# CAREGIVER'S BURDEN: A COMPARISON BETWEEN OBSESSIVE COMPULSIVE DISORDER AND SCHIZOPHRENIA

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## **ABSTRACT**

The present study compared burden of care between the key relatives of patients with obsessive-compulsive disorder (OCD) and schizophrenia. For this study, consecutive key relatives of patients with either OCD (n=30) or schizophrenia (n=41) were evaluated with 40-item burden assessment schedule (BAS). In comparison with schizophrenia group, caregivers in OCD group had significantly high mean scores for the domains, spouse-related factor and caregiver's strategy of BAS. The degree of burden, evidenced by mean scores, was comparable between groups for other domains of BAS. Spouses and unemployed caregivers in OCD group had significantly elevated mean total burden scores. The present findings suggest that caregiver's burden imposed by OCD is either excess or nearly comparable to that of schizophrenia.

Key Words: Obsessive-compulsive disorder, schizophrenia, family burden, caregiver's burden

Recently, there has been growing concern to understand the impact of obsessive compulsive disorder (OCD) on family functioning. Evidences show that family members are frequently drawn into the ritualistic behaviour of their patients (Cooper, 1994; Calvocoressi et al.,1995; Steketee,1997; Black et al.,1998). Also, family members often modify the family functioning and routines to accommodate their relative's rituals (Calvocoressi et al.,1995; Amir et al.,2000) and this family accommodation is frequently linked with global family dysfunction and distress (Calvocoressi et al.,1995).

Of the family members, the consequence of caring is high in the life of a family member who bears maximum responsibility(Cooper, 1996). A few studies have also shown that OCD is often connected with marital discard (Emmelkamp et al., 1990; Cooper, 1996), sexual problems (Stabler et al., 1993), financial hardships (Chakrabarty et

al.,1993; Cooper,1996), inability to maintain relationship with others particularly friends (Cooper,1996), poor family relationship (Hollander, 1996; Calvocoressi et al.,1998), and decline in family routines, including leisure (Chakrabarty et al.,1993). In a recent study, Black et al.(1998) have shown that spouses of patients with OCD are frequently faced with disrupted family/marital social life, sexual problems, anger/frustration, family conflicts, and disrupted personal life. These authors have also noted that OCD families are less healthy than control families in communication, affective involvement and general functioning.

None of the earlier studies, except Black et al.'s study (1998), have examined the impact of OCD on the family members in a comprehensive manner. Besides, even Black et al.'s study (1998) has an important limitation that the instrument used to evaluate caregivers' difficulties has not

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been a standardized tool. Because psychosocial functioning of caregivers is an important variable having bearing on the outcome of OCD and only a few studies have explored this issue, the current study was carried out. The goal of this study was to compare burden of care between the caregivers of patients with OCD and schizophrenia. And, because schizophrenia is an illness proven to be associated with significant burden of care (Gautam &Nijhawan, 1984; Chakrabarti et al., 1995), it was chosen as the comparison group.

#### **MATERIAL AND METHOD**

This cross-sectional study was conduced at the outpatient department of Central Institute of Psychiatry, Ranchi between October,2000 and March 2001. This study included key relatives of consecutive 30 patients with ICD-10 (World Health Organization, 1993) obsessive-compulsive disorder (OCD group) and 41 patients with schizophrenia (schizophrenia group). Details of patients' characteristics are given elsewhere (Jayakumar et al., 2002). A key relative was defined as a relative who had cared the patient continuously for the last two years and spent a lot of time and emotion in caring the patient. Informed consent was obtained before enrolment.

Relevant demographic variables were collected on a data sheet. Caregiver's burden was assessed with burden assessment schedule (BAS) (Thara et al., 1998), a structured instrument with forty items. Each item is rated on a threepoint scale (not at all, to some extent and very much). The items of the schedule are categorized under nine domains such as spouse-related factor, physical and mental health, external support, caregiver's routine, support of patient, taking responsibility, other relations, patients behaviour and caregiver strategy. This schedule measures both subjective as well as objective burden adequately, and, it has been proven to have good inter-rater reliability and face, content and criterion validity.

Data analysis was done with a standard statistical package, SPSS win release 10.0.1. Descriptive statistics, X<sup>2</sup> test and Mann-

Whitney 'U' test were used to illustrate the demographic characteristics. Group differences for different domains of BAS were examined with Mann-Whitney 'U' test and Kruskal-Wallis one-way ANOVA test. The level of significance of 0.05 was adopted in this study.

## RESULTS

<u>Characteristics of participants:</u> A large proportion of the key relatives in OCD group were spouses

TABLE 1
CHARACTERISTICS OF THE PARTICIPANTS

Variable	Group		X²/Z•
	OCD	Schizophrenia	
Relationship			
Parents		18(43.9)	10.58
	d.f.= 2;	p= 005	
Spouse	14(46.7) 3(10.0)	7(17.1)	
Others	3(10.0)	16(39.0)	
Age(vrs.)			
(Mean±SD)	41.97±12.24	45.41±12.87	880
	d.f.≠0; <sub> </sub>	p=.379	
<u>Sex</u>			
Male		28(68.3)	2.07
	d.f.=1; <sub> </sub>		
Female	5(16.7)	13(31,7)	
Marital Status			
Single	1(3.3)	5(12.2)	.800
-	d.f.=1;p	<b>≖.371</b>	
Married	29(96.7)	36(87.8)	
Education			
Undermatric	6(20.0)	17(41.5)	14.44
	d.f.=2;p	=.001	
Matric	4(13.3)	15(36.6)	
Above Inter	20(66.7)	9(22.0)	
Occupation			
Unemployed	1(3.3)	0(0.0)	7.74
	d.f.=2;p		
Employed	24(80.0)	22(53.7)	
Others	5(16.7)	19(46.3)	
Income status			
(Rs./month)			
<2000	8(26.7)	20(48.8)	5.55
	d.f.=2; ;		
2001-5000		14(34.1)	
>5001	12(40.0)	7(17.1)	

Mann-Whitney 'U' test

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(n=14;46.7%) whereas in schizophrenia group, a majority of the caregivers were parents (n=18;43.9%). In comparison to schizophrenia group, more caregivers in OCD group had higher educational background (n=20, 66.7%) and were employed (n=24,80.%). Examination of differences in income status revealed that a great proportion of participants in OCD group (n=12,40%) had a higher income status than that of schizophrenia group (n=7,17.1%). Groups were similar with regard to other variables (table 1).

TABLE 2
CHARACTERISTICS OF THE PARTICIPANTS

Variable	Group		
	Mean±SD	Mean±SD	
Spouse-related	4.46±3.82	0.95±2.64	
•	Z== -3.990; p=.000		
Physical and-	11.40±3.42	10.80±3.23	
mental health	Z° = -,755; p=,450		
External support	9.00±2.26	9.00±2.04	
	Z*=041; p=.967		
Caregiver's routines	8.10±1.63	8.58±1.72	
·	Z*=-1.500; p=.134		
Support of patients	6.00±1.31	8.58±1.72	
	Z*=590; p=.555		
Taking responsibility	6.70±1.51	6.82±1.80	
	Z*=303; p=.762		
Other relatives	6.57±1.977	6.04±1.66	
	Z*= -1.130; p=.259		
Patient's behaviour	8.43±2.15	7.73±2.156	
	Z°=-1.290; p=.197		
Caregiver's strategy	8.20±1.42	7.56±1.32	
-	Z* =2.068; p=.039		
Total burden	68.87±7.61	63.29±9.49	
-	Z*= -1.164; p=.244		

Mann-Whitney 'U' test

Group differences in burden: The spouse-related domain includes items such as spouse helps in family responsibilities, spouse satisfies sexual needs, spouse affectionate, quality of

material relationships and satisfaction over the adequacy of help received from health care professionals. For this domain, caregivers in OCD group had significantly high mean scores than that of schizophrenia group indicating a great degree of burden. A significant group difference was also noted for the domain caregiver's strategy that includes items indicative of caregivers efforts such as getting support from

TABLE 3 DIFFERNECE SIN TOTAL BAS SCORES IN OCD GROUP

Variable	Mean±SD	H <sup>1</sup> /Z <sup>1</sup>
Relationship		
Parents	62.81±8.49	6.078
	d.f.=2; p=.048	
Spouse	69.48±6.93	
Others	66.05±10.89	
Age (Yrs.)		
<20	66.00±12.76	3.274
21-40	66.93±8.76	
	d.f.=2; p=.195	
>41	63.09±9.27	
Sex		
Male	65,71±9.65	-,205
	d.f.=? ; p=.838	
Female	65.44±7.56	
Education	•	
Undermatric	63.26±9.42	4.764
	d.f.=2; p=.092	
Matric	64.26±9.15	
Inter & above	68.45±8.37	
Occupation		
Unemployed	70.00±0.00	8.076
	d.f.=2;p=.018	
Employed	67.89±8.53	
Others	61.17±8.88	
Income status (Rs./month)		
<2000	63.89±8.23	5.539
-2000	d.f.≠2:o≃.063	V. 308
2001-5000	65.12±10.18	
>5001	68.89±9.12	

<sup>\*</sup>Mann-Whitney 'U' test; \*Kruskal-Wallis test.

friends, compensation of patient's shortcoming, doing more to improve situation and seeking

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temporary separation, suggesting greater burden in the key relatives of patients with OCD. Groups were comparable for others domains of BAS such as physical and mental health, external support, care giver routine, support of patient, taking responsibility, other relatives patients behaviour and total burden (Table 2).

## <u>Differences in Total BAS scores in OCD group</u>

Analysis of difference in total BAS score for demographic profiles in OCD group revealed that burden was high among spouses than other relatives. And, burden of care was found more among the caregivers who were unemployed. There was no group difference in total burden score for other demographic varibales (Table 3).

#### DISCUSSION

The present study has shown that caregivers of patients with OCD experienced a high degree of burden in spouse-related areas. The key relatives in OCD group often encountered problems such as poor support from spouse in family responsibilities, inadequate satisfaction of emotional and sexual needs, and deteriorated marital relationship. And, because of persisting problems, they expressed poor satisfaction over quality of health service. The decline in marital and sexual life of caregivers in OCD group noted in this study agrees with earlier findings (Emmelkamp et al., 1990; Staebler et al., 1993; Cooper, 1996; Black et al., 1998). On sub-analysis of OCD group, in the current study, total burden scores were found significantly elevated in spouses than that of parents and other relatives. However, the possibility that higher representation of spouses in OCD group could have contributed to the elevated burden scores noted in this group cannot be ruled out. Another important finding of the current study is significant degree of burden for the BAS domain caregiver's strategy in OCD group. Conspicuously, caregivers in OCD group. had received less support from their friends, had to work more to compensate patients shortcomings, had to work more than the patient to improve patient's situation and often felt the

need for temporary separation. These issues, except the issue of support from other sources (Black et al.,1998), are not explored previously. Nevertheless, these findings, particularly the desire for temporary separation, hint at the magnitude of stress and distress connected with caring of individuals with OCD.

Black et al.(1998) have reported that spouses of OCD patients frequently experience anger/frustration, disturbed personal life and lack of time for self. The key caretakers in OCD group of the present study had similar problems in relation to their mental and physical health. Additionally, there was also impairment in caregiver's routines such as time to look after one's health, sleep, and time for relaxation. Noticeably, the degree of decline in caregivers' health and routines was comparable between OCD and schizophrenia group.

An earlier study (Cooper, 1996) has revealed that about half of the family member of patients with OCD face financial hardships. Another comparative study (Chakrabarty et al., 1993) has documented that the severity of financial burden encountered by families of patients with OCD was comparable to that of families of patients with dysthymia and generalized anxiety. The present study showed that caregivers of both QCD and schizophrenia group had similar level of financial burden. The caregivers in OCD group reported that the current financial situation was inadequate to care for patients, and there was pressing need to work to support their patients. They also described a significant decline in the financial status of the family and worries about patient's future financial needs, and considered that they were responsible to meet patient's needs. Evidently, unemployed caregivers in OCD group had experienced a great degree of burden.

Like other studies (Chakrabarty et al., 1993; Cooper, 1996; Hollander et al., 1996; Black et al., 1998), the key relatives in OCD group of the current study had deterioration in the quality of relationship with other family members and friends, and family stability, although the degree of impairment was comparable to that of

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schizophrenia. Caregivers of both group revealed that patients' behaviours were disturbing.

The current study attempted to illustrate the negative consequences of OCD on the caregivers in a comprehensible way. A few limitations of this study need consideration before generalizing the findings. First, the study had relied on the hospital population than the community sample. Second, this study was limited by small sample size. Third, a relationship between nature and severity of OCD symptoms and degree of burden of care was not examined. A further study with large sample size, preferably including community sample, is essential to confirm the present findings. There is a need to examine the relationship between degree of psychopathology and burden, and to evaluate mental state of caregivers with standardized instruments.

In sum, the present study has shown that caregivers of patients with OCD experience considerable degree of burden. This study also suggests that further studies are warranted in this area and there is a need to couple routine evaluation of caregiver's burden along with other intervention strategies of OCD.

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