ORIGINAL RESEARCH PAPER

# Burden and coping among primary caregivers of persons with alcohol use disorder

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## ABSTRACT

*Background*: Alcohol use disorder (AUD) affects not just the individual who uses it but also their family, especially the primary caregivers. Avoidance, discord, fearful withdrawal, problem-focused, and emotionally focused coping styles are generally identified among families of alcoholics. There are very few studies regarding the primary caregiver's burden and coping with AUD patients in India. This study aims to assess the level of caregivers' burden and coping among primary caregivers of persons with AUD. *Aim*: The present study primarily aims to assess the level of caregiver burden, coping, and general health among the primary caregivers of a person with AUD. *Materials and Methods*: This is a cross-sectional descriptive study conducted in a psychiatry tertiary care hospital. The total sample size was 70, chosen through the non-probability purposive sampling method. The socio-demographic profile of AUD patients and their primary caregivers was assessed using a semi-structured proforma. The burden and coping of the primary caregiver were assessed using the Burden Assessment Schedule and Brief COPE, and the general health questionnaire (GHQ) scale. *Results*: Primary caregivers of subjects with AUD faced a moderate (28.6%) to severe (71.4%) burden and had low coping strategies. The severity of alcohol use, caregiver general health, caregivers' burden, and coping strategies were shown to be statistically significant between different variables. *Conclusion*: The study concluded that the burden level on the primary caregivers of AUD was moderate to severe. The coping strategies of caregivers of AUD were found to be poor.

**Keywords:** Alcohol use disorder, caregivers, burden, coping

## INTRODUCTION

The use of alcohol has become universal and has been gradually rising across the globe. It has been identified as a contributor to over 60 various diseases and is regarded as the third biggest threat for the incidence of diseases worldwide.[1] Nearly 3 million people die each year due to the harmful use of alcohol in society.[2] India and other middle-income countries have a higher disease burden from alcohol than high-income ones.[3] In India, the abuse of alcohol is not sufficiently recognized as an issue of public concern, considering the detrimental effects of alcoholism and the ensuing public medical crisis.[4]

Alcohol use becomes an issue when a person develops an unsafe drinking practice that increases their chance of experiencing unfavourable health outcomes.[5] Conditions such as cancer, diabetes, neuropsychiatric diseases (including alcohol use disorders), cardiovascular disease, liver and pancreas disease, and unintentional and intentional injury are the most prevalent illness classifications triggered entirely or partially by alcohol consumption.[6] Alcohol consumption and misuse also result in harm, car accidents, and violence. Alcohol has a significant impact on employee efficiency and absences from work, relationships with family members, and

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academic achievement, as well as may cause fatalities either directly or indirectly.[7]

In the Indian subcontinent, family is the most significant asset in taking care of patients, including those with mental illnesses. Family carers include those who offer care without compensation to family members with requirements or individuals who supervise or assist others in the family who require oversight or support due to illness or disability.[8] The burden is said to be largely determined by the family environment.[9] The study of family problems has been relatively neglected. The rise in unforeseeable and untrustworthy behaviour in people with AUD causes anxiety and physical discomfort in carers. This results in poor coping and makes them more vulnerable to mental illness.[10]

Coping means "dealing with and attempting to overcome problems and difficulties." Because of the poor infrastructure for providing community care in India, more emphasis is placed on the caregivers. Therefore, an in-depth study is needed to understand the burden faced by the primary caregiver of AUD and the coping strategies adopted among primary caregivers of alcohol dependence in our socio-cultural scenario.

## MATERIAL AND METHODS

The present study adopted a cross-sectional descriptive research design. The purposive sampling technique was used to select the sample. Data were collected from the primary caregivers of persons with AUD. The socio-demographic schedule included age, sex, religion, education, occupation, domicile, marital status, duration of illness and diagnosis, and duration of caregiving by the caregiver. The Alcohol Use Disorders Identification Test (AUDIT) was used to assess alcohol consumption. A score of 8 or more is considered to indicate hazardous or harmful alcohol use.[11] The AUDIT proved to have high internal reliability, with a Cronbach's alpha coefficient of 0.84. In terms of criterion validity, the area under the ROC curve was 0.93 for alcohol dependence.[12] The 12-item General Health Questionnaire (GHQ-12) is used to screen individuals in the general population for psychiatric disorders. GHQ-12 consists of 12 questions and has been proven to be a reliable and valid tool among the Indian population (Cronbach's alpha coefficient = 0.79).[13] To assess the burden, the Thara et al.[14] Burden Assessment Schedule (BAS) was used. This is a 40-item statistically valid scale that measures 9 different facets of caregiver burden, including subjective and objective aspects. The minimum and maximum ratings in BAS are 40 and 120, respectively (Kappa = 0.80). The BAS includes the following domains: (1) spouse-related, (2) physical and mental health, (3) external support, (4) caregiver’s routine, (5) support of the patient, (6) taking responsibility, (7) other relations, (8) patient’s behavior, and (9) caregiver’s strategy. The Brief COPE scale is a multidimensional coping inventory that was administered to caregivers to assess coping responses to stress (Carver, 1997).[15] The Brief COPE is a 28-item measure of coping style use. In Indian conditions, the Brief COPE has also proved to be a reliable and valid tool in the population in southern India. The internal consistency, calculated by Cronbach's alpha, overall and for each subscale, had values of 0.70 and higher, indicating good internal consistency.[16] It is a self-report questionnaire used to assess a number of different coping behaviors and thoughts a person may have in response to a specific situation. It is made up of 14 subscales: active coping and planning, which constitute problem-focused coping; denial, substance use, and behavioral disengagement, which constitute total avoidant coping; instrumental social support, instrumental emotional support, and venting, which constitute socially supported coping; and acceptance, humor, religion, positive reframing, self-blame, and self-distraction, which constitute emotion-focused coping. A total of 70 cases were taken up for this study, with their family member having a diagnosis (psychiatric morbidity) and assessed according to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition, text revision (DSM-5 TR) criteria.[17] Caregivers within the age group of 25-60 years, living with patients for a minimum of one year, caregivers of persons with AUD, and those who gave informed consent for the study were included. Caregivers were excluded if they were found to have organic mental disorders or other comorbid psychiatric disorders. Formal approval was obtained from the institutional ethical committee of DIMHANS. Informed consent was acquired after explaining the purpose of the study. The data collected was analyzed using the Statistical Package for the Social Sciences, version 22.0 (SPSS 22.0) software, and analyzed using descriptive statistics such as mean, standard deviation, and percentage were used. Pearson correlation was adopted to analyze the relationship between the groups. For all tests, a level of statistical significance of $p < 0.05$ was accepted.

## RESULTS

### Socio-demographic Profile

**Table 1: Socio-demographic details of person with AUD (N=70)**

| Variables | f (%) |
|---|---|
| Age of patient (years) | |
| 18-30 | 21(30) |
| 31-52 | 46(66) |
| >53 | 03(4) |
| Mean age | (35.57) |
| Education of patient | |
| Illiterate | 11 (16) |
| Primary | 28 (40) |
| High school | 17 (24) |
| PUC above | 14 (20) |
| Marital status of patients | |
| Single | 22 (31) |
| Married | 48 (69) |
| Religion | |
| Hindu | 57( 81) |
| Muslim | 13 (19) |
| Type of family | |
| Nuclear family | 67 (96) |
| Joint family | 03 (4) |
| Domicile of the individual | |
| Urban | 23 (33) |
| Rural | 47 (67) |
| Occupation of the individual | |
| Unemployed | 07 (10) |
| Coolie | 34 (49) |
| Agriculture | 10 (14) |
| Skilled labor work | 12 (17) |
| Business | 06 (9) |
| Government employee | 01 (1) |
| Duration of alcohol use | |
| 2-5years | 02 (3) |
| 5-10years | 37 (53) |
| > 10 years | 31 (44) |

**Table 2: Socio-demographic details of caregiver respondents (N=70)**

| Variables | f (%) |
|---|---|
| Age of caregivers (years) | |
| 25-40 | 36 (52) |
| 41-55 | 19 (27) |
| >55 | 15 (21) |
| Mean Age | (42.86) |
| Gender of caregivers | |
| Male | 28 (40) |
| Female | 42 (60) |
| Marital status of caregivers | |
| Married | 60 (86) |
| Single | 05 (7) |
| Widow | 05 (7) |
| Educational level of caregivers | |
| Illiterate | 41 (58) |
| Primary school | 18 (26) |
| High school | 09 (13) |
| Graduation and above | 02 (3) |
| Occupational status of caregivers | |
| Coolie | 25 (36) |
| House wife | 17 (24) |
| Agriculture | 15 (21) |
| Skilled labor work | 11 (16) |
| Business | 02 (3) |
| Family income (INR) | |
| <5000 | 32 (48) |
| 5001-10,000 | 14 (20) |
| 10,001-15,000 | 18 (26) |
| >15,001 | 04 (6) |
| Duration of care (years) | |
| <5 years | 28 (40) |
| More than 10years | 42 (60) |
| Relationship of the caregiver with the patient | |
| Parent | 30(43) |
| Spouse | 29 (42) |
| Sibling | 10 (14) |
| Off springs | 01 (01) |

The demographics of the patients with AUD are given in Table 1. The socio-demographic characteristics of the primary caregivers of persons with AUD are presented in Table 2. The mean age of the caregiver respondents was 42.86 years. Out of 70 primary caregivers, 52% belonged to the age group of 25-40 years; 27% belonged to the age group of 41-55 years, and 21% were older than 55 years. The majority (60%) of the respondents were female, with the remaining 40% being male. Regarding education, 58% of participants were illiterate, 26% had primary school education, 13% were educated up to secondary school, and 3% had graduated. In terms of occupation, 36% of participants were coolies, 24% were housewives, 21% were working in agriculture, 16% were skilled workers, and 3% were self-employed. Regarding marital status, 86% of primary caregivers were married, 7% were unmarried, and 7% were widowed. Concerning family income, 48% had a family income of less than Rs. 5000 per month, 26% had a family income of Rs. 10000-15000, 20% had a family income of Rs. 5001-10000, and 6% had a family income of more than Rs. 15000 per month. In terms of religion, 81% were Hindu, and 19% were Muslim. The majority (60%) had stayed with the patients for more than 10 years, while 40% had stayed for less than 5 years. The largest group of respondents were parents of the individual (43%), followed by spouses (42%), siblings (14%), and offspring (1%).

### General health status of the caregivers

The mean value for the anxiety and depression component was 10.64 ± 1.39, followed by social dysfunction at 10.54 ± 2.52, with loss of confidence being the least. This indicates that the higher the mean value, the worse the condition, suggesting higher psychological distress in terms of their general health condition.

### Caregiver burden

**Table 3: Burden in caregivers AUD**

| Domains of BAS | Mean ± SD |
|---|---|
| Spouse related | 3.80 ± 4.59 |
| Physical and mental | 14.87 ± 2.32 |
| External support | 10.29 ± 1.66 |
| Caregivers’ routines | 9.27 ± 1.25 |
| Support of patient | 7.21 ± 1.10 |
| Taking responsibility | 8.89 ± 1.25 |
| Other relations | 7.16 ± 1.41 |
| Patient’s behavior | 10.29 ± 1.52 |
| Caregivers’ strategy | 8.70 ± 1.13 |

Table 3 shows that primary caregivers of patients with AUD experienced the highest burden in terms of physical and mental disturbance (14.87 ± 2.328), followed by lack of external support (10.29 ± 1.661), patient behaviours (10.29 ± 1.524), and caregiver routine work (9.27 ± 1.250). Domains such as patient support (7.21 ± 1.102), taking responsibility (8.89 ± 1.257), caregiver strategy (8.70 ± 1.134), and other relationships (7.16 ± 1.410) had relatively lower scores. Therefore, it can be stated that the major areas of caregiver burden in AUD were caregiver physical and mental healthcare, external support, and caregiver routines.

Findings indicates the degree of caregiver burden in caregivers of persons with AUD. The majority of caregiver respondents (71.4%) reported a severe burden, whereas 28.6% fell under the category of moderate caregiver burden. Thus, it can be stated that caregiver burden was severe among caregivers of persons with AUD.

### Coping styles among the caregiver

Coping style were calculated based on a study conducted by Dr. Ben Buchan, which resulted in 4512 samples used to calculate the range for high, average, and low coping.[18]

**Table 4: Coping style of caregivers of AUD**

| Coping style | f (%) | | |
|---|---|---|---|
| | Low | Average | High |
| Problem Focused | 57(81.4) | 12(17.2) | 1(1.4) |
| Emotional Focused | 49(70.0) | 20(28.6) | 1(1.4) |
| Avoidant | 36(51.4) | 27(38.6) | 7(10.0) |

Table 4 shows the coping styles among the caregiver respondents and the levels of coping styles under each domain. The majority of respondents showed a lower level of coping irrespective of the domain. In total, 81.4% scored low in problem-focused coping, 70% in emotion-focused coping, and 51.4% in avoidant coping. This indicates weaker coping levels among respondents. Although 10.0% of respondents showed a high level of avoidant coping, which indicates better coping, avoidant coping is not a healthy strategy.

### Correlation

### Severity of alcohol intake & general health

Result shows a significant correlation between the severity level of alcohol intake (on AUDIT) among patients with AUD and the general health domains of their caregivers: social dysfunction (r = .306) at a significance level of 0.01, indicating a significant association between the severity of AUD and caregivers' general health.

### Caregiver burden and psychological distress

Findings indicates a significant relationship between caregiver burden and psychological distress. There was a statistically significant positive correlation with physical and mental health (r = .480**, p < 0.01); caregiver routine activity (r = .344**), social support (r = .515**), taking responsibility (r = .382**), and patient behaviours (r = .382**) with a p-value of 0.01. Other relationships (r = .246*) was also statistically significant with a p-value of 0.05.

### Severity of alcohol use, caregiver general health, caregiver burden, and coping

Findings shows the relationship between the severity of alcohol use, caregiver general health, caregiver burden, and coping. The severity of alcohol use has statistically significant positive correlation with psychological distress, caregiver burden, and caregiver distress (r = .315**, p = .008; r = .538**, p = .000) at a 0.01 significance level. Emotional-focused coping showed a negative significance correlation (r = -.239*, p < 0.05) with respect to caregiver burden, and a non-significant relationship (r = -.103) with problem-focused coping.

### Burden, psychological distress & coping

**Table 5 Correlation between burden, psychological distress & coping**

| Variables | Psy. distress | Burden |
|---|---|---|
| Burden | .538** | - |
| Active coping | -.320** | 0.02 |
| Instrumental | .260* | .344** |
| Planning | -.298* | -.381** |
| Positive coping | 0.098 | -0.171 |
| Emotional | -0.001 | 0.031 |
| Venting | -0.047 | 0.02 |
| Acceptance | -0.153 | -0.136 |
| Self-Blame | 0.045 | -.407** |
| Humor | -0.064 | -0.093 |
| Religious | .266* | -0.064 |
| Self-distraction | .245* | 0.222 |
| Denial | .269* | 0.031 |
| Substance Use | -0.125 | -0.201 |
| Behavioral Disengagement | 0.008 | -0.076 |

Table 5 indicates the correlation between caregiver burden, psychological distress, and brief coping. Caregiver burden was positively and statistically significant with psychological distress (r = .538**, p = 0.01). Active coping was negatively and statistically significant with psychological distress (r = -.320**, p = 0.01). Religious coping was positively and statistically significant in relation to psychological distress (r = .266*, p = 0.05). Self-distraction coping was positively correlated with psychological distress (r = .245*), and denial coping was positively significant with psychological distress (r = .269*) at a 0.05 significance level. Caregiver burden was positively statistically significant with instrumental coping (r = .344**, p = 0.01) and negatively significant with planning (r = -.381**, p = 0.01). Similarly, self-blame coping was statistically significant (r = -.407**, p = 0.01). Therefore, these findings indicate a significant relationship between caregiver burden, psychological distress, and coping.

## DISCUSSION

The present study focuses on assessing the burden and coping among primary caregivers of persons with alcohol use disorder (AUD). Conducted using a cross-sectional descriptive research design, the study utilized purposive sampling techniques, with a total of 70 patient caregivers from DIMHANS, Dharwad, seeking tertiary care support for de-addiction, included in the study. All participants were male (100%), possibly due to males being the primary breadwinners of the family, consistent with previous research by Sen et al.[19] The mean age of primary caregivers was 42.86 ± 11.890, with 51.4% belonging to the age group of 25-40, and the largest proportion being female (60.0%). This aligns with findings from Mattoo et al.,[20] indicating predominantly spousal caregivers, as well as higher illiteracy rates among caregivers, possibly linked to rural residence, consistent with Swaroopachary et al.[21] Regarding the duration of dependence, 34% of respondents had 10–14 years of alcohol dependence, reflecting findings from previous studies.[22] Despite similarities in demographics, caregivers experienced severe burden, with significant adverse impacts on physical and mental health, consistent with findings by Mattoo et al.,[20] Vaishnavi,[23] and Bharat Kumar Goit et al.,[24] particularly in larger families. Coping strategies predominantly involved planning, instrumental support, active coping, and emotion-focused strategies, akin to Hoel & Geirdal.[25]

Correlation tests revealed a significant positive association between AUD severity, psychological distress, and caregiver burden (r=.538**, p=0.00, p=0.01), indicating a higher level of burden with increased alcohol use and poorer psychological health. Caregiver burden dimensions, including financial strain and disruption of family activities, also correlated positively, likely due to alcohol-induced family disruptions, similar to findings by Hoel & Geirdal.[25] Additionally, caregivers of AUD patients, compared to non-drinkers, faced heightened risks of psychiatric morbidities, marital discord, and domestic violence, echoing studies by Gandhi et al.[26] and Vishal et al.[27] The study underscores the need for comprehensive programs addressing caregiver burden alongside de-addiction protocols, with future research focusing on rural-urban disparities and expanding sample sizes to enhance generalizability. Despite limitations, this study provides valuable insights for future research and interventions concerning caregiver burden and coping in AUD contexts.

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