

Characteristics of Quality of Life, Burden and Expressed Emotions in Primary Care Givers of Patients Having Alcohol Dependence Syndrome and Schizophrenia: A Descriptive Study

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Abstract

Objective: To access the quality of life, burden, and expressed emotions of primary caregivers of patients diagnosed with alcohol dependence syndrome and schizophrenia.

Methods: This study is a cross sectional study on primary caregivers of all patients with Alcohol Dependence Syndrome and Schizophrenia attending the Outpatient Department of Psychiatry in CMCH, Bhopal fulfilling the inclusion and exclusion criteria were included in study. Calculated sample size for this study was 40 in each group. A semi structured questionnaire was used. For assessing burden, burden assessment scale (BAS) was used, for assessing quality of life of care giver (WHO-QOL BREF) was used and FEICS was applied and expressed emotions were assessed.

Results: The mean for BAS scores in schizophrenia cases has found to be 48.46 in case of wife was caregiver, 47.67 in case of husband was caregiver and 42.52 in case of parents were caregiver. WHO QOL Domain 1 scores was found across the caregiver ($p=0.396$) while in case of ADS in the ADS group the WHO QOL Domain 1 scores was 63.10. Domain 2 scores was found across the caregiver ($p=0.396$), while for ADS group the WHO QOL Domain 2 scores was 58.03. Domain 3 scores was found across the caregiver ($p=0.313$), for ADS group the WHO QOL Domain 3 scores was 50.58. Domain 4 scores was found across the caregiver ($p=0.912$), for ADS WHO QOL Domain 4 scores was 64.2. The mean for BAS scores in ADS cases is 46.68 in the case of the wife being a caregiver and 36.67 in the case of parents being caregivers. The mean for perceived criticism scores in ADS cases is 18.90 in the case of the wife being a caregiver and 16.67 in the case of the parents being a caregiver. The mean for perceived criticism scores in ADS cases is 18.90 in the case of the wife being a caregiver and 16.67 in the case of the parents being a caregiver.

Conclusion: There is impairment in the quality of life of both groups of caregivers. Regarding burden among caregivers of schizophrenia patients husband suffered the maximum burden while in the case of ADS wife suffered the maximum burden. Caregivers with a high burden of care are more likely to have depression, anxiety, and poor quality of life. Among domains of quality of life, the social relationship domain has the lowest mean score for the caregiver of ADS patients while it is lowest in physical health for caregiver of schizophrenic patients.

Therefore, priority interventions to improve social deficits, physical health, and comprehensive interventions that could address psychiatric symptoms among people with schizophrenia and ADS are essential to improve the quality of life of caregivers, also decreases burden on caregiver.

Keywords: Burden Assessment Scale (BAS), Quality of Life Of Caregiver (WHO-QOL BREF), FEICS, Alcohol use disorder (AUD).

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Introduction

Family is the basic unit of society and is extensively involved in the well-being of kith and kin. With the increase in the incidence of mental illness across the world, there is a proportionate rise in the burden of care among caregivers of those who are mentally ill. Apart from providing help with activities of daily living, families also provide emotional, social, and financial support to individuals with mental illness. Chronic mental illnesses in one family member may paralyze the life of others in the family and restrict their avenues for socialization, employment, and leisure. [1]

Schizophrenia is one of the most common serious mental disorders. Although Schizophrenia is discussed as if it is a single disease, it comprises a group of disorders with heterogeneous etiology. Thus, it is sometimes referred to as a syndrome, as the group of schizophrenias. Schizophrenia is a clinical syndrome of variable and profoundly disruptive psychopathology that includes changes in perception, emotion, cognition, thinking, and behavior. Schizophrenia usually begins before the age of 25 years, persists throughout life, and affects people of all social classes. [2] Both patients and their families often suffer from poor care and social ostracism because of widespread ignorance about the disorder. [3,4]

When a person engages in a pattern of drinking that puts him at risk for adverse health occurrences, alcohol use becomes problematic. This course is continuing in an

increasing trend in developing countries as a result of the current globalization. Alcohol use disorder (AUD) is a group of behavioral and physical symptoms that can include withdrawal, tolerance, and craving. Often considered a family disease; AUD also takes a burden on the lives of family members. [5,6] The increase in unpredictable and unreliable behavior in individuals with AUD leads to stress and strain on caregivers. This leads to imperfect coping and increases their vulnerability to mental illness. Family bears the brunt of domestic violence of all forms, that is, physical, verbal, and sexual, poverty, low marital satisfaction, and embarrassment are other impediments to the well-being of caregivers. This ultimately pushes the family to destitution. [7]

Materials and Methods

Study Population: The universe of the study was the primary caregivers of patients with Alcohol Dependence Syndrome and Schizophrenia.

Study Design: The study was a cross-sectional study involving the primary caregivers of the patients with Alcohol Dependence Syndrome and those with Schizophrenia attending the Outpatient Department of Psychiatry in CMCH, Bhopal.

Study Population: The primary caregivers of the patients who have been diagnosed with Alcohol Dependence Syndrome and those with Schizophrenia who attend the Outpatient Department of Psychiatry in

CMCH, Bhopal.

Sample Size and Collection: - 40 patients each, with Alcohol Dependence Syndrome and those with Schizophrenia and their respective caregivers attending the Outpatient Department of Psychiatry in CMCH, Bhopal were included.

Inclusion Criteria for Patients

- Patients between the age group of 18 to 60 years, attending the Outpatient Department of Psychiatry in CMCH, Bhopal diagnosed as a case of alcohol dependence syndrome and Schizophrenia as per ICD 10 (DCR).
- Not in a state of acute intoxication or severe withdrawal state.
- Availability of caregiver for interview.
- Willing to give consent to be a part of the study.

Inclusion Criteria for Primary Caregivers

- The primary caregiver of patients with Alcohol Dependence Syndrome and Schizophrenia diagnosed as per the ICD 10 – DCR criteria, who is above the age of 18 years and who meet the following criteria:
- Is a parent, spouse, sibling, or offspring of the patient.
- Living with the patient for at least one year.
- Who has most frequently been collateral in patients' treatment and is willing to give consent to be a part of the study.

Sampling Method: - The patients along with their caregivers meeting the inclusion and exclusion criteria were included in the study.

Exclusion Criteria for Primary Caregivers

- Not willing to give consent for the study.
- Presence of any syndromal psychiatric illness that may interfere with the

assessment procedure

- Presence of any other chronic medical illness that may interfere with the assessment procedure.

Consent: Written consent was obtained from the relatives of patients after explaining them the nature and purpose of the study. They were assured that confidentiality would be strictly maintained. The option to withdraw from the study was always open.

Burden Assessment Schedule A structured instrument with forty items. Each item is rated on a three- point scale (not at all, to some extent, and very much). This schedule measures both subjective as well as objective burdens adequately. Face, content, and criterion validity has been established by authors during the development of an instrument.

World Health Organization Brief Quality of Life Questionnaire (Who-Qol Bref) The WHOQOL-BREF item scale was used to study the quality of life. The World Health Organization Quality of Life Brief Scale Contains 26 items, which constitute domains- **physical health, psychological health, social relationship, and environment.** In the current study, a 0-100 scale was used for the assessing QOL of caregivers. The instrument has good interred and intra-rater reliability. Domain scores produced by the WHO-QOL-BREF have been shown to correlate at around 0.9 with the WHOQOL 100 domain scores, and hence provide an excellent alternative to the assessment of domain profile using WHO-QOL-100.

Methodology

The subjects for the study were chosen from the primary caregivers of the patients attending the Outpatient Department of Psychiatry in CMCH, Bhopal, 40 in each group. The caregivers of the patients diagnosed with Alcohol Dependence Syndrome and Schizophrenia as per ICD 10 DCR criteria attending the Outpatient

Department of Psychiatry in CMCH, Bhopal were assessed. Then, after applying inclusion and exclusion criteria, suitable subjects were shortlisted.

The selected patients and caregivers were explained about the study and the assessment procedure. For both the patient and the caregiver taken up for the study, the **semi-structured data collection Performa** was used to record information regarding the socio-demographic profile of both patient and the caregiver and the clinical profile of the patient.

On caregivers of patients with Alcohol Dependence Syndrome WHOQOL-BREF

and BAS was applied, and quality of life and burden was assessed respectively. On patients with Alcohol Dependence Syndrome, FEICS was applied and expressed emotions was assessed.

On caregivers of patients with Schizophrenia WHOQOL-BREF and BAS was applied, and quality of life and burden was assessed. On patients with Schizophrenia, FEICS was applied and expressed emotions was assessed. Comparisons was made among different categories.

Observation Chart

Table 1: Association between caregiver and study groups

Caregiver	Group				Chi-Square	P
	Schizophrenia		ADS			
Wife	13	32.50%	31	77.50%	19.360	0.000
Husband	9	22.50%	0	0.00%		
Parents	18	45.00%	9	22.50%		
Total	40	100.00%	40	100.00%		

Table 2: Comparison of mean burden assessment scores in caregivers of all cases

		N	Mean	SD	F	P
Burden assessment score	Wife	44	47.2	5.7	9.810	0.000
	Husband	9	47.67	7.4		
	Parents	27	40.52	7.29		
	Total	80	45	7.15		

Table 3: Comparison of mean who qol domains scores in caregivers of all cases

		N	Mean	SD	F	P
WHO QOL Domain 1	Wife	44	58.41	11.47	1.690	0.190
	Husband	9	52.89	10.19		
	Parents	27	54.3	10.32		
	Total	80	56.4	11.06		
WHO QOL Domain 2	Wife	44	56.32	12.29	0.060	0.940
	Husband	9	57.67	6.87		
	Parents	27	56.41	7.59		
	Total	80	56.5	10.3		
WHO QOL Domain 3	Wife	44	50.36	18.07	3.440	0.030
	Husband	9	62.67	6.8		
	Parents	27	58	12.96		
	Total	80	54.33	16.09		
WHO QOL Domain 4	Wife	44	63.89	16.37	0.500	0.610
	Husband	9	65.89	17.07		
	Parents	27	67.67	13.43		
	Total	80	65.39	15.42		

Table: 4 Comparison of mean perceived criticism and emotional involvement scores in caregivers

Group		N	Mean	SD	t	p
FEICS (Perceived Criticism)	Schizophrenia	40	20.38	3.75	2.409	0.018
	ADS	40	18.4	3.59		
FEICS (Emotional Over Involvement)	Schizophrenia	40	21.43	2.63	2.660	0.009
	ADS	40	19.33	4.24		

Results

In our study we found that the mean age of patients in the ADS group was 30.83 ± 7.76 years whereas in the schizophrenia group the mean age of patients was 30.63 ± 8.83 years ($SD=8.26$). In schizophrenia cases the mean for perceived criticism scores in more than 40 BAS group has found to be 20.54 while in the ≤ 40 BAS group the perceived criticism scores was 20.13. In schizophrenia cases the mean for emotional over involvement scores in more than 40 BAS group has found to be 20.63 while in the less than 40 BAS group the emotional over involvement scores was 22.63. The mean for BAS scores in schizophrenia cases has found to be 48.46 in case of wife was caregiver, 47.67 in case of husband was caregiver and 42.52 in case of parents were caregiver. WHO QOL Domain 1 scores was found across the caregiver ($p=0.396$) while in case of ADS in the ADS group the WHO QOL Domain 1 scores was 63.10. Domain 2 scores was found across the caregiver ($p=0.396$), while for ADS group the WHO QOL Domain 2 scores was 58.03. Domain 3 scores was found across the caregiver ($p=0.313$), for ADS group the WHO QOL Domain 3 scores was 50.58. Domain 4 scores was found across the caregiver ($p=0.912$), for ADS WHO QOL Domain 4 scores was 64.2. The mean for BAS scores in ADS cases is 46.68 in the case of the wife being a caregiver and 36.67 in the case of parents being caregivers. The mean for perceived criticism scores in ADS cases is 18.90 in the case of the wife being a caregiver and 16.67 in the case of the parents being a caregiver. The mean for perceived criticism scores in ADS cases is 18.90 in the case of the wife being a

caregiver and 16.67 in the case of the parents being a caregiver.

There is impairment in the quality of life of both groups of caregivers. Regarding burden among caregivers of schizophrenia patients husband suffered the maximum burden while in the case of ADS wife suffered the maximum burden. Caregivers with a high burden of care are more likely to have depression, anxiety, and poor quality of life. Among domains of quality of life, the social relationship domain has the lowest mean score for the caregiver of ADS patients while it is lowest in physical health for caregiver of schizophrenic patients.

Statistical Analysis:

The data obtained during the study were entered into the excel sheet and analyzed using the Statistical Package for Social Sciences (SPSS) version 21.0. Pearson chi-square (for categorical variables) and independent t-test (for continuous data) were used to compare the sociodemographic and clinical characteristics of the two groups. To compare the burden scores on BAS and quality of scores on WHO-QOL BREF in two groups independent t-test was used. To compare the burden scores on BAS and expressed emotions scores in two groups independent t-test was used.

Discussion

This study aims to examine the sociodemographic factors, the impact on the families of patients with schizophrenia and alcohol dependence. The family impact of schizophrenia has been the subject of numerous researches in the past. In contrast

to schizophrenia, however, there is a dearth of literature describing the hardship on the family of patients who are alcohol addicted. [8,9]

We assessed the quality of life among caregivers of the patient with schizophrenia and found that in domain 1 i.e., physical health, the mean was highest among husbands than other caregivers. A similar finding was described as the caregiver who has a relationship of caregivers as parents have a 1.5 times chance to have a lower quality of life compared to caregivers who have other relationships such as spouse. [10,11]

For burden among caregivers, we found that the husband has the highest mean which suggests that the husband suffered the highest burden than other family members. Caregivers' relationship with the patient was another significant predictor of the burden of care. That is being a spouse, sibling, son or daughter, and other relatives to the patients increases family caregivers' burden as compared to being parents. Providing care for people diagnosed with schizophrenia can be stressful for their caregivers. Caring for their relatives with schizophrenia may result in feelings of burden or strain for caregivers. Indian families have been typically described as often believing in causes like supernatural forces and help sought from magico-religious healers was observed. [12,13]

The negative effects of caregiver burden in schizophrenia have been described as the development of depressive and anxiety disorders, suffering of body pains, a decrease in vitality, and restrictions in the physical role and social function. Longer duration of illness and caregiving become stressors for caregivers. Social isolation may result, leading to increased stress and making them vulnerable to depression and anxiety. Moreover, caregivers are flooded with patient and family responsibilities and are loaded with caregiving duties and persistent worries about their patients. This

will result in withdrawal from society and freedom of activity, leading to poor quality of life. [14]

For expressed emotion, we found that in caregivers of schizophrenia patients, the total mean of emotional involvement is found to be higher as compared to perceived criticism. In perceived criticism, EE is higher in the husband than in other caregivers. In emotional involvement, EE is found to be higher among parents. Similar results were found in other studies. High EE is proven to be a significant family stressor resulting from relationship problems among caregivers and patients with mental illness which is also a strong predictor of schizophrenia course. Hence, family-focused psychosocial interventions primarily emphasize reducing the levels of EE of caregivers by enhancing their knowledge about the illness. [15]

Our study suggests that caregivers of patients with ADS are likely to have a poor quality of life and that burden of care can be predicted by the environmental domain of quality of life. This can be explained by the fact that ADS in one family member, especially when he/she is the sole earner, may cause countless problems for the caregivers. Some of these are occupational dysfunction, premature and compulsory withdrawal from jobs, solitude, changes in responsibilities, disruption of routine and social activities, and financial burden. All these can lead to poor quality of life among caregivers. Similar results were found in other studies.

Among caregivers, it was found that the burden of care is maximum for the wife than for another member. This can be explained by female/wife caregivers differing in their assessment and in coping with stressors, and the lack of social support framework that provides for their needs. The sociocultural expectations imposed on them to adopt a caregiving role despite their difficulties add fuel to the fire. [16-19]

The spouses were dependent on the patients

for various reasons like finance and child-rearing. Moreover, the societal view of being separated from their husbands suffering from alcoholism will cause them more mental trauma and hence most of them chose to live with the patients even though they experienced a significant burden. Frequent arguments, verbal abuse, and physical abuse of family members under the influence of alcohol caused significant disruption in the communication between family members, disruption in their leisure activity, and significant adverse impact on the caregiver's physical and mental health.

Expressed emotion is especially relevant in the Indian cultural context, where patients have longer and more enduring contact with family. Family members play an important role as caregivers during the process of treatment & rehabilitation. Family members also play an important role in bringing the patient in contact with the mental health care professional and providing financial as well as psycho-social support to the patient during the process of treatment & rehabilitation. Our study found that expressed emotion (emotional involvement) mean is higher as compared to the perceived component. Families are likely to offer much EOI because they believe that when they get over-involved, they could help win the loyalty of the patient thus he/she may stop drinking, which instead becomes counterproductive and induces chronic stress.

Conclusion

- In this study, among domains of quality of life, the social relationship domain has the lowest mean score for the caregiver of ADS patients while it is lowest in physical health for caregiver of schizophrenic patients. Therefore, priority interventions to improve social deficits, physical health, and comprehensive interventions that could address psychiatric symptoms among people with schizophrenia and ADS are

essential to improve the quality of life of caregivers.

- Regarding burden among caregivers of schizophrenia patient's husband suffered the maximum burden while in the case of ADS wife suffered the maximum burden. Caregivers with a high burden of care are more likely to have depression, anxiety, and poor quality of life. They should be provided adequate financial, educational, and psychosocial support. In addition, family interventions such as psychoeducation and provision of support groups for caregivers of schizophrenia patients as well as caregivers of ADS need to be initiated to reduce their burden. It is important to alleviate the burden of the caregivers which in turn will lead to better treatment effectiveness.
- There is impairment in the quality of life of both groups of caregivers. The severity of the addiction is directly positively correlated to the level of burden in the caregivers of both groups. The severity of the addiction is negatively correlated to the quality of life in both groups of caregivers.

Limitations of Study

- Although we have used validated scales of assessment, our study has some limitations, such as its small sample size, being a hospital-based study, participant recruitment from a single centre, and being a cross-sectional study, a cause-effect relationship cannot be established.
- We have not taken into consideration the supporting network that our patients and their caregivers might have, which may influence the burden of care.
- Further multicentric cohort studies with large sample sizes are required to obtain further insights into this subject.

Declarations:

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Availability of data and material:

Department of Psychiatry Chirayu Medical College and Hospital, Bhopal.

Code availability: Not applicable.

Consent to participate: Consent taken.

Ethical Consideration: There are no ethical conflicts related to this study.

Consent for publication: Consent taken.

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