

## Caregiver Burden in Substance Use Disorders Patients

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### Abstract

**Background:** Substance Use Disorders (SUDs) impose significant challenges not only on individuals grappling with addiction but also on the caregivers who provide support and care. The caregiving role is associated with multifaceted burdens that require understanding and targeted interventions. Recognizing the diverse dimensions of caregiver burden is crucial for offering effective support. **Objective:** The study aimed to find out the caregiver burden in substance use disorder patients, examining severity and socio-demographic correlations, contributing insights into effective support strategies. **Methodology:** The cross-sectional observational study took place at Sylhet MAG Osmani Medical College's Psychiatry Department and a private psychiatric and drug rehabilitation center in Sylhet from September 1, 2018, to August 31, 2020. The research focused on substance use disorder patients and their caregivers, involving 50 eligible patients selected through inclusion and exclusions criteria. Diagnoses followed DSM IV criteria. Socio-demographics were gathered via semi-structured questionnaires. Caregiver burden was assessed using the Bengali Zarit Burden Interview (ZBI) scale through approximately hour-long interviews, with 1-2 daily. Ethical procedures encompassed informed consent and confidentiality assurance. **Result:** The study included 50 male participants. Patients mean age was 31.92 ( $\pm 8.21$ ) and caregivers mean age was 41.68 ( $\pm 12.89$ ). Mainly, caregivers were mothers (40%) and wives (34%). Caregivers experiencing moderate to severe burden were 58%, mild to moderate burden were 26%, and severe burden were 16%. Mean ZBI score was 48.22 $\pm$ 13.55. Higher burden correlated with illiteracy, low family income, excessive drug spending, prolonged substance use, and multiple drug usage. Alcohol users faced more burden than other substance users. Female caregivers, younger age, and housewives experienced heightened burden. No burden links were found with marital status, habitat, religion, family type, or drug administration method. **Conclusion:** This study concluded that Substance use heightens caregiver burden, notably among female, young, and housewife caregivers. Addressing these trends is vital for effective care of substance use disorder patients.

**Keywords:** Caregiver burden, Substance Use Disorders, Zarit Burden Interview, socio-demographic variables, interventions.

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## INTRODUCTION

Substance use has emerged as a significant global public health concern [1], with substances encompassing chemical agents affecting bodily

functions, moods, perceptions, and consciousness. Substance Use Disorders (SUD) manifest as maladaptive patterns of substance use resulting in significant impairment or distress. Substance dependence involves cognitive, behavioral, and physiological symptoms that

perpetuate substance use despite negative consequences [2]. Substance Dependence, characterized by cognitive, behavioral, and physiological symptoms despite consequential issues, results in compulsive drug use. Substances targeting the brain's reward system by elevating dopamine levels produce pleasurable sensations and reinforce drug use [3].

Classified by the DSM-IV, abusable substances encompass alcohol, amphetamines, caffeine, cannabis, cocaine, hallucinogens, inhalants, nicotine, opioids, and sedatives [2]. Globally, SUD prevalence is 0.6%, with India's rate at 0.69% [4]. In 2015, drug-related deaths totaled 190,900 worldwide [5]. Bangladesh faces a SUD prevalence of 0.63% in adults and 0.8% among 5–17-year-olds [6]. The nation harbors over 6 million drug users, expending 70 million BDT daily on illicit narcotics [7]. Sylhet's substance users largely favor cannabis (95.24%) and yaba (61.90%), with significant numbers addicted to heroin, alcohol, phensedyl, and more [8].

SUD patients grapple with educational, occupational, familial, and psychological challenges. Caregivers endure social, emotional, and financial hardships, impacting their quality of life [9]. Involvement of women caregivers and their inherent disadvantages compound the burden. Caregivers face multifaceted stress, depression, and compromised well-being. This study delves into the caregiver burden of SUD patients, particularly addressing women caregivers [10]. The multifaceted burden stemming from their responsibilities results in a range of negative physical, psychological, and financial outcomes [11].

## OBJECTIVES

### General Objective

- To study the burden and its severity among the caregiver of patients with substance use disorders.

### Specific Objectives

- To find out any possible relationship between socio-demographic factors with the burden of substance use disorders patients.
- To find out the relationship between various types of substance and caregiver burden.
- To find out relationship between duration of substance use & caregiver burden.

## METHODOLOGY

The study was a cross-sectional observational study conducted at the Department of Psychiatry, Sylhet MAG Osmani Medical College, Sylhet, and a private psychiatric and drug rehabilitation center in Sylhet, covering a span from September 1, 2018, to August 31, 2020. A total of 50 patients meeting the inclusion criteria were selected for this study. Patients' previous treatment records were reviewed to preliminarily identify eligible

participants. Patients' diagnosis of substance use disorder was confirmed by psychiatrists based on DSM-IV criteria.

### Inclusion Criteria

- Caregiver of SUD patient age within the range of 18 years and 65 years.
- Substance use disorder patients diagnosed according to DSM-IV criteria.
- Lives with the patient for at least one year.

### Exclusion Criteria

- Patients with other chronic psychiatric illness.
- Patients with known co-morbid chronic medical illness.
- The patients having another family member with psychotic illness or chronic debilitating physical illness
- Caregiver of patients who have co-morbid known chronic medical illness or psychiatric disorders.
- Paid caregiver.

### Data Collection

Socio-demographic information of both the patients and their caregivers was collected using a semi-structured questionnaire. Caregivers were then interviewed using the Bengali version of the Zarit Burden Interview (ZBI) scale. The ZBI scale was utilized to measure the extent of caregiver burden.

### Data Analysis

Statistical analysis was performed by using SPSS (Statistical package for social science) for windows version 25. All data were recorded systematically in a preformed check list and was checked and verified thoroughly to reduce inconsistency and for omission and improbabilities. Then data was edited, coded and entered into computer. Quantitative data were summarized as mean and standard deviation and comparison. Analysis of variance (ANOVA) test was performed to identify the association between different variables of sociodemographic data and Caregiver. A probability ( $p$ ) value of  $<0.05$  was considered statistically significant and  $p>0.05$  was taken as non-significant. This systematic approach enabled insightful data extraction and evaluation of variable relationships.

### Ethical Considerations

The study adhered to ethical guidelines, obtaining informed written consent from all participants. Anonymity was maintained, and Institutional Review Board approval was secured. Participant well-being was prioritized, with minimized risks and withdrawal rights. Transparency was maintained throughout the study, fostering open communication. These ethical measures ensured participants' rights, safety, and privacy while contributing valuable insights into caregiver burden among substance use disorder patient caregivers.

## RESULTS

This is a cross sectional observational study was conducted in the Department of Psychiatry, Sylhet MAG Osmani Medical College Hospital, Sylhet with a view to

evaluating caregiver's burden among the patients with substance use disorders patients. For this purpose, 50 patients with caregivers were selected according to inclusion and exclusion criteria. The outcome of the study was as follows:

**Table 1: Distribution of patients according to age group with Caregivers (n=50)**

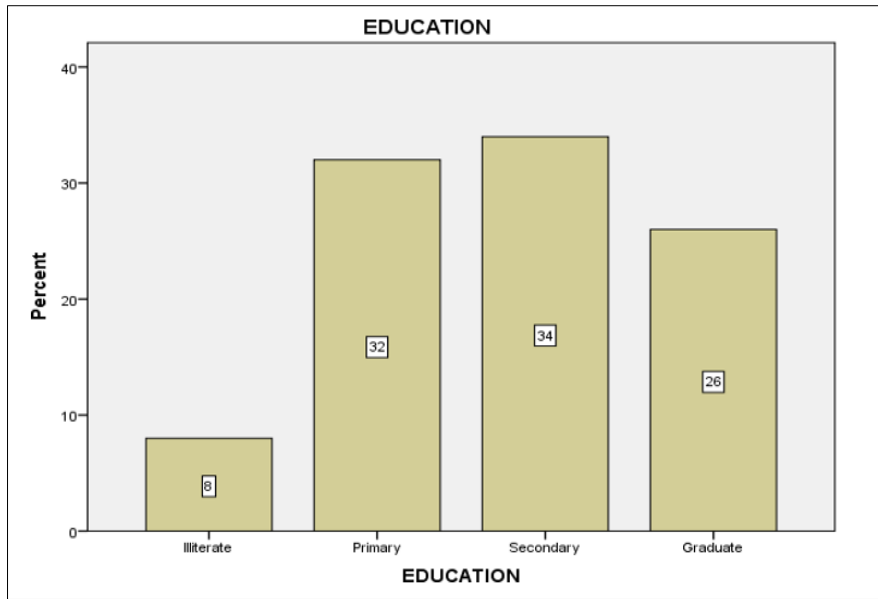
Variable	Frequency	Percent
<b>Age Group</b>		
20-30	26	52%
30-40	20	40%
40-50	2	4%
50-60	2	4%
Mean (SD)	31.92 ( $\pm$ 8.21)	-
<b>Distribution of Caregivers according to age group</b>		
21-30	16	32%
31-40	10	20%
41-50	10	20%
51-60	11	22%
61-70	3	6%
Mean (SD)	41.68 ( $\pm$ 12.89)	-

The mean age of patient was 31.92 ( $\pm$ 8.21). Highest (52.0%) among 20-30 years age group and lowest (8.0%) among >40 years age group, with the mean age of Caregiver was 41.68 ( $\pm$ 12.89). Highest

(32%) among 21-30 years age group and lowest (8%) among >61years age group. Among the caregivers minimum age 25 years & maximum age 69 years.

**Table 2: Association between Substance use disorder with demographic characteristics and caregiver burden**

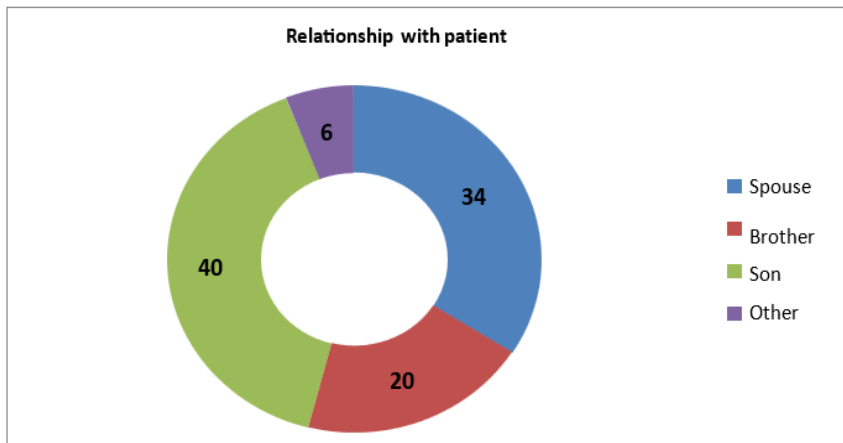
Demography	Mean ZBI Score	Standard Deviation	p-value
<b>Age</b>			
20-30	43.5385	12.72236	0.069
30-40	52.4500	13.29612	
40-50	57.5000	2.12132	
50-60	57.5000	17.67767	
<b>Religion</b>			
Muslim	48.4872	14.41650	0.796
Hindu	47.2720	10.41241	
<b>Marital Status</b>			
Unmarried	45.0000	13.46376	0.201
Married	50.0000	13.15611	
Divorced	56.0000	-	
Widower	70.0000	-	
<b>Education</b>			
Illiterate Primary	58.7500	7.97392	0.014
Secondary	50.2941	14.09239	
Graduate	38.6923	11.10844	
<b>Occupation</b>			
Farmer	58.5000	13.12758	0.045
Service	44.9000	11.09004	
Business	47.7000	16.51969	
Students	49.6667	17.29354	
Unemployed	57.0000	6.61438	
Other	40.0000	10.41153	



**Figure 1: Distribution Patient according to education level.**

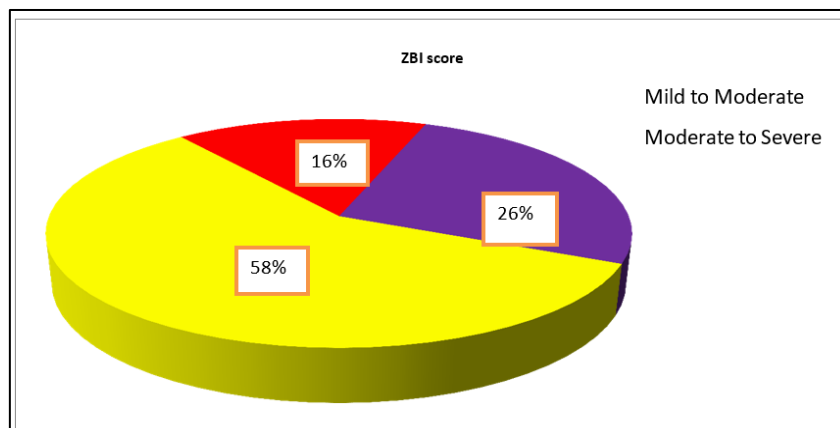
Figure 2 demonstrates the educational level of substance use disorder patients. Most of the patients (34%) studied up to primary level. A good number of the

patients study up to secondary level (32%). Fewer of them have completed graduates (26%) & the rest were illiterate (8%).



**Figure 2: Distribution of caregiver according to relationship with patient.**

Figure shows reveals relationship of caregivers. Most of caregivers are mother (40%), and then spouse (34%).



**Figure 3: Overall burden of caregiver according to ZBI score.**

Overall burden of caregiver according to ZBI score. 58% caregivers experienced moderate to severe burden, 26% were faced mild to moderate burden & 16% were experienced severe burden. Mean score is  $48.22 \pm 13.55$ . Lowest score is 22 & highest score is 77.

## DISCUSSION

To assess the subjective and objective burden of caregiving, the Zarit Burden Interview (ZBI) Bangla version was administered to each caregiver. Concerning the total ZBI score, it was discovered that 58% of caregivers experienced moderate to severe burden, 26% faced mild to moderate burden, and 16% grappled with severe burden. The ZBI scores ranged from 22 (minimum) to 77 (maximum), with a mean  $\pm$  standard deviation (SD) of  $48.22 \pm 13.55$ . These results closely align with findings in Nairobi, who reported 57.2% with moderate to severe burden, 14.4% with severe burden, and 8.6% with mild to moderate burden [12]. These outcomes are also consistent with noted that 12.5% of caregivers faced no burden, 77.5% experienced moderate burden, and 10% dealt with severe burden [13]. A Similarly, that 52.5% of caregivers experienced moderate burden, 45.8% faced severe burden, and 1.7% reported no burden. The discrepancies in these findings can be attributed to variations in the structural questionnaires used and socio-demographic factors [14].

Regarding the initiation of drug use, it was revealed that a majority of users (84%) began between the ages of 11 and 30. This observation corresponds to the similar study findings, who reported that 96% of respondents-initiated substance abuse between the ages of 11 and 30. The most common reasons for early substance use included curiosity, peer pressure, seeking enjoyment, and relief from negative mood states [15]. However, there was no significant relationship between the age of onset of drug use by patients and caregiver burden ( $p=0.714$ ). This could potentially be attributed to caregivers' initial lack of awareness and the use of substances at low doses that do not significantly disrupt daily life. In contrast, identified a higher burden associated with an early start of drug intake [10].

Among substance users, it was found that 30% began drug intake with cannabis, 10% with a combination of cannabis and yaba, 8% combined cannabis and tobacco, 6% combined cannabis and alcohol, 6% combined cannabis and sedatives, and 4% initiated with alcohol alone. This pattern aligns with reported that the majority of users (74.5%) commenced substance abuse with cannabis due to its affordability and availability [16].

Furthermore, the research revealed that 56% of patients primarily used cannabis, 14% used yaba, and 12% used alcohol as their main drug. Similarly, Ahad *et al.*, found that 95.24% used cannabis as their principal drug, while 61.90% were involved in yaba addiction [8]. This could be attributed to the availability and low price

of these drugs. However, Malik *et al.*, observed that a majority of patients (57.1%) had alcohol dependence, followed by alcohol and tobacco combination (50 percent) [10]. These variations can be explained by the small sample size and different socio-demographic characteristics. Moreover, the present study found a relationship between the main drug used and caregiver burden ( $p=0.043$ ).

Among the main drug users, alcohol users exhibited a higher burden (ZBI score=59.00) compared to yaba (ZBI score=46.85), cannabis (ZBI score=45.65), and tobacco (ZBI score=22.00). A similar study found the highest burden associated with alcohol and opium dependence (mean scores 21.0), whereas the lowest burden was linked to tobacco dependence (mean scores 4.7). These scoring differences can be attributed to variations in psychometric measures [10]. Moreover, among the users, it was observed that 90% used a single drug, while 10% used multiple drugs as their primary substances. This resulted in a higher burden among the multiple drug users compared to single drug users (60.4 vs. 46.86). An increased burden among poly-substance users (20.2 vs. 14.4). These variations in scoring are due to the utilization of different scales in the respective studies.

One essential aspect of substance use explored in this study is the route of intake. The research found that smoking and swallowing were the most common methods, with 50% of users employing these routes, while 32% used inhalation. These findings align with also observed high usage of oral and inhalational routes. However, the study did not find a significant relationship between the routes of substance intake and caregiver burden, possibly due to the study's limited sample size [17]. This result contrasts with likewise did not find a substantial burden variation based on substance use routes, and with higher caregiver burden among injectable route users [18].

The duration of substance use was another crucial factor examined. The research revealed a significant correlation between the duration of substance use and caregiver burden. Patients who had used substances for a longer duration experienced higher caregiver burden. The study also indicated a proportional relationship between expenditure on substance use and caregiver burden [19].

The socio-demographic characteristics of both patients and caregivers were analyzed. Patients were predominantly males, consistent with the common representation of males in substance-related studies in Bangladesh and India. While the marital status of patients did not exhibit a statistically significant difference in caregiver burden, the educational status of patients showed a significant relationship, in line with findings in the same geographical area. The occupation of patients was also related to caregiver burden, with



unemployed caregivers experiencing more burden. The age of caregivers was another significant factor, with younger caregivers experiencing higher burden [20].

The relationship between the caregiver and the patient was found to be significant, with spouses experiencing higher burden compared to other relationships. However, religion, habitat background, and household composition did not demonstrate significant relationships with caregiver burden in this study.

In study, caregiver burden in the context of substance abuse is influenced by various factors, including the duration of substance use, expenditure on substance use, socio-demographic characteristics of patients and caregivers, and the relationship between the caregiver and the patient. Understanding these factors can guide the development of targeted interventions and support systems to assist caregivers in coping with the challenges posed by substance abuse within their families.

## CONCLUSION

It can be concluded that all caregivers experience some sort of burden while giving cares to their substance use disorder patient. Among the caregivers most of them exposed to moderate to severe burden. This study concluded that burden is associated with low family income and with patients who are dependent on multiple substances. Higher proportion of severe burden was reported by female caregivers. Among the female caregivers, spouses are the worst sufferer. Burden is also influenced by substance type, and socioeconomic attributes of family. Extent of physical, psychological, interpersonal and financial burden increased along with duration of substance use but routes of substances, educational status of caregiver has no impact on burden. Successful detection of caregivers burden in Substance Use Disorder Patient & professional help enhances their quality of life.

### Limitation of Study

- The study is limited by the small sample size and hospital-based design.
- All patients of the study were male.
- Convenient sampling method was applied which may have chance of bias.

### Recommendations

- Caregiver of Substance Use Disorders patient burdened significantly during caregiving. It is vital to detect the burden which necessitates to be reduced.
- Caregiver's emotional, social, financial, psychological and physical health should be considered in every step of therapeutic process of patient.

- For better understanding of this issue multicenter, population-based studies are required.

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