Original Research Article

QUALITY OF LIFE AND BURDEN IN CAREGIVERS OF MALE ALCOHOL USE DISORDER PATIENTS AND ITS CORRELATION WITH SEVERITY OF ALCOHOL USE

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A B S T R A C T

Background: Alcohol use disorder (AUD) affects not merely the patient, but also his family. It can have a devastating effect on the entire family system; leading to burden and poor quality of life among family members. **Aims:** To assess the caregiver's burden and the quality of life (QoL) in relatives of patients with Alcohol use disorder in male patients, also to determine the correlation of burden and QoL in caregivers of patients of Alcohol use disorder (AUD) with severity of alcohol use.

Materials and Methods: A cross-sectional, hospital-based study includes 80 caregivers of male AUD patients. Burden and quality of life in their caregiver were assessed with the Burden Assessment Scheduled (BAS) and the World Health Organization Quality of Life Assessment-Brief (WHOQOL-BREF) questionnaire. Severity of alcohol dependence was measured using Short Alcohol Dependence Data (SADD) Questionnaire.

Results: This study had that all domains of Quality of life had a statistically significant difference with the severity of dependence (P<0.05). There was a statistically significant difference in components of BAS with the severity of dependence. The correlation between BAS and QoL had shown that, some domains of QoL had significant correlation with components of BAS.

Conclusion: This study shows that, the QoL and BAS depends on the severity of dependence. There was a significant correlation of QoL with some components of BAS.

Keywords: Alcohol dependence, Quality of life, Burden assessment schedule, DSM – 5, Caregivers.

INTRODUCTION

Substance use disorders constitute one of the most serious public health problems. It is well recognized as a complex biopsychosocial phenomenon and considered as a "family disease."[1] Alcohol dependence is a disorder which affects not merely the patients but also the members of the dependent's family or the caregivers. The adverse effects of substance dependence include physical, emotional, social, and financial distress; this leads to problems, difficulties, or adverse events in the lives of the patient and their family members and the adverse impact has been described as burden.[2] Hoenig and Hamilton in 1966 attempted to distinguish between objective and subjective burden. The objective burden includes the effects of the illness on finances and routine of the family, while the subjective burden is defined as the extent to which family members are affected by objective burden.[3]

In India, the family is the key source in providing the care of patients including those with mental illness and substance dependence.[4] Studies have reported significant burden on the caregivers of substance-dependent patients.[5,6,7] A study by Lamichhane N, et al done at Nepal had shown wives as primary care providers to their alcoholic husbands5and bear a considerable amount of burden in taking care.

The quality of marital life among wives of patients with alcohol dependence syndrome (ADS) was poorer when compared to wives of patients with the bipolar affective disorder.[8] Quality of life of the caregivers may improve with abstinence from alcohol by the ADS patients,[9] another study found that significant correlation between quality of life, depression, and stress of caregivers.[10]

There are many studies dealing with consequences of alcohol consumption on the physical and mental health of the patient and problems faced by the family due to alcohol use of the patient. But less attention is given to the assessment of burden and quality of life in caregivers of patients having ADS using standardized measures. In this background, the present study was planned to assess burden and QOL of caregivers of Alcohol Dependence Syndrome patients and compared with severity of alcohol dependence in the tertiary care hospital in South India.

MATERIALS AND METHODS

This is a cross-sectional study conducted at Adichunchannagiri institute of medical sciences, B.G Nagara. Karnataka. India. The Study will be done during the period from October 2018 to September 2019 after getting approval from ethics committee of the institute. Subjects will be approached to collect data with their consent.

The National Mental Health Survey of India 2015–16 found the prevalence of AUDs to be 9% in adult men. Considering this, our sample size was calculated. Hence, Z= 95% confidence interval=1.96. The prevalence was taken p=9%. The allowable error (d) is taken 7% and the estimated sample was 71 male alcohol use disorder patients and their caregivers. Caregivers should be staying together for at least one-year taking responsibilities of caring of AUD patients for most of the time. The samples were inducted based on consecutive sampling method. Patients 18 years and above, diagnosed to have alcohol Use Disorder as per DSM-5 criteria Caregivers 18 years and above, who were without any psychiatric disorder as per DSM - 5 criteria and patients and caregivers willing to give consent were included in to the study. Patients with any other dependence other than alcohol or nicotine and Patients and caregivers who are physically too ill to participate in the study were excluded from the study.

A Semi-structured proforma was used to determine Socio-demographic characteristics and psychiatric disorders of the participants. Burden Assessment Schedule (BAS) containing 40 questions rated on a three-point scale marked from 1 to 3. The responses are 'not at all', 'to some extent' or 'very much'. The scale has nine factorial configurations, spouse related, physical and mental health, external support, caregiver's routines, support of the patient, taking responsibility, other relations, patient's behavior and caregiver's strategy. The minimum total score of burden in BAS is 40 and the maximum score in 120. In this study the severity of burden was categorized into 4 groups, in the following way, 40-60 – Minimum burden, 61- 80 – Moderate burden,81-100 – Severe burden, and 101- 120 – Very severe burden.

The WHOQOL-BREF is a self-reported questionnaire containing 26 items that make up the four domains of physical health (seven items), psychological health (six items), social relationships (Three items), and environment (eight items); there were also two single questions regarding the overall perception of QOL and health. Questions were scored on a series of 5-point scales with higher scores denoting better QOL. The validity and reliability of the scale have been found to be satisfactory with alpha coefficient of internal reliability of the WHOQOL-BREF was reported to be 0.87.[12]

Severity of alcohol dependence was measured using Short Alcohol Dependence Data (SADD) Questionnaire. It has 15 items, each item has four choices of response, and they are: never, sometimes, often and nearly always. Each response carries a score of 0, 1, 2 and 3 respectively. Total score of all these items is calculated and severity is graded as follows 0- No dependence,1-9 – Low dependence,10-28 - Moderate dependence, 30 and above – Severe dependence

The data was analyzed using the Statistical package for Social services (ver 20). Mean and the standard deviation was calculated for all the continuous variables. The student unpaired t-test used to know the differences between two independent variables. Karl Pearson's correlation was used for computing correlations of parametric variables. The significance level was set at P < 0.05.

RESULTS

This study had shown that, about 41.3% of the cases were aged between 31 – 40 years and 55.0% were educated up to higher secondary school. About 70% of the cases were farmers and 85% were married. About 60% belonged to nuclear family and 70.0% of the caregivers were spouses. [Table 1]

The mean QOL values for physical, psychological, social and environmental domains were higher for the patients with lower dependence than higher dependence. This difference was statistically

significant in physical, psychological and environmental domains between the severity of dependence. [Table 2]

The mean values of spouse, CG routine, other responsibility and patient behavior components of Burden assessment scheduled were higher for the patients with high dependence. While, physical/ mental, External support, Support for PT, responsibility and CG strategy were higher for the patients with moderate dependence. These difference in components of Burden assessment were statistically significant between the severity of dependence. [Table 3]

Physical domain of QoL had significant correlation with Spouse, External support, Oher responsibility, Patient behavior, CG strategy and total components of burden assessment schedule. The psychological domain had significant correlation with Spouse, CG routine, Support of PT, Other responsibility and total scores of Burden assessment schedule.

The social domain had significant correlation with physical/ mental, CG routine, Other responsibility, Patient behavior, CG strategy and total scores of BAS. The environmental domain had significant correlation with Physical, mental, external support, CG routine, support of PT, responsibility, other responsibility, patient behavior, CG strategy and total score components BAS.

Age had significant correlation with Physical and psychological domains of QoL, duration with psychological, social and environmental, Caregivers age with social and environmental domains of QoL. [Table 4]

Table 1: Sociodemographic features

Characteristics		Frequency	Percent
Age group	21 – 30 years	19	23.8
	31 – 40 years	33	41.3
	41 – 50 years	24	30.0
	51 – 60 years	4	5.0
Education	Primary and middle school	16	20.0
	Higher secondary school	44	55.0
	Graduate	20	25.0
Occupation	Unemployed	4	5.0
	Farmer	56	70.0
	Skilled worker	4	5.0
	Unskilled worker	8	10.0
	Professional	8	10.0
Marital status	Married	68	85.0
	Unmarried	8	10.0
	Separated/ Divorce	4	5.0
Type of family	Nuclear	48	60.0
	Extended	20	25.0
	Joint	12	15.0
Place	Rural	72	90.0
	Urban	8	10.0
Caregiver	Spouse	56	70.0
	Parents	16	20.0
	Siblings	8	10.0

Table 2: Severity of dependence and QOL (Above): higher the severity of dependence lowers the quality of life

QOL	Severity - Dependence	N	Mean	Std Div	LB	UB	F	P value
Physical	Low	4	69.00	0.000	69.00	69.00	29.800	0.000, Sig
	Medium	32	61.75	11.219	57.71	65.79		
	High	44	46.45	8.312	43.93	48.98		
	Total	80	53.70	12.423	50.94	56.46		
Psychological	Low	4	69.00	0.0000	69.00	69.00	11.632	0.000, Sig
	Medium	32	58.50	10.919	54.56	62.44		
	High	44	49.55	10.017	46.50	52.59		
	Total	80	54.10	11.491	51.54	56.66		
Social	Low	4	81.00	0.0000	81.00	81.00	7.659	0.010, Sig
	Medium	32	58.63	13.382	53.80	63.45		
	High	44	50.55	18.368	44.96	56.13		
	Total	80	55.30	17.447	51.42	59.18		
Environmental	Low	4	75.00	0.0000	75.00	75.00	4.156	0.019, Sig
	Medium	32	56.25	13.928	51.23	61.27		
	High	44	55.91	12.430	52.13	59.69		
	Total	80	57.00	13.324	54.03	59.97		

Table 3: Severity of dependence and Burden Assessment scheduled

Burden	Severity - Dependence	N	Mean	Std Div	LB	UB	F	P value
Spouse	Low	4	7.00	0.000	7.00	7.00	8.395	0.001, Sig
	Medium	32	4.00	4.158	2.50	5.50		
	High	44	7.73	3.908	6.54	8.92		
	Total	80	6.20	4.288	5.25	7.15		
Physical/Mental	Low	4	8.00	0.000	8.00	8.00	4.227	0.018, Sig
	Medium	32	12.38	3.129	11.25	13.50		
	High	44	11.18	3.075	10.25	12.12		
	Total	80	11.50	3.158	10.80	12.20		
Ext support	Low	4	7.00	0.000	7.00	7.00	1.584	0.212, Sig
	Medium	32	9.63	2.959	8.56	10.69		
	High	44	9.45	2.774	8.61	10.30		
	Total	80	9.40	2.818	8.77	10.03		
CG Routine	Low	4	10.00	0.000	10.00	10.00	3.204	0.046, Sig
	Medium	32	9.38	2.587	8.44	10.31		
	High	44	10.73	2.161	10.07	11.38		
	Total	80	10.15	2.366	9.62	10.68		
Support of PT	Low	4	6.00	0.000	6.00	6.00	6.259	0.003, Sig
	Medium	32	9.50	1.760	8.87	10.13		
	High	44	8.55	2.215	7.87	9.22		
	Total	80	8.80	2.215	8.33	9.27		
Responsibility	Low	4	8.00	0.000	8.00	8.00	9.801	0.000, Sig
	Medium	32	9.38	1.519	8.83	9.92		
	High	44	7.73	1.730	7.20	8.25		
	Total	80	8.40	1.783	8.00	8.80		
Other Resp	Low	4	3.00	0.000	3.00	3.00	5.619	0.005, Sig
	Medium	32	5.63	2.379	4.77	6.48		
	High	44	6.45	1.946	5.86	7.05		
	Total	80	5.95	2.216	5.46	6.44		
Pt Behaviour	Low	4	4.00	0.000	4.00	4.00	4.900	0.010, Sig
	Medium	32	8.25	2.995	7.17	9.33		
	High	44	8.27	2.481	7.52	9.03		
	Total	80	8.05	2.783	7.43	8.67		
CG Strategy	Low	4	5.00	0.000	5.00	5.00	7.657	0.001, Sig
	Medium	32	8.13	1.862	7.45	8.80		
	High	44	8.00	1.294	7.61	8.39		
	Total	80	7.90	1.650	7.53	8.27		
Total	Low	4	53.00	0.000	53.00	53.00	8.149	0.001, Sig
	Medium	32	77.25	13.984	72.21	82.29		
	High	44	77.36	10.291	74.23	80.49		
	Total	80	76.10	12.760	73.26	78.94		

Table 4: Correlations between QOL and BAS

	Physical	Psychological	Social	Environmental
Spouse	-0.383** 0.00	-.398** .000	-.061 .591	-.024 .833
Physical/ Mental	-.018 .874	.008 .941	-.570** .000	-.403** .000
Ext support	-.426** .000	-.009 .936	-.080 .482	-.542** .000
CG Routine	-.486** .000	-.313** .005	-.522** .000	-.450** .000
Support of PT	-.041 .720	.351** .001	-.030 .793	-.236* .035
Responsibility	-.116 .307	-.143 .206	-.201 .074	-.569** .000
Other Resp	-.396** .000	-.221* .049	-.717** .000	-.389** .000
Pt Behavior	-.304** .006	-.193 .086	-.680** .000	-.594** .000
CG Strategy	-.355** .001	-.210 .061	-.532** .000	-.371** .001
Total	-.538** .000	-.274* .014	-.674** .000	-.665** .000
Age	-.274* .014	-.367** .001	-.078 .494	-.013 .911
Onset	-.143 .206	-.087 .442	.093 .410	.215 .055
Duration	-.156 .167	-.361** .001	-.236* .035	-.320** .004

C-Age	-.044 .698	-.183 .105	-.247* .027	-.435** .000

DISCUSSION

Substance abuse as such and more so alcohol abuse impacts the families through considerable burden of care. The research in this regard has lot of significance not only as a potential to alter the outcome of the patients but also in formulating interventions to help caregivers cope with the substance dependence.[13] Current study included 80 caregivers out of which majority were (56) wives while,[16] were either of the parents and 8 siblings. In our sample these caregivers had to deal with 76 male individuals who had medium to high dependence and only 4 with low dependence.

The literature evidence points at increased burden or comparable burden in caregivers of alcohol dependent individuals even when compared to other psychosocial disabilities like bipolar disorders,[14] epilepsy,[15] and Schizophrenia.[16] There is elaborate research on different facets of caregiver burden even in the western context with some researchers using Caregiver Burden Inventory in qualitatively describing the negative impact.[17] In Indian context, the burden of caregivers of alcohol dependent patients is seen to be more often assessed with Family Burden Interview Schedule (FBIS).[13,15,16] We have used Burden Assessment Scale (BAS) one other useful tool pertaining to this field and used in a previous study.18 Majority of the caregivers were females; they were predominantly spouses of the patient. In a country like us, there is a cultural belief that men should be the breadwinner of the family and probably this would have shifted the responsibility of caring for the sick to the women.[13] A western study also reported that the female affected family members exceed male caregivers particularly partners were more than mothers and sisters. They also had significant male affected family members such as father, uncle and brothers who are slightly different from our study sample.

In our study, the caregivers experienced significant burden in various domains due to patient's alcoholism. It is probably because the spouses were dependent on the patients for various reasons like finance and child-rearing. Moreover, the societal views of being separated from the 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 significant burden. More than 3/4 of our caregivers were wives having children of varying age.

Similar studies looking at both burden and quality of life in caregivers of alcohol dependent patients have reported significant burden and poor quality of life.[19,20] In addition we have tried to correlate these two parameters with severity of dependence and have found positive correlation with burden and negative correlation with quality of life. Logically also more burden in terms of physical and mental health, routines and external support would result in reduced quality of life accordingly in the domains like physical, psychological and social. Increasing age of patients more so affected the physical and psychological health domains while the increasing age of caregivers and increased duration of dependence appeared to be impacting the social and environmental domains. The sub components of burden had positive correlation with particularly social relationships and environmental domains of quality of life indicating that they take precedence over physical and psychological health aspects. In rural south Indian setting with social stigma playing a major role, social relation of the family member might not be good as others because of the behavior of patient in the society.

The various domains such as financial burden, disruption of routine family activities, disruption of family interaction, effect on the physical health of others, and effect on the mental health of others were also positively correlated with highly significant correlation coefficient value.

This is possibly due to the fact that, in most of the families, patients were the sole earning member of the family and majority of the caregivers were unemployed. Also, money was deviated for procuring the substance and treatment expenditures.[16] 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 caregiver physical and mental health.

The limitations of this study could be its smaller sample size and having done in a rural setup might make it less generalizable. Nevertheless, the inputs from this study can be made use of in devising interventional strategies for family members as done in an interventional study.[21] Keeping in mind the brewing caregiver burden and insights from studies illustrating other psychiatric comorbidity amongst the spouses who happen to be the primary caregivers, its high time the deaddiction programs need to be comprehensive to include steps to alleviate caregiver burden as well.[22,23]

CONCLUSION

This study had shown a significant correlation between the severity of dependence and QoL scores & BAS. The correlation between the QoL and BAS had shown significance in some domains of BAS indicating that the syndrome affects the family life and also quality of life of whole family.

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