

## Comparison of caregiver's burden in schizophrenia and alcohol dependence syndrome

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### Abstract

**Introduction:** Taking care of a family member at home involves sacrifice of leisure time activities, absenteeism from work, financial difficulties and so on. Presence of such difficulties in the lives of caregivers is collectively termed as "Caregivers' burden". Such burden in psychotic illnesses like schizophrenia is well established. Such studies are scarce, especially from this part of the world, on caregivers of those diagnosed to have Alcohol Dependence Syndrome (ADS). This study aims to compare the different domains of burden in caregivers of ADS with those of schizophrenia.

**Materials and Methods:** Sample consisted of 86 caregivers in total, 43 primary caregivers in two groups – Schizophrenia and Alcohol Dependence Syndrome (ADS). Study period was 18 months. Caregivers who matched the inclusion criteria were interviewed using Burden Assessment Schedule (BAS), after taking informed consent.

**Result:** Caregivers of those with ADS reported moderately higher burden, especially the female spouses. Parents in both groups experienced moderate levels of burden. Female caregivers of ADS group and male caregivers of those with schizophrenia scored higher in BAS. Highest burden was seen in the domains – "Physical & mental health of the caregiver", "Patient's behavior" and "Support of Patient".

**Discussion:** Significant burden is present in the lives of caregivers of schizophrenia as well as alcohol dependence syndrome. Multiple directives to ease this burden such as community rehabilitation programs, group therapy advocating healthier coping strategies should be thought about. Cross cultural studies in this direction would be useful.

**Keywords:** Caregiver, Caregiver's Burden, Alcohol Dependence, Schizophrenia, Burden Assessment Schedule.

### Introduction

Chronic mental illnesses are an enduring stressor on the family members who care for the unsound. In India, where the system of joint families still exists, the primary caregiver is expected to meet all the deficiencies of the sick relative. It may take a toll on his daily routine and also on his physical and mental health. They may also have to confront the stigma associated with it. Added difficulties are compromise of personal freedom, sacrifice of leisure time activities, financial difficulties, turbulence in relationships, lack of social support, coping up with frustration, feelings of helplessness, loneliness, and weakness and so on. Patient's unpredictable behavior adds to the crisis. These difficulties faced by a caregiver in the process of caregiving are collectively termed "family burden or caregivers' burden".<sup>(1)</sup>

The way caregivers handle the burden of care and their reactions to the deviant behavior of the sick, differs from family to family. The psychological distress perceived by the caregiver is multifactorial depending upon his/her personality, severity of symptoms, extent of social support, financial resources etc.<sup>(2)</sup> The prognosis of the condition invariably depends on the attitude of the family members towards the sick member, sometimes referred to as "Expressed Emotions" (EE). High levels of EE are associated with higher levels of burden, resulting in poor prognosis of the condition.<sup>(3)</sup> and so are financial difficulties,<sup>(2)</sup> limited coping resources and patient's aberrant behaviors.<sup>(4,5,6)</sup>

Caregivers' burden became a topic of interest since mid-twentieth century and most of the earlier studies were concerning schizophrenia. By now the huge burden associated with caring for a family member with psychotic condition is well established.<sup>(3,7,8,9)</sup> Substance dependence is considered a

"family disease"<sup>(10)</sup> as it impairs family functioning and dynamics. Ill effects of having a family member with alcohol dependence is comparable to chronic medical and mental illnesses.<sup>(11,12,13)</sup> Interpersonal conflicts and violence are also not uncommon.

Caregivers' burden in alcohol dependence has not been closely studied as in schizophrenia, where severe burden has been already established. With the changing beliefs, cultures and priorities of life, also breaking off from traditional joint family system into nuclear setups, it would be interesting to closely observe the different domains of caregivers' burden and to compare such burden in schizophrenia and alcohol dependence.

This study aims to compare the degree of caregivers' burden in ADS with those of long standing schizophrenia and to compare the different domains of caregivers' burden in each study group.

### Materials and Methods

Clearance from the ethical committee of the institution was obtained before the start of the study. This is a cross-sectional study in which 43 consecutive caregivers, each of schizophrenia and ADS meeting the inclusion criteria, attending the outpatient department, were interviewed with Burden Assessment Schedule (BAS). The scale was translated to Malayalam and back to English by 2 individuals to ensure reliability. Informed consent was taken from each caregiver after verbally explaining the nature of the study. A detailed proforma was used to gather socio-demographic

variables like age, gender, relation to patient, education, occupation, income and marital status.

**Patient inclusion criteria:**

- All patients meeting ICD-10 criteria for schizophrenia.
- Duration of Schizophrenia should be at least one year.
- All patients of alcohol dependence syndrome diagnosed under ICD-10 criteria.

**Patient exclusion criteria:**

- Patients having concomitant mental retardation.
- Patients having severe medical illnesses including those with psychotic symptoms due to organic basis.
- Co morbid alcohol dependence with schizophrenia.
- Patients living alone.

**Caregiver inclusion criteria:**

- Age not less than 18 years.
- Caregiver primarily involved in looking after the patient.

**Caregiver exclusion criteria:**

- Caregiver taking care of more than one patient with mental illness or one with severe medical illness.
- Caregiver themselves having a history of mental illness or under treatment for a severe medical illness.

For the purpose of this study, the degree of burden was scored as mild (BAS score 40-70), moderate (71-100) and severe (101-120).

Descriptive statistics such as mean and standard deviation were calculated. Z-test for difference between means were used wherever applicable.

**Results**

Majority of caregivers for people with schizophrenia were males (n=26) and for ADS were females (n=34). Majority of caregivers in schizophrenia group were in the age group 31-50, followed by 51-60 while in ADS, majority were between 21-40, followed by 41-50. Near total sample in both the groups were Hindus. Majority in both groups had attained either elementary or high school education. Most of the caregivers in both groups were either farmers, daily wage labourers or petty shop owners. There were no significant differences between the monthly incomes of primary caregivers in both the groups. Majority of caregivers in both the groups were married and were spouses of the patient and almost all of them were staying with the patient and their children in a nuclear set up.

**Table 1: Educational status of caregivers**

Education	ADS	Schizophrenia	Total
Illiterate	5	5	10
Elementary/Up to 7 <sup>th</sup> std.	17	15	32
High school	15	14	29
Pre-university	2	8	10
Graduate	3	0	3
Post graduate	1	1	2
<b>Total</b>	<b>43</b>	<b>43</b>	<b>86</b>

**Table 2: Marital status of caregivers**

Marital Status	ADS	Schizophrenia	Total
Single	0	3	3
Married	37	37	74
Divorced	1	1	2
Widowed	4	1	5
Separated	1	1	2
<b>Total</b>	<b>43</b>	<b>43</b>	<b>86</b>

**Table 3: Relationship of caregiver to the patient**

Relation to the patient	ADS	Schizophrenia	Total
Children	2	7	9
Parents	8	12	20
Siblings	4	1	5
Spouses	29	23	52
<b>Total</b>	<b>43</b>	<b>43</b>	<b>86</b>

**Comparison of Caregivers' burden**

Caregivers in both the groups, Schizophrenia and ADS, suffered moderate burden. However, the degree of burden in caregivers of ADS was slightly higher than in Schizophrenia.

**Table 4: Caregivers' burden in schizophrenia and ADS**

Total score	Schizophrenia	ADS	p value
Mean	83.4	88.33	0.05
SD	11.44	12.63	

In the Schizophrenia group, male caregivers reported higher burden when compared to their female counterparts. In the ADS group, female spouses formed the vast majority. They reported significantly higher levels of burden when compared to male caregivers.

Parents in both the groups reported comparable, moderate levels of burden. In the ADS group, spouses reported significantly higher levels of burden when compared with parents. Mean of BAS scores of spouses in ADS group corresponded to severe caregivers' burden.

**Table 5: Caregivers' burden in males and females**

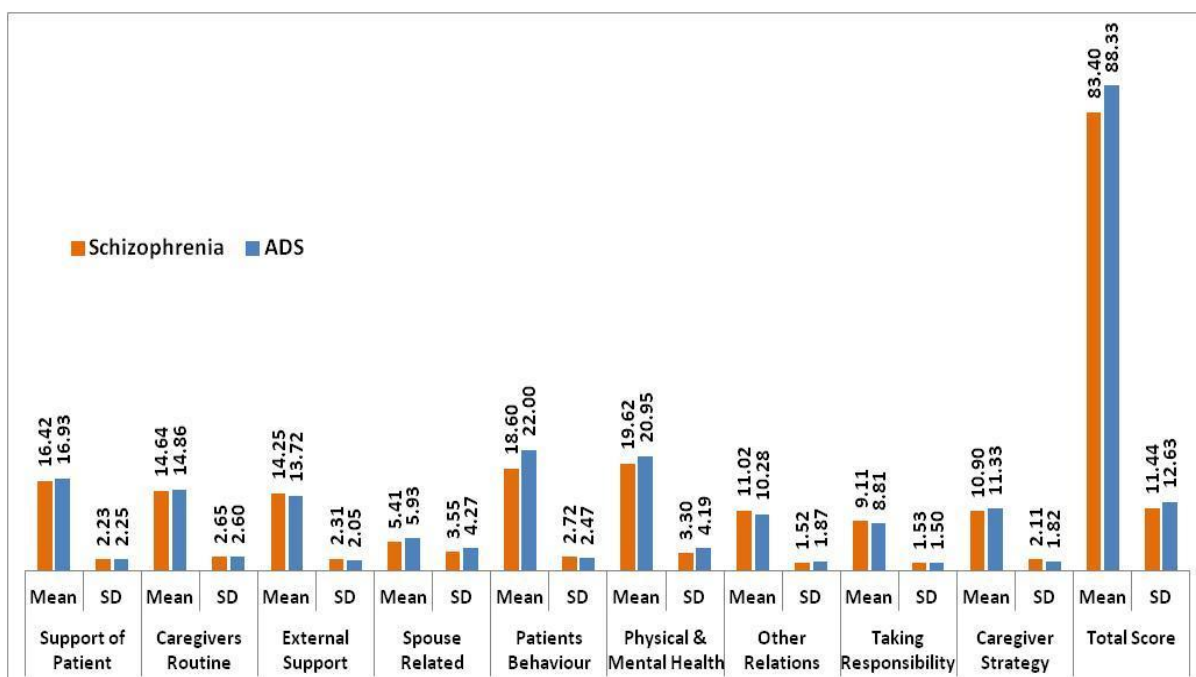
Total Score	Schizophrenia		ADS		p value
	Mean	SD	Mean	SD	
Male	85.27	10.99	75.56	12.46	<0.001
Female	80.53	11.85	91.71	10.45	<0.001
p value	0.05		<0.001		

**Table 6: Caregivers' burden in parents and spouses**

Total Score	Schizophrenia		ADS		p value
	Mean	SD	Mean	SD	
Parent	83.08	13.00	86.88	10.30	0.13
Spouse	85.43	10.06	93.17	8.70	<0.001
p value	0.35		<0.001		

Both the groups reported highest levels of burden in the domains "Physical and Mental health of the caregiver", "Patient's behaviour" and "Support of patient" (Fig. 1).

The least burden in both the groups were reported in the domain – "Spouse related". The degree of burden was comparable between both the groups in all the domains, except: 1) In the domain, "Patient's behaviour", the caregivers of those with Alcohol dependence reported significantly higher level of burden when compared to the Schizophrenia group, 2) In the domain, "Other relations", the caregivers of Schizophrenia group reported moderately higher levels of burden than the caregivers of ADS group.



**Fig. 1: Domains of caregivers burden**

**Discussion**

Significant levels of caregiver burden in schizophrenia has been well established in other studies and our study is at par with the earlier studies. Slightly higher degree of caregivers' burden in ADS is a new finding in this study.

In rural parts of India, like the location of this study, the beliefs on the origin of psychotic illnesses are still complex. Most of the community blame it on supernatural powers and few identifies it early to be a psychiatric illness. This is evident in an OPD setting here, where most of the psychotic patients would have been taken to a faith healer by their relatives before bringing him to a medical care facility. However, at some point through the course of illness, the relatives understand the nature of psychosis and the behavioural and perceptual disturbances associated with it. This is not the same with relatives of those with Alcohol

dependence. Here, the patient is considered responsible for his/her behaviour as it is commonly perceived as avoidable. He/ she is considered as the reason for their socio-occupational dysfunction rather than the illness. In this study, majority of caregivers of those with Alcohol dependence were female spouses. They reported burden much more than their male counterparts and caregivers who were parents. This is not surprising considering the usually timid nature of the rural Indian women. Most of those who were diagnosed to have ADS were spending more than what they earned. This forced their wives, who already had the responsibility of the household, to go for daily wage labour works in order to support themselves and their family. Majority of them were also victims of physical and mental abuse.

Male caregivers in schizophrenia reported higher levels of burden than their female counterparts. Probably explained by the fact that the entire household comes to

a standstill when the ladies at home develops behavioural and perceptual disturbances. We had only 9 females diagnosed to have ADS. They imposed moderate levels of burden on their respective caregivers probably owing to similar reasons.

Moderate levels of burden were seen in all the domains of Caregivers' burden in both the groups. However, highest levels of burden were seen in the domains related to patient's behaviour and physical & mental health of the caregiver. The role of patient's disturbed behaviour in increasing caregivers' burden and consequences of intense caregiving on caregiver's health were reported in earlier studies.<sup>(3,10,14,15,16)</sup>

Caregivers of Schizophrenia reported moderately higher burden than those of Alcohol dependence in the domain "Other relations". This is not surprising considering the stigma associated with mental illnesses. Sufferers from schizophrenia usually restrain themselves from family gatherings or gets restricted by family members fearing the consequences of any unexpected behaviour.

Caregivers of Alcohol dependence syndrome reported higher burden in the domain "Patient's behaviour", probably due to the fact that their disruptive behaviours mostly follows heavy drinking episodes which are considered avoidable and comes unexpected.

This study re-established the existence of high degrees of caregiver's burden in psychotic illness. However, this has been a topic of interest since last few decades. This study calls for attention towards the urgent need to design appropriate family interventions and legal policies to reduce the severity of burden in caring for those with Alcohol dependence, especially the female spouses.

The relevance of family interventional programmes in the outcome of a mental illness has been well established. This study further encourages research in this direction, especially in Alcohol dependence syndrome. Considering our cultural context, it should aim to reduce the stigma associated with mental illnesses, to strengthen support from extended family and society and in organising community rehabilitation programmes. The current scenario also demands a need for a change from conventional family role models and encourage doctrine of autonomy and self-control. Continuous psychological inputs should be given to the caregivers, according to the changing pattern of behaviours. Cross-cultural studies would be helpful in devising appropriate coping strategies for the caregivers.

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