Karachi Medical and Dental College.

Method: The cross-sectional study was conducted among 150 caregivers of Schizophrenic patients from November 2015 to March 2016 attending out patient department of Psychiatry, Abbasi Shaheed Hospital, Karachi Medical and Dental College, Pakistan. The Caregivers were intimate family members who had spent their significant time (at least 2 years) with the schizophrenia patients. The self administered WHO QOL-BREF (validated Urdu version) scale which has 26 items, was used to measure the Quality of Life (QOL). Quality of life Satisfaction was labeled as positive if QOL score was >75% of the total score.

Result: Out of 150 patients, the mean age of the caregivers was 45.36 ± 3.85 years. Most of the caregivers 95 (63.3%) were males and had care giving role of father 49 (32.6%). Most of them were unsatisfied of their QOL, 81 (54%). While only 69 (46%) of the caregivers were satisfied with their QOL. Their QOL was found to be significantly associated with age of the patient (p-value <0.001) and caregiver (p-value <0.002), employment status (p-value 0.040), monthly family income (p-value <0.001), presence of physical illness of caregiver (p-value <0.001) and his/her relationship with the patient (p-value 0.048).

Conclusion: Majority of caregivers of Schizophrenia patients were not satisfied with their Quality of Life. However, there are certain sociodemographic factors such as the age of patient and caregiver, employment and economic status, relationship with the patient and presence of physical illness of caregiver which were found to affect their satisfaction with QOL. Hence focusing those factors in the management plan may improve caregiver's satisfaction level.

Keywords: Quality of life, schizophrenia, caregivers.

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Introduction

Schizophrenia is one of the severe form of the psychiatric disorders which is ranked 11th in the top 20 causes of Global Burden of Diseases. It is a chronic relapsing-remitting kind of severe psychiat-

ric illness that has disabling consequences if left untreated. It significantly affects patients social and occupational functioning, may develop cognitive deficits that impairs judgement and capacity to take rational decisions, physical health is also compromised due to lack of appropriate expression of the problem and poor compliance to healthy life style. According to World health organization (WHO) report about 21 million of the world's population is affected with this serious mental illness¹. This disorder not only affects the patient but the family member/s involved in the care and consequently compromises their Quality of Life (QOL).

^{1,4}Department of Psychiatry, Ruth Pfau Medical College

²Department of Psychiatry, Civil Hospital

³Department of Psychiatry, Dow International Medical College

Correspondence: Dr. Zoobia Ramzan

Department of Psychiatry,
Dow International Medical College

Email: drzoobiarman@yahoo.com

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Various international studies have reported diminished quality of life of patients with Schizophrenia and there are certain studies which are conducted on caregivers as well and identified striking caregiving burden especially when their roles and activities were restricted due to prolonged unsupported care of their patients²⁻⁴. A study conducted in Arab population by Zahid M.A. on caregivers of patients with Schizophrenia to observe their burden of caregiving found around 70% of the caregivers burdened with the care due to restricted life routine in more than half of them.⁶ The Caregiver of the patients with psychiatric illness eventually may develop various physical and psychiatric comorbidities due to unshared caregiving burden. It may present in the form of psychosomatic complaints like headache, mood swings, anxiety, depression and marital problems⁶⁻⁸. One of the study found significantly high levels of depression and anxiety among caregivers of patients with psychiatric illness population⁹. The impact of caregiving burden gets intense further when the contact of caregiving is prolonged as speculated by the work of Kumar S et al¹⁰.

Previous studies found both formal (paid staff) and informal (family member) caregivers are responsible for giving care to their patients with mental illness. Penning M.J et al¹¹ in his work found informal caregivers; spouse, parent or children mostly responsible for giving care to their family member suffering from psychiatric illness. Hence, they have a higher level of apprehensions and concerns for their patient and they are most affected by the behavior of each other. Negative and critical comments by the caregiver may create feeling of rejection and devaluation. Similarly, disrespectful, aggressive or apathetic attitude by patient brings frustration and deterrence in caregiver.

All over the western world there has been set fast emerging trend of urbanization in the family system where protective effects of traditional joint family system is lost and consequently caregivers are more vulnerable to stress and mental health problems. The wave of similar trend has approached

Asian countries as well, Pakistan is also being affected by it. Thus research on caregivers Quality of Life (QOL) is very important in our setup to identify the gap in caregiving created due to this transition in the family system and to bridge the gap in the local literature. It will not only be useful for the caregivers but also for improving the management of the patients suffering from Schizophrenia in order to improve their prognosis. Thus, we conducted this study to assess level of satisfaction of quality of life (QOL) satisfaction and to observe the relation of various socio demographic factors with it among caregivers of the patients with schizophrenia attending large tertiary care public sector hospital of Karachi.

Subjects and Methods

This descriptive cross-sectional study was conducted among caregivers of schizophrenic patients attending outpatient unit of department of psychiatry of a public sector hospital of Karachi, Pakistan from November 2015 to March 2016.

The study was conducted after getting approval from the research evaluation unit of college of physician and surgeon of Pakistan (CPSP/REU/PSY-2010-174-341). Signed informed consent was also obtained from the patients and the caregivers.

The inclusion criteria included all the caregivers of diagnosed schizophrenia patients of either gender; male and female who were aged 16 to 65 years, proficient in using Urdu language, gave consent for the study and living for at least 2 years with the patient. While exclusion criteria contained all those who didn't fulfill the inclusion criteria and who were suffering with a psychiatric illness other than schizophrenia, learning disability, epilepsy or with comorbid chronic physical illness.

The sample size was calculated based on a pilot study data by taking reported proportion of 40%, confidence interval (C.I) 95% and desired level 8%, Sample size is 144 patients. However, a total of 150 participants were selected with non-probability convenient sampling technique to evaluate the

changes in functionality with the help of QOL satisfaction scale after the illness of their schizophrenia patients.

The diagnoses of already diagnosed patients with schizophrenia were verified by using the International Classification of Diseases, Tenth Revision (ICD 10). Patients with positive symptoms like hallucinations and delusions, and negative symptoms like lack of interest in self-care, social withdrawal, disturbed sleep and appetite for at least one month with functional impairment were diagnosed as Schizophrenic. All the patients who fulfilled the selection criteria were included in the study from out patient department of Psychiatry Abbasi Shaheed Hospital Karachi. All caregivers of schizophrenia patients were included who were diagnosed by the Consultant Psychiatrist using ICD-10 diagnostic criteria. After taking informed written consent biodata were collected of patient and their caregivers including their relationship with each other. A predesigned proforma was used for demographic details and a self-administered tool; World Health Organization, Quality of Life (WHO QOL-BREF scale), Urdu version was used to measure satisfactory QOL in caregivers with schizophrenia by the principal investigator. WHO QOL-BREF is a 26-item, five-point likert type self-administered scale, derived from WHOQOL-100 scale¹². It covers major physical, psychological, social or financial aspects of life in an individual. The QOL was labeled as Satisfactory if the score was greater than 75% of the total score (130) i.e. a sum score of 100.

The statistical package for social sciences 21(SPSS 21.0) was used for data analysis. Mean and standard deviation was calculated for age, duration of illness, age of caregivers, duration of living of caregiver with the patient after illness and QoL score. Frequency and percentage were calculated for gender, socioeconomic status, family setup, educational status, and satisfactory quality of life. The outcome variable (QOL satisfaction) was compared with independent variables by applying Chi-square and fisher exact test, where frequency found below five count. The p-value <0.05 was taken as significant.

Results

Out of 150 caregivers of patients with schizophrenia, the mean age of the care givers was 45.36 ± 3.85 years. Most of the caregivers 95 (63.3%) were males and had care giving role of father 49 (32.6%). Regarding literacy distribution, 58 (38.7%) care givers had primary and only 3 (2%) had availed higher education. Most of the caregivers of the patients were married 101 (67.4%) and were currently employed 122 (81.3%). Moreover, most of the care givers 71 (47.3%) belonged to the lower monthly income strata in our study, i.e <40,000 PKR, that was also verified by subjective social status measure; occupation, educational attainment and number of dependant family members. In our subjects 56 (37.4%) were belonged to nuclear family setup and among those,14 (22%) were unsatisfied with QOL however it was not statistically significant ($p=0.05$).

Chronic physical illness such as Hypertension, Diabetes, asthma was observed in 45 (30%) of the care givers. Though information regarding duration of their physical illness in comparison to caregiving was not known. However, statistically its relation with study outcome, QOL satisfaction is significant ($p<0.01$). The overall duration of illness was <15 years in majority of the patients suffering from schizophrenia, 99 (66%). The maximum duration of caregiving was found to be >11 yrs in 87 (58%) of the caregivers although its effect was not found to be statistically significant ($p=0.7$).



Fig 1. QOL satisfaction status of the caregivers of schizophrenia patients (n=150)

Table 1. Comparison of QOL satisfaction scores of caregivers with the general characteristics of the patients (n=150)

VARIABLE	Total n (%)	QOL SATISFACTION SCORES		P-Value
		SATISFIED n (%)	UNSATISFIED n (%)	
Age group of patients				
<30yrs	33 (22)	4 (2.7)	29 (19.3)	<0.001**
>30yrs	117 (78)	65 (43.4)	52 (34.6)	
Age group of caregivers				
<30yrs	18 (12)	4 (2.7)	14 (9.3)	0.002*
31-60yrs	125 (83)	59 (39.4)	66 (44.1)	
>60yrs	7 (5)	6 (4)	1 (0.7)	
Gender				
Male	95 (63)	35 (23.3)	60 (40)	0.053
Female	55 (37)	34 (22.7)	21 (14)	
Educational Status (n=140)				
Primary to matric	125 (89)	51 (40.7)	74 (49.3)	0.064
Graduate	12 (9)	7 (4.7)	5 (3.3)	
Postgraduate	3 (2)	1 (0.7)	2 (1.3)	
Marital Status (n=147)				
φSingle	23 (16)	6 (4.1)	17 (11.5)	0.064
Married	101 (69)	55 (37.4)	46 (31.3)	
Unmarried	23 (16)	8 (5.4)	15 (10.2)	
Family setup				
Joint	94 (62.6)	35 (23.3)	61 (40)	0.05
Nuclear	56 (37.4)	34 (22.7)	22 (14)	
Employment Status				
Employed	122 (83)	61 (40.7)	61 (40.7)	0.040*
Unemployed	28 (56)	8 (5.3)	20 (13.3)	
Monthly family income, PKR (n=135)				
<40,000 58 (43)	34 (30)	24 (17.3)	<0.001**	
40000-100,000	44 (33)	17 (13.3)	27 (22)	
>100,000	33 (24)	10 (2.7)	23 (14.7)	
Duration of Illness				
≤15yrs	99 (66)	48 (32)	51 (34)	0.395
>15yrs	51 (34)	21 (14)	30 (20)	
Duration of Living with Patient				
≤11yrs	63 (42)	28 (18.7)	35 (23.3)	0.745
>11yrs	87 (58)	41 (27.3)	46 (30.7)	
Relationship with patient				
Parent	66 (44)	38 (25.4)	28 (18.7)	0.048*
Spouse	29 (19)	11 (7.3)	18 (12)	
Offspring	30 (20)	12 (8)	18 (12)	
Sibling	21 (14)	8 (5.4)	13 (8.7)	
Other	4 (3)	0 (0)	4 (2.7)	
Physical illness of caregiver				
Yes	45 (30)	42 (28)	3 (2)	<0.001**
No	105 (70)	27 (18)	78 (52)	

Satisfied: QOL score ≥ 75%, Unsatisfied: QOL score <75%

φSingle means separated/divorced/widow

PKR: Pakistani Rupees, QOL: Quality of Life

**p-value <0.001, *p-value<0.05

The findings of the WHO QOL-BREF scores showed that the mean QOL score the care givers was 65.36 ± 5.26 . The overall satisfaction of the participants who scored $\geq 75\%$ was observed in 69 (46%) of the caregivers (Figure 1). A significant association of QOL satisfaction was observed with age (p-value <0.001), employment status (p-value 0.040), monthly family income (p-value <0.001), and physical illness of caregiver (p-value <0.001) (Table 1).

Discussion

This study was conducted in informal caregivers of patients with Schizophrenia to assess their level of satisfaction with Quality of Life and to observe the relation of various socio demographic factors with it. Since the time of deinstitutionalization where the patients are supposed to be integrated into the community, the family is considered to be the main support. In Low and middle income countries like Pakistan, caregivers have to bear all the responsibilities of caring due to various moral and sociocultural reasons and as well as economic restraints that itself pose great burden on caregiving. Our study has found ominously dissatisfaction with QOL due to significant caregiving burden among caregivers of Schizophrenic patients due to various sociodemographic factors, age, gender, marital status, education, income, employment, duration of illness, physical illness in caregiver, relationship with the patient, duration of caregiving and family setup also added. This finding is mirrored in other studies. In a study conducted in Spain, Ribe et al² found significant caregiver burden. Caqueo-Urizar A et al³ in their updated review identified significant association of certain socio demographic, illness and caregiver specific factors with that of caregiver's burden and studied QOL of caregivers with severity of illness and found remarkable association. Zahid et al⁵ in Arab population studied the impact of caregiver burden on quality of care of patient. No study observed impact of family setup in the caregiving role, in this study we however intended to see it but statistically insignificant result was found. It could be due to the fact that our study population is already burdened because of so many other factors and most importantly financial restraint

and nuclear setup at one side gave advantage of reducing size of dependant family members and overall masked the true effect of social deprivation as a drawback of this joint family shift.

In our study, male subjects were found to be predominant in the caregiving role that contrasts with that of other studies such as Studies conducted by Souza et al¹³ and Derajew H et al¹⁴ acknowledged the female parent as the usual carer of the Schizophrenic patient in the adult group and also found direct positive relation of burden of care with the age group of caregivers. However, the current study refutes this finding. In this study males were found to be leading the caregiver role. The reason behind this contradictory finding could be due to the fact that in our society, females are usually ignored, or undermined by providing limited access to outdoor services and even health services and also devalued by not giving the credit of what they are actually doing due to sociocultural and other limitations, hence male to female ratio was significant in that way. Sharma N. et al¹⁵ also discussed this emerging point of male dominance in the care giving role. Despite this gender shift in the caregiving role we have found almost similar level of satisfaction among both genders. While Kumar S¹⁰ and Murthy RS¹⁶ have speculated contradictory finding, they found males to be more satisfied and females more burdened.

In our study, caregivers of above 45 years of age group were found to be more satisfied among other age groups. Similar age presentation was also observed in the work of Shamsai F et al¹⁷. We have also observed an interesting finding in our study related to schizophrenic patients age. The most patients were falling in the young to middle age group, only two patients were in the elderly age (>60yrs). This finding can be explained by the fact that Asian population is majorly belong to young age group and the diseased population usually doesn't survive for longer due to worse health services condition in middle and low income countries like us. Wallace J¹⁸ and Laursen T.M. et al¹⁹ with their work also explained the reason, they suggested patients with Schizophrenia have high mortality rate and around 15 years reduced life expectancy than that of general population. There are also poor resources available for the care of elderly patients especially in low income countries that

may hamper them to seek timely physical and mental health care²⁰.

The current study revealed certain important determining factors for QOL of caregivers such as monthly family income, employment, relationship with the patient and physical well being of the carer. Similar findings were also reported in studies conducted by Shamsei F. et al²¹. In a study conducted in China, Guan L et al²² compared the caregiving burden of caregivers of hospitalized and community based schizophrenia patients and found care givers of hospitalized patients to be less burdened than that of the community. While in our study we approached only community-dwelling schizophrenic patients with accompanying caregivers, hence the difference in burden of caregiving could not be certainly commented but it can be contemplated from the described scenario in low income countries that hospitalizing the patient would not help much to the caregiver in financial, psychosocial domains because they have to stay with their patients and often have to miss daily wages and bare added transportation expense or burden. Somehow, hospitalization may reduce physical burden by reliance on timely medication and availability of hospital staff.

Thus, overall caregiving burden encompasses a range of diverse concerns which include financial (bearing high expenses of psychiatric treatment), physical (taking care of the patient), emotional and social-handling, discriminatory behavior of public, distress due to patient's symptoms and moreover loss of productive time for themselves and poor QOL²³. In low and middle income countries like Pakistan, family member is usually considered to provide all the support like financial, emotional, social and physical to the patient in addition to his/her own genuine family responsibilities. Thus, this study has given a wakeup call to mental health professionals to identify and manage the caregivers' burden by bridging the gap in providing health services. The Stakeholders also have to play their part in budget allocation and provision of resources both for health professionals and patients in collaboration with the developed countries. The modern world has identified the caregiver's role and challenges in caring of patients with chronic mental health problems such as schizophrenia and bipolar spectrum disorder and also working on clinical grounds for preven-

tion and to support family members by offering various awareness, educational and interventional activities which help them to reduce their burden²⁴. This study is the primary step to move forward to the domains of better care and prevention of mental health problems among the caregivers at the national level. More work is needed to further expand the local evidence and to support the concept of intervention either psychological or pharmacological to improve the prognosis and reduce the overall burden of the family. For instance, awareness-raising programs and psycho-educational sessions should necessarily be organized specifically for caregiving individuals to explore their physical, psychological, social and environmental needs and develop care plan accordingly to mitigate imminent caregiving burden. The formal therapy sessions and other potential support resources should also be made available for them through collaborative functioning of social, psychological and psychiatric services, afterall only the least burdened caregiver can provide the efficient caregiving role.

Conclusion

The significant proportion of the caregivers of patients with Schizophrenia were dissatisfied with their quality of life. Nonetheless, in this study significant association of certain socio demographic factors were found with their Qol satisfaction. Those factors are caregiver's age, employment, economic status, relationship with the patient and the presence of physical illness. In order to improve their quality of life, clinicians must expand the horizon of professional care upto caregivers as well along with their patients preferably by providing personalized psycho educational and therapy sessions.

Conflict of Interests

Authors have no conflict of interests and received no grant/funding from any organization

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