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Family burden among caregivers of alcohol dependence: a cross-sectional study

Abstract

Background: Family is the key resource for providing care to patients, including those with alcohol dependence in India. Person with alcohol dependence affects almost every (personal, social, and psychological) aspects of family life. This leads to troubles, difficulty or undesirable procedures which impact on family members and causes gigantic burden on family caregivers. **Aim:** Aim of the study was to assess the level of family burden among the primary caregivers of alcohol dependent patients. **Methods:** A hospital-based study was conducted at a drug de-addiction treatment and training centre in north India. On the basis of purposive sampling technique, 30 alcohol dependent patients were recruited from the outpatient department (OPD) with the availability of primary caregivers. With informed consent from patient and caregiver, 30 caregivers (one for each patient) were included in the study. Assessment for pattern of burden faced by the family caregivers of persons with alcohol dependence was done by using the Family Burden Interview Schedule (FBIS). **Results:** Results showed that 93% caregivers were spouses and most (86.7%) of them were housewives. Every domain of care indicated moderate to severe level of burden. Alcohol dependence was associated with burden in family members. It showed high burden in rural location with low-income families. **Conclusion:** Alcohol dependence adversely affects the patients as well as his caregivers.

Keywords: Spouse. Housewife. Rural. Income.

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INTRODUCTION

Family plays an important role in providing social and financial support to an individual, and helps in dealing with emotional crisis. Family is the key resource in the care; it has been attributed to the Indian tradition of interdependence and the concern of close relatives in adversity, as also to the paucity of mental health professionals.[1] Acute or chronic illnesses influence family burden substantially, evident both in cases of physical as well as mental illnesses.[2] Family has been known as key institution for support and care, especially in Indian context. Role of family becomes much more important here, as in a country with more than 1.3 billion population, there are approximately 5,000 mental health professionals. Because of enormous shortage of mental health establishments and professionals, the community and family have important role to play in mental healthcare of an individual. Prevalence of alcohol use disorders in India is 4.7%.[3]

Substance abuse disorders are two-edged sword that interrupts both the individual as well as his family. "Burden of care" is defined as the presence of problems, difficulties, or adverse effects which affect the life of the household members of the dependent patient.[4] It is also known as the cost that families of patients have to bear in terms of economic hardship, social isolation, and psychological strains, while subjective burden includes caregiver's own perception about his/her mental and physical health.[5] Families of the alcohol dependents face communication problem such as problem solving capacity, low family congeniality, and poor family cohesion.[6,7] It is mainly the spouse of an individual with alcohol dependence that faces major stress. Alcohol abuse is associated with marital dissatisfaction, domestic violence, and marital discord.[8] Poor parenting, childhood abuse, and disregard are present if there is a parent having alcohol dependence in the family.[9]

Illness adversely affects the individual as well as those around in terms of physical, emotional, financial distress, social and occupational dysfunction. This significantly leads to problems, complications, or adverse events on self and others. These difficulties and their results create adverse impact on caregivers that has been described as burden.[4] Burden is largely determined by family environment in terms of coping styles of different family members and their lenience of the patient's deviant behaviour.[10] Even though alcohol abuse is well recognised as a complex biopsychosocial phenomenon, substance dependence is considered as a 'family disease'.[11] Person with alcohol dependence in the family affects almost all aspects of family life, e.g. social and interpersonal relationships, finances and leisure time activities. Substance dependence perpetually intensifies conflicts between families,

destructively affects family members, and increases burdens of the families. Since substance dependence is historically considered as an individual's problem, so challenges of family has been relatively neglected.

Traditionally, the research on families with dependent members has examined the family and the family process almost exclusively as an aetiological entity that affects the subject's substance use.[12] The burden is more often related to disruptive activities of the substance dependent person, and financial difficulties due to loss of income and/or diversion of funds to substance dependence.[13] The families of alcoholics, especially the spouses, have increased risk of stressful life events, medical and psychiatric disorders, and greater use of medical care services.[14-18] Moderately severe objective and subjective burden was reported for families with alcohol dependence.[19] Another study reported severe burden more often than moderate burden on both subjective and objective assessment,[20] and spouses were more tolerant.[21]

Severity of family burden is greatly influenced by sociodemographic variables of the families as well as duration of substance dependence of the patients.[22] Alcohol being the commonest substance for treatment seeking in India,[23] the present investigation aimed to study the pattern of burden borne by the family caregivers of men seeking treatment for alcohol dependence in a de-addiction centre in north India.

MATERIAL AND METHODS

A cross-sectional study was conducted at the State Drug Dependence and Treatment Centre, Institute of Mental Health, Pt. BD Sharma University of Health Sciences (UHS), Rohtak, Haryana, India. It is a multispecialty teaching hospital providing services to a major area of north India. Patients come voluntarily for treatment with family or self-referral, and some of them are referred from other departments of Pt. BD Sharma Post Graduate Institute of Medical Sciences (PGIMS), Rohtak. The institutional research committee approved the study protocol. On the basis of convenience sampling technique, the data collection was made from outpatient department (OPD) between 1st March and 30th June in the year 2016. Written informed consent was acquired from both the patients and the caregivers participating in the study.

Sample was consisted of patients and their caregivers seeking treatment for alcohol dependence. The family caregivers were included in the study who were living with the patients and were indirectly involved in patient care in conditions of general life care (shared kitchen, common expenses, mutual social relations, and household chores, including the care of family members), and directly in terms of his treatment-related assistance or supervision for more than one year. In case of more than one caregiver was available, the most accountable caregiver was included in the study (who was staying together longer and being involved in the care more, as agreed by a consensus among the patient and caregivers).

The patients were males, aged 18 years or more, diagnosed with alcohol dependence according to the World Health Organization's tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10),[24] currently on therapeutic intervention for management. Total duration of illness was between two and five years. Any family member's present major physical/organic illness or mental retardation was the exclusion criteria for the study participation.

Sociodemographic and clinical data of patients and caregivers were collected from the patients, caregivers, and from the record files. Selected participants were interviewed and sociodemographic details were captured with a standard format describing sociodemographic variables, which was designed and standardised at the State Drug Dependence and Treatment Centre, Institute of Mental Health, Pt. BD Sharma UHS, Rohtak.

To know the burden aspects of caregivers, the Family Burden Interview Schedule (FBIS)[25] was administered to assess the extent and pattern of burden on the primary caregiver. It is a semi-structured interview schedule that covers six domains of life, i.e. financial burden, disruption of family routine activities, disruption of family leisure, disruption of family interactions, effect on physical health of others, and effect on mental health of others. There are a total of 24 items, each rated on a three-point scale (mild, moderate, and severe). Inter-rater reliability for all items and the correlational validity are 0.78 and 0.72 respectively. The global subjective burden is assessed by one question at the end.

Statistical analysis

The data were analysed using Statistical Package for the Social Sciences (SPSS) version 20.0 for Windows. Descriptive data were analysed by frequency, percentage, mean, and standard deviation (SD). Pearson correlation was used to understand the association between variables.

RESULTS

Table 1 reveals sociodemographic profile of the participants. Mean age of the individuals with substance dependence was 40.13 years, 96.7% of them were currently living their married life. Fifty per cent of participants had only minimum or no formal education and only ten per cent of them were graduates. 56.7% of the participants were self-employed and most of them (46.7%) were coming from rural background although 33.3% were from urban residential zones. Sixty three per cent of them were from nuclear family and most of the time, they are the breadwinners of the family.

Caregivers are the close family members who are staying with the person with dependence and taking care for the all their needs and requirements in day to day life. Mean age of the caregivers was 38.59 (SD=7.24) years, 93% of them were currently married, and 3.3% were widow. Table 2 explains about caregivers; 93% of them were spouses, only 6.6% of the caregivers were mother or daughters of persons with dependence.

Table 3 shows family burden among the caregivers and in all the six areas, it was found high. In the financial burden, mean score was 6.8 with a highest scoring of 12 that says moderate level of burden; similarly, the disruption of routine family activities was reported to be 6.56, disruption of family leisure was found 5.23 with a highest of eight, and disruption of family interaction was scored 5.2 with a maximum scoring

Table 1: Sociodemographic profile

Variable		Participant (n=30)	Percentage
Age		Mean±SD	40.13±9.56
Marital status	Unmarried	1	3.3
	Married	29	96.7
Education	Illiterate	4	13.3
	Primary	4	13.3
	Middle	7	23.3
	12th	9	30.0
	Graduate	3	10.0
	Higher/professional	3	10.0
Occupation	Never employed	2	6.7
	Currently unemployed	8	26.7
	Fulltime employed	2	6.7
	Part-time employed	1	3.3
	Self-employed	17	56.7
Family type	Joint	11	36.7
	Nuclear	19	63.3
Residence	Urban	10	33.3
	Rural	14	46.7
	Semi-urban	6	20.0

SD: Standard deviation

Table 2: Caregivers relationship with the alcohol dependent patients

Variable		Number	Percentage
Relationship with patient	Wife	28	93.3
	Mother	1	3.3
	Daughter	1	3.3
Caregivers' occupation	Housewife	26	86.7
	Service	2	6.7
	Self-employed	2	6.7

of nine that reveals moderate to severe level of burden in these three domains. Effect of physical health (1.6) and effect on mental health (1.46) also showed mild level of burden. Apart from all the above domains, when we evaluated for the subjective burden of the caregivers, it was at severe level.

Table 4 reveals that duration of illness and the entire group of burden were having positive relationship that explains duration of substance increases the level of burden by the period of time. Findings also showed financial burden was having significant positive correlation with all the sub-domains of burden that reflects presence of financial burden increases all the types of burden among the caregivers or may be vice-versa.

DISCUSSION

In this hospital-based cross-sectional study, 30 cases fulfilling the ICD-10 criteria of "dependence" as well as the other inclusion and exclusion criteria were taken for the study.

Table 3: Family burden of the caregivers

Variables	Level	Mean	SD	Minimum	Maximum
Financial burden	Moderate	6.8	3.11	1	12
Disruption of routine family activities	Moderate	6.56	2.43	0	10
Disruption of family leisure	Severe	5.23	1.77	0	8
Disruption of family interaction	Severe	5.2	1.84	2	9
Effect on physical health of others	Mild	1.6	1.27	0	4
Effect on mental health of others	Mild	1.46	1.38	0	4
Other burden	Mild	0.3	0.53	0	2
Subjective burden	Mild	1.76	0.43	1	2

SD: Standard deviation

Mean age of the persons with alcohol dependence and their caregivers were 40.13 years and 38.59 years respectively which is similar to Indian studies. Mattoo *et al.*[26] in north India found mean age of patients and primary caregivers to be 44.72±8.95 years and 41.17±10.65 years respectively. Another study by Sen *et al.*[22] found maximum patients were coming from 30-49 years age group and maximum caregivers were from age range of 30-39 years.

All the participants in our study were Hindus which can be explained on the basis that geographical religious representation is mainly Hindu followed by Muslims and intake of alcohol is forbidden in Islam. Majority of the patients were married (96%). Seventy three per cent of our patients had received at least middle or higher education and only 13% were illiterate unlike that reported by Malik *et al.*[27] who had found majority of dependent patients to be illiterate (61%) and findings of Sen *et al.*[22] were similar with our findings as they reported 61% of the respondents had minimum primary level of education.

Looking into the family structure, it was found that most of the patients (63%) were from a nuclear family. Our findings were unlike to previous study of Sen *et al.*[22] that found 60% respondents were from joint/extended family and findings of our results were similar to Mattoo *et al.*[26] who found maximum dependent patients (57.5%) from nuclear families. This finding is proving common belief that joint family system protects the individual from substance abuse and other psychiatric morbidities.

In this cultural perspective, most of the time, primary caregivers were spouses. Our study showed 93% of caregivers were spouses which is similar to previous studies by Sen *et al.*[22] as they found 74% caregivers were spouses and Mattoo *et al.*[26] who found 77.5% primary caregivers to be wives of the persons with substance dependence.

In the different areas of family burden, it was found that most of the areas had mild burden followed by moderate and severe burden. Severe burden was found upon the subjective burden of the primary caregivers followed by disruption of routine family activities. Most of the studies done in India have found the primary caregivers to be having moderate to

Table 4: Relationship between total duration of illness and sub-domains of burden

Sub-domains of burden	Routine family activities	Disruption of family leisure	Disruption of family interaction	Effect on physical health of others	Effect on mental health of others	Other burden	Subjective burden	Total duration of illness
Financial burden	0.773**	0.419*	0.466**	0.428*	0.504**	0.411*	0.525**	0.777**
Routine family activities	1	0.370*	0.434*	0.521**	0.574**	0.380*	0.454*	0.750**
Family leisure		1	0.984**	0.271	0.303	0.437*	0.480**	0.666**
Family interaction			1	0.323	0.353	0.516**	0.507**	0.726**
Physical health of others				1	0.959**	0.572**	0.339	0.637**
Mental health of others					1	0.591**	0.359	0.687**
Other burden						1	0.374*	0.629**
Subjective burden							1	0.603**
Total duration of illness								1

**Significant at 0.01 level, *significant at 0.05 level

severe burden, especially in subjective burden,[22] financial areas, disruption of routine activities, family leisure, and family interaction.[26,27]

Thus, it was found that majority of the dependent patients were from the age group of 35-45 years, married, coming from rural background, members of nuclear family with average education, belongs from lower or lower middle socioeconomic class, and most of them having their spouses (housewives) as the primary caregivers. Most of the primary caregivers suffered from moderate to severe family burden, especially in areas such as disruption of routine family activity, recreation, and interaction. Higher subjective burden was also found when the primary caregivers were spouses, patients were from rural areas, having nuclear family type with being illiterate/primary educated. It was also found high if family was from lower socioeconomic group and multiplied if caregivers were financially dependent on others (unemployed/housewife).

Participants in the present study were coming from all segments but mostly they were representing rural and semi-urban areas. The cultural formulation and acceptance of the individuals make family members, especially the wife, accept husband's drinking problem and take the whole responsibility of family on themselves and try to reorganise it.[17] Hence, they are subject to a higher physical and psychological burden as compared to the other caregivers of the family; moderate to severe burden was more in housewife and unemployed group as compared to working caregivers.[22] Family burden was associated with rural location of patients and low socioeconomic status.[26] People living in the rural area have limited work opportunities, and most of them are not highly qualified and do not get high earning jobs; thus, most of them lie in the lower/lower middle socioeconomic group. Poor financial condition and less recourses increase the psychological and financial burden. If any individual develops alcohol dependence and he spends a significant part of earnings in alcohol procuring and/or treatment, that multifold the difficulties and increases the subjective and objective burden of the family. Sub-domains of family burden were having positive relationship with each other similar to previous studies.[26,28] We found positive significant relationship between duration of illness and the level of deferent types of burden which is contrary to previous study[29] that says level of burden decreases among the wives of the alcohol dependents with time. As she understands the patient and develops coping that improves her life satisfaction. Our findings showed that the level of burden increased in all the domains for the family members including wife due the poor role performance and the low social acceptance.

This study was one of the few studies conducted in India, especially Haryana state to evaluate the pattern of family burden among the primary caregivers of dependent patients. The severity of family burden has a temporal association with sociodemographic variables of the families as well as the duration of the substance abuse and dependence of the cases. Hereafter, in the background of these findings, preventive and management strategies must be framed in preferred multidimensional approach.

However, this study had few limitations. It was restricted to a tertiary care medical centre. It may not reflect actual pattern of sociodemographic variables of the alcohol dependent patients and their caregivers. It may not be actually applicable on the severity of family burden extant in the community. The sample size was small and no control group was taken to compare. Also, this being a cross-sectional study, the follow-up of the primary caregivers having severe burden in area of mental health was not done to see if they developed any psychiatric illness in future. Level of motivation of the primary participants was not assessed to find any relation between caregivers' burden and level of motivation. Hence, more number of prospective studies involving larger number of patients, followed up for longer duration need to be conducted for detailed evaluation in this context.

Conclusion

Family burden has been observed very high among the families coming from rural background with low income and it is multiplied for nuclear families with poor earning sources. These findings may narrate some idea for the management and could suggest directions for future research in this area.

AUTHOR CONTRIBUTIONS

SR and BS: Key concept of research. VK: Implementation of research, data collection, and interpretation. BS, PS and RG: Review and content writing.

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