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INTERNATIONAL JOURNAL OF ADVANCED RESEARCH (IJAR)

Article DOI: 10.21474/IJAR01/16708

DOI URL: <http://dx.doi.org/10.21474/IJAR01/16708>



RESEARCH ARTICLE

PSYCHIATRIC MORBIDITIES AND BURDEN IN CAREGIVERS OF PATIENTS OF OBSESSIVE COMPULSIVE DISORDER

Oza Raghav¹, Rathi Pawan¹, Kotadia Hiral², Keshwani Jitendra², Tiwari Apurva¹ and Reddy Srikanth²

1. Department of Psychiatry.
2. Sri Aurobindo Medical College & PG Institute-Indore (M.P.).

Manuscript Info

Manuscript History

Received: 20 February 2023

Final Accepted: 24 March 2023

Published: April 2023

Key words:-

Burden, Coping, Family Caregivers,
Obsessive-Compulsive Disorder, Cross-
Sectional Study

Abstract

Background: Obsessive-compulsive disorder (OCD) is a chronic mental disorder that can be a source of emotional, financial and/or social burden for family caregivers. Few studies have investigated family caregiving for patients diagnosed with OCD in relation to the coping strategies being used from a theoretical perspective. This study evaluated the burden and coping strategies of family caregivers for people diagnosed with OCD. **Methods:** A cross-sectional study was conducted, in which 94 participants diagnosed with OCD and their caregivers were surveyed using Burden assessment schedule (BAS) used to measure burden among caregivers of patients of OCD.

Results: The mean ages of the patients were 36.03 + 12.03 and the caregivers were 43.28 + 14.76. Only 46.8% of the caregivers were female, compared to 74.5% of the patients who were female. Patients' spouses made up half of the caregivers (50%) and parents made up almost a quarter (22%); The average length of the illness was 8.10 ± 6.60 years, and the average length of the cure was 4.04 ± 4.47 years. The mean BAS score for the caregiver was 39.52 ± 12.99. The Relationship Between Sociodemographic, Clinical, Quality-of-Life, and Disease Burden of Patients The BAS scores of caregivers who had patients who thought their income was low were significantly higher than those of the other caregivers (p=0.013).

Conclusions: Designing strategic interventions for family caregiver coping is necessary to support the unique burdens and coping mechanisms faced by family caregivers of people with OCD.

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Introduction:-

OCD is a common psychiatric disorder that affects 2-3% of people worldwide, making it twice as common as schizophrenia or bipolar disorder [1]. Obsessions are persistent, unwanted, and unsettling thoughts that cause distress and anxiety are features of the disorder. People with OCD often engage in repetitive mental behaviors that are unreasonable in an effort to suppress the intrusive thoughts and lessen anxiety [2]. OCD's effects may have an impact on a person's daily activities, relationships, and career to the point where it results in a functional impairment. According to Stengler-Wenzke and colleagues [1], hospitalized OCD patients have more functional impairment than hospitalized patients with depression. Family members and caregivers frequently need to alter their daily routine in order to deal with the clinical presentation. Family caregivers now face a lot of demands as a result

of these changes. In fact, the literature has consistently discussed the effects of providing care for those who have been diagnosed with OCD as well as care to the caregivers [3]. While some families manage to care for loved ones with mental illnesses, others struggle. People differ greatly from one another, and research has linked the ability of caregivers to manage their own lives while providing care for OCD patients to their income, level of education, and age [4–5]. A few theories have been put forth to account for this variation. The "Folkman's Transactional Stress and Coping Framework," created by Lazarus and Folkman [6], is one of these theories.

According to Folkman et al [6] .s framework, coping is a crucial strategy that people occasionally employ to deal with physical or psychological distress that they feel exceeds their personal resources [6]. The framework emphasized the interdependence of each burden, distress, and coping mechanism. However, the framework indicates that individual differences exist in terms of perceived distress and available personal resources. The Folkman et al. framework [6] will be utilized in the current study as a lens to view the burden, distress, and coping mechanisms of family caregivers of those who have been diagnosed with OCD as well as any potential variation.

Due to the disease's impact on their lives, caregivers of OCD patients primarily reported feeling a significant amount of burden. If there is insufficient social or financial support, the burden may increase, resulting in feelings of extreme distress [5-8]. OCD has a well-documented impact on caregivers that has been found to be greater than that of other mental illnesses [7, 8]. This is probably because OCD symptoms, which cause distress, anxiety, and worry. In fact, caregivers felt that their task was more difficult to manage if their family member had severe OCD symptoms [3]. The difficulty of caring for someone as perceived by caregivers and the impact it has on their daily lives can be referred to as the burden [9–11]. The caring role may result in a variety of physical, psychological, social, and financial burdens [7]. Distress, sadness, frustration, and occasionally depression was found to be important signs of a heavy load [12] and could have a negative impact on a family caregiver's health and functionality [7,11].

People often conduct a logical analysis to determine whether a particular stimulus is relevant to their well-being when they come across a specific source of stress [6]. Then comes considering potential alternatives and choosing the best strategies [13]. Coping strategies are what are meant by this. Coping mechanisms include mental, emotional, and behavioral efforts to manage stress and lessen harm and pain [10]. This could entail actively managing and/or changing one's own environment. In the context of providing care, caregivers typically evaluate the impact of the patients' daily needs on their wellbeing and the resources that could be used to address it. However, caregivers often feel burdened in many areas of their daily lives when their perception of distress as a result of providing care for patients with OCD exceeds their social, mental, and financial supportive resources [2]. This can include, but is not limited to, feeling overburdened, helpless, exhausted, having health issues, and being exhausted physically, mentally, and financially. Coping mechanisms are therefore essential components of distress management and lessen the negative effects on family caregivers' perception of burden (Folkman et al., 1986). The following sequence is presented by the framework in Figure 1:

1. Coping mechanisms are linked to the burden on caregivers of patients with OCD;
2. Distress (caused by the worsening of OCD symptoms) is a factor in the burden caregivers of patients with OCD face;
3. Coping mechanisms play a mediating role in the stress and burden on caregivers.

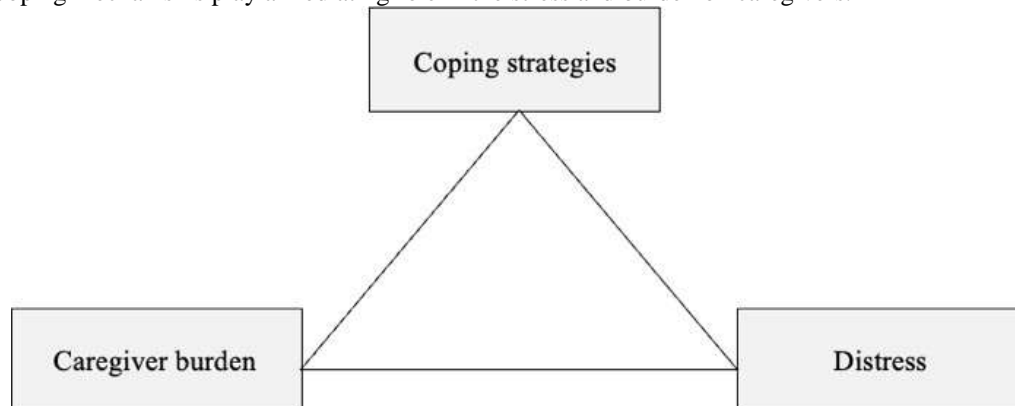


Figure 1:- The Theoretical Framework of Caregiver Burden, Coping Strategies and Distress (adapted from Folkman et al. [6]).

Despite the fact that there is a wealth of evidence in the literature, most of it still lacks a theoretical underpinning [14]. Suculluoglu-Dikici et al.'s study [4] found that a number of factors influence burden. Behavioral management was advised by Suculluoglu-Dikici and colleagues to safeguard family health. In a different recent study, caregivers who took part in an interview discussed the various burdens they faced and the need for training in effective coping mechanisms [7]. This suggests the value of gathering additional data to add to the body of knowledge and develop a comprehensive understanding of how caregivers manage their lives. This could be achieved by carrying out studies that look into the specific aspects of the burden of the disorder on the caregivers and their potential relationships with the sociodemographic characteristics of the caregivers. Finding the areas of a caregiver's life that are most affected could help us better understand and plan more targeted interventions that lessen the burden of caring for people with OCD on family caregivers. Therefore, the purpose of this study was to assess the burden and coping mechanisms of family caregivers of those who have been diagnosed with OCD as well as any potential correlations.

Materials and Methods:-

This cross-sectional study was conducted on 94 patients of OCD and their 94 care giver who presented to the Department of Psychiatric Medicine, SAIMS Hospital between April 2021 and October 2022, with institutional ethics committee approval. Convenience sampling was used to choose the participants. The participants (OCD patients and their caregivers) were informed about the study and written informed consent forms were obtained before being included in the study. Socio-demographic data of the caregivers and will be collected on a semi-structured Proforma. The participation was entirely voluntary, and all participant information was kept private and confidential. The surveys did not gather any personally identifiable information. The scientific research committee's guidelines were followed when storing the anonymous survey data so that the respondents could never be identified again. During the recruitment process, the participant number and phone number were safely stored.

Burden Assessment Scale (BAS):

This is a 19-item self-report scale developed by Reinhard et al. to assess the burden of families with a member having a severe mental illness. The validity and reliability of the Turkish version of BAS was shown by Aydemir et al. . The scale has no cut-off score; as the scale score increases, the burden of disease increases.

Results:-

The mean ages of the patients were 36.03 ± 12.03 and the caregivers were 43.28 ± 14.76 . Only 46.8% of the caregivers were female, compared to 74.5% of the patients who were female. Patients' spouses made up half of the caregivers (50%) and parents made up almost a quarter (22%); the remaining caregivers were siblings, kids, or friends. Table 1 provides an overview of the patients' and caregivers' demographic characteristics. The average length of the illness was 8.10 ± 6.60 years, and the average duration of treatment was 4.04 ± 4.47 years. The mean BAS score for the caregiver was 39.52 ± 12.99 .

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

	Patients		Caregivers	
	Mean/(n=94)	SD/%	Mean/(n=94)	SD/%
Age (Mean±SD)	36.03	12.03	43.28	14.76
Sex (n, %)				
Male	24	25.5	50	53.2
Female	70	74.5	44	46.8
Marital status (n, %)				
Married	59	62.8	72	76.6
Single, widowed	35	37.2	22	23.4
The length of education (years) (Mean±SD)	9.45	4.28	8.89	4.90
Occupational status (n, %)				
Working	24	25.5	41	43.6
Not working	70	74.5	53	56.4
Locality (n, %)				
Rural	39	41.9	39	41.9
Urban	55	58.1	55	58.1
Perceived income level (n, %)				
Low	14	14.9	17	18.1

Middle	64	68.1	58	61.7
High	16	17.0	19	20.2
Caregiver's relation with the patient (n, %)				
Parent	-	-	25	26.6
Spouse	-	-	47	50.0
Sibling, child, friend	-	-	22	23.4
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, %)	56	59.5		
BAS Score (Mean±SD)	39.52	12.99		

The outcomes of the univariate analysis are shown in Table 2. In each of the univariate analyses shown in Table 2, the BAS score served as the dependent variable. The critical p-value was set at 0.05 for all analyses. The Relationship between the Disease Burden and the Sociodemographic Profiles of Caregivers Urban caregivers had significantly lower BAS scores than those who didn't ($p=0.032$), and those who thought their income was low had significantly higher BAS scores than those who didn't ($p=0.012$) (Table 2). In parametric situations where the two means are compared, we used the Student's t-test, and in nonparametric scenarios, we used the Mann Whitney U test. When comparing three means in a nonparametric setting, the Kruskal Wallis Anova test was used.

The Relationship Between Sociodemographic, Clinical, Quality-of-Life, and Disease Burden of Patients The BAS scores of caregivers who had patients who thought their income was low were significantly higher than those of the other caregivers ($p=0.013$) (Table 2). The BAS score and the educational level of the patients were negatively correlated ($r=-0.25$, $p=0.05$). The BAS scores were positively correlated ($p=0.05$) with the length of the disease ($r=0.29$), the length of the treatment ($r=0.28$), and the number of hospitalizations ($r=0.27$). Also positively correlated with disease burden (BAS score) were the patients' YBOCS obsession ($r=0.47$) and compulsion ($r=0.47$), YBOCS total ($r=0.52$), and HAM-D scores ($r=0.32$) ($p=0.05$). Additionally, it was discovered that the patients' QoL in every dimension was inversely correlated with the disease burden ($p=0.05$).

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

Variable	Patient		Caregiver	
	BAS Score		BAS Score	
	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***	

Discussion:-

In this study, we aimed to assess the variables influencing disease burden in caregivers of patients of OCD. We identified the predictors of caregiver burden in caregivers of patients of OCD by selecting variables from the univariate analysis that were significantly related to disease burden.

For patients with OCD and their co-living caregivers, a minimum of one year was required because less time might not have been enough to significantly increase the caregiver's workload. Since these disorders have their own burdens, as shown in prior studies (15,16), and the additional burden would be added to that of OCD, patients with OCD who also have a comorbid psychiatric disorder (except depressive disorder), the presence of neurological/or physical disease, and intellectual disability were excluded from the study. Since comorbid depressive disorder is typically secondary to OCD, it was not disregarded. Despite studies in the literature demonstrating a link between disease burden and psychiatric comorbidity in caregivers of patients with OCD, we excluded all caregivers with psychiatric, neurological/or physical disorders in order to obtain a more pure sample and assess the burden specific to OCD only. There was no evidence of a causal relationship between high family burden and psychiatric disorders in these studies (17,18).

We discovered that only three sociodemographic factors—perceived income level, residence, and patient education levels—were significantly related to the disease burden. The BAS scores of caregivers in rural areas who believed their income to be low were significantly higher. There are two studies that are comparable to our study in the literature (19,20), but only one of them found low perceived income level to be significant (20). These findings may be explained by the challenges in obtaining advanced and skilled healthcare services, such as psychoeducational and family therapies in addition to medication, as psychotherapy is not routinely provided by psychiatric practices in state institutions in our nation for a variety of reasons. For psychotherapy, people should seek out higher tier medical facilities or private clinics. Additionally, it was found in our study that the caregiver burden decreased as the patient's education time increased. Higher educational levels make it easier to access information, which aids in the development of disease coping mechanisms. Our study demonstrated a negative correlation between education years and BAS scores .

Studies demonstrating that disease duration increases disease burden are found in the literature (21,22,23), as are studies demonstrating that it has no impact on disease burden (24,25). In line with Cicek et al findings 's (22) we found a positive correlation between disease burden and both the duration of the illness as well as its treatment. Caregivers may become more exposed to symptoms, lose hope for recovery, develop poor coping mechanisms, and experience burden as the length of the disease and treatment increases. Additionally, extending the course of treatment results in higher medical expenses and a financial burden.

The number of hospitalizations and patients' need for care may rise as the disease's severity does. Because of this, the caregiver's leisure activities may decline, its social functioning may decline, and its professional life may be disrupted, which can add to the caregiver's burden. In line with earlier studies, we discovered that the disease burden increased as the number of hospitalizations increased (19,22).

According to our research, patients' lower QoL in all four areas—physical, psychological, social, and environmental—was associated with a significantly higher disease burden. In our study we considered the caregiver burden as a variable when evaluating the patient's quality of life. Prior research examined the connection between functionality and disease burden, demonstrating that the burden rises as disability does (20,22). However, since functionality and pertinent subjective satisfaction are included in the concept of QoL (29), we believe that our findings are more significant. Researchers have been concentrating on QoL as a criterion that should be improved in the treatment process already in recent years.

Finding the length of treatment rather than the length of disease as a predictor of caregiver burden implies that symptom persistence despite treatment causes more burden than the overall length of the disease. Because in psychiatry, patients frequently seek treatment when their condition has gotten worse rather than when it first started. Obsessive-compulsive symptom severity is inherently a predictor of disease burden because it can be observed externally and caregivers can become accustomed to the symptoms. This is due to the nature of OCD. As the patient's obsessive-compulsive symptoms worsen, the caregiver can assume more of the patient's responsibilities and participate in the patient's rituals to help reduce the stress of the disease, cut down on the amount of time spent on the symptoms, and improve daily functioning. This could lead to a breakdown in domestic harmony and put restrictions on the caregiver's day-to-day activities (30) Due to OCD, the patient may have less working capacity, their professional functionality may decline, treatment costs may rise, and they may require more caregiver support, all of which add to their burden. The environmental dimension of QoL is made up of additional elements like leisure and recreation opportunities, physical circumstances and safety, living conditions, access to healthcare, and new knowledge and skills. Any of these impairments could make it difficult to treat the patient and carry out daily tasks, which would be difficult for the caregiver.

Conclusion:-

Our study broadens the literature with its statistical analysis. Even in caregivers without additional burden, many factors can affect burden. The severity of obsessive-compulsive symptoms, treatment length, and environmental quality of life predict disease burden. These findings suggest that doctors should also treat OCD patient's social and professional expectations, relationships with family and friends, and caregiver's attitudes towards the illness. They should consider the caregiver's needs in OCD treatment and management, and family health benefit from including Caregiver in behavioral and pharmacological treatment. Management should include family consultations and therapies. Group therapies should also accommodate patients and caregivers. However, large-sample follow-ups should confirm our findings. Future research may examine family burden and treatment effects

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