

Caregiver burden and resilience in family members of alcohol dependence patients: a study in rural South India

Dr. Keya Das^{1*}, Dr. Chaitra.M², Dr. Ravikumar.S³, Mr. Janakiraman.P⁴

ABSTRACT

Objectives: Alcohol dependence is a detrimental disease to a person, family, and society. Family support is intrinsically essential for the successful treatment of an alcohol-dependent patient. Family members face substantial subjective and objective crisis as their caretakers. We aimed to determine the extent of burden and resilience among the caregivers of Alcohol dependent patients and the correlation between the two determinants. **Methodology:** A cross-sectional, observational study enrolling 101 Alcohol Dependence Syndrome (ADS) patients was performed. Valid scales namely the Burden Scale for Family Caregivers (BSFC), Severity of Alcohol Dependence Questionnaire (SADQ), and Brief Resilience Scale (BRS) was administered. The data collected were statistically analysed using SPSS 16. **Results:** Majority of patients, 46.53% were Moderately dependent, 60.40% of the caregivers faced Moderate burden and 56.44% of them showed lower resilience. Correlation between caregiver burden and severity of dependence showed that the majority -45.90% faced a moderate burden with Severe dependence. Co-relation of caregiver resilience with Caregiver Burden showed that 29.12% scored <2.5 in the Severe ADS group. **Conclusion:** Although majority had moderate burden and moderate levels of dependence, resilience in caregivers was found to be poor. Severity of dependence was significantly related to poorer resilience in caregivers.

Keywords: Alcohol Dependence Syndrome, Burden scale for Family Caregivers (BSFC), Severity of Alcohol Dependence Questionnaire (SADQ), Brief Resilience Scale (BRS)

Family plays a vital role in defining the course of mental illness especially in a traditional country like India where there is financial and emotional interdependence. Family is the point of care in a rural area providing the necessary support for the near and dear ones in adversities despite economic, social and time constraints [1]. The concept of family has undergone many transitions through various civilizations with time. Family nowadays denotes a group that consists of parents, their children and nearby relatives of the same bloodline [2]. Leff et al in 1990 suggested that traditional joint families help in the

¹Assistant Professor, Department of Psychiatry, PESIMSR, Kuppam, Andhra Pradesh, India

²Second Year Postgraduate Trainee, Department of Pediatrics, University of South Alabama Children's and Women's Hospital, Mobile, Alabama 36617, USA

³Associate Professor, Department of Psychiatry, Koppal Institute of Medical Sciences, Koppal, Karnataka, India

⁴Statistician, Preventive and Social Medicine Department, PESIMSR, Kuppam. Andhra Pradesh, India.

*Responding Author

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diffusion of the burden for mental illness usually leads to the good course and outcome of a major mental disorder [3].

In a developing country like India, health professionals working in the mental health sector and facilities are scarce to provide long term treatments. As a result, clinicians are compelled to rely on the family to cater to the vast majority of the population [4]. Thus, having adequate family support is essential for the care of the patients and to dissipate the burden on clinicians and the healthcare administrators. Alcohol Use Disorder affects people from all walks of life. The consumption of alcohol carries a risk of adverse health and social consequences related to its intoxicating, toxic and dependence-producing properties. According to the report released by the World Health Organization (WHO) alcoholism is responsible for 1 in 20 deaths. Overall, Alcohol Use Disorders (AUDs) causes more than 5% of the global disease burden [5]. General population surveys in India have reported a prevalence of alcohol use ranging from 1.15% to 50% in 2017 [6]. The prevalence of alcohol use disorder was 8.7% among men and 1.9% among women while that of alcohol dependence was 5.5% among men and 1.35% among women [7]

Alcohol Dependence in partners increased the risk for mental health disorders above and beyond significant socio-demographic risk factors, with an associated population - an attributable fraction of 17.5% [8]. “Burden of care” on the Caregivers is defined as the presence of problems, difficulties, or adverse effects that affect the life of the household members of the psychiatric patient [9].

Resilience defined as the ability of an individual to withstand stressors and not to manifest psychological dysfunction [10]. “Resilience” constitutes not just recovery but growth and strengthening from adversity. Resilience has also been described as a measure of stress-coping ability and sustained competence under stress [11]. Resilience is crucial for families in coping with extreme stress and trauma related to living with people with significant interpersonal, familial, marital, social, and occupational dysfunction.

Aims and objectives

1. To categorize the ADS patients based on severity of dependence. To assess the family members of ADS patients for caregiver burden.
2. To co-relate the Caregiver Burden with Severity of dependence in ADS patients.
3. To assess the Resilience in family members of ADS patients.
4. To co-relate the Caregiver Burden with Resilience.

METHODS AND MATERIALS

Study Setting: The ADS patients and their families were enrolled consecutively from the Department of Psychiatry, Adichunchangiri Institute of Medical Sciences, Bellur, Karnataka over 1 year.

Sample Size: 101 patients diagnosed as Alcohol Dependence Syndrome as per ICD 10 with family members were enrolled in a Purposive manner.

Method of Study: Cross-sectional, Observational Design, being descriptive and explorative in nature. All consecutive patients with caregivers were enrolled if they satisfied the Inclusion and exclusion criteria.

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Inclusion Criteria

- Patients satisfying ICD 10 diagnosis of Alcohol Dependence syndrome
- Patients who have presented with caregivers.
- Patients and caregivers who were willing to give consent.

Exclusion Criteria

- Patients with co-morbid psychiatric illness were excluded.
- Patients' caregivers themselves having Alcohol Dependence were excluded.
- Those unwilling to give the Consent.

All total of 101 patients out of 130 interviewed patients & caregivers were finally taken up for the study. Ethical clearance was obtained from our Medical institute board.

Following a diagnosis of ADS as per ICD 10, patients and Caregivers were then queried about the socio-demographic profile followed by the administration of valid and reliable Scales namely.

1. Burden Scale for Family Caregivers (BSFC).
2. Severity of Alcohol Dependence Questionnaire (SADQ).
3. Brief Resilience Scale (BRS).

The key goal of the study was to study the correlation between different determinants that were collected. The important correlations which were studied are as follows.

1. Co-relation between Severity of ADS with Caregiver Burden.
2. Co-relation of Severity of ADS with Resilience in Caregivers.
3. Co-relation of Caregiver Burden with Resilience in Caregivers.

Statistical Analysis using SPSS 16 was done on the Data collected. Descriptive statistics were computed. Categorical variables were described as frequencies and percentages. The central values (mean) and dispersion tendencies (Standard Deviation [SD]) were calculated. A Chi-square test was used to compare categorical variables. Cross-tabulation and Pearson's correlation was used to correlate the variables. A confidence interval of 95% was considered and a p-value of less than 0.05 was taken to be statistically significant.

RESULTS

Table 1. Sociodemographic profile of the patients

Socio- demographic variables.	Sociodemographic sub categories	n =101, frequency (%)
Age	21-30years	17(16.83%)
	31-40years	24 (23.76%)
	41-50years	30 (29.70%)
	51-60 years	29 (28.71%)
	61-70 years	0
Occupation	Unskilled labor	0
	Semiskilled labor	66(65.35%)
	Skilled labor	33(32.67%)

101 patients were Male, with majority 30(29.70%) in the age range of 41-50, followed by 29(28.71%) in 51-60 age group. Mean age was 46.17 and SD was 11.44. Majority were

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employed and belonged to Semiskilled occupation 66(65.35%) and 33(32.67%) were skilled workers.

Table 2. Sociodemographic profile of the caregivers

Socio-demographic variables.	Sociodemographic sub categories	Caregiver n =101, frequency (%)
Age	21-30years	24 (23.76%)
	31-40years	24 (23.76%)
	41-50years	42 (41.58%)
	51-60 years	11(10.89%)
	61-70 years	0
Sex	Male	32 (1.68%)
	Female	69 (68.32%)
Religion	Hindu	87 (86.54%)
	Muslim	6 (5.94%)
	Christian	8 (7.92%)
	Others	0
Education	Illiterate or <6th Std	29 (28.71%)
	Higher Secondary school	50 (49.50%)
	Pre-University	20 (19.80%)
	Graduate	2 (1.98%)
Occupation	Unskilled labor	28(27.72%)
	Semiskilled labor	44(43.56%)
	Skilled labor	29 (28.71%)
SES	Low SES	2(1.98%)
	Lower middle	58(57.43%)
	Middle middle	40.59 (40.59%)
Relationship with Patients	Spouse	69 (68.32%)
	Sibling	26(25.74%)
	Parent	1 (0.99%)
	Extended family	5 (4.95%)
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The majority. i.e. 42 out of 101(41.58%) of the Caregivers were in the age range of 41-50 with mean age being 38.47, SD of 9.2. Majority were Hindu 87(86.54%), majority being Female 69(68.32%), Majority caregivers were Spouse 69(68.32%), followed by Sibling 26(25.74%) and few were Parent 1(0.99%) and Extended family 5(4.95%).44 (43.56%) were Semiskilled workers and 29(28.71%) were skilled with 28 (27.72%) being Housewives/unemployed.

Table 3. Frequency table of Severity of ADS

Sl.no	SADQ	Frequency	%
1.	Mild Dependence	10	9.90
2.	Moderate Dependence	47	46.53
3.	Severe Dependence	44	43.56

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SADQ-Severity of Alcohol Dependence Questionnaire ^[12]

- 20 item scale developed by Maudsley Hospital.
- Score of <16 indicates mild dependence
- Score of 16-30 indicates moderate dependence
- Score of 31 and higher indicates Severe Dependence.

Our study found that the majority of the ADS patients were Moderately dependent 47(46.53%) followed by Severe dependence 44 (43.56%) and the rest 10 (9.90%) faced mild dependence.

Table 4. Frequency table of Caregiver burden

Sl.no	BFSC	Frequency	%
1.	Mild Burden	14	13.86
2.	Moderate Burden	61	60.40
3.	Severe Burden	26	25.74

Burden Scale for Family Caregivers ^[13]

- 28 item scale measuring Subjective Burden, with 4 point on scale for strongly agree to strongly disagree.

Score of

- 0-41 – None to Mild Burden
- 42-55-Moderate Burden
- 56-84-Severe to Very severe Burden

Most of the caregivers experienced Moderate burden 61(60.40%) followed by Severe to very severe burden 26 (25.74%) and the remaining 14 (13.86%) reported mild burden.

Table 5. Frequency table of Caregiver burden.

Sl.no	BRS Score	Frequency	%
1.	<2.5	57	56.44
2.	>2.5	44	43.56

Brief Resilience Scale ^[14]

- 5 item scale with 5 point Likert scale from strongly Disagree to strongly agree by Ohio state University.
- Scoring is obtained by adding the responses varying from 1-5 for all six items giving a range from 6-30. Then divide the total sum by the total number of questions answered.
- Highest Score being 5 indicating Good resilience and 0 being least, we considered the cut-off as 2.5 indicating good resilience.

Majority Caregivers in our study i.e. 57 out of 101(56%) scored <2.5 on BRS indicating lesser resilience with increased Burden.

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Table 6. Co-relation of Severity of ADS with Caregiver Burden

BFSC	SADQ			Chi Sq=17.9 P=0.001
	Mild ADS	Mod ADS	Severe ADS	Total
Mild Burden	4 (28.57%)	10 (71.43%)	0 (0)	14 (100.00)
Mod Burden	0 (0)	10 (38.46%)	16 (61.54%)	61 (100.00)
Severe to V severe Burden	0 (0)	10 (38.46%)	16 (61.54%)	26 (100.00)
Total	10(9.90%)	47(46.53%)	44(43.56%)	101(100.0)

The co-relation of Severity of Alcohol Dependence with Caregiver Burden yielded that the majority of the population faced moderate burden with Severe dependence 28 (45.90%) followed by moderate burden reported in Moderate ADS group 27 (44.26%). This co-relation was found to be statistically Significant, p=0.001.

Table 7. Co-relation of Severity of ADS with Resilience in Caregivers

BRS Score	SADQ			Chi Sq=6.34 P=0.042
	Mild ADS	Mod ADS	Severe ADS	Total
1<2.5	2 (3.51%)	27 (47.37%)	28 (49.12%)	57 (100.00)
2>2.5	8 (18.18)	20 (45.45%)	16 (36.36%)	44 (100.00)
Total	10(9.90%)	47(46.53%)	44(43.56%)	101(100.0)

The co-relation of Severity of Alcohol Dependence with Caregiver Burden showed that the least resilience was found in Severe ADS group 28 (29.12%) followed by moderate ADS group 27 (47.37%). This correlation was statistically significant with p=0.042.

Table 8. Co-relation of Caregiver Burden and Resilience in Caregivers

BSFC Grade	BRS Score		Total	Chi Sq=21.93 P=0.000
	<2.5	>2.5		Total
Mild Burden	4 (7.02%)	12 (27.27%)	16 (15.84%)	146 (100.00)
Mod Burden	24 (42.11%)	28 (63.64%)	52 (51.49%)	61(100.00)
Severe to V severe Burden	29 (50.88%)	4 (9.09%)	33 (32.67%)	26 (100.00)
Total	57(100%)	44(100%)	101(100%)	101(100.0)

Co-relation of Caregiver Burden with Resilience has not been studied to a great extent in the Indian population. Our study found that caregivers experiencing Moderate Burden were the majority, 52(51.49%). Out of 52, marginally more caregivers recorded better resilience of Score >2.5 (28 out of 52) than Score <2.5 (24 out of 52).

Out of the 33 Caregivers reporting Severe to Very Severe Burden, majority 28(50.88%) of them reported Resilience score <2.5, indicating the co-relation between severe burden and poor resilience. This finding was found to be significant with p=0.00.

DISCUSSION

Distribution of Socio-demographic Profile of ADS patients

The patient profile in our study matched Swaroopachary's [15] and Ramanujam's study [16]. In contrast Sen et al's [17] study although reported majority male patients, also reported of few female ADS patients (4%) and also reported majority unskilled workers among the patients.

1. Distribution of Socio-demographic Profile of Caregivers

Study by Swaroopachary et al found average age of caregivers to be 33.03+-9.17, and Sen et al found majority 44% to be in age range of 30-40 and 33% in range of 40-50 which was more in tune with our study and also showed similarities in majority being Hindu, belonging to Lower/middle SES, and majority caregivers being spouse. Similar findings were seen by Matoo et al [18] with mean age being 41.17 +-10.6. Primary caregivers being Spouses, mainly Wife by found by Matoo et al 77.5% and 74% by Sen et al ⁽¹⁴⁾ with our findings being similar with 69% wives caring for the patient. Contrasting to prior studies we found the next majority of caregiving in Siblings 25.74% as against 10% caregiving by parent in Sen et al's study.

2. Distribution of ADS Severity

A study in 2017 by Ramanujam et al found that (52%) 104 patients reported mild dependence, (31%) 62 patients experienced moderate dependence, (15%) 30 patients faced Severe dependence, and only (2%) 4 patients were very severely dependent.

In another study in 2017 by Swaroopachary et al in Mahbubnagar reported that the majority of the patients 40 (57.1%) faced Severe dependence followed by moderate dependence in 28 (40%) of the patients. Swaroopachary et al also reported 28% with Moderate Burden and 40% with Severe Burden.

3. Distribution of Caregiver Resilience

Majority Caregivers in our study, ie. 57 out of 101(56%) scored <2.5 on BRS indicating lesser resilience. Literature regarding Caregiver Resilience is sparse in India. Sreekumar et al reported higher scores on resilience were inversely related to the duration of ADS.

4. Co-relation Studies

4.1 Co-relation of ADS Severity with Caregiver Burden: A study by Swaroopachary et al, found Caregiver Burden to be more in Caregivers who's family member had Severe Alcohol Dependence, ie. Out of 40 % (40) of the Severe Burden group, 61.3% (27) belonged to the Severe ADS category. However, this finding was not statistically significant ($p=0.018$). Ramanujam et al study, the results showed that there was a significant correlation of 0.67 at p value <0.001 between the severity of dependence and the total objective burden scores. The caregiver subjective burden scores also significantly correlated at 0.48 with p value <0.001. Our study showed more Moderate Caregiver Burden followed by the Severe Burden group, and Moderate Burden was found to have almost equal co-relation with Moderate ADS and Severe ADS, 44.26 % vs 45.90% and Severe Burden Group was found to be more co-related with Severe ADS than Moderate ADS, 68.14% vs 38.46%. This co-relation was found to be statistically significant, $p=0.001$.

4.2 Co-relation of ADS Severity with Resilience: Our study found Resilience in the Caregivers to be on the lower end as per the Brief resilience scale, with Majority 57 (56.43%) scoring < 2.5. Among the 57, there was almost equal co-relation with Moderate ADS and

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Severe ADS. (47.37% vs 49.12%) with $p=0.042$. Hence resilience was found to be less in Caregivers whose family members suffered from Moderate to Severe ADS, implying poor resilience in those caregivers whose family members had increased severity of ADS.

Sreekumar et al found Resilience was associated with a shorter duration and lower severity of alcohol dependence, an absence of domestic violence and the involvement in external support groups. Poor resilience was associated with higher depression scores. These factors remained significant after adjusting for age using multiple linear regression.

Although our study did not study the factors associated with Resilience, we found similarity with Sreekumar's findings in terms of poor resilience association with the Severity of ADS.

4.3 Co-relation of Caregiver Burden with Caregiver resilience: Co-relation of Caregiver Burden with Resilience has not been studied, our study found that caregivers experiencing Sever/Very Severe Burden are poorly resilient hence showing the correlation between both.

CONCLUSION

Alcohol Dependence Syndrome has a significant negative impact not just on the individual but also on the spouse, family, and the community. This study attempts to add to the meagre literature in Caregiver perspective, mainly need to address that higher rates of burden is experienced with severity of dependence and possible ensuing risk of psychiatric issues. The role resilience plays in this complex admixture has also been attempted to be understood with findings suggesting poorer resilience in caregivers of moderate to severe dependence. Further study in the Indian context, pertaining to the specific factors underpinning Resilience in order to strengthen the same through timely & appropriate intervention thereby bringing about a decrease in perception of Burden in Caregivers is recommended.

Key points

1. Higher burden in caregivers with increasing severity of Dependence.
2. Poorer resilience in caregivers of those with moderate to severe levels of alcohol dependence.
3. Further research into factors influencing resilience as a means of reducing caregiver burden needs to be explored.

Limitations

This study is a preliminary attempt to address burden and resilience in caregivers of substance dependence. Being a cross sectional study there was inability to recognise directional causality. Detailed objective factors pertaining to burden were not included in the study and factors underpinning resilience were not included. Possible evaluation of immediate psychiatric co-morbidities might have been fruitful.

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Conflict of Interest

The author declared no conflict of interest.

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