

Original Research Article

Burden and quality of life in caregivers of obsessive-compulsive disorder and schizophrenia: a cross-sectional study

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ABSTRACT

Background: Obsessive-compulsive disorder (OCD) and schizophrenia both are chronic and disabling mental illness which imposes considerable burden on caregivers. Many studies have also reported that both of them have a negative impact on the quality of life (QOL) of both the patients and the caregivers living with the patients. The aim of the study was to assess and compare the burden of care and quality of life (QoL) in the care givers of patients with Obsessive-Compulsive Disorder (OCD) and Schizophrenia.

Methods: The present study is a hospital based, cross-sectional and comparative study. 30 patients with schizophrenia and 30 Obsessive-Compulsive Disorder patients and their caregivers attending the OPD and family ward of Institute of Mental Health and Hospital, Agra were selected through purposive sampling with specific inclusion and exclusion criteria. World Health Organization Quality of Life Scale (BREF version), Burden Assessment Schedule, Positive and Negative Syndrome Scale (PANSS), Yale-Brown Obsessive Compulsive Scale (Y-BOCS) were used for assessment.

Results: The findings of this study revealed remarkable burden in the caregivers of OCD and Schizophrenia patients along with considerable and comparable impairment of their quality of life. Caregivers of Schizophrenia patients experienced more burden and have poor quality of life than the caregivers of OCD patients.

Conclusions: It is suggested to develop effective strategies for family intervention with the purpose of supporting the caregivers and improving their quality of life.

Keywords: Burden of care, Families of psychiatric patients, Schizophrenia, Obsessive-compulsive disorder, Quality of life

INTRODUCTION

Obsessive-compulsive disorder (OCD) is a chronic and disabling mental illness and its lifetime prevalence rate is approximately 2.5% to 3.29%.^{1,2} Due to high prevalence it is considered as the fourth most common psychiatric disorder and currently demands more attention from the clinicians and researchers for its treatment as well as management.¹ Most of the OCD patients develop comorbid psychiatric conditions in due course of time. The symptom severity combined with associated psychiatric

conditions causes the OCD patients to develop general impairment in many areas such as in marital, occupational, emotional and social functioning and they face difficulty even in performing their routine work.^{3,4} Many studies have reported that OCD have a negative impact on the quality of life (QOL) of both the patients and the caregivers living with the patients.⁴⁻⁸ QOL concept comprises different dimensions: individual's physical and emotional health, psychological and social well-being, fulfilment of personal expectations and goals, economic assurance and finally functional capacity to develop daily routines

normally.^{9,10} Few researchers in their studies have mentioned that the treatment responders also have experienced poor QoL.^{11,12} They also reported poor QoL in the domains of physical wellbeing, psychological wellbeing and social relationships.⁷ Studies on comparing the QoL of OCD patients with other similar psychiatric conditions revealed that OCD patients have shown similar or more impairment in several areas as compared to other psychiatric patients.^{4,7,11,13}

Literature on burden in caregivers of psychiatric patients have shown that OCD imposes considerable burden on caregivers due to the nature of illness.¹⁴⁻¹⁸ The burden of care is conceptualized as a syndrome of multiple factors that can have an effect on carers' general and mental health. Repeated compliance to the OCD behaviour of the patient, caregivers develop anger/frustration/fatigue, depression which puts an extra burden on them.

Schizophrenia as a chronic mental illness also produce substantial burden among the family members. Caregivers are significantly stressed and experience high levels of burden. In schizophrenia patients caregiver's burden has been found to be associated with reduction in their QOL, resulting deterioration in their health status.¹⁹

Many investigators have conducted comparative studies by measuring the impairment in OCD and schizophrenic patients across several dimensions.^{4,20} Some studies have reported more and others reported similar or lower level of burden in the caregivers of schizophrenia patients as compared to OCD patients.²¹⁻²³ This controversial issues needs to be resolved by undertaking more similar studies. Some researchers also suggested that currently informal and formal caregivers are being considered as a valuable component of an integral treatment for patients, thus their QOL and burden are being evaluated.^{24,25} Schizophrenia as a psychotic disorder, and OCD, being a neurotic disorder having similar type of impairment as well as disabling potential. So the challenges faced by caregivers in taking care of their relatives suffering from Schizophrenia and OCD needs to be compared. Caregiver's burden and quality of life have been studied in patients with schizophrenia and affective disorders but literature is less with regard to caregiver's burden and quality of life in OCD.

Aim

To assess and compare the burden of care and quality of life (QoL) in the care givers of patients with Obsessive-Compulsive Disorder (OCD) and Schizophrenia.

METHODS

Study site

The study was conducted at the Institute of Mental Health and Hospital, Agra. It is a tertiary referral centre with bed strength of 800 and a postgraduate teaching hospital. This

hospital has a wide catchment area which includes the states of Uttar Pradesh, Madhya Pradesh, Rajasthan, Haryana and Uttarakhand.

Study design

The present study is a hospital based, cross-sectional and comparative study.

Sample

30 Schizophrenia patients, 30 Obsessive-Compulsive Disorder patients and their caregivers attending the outpatient department and family ward of the hospital were selected through purposive sampling with the following inclusion and exclusion criteria.

Inclusion criteria for patients

Patients fulfilling the diagnostic criteria of Obsessive-compulsive Disorder and Schizophrenia as per ICD-10 DCR criteria. Age group of both patients and caregivers ranging from 18-60 years. Patients and caregivers of either sex. At least 2 years minimum duration of illness and 1 year spousal exposure to illness. Presence of a key caregiver having adequate knowledge about patient and his/her illness and with the maximum contact with the patient (parents/spouse/sibling/children). Those who gave informed consent to participate in the study.

Exclusion criteria for patients

Patients and caregivers with a history of neurological disorders such as seizures, movement disorders, cerebral palsy and concomitant severe medical illnesses (example, uncontrolled endocrine abnormalities, cardiovascular or pulmonary diseases). Patients and caregivers having another family member with mental illness or chronic medical illness in the same household

Tools

Following tools were used to collect the data: a semi-structured proforma was designed to collect socio-demographic information like age, sex, residence etc. about the patients and their caregivers along with the clinical information like the age of onset, duration of illness, treatment taken etc.

World Health Organization quality of life (BREF version)²⁶

WHO quality of life scale is a highly validated instrument, purports to measure the individual's perception of their life in terms of their goal, satisfaction and achievements in their social, cultural and economic background. WHO-QOL BREF is an abbreviated version with about 26 items measuring the quality of life across four domains viz physical, psychological, social relationship and environmental domains. It is available in the Hindi

language and evaluates subjective QOL in the past 2 weeks. The responses range from 1 (very dissatisfied) to 5 (very satisfied). The total score range between 26 and 130 and higher score indicates a better QOL.

Burden assessment schedule (BAS) (Thara et al)²⁷

The Burden Assessment Schedule (BAS) is an Indian based culturally sensitive semi-structured reliable and valid interview devised for assessment of perceived burden in the caregivers of subjects with chronic psychiatric illness developed by Thara et al.²⁷ It is a 40-item scale measuring 9 different areas of objective and subjective caregiver burden. Each item is rated on a 3-point scale with 1- not at all, 2- to some extent, 3- very much. Total scores range from 40 to 120 with higher scores indicating greater burden.

Positive and negative syndrome scale for schizophrenia (PANSS) (Kay et al)²⁸

The PANSS is a clinician-administered, 30-item semi-structured interview consisting of 7 items assessing positive symptoms (example- hallucinations, delusions, conceptual disorganization), 7 items assessing negative symptoms (example- blunted affect, passive/ apathetic social avoidance) and 16 items assessing global psychopathology (example- depression, anxiety, lack of insight, guilt). All items are scored between 1 (not present) and 7 (severe).

Yale brown obsessive-compulsive scale (Y-BOCS) (Goodman et al)²⁹

It is a clinician-rated scale used for assessing the severity of illness in patients of OCD. It consists of 10-items, each item rated from 0 (no symptoms) to 4 (extreme symptoms)

having range of 0–40, with separate subtotals for severity of obsessions and compulsions.

Procedure

After getting the Ethical clearance from the hospital ethics committee, and getting the written informed consent from the participants, the investigator selected 30 schizophrenia patients, 30 OCD patients and their caregivers through purposive sampling on the basis of prefixed inclusion and exclusion criteria from outpatient /in patient department of the hospital. Detailed socio-demographic and clinical information of patients and their caregivers was recorded on the socio-demographic and clinical data sheet designed for this purpose. Subjects were assessed by the investigator by using following tools such as (WHO-QOL) BREF, Burden Assessment Schedule (BAS), Positive And Negative Syndrome Scale For Schizophrenia (PANSS) and Yale Brown Obsessive-compulsive Scale (Y-BOCS). Data were recorded in data sheets for analysis. Minimum one patient or maximum two patients were assessed per day. This procedure continued till completion of all the participants.

Statistical analysis

The Statistical package for the social sciences version 20 (SPSS-20) was used for analysis. Frequency, percentage, Mean, standard deviation Independent t- test Chi- square test and correlations were computed.

RESULTS

Table 1 shows the socio-demographic details of the participants and caregivers. The mean age of the patient was 31.53±6.842 years and 31.60±7.740 years in schizophrenia and OCD groups respectively.

Table 1: Socio-demographic characteristics of patients and caregivers.

| Variables | Schizophrenia Mean / SD Frequency (Percentages) | OCD Mean /SD Frequency (Percentages) | t-value/ Chi-square value | Significance level | |
|----------------------------|---|--------------------------------------|---------------------------|--------------------|-----------|
| Age of patient (years) | 31.5 ± 6.84 | 31.6 ± 7.74 | 0.03 | P> 0.05 | |
| Caregivers age (Years) | 39.7 ±12.2 | 41.1 ±11.6 | 0.43 | P> 0.05 | |
| Sex of patient | Male | 21 (70) | 5.45 | P<0.05 | |
| | Female | 9 (30) | | | 18 (60) |
| Religion of patient | Hindu | 24 (80.0) | 0.11 | P>0.05 | |
| | Islam | 6 (20.0) | | | 5 (16.7) |
| Domicile of patient | Urban | 12 (40.0) | 6.79 | P<0.05 | |
| | Rural | 18 (60.0) | | | 8 (26.3) |
| Marital status of patients | Married | 14 (46.7) | 6.42 | P<0.05 | |
| | Unmarried | 8 (26.7) | | | 11 (36.7) |
| | Divorced | 8 (26.7) | | | 1 (3.3) |
| Socioeconomic status | Lower | 18 (60.0) | 5.45 | P<0.05 | |
| | Upper, middle | 12 (40.0) | | | 21 (70.0) |

Continued.

| Variables | | Schizophrenia Mean / SD Frequency (Percentages) | OCD Mean /SD Frequency (Percentages) | t-value/ Chi- square value | Significance level |
|-----------------------------------|------------|--|---|-------------------------------------|-----------------------|
| Family type | Nuclear | 21 (70.0) | 23 (76.7) | 0.34 | P>0.05 |
| | Joint | 9 (30.0) | 7 (23.3) | | |
| Educational qualification | Illiterate | 6 (20.0) | 4 (13.3) | 5.74 | P<0.05 |
| | Up to HSC | 17 (56.7) | 10 (33.3) | | |
| | Above HSC | 7 (23.3) | 16 (53.3) | | |
| Occupation of patients | Unemployed | 23 (76.7) | 18 (60.0) | 1.93 | P>0.05 |
| | Employed | 7 (23.3) | 12 (40.0) | | |
| Sex of caregiver | Male | 16 (53.3) | 19 (63.3) | 0.62 | P>0.05 |
| | Female | 14 (46.7) | 11 (36.7) | | |
| Education qualification caregiver | Illiterate | 2 (6.7) | 1 (3.3) | 1.31 | P>0.05 |
| | Up to HSC | 19 (63.3) | 16 (53.3) | | |
| | Above HSC | 9 (30.0) | 13 (43.3) | | |
| Occupation of caregiver | Unemployed | 15 (50) | 11 (36.7) | 1.09 | P>0.05 |
| | Employed | 15 (50) | 19 (63.3) | | |
| Duration of contact with patient | ≤12 hours | 10 (33.3) | 11 (36.7) | 0.07 | P>0.05 |
| | >12 hours | 20 (66.7) | 19 (63.3) | | |
| Caregivers relationship | Parent | 10 (33.3) | 9 (30.0) | 1.59 | P>0.05 |
| | Spouse | 13 (43.3) | 17 (56.7) | | |
| | Sibling | 6 (20.0) | 3 (10.0) | | |
| | Children | 1 (3.3) | 1 (3.3) | | |

Table 2: Clinical variables of patients.

| Variables | Schizophrenia Mean / SD | OCD Mean /SD | t/chi-square | Significance level |
|----------------------------|----------------------------|-----------------|--------------|--------------------|
| Age of onset (years) | 22.90 ± 4.49 | 24.96 ± 6.83 | 1.38 | P > 0.05 |
| Duration of illness | 8.60 ± 5.29 | 6.63 ± 4.42 | 1.56 | P > 0.05 |
| PANSS | 80.77 ± 12.06 | 27.80 ± 4.64 | 0.07 | P > 0.05 |
| Treatment adherence | | | | |
| Good | 14 (46.7) | 24 (80) | 7.18 | P<0.05 |
| Poor | 16 (53.3) | 6 (20) | | |
| Family history | | | | |
| Absent | 24 (80) | 28 (93.3) | 2.30 | P>0.05 |
| Present | 6 (20) | 2 (6.7) | | |
| Suicidal attempt | | | | |
| Absent | 21 (70) | 27 (90) | 3.75 | P>0.05 |
| Present | 9 (30) | 3 (10) | | |

Table 3: Comparison of burden score in caregivers of OCD and schizophrenic patients.

| Variables | Diagnosis of patient | N | Mean/SD | t-value | Sig. level |
|-----------------|----------------------|----|--------------|---------|------------|
| BAS Total Score | Schizophrenia | 30 | 89.17 ± 8.14 | 3.17 | P<0.01 |
| | OCD | 30 | 81.13±11.24 | | |

70% male patients were in schizophrenia group and 60% female patients were in OCD group. Majority of patients were Hindu i.e 80% to 83.3% in both the groups. 60% of

schizophrenic patients belonged to rural area and 66.7% patients of OCD belonged to urban area. Divorced patients were more in the schizophrenia group as compared to OCD group.

Table 4: Comparison of quality of life score in caregivers of OCD and schizophrenic patients.

| Variables | Diagnosis of patient | N | Mean | t-value | Sig. level |
|---------------------------------------|----------------------|----|--------------|---------|------------|
| WHOQOL-BREF Raw Score Domain 1 | Schizophrenia | 30 | 21.50 ± 1.83 | 0.36 | P>0.05 |
| | OCD | 30 | 21.27±3.03 | | |
| WHOQOL-BREF Raw Score Domain 2 | Schizophrenia | 30 | 18.43±1.73 | 2.50 | P<0.01 |
| | OCD | 30 | 19.97±2.88 | | |
| WHOQOL-BREF Raw Score Domain 3 | Schizophrenia | 30 | 8.83± 1.34 | 1.40 | P>0.05 |
| | OCD | 30 | 9.40 ±1.75 | | |
| WHOQOL-BREF Raw Score Domain 4 | Schizophrenia | 30 | 17.10 ± 4.16 | 4.73 | P<0.01 |
| | OCD | 30 | 22.07±3.96 | | |

The rate of unemployment is high and socioeconomic status is low in schizophrenia group as compared to OCD group. Majority of patients were from nuclear family type in both the groups.

The mean age of caregiver was 39.77±12.249 years and 41.10±11.621 years in the schizophrenia and OCD groups respectively. Majority of caregivers were male in both the groups. 50% of the caregivers were employed in the schizophrenia group while in OCD group 63.3% of the caregivers were employed. Spouses were the major caregivers in both the groups.

Table 2 shows the clinical characteristics of patients. The mean and SD of onset age of illness was 22.9±4.497 years and 24.966±6.835 years in schizophrenia and OCD respectively. The mean and SD of total duration of illness was 8.6±5.295 years for schizophrenia and 6.633±4.421 years for OCD. The mean and SD of PANSS total score was 80.77±12.065. in schizophrenia and total Y-BOCS score was 27.80±4.642 in OCD group. Treatment adherence was poor (53.3%) in the schizophrenia group while there was good treatment adherence (80%) in the OCD group. History of suicidal attempts was present in 30% and 10% of patients with schizophrenia and OCD respectively.

Table 3 shows the comparison of burden scores in schizophrenia and OCD group. The mean and SD of burden score was 89.17±8.137 in Schizophrenia and 81.13±11.236 in OCD groups. The t-value was 3.17 which is significant at 0.01 level.

Table 3 shows the comparison of quality of life scores in schizophrenia and OCD group. In physical health (Domain-1) the mean and SD of quality of life score was 21.50±1.83 in Schizophrenia and 21.27±3.03 in OCD group. The t value was 0.36 which is not statistically significant.

In psychological domain (Domain-2) the mean and SD of quality of life score was 18.43±1.73 in Schizophrenia and

19.97±2.88 in OCD group. The t value was 2.50 which is statistically significant at 0.01 level.

In social relationships domain (Domain-3) the mean and SD of quality of life score was 8.83±1.34 in Schizophrenia and 9.40 ±1.75 in OCD group. The t value was 1.40 which is not statistically significant.

In Environment domain (Domain-4) the mean and SD of quality of life score was 17.10±4.16 in Schizophrenia and 22.07±3.96 in OCD group. The t value was 4.73 which is statistically significant at 0.01 level.

DISCUSSION

Socio-demographic data Socio-demographic and clinical characteristics of the patients (Table 1, 2) such as occupation, educational qualification, age, family type, religion, patient locality (urban or rural), total duration of illness, age of onset of illness and family history of illness are comparable in both study groups, except for patients' marital status, gender, treatment adherence and socioeconomic status.

Divorce and separation are found to be more prevalent in the case of patients with schizophrenia group as compared to OCD group. This finding is supported by Oza et al who found similar results. Most of the patients in the schizophrenia group had poor treatment adherence and were from lower socioeconomic status than the OCD group.³⁰ This can be understood in the light of the chronic debilitating nature of illness, symptom severity that leads to significant impairment in socio-occupational functioning.

The analysis of gender revealed that females outnumbered the males in the OCD group and majority of patients with OCD were from urban background. This finding is in agreement with the study by Thomas et al²² and Siddharth et al.³¹ The poor representation of rural population may be due to the inability to understand this being an illness. The socio-demographic characteristics of caregivers in both the groups as (Table 3) are comparable in terms of age, gender,

educational level, occupation, duration of contact with the patient and caregiver's relationship with patient. Kaushal et al in their studies reported similar results.³²

Comparison of caregivers burden in OCD and schizophrenia

Burden scores in schizophrenia and OCD (Table 4) revealed that caregivers of patients in both groups have experienced considerable burden. However, on comparison it is seen that caregivers of schizophrenic patients reported greater burden than the OCD group. Other Indian studies also supported our finding and revealed that families of patients with schizophrenia experience greater burden which is reflected in the areas of family finances, family routine, family leisure and family interactions as compared to families of OCD.^{6,22,32} This can be partly attributed to the nature of chronic illness which causes significant psychosocial dysfunction in patients leading to greater degree of perceived burden in caregivers.

On the contrary Veltro et al found only modest qualitative and quantitative difference between key relatives of schizophrenic and neurotic patients with regard to their perception of burden.³³ Few researchers have also reported no statistically significant difference in the burden or more burden experienced by families of patients with OCD as compared to schizophrenia.^{21,23,34}

Some possible reasons for the greater extent of burden in OCD could be due to longer duration and increased severity of symptoms, which the authors have not specifically addressed in their studies. The healthy coping mechanisms adopted by the caregivers might play a significant role in reducing burden in schizophrenia.

Comparison of quality of life in caregivers of OCD and schizophrenia

Quality of life scores (Table 5) of caregivers of patients with schizophrenia and OCD group revealed significant impairment in all domains such as physical health, psychological well-being, social relationships and quality of environment. Caregivers of schizophrenia group scored significantly less as compared to OCD group. This implies that caregivers of OCD group had better psychological well-being and quality of environment as compared to schizophrenia group. This is in agreement with the study by Kaushal et al who reported that caregivers of OCD group had better physical, psychological well-being and quality of environment as compared to schizophrenia group.³²

Schizophrenia being a lifelong psychotic illness is associated with prevailing stigma causes higher psychological distress in caregivers of schizophrenics. Deterioration in socio-occupational functioning of patients puts an extra demand on the caregivers to perform all the

routine activities of the patients. Most of the caregivers accept caregiving as their moral responsibility particularly in Indian setting and try to fulfil all the demands of their ill relatives paying no or little attention to their own health and care.

Studies conducted by Negm et al and Solanki et al have documented that in the QoL domains, there was no statistically significant difference between the schizophrenic and OCD groups which is the opposite findings of our study. Detail interview with the patients may specify some points contributing to this findings.^{34,35}

Limitations

The study is limited by not incorporating many variables such as stigma, coping, social support etc. which may have influence on burden and Quality of life. These variables may be taken in future along with devising appropriate intervention strategies to improve quality of life and reduce burden.

CONCLUSION

The findings of this study revealed remarkable burden in the caregivers of OCD and Schizophrenia along with considerable and comparable impairment of their quality of life. Caregivers of Schizophrenia experienced more burden and have poor quality of life. It suggest to develop effective strategies for family intervention with the purpose of supporting the caregivers and improving their quality of life.

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