



FAMILY BURDEN PERCEIVED BY PRIMARY CARE-GIVER OF INDIVIDUALS WITH SUBSTANCE USE DISORDER.

Dr. Muhammad Ilyas Jat¹, Dr. Muhammad Tarique Arain², Dr. Anil Kumar Wadhwani³, Dr. Washdev.⁴ Dr. Anoop Kumar^{5*}, Dr. Haresh Kumar⁶, Dr. Vinay Kumar Gemnani⁷

¹MBBS, FCPS. Assistant Professor Psychiatry, Dr. AQ Khan Institute of Behavioral Sciences, Dow International Medical College, Dow University of Health Sciences, Karachi. ilyas.jat84@gmail.com

²MBBS, FCPS. Assistant Professor Psychiatry, Department of Psychiatry, Dr. Ruth KM Pfau, Civil Hospital, Dow University of Health Sciences, Karachi. drtariquearain@gmail.com

³MBBS, FCPS. Assistant Professor Psychiatry, Dr. AQ Khan Institute of Behavioral Sciences, Dow International Medical College, Dow University of Health Sciences, Karachi. wadhwaniapsy@gmail.com

⁴MBBS, FCPS. Associate Professor Psychiatry, Department of Psychiatry, Dr. Ruth KM Pfau, Civil Hospital, Dow University of Health Sciences, Karachi. devamar88@gmail.com

^{5*}MBBS, FCPS. Assistant Professor Psychiatry, Department of Psychiatry, Chandka Medical College. Anoopkumar771@yahoo.com

⁶MBBS, FCPS. Associate Professor Psychiatry, Department of Psychiatry, Khairpur Medical College.

⁷MBBS House officer CMC (SMBBMU) Larkana

***Corresponding Author:** Dr. Anoop Kumar.

^{*}MBBS, FCPS. Assistant Professor Psychiatry, Department of Psychiatry, Chandka Medical College. 03323953042 Anoopkumar771@yahoo.com

Abstract

Objective: To assess the family burden perceived by the primary caregivers of individuals with substance use disorder.

Study Design and Duration: This was a cross-sectional descriptive study. Dr. Ruth KM Pfau Civil Hospital, Dow Medical College, Department of Psychiatry, Karachi, during the period April 1, 2023–September 30, 2023.

Methodology: To evaluate the burden caregivers were bearing, the Zarit Burden Interview was given to them. The diagnosis of substance use disorder was made under the ICD-10 criteria. A sample size of 180 caregivers was calculated through a standard formula. The sampling technique was nonprobability consecutive samplings. Ethical approval was sought before the commencement of the study.

Results: The participants' mean age was 39.36 +/- 12.70 years. Among all participants 96 (53.3%) were males and 84 (46.7%) were females. The relationship of caregivers with patients was wife 54 (30.0%), Son 33 (18.3%), Brother 29 (16.1%), Father 34 (18.9%), Sister 13 (7.2%), Mother 17 (9.4%). The perceived burden by a caregiver was Little or no burden 20.0%, Mild to moderate burden at 20.0%, moderate to severe burden at 40.0%, and severe burden as 20.0% as per Zarit Burden scale. Type of substance used, Relationship of the caregiver with the patient, and Gender of the caregiver were significantly related to the perceived burden by the caregiver having a P value of less than 0.05.

Conclusion: Looking at the findings of our study, it could be concluded that substance dependence was associated with a substantial burden for the caregiver.

Keywords: Caregiver, Perceived burden, Substance use, Zarit Burden scale.

Introduction:

Addiction and substance abuse have a serious negative impact on people, families, and society at large. While some negative effects of substance use are directly caused by it, other negative effects result from related behavioral patterns, the expression of which is dependent on complex relationships between drugs, individuals, and society. Operationally speaking, the burden is described as "the impact of the subject on the family" for research purposes in a number of areas, including special money, routines for the family, entertainment, relationships, and the physical and emotional well-being of others¹.

The impact that a family member's substance abuse has on the family has been the subject of discussion since the 1990s. In 1966, Hoenig and Hamilton made an effort to differentiate between subjective and objective burdens. While the latter is defined as the extent to which family members are impacted by objective burdens, the former covers the impact of illness on family finances and customs. An estimated 246 million individuals, or 1 in 20 persons between the ages of 15 and 64, used illicit drugs in 2013. Compared to last year, there has been a 3 million increase in this.

When we take into account that over 10% of drug users are problem users, have a drug use disorder, or are dependent on drugs, the scope of the worldwide drug problem becomes even more apparent. Addiction to drugs cannot be cured quickly or easily. It is a chronic illness, and like other chronic illnesses, its victims must get long-term, continuous care since they are susceptible for the rest of their lives.³ Four villages in Punjab were surveyed, and the results showed that 78.28% of the people there drank alcohol⁴.

In a 2,992-person epidemiological study aimed at estimating the incidence of drug and alcohol addiction in impoverished and rural regions, 6.88% of respondents satisfied the International Classification of Diseases, Tenth Revision (ICD-10) dependent criteria. In most slums, both urban and rural, alcohol is the primary narcotic. Most aspects of life are impacted by alcohol and drugs, including employment (64.28%), family (77.31%), marital status (70.59%), and health (85.71%).⁵ A government-conducted survey in Punjab indicates that one in three pupils there suffers from drug addiction. It was discovered that Punjab consumes three times as much opium as the stated national average.

The state of Punjab is experiencing an epidemic level of drug addiction.⁶ Almost every element of family life is impacted by drug addiction, including economics, social and interpersonal interactions, and leisure activities. Dependence on addictive substances always increases conflict, negatively affects family members and creates a burden for the family⁷. The quantity, kind, and history of substance use, together with the guardian's gender, type, and socioeconomic status of the family, all impact the load placed on family members. These findings could point the way for further study in this field. Families are intricately involved with drug addiction. Consequently, it is imperative that families and healthcare professionals communicate better, and that families actively participate in the treatment process. Treatment efficacy can be increased by offering services to the entire family and easing their load.

Inclusion Criteria:

1. Caregivers of diagnosed cases of substance use disorders.
2. Caregivers will be close relatives, friends, or any other person who is living with the patient and/or taking care of the patient.
3. Persons of both genders, with ages between 18 and 60, of different religions, and of different education and employment levels were selected.

Exclusion Criteria:

1. Caregivers on any kind of medication, as this may result in abnormalities related to cognition and psychology.
2. Caregivers having mental and behavioral disorders due to psychoactive substance use.
3. Caregivers who also manage other medical co-morbidities, such as patients in urgent need of medical attention.
4. Those who did not give consent for the study.

Methods:

The present study was a cross-sectional hospital-based investigation carried out between April 1, 2021, and September 30, 2021, at the in-patient and out-patient Department of Psychiatry, Dow Medical College, Dr. Ruth KM Pfau Civil Hospital, Karachi. The Zarit Burden Interview was used with caregivers to estimate their level of burden.

The diagnosis of substance use disorder was made under the ICD-10 criteria. A sample size of 180 caregivers was calculated through a standard formula. The sampling technique was nonprobability consecutive samplings. After guaranteeing confidentiality, the study's purpose was explained to caregivers, and their written informed consent was obtained.

Results:

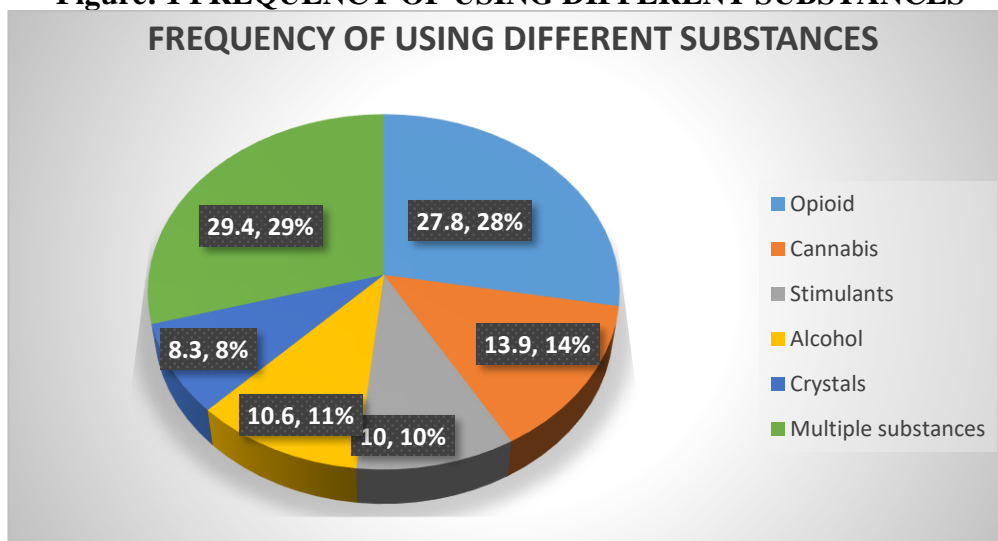
This study involved 180 patients, with a mean age of 39.36 ± 12.70 years, with 96 (53.3%) males and 84 (46.7%) females. In marital status 136 (75.6%) were married, 41 (22.8%) were single and 03 (1.7%) were divorced/widowed. Out of 180 cases 47 (26.1%) were primary passed while 26 (14.4%) had some sort of Deeni-Taleem, 33 (18.3%) were middle, 15 (8.3%) were matriculated, 27 (15.0%) were intermediate and 3 (1.7%) were graduate and 29 (16.1%) were Illiterate. Among a total 88 (48.9%) were Household by profession while 22 (12.2%) were students, 18 (10.0%) were Shopkeepers, 10 (5.6%) were Professional, 31 (17.2%) were Jobless and 11 (6.1%) were doing some other jobs as shown in **Table. I**.

Table. I FREQUENCIES OF DEMOGRAPHICS CHARACTERISTICS OF PARTICIPANTS

Number of participants N= 100 (%)		
<u>Gender</u>	Male	96 (53.3)
	Female	84 (46.7)
<u>Marital Status</u>	Married	136 (75.6)
	Single	41 (22.8)
	Widowed	03 (1.7)
<u>Education</u>	Deeni-Taleem	26 (14.4)
	Primary	47 (26.1)
	Middle	33 (18.3)
	Matric	15 (8.3)
	Intermediate	27 (15.0)
	Graduate	3 (1.7)
	Illiterate	29 (16.1)
	Student	22 (12.2)
<u>Occupation</u>	House-hold	88 (48.9)
	Professional	10 (5.6)
	Shopkeeper	18 (10.0)
	Jobless	31 (17.2)
	Other	11 (6.1)

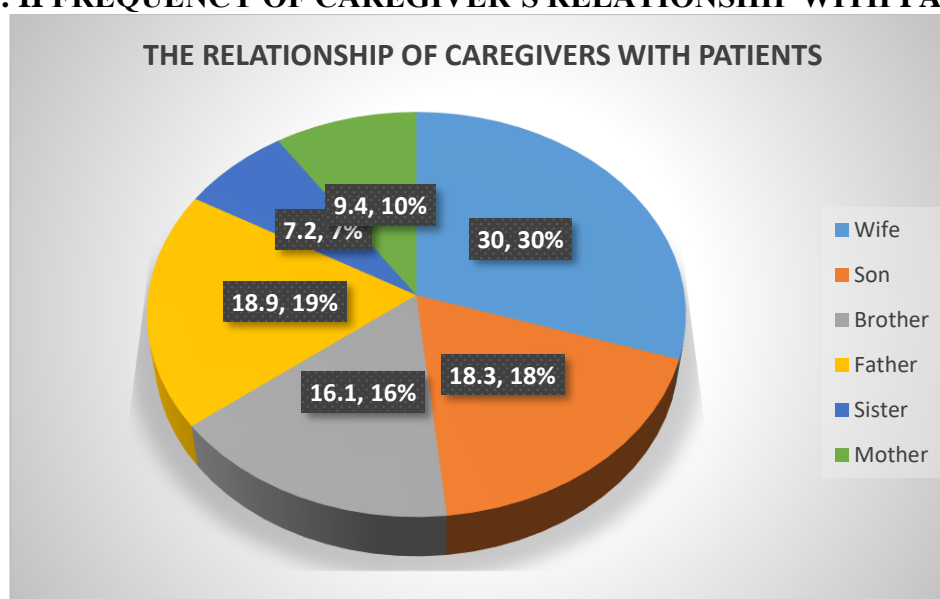
Out of 180 cases, 53 (29.4%) were using multiple substances while 50 (27.8%) were cases of Opioid use and 25 (13.9%) were cannabis users, 19 (10.6%) were alcohol users, 18 (10.0%) were cases of stimulants use and 15 (8.3%) were using crystals. **Figure:1**

Figure: 1 FREQUENCY OF USING DIFFERENT SUBSTANCES



The relationship of caregivers with patients was wife 54 (30.0%), Son 33 (18.3%), Brother 29 (16.1%), Father 34 (18.9%), Sister 13 (7.2%), Mother 17 (9.4%).

Figure: II FREQUENCY OF CAREGIVER'S RELATIONSHIP WITH PATIENTS



The perceived burden by a caregiver was Little or no burden at 20.0%, Mild to moderate burden at 20.0%, moderate to severe burden at 40.0% and severe burden as 20.0% as per Zarit Burden scale. Type of substance used, Relationship of caregiver with the patient, and Gender of the caregiver were significantly related to the perceived burden by the caregiver having a P value of less than 0.05 as shown in **Table II,III, Fig III**.

Table. II STRATIFICATION OF CARE BURDEN WITH TYPE OF SUBSTANCE USED

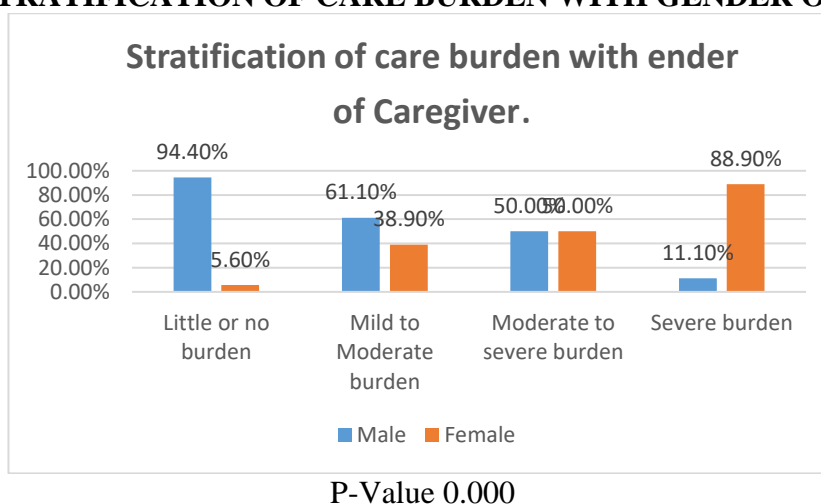
Zarit Burden	Type of Substance						P-Value	
	Opioids	Cannabis	Stimulants	Alcohol	Crystals	Multiple Substances	Total	
Little or no burden	5 13.9%	12 33.3%	4 11.1%	13 36.1%	2 5.6%	0 0.0%	36 100.0%	0.000
Mild to Moderate burden	4 11.1%	6 16.7%	8 22.2%	4 11.1%	5 13.9%	9 25.0%	36 100.0%	

Moderate to severe burden	32 44.4%	3 4.2%	4 5.6%	2 2.8%	6 8.3%	25 34.7%	72 100.0%
Severe burden	9 25.0%	4 11.1%	2 5.6%	0 0.0%	2 5.6%	19 52.8%	36 100.0%
Total	50 27.8%	25 13.9%	18 10.0%	19 10.6%	15 8.3%	53 29.4%	180 100.0%

TABLE: III STRATIFICATION OF CARE BURDEN WITH RELATIONSHIP OF CAREGIVER WITH PATIENT.

Zarit Burden	Relationship of caregiver with patient							P-value
	Wife	Son	Brother	Father	Sister	Mother	Total	
Little or no burden	0 (0.0%)	26 (72.2%)	8 (22.2%)	0 (0.0%)	2 (5.6%)	0 (0.0%)	36 (100.0%)	0.000
Mild to Moderate burden	3 (8.3%)	4 (11.1%)	15 (41.7%)	3 (8.3%)	11 (30.6%)	0 (0.0%)	36 (100.0%)	
Moderate to severe burden	36 (50.0%)	3 (4.2%)	4 (5.6%)	29 (40.3%)	0 (0.0%)	0 (0.0%)	72 (100.0%)	
Severe burden	15 (41.7%)	0 (0.0%)	2 (5.6%)	2 (5.6%)	0 (0.0%)	17 (47.2%)	36 (100.0%)	
Total	54 (30.0%)	33 (18.3%)	29 (16.1%)	34 (18.9%)	13 (7.2%)	17 (9.4%)	180 (100.0%)	

FIGURE: III STRATIFICATION OF CARE BURDEN WITH GENDER OF CAREGIVER.



Discussion

This study measured the burden of caregivers who live with patients with substance disorders. In our study, the number of male caregivers is higher than female caregivers at 53% and 47% respectively, and this in comparison with previous studies^{8,9}. In this study the typical profile of the caregiver was a male, usually the father followed by brother and son, with primary to middle education, with the occupation of the student to jobless. In female caregivers, the wife was more dominant facing the burden followed by the mother and sister usually not formally educated and doing household chores. This is inconsistent with many previous studies^{10,11} and also in contrast with some studies where mother was the prominent caregiver as shown mothers reported higher proportion of severe burden than wives¹². In this study, males made up 54% of the participants, while females made up 46%. The results showed that females felt a greater perceived burden than males did, and the majority of the subjects whose relatives were undergoing treatment at drug de-addiction centers reported feeling a greater burden because they were less social. The burdens were moderate to severe for both genders, but they were heavier for women than for men¹³.

In our study, most of the caregivers 54 (30%) were spouses of patients while 33 (18.3%) were sons, Brother 29 (16.1%), Father 34 (18.9%), Sister 13 (7.2%), Mother 17 (9.4%) while in other studies this ratio of caregivers is different in different studies such as a study showing that the relationship

between caregiver and patient, 52% of the caregivers were mothers of the patients, 25% were fathers, 15 (15%) were spouses, and 8 (8%) were siblings¹⁴. The study included caregivers aged 35 to 50, with a mean age of 45.85 ± 12.92 . Males made up the bulk of caregivers (53%) while females made up just 47% of the caretakers.

In our study, most of caregivers 18% were having Deeni-Taleem followed by illiterate 16%, primary passed 14% and then middle, matriculated and intermediated which is also similar to other studies Lamichhane et al.'s findings, which showed that 46.7% of caregivers were homemakers and 66.7% of caregivers were literate, corroborate these findings, which is consistent with our study where household work was done 48% of caregivers. Our study revealed that most of caregivers were spouses followed by sons, father, mother, brother and sister and this in contradiction with previous studies where maximum numbers of the caretakers were mothers followed by wives, followed by fathers, and other relatives¹⁶. In our study the perceived burden by caregiver was Little or no burden 20.0%, Mild to moderate burden 20.0%, moderate to severe burden 40.0% and severe burden as 20.0% as per Zarit Burden scale which is also reported by some other studies showing burden as 65.3% had moderate burden and 34.7% had severe burden¹², the difference could be due to methodology and research population. We found that caregiver burden was associated neither with Type of substance used, Relationship of Caregiver with patient, Gender of Caregiver.

Conclusion:

Looking at the results of our study, we can conclude that substance dependence is associated with significant caregiver burden. Female caregivers reported higher rates of severe burden. These findings could point the way for further study in this field. Families are intricately involved with drug addiction. Consequently, it is imperative that families and healthcare professionals communicate better, and that families actively participate in the treatment process. Treatment efficacy can be increased by offering services to the entire family and easing their load.

Limitations

As a consequence of the limited sample size and tertiary care facility recruitment, it is not possible to extrapolate the findings to other treatment facilities. The load was measured cross-sectionally and without blinding participants; stresses and life events were not included in the assessment process. Evaluation, emotional expression, and social support were not measured because all data came from a family caregiver and the burden was measured using a scale.

Financial support and sponsorship

None in terms of sponsorship or funding.

Conflicts of interest

No conflicts of interest exist.

References

1. Shyangwa PM, Tripathi BM, Lal R. Family burden in opioid dependence syndrome in the tertiary care center. *J Nepal Med Assoc*, 2008;47:113-9.
2. Lamichhane N, Shyangwa PM, Shakya R. Family burden in substance dependence syndrome. *J Gandaki Med Coll Nepal* 2008;1:57-65.
3. United Nations Office on Drugs and Crime. World Drug Report 2015. Sales No. E.15.XI.6, UNODC. New York: United Nations Publication; 2015.
4. Deb PC, Jindal RB. Drinking in Rural Areas: A Study in Selected Villages of Punjab. Ludhiana: Monograph Submitted to Punjab Agricultural University; 1974.
5. Chavan BS, Arun P, Bhargava R, Singh GP. Prevalence of alcohol and drug dependence in rural and slum population of Chandigarh: A community survey. *Indian J Psychiatry* 2007;49:44-8.
6. Singh A. Drug abuse among rural youth: A sociological study of Punjab. *Int Refereed Res J* 2010;1:15-8.

7. Mattoo SK, Nebhinani N, Kumar BN, Basu D, Kulhara P. Family burden with substance dependence: A study from India. *Indian J Med Res*, 2013;137:704-11.
8. Rehm J, Shield KD. Global Burden of Disease and the Impact of Mental and Addictive Disorders. *Curr Psychiatry Rep*. 2019;21(2):10.
9. Mousavi SB, Higgs P, Piri N, Sadri E, Pourghasem M, Jafarzadeh Fakhari S, et al. Prevalence of Substance Use among Psychotic Patients and Determining Its Strongest Predictor. *Iran J Psychiatry*. 2021;16(2):124–30.
10. Sapna Ganesh "Burden and Quality of Life among Care Givers of Persons with Alcohol Dependence Syndrome - A Hospital based Interventional Study." *IOSR Journal Of Humanities And Social Science (IOSR-JHSS)*. vol. 22 no. 12, 2017, pp. 20-28.
11. Deepa Anand Bapat, Aparna Shankar, A review of caregiver distress in epilepsy in India: Current issues and future directions for research, *Epilepsy & Behavior*, Volume 116, 2021, 107787, ISSN 1525-5050, <https://doi.org/10.1016/j.yebeh.2021.107787>.
12. Sharma A, Sharma A, Gupta S, Thapar S. Study of family burden in substance dependence: A tertiary care hospital-based study. *Indian J Psychiatry*. 2019 Mar-Apr;61(2):131-138. doi: 10.4103/psychiatry.IndianJPsychiatry_123_15. PMID: 30992606; PMCID: PMC6425802.
13. Jan N. A Descriptive Study to Assess the Perceived Social Burden of Substance Abuse among Family Members of Drug Addicted Patients at Drug Deaddiction Centre. *Ind J Holist Nurs*. 2022;13(2):16-24.
14. Selçuk M, Öztürk Hİ, Uygur H, Varsak N, Özbek S, Eren İ. Predictors of caregiver burden in family caregivers of male patients with opioid use disorders. *Psychiatr Clin Psychopharmacol*. 2022;32(1):54-62.
15. Lamichhane N, Shyangwa PM, Shakya R. Family burden in substance dependence syndrome. *J Gandaki Med Coll Nepal*. 2008;1:57–65.
16. Mattoo SK, Ghosh A, Basu A. Substance use and family burden: A narrative review. *Indian J Soc Psychiatry* 2019;35:158-63