

# Caregiver Burden and Its Correlation with Coping Skills among Caregivers of Mentally Ill Patients with Deaf Perceptions - A Cross Sectional Study

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## ABSTRACT

**Background:** Mental illness is a leading cause of global burden of disease among both general and deaf persons. Family burden is viewed as the non-mediated effect on families living with and caring for a relative affected by mental illness. Family burden positively affected caregivers financial, physical, mental, and social well-being. To alleviate impact of burden proper coping skills to be implemented by caregivers.

**Aim:** To assess caregivers' burden and to correlate with coping skills among caregivers.

**Materials & Methodology:** A cross sectional study carried out at SCB medical college, a tertiary care hospital of Odisha with 120 voluntary participants. This study was conducted by collecting data from caregivers by applying Family burden interview schedule and brief COPE inventory questionnaires. Statistical analysis was done on categorical variables, and they were expressed as frequencies and percentages. Continuous variables were measured using mean and standard deviation. The correlation between caregiver burden and the various coping skills was done by using Pearson's correlation test.

**Results:** Severe burden accounted for 60% and moderate for 40%. The highest amount of burden was seen in the areas of physical, financial, mental health, and in areas of external support. The brief COPE showed that the most often used coping styles were practicing religion, problem solving, active coping, and planning.

**Conclusion:** We concluded that caregivers for people with mental illnesses is extremely burdensome. Female caregivers having more burden than male caregivers. Therefore, it's important to come up with helpful strategies, like giving them access to counselling services and a support system. Patients with mental illnesses may also have less relapse prevention as a result.

**Keywords:** Family burden, Coping strategy, Caregiver, Mental illness.

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## INTRODUCTION

Deafness affects about 15–26% of the world's population, and low-income countries having the highest prevalence<sup>1-3</sup>. Many studies revealed about high prevalence of mental illness among deaf patients<sup>4-7</sup>. The caregiver burden arises from the distressing nature of mental illness, not only for affected people but also for their family members. There are two defined types of burden: objective burden, which refers to the observable costs to the family that result from the disease; and, subjective burden, which includes the individual's perception of the situation as burdensome<sup>8</sup>. Specifically, the burden of caring for people with mental illness include disruption of everyday life routine, stigma and blame, dissatisfaction with family and relatives, financial problems, physical burden, troubles with adherence of the patients to treatment and problems with health services and governmental support. Global burden for mental disorders in terms of disability adjusted life year attributable is 16% which increased threefold from previous estimates<sup>9</sup>. The natural preference of families to be involved in the care of their mentally ill kin is encapsulated by what has been referred to as the "cure versus care" dichotomy, where family members believe that it is the duty of professionals to cure their patient, while providing care is their responsibility<sup>10</sup>. This article intends to briefly consider several aspects of research on family care giving and its impact on routine clinical practice to lifestyles of caregivers. Family caregivers of patients with mental disorders play the most significant role in the care of psychiatric patients and preventing their relapse.

These caregivers face different challenges in diverse cultures. We conducted the study to determine the challenges of caregivers of patients with mental disorders. Mental illness is a condition characterized by significant disturbance in cognitive, emotional regulation, and behavioral functioning. Mental illness results in an enormous social and economic burden to individuals affected by the illness, their families and communities<sup>11</sup>. Burden of caregiver is any unwanted or negative consequences experienced by caregivers of People With Mental Illness (PWMI) as a result of taking care of responsibility for PWMI, and burden among caregivers encompasses physical, psychological, emotional, social, and financial difficulties that family members faced because of taking care of responsibility for PWMI<sup>12</sup>. Studies showed that one in four families has at least one member currently suffering from some sort of mental illness and more than 90% of these PWMI live with and gets continuous support from their families<sup>8,12,13</sup>.

Majority of caregivers (52.2%) experienced a moderate level of the burden, and caregivers utilize problem-focused strategy, religion and planning coping skills to manage family burden<sup>14,15</sup>.

"Cognitive and behavioral efforts to manage demands perceived as taxing or exceeding the resources of an individual" is the definition of coping. Coping strategies are

ways of solving problems that may be useful in reducing, managing, or enduring stress or conflict. Specific mental health symptoms, carer circumstances, and the difficulties they bear can all have an impact on coping<sup>16</sup>. Therefore, the purpose of the current study was to investigate coping mechanisms and the stress that carers of patients with significant mental illness (schizophrenia, depression, and bipolar disorder) at a tertiary care hospital faced, as well as to evaluate the relationship between them.

## MATERIALS AND METHODS

This is a cross-sectional study and conducted between January 2020 and January 2021 in two tertiary care centers of Cuttack and Bhubaneswar of Odisha. Primary caregivers, who were family members, more than 18 years of age, male or female, who were able to read and write English or Odia and had been living with the mentally ill patient for more than a year, and were closely associated with the patient's daily activities were included in the study. Those with a known diagnosis of mental illness as per ICD-DCR 10 and caregivers who were home nurses were excluded from the study<sup>17</sup>. Of the eligible population, 120 participants were sampled using the purposive sampling method.

Appropriate ethical clearance was obtained from the Institutional Ethics Committee of a tertiary care hospital and measures were undertaken to maintain confidentiality of caregivers throughout the study and also during the analysis of data. All participants were fully informed about the purpose of the study. Written informed consent was obtained from each participant after the consent form was read by the participants. Confidentiality was maintained throughout the study. During data collection, each person was identified by giving them a unique identification number. The participant was required to enter their name only while signing for written consent.

## STUDY TOOLS

Family Burden Interview Schedule (Shaila, Pai & Kapoor, R.L., 1981): This is a semi-structured interview schedule comprising of 24 items grouped under 6 dimensions: Financial burden, Disruption of routine family activities, Disruption of family leisure, Disruption of family interaction, Effect on physical health of others, Effect on mental health of others. All the items of this scale are rated on a 3point scale (viz, severe burden, Moderate burden and No burden). The validity and reliability for each item was reported to be more than 0.78 by the authors which mediates that this present schedule is reliable tool. The validity of the schedule was also assessed by co-relating objective burden rating and as reported by the relatives of patients. The correlation was found to be 0.72 which can be considered significant<sup>18</sup>.

### Brief Cope Scale

The 28-item Brief Cope scale (BCS) was used to assess the coping. The Brief COPE is comprised of 14 scales, each of which assesses the degree to which a respondent

utilizes a specific coping strategy. These scales include: (1) active coping, (2) planning, (3) positive reframing, (4) acceptance, (5) humor, (6) religion, (7) using emotional support, (8) using instrumental support, (9) self-distraction, (10) denial, (11) venting, (12) substance use, (13) behavioral disengagement, and (14) self-blame<sup>19</sup>.

Respondents' rate items on a 4-point Likert scale such as 1 never does it, 2 does it a few times, 3 does it mostly but not always, and 4 does it always. Each of the 14 scales is comprised of 2 items; total scores on each scale range from 2 (minimum) to 8 (maximum). Higher scores indicate increased utilization of that specific coping strategy. Carver (1997) classifies emotion-focused tactics as acceptance, humour, emotional social support, positive reframing, and religion. However, problem-focused techniques include planning, instrumental support, and active coping. Dysfunctional coping mechanisms include behavioral disengagement, denial, self-distraction, self-blaming, substance abuse, and venting. Three factorial analyses help-seeking, problem-solving, and avoidant coping skills were employed in this study.

### Statistical Analysis

Statistical Package for the Social Sciences, SPSS version 25 (IBM Corp., Armonk, NY, USA) was used to analyze

the data. Descriptive statistics were used to get the mean scores of sociodemographic variables. Comparison of Family Burden of the male and female caregivers with mental ill patients was carried out using independent t test. The correlation between caregiver burden and the various coping styles was done by using Pearson's correlation test.

The factors with significant P values from the univariate analysis were taken for multivariate analysis to account for confounding variables. The odds ratio (OR) was computed using binomial logistic regression and 95% confidence intervals. It was deemed statistically significant when  $P < 0.05$ .

## RESULTS

A total of 150 caregivers taken part in this study. But thirty participants withdrawn consent from participation during the due course. Table 1 shows the distribution of sociodemographic data among the caregivers. The mean age of participants was found to be  $38.77 \pm 7.88$ . Out of 120 participants, 75% were married, while 25% were unmarried. Around 48% have primary level of education, 21% have secondary level of education, and 31% participants have higher education status. Among all participants 74% belong to rural areas and 26% belong to

**Table 1:** Sociodemographic variables of participants.

Variables	Frequency (%)
<b>Age(years)</b>	
18-35	30(25)
36-50	78(65)
>50	12(10)
<b>Gender</b>	
Male	60(50)
female	60(50)
<b>Marital status</b>	
Married	90(75)
Unmarried	30(25)
Rural	88(74)
urban	32(26)
<b>Education</b>	
Primary level	58(48)
Secondary level	25(21)
Higher education	37(31)
<b>Family income</b>	
0-5000	10(8)
5000-10000	46(38)
More than 10000	64(54)
<b>Socioeconomic status</b>	
Lower class	56(47)
Middle class	64(53)
Upper class	0
<b>Duration of Disease</b>	
Less than 5 years	52(45)
More than 5 years	68(55)
<b>Duration of care to patients</b>	
< 1year	18(15)
1-5 year	33(27)
>5 year	69(58)

**Table 2:** Severity of burden (n=120).

Burden Severity Levels (Scores)	Frequency(n) %
No Burden(0)	0
Moderate Burden(1-24)	48(40)
Severe Burden(25-48)	72(60)

**Table 3:** Comparison of caregiver burden between male and female caregivers.

Care giver burden domains	Gender groups of caregivers		T	df	p
	Male (N=60) Mean + SD	Female(N=60) Mean + SD			
Financial burden	11.98±3.27	12.11±3.29	2.546	58	0.008*
Disruption of family activities	8.46±1.88	8.78±1.97	3.587	58	0.012*
Disruption of family leisure	6.67±1.37	7.40±1.43	3.108	58	0.034*
Disruption of family interaction	9.40±2.57	9.67±2.76	2.765	58	0.006*
Effect on physical health of others	9.90±2.77	10.12±3.01	2.087	58	0.023*
Effect on mental health of others	3.40±0.88	4.01±0.91	1.009	58	0.102
Total Burden	8.301±2.12	8.68±2.22	2.649	58	0.061*

shows total family burden of caregivers and also a comparison of burden between male and female caregivers.

**Table 4:** Correlation of coping skills with domains of caregiver burden.

Coping skills	Financial burden		Disruption of family activities		Disruption of family leisure		Disruption of family interaction		Effect on physical health of others		Mental health of others		Total caregiver burden	
	r	p	r	p	r	p	r	p	r	p	r	p	r	p
Problem solving	0.3	0.006*	0.2	0.006*	-0.1	0.05*	0.1	0.001*	0.1	0.45	0.2	0.12	0.1	0.045*
Avoidant	0.4	0.016*	0.2	0.043*	-0.2	0.28	0.4	0.66	0.6	0.001*	0.1	0.001*	0.4	0.002*
Help seeking	0.2	0.11	0	0.87	-0.2	0.33	0.1	0.28	0.2	0.005*	0.5	0.042	0.2	0.11

shows correlation between coping skills domain with each component of caregiver burden domain.

urban areas. On assessing financial and socio-economic status, 47% belong to lower income groups and 53% belong to middle income groups (Table 1).

The findings from this study revealed that caregiving leading to severe burden was reported by 60% and moderate burden by 40% as shown in (Table 2,3).

Total family caregiver burden of male and female caregivers is 8.301±2.12 and 8.68±2.22 respectively. And on comparison with independent T test ,both the differences are come to be significant with p-value <0.05. Around five domains of caregiver burden when compared between male and female caregivers are come to be significant. These domains are financial burden, Disruption of routine family activities, Disruption of family leisure, Disruption of family interaction, Effect on physical health of others. One domain, i.e. effect on mental health of others was not significant(Table 4).

As per three factorial analysis of the Brief COPE Inventory all domains were measured under problem-solving coping skills, avoidant coping skills, and help-seeking coping skills.

## DISCUSSION

Caregivers who have sole accountability for providing care to an individual with mental illness, are subjected to detrimental degrees of extreme strain. The caregivers need sympathy and help in terms of managing self. Additionally, they may be dominated by the mentally ill

patient; as a result, their distress level may increase and their capacity to manage the crisis may be compromised<sup>20</sup>. Caregivers who have a low quality of life may find it difficult to provide high-quality care for the people they are responsible for, and their own well-being may also suffer as a result. An inability to handle the situation could increase the likelihood that the patient will be abused, which would worsen their condition<sup>21</sup>.

The results, which assess the participants' sociodemographic profile, are consistent with earlier research conducted in India as well as in the West<sup>22,23</sup>. The majority of the participants in our study were middle-aged, as indicated by their mean age of 38.77±7.88, which was likewise the finding of a study by Saha et al, the majority of participants (58%) were having education up to primary level and rest are having higher education profiles, and almost all participants are literate, which is consistent with previous research<sup>24,25</sup>.

According to research done in the last few years, female carers bear the majority of the stress because of their obligations to the mentally ill patients and their families<sup>26,27</sup>. Taking this into account, we discovered that the overall Burden score in our investigation was of moderate severity, which was consistent with a number of earlier Indian research<sup>24-27</sup>. The prevailing cultural beliefs in our nation depict men as the family's principal provider of income, while women are viewed as the primary healers of the sick. Women spend more time providing care than engaging in personal interests due to unequal

opportunity distribution and gender role socialization, which causes them to shoulder the majority of the care burden, as confirmed. In this study, female caregivers shown to have higher burden in comparison to male counterparts.

In this study, severe burden due to caregiving accounted for 60% and moderate burden was found among 40%, which is comparable to a study conducted by Patel et al. that involved thirty carers of schizophrenia patients in a tertiary care general hospital in northern India<sup>28</sup>. Few studies showed moderately severe to moderate burden among caregivers<sup>29</sup>.

On analyzing correlation of coping skills with different domains of caregiver burden, it was found to be positively correlated and statistically significant. As per three factorial domain of brief COPE inventory, domains like problem solving and avoidant skills are positively correlated and significant with value of (r,p) as following respectively (0.11,0.045) and (0.43,0.002). Coping strategies used by wives of alcoholics and other addiction were reported in three major styles: engaged, tolerant and withdrawal<sup>30,31</sup>.

Both external factors and the caregiver's personality influence the coping mechanism they employ. As a result, the study's three coping mechanisms which were found to be associated with burden and out of which problem solving and avoidant coping skills are significantly correlated with a substantial relationship with the burden of care. This shows that problem-solving and avoidant coping strategies emerge as a defensive mechanism used by the caregivers to lessen the burden of caring as it increases.

## CONCLUSION

According to the study's findings, 60% of the severe burden is borne by those who care for deaf and mentally ill people. The domains like financial strain, family leisure activities, physical and mental health, as well as external support was found to be the most stressful and bearing highest burden. Severe burden was higher among female caregivers and lower socioeconomic group than male caregivers and higher socioeconomic groups. And in caregivers who had been caring for the mentally ill patient longer than five years are having higher burden as compared to caregivers of less than five years. Caregivers burden and their coping skills plays a vital role in relapse prevention and establishment of patient's social life. Psychoeducation, mental health awareness, discharge counselling and proper usage of resources with adaptive coping skills will help them to alleviate stress and strain.

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