

BURDEN AND QUALITY OF LIFE OF THE CAREGIVERS OF DISSOCIATIVE DISORDER PATIENTS: A CROSS-SECTIONAL STUDY

Shanu Soni¹, Sudhir Kumar², Haseeb Khan³, Saurabh Upadhyay⁴, Zain⁵

¹Junior Resident, Department of Psychiatry, Hind Institute of Medical Sciences, Lucknow, Uttar Pradesh, India

²Dean and Pro-Vice Chancellor, Dr. KNS Memorial Institute of Medical Sciences, Barabanki, Uttar Pradesh, India

³Professor and Head, Department of Psychiatry, Hind Institute of Medical Sciences, Lucknow, Uttar Pradesh, India

⁴Assistant Professor, Department of Psychiatry, Hind Institute of Medical Sciences, Lucknow, Uttar Pradesh, India

⁵Senior Resident, Department of Psychiatry, Hind Institute of Medical Sciences, Lucknow, Uttar Pradesh, India

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Corresponding Author:

Dr. Saurabh Upadhyay,

Email: saurabhupadhyay450@gmail.com

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Abstract

Background: Dissociative disorders being chronic, relapsing illnesses, imposes a significant caregiver burden. The burden can be felt through interrupted family relations, health problems, financial strain, and the need to give up their desires. The objectives of the current study were to estimate the burden and quality of life in caregivers of patients with dissociative disorder and to assess the association between caregiver burden and quality of life. **Materials and Methods:** A descriptive cross-sectional study was done at a tertiary care center at Barabanki district with 70 caregivers of dissociative disorder patients (20-55 years). Validated tools were used to assess the caregiver burden (BAS scale) and quality of life (WHOQOL-BREF scale) of caregivers of dissociative disorder patients. **Result:** The majority of caregivers reported moderate to severe caregiver burden. The caregiver burden was reported higher in older age group caregivers (46-55 years) with higher scores in the “support of patient” and “taking responsibility” domains. The caregiver burden was found to be affected by the relationship with the patient, QOL score was lower in the spouse. There was a negative correlation between caregiver burden and the quality of life of the caregivers. **Conclusion:** The present study emphasizes caregiver burden and quality of life in dissociative disorders patients. There is a need to understand and formulate newer modalities for a holistic approach to managing the caregiver burden and the patient of concern disorder.

INTRODUCTION

Dissociative disorders are a type of neurotic disorder characterized by disruptions in consciousness, identity, perception, memory, motor control, emotion, and behavior.^[1,2] These disorders are often triggered by psychological stress, but a diagnosis should not be dismissed if no stressor is found.^[3] Common stressors include physical or sexual abuse in childhood, interpersonal conflict, and poor family dynamics. Factors such as punitive parenting, lack of family cohesion, and poor communication are linked to the development of dissociative disorders.^[4] In developing countries, the prevalence of dissociative disorders can be as high as 31%.^[5]

A caregiver is a family member who has lived with the patient for over a year and is involved in daily activities, conversations, and medical treatment.^[6] The WHO defines caregiver burden as the emotional,

physical, and financial demands and responsibilities placed on those involved with the patient outside the healthcare system.^[6] This burden has two aspects: objective (measurable difficulties like expenses and lost leisure time) and subjective (the psychological toll on the family).^[7] Several factors influence caregiver burden, including the caregiver's age and gender, their relationship with the patient, the severity and duration of the patient's illness, the caregiver's coping strategies and perceptions, family support, and socio-cultural-ethnic factors.^[8] The WHO defines Quality of Life (QOL) as an individual's perception of their position in life within their cultural and value systems, in relation to their goals, expectations, standards, and concerns. Studies have shown that caregiver burden negatively impacts QOL, particularly in caregivers of patients with chronic illnesses, affecting the psychological domain more than the physical domain.^[9] Dissociative

disorders are chronic and relapsing, but there is a lack of studies assessing caregiver burden and QOL in caregivers of patients with these disorders. This study aims to assess the severity of caregiver burden and QOL and explore any correlations between the two.

MATERIALS AND METHODS

This study was a cross-sectional observational study, conducted over 12 months. The sample was taken from the Department of Psychiatry of a tertiary care centre, UP, India. Seventy patient-caregiver participants were selected as per the defined criteria, who were visiting outpatient and inpatient services via consecutive sampling method. Patients with ICD-10 DCR diagnosis of dissociative disorder and an accompanying key caregiver were selected. The key caregiver was defined as a family member who has resided with the patient for more than a year and has been involved in everyday activities, conversations, and medical treatment of the patient. The caregivers of aged 20-55 years and willing to participate, were included. Significant neurological, psychiatric, and major physical illness and who refused to participate were kept as exclusion criteria. The code of ethics (Declaration of Helsinki) about research on human subjects were followed and the confidentiality of participants were ensured. The caregiver as well as patient were explained about the study in detail.

Instruments

Semi-structured questionnaire for sociodemographic details was used to collect social and demographic details of the caregivers as well as patients. The Burden Assessment Schedule Scale developed by the schizophrenia research foundation (SCARF) in collaboration with the WHO was used to assess the burden of caregivers. The BAS assesses both "objective and subjective burden" for primary caregivers of chronically mentally ill patients.(10) The stepwise ethnographic exploration method was used to create a scale that reflects the perspectives of caregivers, rather than those of the researchers. "It measures burden in nine areas: Spouse related, Physical and mental health, External support, Caregiver's routine, Support of patient, Taking responsibility, Other relations, Patient's behavior, and caregivers' strategy. There are 40 items evaluated on a 3-point scale from 1 to 3. The responses include 'not at all', 'to some extent', and very much with some items being reverse-coded. Inter-rater reliability among interviewers is good (Kappa = 0.80) and the criterion validity ranges from 0.71-0.80. A BAS score of up to 40 indicates no burden, 41-60 mild burden, 61-80 moderate burden, 81-100 severe burden, and 101-120 very severe burden.(9)The WHOQOL-BREF, used for assessment of quality of life of caregivers, is a shorter version of the WHOQOL-100 designed for time-constrained scenarios. This instrument is a multilingual, person-centered tool for subjective assessment. It can be used to compare a variety of

diseases and disorders. The WHOQOL-BREF instrument constitutes 26 items, which assess the QOL in the following four domains viz "Physical health, Psychological health, Social relationships, and Environment". "Question 1 asks about an individual's overall perception of QOL" and "Question 2 asks about an individual's overall perception of his or her health" were assessed separately. Responses to the items were recorded using a 5-point Likert scale, ranging from "very poor to very good, very dissatisfied to very satisfied, not at all to very possible, and never to always". Domain scores were scaled in a positive direction (higher scores indicate greater QoL), with a score range of 4-20, and converted to a 0-100 scale using the standard approach outlined in the WHOQOL user manual. Domain scores are derived by averaging all entries inside a specific domain. To compare domain scores to WHOQOL-100 scores, mean scores are multiplied by '4'. These scores are then converted to a 0-100 scale. The WHOQOL instruments (WHO QOL-100 and WHO QOL-BREF) have been validated internationally and are accessible in 30 languages, making them applicable to a wide range of people. Test-retest reliability (Cronbach alpha 0.66-0.84) was determined to be appropriate for all four domains.^[11-13]

Data Analysis

Data were analyzed by SPSS version 26 software. Quantitative variables are expressed in mean and standard deviation while the categorical variables are represented as frequency and percent. Data analysis included statistical tests as analysis of variance (ANOVA), t-test, and measures of central tendency (mean and standard deviation) were appropriate. Post hoc analysis was done for both scales.

RESULTS

The sociodemographic characteristic of the caregivers and patients of dissociative disorder is given in Table. The mean age of caregivers was 37.66 ± 10.26 years, out of which 67.1% were male and 32.9% were female. Out of total caregivers 82.9% were married, majority of the families were living in rural area and in a nuclear family setting.

The overall burden in the caregiver group came out to be 70.20 ± 10.44 . The mean score on various domains of BAS were as follows: Spouse Related (9.09 ± 1.90), Physical and Mental Health (13.24 ± 2.53), External Support (8.69 ± 1.90), Caregiver's Routines (8.50 ± 1.37), Support of Patient (6.27 ± 0.99), Taking Responsibility (8.84 ± 1.56), Other relations (5.74 ± 1.20), Patient's behavior (7.84 ± 1.48), and Caregiver's strategy (7.89 ± 1.63). On WHOQOL-BREF, total score among the care givers came out to be (330.09 ± 60.46). The mean score on various domains of WHOQOL-BREF were as follows: Physical Health (101.88 ± 23.12), Psychological (77.05 ± 21.61), Social Relationships (35.36 ± 10.36) and Environment (115.80 ± 22.74)

Table 1: Sociodemographic profile of caregivers and patients.

Caregiver: sociodemographic variables	
Age (years); Mean ± SD	37.66 ± 10.26
Gender	
Male	47 (67.1%)
Female	23 (32.9%)
Education	
Illiterate	11 (15.7%)
Primary	19 (27.1%)
High school	25 (35.7%)
Intermediate	9 (12.9%)
Graduate	5 (7.1%)
PG and above	1 (1.4%)
Marital status	
Unmarried	10 (14.3%)
Married	58 (82.9%)
Separated/divorced	1 (1.4%)
Widowed	1 (1.4%)
Family type	
Nuclear	50 (71.4%)
Joint	20 (28.6%)
Residence	
Urban	5 (7.1%)
Rural	65 (92.9%)
Relation to Patient:	
Father	15 (21.4%)
Mother	16 (22.9%)
Spouse	23 (32.9%)
Offspring	6 (8.6%)
Sibling	7 (10.0%)
Distant	3 (4.3%)
Duration of caregiving	
0-6 months	39 (55.7%)
7-24 months	24 (34.3%)
> 24 months	7 (10.0%)
Patient: Sociodemographic variables	
Age (years); Mean ± SD	24.94 ± 8.52
Gender	
Male	3 (4.3%)
Female	67 (95.7%)
SD=Standard Deviation	

Table 2: Burden and Quality of Life in relation to age range and gender

	Age Range Mean (SD)					Gender Mean (SD)			
	20-30 Years	31-45 Years	46-55 Years	ANOVA (F)	p	Male	Female	t-Test (t)	p
BAS									
Spouse Related	8.80 (2.09)	9.18 (1.88)	10.00 (1.41)	0.335	0.719	9.23 (1.82)	6.00	1.730	0.098
Physical and Mental Health	12.68 (2.73)	13.67 (2.48)	13.13 (2.35)	1.011	0.369	13.09 (2.62)	13.57 (2.39)	-0.741	0.461
External Support	8.50 (1.50)	8.55 (2.03)	9.27 (2.15)	0.886	0.417	8.70 (1.88)	8.65 (1.99)	0.102	0.919
Caregiver's Routines	8.05 (1.46)	8.82 (1.28)	8.47 (1.30)	2.177	0.121	8.49 (1.47)	8.52 (1.16)	-0.092	0.927
Support of Patient	6.00 (0.81)	6.21 (1.02)	6.80 (1.01)	3.207	0.047*	6.23 (0.96)	6.35 (1.07)	-0.448	0.655
Taking Responsibility	8.32 (1.64)	8.76 (1.50)	9.80 (1.20)	4.498	0.015*	8.81 (1.58)	8.91 (1.56)	-0.260	0.795
Other relations	6.27 (1.24)	5.45 (1.20)	5.60 (0.91)	3.429	0.038*	5.83 (1.22)	5.57 (1.16)	0.865	0.390
Patient's behavior	7.64 (1.49)	8.09 (1.46)	7.60 (1.50)	0.876	0.421	7.83 (1.55)	7.87 (1.35)	-0.105	0.917
Caregiver's strategy	7.95 (2.01)	7.97 (1.55)	7.60 (1.24)	0.285	0.753	7.96 (1.76)	7.74 (1.35)	0.521	0.604
TOTAL	74.22 (11.81)	75.75 (10.28)	75.40 (9.20)	0.141	0.868	76.34 (11.49)	72.86 (7.59)	1.312	0.194
WHOQOL BREF									
Physical Health	104.26 (22.36)	99.81 (22.01)	102.92 (27.53)	0.258	0.773	105.19 (22.99)	95.11 (22.37)	1.737	0.087
Psychological	80.97 (23.34)	74.43 (20.33)	77.08 (22.36)	0.596	0.554	79.12 (21.70)	72.83 (21.28)	1.147	0.255
Social Relationships	39.20 (10.94)	33.52 (8.95)	33.75 (11.52)	2.296	0.109	35.64 (10.66)	34.78 (9.94)	0.322	0.748

Environment	121.31 (20.19)	115.72 (19.71)	107.92 (30.57)	1.572	0.215	114.76 (23.32)	117.93 (21.83)	-0.546	0.587
TOTAL	345.74 (61.85)	323.48 (50.05)	321.67 (77.41)	1.082	0.345	334.71 (61.95)	320.65 (57.48)	0.912	0.365
SD=Standard Deviation; BAS=Burden Assessment Schedule; WHOQOL BREF=World Health Organisation Quality of Life Brief Version; * p<0.05									

Table 3: Burden and Quality of Life in relation to family type and caregiving duration

	Family Type Mean (SD)		t-Test (t)	p	Care Giving Duration Mean (SD)			ANOVA (F)	p
	Nuclear	Joint			0-6 m	7-24m	>24m		
BAS									
Spouse Related	9.08 (1.89)	9.10 (2.02)	-0.028	0.978	8.82 (2.08)	9.43 (1.90)	9.20 (1.78)	0.214	0.809
Physical and Mental Health	13.20 (2.26)	13.35 (3.18)	-0.222	0.825	12.72 (2.68)	13.67 (2.31)	14.71 (1.70)	2.441	0.095
External Support	8.86 (1.88)	8.25 (1.94)	1.213	0.229	8.46 (1.93)	9.13 (1.87)	8.43 (1.90)	0.968	0.385
Caregiver's Routines	8.48 (1.18)	8.55 (1.79)	-0.192	0.848	8.28 (1.33)	8.63 (1.34)	9.29 (1.49)	1.784	0.176
Support of Patient	6.38 (0.87)	6.00 (1.21)	1.460	0.149	6.15 (0.90)	6.33 (1.00)	6.71 (1.38)	1.020	0.366
Taking Responsibility	8.90 (1.51)	8.70 (1.72)	0.480	0.633	8.69 (1.68)	8.79 (1.38)	9.86 (1.21)	1.694	0.192
Other relations	5.64 (1.17)	6.00 (1.25)	-1.136	0.260	5.64 (1.38)	5.83 (1.00)	6.00 (0.57)	0.362	0.697
Patient's behavior	7.86 (1.41)	7.80 (1.67)	0.152	0.880	7.51 (1.41)	8.04 (1.48)	9.00 (1.29)	3.570	0.034*
Caregiver's strategy	7.76 (1.36)	8.20 (2.19)	-1.016	0.313	7.56 (1.53)	8.13 (1.84)	8.86 (0.90)	2.325	0.106
TOTAL	74.76 (8.78)	76.30 (13.98)	-0.554	0.581	72.64 (10.52)	76.54 (9.63)	84.85 (6.30)	4.844	0.011*
WHOQOL BREF									
Physical Health	101.75 (19.76)	102.19 (30.57)	-0.071	0.944	105.77 (23.49)	95.31 (21.74)	102.68 (23.89)	1.548	0.220
Psychological	77.25 (19.99)	76.56 (25.79)	0.119	0.905	80.77 (21.43)	72.40 (21.95)	72.32 (20.36)	1.313	0.276
Social Relationships	36.00 (8.61)	33.75 (13.96)	0.819	0.416	36.70 (10.45)	33.07 (10.00)	35.71 (11.24)	0.911	0.407
Environment	115.00 (18.94)	117.81 (30.77)	-0.465	0.644	118.91 (22.64)	112.24 (23.49)	110.71 (20.95)	0.830	0.441
TOTAL	330.00 (48.85)	330.31 (84.39)	-0.019	0.985	342.15 (60.16)	313.02 (60.17)	321.43 (55.18)	1.848	0.166
SD=Standard Deviation; BAS=Burden Assessment Schedule; WHOQOL BREF=World Health Organisation Quality of Life Brief Version; * p<0.05									

Table 4: Burden and Quality of Life in relation to caregiving relation

	Care Giver Relation Mean (SD)							
	Father	Mother	Spouse	Offspring	Sibling	Distant		
BAS								
Spouse Related	-	-	9.09 (1.90)	-	-	-	-	-
Physical and Mental Health	12.33 (2.66)	14.06 (2.14)	14.35 (1.96)	12.17 (3.37)	10.86 (2.34)	12.67 (1.15)	3.665	0.006*
External Support	8.93 (1.90)	8.38 (2.15)	8.96 (2.01)	8.17 (0.75)	7.86 (1.67)	10.00 (1.73)	0.857	0.515
Caregiver's Routines	8.33 (1.39)	8.81 (1.22)	8.83 (1.33)	8.17 (1.72)	7.57 (1.51)	8.00 (0.00)	1.293	0.278
Support of Patient	6.47 (1.12)	6.25 (1.12)	6.22 (0.90)	6.17 (0.75)	6.14 (0.90)	6.33 (1.52)	0.160	0.976
Taking Responsibility	8.93 (1.75)	9.13 (1.45)	9.00 (1.27)	7.50 (1.97)	8.71 (1.89)	8.67 (1.52)	1.064	0.389
Other relations	5.33 (0.97)	5.38 (1.20)	6.30 (1.10)	6.00 (0.63)	5.14 (1.57)	6.33 (1.52)	2.437	0.044*
Patient's behavior	7.20 (1.56)	8.19 (1.37)	8.35 (1.22)	7.33 (1.63)	7.29 (1.79)	7.67 (1.52)	1.706	0.146
Caregiver's strategy	7.27 (1.33)	7.81 (1.47)	8.52 (1.67)	7.67 (1.36)	7.29 (2.43)	8.33 (1.15)	1.426	0.227
TOTAL	70.53 (8.60)	73.56 (7.58)	84.13 (6.62)	68.66 (9.77)	66.00 (13.17)	73.33 (6.35)	8.774	0.000*
WHOQOL BREF								
Physical Health	107.08 (24.42)	95.70 (26.19)	99.18 (17.09)	106.25 (13.11)	115.18 (35.32)	89.58 (15.72)	1.128	0.354

Psychological	79.17 (23.22)	73.44 (20.72)	70.92 (16.05)	81.25 (24.68)	104.46 (17.57)	60.42 (13.01)	3.770	0.005*
Social Relationships	34.17 (8.47)	33.20 (9.87)	35.33 (10.59)	42.71 (7.30)	36.61 (15.06)	35.42 (14.43)	0.790	0.561
Environment	112.92 (27.39)	118.36 (20.85)	114.40 (13.64)	123.96 (13.92)	116.96 (42.49)	108.33 (30.83)	0.313	0.904
TOTAL	333.33 (63.89)	320.70 (63.35)	319.84 (39.51)	354.17 (31.54)	373.21 (104.44)	293.75 (53.40)	1.373	0.246
SD=Standard Deviation; BAS=Burden Assessment Schedule; WHOQOL BREF=World Health Organisation Quality of Life Brief Version; * p<0.05								

DISCUSSION

The socio-demographic variables of caregivers in this study align with previous research on caregiver burden and quality of life (QOL) associated with various disorders. The average age of caregivers in this study was 37.66 years, similar to findings by Kaushal et al. (2016),^[14] which reported mean ages of 40.67 years for caregivers of OCD patients and 47.03 years for schizophrenia caregivers. Most caregivers in this study were male, reflecting Indian family norms where men typically make decisions and care for sick family members.^[14-16] Over 90% of participants were from rural areas, consistent with Gupta et al. (2015),^[15] where 74% of participants were rural residents. This was expected as two-thirds of India's population lives in rural areas. Most caregivers were married, echoing previous studies, as caregiving often falls on spouses.^[14,16-18]

The total burden assessment scale (BAS) score in this study was 75.20, indicating a moderate burden, with the highest scores in physical and mental health domains, followed by spouse-related and taking responsibility domains.^[14,16] Although there was no significant difference in total BAS scores across age groups, older caregivers reported higher burdens in patient support and responsibility domains. The WHO-QOL BREF score was highest in the environment domain, supporting findings by Kate et al,^[19] (2013) on caregivers of schizophrenia patients. Older caregivers reported lower QOL, but differences were not significant. No previous studies have compared QOL across age groups. Females scored higher than males in the environment domain, consistent with Srivastava et al (2016) on dementia caregivers.^[20]

Spouses reported higher burden, significantly greater than with other relations like parents, siblings, and offspring. This was consistent with Mohanty and Kumar (2013),^[21] who found high burden scores for spouses of schizophrenia patients, Agarwal et al,^[16] (2017) also reported similar findings. The burden score was highest for caregiving durations over 24 months, aligning with previous research indicating increased burden with longer caregiving durations.^[22] Spouses reported the lowest QOL in the psychological domain, which was significant, consistent with Kumar and Mohanty (2007),^[23] linking high caregiver burden to low QOL. Longer caregiving durations (over 24 months) correlated with poorer QOL in psychological and environmental domains, supporting Kaushal et al. (2016).^[14]

Previous studies by Kumar and Mohanty,^[23] (2007) and Pattayak et al. (2010),^[17] reported non-significant differences in burden between family types. The joint family system is quite common in Indian society, as in many other Asian societies. We anticipated that caregivers from these joint families would experience relatively less burden. Interestingly, the burden was higher in joint families compared to nuclear families, also QOL was slightly better in joint families, though not significantly. Although the whole family is involved in care to some extent, the primary caregiver often bears the main responsibility. Sometimes, this caregiver may not receive enough assistance from the rest of the family, leading to an increased perception of burden. Higher caregiver burden negatively impacts QOL, so was the findings of current study, affecting physical and psychological well-being, social relationships, and environment, consistent with previous research.^[14,20,24] This study highlights the significant burden on caregivers of patients with dissociative disorders, comparable to those caring for patients with more severe psychiatric disorders like schizophrenia and OCD. Low education levels, the relapsing-remitting nature of the disorder, high family expressed emotion, poor illness understanding, misconceptions from faith healers, and frequent treatment visits may contribute to this burden.

Limitations

Relatively small sample size, hospital-based study, and limited generalizability of the results on the general populations are some of the limitations of the study. Other factors confounding the response of the caregivers, like psychological profile which have impact on the response of caregiver, were not assessed. While majority had responded well regarding the burden but few had shown objection towards the term "burden", they reported the term being harsh and insensitive. Few of the parents reported caregiving as their duty towards their offspring rather than "burden". Future studies should be designed to evaluate the psychological aspect along with the positive and spiritual aspect of the caregiving, specially in Asian scenario.

CONCLUSION

The current study highlights the burden and quality of life of caregivers of dissociative disorder in Indian scenario. In conclusion, caregiver burden as well as their quality of life one of the under evaluated aspect

in management which needs additional attention. Mental health professionals should be aware of caregiver burden in psychiatric disorders and develop strategies to improve understanding and culturally accepted management, focusing on responsibility, psychoeducation, spouse mental health, external support, and caregiver strategies.

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