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Original Research Article

Burden, quality of life, and coping of caregivers of obsessive-compulsive disorder and healthy controls

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ABSTRACT

Background: Caregiver burden refers to the detrimental effects of caregiving on a caregiver's health, well-being, quality of life (QoL), and adaptation to challenging circumstances. The trajectory of any chronic mental disease is determined by the burden of morbidity, treatment costs, and the caregivers' responsibilities during the rehabilitation process. Caregivers of individuals with chronic mental illness frequently exert a detrimental influence on daily living. Obsessive-Compulsive Disorder (OCD) is one of the long-standing, debilitating disorders that impacts the physical and mental health well-being due to its characteristics and progression. This study aims to look at how much stress caregivers feel, their QoL, and how they cope while caring for people with OCD compared to caregivers of healthy individuals, as well as exploring how these factors are connected in both groups.

Methods: This research used a comparative and correlational research design. We used the purposive sampling method to collect a total of 100 samples, with 50 samples from each group.

Results: The study groups were equivalent in all sociodemographic factors. Statistically significant differences ($p<0.05$) were seen in caregiving burden, QoL, and coping mechanisms. A negative correlation was identified between caregiver burden and the quality of life of caregivers of individuals with OCD, whereas no significant relationship was observed between caregiver burden and coping strategies.

Conclusion: Providing care for an individual with OCD significantly affects health outcomes, adversely impacting the well-being and QoL of caregivers. The subjective and objective burdens faced by caregivers of individuals with OCD are significantly detrimental to their well-being and quality of life, resulting in adverse health effects while also fostering resilience in coping strategies.

Keywords: Caregiver burden, Quality of life, Coping, Obsessive-compulsive disorder, Healthy controls, Mental well-being

INTRODUCTION

About 2-3% of people worldwide suffer from obsessive-compulsive disorder (OCD), one of the most prevalent and incapacitating mental illnesses.[1] It is twice as common as bipolar disorder and schizophrenia.[2] Compulsive rituals and enduring obsessions are its defining characteristics.[3] By altering family routines to accommodate the patient's repetitive behaviors, family members who live with and care for them are mostly compelled to carry out the ritualistic activities that the patients undertake. Global family dysfunction has often been the result of this maladjustment.[1] Caregivers of patients with chronic illnesses frequently have more challenges in their day-to-day lives than those of a healthy individual. Because of socio-cultural considerations, family members play an important part in caring for an affected family member's disease process in

India. Another factor contributing to the caregiving burden in India is a lack of rehabilitative services, inadequate institutional facilities, and an insufficient welfare support system.[4] A caregiver is someone who looks after the physical and psychological well-being of another person as part of a relationship or profession.[5] A key relative/caregiver is defined as a family member who has lived with the patient for at least a year, was present at the outset of the illness, and is actively involved in patient care.[5,6] Caregiver burden has an impact on the physical, psychological, social, emotional and spiritual health of the person who cares for a chronically mentally ill patient.

The psychological stress caused by obligatory caring responsibilities not only interferes with quality of life (QoL) but also influences the caregiver's coping strategies.[1,5] The relevance of caregiving has always been important in the life of a caregiver, who is mostly responsible for the patient's well-being. Caregivers commonly experience adjustment challenges, engage in maladaptive coping techniques, and show concern about their low quality of life as a result of caregiving.[7] Many studies have found a strong negative association between the severity of OCD and low QoL.[6,8] The World Health Organization describes QoL as an individual's view of their place in life in relation to the culture and value systems in which they live, as well as their goals, expectations, standards, and concerns.[9]

Caregivers assume various duties in the care of people suffering from chronic mental illnesses, including managing daily routine activities, supervising medical consultations, and dealing with financial demands, all of which cause them significant stress and hardship. As a result, they require support in navigating the caregiving process. Researchers describe coping as "the thoughts and behaviors used to manage the internal and external demands of stressful situations".[10] A dysfunctional coping strategy is likely to impair the caregiving process.[11] Coping may be adaptive or maladaptive. Adaptive coping strategies assume approaching problems/stressful situations directly and making rationally practical assessments of problems, whereas maladaptive coping involves using maladaptive methods (e.g., alcohol or drug use) to escape problems or stressful situations, resulting in negative health consequences for the caregiver.

Objective

The objective of the research study was to evaluate caregiver burden, QoL, and coping among caregivers of OCD patients and compare them to caregivers of physically and mentally sound people.

Aims

Evaluate and compare caregiver burden between OCD caregivers and healthy controls. Evaluate and compare the QoL of caregivers of both groups. Evaluate and compare the coping strategies of caregivers of both groups. Evaluate the interrelationship between caregiver burden and QoL for caregivers of both groups. Determine the relationship between caregiver burden and coping among caregivers of both groups.

METHODS

Ethics

Prior to the start of the investigation, Institutional Ethics Committee clearance was acquired (IEC Appln. No: 950, Dt: 01/12/2021).

Study design

This study used a comparative and correlational research design. Sampling Method: The purposive sampling method was used to choose 100 samples (50 from each group).

Inclusion criteria

A primary caregiver must live with the patient (at least for 1 year), be present when symptoms begin, and participate substantially in patient care. Age group of caregivers was 20 to 60 years. Duration of illness for patients was 2 years or more. Healthy controls were those who were taking care of a family member who did not have any serious medical or mental illness. The minimum educational qualification for caregivers was higher secondary. Those who could read/understand Odia, English, and Hindi. Persons who agreed to participate in the study by giving written consent.

Exclusion criteria

Caregivers who had a comorbid chronic medical or psychiatric illness and those who had also taken care of someone with any chronic physical or mental disorder. Caregivers with below-average intelligence or any such disorder, which could influence their cognition. Caregivers of those patients who had comorbid other serious physical or mental illnesses other than OCD.

Tools used

ICD-10 diagnostic criteria for research

The International Statistical Classification of Diseases and Related Health Problems, 10th Revision, was used to diagnose the cases of OCD.[3]

Self-Reporting Questionnaire-20

This instrument was developed by the World Health Organization.[12] The test was used to screen out psychiatric disturbances/symptoms in healthy controls. It comprises 20 items, and each item shall be assigned a score of “0” for “No” and “1” for “Yes.” The highest

possible score is 20, and the cut-off score is 7/8. The inter-rater reliability coefficient is 0.963.

Socio-demographic data sheet

This sheet was used to accumulate demographic variables, i.e., age, sex, religion, qualification, employment, marital status, family type, domicile, socio-economic status, and family history of psychiatric illness of the study population.

The socioeconomic status scale by Kuppuswamy (modified for February 2019)

The modified Kuppuswamy scale was used to measure SES in urban and rural areas.[13]

Yale-brown obsessive-compulsive scale

Goodman et al designed this scale to measure the severity of OCD symptoms. This is a clinician-rated scale comprising 10 items, and each to be rated on a scale of 0 to 4. The higher the score, the higher the symptom severity will be.[14]

Burden assessment schedule

The Burden assessment schedule (BAS) was developed by Thara et al.[15] It aims to assess both objective and subjective burdens experienced by the primary caregivers. It consists of 40 items, and each is to be rated on a three-point scale (1 to 3). The possible responses are "Not at all," "To some extent," or "Very much." The scores of each item will vary based on the framing of the questions. The inter-rater reliability of the scale is excellent (kappa of 0.80). The validity of the scale is also high (0.71-0.82).

WHO quality of life bref (Odia Version)

WHO-QOL Bref is a short version of WHOQOL-100. WHOQOL-Bref has been translated into Odia language by Kar et al.[9,16] This scale comprises 26 items categorized into four domains: physical health, psychological well-being, relationships, and environment. Every item is to be graded on a 5-point scale (1 to 5). The Cronbach's alpha is 0.89. The higher the scores, the better the quality of life for an individual.

Stress coping behavior assessment scale

The stress coping behavior assessment scale was developed by Janghel et al, and Shrivastava et al in Hindi in 2017.[17] This scale is based upon the "Brief Cope" scale developed by Carver et al in 1997.[18] The purpose of this scale is to assess an individual's stress-coping behavior. This comprises 23 items categorized into two dimensions: adaptive coping and maladaptive coping. The psychometric properties indicate that this scale demonstrates both reliability and validity within the Indian population. The SCBS scale illustrates a Cronbach's alpha of 0.82, indicating a high degree of reliability.

Procedure

This research investigation was conducted at the OPD of the Mental Health Institute (Centre of Excellence) at S.C.B. Medical College, Cuttack, Odisha, India. Caregivers of OCD patients who had been diagnosed by consultants in accordance with ICD-10-DCR were chosen using inclusion criteria. Participants for the matching healthy control group were chosen from the community. We gave all participants a comprehensive explanation of the study's procedures before they agreed to grant signed consent to participate. SRQ-20 was used to screen out psychiatric symptoms among the matched healthy controls. Participants who scored below the cut-off mark were included as the control group. With the help of Y-BOCS, the severity of symptoms experienced by OCD patients was evaluated. After collecting socio-demographic information from each participant, BAS, WHOQol Bref (Odia version), and SCBS were administered to caregivers of both groups to assess caregiving burden, QoL, and coping.

Statistics analysis

SPSS, Version 22.0 (SPSS Inc., Illinois, USA), was used to analyze the data. The quantitative variables were analyzed through t-tests, whereas the qualitative factors, such as sociodemographic variables, were assessed using chi-square tests. The study used Pearson correlation to investigate the association between caregiving burden and QoL, as well as caregiving burden and coping strategies in both groups. Parametric statistics (Independent samples t-test, Pearson correlation) were applied due to the normally distributed data, a large sample size (more than 30), and the data rated on an interval scale.

RESULTS

This study examined caregiver burden, QoL, and coping mechanisms among OCD caregivers and healthy controls. The study comprised 100 caregivers, 50 from each group. The Burden Assessment Schedule, WHOQOL-Bref, and stress coping behavior assessment scale were used to assess each participant's caregiving burden as well as specific domains of QoL and coping strategies. Authors used the SRQ-20 to rule out any psychiatric symptoms in the healthy control group. The mean SRQ-20 score was 3.16, indicating "No psychiatric disturbances." The severity of OC symptoms was assessed in 50 OCD patients using the Y-BOCS. The mean Y-BOCS score was 25.5, with a standard deviation of 4.22, indicating a "severe level of obsessive-compulsive symptoms" among OCD patients. A comparison was made between the socio-demographic characteristics of the two groups. Table 1 illustrates that the differences between the groups were statistically insignificant, indicating that the research groups were fundamentally equivalent. The average age

of caregivers with OCD was 41.2±8.54 years, while healthy controls were 38.08±9.28 years. The number of males and females in the OCD group was about equal, while females outnumbered males in the control group. The average age of OCD patients was 34.64±11.43 years, while family members of healthy controls were 46.6±13.63 years. In terms of age or duration of care, there was no statistically significant difference between the two groups.

Table 2 compares the caregiving burden between OCD caregivers and healthy controls. A statistically significant difference ($p<0.05$) was observed between the two groups. The finding suggests that caregivers with OCD have a much higher caregiver burden, both objective and subjective, than the control group. Table 3 compares several domains of QoL between OCD caregivers and healthy controls. There were significant differences ($p<0.05$) in physical health, psychological well-being, social relationships, and environmental domains of QoL between the two groups. Caregivers with OCD had a lower quality of life in terms of physical health, psychological well-being, social interactions, and the environment in which they reside than control subjects. Table 4 presents a comparison of coping mechanisms utilized by caregivers of individuals with OCD and those of healthy controls. The domains of adaptive and maladaptive coping mechanisms showed statistically significant differences ($p<0.05$) between these two groups. Healthy controls exhibit a higher mean score on the adaptive coping approach compared to OCD caretakers. Conversely, caregivers of individuals with OCD exhibit a higher mean score in maladaptive coping strategies compared to the healthy group. This finding suggests that while healthy controls have adopted more adaptive coping mechanisms to deal with caregiver burden, OCD caregivers have adopted more dysfunctional coping mechanisms.

Table 1: Sociodemographic data of caregivers of OCD and healthy controls.

Variables		Caregivers of OCD (n=50)	Caregivers of healthy controls (n=50)	t value	P value
		Mean±SD	**Mean±SD**		
Age (in years)		41.2±8.54	38.08±9.28	1.74	0.08*
Duration caregiving		6.1±2.1	7.2±4.6	-1.51	0.13*
		N (%)	**N (%)**	**Chi-square**	
Gender	Male	27 (54)	20 (40)	1.96	0.16*
	Female	23 (46)	30 (60)		
Religion	Hindu	43 (86)	37 (74)	2.25	0.13*
	Muslim	7 (14)	13 (26)		
Education	HSC	10 (20)	9 (18)	3.43	0.32*
	CHSE	8 (16)	4 (8)		
	Graduation	18 (36)	15 (30)		
	Widow	14 (28)	22 (44)		
Occupation	Employed	31(62)	36 (72)	1.13	0.28*
	Unemployed	19 (38)	14 (28)		
Marital status	Married	36 (72)	33 (66)	0.44	0.80*
	Unmarried	13 (26)	16 (32)		
	Widow	1 (2)	1 (2)		
SES	Upper lower	6 (12)	4 (8)	2.46	0.48*
	Lower middle	12 (24)	7 (14)		
	Upper middle	19 (38)	22 (44)		
	Upper	13 (26)	17 (34)		
Domicile	Rural	15 (30)	7 (14)	3.77	0.15*
	Semi-urban	13 (26)	15 (30)		
	Urban	22 (44)	28 (56)		
Relationship	Spouse	21 (42)	17 (34)	2.84	0.41*
	Parents	13 (26)	9 (18)		
	Child	12 (24)	19 (38)		
	Other	4 (8)	5 (10)		
Family type	Joint	18 (36)	17 (34)	0.04	0.83*
	Nuclear	32 (64)	33 (66)		

*p>0.05 (Statistical Non-significance at 0.05 level)

Table 2: Comparison of caregiver burden between caregivers of OCD and healthy controls.

Caregiver burden	OCD (n=50) Mean±SD	Healthy Controls (n=50) Mean±SD	t value	P value
BAS	80.18±10.33	57.40±9.55	11.44	0.00*

*p<0.05 (Statistical significance at 0.05 level)

Table 3: Comparison of domains of quality of life between caregivers of OCD and healthy controls.

WHOQOL Bref domains	OCD (n=50) Mean±SD	Healthy controls (n=50) Mean±SD	t value	P value
Physical Health	56.32±11.19	70.14±7.85	-7.14	0.00*
Psychological	58.50±15.34	72.38±9.67	-5.41	0.00*
Social Relationship	58.66±18.81	72.52±9.08	-4.69	0.00*
Environment	64.36±17.64	74.56±9.51	-3.59	0.00*

*p<0.05 (Statistical significance at 0.05 level)

Table 4: Comparison of coping strategies between caregivers of obsessive-compulsive disorder and healthy controls.

Coping	OCD (n=50) Mean±SD	Healthy controls (n=50) Mean±SD	t value	P value
Adaptive coping	-0.21±0.69	0.41±0.39	-5.59	0.00*
Maladaptive coping	-0.22±0.90	-0.87±68	4.06	0.00*

*p<0.05 (Statistical significance at 0.05 level)

Table 5: Correlations between caregiver burden and quality of life & caregiver burden and coping strategies of caregivers of OCD and healthy controls.

	Domains of WHOQOL Bref				Coping	
	Physical	**Psychological**	**Social relationships**	**Environment**	**Adaptive coping**	**Maladaptive coping**
Burden of OCD caregivers	-0.35*	-0.41**	-0.51**	-0.37**	-0.20	0.11
Burden of healthy controls	0.08	0.02	-0.20	-0.30	-0.10	0.01

*Correlation (r) is significant at 0.05 level, **Correlation (r) is significant at 0.01 level

Table 5 displays the relationships between QoL and caregiver burden in OCD caregivers and healthy controls. A statistically significant negative association was observed between caregiver burden and four domains of QoL in caregivers of individuals with OCD. In healthy controls, there was no significant correlation. Thus, in the case of OCD caregivers, their QoL declines as the caring load increases. This table also displays the relationships between coping strategies and caregiver burden in both OCD caregivers and healthy controls. The findings indicated that in these two groups, there was no statistically significant association between coping and caregiver burden. It suggests that caregivers of both groups tried to manage the situation as the caregiver burden rose.

DISCUSSION

In the Indian culture, the family is essential in the care of an ill individual, regardless of whether it is a physical or psychiatric condition. The caregiver's overall functioning is directly impacted by the strain and burden that are imposed on them by the regular care of a mentally ill patient. This study was conducted to evaluate the burden, QoL, and coping strategies of caregivers of OCD and healthy controls, as well as to investigate the correlation between these variables. Caregivers of OCD had an average age of 41.2 years, while healthy controls had an average age of 38.08 years. The mean duration of caregiving for OCD caregivers and healthy controls was 6.1 years and 7.2 years, respectively. The sociodemographic variables of both groups, such as age and caregiving duration, were inherently comparable due to the absence of statistically significant differences. The burden of both the caregivers of OCD and healthy controls was analyzed, and statistically significant differences ($p<0.05$) were identified between the two groups. In terms of the subjective and objective burden, caregivers of OCD patients are burdened more than those of healthy individuals, as the multiple dimensions of caregiving are considered. Emotional disturbances, financial difficulties, disruption of routine, disturbances of family stability, and disruption of social relationships all contribute to the caregiving burden during the ongoing course of illness. Other prior investigations also support this discovery.[19-25]

The results of the study indicated that the QoL of OCD caregivers is suboptimal in comparison to that of healthy controls. All domains of QoL-physical health, psychological, social relationships, and environment-significantly suffer in OCD caregivers. This discovery is in accordance with other investigations.[19-22,24,26] The chronic nature and considerable disability burden of OCD

itself suggest that the burden of caring for a patient with OCD not only impacts the physical and psychological well-being of a caregiver but also negatively impacts the psychosocial environment and social relationships. Caregivers of OCD adopted a more maladaptive pattern of coping strategies in response to the caregiving process, whereas the healthy control group adopted a more adaptive approach to coping strategies.[2,27] Maladaptive strategies, including self-blame, self-distraction, behavioral disengagement, venting, and substance use, were employed by the caregivers during the caregiving process. These strategies subsequently impacted the individual's well-being.

In the case of OCD caregivers, the study's results indicated a negative correlation between caregiver burden and QoL. It suggests that as the caregiving burden increases, their overall quality of life also deteriorates.[1,22,26,28] The physical health, psychological well-being, and environmental and social components of QoL are all significantly impacted by the negative health consequences that caregivers experience during the caregiving process when they have a chronic course of OCD. This is due to the disruption of daily routines and psychosocial components. The coping strategies of caregivers of OCD were not found to be significantly associated with the caregiving burden. It suggests that the caregivers are mentally accepting the disease's course and are attempting to manage the situation by using maladaptive coping strategies as the disorder persists in the long term.[27] Caregivers may also perceive certain positive aspects of caring by dedicating time to them and becoming attentive to their needs. However, during the process, they adopt maladaptive coping strategies that have adverse health consequences during the progression of the disease.[29,30]

The research study may be conducted in different population groups of different regions to generalize the conclusive findings on the caregiver burden of OCD, considering variations in coping mechanisms and quality of life related to age, gender, and socio-cultural background.

CONCLUSION

The findings of this research indicate that the caregiver's subjective and objective burden during the caregiving process for OCD patients is of enormous significance, which exacerbates the negative health consequences for the caregiver. The caregiving of OCD patients significantly impacts the caregivers' QoL across all four dimensions. Caregivers of OCD have adopted maladaptive coping strategies, including substance use, behavioral disengagement, self-blame, self-distraction, and ranting, which have adverse effects on their mental health. As the caregiving burden increases, it proportionally impacts QoL and leads to the implementation of maladaptive coping strategies. Thus, caring for a person with OCD greatly affects the caregiver's health, negatively impacting their well-being, coping mechanisms, and quality of life.

Implications

It is common practice to disregard the mental health of the caregiver; therefore, it is essential to seek mental health expert interventions in the field of psychosocial care to address this problem. It is important to remember that a caregiver who is in good health, both physically and mentally, may be able to provide the highest quality of care to those who are in need of it.

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