

IMPACT OF FAMILY STIGMA AND CAREGIVER BURDEN ON QUALITY OF LIFE AMONG WIVES OF PATIENTS WITH ALCOHOL AND OPIOID USE DISORDER

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Received: 28 August 2021, Revised and Accepted: 09 October 2021

ABSTRACT

Objectives: Spouses of patients with alcohol use disorder (AUD) and opioid use disorder (OUD) suffer from burden, stigma, and low quality of life (QoL). The present study assessed the impact of stigma and burden on QoL among wives of patients with AUD and OUD.

Methods: 90 wives of in-patients with severe AUD (n=54) and OUD (n=36) as per DSM-5 were assessed using socio-demographic pro forma, WHO QoL Bref Hindi, Hindi family stigma scale and Family Burden Interview Schedule. Statistical Package for the Social Sciences Inc., Chicago, IL, version 25.0 for Windows was used for analysis. Appropriate statistical tests including Kolmogorov-Smirnov tests of normality, Mann-Whitney test, and Kruskal-Wallis test were used. To see the relationship between two variables Pearson Correlation coefficient was calculated. All statistical tests were two-sided and performed at a significance level of $\alpha=.05$.

Results: Majority of the wives were more than 30 years old, literate and belonged to rural areas. Higher financial burden reduced overall QoL ($p=0.001^{**}$), satisfaction with physical health (0.006^{**}), psychological health ($p=0.032^*$), and environment ($p=0.001^{**}$). There was a negative correlation of satisfaction with environment with disruption of family interaction ($p=0.003^{**}$), burden on mental health ($p=0.001^{**}$), overall burden ($p=0.000^{**}$), and discrimination ($p=0.032^*$).

Conclusion: QoL of spouses of patients with AUD and OUD reduces significantly due to stigma and burden. Enhancing QoL of spouses should be a part of management of AUD and OUD.

Keywords: Alcohol, Burden, Opioid, Quality of life, Stigma, Wives.

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INTRODUCTION

Substance use disorders (SUD) cause significant burden and stigma to patients as well as their family members. It leads to a significant reduction in quality of life (QoL) of patients and their spouses [1]. Caregiver burden is the strain or load borne by a person caring for an elderly, chronically ill or disabled family member [2]. Multiple studies have demonstrated very high caregiver burden among spouses of patients with SUD [3]. The burden could be financial, psychological, physical, disruption in family routine, interaction, leisure activities, etc. [3]. Wives of persons with SUD face stigma and discrimination which causes avoidance, reduced life opportunities, guilt, social exclusion, reduced self-esteem, hopelessness, treatment gap, poor compliance, etc. [4]. To the best of our knowledge of the authors, no study from India has assessed the impact of caregiver burden and family stigma on QoL. Studies from elsewhere have reported that family stigma reduced QoL, anticipated stigma had direct negative impact on psychological and physical health, and caregiver burden significantly reduces QoL of spouses of patients with SUD [5-7]. The present study was planned to assess the impact of burden and family stigma on QoL among spouses of patients with SUD.

METHODS

It was a descriptive, cross-sectional study conducted from January to October 2019 at the 50 bedded Model De-addiction Centre of Department of Psychiatry, Government Medical College and Hospital in North India. 90 wives between 18 and 65 years, who were the primary caregivers and gave written informed consent, were included. The wives of only those patients were included who fulfilled criteria for severe dependence and required admission. Wives who were suffering from SUD and psychiatric illness (as assessed clinically using DSM-5

criteria) were excluded from the study. Wives were excluded if they or their patient suffered from any other medical or surgical disorder which would lead to a reduction in QoL or is stigmatizing such as HIV, hepatitis, leprosy, tuberculosis, and physical handicap. Wives of patients with dual diagnosis or multiple SUD except nicotine and caffeine were also excluded from the study. Wives who refused to participate in the study or whose husband's prohibited them from doing so were excluded. Those who agreed were then assessed using the following tools.

Socio-demographic and clinical pro forma

A semi-structured pro forma was prepared to record the sociodemographic and clinical variables.

WHO QoL Bref Hindi version

WHO QoL Bref Hindi version was used to measure subjective health related QoL. The 26 items are further divided into four domains (satisfaction with physical health, psychological health, social relations, and environment) and two general questions related to satisfaction with overall QoL and overall health. This is one of the most commonly used scales to measure QoL and has excellent reliability and validity [8].

Stigma scale

The Hindi self-stigma scale previously standardized in India was used for the study. It has 28 self-rated items with each item rated from 0 to 2 (agree, neither agree nor disagree and disagree). The 28 items are divided into three domains namely discrimination (13 items), disclosure (ten items), and positive aspects of stigma (five items). Higher score on each domain and the total scale score denotes higher stigma. The scale has been previously standardized in India on a variety of patients with mental illnesses and was found to have good internal consistency and test-retest reliability [9].

Family burden interview schedule

It has been developed in India and consists of 24 items grouped into six areas, namely, financial burden, disruption of family activities, family leisure, family interaction, and effect on physical and mental health of others. This is a semi-structured interview schedule with each item rated on a 0-2 scale. The total score could range from 0 to 48 and the scale has good reliability and validity in India [10].

Ethical considerations

The study was approved by the institutional ethics committee. Written informed consent was obtained from the wives and assent was obtained from the patients. The Indian Council of Medical Research ethical guidelines on biomedical research on human participants were adhered to.

Statistical analysis

(Statistical Package for the Social Sciences Inc., Chicago, IL, version 25.0 for Windows) was used for analysis. Quantitative variables were estimated with measures of central location and dispersion. Kolmogorov-Smirnov tests of normality were used to check normality of data. For skewed data, Mann-Whitney test was applied for two groups and Kruskal-Wallis test for more than two groups. Proportions were compared using Chi-square or Fisher's exact test which ever was applicable. To see the relationship between two variables Pearson Correlation coefficient was calculated. All statistical tests were two-sided and performed at a significance level of $\alpha=0.05$.

RESULTS

The sociodemographic data of the sample and its distribution according to QoL are shown in Table 1. Out of 90 wives, 63 (70%) were more than 30yrs old and literate but only 21 (23%) were working. Approximately 60% belonged to rural areas, living in nuclear family and were wives of patients with alcohol use disorder (AUD). Only 53% of the families had monthly income more than 10,000 and 53% of the wives had their husbands admitted in the past for treatment. The mean duration of SUD was 145.60±104.92 (range 16-444) months.

The distribution of sociodemographic profile with QoL showed that housewives had significantly better satisfaction with psychological health ($p=0.016^*$) on WHO QoL Bref as compared to working women. Other sociodemographic variables were not found to be significant.

There was a significant negative correlation between discrimination and Satisfaction with environment ($p=0.032^*$) as shown in Table 2.

Financial burden was significantly negatively correlated with overall QoL ($p=0.001^{**}$), satisfaction with physical health (0.006^{**}), with psychological health ($p=0.032^*$), and with environment ($p=0.001^{**}$) as shown in Table 3. Satisfaction with physical health was significantly negatively correlated with disruption in family activities ($p=0.051^*$). Satisfaction with environment was significantly negatively correlated with disruption of family interaction ($p=0.003^{**}$), effect on mental health ($p=0.001^{**}$), and overall burden of care ($p=0.000^{**}$).

DISCUSSION

To the best of our knowledge, this is the first Indian effort to study the impact of family-stigma and burden on QoL of wives of patients with SUD. The scores on WHO QoL Bref were in the range of 50-60 in the first three domains (satisfaction with physical health, psychological health, and social relations) and nearly 40 in domain four (satisfaction with environment). The scores in our study are comparable to a previous study among family members of patients with heroin dependence which found that QoL as measured using WHO QoL Bref was between 50 and 60 on all domains and were much lesser than family members of the control group [7]. Although we did not take any control group in the present study, the scores in the present study were much lower than the healthy general population in a previous study [11]. Some other studies from India and elsewhere have also found that the QoL among

Table 1: Distribution of QoL according to sociodemographic data (n=90)

Socio demographic variables	Category (n)	WHO QoL Bref Q1		WHO QoL Bref Q2		Satisfaction with Physical Health		Satisfaction with Psychological Health		Social Relationships		Satisfaction with environment	
		Mean±SD	p-value	Mean±SD	p-value	Mean±SD	p-value	Mean±SD	p-value	Mean±SD	p-value	Mean±SD	p-value
Age	18-30 (27) >30 (63)	2.11±0.60 2.62±0.92	0.112	3.33±1.00 3.14±1.24	0.670	59.67±15.79 55.67±14.99	0.780	52.89±20.18 53.05±12.08	0.697	49.89±25.65 61.62±21.97	0.371	43.00±17.91 41.14±14.79	0.853
Education	Illiterate (27) Literate (63)	2.67±1.00 2.38±0.80	0.695	3.22±1.30 3.19±1.12	0.887	58.33±21.16 56.24±12.21	0.352	55.67±17.64 51.86±13.41	0.582	61.11±24.56 56.81±23.28	0.422	44.44±19.61 40.52±13.77	0.677
Occupation	Working (21) Housewife (69)	2.00±1.00 2.61±0.78	0.185	3.29±1.50 3.17±1.07	0.797	53.43±4.72 57.91±16.99	0.338	43.14±4.14 56.00±15.35	0.016*	58.86±7.27 57.87±26.51	0.709	49.29±12.32 39.39±15.85	0.067
Family	<5000 (42) >10,000 (48)	2.57±0.94 2.38±0.81	0.653	3.29±1.14 3.13±1.20	0.679	58.50±19.46 55.44±10.31	0.468	57.21±16.97 49.31±11.45	0.214	59.36±23.20 57.00±24.15	0.514	43.36±18.44 40.25±12.84	0.815
Income	Nuclear (54) Joint (36)	2.33±0.69 2.67±1.07	0.492	3.50±0.99 2.75±1.29	0.096	56.56±14.67 57.33±16.31	0.663	53.22±16.66 52.67±11.50	0.716	53.44±20.99 65.08±25.79	0.191	43.17±17.76 39.50±11.69	0.697
Family Type	Rural (57) Urban (33)	2.47±0.90 2.45±0.82	0.609	3.05±1.13 3.45±1.21	0.356	57.26±15.64 56.18±14.75	0.877	52.68±14.91 53.55±14.73	0.879	58.21±27.24 57.91±15.57	0.744	39.74±14.95 45.09±16.56	0.291
Locality	Yes (48) No (42)	2.50±0.63 2.43±1.09	0.458	3.00±1.21 3.43±1.09	0.286	51.56±14.09 62.93±14.27	0.063	48.06±12.85 58.64±14.84	0.064	58.19±24.56 58.00±22.76	0.817	38.38±13.41 45.50±17.30	0.288
Admission in past	AUD (54) OUD (36)	2.39±0.78 2.58±1.00	0.697	3.22±1.06 3.17±1.34	0.947	57.67±15.73 55.67±14.63	0.777	53.61±15.99 52.08±12.83	0.915	57.89±17.15 58.42±31.31	0.881	43.11±16.58 39.58±14.14	0.589

QoL: Quality of life, AUD: Alcohol use disorder, OUD: Opioid use disorder

Table 2: Correlation of QoL with Stigma (Pearson Correlations)

WHO QoL Bref	Discrimination Total	Disclosure Total	Positive Aspects Total	Total Stigma Scale
WHO QoL Bref Q1				
Pearson Correlation	-0.024	-0.077	-0.082	-0.076
p-value	0.899	0.685	0.665	0.689
WHO QoL Bref Q2				
Pearson Correlation	0.061	0.167	0.157	0.165
p-value	0.748	0.379	0.408	0.385
Satisfaction with Physical health				
Pearson Correlation	-0.117	-0.219	-0.028	-0.200
p-value	0.538	0.245	0.883	0.289
Satisfaction with Psychological health				
Pearson Correlation	-0.155	-0.067	0.121	-0.095
p-value	0.412	0.726	0.525	0.616
Social relationships				
Pearson Correlation	0.148	0.020	0.036	0.093
p-value	0.435	0.916	0.852	0.626
Satisfaction with environment				
Pearson Correlation	-0.392*	-0.124	-0.144	-0.299
p-value	0.032*	0.515	0.447	0.108

QoL: Quality of life

Table 3: Correlation of QoL with Burden (Pearson Correlation)

WHO QoL Bref	Financial Burden	Disruption of family activities	Disruption of family leisure	Disruption of family interaction	Burden on physical health	Burden on mental health	Overall Burden
WHO QoL Bref Q1							
Pearson Correlation	-0.561**	-0.108	-0.144	-0.187	0.150	-0.082	-0.234
p-value	0.001**	0.572	0.448	0.323	0.429	0.666	0.212
WHO QoL Bref Q2							
Pearson Correlation	-0.292	-0.224	0.091	0.130	-0.082	0.017	-0.046
p-value	0.118	0.233	0.633	0.492	0.667	0.930	0.809
Satisfaction with Physical health							
Pearson Correlation	-0.488**	-0.359*	-0.148	-0.190	-0.162	-0.254	-0.342
p-value	0.006**	0.051*	0.436	0.315	0.391	0.175	0.064
Satisfaction with Psychological health							
Pearson Correlation	-0.392*	-0.331	-0.102	-0.185	0.032	-0.163	-0.245
p-value	0.032*	0.074	0.592	0.329	0.865	0.391	0.193
Social relationships							
Pearson Correlation	-0.086	-0.018	-0.049	0.120	0.144	-0.320	-0.045
p-value	0.653	0.925	0.798	0.527	0.446	0.085	0.813
Satisfaction with environment							
Pearson Correlation	-0.251**	-0.293	-0.310	-0.071**	-0.145	-0.217**	-0.291***
p-value	0.001**	0.093	0.096	0.003**	0.068	0.001**	0.000**

wives of patients with AUD and OUD is very low [12- 15]. QoL was found to be lowest in the domain four of WHO QoL Bref (satisfaction with environment). This domain measures QoL in terms of satisfaction with safety, finances, leisure activities and access to health-care services. The safety of women may be compromised due to high levels of domestic violence at the hands of persons with SUD [16]. The present study also found high financial burden and burden on disruption of leisure activities, which could have led to low QoL on domain four. The partner of a person with SUD may have interference in their tasks, interpersonal relations, social relations, poor mental and physical health, social isolation, and poor family conditions [1]. All these factors in combination negatively impact the QoL of spouses of patients with AUD and OUD.

Our study shows that increasing discrimination stigma had a significant negative impact on QoL with respect to satisfaction with environment. Although, the impact of family-stigma on QoL of wives has not been studied in India, two studies from elsewhere have reported that family stigma reduced QoL among caregivers and anticipated stigma had direct negative impact on psychological and physical health of caregivers of Substance dependent patients [5,6]. Wives of patients with substance use disorders suffer stigma in the form of blame, shame and contamination. They are often blamed for the initiation and continuation of substance use among their husbands and suffer

shame because of the same. This leads to a significant impact on their emotional health which can worsen QoL [4].

Higher burden of caregiving (mainly financial burden) was significantly negatively correlated with QoL, which is supported by previous study [7]. Financial burden is due to money spent on substance use, loss of productivity, expenses related to treatment of SUD, debts, etc. Over the course of illness, SUD negatively impacts the physical health, psychological health, marital relations, and lead to psychiatric morbidity among wives. All these factors may lead to significant reductions in QoL.

Although the study was conducted using stringent methodology and standardized scales in local language, a few limitations should be noted while interpreting the results. Small sample size, cross sectional nature, inclusion of wives of only in-patients and patients with severe SUD were the major limitations of the study. All the variables including QoL, stigma, and burden are dynamic in nature and affected by multiple variables, some of which might have been missed, thus limiting the results further.

CONCLUSION

Wives of patients with SUD face significant burden and stigma which reduces their QoL significantly. Thus, management wives along with

the patients of SUD should also be part of de-addiction treatment protocol.

AUTHORS' CONTRIBUTIONS

All the authors have made considerable contributions in the research work and formulation of the manuscript.

CONFLICTS OF INTERESTS

The authors confirm that this article has no conflict of interests.

AUTHORS FUNDING

No funding was received for the research.

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