

A Study of Burden in Primary Caregiver of Alcohol Use Disorder Patients

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Abstract

Background: Alcohol Use Disorder is well recognized as a complex bio-psycho-social phenomenon; it is a major social and personal threat and is considered as “family disease”. The aim is to assess the level of Burden in Primary Caregiver of Alcohol Use Disorder (AUD) patient. **Material and Methods:** It is a cross-sectional observational study done among 100 patients with AUD and their primary caregivers were taken according to inclusion and exclusion criteria. Patients were screened for AUD by AUDIT and Severity by SADQ. Caregiver burden and distress were assessed by Family Burden Interview Schedule (FBIS) and Psychiatric morbidity in caregiver was assessed by M. I. N. I. Statistical analysis. **Results:** The result demonstrates that primary caregivers of AUD experienced severe burden in all the domains of FBIS. 50% of the caregivers were having psychiatric illness of which major depressive episode, dysthymia & anxiety disorders were most common. Severity of caregiver burden in domains of routine family activities disruption, financial burden & disruption of family leisure had strong positive correlation with alcohol dependence severity. Significant correlation between Objective & Subjective burden and psychiatric morbidity in caregivers was also found. **Conclusion:** The study has illustrated that significant amount of burden has been experienced by all the primary caregivers of alcohol use disorder patients. It also found that the burden of care was positively correlated with severity of alcohol dependence in the patients and psychiatric morbidity in primary caregivers.

Keywords: Alcohol Use Disorder, Primary Caregiver, Burden, Psychiatric Comorbidity.

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INTRODUCTION

Alcohol use disorder (AUD) is a maladaptive pattern of alcohol use for duration of 12 months. A need for recurrent use of large amounts of alcohol for adequate functioning associated with certain behaviours like inability to cut down or stop drinking; repeated efforts to control or reduce excessive drinking and continuation of drinking despite a serious physical disorder. It impairs social, occupational and interpersonal functioning.^[1,2]

Global prevalence rates of AUD among adults were estimated to range from 0% to 16% according to World Health Organisation. In addition, alcohol use disorders account for 1.4% of the global disease burden.^[3] The lifetime risk for AUD is more than 15% for men and 1-year prevalence of alcohol abuse and dependence is estimated to be 6% or more.^[4]

The primary caregivers are those who provide care to other family members who need supervision or assistance in illness or disability.^[5] Family plays a crucial role in providing care for mentally ill patients. In India, it is substantially true because of factors like the tradition of interdependence, the concern for the family and insufficient mental health professionals.^[6] Families of alcohol dependent patients have increased risk of stressful life events, medical disorders and psychiatric disorders.^[7]

Caregiver burden is the stress or strain caregivers experience because of problems and challenges of care-giving.^[8]

Caregiver's burden has two aspects: 1) Objective burden - effects on the household matters including financial loss; effects on health, effect on children and family routine; and the abnormal behaviours shown by the patient. 2) Subjective burden - the extent to which relatives felt they carried a burden. The subjective experience or emotional impact of caring.^[9]

An Indian study comparing the family burden of patients with schizophrenia, alcohol dependence and opioid dependence by using FBIS showed moderate to severe burden in all the three groups.^[10] A study from Chandigarh that used FBIS to assess family burden in 120 subjects with alcohol and/or opioid dependence found that almost all (95–100%) caregivers had severe burden.^[11] Because of historical emphasis on AUD as an individual's problem, the study of caregiver problems has been relatively neglected. This study assumes importance because very little attention has been paid to caregiver burden in AUD patients and only few published papers are available on this

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subject. So, the present study was conducted with aim to assess the level of Burden in Primary Caregiver of Alcohol Use Disorder (AUD) patient.

MATERIALS AND METHODS

Study was conducted in Department of Psychiatry in a General Hospital attached to a Medical College, from April 2017 to March 2018 in Indoor and OPD patients with Alcohol Use Disorder patients and their Primary Caregiver. convenience sample of 100 patients and their primary caregiver is taken after ethical permission of institutional ethical committee. Written informed consent has been taken. The inclusion criteria were patients diagnosed as having AUD as per the Alcohol Use Disorder Identification Test (AUDIT), OPD and Indoor cases, whose age is between 18 years to 65 years, presence of a primary caregiver attending the hospital with the patient whose age is between 18 years to 65 years, the study used the Pollak and Perlick (1991) method to identify the primary caregiver. A primary caregiver is one who satisfied 3 or more of the following 5 criteria: Spouse, parent, or spouse equivalent, Most frequent contact with patients, Support patient financially, Most frequent collateral participant in patient's treatment, Is the person contacted in case of emergency. Exclusion criteria was patients attending alone, Non-availability of caregiver, all the patients with serious Medical co-morbidity which is not the consequence of chronic alcohol use, co-morbid substance use other than tobacco in the patients. Socio-demographic data was collected by a semi-structured interview of the patients and their primary caregiver who attended outpatient and inpatient department.

Tools:

1. Alcohol Use Disorder Identification Test (AUDIT).^[13]

AUDIT is developed by the WHO to assess alcohol consumption, drinking behaviours and alcohol-related problems. It is the only screening test which is specifically designed for international use and is used in this study for screening of AUD Patients. It is a 10-item screening questionnaire with 3 questions on the amount and frequency of drinking, 3 questions on alcohol dependence, and 4 on problems caused by alcohol. Both a clinician-administered version and a self-report version are available. The clinician-administered version used in this study. A score of 8 or more is considered to indicate hazardous or harmful alcohol use. AUDIT Score range: 0 – 7: Low-risk/non-hazardous/non-

harmful, 8 – 15: Risky or hazardous level, 16 – 19: High-risk or harmful level, 20 or more: High-risk. In addition to the total AUDIT score, a secondary „dependence’ score of 4 or more as a subtotal of questions 4 to 6 suggests the possibility of alcohol dependence and the need for more intensive intervention.

2. Severity of Alcohol Dependence Questionnaire (SADQ).^[14]

The SADQ is a self-administered, 20-item questionnaire designed to measure severity of dependence on alcohol as formulated by Edwards & Gross (1976). There are five subscales with four items in each: Physical Withdrawal, Affective Withdrawal, Withdrawal Relief Drinking, Alcohol Consumption, and Rapidity of Reinstatement. Each item is scored on a 4-point scale, ranging from “Almost Never” to “Nearly Always,” resulting in a corresponding score of 0 to 3. Thus the total maximum score possible is 60 and the minimum is 0. The scale was translated in vernacular language by experts, back translated and then given to the patients.

Caregiver burden and distress were assessed by 2 questionnaires.

1. Family Burden Interview Schedule (FBIS).^[15]

Developed by Shaila Pai and Kapur (1981) is a semi-structured interview which consists of 6 domains and 24 items each rated on a three-point scale: 0, no burden; 1, moderate burden and 2, severe burden.^[10] It comprises of 6 domains as follows: 1) Financial Burden [6 items] - scores range from 0 to 12; 2) Disruption of routine family activities [5 items] - scores range from 0 to 10; 3) Disruption of family leisure [4 items] - scores range from 0 to 8; 4) Disruption of family interactions [5 items] - scores range from 0 to 10; 5) Effect on physical health [2 items] - scores range from 0 to 4; 6) Effect on mental health [2 items] - scores range from 0 to 4. The total score of the six domains is the objective burden and ranges from 0 to 48. A standard question for assessment of “subjective” burden assessment is included in the schedule.

2. Mini-International Neuropsychiatric Interview (M. I. N. I.).^[16]

The Mini-International Neuropsychiatric Interview (M. I. N. I.) is a short structured diagnostic interview, developed jointly by psychiatrists and clinicians in the United States and Europe, for DSM-IV and ICD-10 psychiatric disorders. Time required for administration is approximately 15 minutes.

Analysis is done by using SPSS Version 16. After that Mean, Standard deviation and Chi-square tests used to analyze further. $P < 0.05$ is considered as statistically significant. Pearson's Correlation has been applied to compare the correlation between results of FBIS and SADQ.

RESULTS

Table 1: Socio-demographic variables of Patient and their primary caregiver

Socio-demographic variables	Patient n = 100 (%)	Primary caregiver n = 100 (%)
Age [mean± SD]	36.38 ± 9.45	40.71 ± 10.54
Gender		
Male	99	25
Female	1	75
Marital status		
Single	22	4
Married	73	84
Remarried	0	1
Widowed	0	8
Divorced	1	1
Separated	4	2

Education		
Professionals or Honours	1	1
Graduate or postgraduate	3	4
Intermediate or post high school diploma	10	1
High school certificate	25	9
Middle school certificate	29	2
Primary school certificate	27	36
Illiterate	5	47
Occupation		
Professional	2	1
Semi-professional	7	2
Clerical/shop owner/farmer	13	9
Skilled worker	43	29
Semiskilled worker	20	14
Unskilled worker	8	9
Unemployed	7	36
Religion		
Hindu	89	89
Muslim	9	9
Christian	2	2
Family type		
Nuclear	52	52
Extended/Joint	48	48
Locality		
Urban	93	93
Rural	7	7

[Table 1] show that the mean age of the patients was 36.38 years and that of caregivers was 40.71 years. Majority of the patients were males (99%) while most of the caregivers were females (75%). In this study, most of the patients (73%) and caregivers (84%) were married and have taken formal school education. Most of the population belonged to urban area and were Hindu. In occupation, skilled work was commonly

observed among patients while many of the caregivers were employed.

Study observed that majority of the patients (55%) were consuming alcohol for more than or equal to 10 years. Alcohol use for the first time was most commonly observed between 19 to 25 years of age.

Table 2: Characteristics and pattern of Alcohol consumption in patients of alcohol use disorder

Total AUDIT Score		Dependence score (AUDIT) (Q:4, 5&6)	
Score	Frequency (N=100)	Score	Frequency (N=100)
Risky to Hazardous (8-15)	26	≤ 4	25
		>4	1
High risk or Harmful (16-19)	24	≤ 4	5
		>4	19
High risk (>20)	50	≤ 4	1
		>4	49
		Mean	Std. Deviation
AUDIT Score		20.68	7.18
Duration of alcohol use (in years)		11.88	8.24

[Table 2] shows characteristics and pattern of alcohol consumption in patients. Mean duration of alcohol use was 11.88 years and mostly of country made liquor. Among 100

patients in this study, 69 patients had alcohol dependence according to AUDIT and others had high-risk or hazardous drinking pattern.

Table 3: Classification of alcohol dependent patients based on severity

Severity of Alcohol Dependence	SADQ total score	n = 100 (%)
Non-dependent	0 – 7	0
Mild dependence	8 – 15	16
Moderate dependence	16 – 30	37
Severe dependence	31 – 60	47

[Table 3] depicts moderate and severe alcohol dependence was more commonly observed among patients. 16 patients were having mild dependence, 37 patients had moderate dependence and 47 patients had severe dependence as per SADQ score. The average score on SADQ was 28.81±11.13. [Figure 1] shows the level of burden felt by primary caregiver in different domains of family burden. Caregivers

experienced severe burden in all the domains of family burden except effect on physical health where 50% of the caregivers felt no burden. Disruption of routine family activities was the area in which maximum severe burden (66%) was felt.

[Figure 2] show Prevalence and pattern of Psychiatric morbidity in the study population (100 caregivers), of which 50 (50%) caregivers had psychiatric morbidity. Major depressive episode

(20%), dysthymia (16%) and anxiety disorders (6%) was more prevalent psychiatric conditions among caregivers.

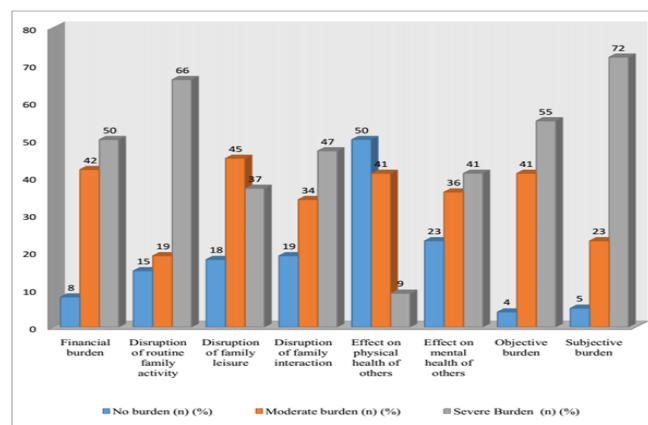


Figure 1: Distribution of type and severity of Family burden experienced by primary caregiver

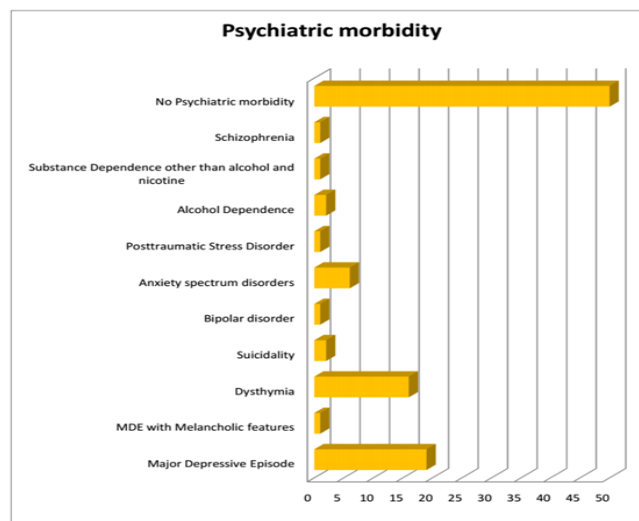


Figure 2: Prevalence and pattern of Psychiatric morbidity in Primary caregiver.

Table 4: Correlation between Severity of Dependence and Burden on Primary Caregiver

FBIS domain	Correlation coefficient (Between FBIS score and SADQ score)
Financial burden	0.675
Disruption of routine family activity	0.720
Disruption of family leisure	0.597
Disruption of family interaction	0.343
Effect on physical health of others	0.416
Effect on mental health of others	0.412
Objective burden	0.685
Subjective burden	0.350

[Table 4] depicts severity of alcohol dependence in patients is correlated with the burden faced by their caregivers. Significant correlation with alcohol dependence severity was found in all the areas of family burden. Disruption of routine family activity was the area having the strongest correlation with dependence.

Present study correlates the severity of Objective burden experienced by primary caregiver with the occurrence of psychiatric morbidity in them, which is statistically significant at p value 0.0001 and correlates the severity of subjective burden experienced by primary caregiver with the occurrence of psychiatric morbidity in them which is statistically significant at p value 0.0001. Present study also observed that alcohol dependence severity in patients as per SADQ is correlated with the prevalence of Psychiatric morbidity among caregivers. The results obtained were statistically significant. In the present study, no significant correlation was found between socio-demographic variables and years of alcohol dependence in patients with the level of burden experienced by the caregivers.

DISCUSSION

Alcohol Use disorder is a major mental health problem having negative effects on the health and psychosocial environment of the patient and their family members.

Socio-demographic variables: In the present study, out of 100 patients, majority were males (99%) which show that at this centre alcohol consumption and de-addiction treatment

seeking was more common in males than in females similar to other parts of the country. The majority of the caregivers were wives and so females were the majority in the caregiver sample. Most of the patients and caregivers were married, taken formal school education and were employed. Unlike the results of this study, SK Sen et al,^[17] found that majority of the caregivers were unemployed. It explains that caregivers were engaged in some or the other work to cope with the financial demand of the family. Majority belonged to urban area and were Hindu. There were very few patients with alcohol use disorder who were Muslim, which can be explained on the basis that alcohol intake is not accepted and is banned in Islam, which was similar to a study, by N. Lamichhane et al,^[18] and Mattoo et al.^[10] Pattern of majority of socio-demographic variables of the study were also similar to studies done by Vaishnavi et al,^[15] Kiran M. et al,^[19] Tajudeen Nuhu, F. et al.^[20]

Clinical variables of the patient: In this study, majority of the patients had more than or equal to 10 years of alcohol dependence. The mean duration of alcohol use was 11.88 ± 8.24 years that is quite similar to mean duration of alcohol dependence 12.92 ± 9.18 years in a study by Mattoo et al.^[10] These results were also similar to a study done by Sen SK et al,^[17] which showed 32% cases had 10–14 years of dependence, and to a study by Malik et al,^[21] in which 42.9% of patients had 6–15 years of dependence. The most common age-range at the initiation of drinking was 19–25 years of age that is quite similar to that found in different studies, even with vast differences among population, regions and years of studies.^[22–25]

Pattern of alcohol consumption according to AUDIT and

Classification of alcohol dependence as per SADQ: In the present study, according to AUDIT score, 31% had hazardous or high risk or harmful pattern of alcohol use and 69% had alcohol dependence among current alcohol consumers. S Ghosh et al,^[26] reported 78% had the non-hazardous pattern, 8% had harmful or hazardous pattern and 14 %had alcohol dependence on AUDIT, which is much lower than in the present study. According to SADQ, 47% had severe dependence in this study which is much higher than reported by Vaishnavi R et al,^[15] in their study that is 17% had severe dependence.

Distribution of type and severity of Family burden: When different domains of the family burden were compared it was found that caregivers experienced severe burden followed by moderate burden in all the areas of family burden except in the area of effect on physical health. Disruption of routine family activity was the area where maximum severe burden was observed, which may be due to the reason that patients did not help in household activities and also patient's lack of attention towards other family members due to his alcohol use. Unlike our results, many other studies in India found that the primary caregivers experienced moderate burden in most of the areas especially in financial area, disruption of routine family activity, family leisure and family interaction.^[10,17,21] Effect on physical health was the area where burden was not experienced by majority of the caregivers which was similar to studies by SK Sen et al,^[17] and Vaishnavi R et al.^[15]

Correlation between Severity of Dependence (SADQ) and years of alcohol dependence with Burden on Primary Caregiver (FBIS): Various domains of family burden like financial burden, disruption of routine family activities, family leisure and family interaction, effect on the physical health and effect on the mental health were positively correlated with severity of alcohol dependence of the patient. The correlation found was statistically significant. Correlation was strongest for routine family activity disruption compared to other domains with severity of alcohol dependence. The results were similar to findings by Vaishnavi R et al,^[15] except they found strongest correlation of financial burden with alcohol dependence severity.

When the severity of total objective and subjective burden was compared with the years of alcohol dependence, no statistically significant results were found in this study. These results were dissimilar to studies done by SK Sen et al,^[17] and Malik et al,^[21] who found statistically significant correlation that is cases having longer duration of dependence had more severe burden in different domains of family burden.

Prevalence and pattern of Psychiatric morbidity in primary caregiver: In present study it was found that 50 out of 100 caregivers of alcohol dependent patients had clinically significant psychiatric morbidity. Majority had symptoms of major depressive disorder (19%), dysthymia (16%) and anxiety disorders (6%).

Kishor M et al,^[27] found that more than half of the spouses (65%) had a psychiatric disorder which is nearly similar to the present study (50%). Major depressive disorder was present in 43% in spouses of alcohol dependent patients which is almost double than the results of the current study. In the present study substance abuse (alcohol and other

substances except nicotine) is only 3% in caregivers and it was not found among the spouses of the patients who are the major care-giving person which shows the impact of Indian culture. This is quite different from western countries where substance dependence is commonly found as co-morbidity.^[27,28]

On comparing psychiatric morbidity with the severity of alcohol dependence of the patients, a positive correlation was found between the two. This shows that psychiatric morbidity among caregivers increases with the increase in alcohol dependence severity in patients.

Correlation between burden of care and psychiatric morbidity: There is a statistically significant correlation between total objective burden and subjective burden assessed by FBIS and psychiatric morbidity assessed by MINI. This indicates that as the family burden increases, psychological distress and psychiatric morbidity among caregivers increases.

Various factors can be responsible like socio-occupational impairment; patient's lack of attention towards the family members which disrupts routine activities and general atmosphere in the family, lack of awareness, and stigma related to alcohol use disorder and psychiatric disorders. These factors pose significant burden and psychological distress to the caregivers, which endanger their physical and mental health. There is only sparse literature available, which shows correlation between burden of care and psychiatric morbidity in primary caregiver of patients with alcohol use disorder.

It is one of its kinds of study, which evaluates the burden in primary caregivers of AUD patients. Most of the studies of caregiver burden have been done in other disorders like schizophrenia, dementia and substance use other than alcohol. Still the study is limited by its small sample size and subjects recruited from a single tertiary care hospital. So the results of the study cannot be generalised to a community. A further study with large sample size, preferably including community sample is essential to confirm the present findings.

CONCLUSION

The study has illustrated that significant amount of burden has been experienced by all the caregivers of alcohol use disorder patients. Also level of burden borne by caregivers was positively correlated with the severity of alcohol dependence in patients and psychiatric morbidity in caregivers. This has to be addressed while treating the patients with alcohol use disorder that it is not the problem of an individual only but affects every aspect of family. Inferences of this study signify the need for designing interventions for the caregiver to cope with the alcohol dependence of the patient. It will also be useful for better treatment effectiveness of the patients.

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Conflicts of interest

There are no conflicts of interest.

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