

## Research Article

# A Study to Assess the Quality of Life among Caregivers of Patients of Schizophrenia in a Tertiary Care Centre of Western Maharashtra

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## ABSTRACT

**Introduction:** Treatment of the chronic mentally ill like patients of schizophrenia, mainly focuses on the patient and the caregivers get no attention. In bargain to providing care to patients, these caregivers experience poor quality of life (QOL). **Aims and Methods:** The present paper reports on the QOL of caregivers of schizophrenia patients attending the OPD of a tertiary care center in, Maharashtra India. Thirty caregivers were selected, with age between 20 and 50 years and providing care for more than 1 year after taking consent from them. Data were collected using WHOQOL BrefScale. **Results:** The four domains – physical health, social relationship, psychological, and environmental factors, were used to understand the QOL of the caregivers. The domain with the highest score was environmental factors (mean is 59.7), which consists of the following factors: Financial resources freedom, physical safety, and security health and social care, opportunities for acquiring new information, etc. The domain with the least score was physical health (54.65), related with the following factors – activities of daily living, fatigue mobility pain, discomfort sleep, and rest work capacity. Psychological and social relationship scores were 58.2 and 59.0, respectively. **Conclusion:** In this study, the QOL of these caregivers was obtained lowest in the physical domain. It is evident that the caregivers suffer from fatigue, insomnia, and their activities of daily living are hampered in the behest of caring for their loved one.

**Keywords:** Caregiver, Quality of Life, Physical health, Schizophrenia

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## Introduction

Schizophrenia is one of the most common psychiatric disorders, affecting approximately 1% of the world's population and is a leading cause of disability. Lifetime prevalence of schizophrenia is high, ranging from 0.4 to 1.4%, due to the early age of onset and chronic course of the disease.<sup>[1]</sup> Schizophrenia is ranked among the top ten leading causes of disease-related disability in the world. The chronic nature

of schizophrenia particularly affects the social dimension of patients.<sup>[2]</sup>

Decreased cognitive and social skills, and hypersensitivity to criticism and stress, can lead to patients becoming isolated from society and the object of stigmatization.<sup>[3]</sup> Therefore, treatment goals for patients with schizophrenia should not only include reducing the frequency, duration, and severity of episodes and overall morbidity but also to improve the quality of life (QOL) of caregiver of the patient which would help in better patient outcome.

A caregiver is a person who fulfills the need of physical and psychological well-being of the diseased individual. Caregiver's QOL is a multi-dimensional response to the perceived stress and negative appraisal resulting from taking care of an ill individual.

A caregiver plays a significant role both physically and mentally by taking care of a chronic mentally ill person. QOL of the caregivers is affected by the psychological, physical, social, and environmental factors which in turn directly affects the care received by the patients.<sup>[4]</sup> Treatment of the

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mentally ill mainly focuses on the patient and the caregivers gets no attention. Caring of the person looking after the patient is equally important especially in the caregivers of chronic mental illness like schizophrenia which is long-term care.

A person suffering from schizophrenia is less likely to get a good employment and to marry which produce higher amount of burden on the family of the patient in financial, routine activities, family interaction, physical health, and mental health of the family members. Due to this burden, the QOL of the caregivers gets affected in care giving of chronic mental illness which includes financial stress, domestic routine disturbance, disruption of social, and leisure activities of the family and less caring for other family members.<sup>[5]</sup>

A few decades ago, hospitals, or psychiatric institutions were in charge of caring for patients with schizophrenia; however, nowadays, with increased deinstitutionalization and focus on the community care this role is performed by the patient's family. Studies have shown that in Asia 70% of the schizophrenia patient live with their families. With not much knowledge and the care being a long term for these patients, it becomes a challenging role for the caregiver of the patient.<sup>[5]</sup>

The previous studies have found that caregivers of family members with various mental illnesses experience high psychological distress, severe financial and socio-psychological problems, as well as problems connected with everyday life which in turn result in a low QOL.

Family members are often inadequately prepared to be the main caregiver for their ill relatives and often experience stress given that these illnesses are long-lasting and have an unpredictable course.

Socio-demographic characteristics including age, marital status, education, employment status, and diagnosis of the ill relative have been shown to be associated with the psychological status and QOL of primary caregivers.

Caregivers experience psychological and emotional distress, reduction in social contact, financial difficulties, report lower life satisfaction, and poor physical and mental health as a result of caregiving. This chronic stress and daily hassles cause profound objective and subjective burden for caregivers of relatives with severe mental illness. Research has shown psychological distress such as anxiety, depression, and insomnia among caregivers of psychiatric out-patients to be twice as high as in the general population. Even with all these associated problems the family caregivers in chronic mental illness and in medical illness show their support for caring because of the sense of love or reciprocity, spiritual fulfillment, a sense of duty, guilt, and social responsibility and at times because of social pressure. Magliano *et al.* 2015 in study assessed the family burden in long-term diseases – comparative study in schizophrenia versus physical disorders. The study revealed that family caregivers in chronic mental illness and in medical illness show their support

for caring because of the sense of love or reciprocity, spiritual fulfillment, a sense of duty, guilt, and social responsibility and at times because of social pressure. Family caregivers, who accept caregiving as social and cultural norms, are more likely to suffer from psychological distress than caregivers with more positive motivation toward caregiving.<sup>[6]</sup>

### Assumption

The QOL among caregivers of patients of schizophrenia will be poor in the individual and social spheres.

### Inclusion criteria

The following criteria were included in the study:

1. Inclusion criteria were key caregivers of patients with schizophrenia with duration of illness of minimum 1 year and who are responsible for providing care to the patient on the day to day basis.
2. Age range of caregivers was 20–60 years.
3. Those who had given written informed consent to take part in the study.
4. Caregiver staying with the patient for at least previous 1 year.

The purpose of the study was described to them.

### Exclusion criteria

The following criteria were excluded from the study:

1. The caregivers with physical or mental comorbidities.
2. The caregivers who were caring for other members of the family also with any other chronic illness.
3. Caregivers not able to read or write English, Hindi, or Marathi.

### Operational definitions

1. QOL: It is the general well-being of individuals caring for schizophrenia patients who include life satisfaction, physical health, wealth, safety, security to freedom, religious beliefs, and mental well-being.
2. Schizophrenia: It is a chronic mental illness which is characterized by disturbances in cognition, perception, and affects the behavior of individual.
3. Caregiver: It includes the family member (spouse, siblings, parents, children, or close relative) who are regularly looking after the schizophrenic patients in terms of meeting the physical needs, emotional support, and providing financial aid, etc., for more than 1 year.

### Materials and Methods

#### Design

This was a cross-sectional descriptive study.

## Setting

This study was conducted at the psychiatric department OPD of a tertiary care center of Western Maharashtra.

## Population

Caregivers of schizophrenic patients.

## Target population

Caregivers of schizophrenia patients attending the OPD of psychiatric department of a tertiary care center of Western Maharashtra.

## Accessible population

Caregivers of schizophrenia patients attending the OPD of psychiatric department of a tertiary care center of Western Maharashtra at the time of data collection.

## Sample frame

Caregivers of the schizophrenic patients taking treatment from psychiatric OPD of a selected tertiary center Western Maharashtra who meet the inclusion criteria in the time period of research, i.e., 2 weeks.

## Sampling method

The sampling method was convenient sampling.

## Data collection tool

Two questionnaires were administered to the participants.

1. Socio-demographic data questionnaire was administered to collect data related to age, sex, duration of stay with patient, and relation with patient.
2. QOL was assessed using the World Health Organization (WHO) QOL BREF (WHOQOL-BREF) The WHO QOL assessment-abbreviated version (WHOQOL-BREF) is a 26-item, self-administered instrument. All items are constructed on variations of a 5-point Likert Scale, with scores from 1 to 5, enquiring on "how much," "how completely," "how often," "how good," or "how satisfied" the individual felt. Domain scores are scaled in a positive direction, with higher scores denoting higher QOL except for items 3, 4, and 26 which need to be reversed scored.

The various aspects of QOL are grouped into four domains – physical health, social factors, psychological, social relationship, and physical factors. The following table describes the various domains [Table 1].

The WHOQOL-BREF (Field Trial Version) produces a QOL profile. It is possible to derive four domain scores. There are also two items that are examined separately: Question

1 asks about an individual's overall perception of QOL and question 2 asks about an individual's overall perception of their health. The four domain scores denote an individual's perception of QOL in each particular domain. Domain scores are scaled in a positive direction (i.e., higher scores denote higher QOL). The mean score of items within each domain is used to calculate the domain score. Mean scores are then multiplied by 4 to make domain scores comparable with the scores used in the WHOQOL-100.

## Data measurement

Data measurement was done by self-administered questionnaire.

## Method of data collection

1. Consent was taken from the psychiatric department to conduct the study.
2. Participants who were meeting the inclusion criteria were selected by convenient sampling, at the OPD.
3. Consent from the participants was obtained and the purpose of the study was explained to them.
4. Socio-demographic data were collected from the participants.
5. The self-administered WHO QOL questionnaire was given to the participants and explained the components.
6. Few of the participants required assistance in completing the questionnaire in the form of clarifying doubts.
7. Participants who were unwilling to complete the questionnaire due to personal reasons were free to withdraw from the study.
8. The questionnaire was taken from the participants and analysis was performed further.
9. Confidentiality of the collected data was maintained and used only for the research purpose.

**Table 1:** Domains of quality of life

Domain	Facets incorporated within domains
1. Physical health	Activities of daily living dependence on medicinal substances and medical aids energy and fatigue mobility pain and discomfort sleep and rest work capacity
2. Psychological	Bodily image and appearance negative feelings positive feelings self-esteem spirituality/Religion/Personal beliefs Thinking, learning, memory and concentration.
3. Social relationships	Personal relationships social support Sexual activity
4. Environment	Financial resources freedom, physical safety and security health, and social care: Accessibility and quality home environment opportunities for acquiring new information and skills participation in and opportunities for recreation/leisure activities physical environment (pollution/noise/traffic/climate) transport

10. Data collection was done from 30 participants on various OPD days.

## Statistics and results

The data were analyzed using descriptive statistical measures, i.e., mean, frequency, and percentage distribution. The data are presented in tables and illustrated diagrams.

The data are presented under the following headings:

Section I: Description of socio-demographic variables in frequency and percentages.

Section II: Description of the assessment of QOL among the caregivers.

Section I: Assessment of socio-demographic data

Table 2 shows that out of the 30 samples the age of the caregivers on an average is 47.52, out of which based on the class interval given 11 (33%) fall between the age group of 30 and 39 years. The minimum of the participants, i.e., only 1 (3.3%) falls in the age group of 20–29 years. Youngest was a caregiver of 28 years and the oldest was of 56 years.

Table 3 shows that out of the total participants, females' caregivers remain the majority that is 60% of all the caregivers. From Table 4, it is revealed that the religious back ground of the participants was of Hindu – 50%, Muslim – 26.6%, and Christian – 23.4% denomination, out of which majority belonged to Hinduism.

As depicted in Table 5, the participants in the present study belonged to both nuclear and joint family but majority were from nuclear family 76.6%, as shown in Table 5.

**Table 2:** Age of the caregivers (n=30)

Age in years	f (%)
20–29	01 (3.3)
30–39	11 (33.3)
40–49	09 (30)
50–60	09 (33.3)

**Table 3:** Sex of the caregivers (n=30)

Sex	f (%)
Male	12 (40)
Female	18 (60)

**Table 4:** Religion status of the participants (n=30)

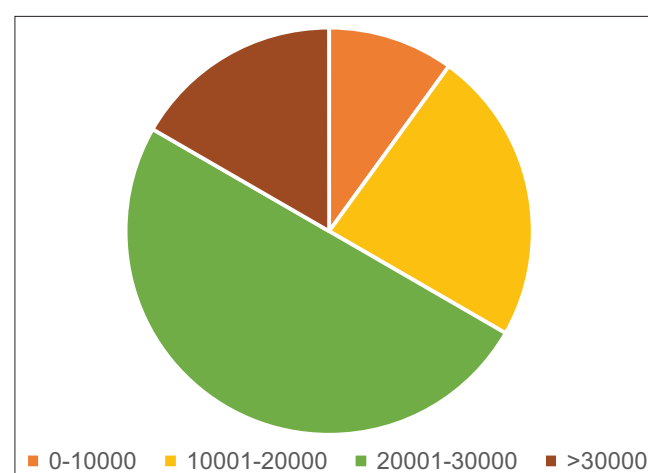
Religion	f (%)
Hindu	15 (50)
Muslim	8 (26.6)
Christian	7 (23.4)

**Table 5:** Family status of the participants (n=30)

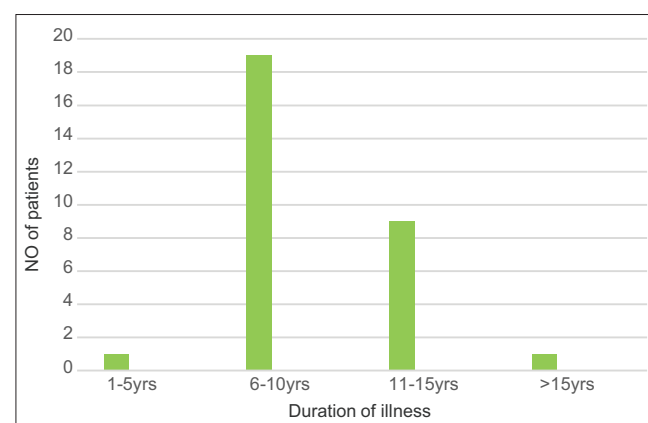
Family type	f (%)
Nuclear	23 (76.6)
Joint	7 (23.4)

Figure 1 shows the financial status of the participants and plays a key role in the QOL. The present study shows that maximum caregivers had an income of 20,001 to 30,000 showing that they were able to manage things financially. Only three caregivers income fell in the category of <Rs. 10,000, seven caregivers had income between Rs. 10,001 and 20,000, and only five caregiver had income of more than Rs. 30,000.00/month.

The duration of illness of patients in the present study is mentioned in Figure 2, of which maximum duration was between 6 and 10 years, nine patients duration was between 11 and 15 years. One patients in each 1–5 years and >15 years.



**Figure 1:** Monthly income of the caregivers



**Figure 2:** Duration of illness

**Table 6:** Quality of life assessment (n=30)

Domains	Caregivers of schizophrenia (mean)
Physical health	57.82
Psychological factors	58.20
Social relationship	59.06
Environment factors	59.71



## Section II: Assessment of QOL

Domains of QOL are divided into four. Physical health domains mean score is the least with 57.82 mean score [Table 6]. Psychological factors domain mean score is 58.2. The social relationship domain is of 59.06 mean score. The environment factor domain is 59.71 which is the highest mean score.

Each domain score was calculated after the raw data were converted into scores out of 100 as per the given scoring guidelines by WHO QOL BREF questionnaire. Then, the total mean was calculated. Few of the questions were reverse scored such as question number 3, 4, and 26.

### Significant findings

The socio-demographic parameters (age, sex, religion, type of family, income, and duration of disease condition) were assessed.

The mean age of the caregivers was found to be 47.2 years. Youngest was a caregiver of 28 years and the oldest was of 56 years.

The average duration of the disease condition was found to be 4.2 years with a minimum of 2 years to a maximum of 17 years.

Of the 30 participants, 18 of the caregivers were female as compared to 12 males, which were irrespective of the gender of the patients. This also correlates to the fact that majority of the caregivers are females in the families of the chronically ill patients.

The majority of the caregivers belonged to middle class family on the basis of income.

The four domains assessed as per the scale were physical health, social relationship, psychological, and environmental factors to understand the QOL of the caregivers.

The domain with the highest score is environmental factors (mean is 59.7), which consists of the following factors: Financial resources freedom, physical safety, and security health, and social care: Accessibility and quality home environment opportunities for acquiring new information and skills participation in and opportunities for recreation/leisure activities physical environment (pollution/noise/traffic/climate) transport.

The domain with the least score is physical health (54.65), related with the following factors – activities of daily living dependence on medicinal substances and medical aids energy and fatigue mobility pain and discomfort sleep and rest work capacity.

In the present study, the other domains had a respective mean of 58.23 (psychological) and 59.06 (social relationship)

### Discussion

It is evident that caregivers experience distress while caring for the patients especially for chronic patients like

schizophrenia where the patient requires long-term care. The caregivers experiences not only physical fatigue but also psychological and emotional drain out also. The long-term caregiver with daily hassles of providing care for the relative or loved one experiences poor QOL. Various studies have shown that caregivers experience psychological distress such as anxiety, depression, and insomnia and are at twice the risk of developing these conditions as compared to the common population.

Mental illnesses like schizophrenia are chronic and thus the psychiatric patient's family members who mainly are the caregivers experience stress. They may not only experience frustration, loneliness, and boredom but also feel that their own needs are unmet. This causes disturbance of the QoL and also mental decline in the health of family members as well as family dysfunction and ultimately diminishing family health.

The findings of this study revealed that the caregivers of schizophrenia patients scored low in all the four domains of WHO QOL. Moreover, it is evident from the present study that the physical health domain had scored the lowest which means that the caregivers suffered from fatigue, insomnia, reduced time for their own activities of daily living, reduced resources of income, and experienced poor facility for treatment.

The present study showed that the family caregivers had low QoL, which is consistent with the results of Caqueo-Úrizar *et al.*'s (2017)<sup>[7]</sup> studies. The results of the previous study also showed that the caregiver had lowest score in the physical health domain. The caregivers of patients with schizophrenia encountered common problems such as disturbance of sleep, reduced rest time, pain and discomfort, reduced energy, fatigue, and increased dependence on medical services and aids which are all belong to the physical domain of the questionnaire, resulting in low QoL of these caregivers.

Another significant finding is that the majority of the caregivers consisted of women. In the present study, 60% of the caregivers were females.

Women are still considered the main caregivers all over the world. In the United States, female caregivers comprise 66% of all caregivers. Women are expected to be more caring and shoulder the role of caring for the sick in the family by default. It seems the role of caregivers comes easy to the female gender as compared to the males. The women undertake this role more frequently than men therefore the burden of caregiving mainly is on the females in the family and accordingly they experience more negative impacts in their life.

### Conclusion

A descriptive study was carried out in 30 participants who were caregivers of schizophrenia patient. The study revealed poor QOL with the physical domain being the most affected in the caregivers. The study thus highlights the need to assess

and care for the caregivers who in turn suffers because of providing care for their patient.

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### References

1. National Collaborating Centre for Mental Health UK. Psychosis and Schizophrenia in Adults: Treatment and Management. National Institute for Health and Care Excellence (NICE) Clinical Guideline 178, February 2014. Available from: <http://www.nice.org.uk/guidance/cg178/resources/guidance-psychosis-and-schizophrenia-in-adultstreatment-and-management>. [Last accessed on 2019 Apr 15].
2. Rössler W, Salize HJ, van Os J, Riecher-Rössler A. Size of burden of schizophrenia and psychotic disorders. *Eur Neuropsychopharmacol* 2005;15:399-409.
3. Baronet AM. Factors associated with caregiver burden in mental illness: A critical review of the research literature. *Clin Psychol Rev* 1999;19:819-41.
4. Lee T, Yang Y, Chen P, Hung N, Lin S, Chang F, *et al*. Different dimensions of social support for caregivers for patient with schizophrenia: Main effect and stress-buffering models. *Psychiatry Clin Neurosci* 2006;60:546-50.
5. Sefasi A, Crumlish N, Samalini P, Kinsella A, O'Callaghan E, Chilale H. A little knowledge: Caregiver burden in schizophrenia in Malawi. *Soc Psychiatry Psychitry Epidemiol* 2008;43:160-4.
6. Magliano L, Fiorillo A, De Rosa C, Malangone C, Maj M. National mental health project working group. Family burden in long-term diseases: A comparative study in schizophrenia vs. physical disorders. *Soc Sci Med* 2005;61:313-22.
7. Caqueo-Úrizar A, Alessandrini M, Urzúa A, Zendjidian XX, Boyer L, Williams RD. Caregiver's quality of life and its positive impact on symptomatology and quality of life of patients with schizophrenia. *Health Qual Life Outcome* 2017;15:76.