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**Research Paper** 



# Burden of care giving in primary care givers of alcoholic patients

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# **ABSTRACT**

Alcohol dependence is a highly disabling condition associated with high rates of medical and psychiatric co-morbidities. Having a family member with Alcohol Dependence Syndrome (ADS) creates anticipated crisis and alters family patterns in ways that are stressful. Admission of such patients in General Hospital Psychiatry Unit (GHPU) subjects their Primary Care Giver (PCG) to immense stress and burden. Thus, there is a need to study the burden of caregiving, in order to plan timely intervention for the caregivers, as how they cope with this will influence the quality of care they render to the patient. *Objectives:* To assess the burden on primary caregivers of ADS patients. To assess the effect of the sociodemographic profile of PCG on the perceived severity of caregiver burden. **Methodology:** In this study, sixty consecutive PCGs of ADS patients, were interviewed on the 3rd day of inpatient care in a GHPU for assessing their burden of caregiving. The sociodemographic details of the PCGs were collected using a semi-structured proforma. Primary care giver burden was assessed using Burden Assessment Schedule (BAS). Results: Women constituted 83.3% of the PCGs. 86.7% of the PCGs were married men and women of whom 83.3% of them were patients' spouses. Majority of them were from nuclear families (83.3%). 55% of the PCGs experienced severe burden of caregiving. Being illiterate and having no formal education (42.4%) was associated with severe burden. Also, 60.6% of those having a low income experienced severe burden. Conclusions: It is important to address the burden and psychological stress experienced by the PCGs to help improve their state of well-being, and to aid them in better caregiving.

**Keywords:** ADS, Primary care giver, psychological burden.

Alcohol dependence syndrome (ADS) is a highly disabling condition associated with high rates of medical and psychiatric co morbidities. According to WHO, in 2010 the prevalence of ADS in India was 2.1% (males 3.8%, females 0.4%). Alcohol dependence in a member of the family affects almost all aspects of family life.

Primary care giver (PCG) is the person who spends most of his/her time caring for the ill person (more than 36 hrs/week). In case of ADS patients, PCGs are usually their spouses.<sup>2</sup>

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Care giver burden can be objective or subjective.<sup>2</sup> PCGs experience a lot of burden in the form of time and money spent in care giving, chronic stress, and physical or mental ill-health in the process. This can interfere with their care giving ability.<sup>3</sup>

Most PCGs are ill-prepared for their role and provide care with little or no support. 4-6 Identifying the burden on PCGs will help in addressing their problems and finding ways to deal with them. This in turn, will help them provide better care giving. Not many studies on PCG burden of ADS patients have been conducted in India.

# Aim of the Study

To assess burden of caregiving among primary caregivers of patients with alcohol dependence syndrome, admitted in psychiatric inpatient unit in a tertiary care hospital.

# Objectives of the study

- 1. To study the socio-demographic profile of primary caregivers (PCG) of alcohol dependence syndrome (ADS) patients.
- 2. To study the burden of caregiving in PCGs of ADS patients.
- 3. To find correlation between socio-demographic profile of PCGs and the burden of caregiving.

# METHODOLOGY

- 1. Sixty adult caregivers of ADS patients admitted under psychiatry unit in a tertiary care hospital in Raichur, and satisfying inclusion criteria for the study were recruited after taking informed consent.
- 2. Burden Assessment Schedule (BAS)<sup>7</sup> was administered for assessing caregiving burden.
- 3. A specifically designed proforma for studying socio-demographic profile of PCGs were used.

# Inclusion criteria

- 1. Healthy, adult primary caregivers aged between 18 60 years
- 2. PCGs who stayed with patient for at least the past 6 months

#### Exclusion criteria

- 1. Primary caregivers looking after another seriously ill family member
- 2. PCGs suffering from any mental illness themselves

# RESULTS

Distribution according to age, and gender

Age	No. of primary care givers (n=60)	%
18-30	21	35.0
31-40	23	38.3
41-50	14	23.3
51-60	2	3.3

P value=0.586 (not significant)

Gender of PCG	No. of primary care givers (n=60)	%
Male	10	16.7
Female	50	83.3

*P value=0.318 (not significant)* 

Distribution according to locality, and family income

Locality	No. of primary care givers (n=60)	%
Urban	25	41.7
Rural	35	58.3

P value=0.318 (not significant)

Income	No. of primary care givers (n=60)	%
>15000 Rs	31	51.7
<15000 Rs	29	48.3

 $P \ value = 0.035*significant$ 

Distribution according to marital status, and relationship with patient

		2.1
Marital status	No. of primary care givers (n=60)	%
Single	4	6.7
Married	52	86.7
Separated	1	1.7
Widowed	3	5

P value =0.017\*significant

Relationship with patient	No. of primary care givers (n=60)	%
Wife	48	80
Husband	2	3.3
Father	1	1.7
Mother	2	3.3
Son	3	5
Daughter	1	1.7
Brother	1	1.7
Others	2	3.3

P value =<0.001\*\*significant

Distribution according to educational status, and occupational status

Education	No. of primary care givers (n=60)	%
Illiterate	10	16.7
Primary	22	36.7
Secondary	18	30
PUC	9	15
UG	1	1.7

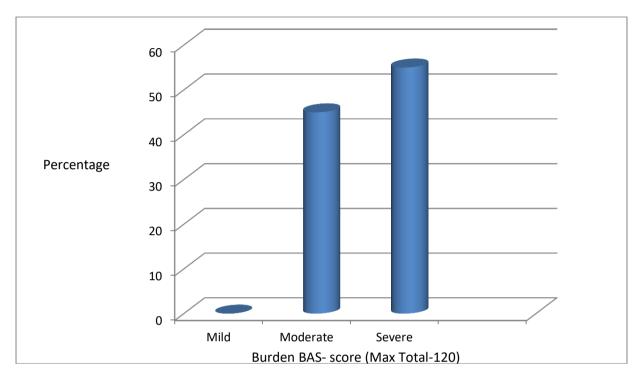
 $P \ value = <0.001**significant$ 

<b>Current occupation of PCG</b>	No. of primary care givers (n=60)	%
Housewife	38	63.3
Self Employed	11	18.3
Agriculture	11	18.3

*P value* =<0.001\*\*significant

Distribution according to BAS score

BAS score (Max total-120)	No. of primary care givers (n=60)	%
0-40 (Mild)	0	0
41-80 (Moderate)	27	45
81-120 (Severe)	33	55



### RESULTS

- Women constituted 83.3% of the sample and 63.3% were house wives. Majority of the PCGs were spouses of patients (83.3%). Most of them were Hindus (86.7%). Many of them lived in rural areas (58.3%).
- 97% of the people with severe burden were married (marital status; p value 2. significant) and among the people with moderate burden 66.7% were married.
- 3. Being illiterate and having no formal education (42.4%) was associated with severe burden.
- 4. 51.9% with moderate burden and 51.5% with severe burden were semiskilled workers.
- 60.6% with severe burden belonged to lower income group.

#### Discussion

- This study showed significant overall burden in all the PCGs (100%), 55% showed severe burden, and rest 45% showed moderate burden.
- In this study, the average PCG is a middle aged woman, usually the wife of the patient, many of them from a lower socio-economic group. These findings were similar to a study done in North India. Unlike our study, this study found no association of burden with educational, or occupational status of caregiver; whereas it found association with rural background of caregiver.
- Most PCGs were in their most productive part of life between the years 31 to 50 years (61.6%). This is similar to an American study, where majority of the caregivers were middle-aged people.9

- 4. Principal role of caregiving was borne by women in this study, which is a similar finding to that of a Spanish study. 10 The same study also noted that majority of the PCGs were under-educated and unemployed, in keeping with our study.
- The caregivers, who were mostly spouses, expressed greater stress as they were also tasked with the role of primary bread winner in most cases. Nevertheless, compared to other family caregivers, the spouses were more tolerant and reported a lower perceived burden.<sup>11</sup>
- The PCGs in this study were mostly housewives (unemployed), while the rest were employed, and majority of both groups had experienced moderate to severe burden. An American study concluded that employed caregivers do not provide significantly less care than do unemployed caregivers, and unemployed caregivers may remain unemployed partly because of care giving responsibilities. 12

# CONCLUSION

- In the Indian set-up, women in their productive part of life, provide majority of the informal caregiving for ADS patients. Usually, they are forced into this role, as a result of them being spouses to the patients.
- Having to give extra care to the patient, and, in addition, being tasked with the role of primary bread-winner in the family, the caregivers are unable to provide as much care to the rest of the family.
- Their burden, both objective and subjective, mostly goes unrecognized. Identifying it and providing the necessary support for them, will improve their mental health, and that of their family.

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#### Conflict of Interest

The authors colorfully declare this paper to bear not conflict of interests.

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