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The Quality of Life Experienced by Caretakers of Individuals Diagnosed with Obsessive Compulsive Disorder (OCD) and the Risk Factors Associated With this Care Giving Role

Vaibhav Chaturvedi, Aditya Shrivastava and Suvaran Sagar Bajpai

Department of Psychiatry, Index Medical College Hospital and Research Centre, Indore, India

ABSTRACT

Obsessive-compulsive disorder (OCD) is a persistent psychiatric condition that may impose emotional, financial and/or social strain on family carers. Limited research has been conducted on the topic of family caregiving for individuals diagnosed with obsessive-compulsive disorder (OCD) with regards to the employment of coping mechanisms from a theoretical standpoint. The present investigation assessed the extent of the burden experienced by family carers of individuals diagnosed with obsessive-compulsive disorder (OCD), as well as the coping strategies employed by these carers. A cross-sectional study was carried out, wherein a cohort of 50 individuals who had been diagnosed with OCD and their respective carers were subjected to a survey utilising the burden assessment schedule (BAS), a tool commonly employed to gauge the level of burden experienced by carers of OCD patients. The study reports that the average age of patients was 36.03 years with a standard deviation of 12.03, while the average age of carers was 43.28 years with a standard deviation of 14.76. The proportion of female carers was 46.8%, whereas the proportion of female patients was 74.5%. The study revealed that 50% of the carers were spouses of the patients, while almost a quarter 22% were parents. The average duration of the illness was found to be 8.10±6.60 years, whereas the average duration of the cure was 4.04±4.47 years. The average score on the Burden Assessment Schedule (BAS) scale for the carer was 39.52 with a standard deviation of 12.99. The present study aims to investigate the correlation among sociodemographic factors, clinical characteristics, quality-of-life and disease burden in patients. There was a statistically significant difference ($p = 0.013$) in the BAS scores between carers whose patients perceived their income to be low and those whose patients did not hold this perception. The former group of carers had higher BAS scores compared to the latter. It is imperative to develop strategic interventions aimed at facilitating coping among family carers who are confronted with the distinctive challenges and coping mechanisms associated with caring for individuals with OCD.

Key Words
Burden, coping, family caregivers, obsessive-compulsive disorder, cross-sectional study

Corresponding Author
Suvaran Sagar Bajpai,
Department of Psychiatry, Index Medical College Hospital and Research Centre, Indore, India
Tel: 9993549161

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INTRODUCTION

Obsessive-compulsive disorder (OCD) is a prevalent psychiatric condition that impacts approximately 2-3% of the global population, rendering it twice as prevalent as schizophrenia or bipolar disorder[1]. The disorder is characterised by obsessions and persistent, unwanted and unsettling thoughts that elicit distress and anxiety. Individuals diagnosed with obsessive-compulsive disorder (OCD) frequently exhibit repetitive cognitive rituals that lack rationality, as a means of mitigating the impact of intrusive thoughts and reducing associated anxiety[2]. The impact of OCD may lead to functional impairment in an individual's daily activities, relationships and career. Stengler-Wenzke *et al.*[1] reported that hospitalised patients with OCD exhibit greater functional impairment compared to those with depression. Due to the clinical presentation of OCD, family carers often find it necessary to modify their daily routine to accommodate the compulsive symptoms exhibited by their affected family member. The alterations in the contemporary landscape have led to an increase in the demands placed upon family carers. The scholarly literature has consistently examined the impact of caring for individuals diagnosed with OCD on the welfare of their carers[3]. While certain families are able to provide care for their loved ones with mental illnesses, others encounter difficulties. Individuals exhibit significant variations and scholarly investigations have established a correlation between the capability of carers to effectively handle their personal lives while catering to patients with OCD and their income, educational attainment and age[4-5]. Several theoretical explanations have been proposed to elucidate this variability. One of the theories that has been developed in the field of stress and coping is the "Folkman's Transactional Stress and Coping Framework," which was formulated by Lazarus and Folkman[6].

As per the framework proposed by Folkman *et al.*[6], coping is an essential approach that individuals sometimes utilise to manage physical or psychological distress that surpasses their individual resources. The framework highlights the interconnectedness of individual burdens, distress and coping mechanisms. The framework posits that there are variations in perceived distress and personal resources among individuals. In the present study, the framework proposed by Folkman *et al.*[6] will be employed as a theoretical framework to examine the burden, distress and coping strategies of family carers of individuals diagnosed with OCD, along with any potential variations.

The study found that family carers of individuals with OCD primarily experienced a notable level of burden as a result of the disease's impact on their daily lives. Inadequate social or financial assistance may lead to an escalation in the load, culminating in heightened levels of emotional turmoil[5-8]. The impact of OCD on carers has been extensively documented and has been observed to surpass that of other mental disorders[7,8]. The likely explanation for this phenomenon is the manifestation of symptoms associated with obsessive-compulsive disorder (OCD), resulting in significant levels of distress, anxiety and apprehension. According to a study, carers perceived their responsibility to be more challenging when their family member exhibited severe symptoms of OCD[3]. The notion of burden pertains to the perceived level of challenge that carers experience in providing care for another individual and the consequential effects it has on their daily routines[9-11]. The provision of care may give rise to a range of burdens, including those of a physical, psychological, social and financial nature[7]. The presence of distress, sadness, frustration and at times depression have been identified as significant indicators of a substantial burden[12], which may adversely affect the physical and mental well-being as well as the efficacy of a carer within a family setting[7,11].

Individuals frequently engage in a process of logical examination in order to ascertain the pertinence of a given stimulus to their overall state of welfare upon encountering a particular stressor[6]. Subsequently, the process involves the evaluation of potential alternatives and the selection of optimal strategies[13]. This refers to the utilisation of coping mechanisms. Coping mechanisms refer to a range of mental, emotional and behavioural strategies employed to effectively manage stress and mitigate the negative impact of stressors[10]. This may involve proactively controlling and/or modifying one's personal surroundings. In the realm of caregiving, carers commonly assess the effects of patients' daily requirements on their overall health and the available means of remedying them. The provision of care for patients with OCD can lead to a perception of distress among carers, which may exceed their available social, mental and financial supportive resources. This burden can manifest in various areas of their daily lives[2]. This may encompass a range of experiences, such as a sense of being overwhelmed, disempowered, fatigued, experiencing health challenges and facing physical, mental and financial exhaustion. The utilisation of coping mechanisms is a crucial aspect of managing distress and mitigating the adverse impact on the perception of burden among family carers[6].

Notwithstanding the abundance of evidence available in the literature, a significant portion of it remains devoid of a theoretical foundation[14]. Suculluoglu-Dikici[4] revealed that various factors have an impact on the level of burden experienced.

Suculluoglu-Dikici *et al*.[4]. recommended the implementation of behavioural management strategies as a means of protecting the health of families. In a recent study, carers were interviewed to discuss the challenges they encountered and the necessity of receiving training in coping strategies[7]. The aforementioned statement implies the significance of procuring supplementary information to augment the existing pool of knowledge and cultivate a holistic comprehension of how carers navigate their daily routines. The attainment of this objective may be facilitated through the conduct of research endeavours that investigate the distinct facets of the disorder's impact on carers, as well as the plausible associations between such impact and the sociodemographic attributes of the carers. Identifying the domains of a caregiver's life that are most impacted may facilitate a more comprehensive comprehension and strategic implementation of interventions aimed at mitigating the challenges associated with providing care for individuals with OCD, thereby alleviating the burden on family carers. The aim of this investigation was to evaluate the encumbrance and adaptive strategies employed by family carers of individuals diagnosed with obsessive-compulsive disorder (OCD), along with any possible associations.

MATERIALS AND METHODS

The present cross-sectional investigation was carried out on a sample of 50 individuals diagnosed with obsessive-compulsive disorder (OCD) and their respective 50 carers who sought medical attention at the Department of Psychiatric Medicine, teaching Hospital, during the period spanning from April 2021 to October 2022. The study was conducted with the approval of the institutional ethics committee. The participants were selected through the use of convenience sampling. Prior to inclusion in the study, the individuals diagnosed with OCD and their respective carers were apprised of the study's details and provided with written consent forms to authorise their participation. The semi-structured Proforma will be utilised to gather socio-demographic information pertaining to the carers. The involvement in the study was completely voluntary and the confidentiality of all participants' information was maintained. The conducted surveys did not collect any data that could be used to identify individuals. The anonymous survey data was stored in accordance with the guidelines set forth by the scientific research committee to ensure that the respondents' identities could not be ascertained. Throughout the recruitment procedure, the participant's identification number and contact details were securely stored.

The burden assessment scale (BAS) is a tool used to measure the level of burden experienced by individuals in various contexts. The burden of families with a member experiencing a severe mental illness can be assessed using a self-report scale consisting of 19 items, developed by Reinhard and Aydemir. Demonstrated the validity and reliability of the Turkish adaptation of the BAS. The absence of a predetermined threshold score characterises the scale, whereby an increase in the scale score corresponds to a proportional increase in the burden of disease.

RESULTS

The study findings indicate that the average age of patients was 36.03 years with a standard deviation of 12.03, while the average age of carers was 43.28 years with a standard deviation of 14.76. The proportion of female carers was 46.8%, whereas the proportion of female patients was 74.5%. The study findings indicate that a significant proportion of carers were spouses of the patients, accounting for 50% of the total carers. Additionally, parents constituted almost a quarter 22% of the carers, while the remaining carers were comprised of siblings, children, or friends. Table 1 presents a comprehensive summary of the demographic features of both patients and carers. The mean duration of the illness was 8.10±6.60 years, while the mean duration of the recovery period was 4.04±4.47 years. The average score on the burden assessment schedule (BAS) measure for the carer was 39.52 with a standard deviation of 12.99.

The present study investigates the correlation between the disease burden and the sociodemographic profiles of carers. The results of Table 2 indicate that individuals who reside in urban areas and provide care for others exhibited notably lower scores on the BAS scale compared to those who do not provide care ($p = 0.032$). Additionally, individuals who perceived their income to be low demonstrated significantly higher scores on the BAS scale compared to those who did not perceive their income to be low ($p = 0.012$). The Student's t-test was employed in instances where two means were compared under parametric conditions, while the Mann Whitney U test was utilised in nonparametric situations. The present study investigates the correlation among sociodemographic factors, clinical characteristics, quality-of-life and disease burden of patients. The study findings indicate that carers whose patients perceived their income as low had significantly higher BAS scores compared to their counterparts ($p = 0.013$), as shown in Table 2. A negative correlation ($r = -0.25$, $p<0.05$) was observed between the BAS score and the educational level of the patients. The

Table 1: Sociodemographic, clinical characteristics and scale scores of the patients and caregivers

	Patients	SD (%)	Caregivers	SD (%)
	Mean (n = 50)		Mean (n = 50)	
Age (Mean±SD)	36.03	12.03	43.28	14.76
Sex (n, %)				
Male	13.00	25.50	27	53.20
Female	37.00	74.50	23	46.80
Marital status (n, %)				
Married	31.00	62.80	38	76.60
Single, widowed	19.00	37.20	12	23.40
The length of education (years) (Mean±SD)	2.00	4.28	2	4.90
Occupational status (n, %)				
Working	13.00	25.50	22	43.60
Not working	37.00	74.50	28	56.40
Locality (n, %)				
Rural	21.00	41.90	21	41.90
Urban	29.00	58.10	29	58.10
Perceived income level (n, %)				
Low	7.00	14.90	9	18.10
Middle	34.00	68.10	31	61.70
High	9.00	17.00	10	20.20
Caregiver's relation with the patient (n, %)				
Parent	-	-	13	26.60
Spouse	-	-	25	50.00
Sibling, child, friend	-	-	12	23.40
Duration of the disease (years) (Mean±SD)	8.10	6.60		
Duration of the treatment (years) (Mean±SD)	4.04	4.47		
Depressive disorder as a comorbidity (n, %)	30.00	60.00		
BAS score (Mean±SD)	39.52	12.99		

SD: Standard deviation

Table 2: The association between burden and the socio-demographic characteristics of the patients and caregivers

	BAS Score			
	Patient		Caregiver	
Variables	Mean	SD	Mean	SD
Gender				
Male	42	15.58	38.92	12.01
Female	38.67	11.99	40.20	14.13
	p = 0.448*		p = 0.225**	
Marital status				
Married	39.66	12.75	39.93	13.82
Single, widowed	39.29	13.57	38.18	9.98
	p = 0.817**	p = 0.778*		
Perceived income level				
Low	45.79	16.78	48.82	14.77
Middle	40.14	12.01	38.26	11.87
High	31.56	9.54	35.05	11.13
	p = 0.013***		p = 0.012***	
Post hoc**	a<(b = c)		a<(b = c)	
Occupational status				
Working	38.21	12.89	38.10	11.11
Not working	39.97	13.09	40.85	15.33
	p = 0.474*		p = 0.126**	
Locality				
Rural	-	-	42.92	13.72
Urban	-	-	37.11	11.99
			p = 0.032*	
Relation to the patient				
Parent	39.72		15.35	
Spouse	40.36		13.28	
Sibling, friend, child	37.50		9.26	
			p = 0.803***	

study found a significant positive correlation ($p<0.05$) between the scores on the BAS and three variables: The duration of the disease ($r = 0.29$), the duration of treatment ($r = 0.28$) and the number of hospitalisations ($r = 0.27$). Furthermore, there exists a positive correlation between the disease burden, as measured by the BAS score. Furthermore, it was ascertained that the quality of life (QoL) of the subjects in all dimensions exhibited a negative correlation with the burden of the disease ($p<0.05$).

DISCUSSIONS

The objective of this investigation was to evaluate the factors that impact the level of illness burden experienced by carers of individuals with OCD. The present study employed a variable selection approach based on univariate analysis to identify predictors of carer burden in individuals with OCD. Specifically, variables that demonstrated a significant association with disease burden were included in the analysis.

A duration of at least one year was deemed necessary for patients diagnosed with OCD and their co-residing carers, as a shorter period may not have been sufficient to yield a substantial increase in the caregiver's responsibilities. The study excluded patients with OCD who had comorbid psychiatric disorders (excluding depressive disorder), neurological or physical diseases and intellectual disabilities due to the additional burden that these disorders may add to the existing burdens of OCD, as evidenced by previous research[15,16]. Given that comorbid depressive disorder is commonly considered to be a secondary condition to OCD, it was not dismissed. Although previous literature has shown a correlation between disease burden and psychiatric comorbidity in carers of individuals with OCD, we opted to exclude carers with psychiatric, neurological, or physical disorders to obtain a more homogeneous sample and evaluate the burden that is specific to OCD. The studies of Senaratne *et al*.[17] and Oza *et al*.[18] did not provide any indication of a causal association between elevated family burden and psychiatric disorders.

The study findings indicate that the disease burden was significantly associated with three sociodemographic factors, namely perceived income level, residence and patient education levels. There was a statistically significant increase in the BAS scores of carers residing in rural areas who held the belief that their income was low. Two studies in the literature are deemed comparable to our study[19,20], however, only one of them reported a significant association between low perceived income level and the outcome of interest[20]. The aforementioned results can be elucidated by the difficulties encountered in accessing sophisticated and proficient healthcare amenities, such as psychoeducational and familial interventions, in conjunction with pharmacotherapy. This is due to the fact that psychiatric establishments in our country do not typically offer psychotherapeutic services for various reasons. It is recommended that individuals seeking psychotherapy services consider higher-tier medical facilities or private clinics. Furthermore, our study revealed a negative correlation between the level of education attained by the patient and the extent of carer burden experienced. Attainment of higher levels of education facilitates the acquisition of information, thereby facilitating the development of coping mechanisms for diseases. Our study is the initial research to exhibit an inverse association between the number of years of education and BAS scores.

The literature contains studies that indicate a positive correlation between disease duration and disease burden[21-23], as well as studies that suggest no significant impact of disease duration on disease burden[3,24]. Consistent with the findings of Cicek *et al*.[22], our study revealed a significant positive correlation between disease burden and both the duration of illness and treatment. As the duration of the disease and treatment regimen increases, carers may be at an elevated risk of symptom exposure, diminished expectations for recovery, maladaptive coping strategies and increased burden. Moreover, prolonging the duration of the therapeutic intervention leads to increased healthcare costs and a subsequent economic strain.

As the severity of the disease increases, there may be a corresponding increase in the number of hospitalisations and the level of care required by patients. As a result of this, the leisure activities of the carer may experience a decline, their social functioning may also be impacted and their professional life may become disrupted, thereby exacerbating the caregiver's overall burden. Consistent with prior research, our findings indicate a positive correlation between the frequency of hospitalisations and the burden of disease[19,22].

The study findings indicate that a greater disease burden was significantly correlated with lower quality of life scores across all four domains, namely physical, psychological, social and environmental, among the patient population. This study represents a novel approach by incorporating carer burden as a factor in the assessment of the patient's quality of life. Previous studies have investigated the correlation between functionality and disease burden, revealing that the burden increases in tandem with disability[20,22]. Notwithstanding, given that the notion of quality of life encompasses both functionality and relevant subjective contentment, we contend that our results carry greater significance[25]. In recent years, scholars have focused on quality of life (QoL) as a crucial criterion for enhancing the treatment process.

The utilisation of treatment duration as a predictor of carer burden, as opposed to disease duration, suggests that the persistence of symptoms despite treatment is a greater contributor to burden than the overall duration of the disease. In the field of psychiatry, it is common for patients to seek treatment at a later stage of their condition, rather than during its initial onset. The severity of obsessive-compulsive symptoms can serve as a predictor of disease burden due to its external observability and the potential for carers to become habituated to the symptoms. This can be attributed to the inherent characteristics of obsessive-compulsive disorder (OCD). As the severity of the patient's obsessive-compulsive symptoms increases, the carer may take on additional responsibilities and engage in the patient's rituals as a means of mitigating the disease-related stress, reducing the time spent on symptom management and enhancing daily functioning. The aforementioned circumstance has the potential to result in a disruption of familial concord and impose limitations on the caregiver's routine undertakings[26]. The presence of OCD may result in reduced work capacity, decreased professional functionality, increased treatment expenses and heightened reliance on carer support, thereby exacerbating the patient's burden. The ecological aspect of quality of life (QoL) comprises supplementary factors such as prospects for leisure and recreation, physical surroundings and security, residential conditions, availability of healthcare and acquisition of novel knowledge and skills. The presence of any of these impairments may pose challenges in the treatment of the patient and execution of routine activities, thereby causing difficulties for the carer.

CONCLUSION

The statistical analysis employed in our study contributes to the existing literature. Numerous factors can impact the burden experienced by carers, even in those without any additional burden. The disease burden can be predicted by the severity of obsessive-compulsive symptoms, treatment duration and environmental quality of life. The results indicate that medical practitioners should address not only the clinical symptoms of individuals with OCD but also their social and occupational aspirations, familial and social connections and the attitudes of their healthcare providers towards their condition. It is important to take into account the needs of the carer. The inclusion of carers in both behavioural and pharmaceutical treatment has been shown to have positive effects on the management of OCD treatment and the overall health of the family. It is recommended that psychiatry incorporate family consultations and therapies into its treatment approach. It is imperative for group therapies to be inclusive of both patients and their carers. Nevertheless, it is imperative to conduct follow-up studies with a substantial sample size to validate our results. Subsequent investigations could potentially explore the impact of family burden and treatment outcomes.

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