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Comparison of caregiver burden in schizophrenia and obsessive–compulsive disorder

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Summary

Aims and objectives: To assess and compare the burden of care and psychiatric morbidity in caregivers of patients with schizophrenia and obsessive–compulsive disorder (OCD), and to study the burden of care in relation to socio-demographic characteristics and disease-related factors.

Materials and methods: The study was conducted at the Department of Psychiatry, Civil Hospital, Ahmedabad. Fifty consecutive patients with schizophrenia and OCD and their primary caregivers were assessed. Burden of care was assessed using the Family Burden Interview Schedule (FBIS). Psychiatric morbidity was assessed using the General Health Questionnaire-28 (GHQ-28). The data were analyzed with SPSS, chi-squared test, *t*-test and Pearson correlation.

Results: Burden of care was higher in caregivers of schizophrenia patients in 5 domains – financial burden, disruption of family routine, disruption of family leisure, disruption of family interaction and effect on physical health. However, a statistically significant higher score was observed only for the domain of disruption of family routine. Caregivers of patients with schizophrenia had higher psychiatric morbidity but anxiety and insomnia were significantly higher in caregivers of patients with OCD. Suicidality was significantly higher in the schizophrenia group caregivers. Spouses in the schizophrenia group had higher burden and distress. As family burden increased, psychiatric morbidity in caregiver also increased.

Conclusions: Though the extent of burden of care and psychiatric morbidity was higher in caregivers in the schizophrenia group, caregivers in the OCD group also had considerable burden of care as well as psychiatric morbidity.

schizophrenia / obsessive–compulsive disorder / caregiver / burden

INTRODUCTION

Chronic psychiatric disorders create numerous psychosocial difficulties for patients and caregivers. These psychosocial difficulties are collectively known as "burden of care". The burden of care can be conceptualized as a syndrome of varying factors that can affect the caregivers' general and mental health.

Caregiver burden has two dimensions:

- Objective burden – effects on the household, including financial loss; impact on family members' health, on children and on family routines; and the abnormal behaviours shown by the patient.

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- Subjective burden – the extent to which relatives feel they carry a burden [1]. Some researchers have erroneously considered it the same as stress.

The assessment of disability in patients with chronic psychiatric illness has become an important issue in recent years. Considerable research has been done assessing the burden of care in caregivers of patients with chronic psychiatric illnesses such as schizophrenia or affective disorder. Several studies have found considerable burden of care in caregivers of patients with schizophrenia [2-5]. Indian studies on family burden have mainly focused on schizophrenia and mood [6-11]. In general, they found higher burden of care among caregivers of patients with schizophrenia.

In comparison, there is very little research related to the burden experienced by caregivers of people with obsessive–compulsive disorder (OCD) and there has been a growing commitment recently to understanding the impact of OCD on family functioning. Two studies suggested that family members often modify the family routines and other functioning to accommodate their relative's rituals [12,13]. Family members are also frequently drawn into the ritualistic behaviors of OCD patients [12,14,15]. A few studies have shown that OCD is often associated with marital discord [16,17], inability to maintain relationships with others, especially friends [16], sexual problems [18], financial hardship [16,19], cutting down on family routines including leisure [19], and poor family relationships [20,21].

Black et al. [22] have shown that spouses of patients with OCD frequently face disrupted marital/family/social life, sexual problems, family conflicts, anger/frustration and disrupted personal life [22]. The authors have also noted that OCD families are less healthy than control families with regard to communication, affective involvement and general functioning.

Jayakumar et al. [23] and Thomas et al. [24] studied the impact of OCD and schizophrenia on family members in a comprehensive manner. Jayakumar compared the burden in key relatives of patients with OCD and schizophrenia [23]. They found that caregivers' burden associated with OCD is either greater than or nearly comparable to that of schizophrenia. In a similar comparative study, Thomas et al. [24] found that the extent of psychosocial dysfunction was greater in patients with schizophrenia, but OCD patients were also significantly impaired in their psychosocial functioning with a positive correlation with the burden of care.

There is a dearth of studies comparing psychosocial dysfunction and related family burden in psychotic and non-psychotic disorders. Hence, the aim of the present investigation was to assess and compare the extent and pattern of psychosocial dysfunction and family burden in schizophrenia and OCD, and to find relationships between these two constructs in the two disorders.

AIMS AND OBJECTIVES

To assess and compare the burden of care and psychiatric morbidity in caregivers of patients with schizophrenia and OCD.

To study burden with relation to socio-demographic characteristics and disease-related factors.

MATERIALS AND METHODOLOGY

Setting and duration

The study was conducted at Civil Hospital, Ahmedabad, which is a 5000-bed hospital affiliated to B. J. Medical College in Ahmedabad, India, between November 2014 and July 2015. Ethical permission was granted by the institutional ethics committee.

SAMPLE

Fifty consecutive caregivers of OCD patients and 50 consecutive caregivers of schizophrenia patients were studied. For the purpose of this study, the Pollack & Perlick method of identifying a primary caregiver [25] was used: "Primary caregiver is one who satisfied 3 or more of the following 5 criteria: spouse, parent or spouse equivalent, most frequent contact with patients, supports patient financially, most frequent collateral participant in patient's treatment, is the person contacted in case of emergency."

Inclusion criteria included the presence of primary caregiver attending hospital, illness duration of at least 1 year, and psychiatric diagnosis of either schizophrenia or OCD according to DSM-5 diagnostic criteria [26]. Exclusion criteria were no caregiver consent to participate in the study as well as patient-related characteristics: duration of illness less than 1 year, chronic medical comorbidity, chronic psychiatric comorbidity (depression, anxiety disorders, personality disorders or substance use disorder).

METHODOLOGY

Written informed consent was obtained from all caregivers who participated in the study. Patient consent was not required as the caregivers were the primary focus of the study. Socio-demographic data for both caregivers and patients were collected via a semi-structured interview involving the caregivers of patients who attended the hospital's outpatient or inpatient department along with the patient. The caregiver burden was measured with the Family Buden Interview Schedule (FBIS) [1] and psychiatric morbidity was measured with the General Health Questionnaire-28 (GHQ-28) [27].

The FBIS, developed by Pai & Kapur, is a semi-structured interview which consists of 6 domains and 24 items [1]. It comprises 6 following subscales: financial burden (6 items), disruption of routine family activities (5 items), disruption of family leisure (4 items), disruption of family interactions (5 items), effect on physical health (2 items), and effect on mental health (2 items). Each item is scored 0, 1 or 2 depending on severity. At the end, subjective burden is also assessed and rated by severity at 0, 1 and 2. The validity and reliability of the scale has been shown to be satisfactory; the inter-rater reliability for all items was reported to be more than 0.78.

The GHQ-28 [27] consists of 28 questions. The validity and reliability of the scale has been shown to be satisfactory. A csut-off score of 4 or more is indicative of psychiatric morbidity.

ANALYSIS

The data were first analysed using SPSS version 17, and chi-square and *t*-test were used in further analysis. $P < 0.05$ is considered as statistically significant. Bivariate correlation (Pearson correlation) was calculated between the FBIS and GHQ scores.

RESULTS

Table 1 shows the comparison of socio-demographic characteristics of patients with schizophrenia and OCD. Most of the socio-demographic variables are comparable in both groups. Patients with OCD attained higher education than patients with schizophrenia, whereas divorce and separation were more frequent among patients with schizophrenia.

Table 1. Comparison of socio-demographic characteristics of patients with schizophrenia and OCD

Variable		OCD (N=50) n (%)	Schizophrenia (N=50) n (%)	Chi-square test
Caregiver	Spouse	19 (38)	19 (38)	χ^2=2.762
	Parents	22 (44)	16 (32)	df=3
	Siblings	7 (14)	10 (20)	p=0.42
	Children	2 (4)	5 (10)	
Gender	Male	34 (68)	34 (68)	χ^2=0
	Female	16 (32)	16 (32)	df=1
				p=1
Marital status	Single	22 (44)	13 (26)	χ^2=6.16
	Married	25 (50)	27 (54)	df=2
	Divorced/Separated	3 (6)	10 (20)	p=0.04

Occupation	Professional & skilled Semi & unskilled Unemployed	13 (26) 19 (38) 18 (36)	7 (14) 26 (52) 17 (34)	χ^2=2.917 df=2 p=0.23
Education	Graduate/post-graduate High school & diploma Up to 10th Standard Illiterate	13 (26) 11 (22) 21 (42) 5 (10)	3 (6) 7 (14) 31 (62) 9 (18)	χ^2=10.2 df=3 p=0.01
Income	<5,000 5,000-10,000 >10,000	14 (28) 20 (40) 16 (32)	18 (36) 24 (48) 8 (16)	χ^2=3.53 df=2 p=0.17
Family type	Nuclear Extended	34 (68) 16 (32)	36 (72) 14 (28)	χ^2=0.1905 df=1 p=0.66
Religion	Hindu Islam Christian	44 (88) 5 (10) 1 (2)	46 (92) 4 (8) 0 (0)	χ^2=1.156 df=2 p=0.56
Locality	Urban Rural	41 (82) 9 (18)	34 (68) 16 (32)	χ^2=2.613 df=1 p=0.10

Table 2 shows disease-related characteristics of the patients. These parameters are also almost identical, except for age.

Table 2. Disease-related patient characteristics

Variable	Descriptives	OCD (N=50)	Schizophrenia (N=50)	T-test
Age	Range Mean (SD)	19-65 35.34 (11.15)	20-58 35.90 (7.73)	F=2.08061, df=49,49 p=0.01
Duration of illness	Range Mean (SD)	1-27 8.66 (6.59)	2-26 8.80 (5.07)	F=1.68949, df=49,49 p=0.07
Age at onset	Range Mean (SD)	15–51 26.68 (7.48)	17–44 27.10 (5.67)	F=1.74035, df=49,49 p=0.06 (0.0552)
Family history	Yes No	13 (26) 37 (74)	16 (32) 34 (68)	χ^2=0.4371, df=1 p=0.51

Table 3 is a comparison of subscales and total scores of FBIS in the schizophrenia and OCD caregiver groups. The table shows that burden of care was higher in the schizophrenia group on all domains except "effect on mental health", where burden was slightly higher in the OCD group. The difference was statistically significant for the domain of "disruption of routine family activities", which was higher in schizophrenia caregivers (p=0.0377).

Table 3. Comparison of subscales and total score of FBIS in schizophrenia and OCD caregivers

Variable	Descriptives	OCD (N=50)	Schizophrenia (N=50)	T-test
Financial burden	Range (12) Mean (SD)	3–10 6.54 (2.15)	3–10 7.84 (1.80)	F=1.4267 df=49,49 p=0.21
Disruption of routine family activities	Range (10) Mean (SD)	2–9 5.24 (1.81)	4–9 6.58 (1.34)	F=1.82452 df=49,49 p=0.04
Disruption of family leisure	Range (8) Mean (SD)	1–6 3.52 (1.28)	2–6 4.14 (1.14)	F=1.2607 df=49,49 p=0.42
Disruption of family interaction	Range (10) Mean (SD)	1–8 4.70 (1.92)	3–9 6.02 (1.68)	F=1.30612 df=49,49 p=0.35
Effect on physical health	Range (4) Mean (SD)	0–3 1.44 (0.79)	0–4 1.96(0.81)	F=1.05127 df=49,49 p=0.86
Effect on mental health	Range (4) Mean (SD)	1–4 2.18 (1.04)	0–4 2.12(1.00)	F=1.0816 df=49,49 p=0.78
Total (global) burden score	Range (48) Mean (SD)	10–38 23.62 (7.88)	16–38 28.66 (6.36)	F=1.53511 df=49,49 p=0.13
Subjective burden	Range (2) Mean (SD)	1–2 1.56 (0.50)	1–2 1.70 (0.46)	F=1.18147 df=49,49 p=0.56

Table 4 shows a comparison of subscales and total GHQ-28 scores in caregivers of both patient groups. On all subscales except the anxiety and insomnia subscale scores were higher in caregivers of patients with schizophrenia. Anxiety and insomnia were significantly higher among caregivers in the OCD group (p=0.0251). However, the difference on the total GHQ score was statistically non-significant.

Table 4. Comparison of subscales and total score of GHQ-28 in caregivers of both the groups

Variable	Descriptives	OCD (N=50)	Schizophrenia (N=50)	T-test
Somatic symptoms	Range (0–7) Mean (SD)	0–5 2.02 (1.45)	0–5 2.18 (1.27)	F=1.30355 df=49,49 p=0.35
Anxiety/insomnia	Range (0–7) Mean (SD)	0–6 2.68 (1.48)	0–4 1.92 (1.07)	F=1.91318 df=49,49 p=0.03
Social dysfunction	Range (0–7) Mean (SD)	0–4 1.22 (1.39)	0–5 1.80 (1.62)	F=1.35831 df=49,49 p=0.28

Depression	Range (0–7) Mean (SD)	0–6 1.48 (1.34)	0–6 2.40 (1.64)	F=1.49788 df=49,49 p=0.16
Total	Range (0–28) Mean (SD)	1-20 7.40 (5.21)	1-20 8.30 (4.95)	F=1.10781 df=49,49 p=0.72

Table 5 shows that burden of care scores were higher in caregivers (spouses and parents) of the schizophrenia group as compared with the OCD group. In case of Others (Divorced and separated), it was higher in OCD group. Burden of care scores were highest among spouses in case of schizophrenia and highest among parents in case of OCD.

Table 5. Caregiver relationship and burden score on FBIS

Caregiver Relationship	Descriptives	OCD (N=50)	Schizophrenia (N=50)	T-test
Spouse	Range Mean (SD)	10–36 20.68 (7.77)	18–38 31.37(5.17)	F=2.25871 df=18,18 p=0.09
Parents	Range Mean (SD)	13–38 25.32 (7.61)	21–38 30.69 (5.77)	F=1.73947 df=21,15 p=0.27
Others	Range Mean (SD)	14–38 25.67 (7.73)	16–33 23.07 (4.82)	F=2.57196 df=8,14 p=0.11

Table 6 shows psychiatric morbidity among caregivers (GHQ-28 score of 4 or higher) in both groups. In 30 out of 50 caregivers of OCD patients (60%) and in 36 out of 50 caregivers (72%) of schizophrenia patients psychiatric morbidity was present. However, the difference was not statistically significant (p=0.20). A greater number of spouses and parents than other carers of schizophrenia patients had psychiatric morbidity and the difference between carers with psychiatric morbidity and those without was statistically significant (p=0.003).

Table 6. Caregiver psychiatric morbidity based on GHQ-28 score of 4 or higher

	OCD		Schizophrenia	
Relationship	Psychiatric morbidity present	Psychiatric morbidity Absent	Psychiatric morbidity present	Psychiatric morbidity Absent
Spouse	9	10	17	2
Parents	15	7	13	3
Divorced/Separated	6	3	6	9
Chi square statistics	χ^2=2.043, df=2, p=0.36		χ^2=11.18, df=2, p=0.003	

There was a very high positive correlation between the FBIS and GHQ scores. Pearson correlation (*r*) for caregivers of patients with schizophrenia was *r*=0.819, p=0.00 and for caregivers of patients with OCD was *r*=0.852, p=0.00.

DISCUSSION

The present study arose from a concern that patients with non-psychotic disorders, particularly OCD, have dysfunction in psychosocial

function too and that their families experience considerable burden of disease. The study explores burden of care in two different disorders: schizophrenia and OCD. It also compares psychiatric morbidity in caregivers of patients with these two disorders.

SOCIO-DEMOGRAPHIC DATA

Socio-demographic characteristics such as gender, occupation, family income, family type, religion and patient locality (urban or rural) were comparable in both study groups, except for patients' marital and educational status. Divorce and separation were more prevalent in the case of patients with schizophrenia, which is an additional factor increasing the burden on the family.

Educational status was higher in OCD patients than in schizophrenia patients, which might have had some positive effect on burden of care. Schizophrenia is a psychotic illness and patients have impaired reality testing, which results in more socio-occupational problems. In comparison, OCD is a neurotic illness and patients have intact reality contact. So they continue to study despite their illness and do comparatively better in their work, self-care, communication and interpersonal activities. We also found that divorce and separation were more prevalent in schizophrenia. Impaired reality testing and social impairment might be contributing factors for this.

BURDEN OF CARE

The FBIS questionnaires uncovered considerable burden of care among caregivers in both disorders. The mean total burden score for schizophrenia was higher than that for OCD but the difference was not statistically significant, which indicates comparable burden of care in caregivers of both groups. The findings are comparable to those of Thomas et al. [24].

Chronic psychiatric disorders such as schizophrenia and OCD are fairly disabling for both patients and their relatives. According to the World Health Organization (WHO) 2000 estimate of leading causes of DALYs (disability-adjusted life years) worldwide in 15 – to 44-year-olds, schizophrenia was 8th among the top 20 diseases [28]. The 1996 Global Burden Study (sponsored by WHO and the World Bank) identifying leading causes of disability placed schizophrenia in the 9th and OCD in the 10th place among the top 10 causes of disability in the world [29]. In developing countries, schizophrenia is the 10th among top 10 causes of disability [29]. It is understandable that burden of care is somewhat higher in schizophrenia than in OCD because of lack of insight in patients as well as reduced involvement in treatment compared with OCD.

It would appear that caregiver burden in OCD is somewhat smaller than in schizophrenia. Patients with OCD have intact reality testing and have better insight concerning their illness. Their socio-occupational impairment is also lesser than in schizophrenia patients. Sometimes patients with OCD keep their problems to themselves and do not reveal them to others. They may try to cope with their symptoms on their own. In comparison, patients with schizophrenia have impaired reality contact and lack insight about their illness, which makes things difficult for their caregivers; patients may not remember to take their medications and may need caregiver help in taking care of their daily routine as well. Socio-occupational impairment is also significant in schizophrenia.

Financial burden, disruption of routine family activities, disruptions of family leisure, disruption of family interaction and effect on physical health – all five subscales show higher burden in the schizophrenia group than in the OCD group. But the difference is not statistically significant except for disruption of routine family activities, a finding similar to that of Thomas et al. [24].

In the present study, families of patients with schizophrenia reported greater burden than the OCD group but the difference was not statistically significant except for one domain. This finding is more or less in line with a study by Veltro et al. [30]. Disruption of family routine is the area in which the burden experienced by caregivers of patients with schizophrenia is statistically significant. Most families found the patient's inability to work distressing and inconvenient. Caregivers sometimes have to take care of patients' personal hygiene, food intake, compliance with treatment and other areas of daily routine activities, which place significant burden on them.

Disruption of family interactions is another important and significant aspect of burden in schizophrenia. As a consequence of the patient's illness, family members tended to be tense and irritable, and had frequent quarrels/conflicts among themselves about caring for the patient. A significant number of caregivers reported reduced interaction with friends and neighbours. A possible factor for this is stigma related to schizophrenia in the society.

Jayakumar et al. [23] compared the burden of care in key relatives of patients with OCD and schizophrenia and found that the burden posed by OCD is either greater than or nearly comparable to that of schizophrenia. Similar results emerged in studies by Lasebikan et al. [4], Kate et al. [5], Roick et al. [31] and Van Wijngaarden et al. [32].

Verma et al. [33] and Ramos-Cerqueira et al. [34] found high levels of burden of care and psychological morbidity among caregivers of patients with OCD. Several studies have found significant burden of care among caregivers of schizophrenia [2,3,8]. Tynes et al. found that relatives experienced frustration with the symptomatic behavior of their family member with OCD [35].

This study found that caregivers in both OCD and schizophrenia groups experienced a comparable level of financial burden, and although it was apparently higher in the schizophrenia group, the difference is not statistically significant. They also described a significant decline in the financial status of the family and worries about the patient's future financial needs, and believed that they were responsible for meeting them.

An earlier study has revealed that about half of the family members of patients with OCD face financial hardships [16]. Another comparative study has documented that the severity of financial burden experienced by families of patients with OCD was comparable to that of families of patients with dysthymia and generalized anxiety [19]. Like in other studies, primary caregivers in patients with OCD reported deterioration in the quality of relationships with family members and friends as well as family stability, although the degree of impairment was comparable with that in schizophrenia [16,19,20,22]. Caregivers of both groups revealed that they found patients' behaviors disturbing.

PSYCHIATRIC MORBIDITY AMONG CAREGIVERS

The total mean score of GHQ-28 was higher in the schizophrenia group. On all 4 subscales, somatic symptoms, social dysfunction and depression scores were higher in caregivers in the schizophrenia group. But the difference was not statistically significant, which shows that caregivers of patients with OCD also experience considerable psychosocial distress. Anxiety and insomnia are significantly higher in caregivers of patients with OCD. This finding is in line with the results on the FBIS subscale "effect on mental health", which show marginally higher scores in caregivers in the OCD group.

The GHQ-28 suicidal subscale shows a significantly stronger death wish in caregivers of patients with schizophrenia and the overall score for the suicidal subscale is also significantly higher in the schizophrenia group. This finding is similar to that of Jayakumar et al. [23], though the difference was not statistically significant.

Spouses of patients with schizophrenia show greater burden of care than spouses of patients with OCD. Although the difference is not statistically significant, it is considerably higher. Psychiatric morbidity was significantly higher in spouses of patients with schizophrenia ($p=0.004$). This may be the reason for the higher rates of divorce and separation in this patient group. Black et al. [22] have reported that spouses of OCD patients frequently experience anger/frustration, disturbed personal life and lack of time for self. The key caretakers in the OCD group of the present study had similar problems in relation to their mental and physical health. Additionally, there was also impairment in caregivers' routines, such as time to look after one's health, sleep and time for relaxation. The degree of decline in caregivers' health and routines was comparable in the OCD and schizophrenia groups [22].

BURDEN OF CARE AND PSYCHIATRIC MORBIDITY

There is a strong positive correlation between the FBIS and GHQ-28 scores for both study groups. This indicates that as family burden increases, psychological distress and psychiatric morbidity among caregivers also increase.

The correlation is statistically significant for both study groups. Various factors can be responsible for this. One is socio-occupational impairment of the patient as it imposes additional financial and social burden on the family. In some type of illness, one caretaker has to present with the patient most of the time to take care of the patient, which compromises their routine activities. Lack of awareness and stigma related to psychiatric illness are also major contributing factors, particularly in the developing country such as India. These factors pose a significant burden and psychological distress to the caregivers, which affects their physical and mental health.

LIMITATIONS AND FUTURE RECOMMENDATIONS

- The relationship between the severity of schizophrenia and OCD symptoms and the degree of burden of care was not examined.
- Emotional climate and interaction patterns within the family and the social support perceived by both patients and relatives could not be assessed.
- A further study, preferably including a community sample, would be essential to confirm the present findings. There is a need to examine the relationship between the degree of psychopathology and burden of care and to evaluate caregivers' mental state with standardized instruments.

SUMMARY AND CONCLUSION

The study was carried out to compare the burden of care and psychiatric morbidity among caregivers of patients with schizophrenia and OCD. It was a cross-sectional study.

It is clear that although the extent and pattern of burden among families of schizophrenic patients was greater than that among the families of OCD patients, the latter also experienced considerable burden. Similarly, psychiatric morbidity and suicidality among the caregivers of patients with schizophrenia were greater than among the caregivers of OCD patients, but considerable psychiatric morbidity was also present in caregivers of OCD patients.

Burden of care has a strong positive correlation with psychiatric morbidity in the caregiver. As burden of care increases, distress and psychiatric morbidity in the caregiver also increase.

Although conducted on a moderate number of patients and caregivers (and needs to be replicated in larger study groups), the clinical inference of our study is quite clear. Caregivers of schizophrenia as well as OCD patients both have considerable burden of care and associated psychiatric morbidity.

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